Self-management of adults living with HIV on antiretroviral therapy in North-west Ethiopia

Habtamu Abera Areri

A thesis submitted to fulfil the requirements of
the degree of Doctor of Philosophy

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This thesis is dedicated

to my beloved daughters *Rodas Habtamu and Soliyana Habtamu*

for their patience and understanding while I was abroad and far from them.

to Father Abera Areri Chibessa,

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Abstract

Background: As a result of the introduction of antiretroviral therapy (ART), human immunodeficiency virus (HIV) is becoming a long-term condition requiring effective self-management behaviour to maintain physical health and well-being. In Ethiopia, treatment guidelines have been revised to encourage individual engagement in self-management behaviours. However, HIV-related complications remain common. There is no established evidence on the self-management behaviour of adults living with HIV (ALWHIV) on ART in Ethiopia.

Aim: The overall aim of this study was to determine the daily self-management behaviours and influencing factors among adults living with HIV on ART in Ethiopia and the most effective interventions to improve these behaviours.

Methods: Individual and Family Self-Management Theory guided the studies included in this thesis. The study employed a systematic review and sequential explanatory mixed methods. A systematic review of experimental studies addressing interventions to improve self-management of adults living with HIV on ART was also conducted. The reviewed papers' methodological quality was assessed using the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI SUMARI). The JBI SUMARI standardized data extraction tool was used for data extraction. Finally, a narrative synthesis was undertaken for the included studies; due to study heterogeneity, it was not possible to conduct a meta-analysis. The study employed sequential explanatory mixed methods. A quantitative study on a sample of 415 adults living with HIV on ART was carried out to identify the level of self-management (SM) and influencing factors in the study population. A face-to-face survey tool was used, and the data were entered and analysed using SPSS version 25.0. A qualitative study, informed by the survey findings was conducted to explore the key findings of the survey in greater depth. Eleven interviews were conducted to explore the self-management (SM) behaviours. The participants volunteered to be contacted during the preceding quantitative study. The audio-recorded interview data and field notes were transcribed and translated into English. Data were entered into NVivo 12 for data management and analysis. The interview data were coded inductively and subjected to thematic analysis.

Results: The survey findings indicated a low level of SM behaviours amongst the study population compared to global studies. Factors influencing self-management were interconnected and included educational status, residence, self-efficacy, spiritual practices, income, medication adherence support, disclosure of HIV status, and experiences of stigma and discrimination. The systematic review identified multi-component interventions to improve self-management behaviours. Skills training with phone counselling, counselling with a symptom management manual, and technology-assisted interventions were commonly identified as effective interventions to enhance self-management behaviours.

Conclusions: This study set out to add to the understanding of SM of ALWHIV in the Ethiopian context and identify feasible interventions that could be implemented to address known barriers to SM. The barriers have been mapped to contextually appropriate, evidence-informed interventions to generate policy and practice recommendations that could help to address the SM challenges faced by ALWHIV in Ethiopia. The thesis has elucidated the complex, inter-related factors at the individual, socio-demographic, disease-related and health care level that influence an individual’s ability to self-manage their HIV condition. Multi-component practical interventions are suggested for HIV care providers.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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- **23rd December 2021**

Habtamu Abera Areri **Submission date**

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Journal articles in this thesis

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- Areri, H, Marshall, A & Harvey G 2020, ‘Factors influencing self-management of adults living with HIV on antiretroviral therapy in Northwest Ethiopia: a cross-sectional study’, *BMC Infectious Diseases*, vol. 20, no. 1, art. 879, <https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-020-05618-y>.

- Areri, H, Marshall, A & Harvey, G, ‘Medication adherence as a key behavioural outcome of self-management and associated factors among adults living with HIV on antiretroviral therapy in Ethiopia’ [submitted for publication].

- Areri, HA, Marshall, A & Harvey, G, ‘Self-efficacy for self-management and its influencing factors among adults living with HIV on antiretroviral therapy in northwest Ethiopia’, *AIDS Care* <https://doi.org/10.1080/09540121.2021.2007839>.

- Areri, H, Marshall, A & Harvey, G 2020, ‘Exploring self-management of adults living with HIV on antiretroviral therapy in north-west Ethiopia: qualitative study’, *HIV AIDS (Auckl)*, vol. 12, pp. 809-820, <https://doi.org/10.2147/HIV.S287562>.

Conference presentations from this thesis

Areri, HA, Marshall, A and Harvey, G. **14th Florey Postgraduate Research Conference**, University of Adelaide, Adelaide, September 2020

> **Poster presentation:** Interventions to improve self-management of adults living with HIV on antiretroviral therapy: a systematic review

Areri, HA, Marshall, A and Harvey, G. **Adelaide Nursing School Research Conversazione,** University of Adelaide, Adelaide, September 2020

> **Oral presentation:** Self-management of adults living with HIV on antiretroviral therapy in northwest Ethiopia.

List of abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ALWHIV	Adults living with HIV
CD4	Cluster of differentiation 4
CDC	Centres for Disease Control and Prevention
CSA	Central Statistical Agency
DMRH	Debre Markos Referral Hospital
EMOH	Ethiopian Ministry of Health
ETB	Ethiopian birr (currency)
HIV	Human immunodeficiency virus
IFSMT	Individual and Family Self-Management Theory
JBI	Joanna Briggs Institute
SM	Self-management
SD	Standard deviation
SUMARI	System for the Unified Management, Assessment and Review of Information
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organization

Chapter 1: Introduction

1.1 Global picture of HIV/AIDS and ART

Worldwide, since the start of the human immunodeficiency virus (HIV) epidemic, over 70 million people have been infected, and 32 million of them have died of acquired immunodeficiency syndrome (AIDS) related illnesses (UNAIDS 2020). Currently, 38 million people are living with HIV, of which 36.2 million are adults. However, 7.1 million people living with HIV do not know they are living with HIV (UNAIDS 2020). In the year 2019, 1.7 million new infections and 690,000 AIDS-related deaths were reported globally. The United Nations Programme on HIV/AIDS (UNAIDS) set a powerful goal in 2014: the 90-90-90 ambitious treatment target to end the AIDS epidemic by 2020. The numbers 90-90-90 imply that, by the end of 2020, 90% of all people living with HIV will know their HIV status, 90% will receive antiretroviral therapy, and 90% will have viral suppression (UNAIDS 2014). However, by the end of 2019, 81% knew their HIV status, 67% of people living with HIV were receiving antiretroviral therapy, and 59% had achieved HIV viral suppression (UNAIDS 2020; WHO 2020).This implies significant number of people living with HIV did not achieve the fast tracking target by the year 2019.

In Africa, around 25.7 million individuals were living with HIV in 2019, and 70% of them were on antiretroviral therapy. In 2020, 460,000 people died from AIDS-related illnesses while 880,000 people were newly infected with HIV (WHO 2020). According to World Health Organization data, in 2019, 84% of people in Africa who were living with HIV knew their HIV status and 61% of them had suppressed viral load (WHO 2020). Eastern and southern Africa remain the regions most affected by HIV in the world and are home to a large number of people living with HIV. In this region, 20.7 million (out of the total 25.7 million in Africa) people are living with HIV of which 87% know their HIV status, 72% are on antiretroviral treatment, and

65% have viral suppression. In the year 2019, 730,000 new HIV infections and 300,000 AIDS-related deaths were reported in eastern and southern parts of Africa (Avert 2020).

1.2 Overview of HIV/AIDS and ART in Ethiopia

In Ethiopia, which is the focus of this study, over 690,000 people are living with HIV. Of these, 410,000 are women (UNAIDS 2020). Among people living with HIV and on therapy, 67% of them know their HIV status, 74% have access to HIV treatment, and 66% have suppressed their viral load. The data implies Ethiopia is lagging in terms of awareness of HIV status compared to other countries in eastern and southern Africa. There are still many people without access to antiretroviral therapy (ART) (UNAIDS 2020). The rate of new HIV infections in Ethiopia declined by 46% from 2010 to 2019 (from 29,000 to 15,000). Although in the year 2019, over 12,000 people died from AIDS-related complications in Ethiopia (UNAIDS 2020), over the last three decades, the AIDS-related death rate declined in the country as a result of increased antiretroviral therapy coverage (EMOH 2017; Girum, Wasie & Worku 2018; UNAIDS 2020). The improvement in HIV treatment and increased survival rates have changed the nature of HIV from an acute to a chronic condition, which requires the individual living with HIV to learn how to live with chronic HIV conditions and self-manage their unique symptoms, medical challenges and psychosocial stressors that they face daily (Swendeman, Ingram & Rotheram-Borus 2009).

Reflecting on these changes and the introduction of a simpler regimen, the Ethiopian Ministry of Health (EMOH) revised the existing ART guidelines in 2014 to include a chronic care model that focuses on coping and living a positive, healthy lifestyle despite current HIV-related challenges (EMOH 2014). Ethiopia had also adopted the global prevention target of 95-95-95 by 2030. The 95-95-95 principle requires patient’s involvement to achieve the desired viral suppression (EMOH 2018). Currently, the frequency of patients’ antiretroviral therapy clinic visits has changed from every three months to every six months for stable patients, which places more responsibility on the patient for the management of their condition (EMOH 2018). These individuals' engagement in their medical conditions is technically referred to as "self-management". Self-management (SM) is widely conceived as managing illness needs (managing medication, daily physical health), activating social support (family, peers and HIV care providers), and living with chronic illness (Russell et al. 2016; Ryan & Sawin 2009; Schulman-Green et al. 2012). SM requires the individual to perform tasks related to living with HIV including dealing with medical and emotional management (Ryan & Sawin 2009). Hence, it is a vital strategy in chronic disease management, illness prevention and health promotion (Gifford & Groessl 2002; Grady & Gough 2014; Khalesi, Irwin & Sun 2018). In Ethiopia, the current HIV treatment policy and guidelines focus more of on the prevention of infection and control of spread. There is also much attention given to overall HIV care and treatment but not specific to self-management (EMOH 2018).

Emphasizing the SM of individuals living with HIV is essential for both economic and clinical reasons. It promotes the well-being of the patients and reduces their care costs since it reduces the frequency of hospital visits. Effective self-management helps adherence to medication, diet physical health practice and utilization of available resources (Russell et al. 2016; Swendeman, Ingram & Rotheram-Borus 2009). That is why effective and prolonged SM behaviour is required for antiretroviral therapy to be successful. Proactive engagement in the process of SM helps to optimize the level of adherence to ART programs and to lead a healthier life (Gifford & Groessl 2002; Russell et al. 2016). Besides, the primary goals of ART in HIV care are improving functioning, alleviating HIV-related symptoms, preventing complications, and improving the overall quality of life of adults living with HIV (ALWHIV). For these goals to be achieved, the optimal level of medication adherence is required. These all require the proactive role of ALWHIV in managing their condition with minimal support from HIV care providers (Chiaburu, Baker & Pitariu 2006; Ellis 2015a).

HIV care providers can empower ALWHIV to take control of their HIV conditions and their overall health status (Swendeman, Ingram & Rotheram-Borus 2009). The goal of HIV SM is to help ALWHIV work towards managing their health conditions and improving adherence to medication through social support, coaching and counselling. Whenever possible discussion between ALWHIV and HIV care providers should be based on a sense of partnership that helps build a strong relationship between HIV care providers and ALWHIV, enhancing engagement in SM programs. Therefore, HIV care providers should provide proper information and feedback on SM (CDC 2017).

Eating a healthy diet, performing physical activities, maintaining medication adherence, improving psychological and emotional functions like self-efficacy, and reducing stress helps ALWHIV to cope and improve their use of social resources for SM (Swendeman, Ingram & Rotheram-Borus 2009). Effective SM requires patient knowledge of treatment, self-confidence (self-efficacy for SM), support from families/friends, skills in dealing with an existing health condition and appropriate patient-centred interventions designed by HIV care providers (Chiou et al. 2004; Côté et al. 2015; Johnson et al. 2010). Evidence indicates individual engagement in the SM of chronic illness results in an improvement in adherence to medication, SM skills, symptom management, psychological and physical functioning, and reduced healthcare costs (Russell et al. 2016; Swendeman, Ingram & Rotheram-Borus 2009).

1.3 Study setting

The study was conducted in Ethiopia, historically called Abyssinia, which is located in the horn of Africa. The country is the African Union’s home; the headquarters of the United Nations Economic Commission for Africa and numerous other international organizations (Marcus, Mehretu & Crummey 2020). Ethiopia has 12 administrative regions: 10 regional states and 2 city administrations. Amhara regional state is the second-largest region in population size and the focus of this study. It is located in northwest Ethiopia.

The healthcare delivery system of Ethiopia comprises three tiers: (1) primary-level health care, (2) secondary-level health care and (3) tertiary-level health care delivery. Primary health care is staffed mostly by mid-level professionals and consists of rural and urban health centres, district hospitals and health posts. Primary health care units provide health promotion, disease prevention, and curative and rehabilitative services to community problems for a population ranging from 5,000 to 1.5 million. The secondary level health care delivery system consists of general hospitals designed to provide services to 1–1.5 million people. General hospitals provide inpatient and ambulatory services and are staffed by different types of health professionals such as nurses, medical doctors, pharmacists, and laboratory technicians. They serve as referral centres for primary healthcare units. The third level of the healthcare delivery system is specialized hospitals that provide services to about 3.5 to 5 million people. They provide specialized hospital services and serve as referral centres for general hospitals (EMOH 2015). Specialized hospitals staffed by varied well trained health professionals in Ethiopia provide a full range of HIV care. Therefore, this study collected data from one referral hospital (Debre Markos Referral Hospital) of the five tertiary referral hospitals providing HIV care in Amhara region. Debre Markos Referral Hospital provides health services for a total population of 3.6 million. The selected referral hospital is located in the northwest of Ethiopia. This hospital provides referral services for healthcare providers from three administrative zones of the region (Central Statistical Agency (CSA) 2013).

1.4 Statement of the problem

In Ethiopia, it has proved difficult to avoid HIV-related complications, which cause frequent hospital visits across the country (Alemayehu et al. 2017; Mitiku, Weldegebreal & Teklemariam 2015). Sub-optimal levels of medication adherence, fear of stigma and discrimination, nondisclosure of HIV status, cultural and spiritual practices, transportation difficulties and opportunistic infection treatment costs remain a major challenge for ALWHIV in Ethiopia (EMOH 2017; Ketema & Weret 2015; Tiruneh & Wilso 2016). The existing ART guidelines are revised periodically to enhance individual engagement in the treatment program with an emphasis on SM behaviours. Although the principles of the chronic care model are incorporated and implemented in the HIV program of the country, there is no established evidence on the SM behaviour of ALWHIV on ART in Ethiopia.

1.5 Research aim

The study aimed to examine SM behaviours (SM practice and medication adherence) and interventions to improve the SM of adults living with HIV on ART in the north-west of Ethiopia. This was addressed through the following objectives:

1. Determine the daily self-management behaviours of ALWHIV on ART.
2. Identify the factors influencing self-management behaviours of ALWHIV on ART.
3. Make evidence-informed recommendations for improving the SM behaviours of ALWHIV in Ethiopia.

1.6 Study overview

This thesis is by publication. It comprises a published systematic review on interventions to improve SM using experimental studies and original research articles. The findings of the review help to synthesize strong possible evidence for policymakers and implementers in the area of HIV SM (Chapter 3). The empirical research involved a sequential explanatory mixed-methods study carried out in two phases. Phase 1 was a quantitative investigation of factors influencing SM practice, medication adherence and self-efficacy for SM. Phase 2 was a qualitative exploration of factors influencing the SM of ALWHIV.

1.7 Structure of the thesis

The thesis has nine chapters. Following this introductory chapter, Chapter 2 presents the theoretical framework, search strategy and literature review performed. The literature review was guided by the theoretical framework that underpins the study design, namely the Individual and Family Self-Management Theory (IFSMT).

Chapter 3 describes a systematic review of interventions to improve self-management of adults living with HIV on therapy (published journal article).

Chapter 4 presents the overall research methodology and the methods followed to answer the research questions of the study.

Chapters 5, 6 and 7 present quantitative survey findings relating to SM behaviours, overall level of SM, self-efficacy for SM and medication adherence levels and behaviours (one published journal article and two article manuscripts submitted to journals).

Chapter 8 presents a qualitative study exploring the self-management of adults living with HIV using in-depth semi-structured interviews (published journal article).

Chapter 9 presents a discussion of the integrated findings in relation to the existing literature, the implications for policy, practice and research, and some conclusions.

Chapter 2: Literature review

2.1 Introduction

This chapter presents the literature review through the lens of Individual and Family Self-Management Theory (IFSMT) and its core constructs. The literature review aimed to review and critically evaluate studies conducted on self-management behaviours globally, to identify factors influencing the SM of ALWHIV. However, there is a lack published evidence on self-management of people living with HIV in Ethiopia. The IFSMT is first outlined and then applied to structure the literature review findings from global studies.

2.2 The theoretical framework

Individual and Family Self-Management Theory (IFSMT) was developed by researchers at the University of Wisconsin, Milwaukee, College of Nursing in the Self-Management Science Centre. The theory is descriptive and positions SM as a process by which individuals living with chronic conditions achieve health-related outcomes (Ryan & Sawin 2009). The theory consists of the interrelated constructs of the context, the process of SM, SM interventions and outcomes. The "contextual factors: risk and protective factors" include condition-specific factors, the physical and social environment, and individual factors that could enhance or prevent engagement in SM programs. The "process of self-management" is influenced by the individual's knowledge and self-efficacy, self-regulation abilities, and social facilitation such as support and collaboration. Outcomes comprise both proximal (SM behaviours) and distal (health status, quality of life and cost of health care) outcomes. The proximal outcomes (SM behaviours) are a primary interest of this thesis. Recommendations regarding HIV SM in Ethiopia are recent. SM interventions are positioned as the construct that could address barriers related to contextual factors and the process of self-management and, in turn, enhance the outcomes of SM. The contextual factors influence an individual's engagement in the process of SM and directly influence SM outcomes, which implies they either help or prevent engagement in SM behaviour (Ryan & Sawin 2009).

The factors included in IFSMT are consistent with the literature addressing SM behaviours of adults living with HIV as a chronic condition (Martin et al. 2013; Russell et al. 2016; Schulman-Green et al. 2012; Swendeman, Ingram & Rotheram-Borus 2009; Webel et al. 2012), which makes the theory an appropriate one to guide the study. For easy visualization of the concepts included in the study, the researcher has developed a schematic representation adapted from IFSMT and the literature review (see Figure 1).

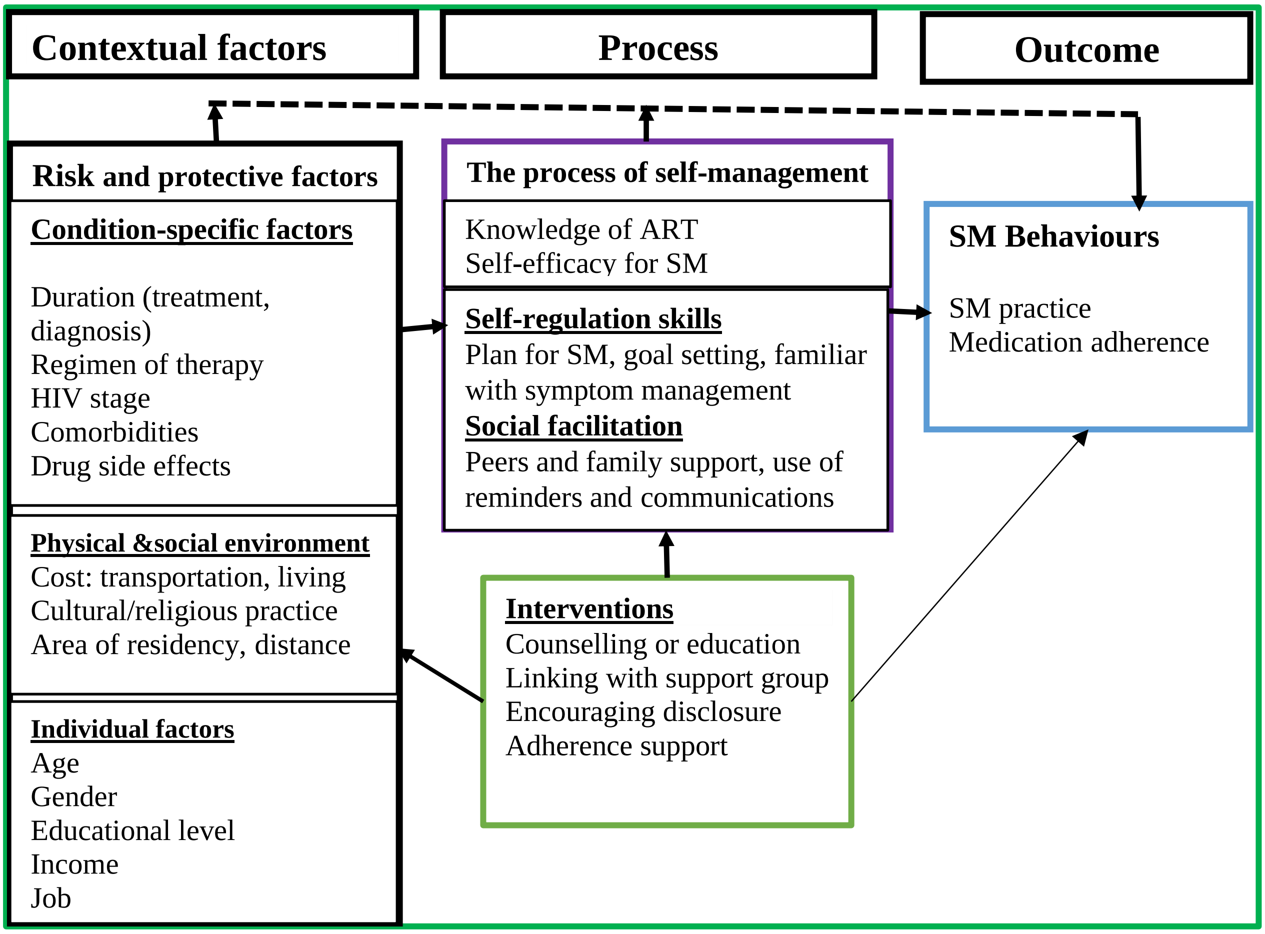

Figure 1. The theoretical framework of the study

The theory has been tested and used to explain SM behaviours in the management of different chronic diseases and health outcomes including HIV conditions in other settings. It has been documented that the practices of SM behaviour using this theory have improved clinical outcomes (Casida et al. 2018; Colorafi 2016; Colorafi 2015; Ellis 2015a; Khalesi, Irwin & Sun 2018; Sawin et al. 2017; Verchota & Sawin 2016). This theory has been applied in different areas, as summarized in Table 1.

Table 1. Summary of application of IFSMT

Author	Participants of the study	Outcome variable
Khalesi, Irwin and Sun (2018)	Hypertensive patients, Australia	SM skills
Al Thomali et al. (2017)	Orthopaedic patients, Saudi Arabia	Quality of life
Casida et al. (2018)	Patients with a heart problem, USA	SM
Colorafi (2016)	Diabetic patients, USA	Social support mobilization
Jiang et al. (2017)	Cancer patients, USA	eHealth applications for SM
Verchota and Sawin (2016)	Type 1 diabetic patients, USA	Testing the components of SM
Ellis (2015a)	Women living with HIV, USA	Nutritional supplementation
Colorafi (2015)	Adults with multi-morbidities, USA	Patient-centred health information
Heinze (2016)	Cancer patients, USA	Patients’ and families’ response to bone marrow transplant
Webel et al. (2012)	Women living with HIV, USA	HIV SM scale development
Ryan et al. (2013)	Midlife women with osteoporosis, USA	Calcium and vitamin D intake SM
Marek et al. (2013)	Frail older adults receiving home care, USA	SM of medications

The constructs of IFSMT are used to guide the structure of the literature review, designing the methods sections, determining the variable of interest, data collection, analysis, discussion, and conclusions.

2.3 Theoretical assumptions

Despite the current emphasis on the need of self-management behaviours, different factors could influence engagement. To this end, IFSMT includes certain assumptions: (1) numerous contextual factors can influence an "individual's ability and desire to engage" in SM, (2) "the process of SM can direct, encourage and support engagement" in SM behaviours and achievements of outcomes, and (3) person-centred interventions are most effective in fostering engagement in SM behaviours and achievement of outcomes (Ryan & Sawin 2009).

2.4 Search strategy

Although the literature review is not a systematic review a comprehensive search was conducted of multiple databases including CINAHL, Pub Med, Embase, Scopus following a preliminary search in Google Scholar. The keywords used for this search were "self-management", "HIV" and "antiretroviral therapy/drug therapy". These terms were used both singly and in combinations. The keywords were then converted into search terms according to the requirements of the databases. The search terms used in each database are presented in Table 2. The search was limited to reports on programs [HIV SM] that were implemented from 2001 onwards as it reflected the time from when the main research on HIV self-management commenced.

Table 2. Search strategy summary

Search terms used in PubMed database (n = 425)		
Self-management	**Living with HIV**	**Antiretroviral therapy**
Self-management[mh] OR Self-management*[tiab] OR self-care[mh] OR self-care*[tiab]	HIV [mh] OR HIV [tiab] OR HIV-1*[tiab] OR HIV-2*[tiab] OR Human Immunodeficiency Virus*[tiab] OR AIDS virus*[tiab] OR Acquired Immune Deficiency Syndrome Virus*[tiab] OR Acquired	Antiretroviral therapy[mh] OR Drug therapy[mh] OR Antiretroviral therapy[sh] OR Drug therap*[tiab] OR Antiretroviral therapy*[tiab]

	Immunodeficiency Syndrome Virus*[tiab]	
Search terms used in CINAHL (n = 334)		
Self-management	**HIV**	**Antiretroviral therapy**
MH “Self-management +” OR TI “Self-management*” OR TI “self-manag*” OR AB “self-manag*” OR MH “self-care+” OR TI “self-care+” OR AB “self-car*” AB “Self-management*” OR AB “self-car*” OR AB “self-manag*”	MH HIV, AIDS OR MH HIV-1 OR HIV-2 OR MH Human Immunodeficiency Virus OR MH AIDS virus OR MH Acquired Immune Deficiency Syndrome Virus OR MH Acquired Immunodeficiency Syndrome Virus	MH Antiretroviral therapy OR MH Drug therapy + TI “Antiretroviral therapy” OR AB “Antiretroviral therapy” OR TI “Drug therapy” OR AB “Drug therapy”
Search terms used in EMBASE (n = 122)		
Self-management	**HIV**	**Antiretroviral therapy**
“self-care”/de OR “self-management”: ti,ab OR “self-care*”:ti,ab OR “selfcare”:ti,ab	“Human immunodeficiency virus”/exp OR HIV:ti,ab OR HIV-1:ti,ab OR HIV-2:ti,ab OR “Human Immunodeficiency Virus”:ti,ab OR “AIDS virus”:ti,ab OR “Acquired Immune Deficiency Syndrome Virus”:ti,ab OR “Acquired Immunodeficiency Syndrome Virus”:ti,ab	“Antiretroviral therapy”/exp OR “Drug therapy”/exp OR “HIV Medication”/:ti,ab OR “Antiretroviral therapy”:ti,ab OR “Drug therapy”:ti,ab OR “HIV medication”:ti,ab OR “Drug therapy*”:ti,ab OR "Antiretroviral therapy*”:ti,ab
Search terms used in SCOPUS (n = 251)		
Self-management	**HIV**	**Antiretroviral therapy**
“self-care” OR “self-management”	HIV OR HIV-1 OR HIV-2 OR “Human Immunodeficiency Virus” OR “AIDS virus” OR “Acquired Immune Deficiency Syndrome Virus” OR “Acquired Immunodeficiency Syndrome Virus”	“HIV Medication" OR “Antiretroviral therap*” OR “Drug therap*” OR "Antiretroviral therap*"

The next section of this chapter presents the literature reviewed and is presented according to the constructs of IFSMT.

2.5 SM of ALWHIV through the theoretical lens of IFSMT

To the knowledge of the investigator, there is no study of self-management behaviours of people living with HIV in Ethiopia. Indeed, there are limited studies on SM of people living with HIV in other low-income countries also. It is possible to say this study is an initial investigation on SM of adults living with HIV in low-income countries including Ethiopia. There are some studies that have been conducted in high income countries but a gap in the literature is apparent. Therefore, it is important to frame such a study with an established theoretical framework that could guide the conduct of the study including the background literature review. Therefore, the literature review was framed by Individual and Family Self-Management Theory under the theoretical constructs such as contextual factors, the process of SM and SM outcomes. Therefore, the review focuses on contextual and process factors and interventions influencing engagement in SM of ALWHIV on ART.

2.6 Contextual factors: Risk and protective factors

The contextual factors of risk and protective factors include condition-specific factors such as, the physical and social environment, and individual factors which could promote or prevent engagement in SM behaviours.

2.6.1 Condition-specific factors

Condition-specific factors are related to the characteristics of the disease and its treatment, and the behaviours needed to manage the condition during times of stability or transition (Ryan & Sawin 2009). Condition-specific factors identified in the literature that affected the SM of ALWHIV included comorbidities, side effects of HIV medication, duration of HIV therapy, and awareness of HIV status.

HIV and its treatment are complex because of duration of ART, co-morbidities, level of awareness of HIV status, psychosocial factors and deterioration of the immune system (Almodovar 2014; Edelman et al. 2013). Thus, HIV management requires both HIV care providers and ALWHIV to be proactive (Chiaburu, Baker & Pitariu 2006). Treatment outcomes could be related to the number of drugs the patient is taking, the side effects of medication, and the related restrictions of alcohol and diet (Tessema et al. 2010).

Comorbidities such as cardiovascular disease, cancer and ageing are more common in people living with HIV than in non-infected ones and create a new challenge in the management of HIV (Almodovar 2014; Cantudo-Cuenca et al. 2014; Costagliola 2014; Guaraldi, Silva & Stentarelli 2014). The existence of comorbidity means ALWHIV often take multiple drugs, which will affect SM behaviours (Edelman et al. 2013; Kendall et al. 2014; Monroe et al. 2013) and increase the risk of drug side effects (Edelman et al. 2013). Drug side effects, in turn, can also affect the level of SM (Cantudo-Cuenca et al. 2014; Gebrezgabher et al. 2017; Gonah & Mukwirimba 2016). A study conducted in Iran confirmed that medication side effects are a barrier to the self-care of women with HIV/AIDS (Oskouie et al. 2017). Therefore, the existence of comorbidities could create additional stress on the SM of HIV patients and reduce coping.

The duration of antiretroviral therapy is another contextual factor influencing HIV management. Houston and Fominaya (2015), argue that, as the duration of therapy increases, the level of adherence decreases. Studies conducted in Botswana (Do et al. 2010) and Ethiopia (Belayihun & Negus 2015; Gebrezgabher et al. 2017) support the finding that a longer duration of therapy leads to nonadherence, possibly because as the duration of treatment increases health status improves, with a resultant tendency to ignore or not follow medical and lifestyle recommendations. However, a study conducted in Nepal showed contradictory findings, reporting that ALWHIV who had been on ART for less than or equal to 24 months were three times more likely to be nonadherent compared to those on ART for more than 24 months (Wasti et al. 2012). This implies that the duration of therapy affects medication adherence in different ways depending on the context.

Awareness of one's HIV status (awareness of positive or negative status) is another condition-specific factor and could help ALWHIV to better self-manage. A study conducted in Korea showed that respondents who had a better understanding of their HIV condition like CD4 (cluster of differentiation 4) were better in their SM (Kim et al. 2015). Similarly, World Health Organization HIV guidelines also indicate that better awareness of HIV treatment is essential for engagement in self-management behaviours (WHO 2016).

2.6.2 The physical and social environment

Factors identified influencing the SM of ALWHIV that relate to the physical and social environment include the cost of transportation, prescription, diagnosis, food (Johnston, Liddy & Ives 2011; Wasti et al. 2012), religious practices, and fear of stigma and discrimination (Bezabhe et al. 2014; Denison et al. 2015; EMOH 2018). Place of residence (Nozaki et al. 2011) and distance from health facilities (Kisenyi, Muliira & Ayebare 2013) were common physical factors responsible for medication nonadherence. The distance from healthcare facilities and related cost of transportation plays a role in the level of SM, especially adherence behaviour. Those travelling for more than an hour to the hospital were found to be more likely to be nonadherent than those who travel less than an hour (Gonah & Mukwirimba 2016; Kisenyi, Muliira & Ayebare 2013; Tegegne, Ndlovu & Zewotir 2018; Wasti et al. 2012). Based on this, patients from rural parts of Ethiopia are at higher risk for low SM behaviours like medication adherence and follow-up recommendations (Tegegne, Ndlovu & Zewotir 2018). A similar study conducted in China showed that those living in rural areas had poorer self-management than people living with HIV in an urban area (Wang et al. 2019). Stigma and discrimination are prominent in a rural community setting. A study conducted in Iran confirmed that social stigma and psychological problems were key barriers to self-care in women with HIV/AIDS (Oskouie et al. 2017). Even though gaining and maintaining employment is an important issue for adults living with HIV, work area stigma and discrimination remained major social obstacles for those with a job or looking for employment. Unemployment also leads to stress due to precipitating financial difficulties (Arns, Martin & Chernoff 2004; Brooks et al. 2004). That is why SM is essential for ALWHIV who are socially isolated, poor and have limited access to health care to improve their well-being and reduce health service costs (Sawyer & Aroni 2005).

Religious practices like fasting and using holy water (Bezabhe et al. 2014) and cultural practices remain significant constraints for SM behaviours, especially adherence to medication (Denison et al. 2015; Sunil & McGehee 2007; Syed et al. 2015). Overall, religious/cultural practices, area of residency and distance have been identified as significant barriers to engagement in SM behaviours in the literature.

2.6.3 Individual factors

Individual factors found to influence the SM of ALWHIV were age, gender, educational level, job status and financial capacity (Sunil & McGehee 2007). For instance, both early adult and late adult age categories were a risk for lower SM (Gonah & Mukwirimba 2016; Nozaki et al. 2011). Gender is another individual factor influencing the level of SM behaviours (Ellis 2015b). Women are often better at medication adherence than their male counterparts (Maqutu et al. 2010; Sunil & McGehee 2007; Wasti et al. 2012), whereas men have an up to five times greater risk of treatment failure due to poor adherence (Haile et al. 2016). The finding is supported by a study conducted in China, where being a female was found to be a predictor of better SM practice (Wang et al. 2019).

Inadequate income was another individual factor that influenced SM among people living with HIV in China (Gaden 2017; Wang et al. 2019), India (Joglekar et al. 2011) and Iran (Oskouie et al. 2017). Financial difficulty was identified across different studies as a barrier to SM. It leads to a lack of proper diet, which could be a risk for serious side effects, and then poor SM behaviour usually occurs (Kisenyi, Muliira & Ayebare 2013; Oskouie et al. 2017; Wang et al. 2019; Wang et al. 2016; Wasti et al. 2012). A study conducted in Australia identified that employed adults living with HIV with better incomes had enhanced engagement in social activities like relaxation with friends. In turn, this could help them to reduce stress through both income and social connections. Lack of employment usually compounds social isolation and loneliness, which could lead to reduced motivation to engage in health-related behaviours (McDonald et al. 2016). A study conducted in Iran also showed a difference in SM practice among participants with different job statuses (Hafezieh et al. 2020). In countries such as Ethiopia with low socioeconomic status, fulfilling basic daily requirements is challenging, which adds to the difficulty of living with HIV. Fulfilling basic daily requirements could be especially difficult for ALWHIV with low socioeconomic status (Gaden 2017; Russell et al. 2016). However, SM is a critically important strategy for reducing the healthcare costs of ALWHIV (Schaffler et al. 2018).

Educational level is another determinant of SM behaviour among ALWHIV (Ellis 2015b). A systematic review found that illiterate people are five times more likely to be nonadherent to medication than those who are literate (Wasti et al. 2012). A primary study conducted in China showed significant differences in SM scores among people with different levels of education (Wang et al. 2019). Similarly, in Ethiopia, illiterate ALWHIV were more likely to be nonadherent than educated ones ($p < 0.001$) (Tegegne, Ndlovu & Zewotir 2018). Therefore, individual factors influencing the SM of ALWHIV include age, gender, educational level, occupation, and income. These individual factors are also linked to the level of self-efficacy for SM (Yoo et al. 2011).

2.7 The process of self-management

The process of self-management is important for individuals living with a chronic condition (such as HIV), and it depends on the dynamic interaction of knowledge, condition-specific self-efficacy, the use of self-regulation skills, and social facilitation (Ryan & Sawin 2009). This section discusses process-related factors influencing SM behaviours.

2.7.1 Knowledge about HIV therapy

The literature identifies that inadequate knowledge about HIV and its treatment can lead to poor SM. Those with at least a basic knowledge of treatment and expected outcomes were found to be better in SM (Joglekar et al. 2011; Russell et al. 2016; Russell et al. 2015; WHO 2016). Effective SM requires knowledge and skill for managing physical health and adjusting to life changes (Russell et al. 2016). A basic understanding of how to take medication, concepts relevant to the disease and its treatment enhance engagement in treatment programs (SM practice) (Dongbo et al. 2006). Self-understanding and self-development are important areas for the empowerment of ALWHIV to promote self-healing (Omisakin & Ncama 2011). More importantly, living with a chronic condition such as HIV requires active and informed self-management of the condition (Ellis 2015b; Swendeman, Ingram & Rotheram-Borus 2009). Therefore, knowledge of the disease, medications and treatment outcomes is crucial in the process of SM.

In the literature, the level of SM was highly related to the knowledge level of patients about the disease and its treatment. For instance, understanding the condition and its treatment improves overall SM behaviours (Baker et al. 2005; Hafezieh et al. 2020; Persell et al. 2004). A low level of understanding about their own health condition and a lack of accurate information about treatment are causes of overall poor engagement of ALWHIV in a treatment program (Murray et al. 2009; Persell et al. 2004; Wasti et al. 2012). Better knowledge about the side effects of HIV medications improves the adherence level up to eight times compared to those with inadequate knowledge (Wang & Wu 2007). Furthermore, reasons for not disclosing one's HIV status are also related to the level of understanding. A study in Nigeria among ART patients found about 77.7% and 75.2% of HIV patients had good knowledge about HIV and ART, respectively. Those respondents who had good knowledge were better engaged in treatments (Olowookere, Fatiregun & Adewole 2012). Therefore, knowledge of ART is an important factor for enhancing the engagement of individuals in SM programs. However, there is no study on the effect of knowledge on SM in Ethiopia

2.7.2 Self-efficacy for self-management

Self-efficacy is a behaviour-specific concept and refers to the degree of confidence an individual has in his/her ability to successfully engage in behaviour under both normal and stressful situations (Ryan & Sawin 2009). Self-efficacy for SM also refers to one's belief in one's ability to perform tasks necessary for SM (Wallston et al. 2011). It is central in the process of SM and is used as a self-regulatory behaviour for effective SM (Bandura 2004; Joglekar et al. 2011; Wallston et al. 2011). Self-efficacy is important in successfully executing SM programs for individuals living with chronic conditions (Baker et al. 2005; Foster et al. 2015; Nokes et al. 2012). A systematic review conducted on the SM of chronic diseases showed improved self-efficacy should be a major area of emphasis for improving SM programs (Boger et al. 2015). Therefore, it is possible to say self-efficacy for SM is influential in enhancing SM behaviours of patients living with various chronic conditions, including HIV (Lorig & Holman 2003).

Studies have also shown that the improved self-efficacy of ALWHIV helps them to mobilize resources, manage illness needs and better cope with existing difficulties (Cha et al. 2008; Wolf et al. 2007). It is proven that perceived self-efficacy about treatment is associated with improved utilization of health behaviours (Adefolalua et al. 2014; Dongbo et al. 2006; Jones

2006; Tan et al. 2012). Enhanced self-efficacy for SM has a positive impact on the SM of individuals living with HIV as a chronic condition and on therapy (Russell et al. 2016). It is also reported that a higher self-efficacy score is associated with better SM across other chronic diseases (Cha et al. 2008; Huang et al. 2013; Weng et al. 2010; Xu et al. 2008). A study conducted in Iran also found a positive correlation between self-efficacy and SM outcomes. Self-efficacy was a significant predictor of SM ($\beta = 0.21$, CI: 0.08–0.34, $p < 0.001$) (Hafezieh et al. 2020).

2.7.3 Self-regulation skills

Self-regulation is an iterative process individuals engage to achieve a change in health behaviours. Self-regulation skills include goal setting, problem solving, planning for emotional SM and being familiar with symptom management (Ryan & Sawin 2009). Goal setting and action planning are mostly related to physical health, healthy eating, and adherence to medications. Therefore, during follow up, healthcare providers need to discuss the importance of setting a goal and planning for emotional SM (Lenzen et al. 2017). For instance, having set a goal was associated with adherence to HIV medication in a study conducted in the Amhara region of Ethiopia (Tessema et al. 2010).

Setting a goal in a treatment program, planning for emotional SM and familiarity with symptom management are core skills. SM skills training helps people to acquire these skills that are essential to carry out the required SM tasks (Lorig & Holman 2003). Overall, coping with psychosocial problems, maintaining a healthy lifestyle, or complying with behavioural recommendations for HIV treatments are the SM skills one has to develop. The individual is also expected to be relaxed and not afraid of living with the disease (Boger et al. 2015; Dongbo et al. 2006). Similarly, a systematic review on chronic disease SM identified that the skills that are essential for enhancing SM and the health status of individuals are goal setting, and managing emotion and stress (Boger et al. 2015). Therefore, these skills are vitally important in the process of SM of ALWHIV.

2.7.4 Social facilitation

Social facilitation is a means of social influence, support and negotiated collaboration. Social support consists of emotional, instrumental, or informational support provided to a person with the explicit goal of facilitating engagement in recommended health behaviours. It also involves communication about HIV with families, peers and healthcare providers (Ryan & Sawin 2009).

The World Health Organization (2016), also regards patient-centred health services as a strategy to improve the HIV care delivery system. In HIV management, providing the required information and then supporting patients to make informed decisions and allowing them to engage in their care plan is critically important. However, its effectiveness depends on the available social support, the patient's role, and the relationship between patients and HIV care providers (Webel et al. 2013).

Reported facilitators for SM include family support, use of reminders, social networking and maintaining medication adherence (Holtzman, Brady & Yehia 2015; Russell et al. 2016; Wang et al. 2016; Wang & Wu 2007). Meanwhile, the barriers to SM are lack of family and social support, and fear of stigma and discrimination (Gilbert & Walker 2009; Hodgson et al. 2014; Wang et al. 2016). A study conducted in Australia identified that a strong social network enhances engagement in the desired health behaviour (McDonald et al. 2016). However, stigma remains a significant barrier to the health management of people living with HIV. As a result, unwillingness to disclose has significant implications for the SM of people living with HIV (McDonald et al. 2016). That is why disclosure is so important for ALWHIV to utilize available community resources. However, fear of stigma and discrimination prevents many ALWHIV from disclosing their status and remains a major obstacle in the process of social facilitation. It prevents ALWHIV from utilizing available support from family, peers, and community. Therefore, encouraging disclosure of HIV status is a vital intervention area to enhance engagement in SM programs (Do et al. 2010; Nabunya et al. 2020; Syed et al. 2015).

The level of SM is related to fear of social consequences, lack of social support, family emotions and fear of stigma (Bezabhe et al. 2014; Gilbert & Walker 2009; Wasti et al. 2012). It is also affected by healthcare factors like care providers' support, social networking, communication between care providers and individuals, frequency of clinic visits and access to health care (Modi et al. 2012). In a study conducted in China, family support after disclosure facilitated engagement in SM programs (Gaden 2017). However, fear of stigma and discrimination remained an obstacle to mobilizing other existing community resources for SM (Gaden 2017). Stigma was also found to be a barrier for SM of women living with HIV. In addition, lack of support from family and one's significant other can be a barrier to engaging in SM programs (Wang et al. 2016). SM, overall, requires better social support to enhance disclosure and normalize feelings (Wang et al. 2019).

In summary, the process of SM can be affected by barriers such as lack of knowledge about ART and drug side effects, fear of stigma and discrimination, and low social facilitation, whereas better self-efficacy indicates improved engagement in SM behaviours. Self-regulation skills like goal setting, planning for emotional SM and being familiar with symptom management are likely to improve SM. Moreover, the presence of family support, reminders, and disclosed HIV status are regarded as factors in improving SM behaviours.

2.8 Outcome: Self-management behaviours

SM behaviours are the individual behaviours by which ALWHIV carry out their treatment recommendations (Schulman-Green et al. 2012). A focus on SM is a key approach to maintaining optimal utilization of medical, emotional and psychological recommendations

(Boger et al. 2015). Grady and Gough (2014) argue that SM is a growing area of intervention for managing chronic diseases, preventing illness, and promoting the physical, the social and emotional well-being of those individuals with the condition. However, it requires a proactive personality and self-engaging activities to improve well-being and reduce health service costs (Chiaburu, Baker & Pitariu 2006). Various studies agree that the most critical SM tasks for adults living with HIV are adherence to medication, mobilizing resources, living with HIV as a chronic condition and performing daily physical health practices (Grey et al. 2015; Martin et al. 2013; Millard, Elliott & Girdler 2013; Swendeman, Ingram & Rotheram-Borus 2009).

According to IFSMT, SM behaviours can be categorized as SM practice and medication adherence (Ryan & Sawin 2009). SM practice includes three domains: daily physical health practices, activating resources and living with HIV as a chronic condition (Ryan & Sawin 2009; Swendeman, Ingram & Rotheram-Borus 2009; Webel et al. 2012). Schulman-Green et al. (2012) use three slightly different broad categories: illness needs (physical health and medication adherence), activating resources (from family, HIV care providers and peers), and living with chronic conditions (adjusting, integrating illness into daily life, meaning-making). Even though the task of SM looks different across quantitative and qualitative studies the focus of the outcomes centred on similar areas: physical health practice, social support and living with chronic HIV conditions. So far, some studies using a quantitative approach have been conducted on the SM of ALWHIV. Surveys conducted in different areas using the same HIV SM tool to assess SM practice showed a variable level of SM among people living with HIV on ART. The overall mean level of SM of people living with HIV in the USA was 2.28 (SD 0.61) (Webel et al. 2013), in Korea 2.00 (SD 0.49) (Kim et al. 2015) and in China 1.91 (SD 0.36) (Wang et al. 2019). However, there is no similar study conducted in Ethiopia and the rest of Africa to determine the level of SM practice.

Daily physical health practices refer to physical activities (exercise, walking, working), diet management, reducing stress, symptom management and managing drug side effects (Ryan & Sawin 2009; Webel et al. 2012). Lifestyle modification is recommended for better SM of chronic conditions (Dongbo et al. 2006). Thus, HIV SM requires lifestyle changes like physical exercise, diet management and stress reduction activities. In addition to these, patients also need to manage their drug side effects, symptoms and clinical follow-up. In a systematic review of SM of various chronic diseases, physical health, managing emotions, stress reduction and diet management were among the essential tasks in SM programs (Boger et al. 2015). Studies showed variable levels of daily physical health practices. For instance, a survey conducted in the USA found a mean score of daily physical health practices of 2.19 (SD 0.53), which was considered moderate (Webel et al. 2013), while a similar study conducted in China found a mean score of daily physical health practices of 1.80 (SD 0.42), which was interpreted as low (Wang et al. 2019). Experimental studies have identified that skills training, social support, counselling and phone calls improved the daily physical health practices of the participants (Chiou et al. 2004, 2006; Côté et al. 2015; Webel et al. 2019).

Resource mobilizing is the second domain of SM practice, and it refers to the use of families, healthcare providers and social networking (peers) to enhance SM. Using supports from social networking, listening to other stories as a motivator, and talking to a counsellor or HIV care provider when needed are essential for SM practice (Ryan & Sawin 2009; Webel et al. 2012). SM requires mobilizing resources and creating a good relationship with healthcare providers to improve engagement in one’s own care (Wang & Wu 2007).

ALWHIV are highly susceptible to psychosocial distress, and face difficulties in daily life due to poverty, limited access to health care and social problems (Webel et al. 2013). Continuous counselling and health information on HIV-by-HIV care providers are vital for effective SM practice. For this purpose, individuals living with HIV must establish a positive relationship with HIV care providers. Emotional support from families and social groups is another important strategy for coping and improving well-being (Russell et al. 2016). Knowledge of SM is primarily acquired from healthcare providers, which helps to prevent frequent visits to health institutions and reduces the chance of hospitalization. The more patients are informed, accept instruction and trust their providers, the more they can perform their care activities (Gaston 2013). Finding and utilizing resources for SM is therefore a crucial skill required from ALWHIV on ART. SM training helps them to acquire the skills that are essential to carry out the required SM tasks, especially learning how to mobilize available resources (Lorig & Holman 2003). Studies conducted on interventions to improve resource mobilization showed skills training, counselling, provision of a symptom management module and online peer-based programs improved mobilization of available social support (Côté et al. 2015; Johnson et al. 2010; Miles et al. 2003; Millard et al. 2016).

ALWHIV need social support from family, HIV care providers or peer networks to effectively engage in SM practice. A scoping review showed the need for peer support around SM in individuals with chronic HIV is increasing. Peer support increases engagement in self-management of people living with HIV. The most common key areas of peer support are linkage to community resources, assistance in daily management, and social and emotional support. These peer supports were found to minimise risk of stigma and discrimination and enhance active engagement in self-management behaviours (Øgård-Repål et al., Daaleman and Helton, 2018). Peer-support is superior to routine clinic follow-up in improving outcomes for people living with HIV. It is a feasible and effective approach in enhancing active engagement in HIV care (Berg et al., 2021).

Support from families after disclosure of HIV status improves engagement in SM practice (Wang et al. 2016). Families, HIV care providers and social groups are essential resources that can be mobilized to enhance SM. A study conducted in the USA found the mean score for resource mobilization for HIV SM was 2.0 (SD 0.88) (Webel et al. 2013). A similar study conducted in China found the mean score for resource mobilization for HIV SM was 1.47 (SD 0.63), which is considered a low level (Wang et al. 2019). However, various experimental studies have identified different effective interventions to mobilize social support for SM. The interventions consisted of technology-assisted interventions like phone calls, online support and text messaging (Côté et al. 2015); counselling and skills training (Johnson et al. 2010); and online peer-based programs (Millard et al. 2016).

Living with HIV as a chronic condition is the third main domain of SM, involving adjusting to and dealing with stigma and giving meaning to life with existing HIV-related conditions (Russell et al. 2016; Webel et al. 2012). Understanding life with HIV and accepting and living with HIV as a chronic condition enhances engagement in SM practice. Lack of understanding about the disease and its outcome leads to overall poor SM practice. SM practice can be affected by a belief about the disease and its treatment. A social context like accepting HIV as a chronic condition is a facilitator for improved HIV SM practice (Webel et al. 2013). A study conducted in China showed coping with HIV enhanced engagement in SM practice (Gaden 2017). The ability to cope is essential in the process of accepting and living with HIV and it also improves SM practice (Wang et al. 2016; Webel et al. 2013). That is why accepting and living with HIV is a recommended lifestyle change to improve overall SM behaviours.

Survey findings have produced variable scores for those living with HIV as a chronic condition and SM practice. For instance, a study conducted in the USA found a mean score for living with HIV as a chronic condition was 2.64 ± 0.43 (Webel et al. 2013). A similar study conducted in China found a slightly lower mean score for living with HIV as a chronic condition of 2.46 ± 0.43 (Wang et al. 2019). In a systematic review of SM of various chronic diseases, feeling normal and coping with a chronic condition were major health outcomes identified in SM programs (Boger et al. 2015). Various experimental studies identified SM skills training as the main intervention identified, and it was linked with improved coping and quality of life. Symptom management interventions like symptom management modules were also found to improve quality of life, reduce stigma and emotional distress, and help understanding and acceptance of living with HIV as a chronic condition (Chiou et al. 2006; Johnson et al. 2010; Millard et al. 2016; Webel et al. 2019; Webel 2010). Another effective intervention was counselling, which helped people to cope with HIV as a chronic condition (Chiou et al. 2006; Johnson et al. 2010). The next section details medication adherence component of SM behaviour.

2.9 Adherence to antiretroviral therapy

Adhering to antiretroviral therapy is a vital behaviour in the SM process to lead a better life while living with HIV as a chronic condition (Russell et al. 2016). An optimal level of adherence is vital for enhanced well-being. Taking greater than or equal to 95% of one’s HIV medication is required to achieve the desired health outcome (Belayihun & Negus 2015; Houston & Fominaya 2015; Wang & Wu 2007). However, globally, the literature reports different degrees of adherence across nations. For instance, the adherence level in India was 75.5% (Joshi et al. 2014), South Africa 79% (Maqutu et al. 2010), and Uganda 66% (Kisenyi, Muliira & Ayebare 2013).

Similarly, in Ethiopia, different levels of medication adherence and factors influencing adherence have been identified across regions. For instance, a study conducted in Hara town, north-eastern Ethiopia, found a low level of adherence of 71.8% (Legesse & Reta 2019). Nondisclosure of HIV status and the presence of drug side effects were identified as factors affecting the level of adherence (Legesse & Reta 2019). Another study conducted in Harar also showed a sub-optimal level of adherence of 87%. The main reasons for nonadherence were forgetfulness, travelling away from home, and being busy doing other things (Mitiku, Abdosh

& Teklemariam 2013). A similar study at the University of Gondar Referral Hospital identified a sub-optimal level of medication adherence of 88.2%, and factors associated with better adherence were living in an urban area, better knowledge of HIV treatment, and disclosed HIV status (Molla et al. 2018). Dubti Hospital, eastern Ethiopia, also indicated a low level of adherence of 81.1%, while the duration of therapy was a factor affecting the adherence level; the longer the therapy time, the less likely the patient was adhering (Belayihun & Negus 2015) . The medication adherence level of people living with HIV in the Jimma University teaching hospital was 63.8% while its influencing factors were educational level, area of residence and occupation status (Abera et al. 2015) . Similarly, sub-optimal adherence was reported in a study conducted in Harar and Dire Dawa health facilities at 85%. These findings demonstrate that a sub-optimal level of medication adherence is still a problem and needs further investigation.

The reasons identified in the literature for nonadherence consist of nondisclosure of HIV status, being male, lack of social support, stigma, social isolation and substance use (Letta et al. 2015b; Mohammed, Ahmed & Tefera 2015). Whereas, the factors promoting better adherence include family support, a trusting relationship with healthcare providers (Negesa, Demeke & Mekonnin 2017), being in middle age and the absence of opportunistic infection (Letta et al. 2015b). A social context like accepting HIV as a chronic condition is a facilitator for improved adherence to antiretroviral drugs as part of one’s routine (Gilbert & Walker 2009).

The literature also identifies that factors associated with poor adherence include drug side effects, fatigue, confusion and anxiety(Al-Dakkak et al. 2013) . However, the interventions that are most commonly identified as effective in enhancing adherence to medication in experimental studies are skills training and counselling (Chiou et al. 2004, 2006; Côté et al. 2015; Johnson et al. 2010; Kalichman et al. 2011). Symptom management instructions also help in improving adherence to medication (Chiou et al. 2004, 2006; Côté et al. 2015).

SM behaviours identified in the literature consist of SM practice and medication adherence. For instance, quantitative studies conducted on SM behaviours of people living with HIV have focused on SM practices with less or no emphasis on maintaining medication adherence. However, qualitative studies included in the literature review address both SM behaviours. Adults living with HIV as a chronic condition who are on therapy need to engage in multiple SM behaviours to enhance their well-being. Therefore, this study focused on both categories of SM to get a full picture of the SM behaviour of ALWHIV on therapy in Ethiopia. Self-efficacy for self-management was identified as a key factor influencing the self-management behaviour of ALWHIV in different kinds of literature. However, evidence is lacking on what factors influence self-efficacy for self-management in the area of ART amongst ALWHIV specifically. Therefore, this study also investigated the possible factors influencing self-efficacy for self-management in the study area.

2.10 Self-management interventions

SM interventions are designed to overcome barriers and enhance SM behaviours. SM interventions interact with and can influence contextual factors, the process of SM and SM behaviours (Ryan & Sawin 2009). Interventions delivered by HIV care providers can influence the engagement of ALWHIV in SM behaviours (Ryan & Sawin 2009; Wang et al. 2016). Routine interventions that enable engagement in SM behaviours include counselling, encouraging disclosure and medication adherence support (Holtzman, Brady & Yehia 2015; Wang et al. 2016). SM support/interventions are also needed for those taking HIV medications to overcome the barriers related to religious and cultural practices and enhance SM behaviours (Johnston, Liddy & Ives 2011).

The most common enabling interventions for the SM of ALWHIV are counselling on the benefits of medication adherence and the presence of adherence support (Holtzman, Brady &

Yehia 2015). The SM interventions need to address the required technical knowledge, interpersonal skills, cognitive skills, planning and role management skills. For effective SM, knowledge about ART and adherence and proactive communication with healthcare providers are identified as essential (Elzarrad, Eckstein & Glasgow 2013). The communication between HIV care providers and ALWHIV should be based on a sense of partnership and motivation. Motivational interviewing is important when planning to discuss behavioural modifications like encouraging disclosure of HIV status (CDC 2017). It is vital to encourage the decision to disclose one's status and link to support groups to get better support and information from others. Taking medication for a chronic condition for life requires adherence supporters (Nakamanya et al. 2019). A study conducted in South Africa showed utilization of adherence support significantly improved viral load for a longer period, with a 95% improvement in patients remaining in care and attending treatment (Igumbor et al. 2011). A systematic review on the impact of community-based adherence support in resource-limited countries showed enhanced adherence, immunological outcomes, patient retention and survival (Wouters et al. 2012). In Ethiopia, adherence supporters (or expert patients) are people living with HIV on ART who have a better understanding of life with HIV as a chronic condition and are better at SM. They are trained in HIV care and employed in treatment centres to help colleagues who have problems with coping, side effects/symptoms or medication adherence, and to clarify the confusion of people living with HIV. They also serve others as a mechanism for finding purpose in life (Hussen et al. 2014). This implies that peer support is a key intervention area to enhance SM behaviour of people living with HIV.

Promoting SM behaviour requires interventions that focus on enhancing skills and knowledge, coping with existing psychosocial distress, and symptom management instructions. Improved SM helps to reduce symptoms of illness and enables decision making regarding disclosure of HIV status to support groups (Merolli, Gray & Martin-Sanchez 2013; Wang et al. 2016).

Interventions designed to enhance SM behaviour are also essential to improve self-efficacy to manage illness-related issues like medication adherence and health-promoting behaviours like physical activities (Bourbeau, Nault & Dang-Tan 2004). Improved SM could help to prevent the worsening of HIV symptoms, reduce hospital visits, enhance clinical care and outcomes, and reduce the burden of comorbidities. Therefore, identifying interventions to enhance SM is critical for implementing and maximizing the benefits of a HIV treatment program for ALWHIV (Bourbeau, Nault & Dang-Tan 2004; Webel et al. 2013). However, various skills of SM are required to achieve the optimal level of well-being. Skills identified for effective SM behaviours can be enhanced through SM interventions consisting of adherence to medication, symptom and emotion management, adapting to living with HIV, using available resources, and developing positive social and family relationships (Lorig & Holman 2003; Schulman-Green et al. 2012; Swendeman, Ingram & Rotheram-Borus 2009).

Various experimental studies have demonstrated the effectiveness of different interventions to improve SM across the globe. Most of the studies centred in the USA and the remaining studies were conducted in Australia, Canada and Taiwan. A quasi-experimental study conducted in Canada showed an intervention focused on SM skills training and social support improved symptom management, mobilization of social support, CD4, self-efficacy and adherence ($p < 0.05$) (Côté et al. 2015). A similar study in Taiwan found that symptom management instructions, SM skills training and phone counselling improved adherence, CD4 count and quality of life (Chiou et al. 2006). An Australia study also found that training, disclosure, and maintaining social connectedness significantly enhanced quality of life ($p < 0.05$) and self-efficacy ($p < 0.05$) (Millard et al. 2016).

The remaining experimental studies were conducted in the USA, and the focuses of the interventions were different. Self-regulation phone counselling interventions demonstrated significant improvements in adherence ($p < 0.01$) and self-efficacy for SM ($p < 0.05$)

(Kalichman et al. 2011). Cognitive reframing training with the provision of self-care symptom management modules was shown to reduce emotional distress, especially stigma, and quality of life ($p < 0.05$) (Miles et al. 2003). An intervention focused on peer-based symptom management behavioural training showed no change in adherence but improved the desire to disclose HIV-positive status (Webel 2010). Similarly, peer mentoring and encouraging engagement in SM behaviours did not increase re-engagement in outpatient appointments and CD4 ($p > 0.05$) (Giordano et al. 2016). Interventions provided by HIV care providers were found to be more effective than peer-based interventions. An ongoing medication counselling and consultation, enhanced confidence (self-efficacy), understanding of the treatment plan, and medication adherence ($p < 0.001$) (Smith et al. 2003). A study focused on coping with ART side effects, adherence to medication and social support using counselling was effective in improving access to information ($p < 0.01$), mobilizing social support for coping with HIV treatment side effects ($p < 0.01$) and adherence to medication (Johnson et al. 2010). SM skills training with various kinds of interventions and counselling were widely applied and were effective in improving SM outcomes. Overall, patient-centred interventions are seen to be the most effective in fostering engagement in SM behaviour (Asfaw et al. 2014; Holtzman, Brady & Yehia 2015; Ryan & Sawin 2009). While a range of literature has been identified pertaining to the use of interventions to support the SM of ALWHIV, this review identified no consolidated source of information that identifies which interventions are most effective in which contexts and for whom. This is a significant gap in the literature and would be of benefit to those seeking to design and implement SM interventions for ALWHIV.

2.11 Summary

The literature identified different contextual factors, processes, outcomes and interventions used to enhance SM behaviours. The factors influencing SM behaviours are multiple and interrelated. However, most of the literature does not come from low-income countries like

Ethiopia. At the same time, the literature from Ethiopian studies lacks a comprehensive examination of SM behaviours. Different literature internationally and the IFSMT show that SM behaviours consist of SM practice and medication adherence. For instance, the quantitative studies conducted on SM behaviours of people living with HIV focused on SM practices with less or no emphasis on maintaining medication adherence. However, qualitative studies included in the literature review addressed both SM behaviours. Adults living with HIV as a chronic condition who are on therapy need to engage in multiple SM behaviours to enhance their well-being. Living with HIV as a chronic condition requires effective SM behaviours with some interventions from HIV care providers. However, the literature review identified a lack of unified and consolidated evidence on interventions to improve SM behaviours in resource-limited settings, indicating a systematic review of existing evidence would be of utility. In addition, currently, there is a lack of evidence from Ethiopia on the level of SM behaviours and their influencing factors. A study is required to:

- Determine the daily self-management behaviours among ALWHIV on ART
- Identify factors influencing the SM behaviours of ALWHIV on ART
- Make evidence-informed recommendations for improving the SM behaviours of ALWHIV in Ethiopia.

Identifying different experimental studies conducted in developed countries, a synthesis of evidence was conducted and published on interventions to improve the self-management behaviours of ALWHIV on ART. Chapter 3 will discuss the systematic review in detail.

Chapter 3: Paper 1

Interventions to improve self-management of adults living with HIV on antiretroviral therapy: A systematic review

3.1 Preface

This chapter presents the first paper contributing to the aim of the thesis. The paper has been published in the journal *PLoS One*. The objective of the review was to synthesize evidence on interventions to improve the self-management of ALWHIV on ART. Based on the findings of the review, we then discussed the implications and drew a conclusion. Then, recommendations were directed to policymakers and HIV care providers for the possible use of the review evidence to enhance the SM of ALWHIV in Ethiopia.

The review included published experimental studies from 2001 to 30 March 2019 on interventions to enhance the self-management of ALWHIV on therapy globally. IFSMT guided the outcomes included in the systematic review. Before the final review, a protocol was developed in line with JBI guidelines and registered on PROSPERO (Appendix 1). The PRISMA checklist was used to write the final report (Appendix 2 supplement 1). Twelve studies meeting the inclusion criteria were included in the final report. The review identified multi-component interventions to enhance self-management behaviours. Skills training with phone counselling, counselling with symptom management instructions and technology-assisted interventions were commonly employed and effectively enhanced self-management. The findings of this review will inform HIV care providers and policymakers to revise clinical practice guidelines in the area of self-management behaviours of ALWHIV on ART.

3.2 Publication

Areri, HA, Marshall, A & Harvey, G 2020, ‘Interventions to improve self-management of adults living with HIV on antiretroviral therapy: a systematic review’, *PLoS ONE*, vol. 15, no. 5, e0232709, <https://doi.org/10.1371/journal.pone.0232709>.

Statement of Authorship

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Principal Author

Name of Principal Author (Candidate)	Habtamu Abera Areri		
Contribution to the Paper	Conceived the study, designed the study, conducted data extraction and analysis, and drafted the manuscript		
Overall percentage (%)	70-80%		
Certification:	This paper reports on original research I conducted during my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	10/1/2020

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Amy Marshall		
Contribution to the Paper	Contributed to the design of the study, validated the data extraction and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	10/1/2020

Name of Co-Author	Professor Gillian Harvey		
Contribution to the Paper	Contributed to the design of the study, validated the data extraction and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	10/1/2020

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PLOS ONE

RESEARCH ARTICLE

Interventions to improve self-management of adults living with HIV on Antiretroviral Therapy: A systematic review

Habtamu Abera Areri[1,2☯]*, **Amy Marshall**[1☯], **Gillian Harvey**[1☯]

1 Adelaide Nursing School, Faculty of Health and Medical Sciences, the University of Adelaide, Adelaide, South Australia, Australia, 2 School of Nursing and Midwifery, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia

☯ These authors contributed equally to this work.
* habtamu.areri@adelaide.edu, au/habtamu.abera64@gmail.com

Abstract

Introduction

Since its initial recognition, HIV has been responsible for around 35 million deaths globally. The introduction of Antiretroviral Therapy has helped to reduce mortality from HIV. However, the resulting increased longevity has influenced the experience of people living with HIV, which now manifests as a chronic condition requiring effective self-management. This review aimed to identify and evaluate the effectiveness of interventions to improve self-management of adults living with HIV on Antiretroviral therapy.

Methods

The review included published experimental studies addressing interventions to improve self-management of adults living with HIV on Antiretroviral Therapy. Studies were included if they addressed two or more outcomes of self-management, as defined by the Theory of Individual and Family Self-Management. The search covered four databases and was limited to papers published in the English language from 2001 to March 30, 2019. The reference lists of included studies were further searched for additional studies. Two independent reviewers using the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI SUMARI) assessed the methodological quality of the reviewed papers. Data extraction was undertaken using the JBI SUMARI standardized data extraction tool. As the included papers were not homogeneous, it was not possible to conduct a meta-analysis. A narrative synthesis was undertaken to synthesize the findings of the included studies.

Results

The search identified 337 articles from which 10 experimental and 2 quasi-experimental studies were included. The total participant sample in the included studies was 1661 adults living with HIV. The overall evidence quality of the findings was considered moderate. Many of the studies included in this review comprised multi-component interventions to improve

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self-management. Skills training, in conjunction with other forms of interventions, particularly phone counseling, was commonly employed and generally effective in improving self-management outcomes. Counseling with a symptom management manual was another employed and effective intervention, followed by technology-assisted self-management interventions. The most common outcomes measured were maintaining medication adherence and quality of life, followed by symptom management, self-efficacy, coping, and social support.

Conclusions

Interventions to improve self-management varied across studies. However, promising outcomes achieved in the majority of studies through interventions comprising a combination of skills training, phone counseling, counseling with symptom management manuals, and technology-assisted interventions.

Introduction

HIV/AIDS has been responsible for an estimated 35 million deaths from a population of around 78 million people infected with the virus since the start of the global epidemic [1].

The advancement of care and treatment of HIV has significantly improved the life expectancy of adults living with HIV. The introduction of Antiretroviral Therapy (ART) has helped to reduce the death rate and increase longevity for adults with HIV. In turn, this has resulted in the re-labeling of HIV as a chronic condition [2]. In common with other chronic conditions, effective self-management is critically important due to the improved survival of adults living with HIV and on ART [3]. Self-management is the ability of adults living with HIV to manage the physical, psycho-social, and behavioral changes associated with the condition [4].

Grady and Gough [5] noted that self-management is regarded as an essential aspect of managing chronic disease, with a focus on illness prevention and promoting wellness. Adults living with HIV (ALWHIV) are required to self-manage their course of treatment, including physical health practice, psychosocial functioning, and daily adjustment to living with chronic illness [2, 5]. The need for promoting self-management behaviors is increasing in HIV treatment [6] as improved self-management can help to reduce the symptoms of the disease and enable decision-making regarding the disclosure of HIV status [7]. Self-management also contributes to improved health status by building the individual's knowledge, skills, and confidence to manage their illness, including the prescribed treatment schedule [8]. Overall, improved self-management could help to prevent the worsening of HIV, reduce hospital visits, improve clinical care and outcomes, and reduce the burden of comorbidities [8, 9]. Skills that have been identified as necessary for effective self-management include maintaining medication adherence, managing negative emotions, adapting to the nature of the illness, problem-solving, using the available resources, coping with HIV-related conditions, and developing positive social and family relationships [2, 10, 11]. Identifying interventions to improve self-management is critical for implementing and maximizing treatment benefits for ALWHIV on ART.

The review reported here was guided (Fig 1) by the Individual and Family Self-Management Theory (IFSMT). The theory represents the complex, multi-dimensional nature of self-management and encompasses context, process, and outcome components. Contextual factors include condition-specific considerations, the physical and social environment, and individual

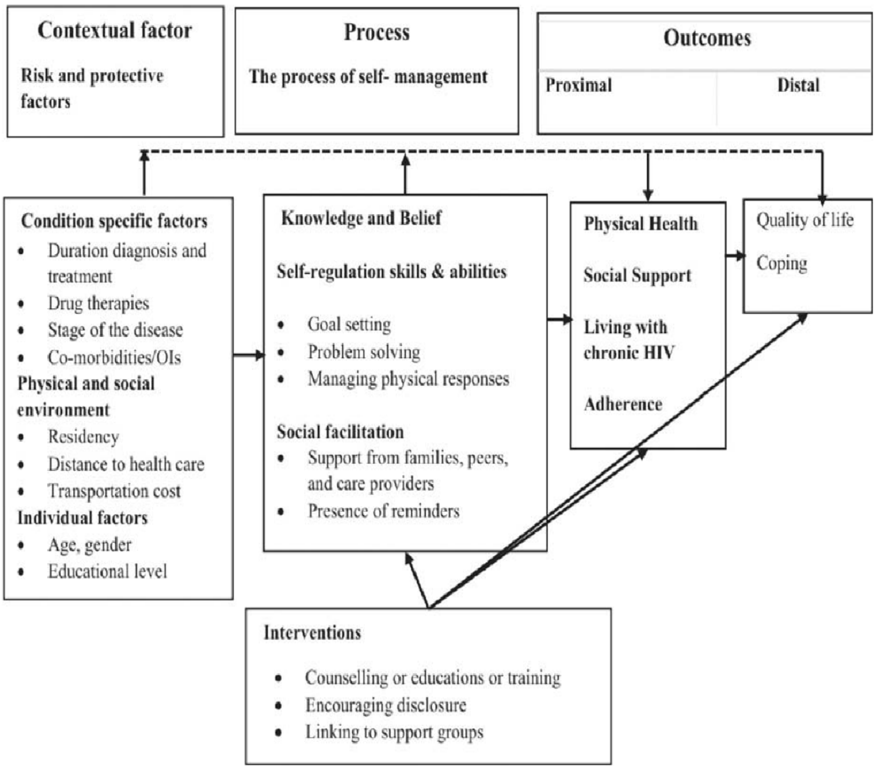

Fig 1. Individual and Family self-management Theory[17].

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and family factors. The self-management process–the typical target for self-management interventions–includes factors relating to knowledge and beliefs, self-regulation skills and abilities, and social facilitation. Outcomes are classified as proximal or distal and encompass physical health, psychological and behavioral health outcomes [12, 13]. Concerning HIV, proximal self-management outcomes related to physical health practice, social support, and self-management, living with a chronic HIV condition, and maintaining medication adherence [2, 3, 11, 14–16]. Distal health outcomes are focused on the quality of life and coping with HIV-related conditions [2, 16, 17]. This theoretical classification of the intervention processes and outcomes of self-management was applied to frame the conduct of the systematic review.

Whilst there is increasing awareness of and attention to interventions to improve the self-management practice of ALWHIV, there have been few attempts to summarize the existing evidence base. A systematic review focused on the specific intervention of a self-management education program for people living with HIV for five or more years and found a statistically significant improvement in physical, psychological, knowledge, and behavioral outcomes [13]. Another review conducted on general chronic disease self-management interventions in sub-Saharan Africa and inferred relevance to the HIV population in the region, although concluded that there was limited and inconclusive evidence to inform policy and practice in the area[18]. To date, there have been no systematic reviews in a comprehensive way that focused on the effectiveness of the overall self-management interventions for ALWHIV. This is the aim of the current review, namely, to identify and evaluate the effectiveness of interventions that have been employed to improve the self-management of adults living with HIV on ART.

Methods

Protocol registration

The systematic review was conducted following the Joanna Briggs Institute methodology for systematic reviews of the effectiveness of evidence (Joanna Briggs Institute 2014). The protocol was registered on PROSPERO, the international prospective register of systematic reviews (registration number CRD42018118257), and was conducted according to the prior registered protocol [19].

Search strategy

The search strategy was developed in conjunction with a University Librarian and applied the PICO format to specify the population of interest and intervention. The search strategy applied a three-step process to identify published papers. The first step of the search was limited to PubMed and CINAHL to identify keywords and terms contained in the title and abstract, and the index terms used to describe articles. The second step search was conducted using the pre-identified keywords and index words across four databases: PubMed, Google Scholar, CINAHL, and EMBASE. Initial keywords were: "Interventions", "self-management", "self-care", "Strategies", "Improve", "ART Drugs", "ARV drugs", "HAART", "HIV patients", "interventions to improve self-management among ART patients". The search terms were used separately and in combination using Boolean operators "OR" or "AND". Finally, for the third step, the reference lists of all identified reports and articles were searched for additional studies (S1 Appendix).

Types of studies

The review considered only peer-reviewed published papers of both experimental and quasi-experimental studies, including randomized controlled trials (RCTs) and non-randomized controlled trials on interventions to improve the self-management of ALWHIV on ART. The reason for including only published experimental studies was to get the most reliable possible evidence on self-management interventions to inform recommendations about which interventions are the most efficacious and should be implemented.

Population

The review included studies on adults living with HIV on ART (limited to adults as most studies used age (18 +) as an inclusion criterion) and published in the English language from January 2001 to March 30, 2019. The start date of 2001 was selected as it reflected the time from when the main comprehensive research on HIV self-management commenced. The review considered participants receiving HIV care and treatment in health care facilities, community settings, and nursing homes. Finally, studies that measured at least two outcomes of self-management, as defined by the Individual and Family Self-Management Theory [17], were included in this review. According to the theory, self-management is a holistic behavioral practice that typically requires multiple interventions to achieve improvements in multi-dimensional outcomes [11, 17]. Therefore, out of the primary outcome categories specified in the Individual and Family Self-Management Theory, the review planned to include studies that targeted at least two outcomes as a single outcome measure was deemed insufficient as an indicator of effective self-management. The review excluded studies with children as participants as they may be unable to exercise independent self-management. Additionally, grey literature was excluded, as well as studies that reported only a single outcome, or unrelated outcome measures. Pilot studies and studies with a sample size of less than 40 [20] were also excluded.

Intervention(s)

The review considered studies that evaluated interventions intended to improve the self-management of ALWHIV on ART. These are defined as interventions that help ALWHIV to manage their condition and achieve optimal functioning actively. Interventions could address one or more of the domains in the IFSMT and included training or education about self-management, provision of social support, counseling on HIV treatment, peer mentoring, provision of technology-assisted supports, such as text messaging, phone calls/counseling and online support.

Comparator(s)

The review considered studies that compared self-management interventions to usual care or standard care.

Outcomes

As described, the review included studies that measured two or more self-management outcomes. The protocol [19] distinguished between proximal [primary] and distal [secondary] outcomes, as follows. Proximal [Primary] outcomes included immediate self-management behaviors such as maintaining medication adherence, mobilization of social support, living with chronic HIV conditions, physical health practice, coping, and self-efficacy. Distal [secondary] outcomes were concerned with the long-term effects of self-management interventions and included quality of life, reduced mortality, morbidity, and hospital visits. Deviation from the proposed protocol encountered related to some of the anticipated outcomes as these were addressed differently in different studies. As a result, the review focused more generally on outcomes, without explicitly distinguishing between proximal and distal outcomes.

Study selection

Following the search, all identified citations were collated and uploaded into EndNote version 8.0, and duplicates were removed. Titles and abstracts were then screened by two independent reviewers (HA & AM) for assessment against the inclusion criteria for the review. Potentially relevant studies were retrieved in full, and their citation details imported into the Joanna Briggs Institute System for the Unified Management, Assessment, and Review of Information [21]. The full text of selected citations was assessed in detail against the inclusion criteria by two independent reviewers (HA & GH). Reasons for exclusion of full-text studies that did not meet the inclusion criteria were recorded and reported in the systematic review. Any disagreements that arose between the reviewers at each stage of the study selection process were resolved through discussion.

Assessment of methodological quality

Eligible studies were critically appraised by two independent reviewers (HA & GH) using the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument [21] for experimental and quasi-experimental studies. Any disagreements that arose were resolved through discussion. The results of critical appraisal were reported in narrative form and a table. A minimum of 50 percent "yes" ratings on the JBI critical appraisal instrument for RCT and quasi-experimental studies were applied as a cut-off point for inclusion in the review [22]. The level of evidence of the findings was also assessed using GRADE pro software.

Data extraction

Data extraction was undertaken by two independent reviewers (HA & AM). One reviewer (HA) initially extracted data from the included papers using the JBI-SUMARI standardized data extraction tool, and a second reviewer (AM) checked the extraction. Interpretation and data extraction differences resolved through discussion. The data extracted included specific details about the participants, study methods, sample size, study design, publication year, completion rate, study area, interventions, and outcomes of significance to the review objective.

Data synthesis

Differences in populations, interventions, comparators, and outcomes of the included studies did not allow for direct comparison, and therefore statistical pooling of data was not possible for this review due to significant heterogeneity across studies. Consequently, the results synthesized in narrative and tabular form to aid data presentation.

Results

Selection of the studies

Initial database searching recovered 337 unique records, which were catalogued in citation management software (EndNote X8). Following the removal of duplicate studies, the titles and abstracts were evaluated, and studies were excluded if they did not meet the pre-specified inclusion criteria. Then, 189 studies were included for further assessment. After reviewing the full text, studies that were not about HIV self-management had a sample size of < 40 participants, included only medication adherence as an outcome, and pilot studies were excluded, leaving 25 studies. A further four studies were excluded based on the interventions that were evaluated as they did not fit with the objectives of the review. Nine studies were also excluded on the grounds of eligibility criteria—detailed information in Fig 2 [23].

Methodological quality

The appraisal results for the included studies are outlined in Tables 1 and 2. The review included 10 RCT and 2 quasi-experimental studies, and therefore, according to the JBI systematic review guideline, the level of evidence is ranked as level 1b [21]. Using the GRADE pro software, the level of evidence of the review findings rated as moderate (S1 Table). All studies included in the review got over 50% "yes" answers in the critical appraisal checklist. Two of the studies (quasi-experimental) lacked true randomization [24, 25], while in two other studies, the process of randomization was not clearly described [26, 27]. Concealment of group allocation occurred in one study [28], was unclear in three articles [26, 29, 30], and did not occur in the remaining studies. In many of the included studies, blinding did not occur due to practical difficulties. The study reported by Kalichman et al. [28] was the exception as it did employ blinding procedures. All studies included in the review reported in a reliable way, the outcome measured.

Characteristics of included studies

Detailed information about the setting, participants, design, interventions, outcomes, and summary of the results is provided in Table 3. The studies included in the review were undertaken in four different countries: eight were from the USA [26–32, 35], two from Taiwan [25, 34], one from Canada [24], and one from Australia [33]. None of the included intervention studies were undertaken in African countries or other middle- and low-income countries.

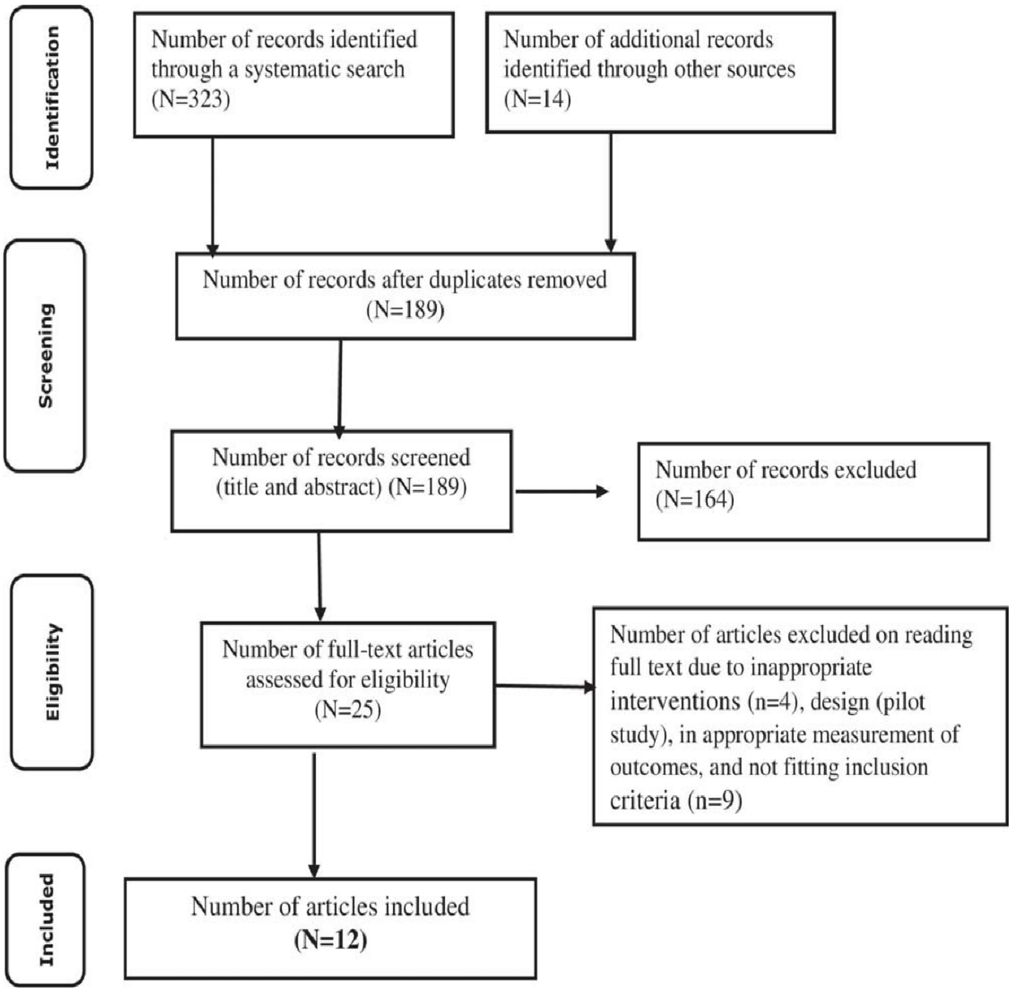

Fig 2. Flowchart of the study selection and inclusion process [23].

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Table 1. Methodological quality of quasi-experimental study.

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Côté et al. 2015 [24]	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chiou et al. 2006 [25]	Y	U	Y	Y	Y	Y	Y	Y	Y
%	100	50	100	100	100	100	100	100	100

JBI Methodological quality appraisal Checklist to be score as "Yes, No or Uncertain".Q1. Is it clear in the study what is the "cause" and what is the 'effect' (i.e. there is no confusion about which variable comes first)? Q2. Were the participants included in any comparisons similar? Q3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest? Q4. Was there a control group? Q5. Were there multiple measurements of the outcome both pre and post the intervention/exposure? Q6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed? Q7. Were the outcomes of participants included in any comparisons measured in the same way? Q8. Were outcomes measured in a reliable way? Q9. Was an appropriate statistical analysis used?

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Table 2. Methodological quality of Randomized controlled trial.

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13
Kalichman et al. 2011 [28]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y
Miles et al. 2003 [29]	Y	U	Y	U	N	Y	Y	Y	Y	Y	Y	Y	U
Smith et al. 2003 [30]	Y	U	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y
Webel AR. 2010[26]	U	U	Y	N	U	U	N	Y	Y	Y	Y	Y	Y
Giordano et al. 2016 [31]	Y	N	Y	N	N	Y	N	Y	Y	Y	Y	Y	Y
Inouye et al. 2001[27]	U	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y
Johnson et al. 2010 [32]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y
Millard et al. 2016[33]	Y	N	Y	N	N	U	Y	Y	Y	Y	Y	Y	Y
Chiou et al. 2004 [34]	Y	N	Y	N	U	N	Y	Y	Y	Y	Y	Y	Y
Webel et al. 2018 [35]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y
%	80	10	100	10	10	20	80	100	100	100	100	100	90

JBI Methodological quality appraisal Checklist to be score as "Yes, No or Uncertain". Q1. Was true randomization used for the assignment of participants to treatment groups? Q2. Was allocation to groups concealed? Q3. Were treatment groups similar at the baseline? Q4. Were participants blind to treatment assignment? Q5. Were those delivering treatment blind to treatment assignments? Q6. Were outcomes assessors blind to treatment assignment? Q7. Were treatment groups treated identically other than the intervention of interest? Q8. Was follow up complete, and if not, were differences between groups in terms of their follow up adequately described and analyzed? Q9. Were participants analyzed in the groups to which they were randomized? Q10. Were outcomes measured in the same way for treatment groups? Q11. Were outcomes measured in a reliable way? Q12. Was an appropriate statistical analysis used? Q13. Was the trial design appropriate for the topic, and any deviations from the standard RCT design accounted for in the conduct and analysis?

https://doi.org/10.1371/journal.pone.0232709.t002

The included studies recruited participants from different settings, including hospitals [24, 30, 31], HIV specialized care clinics [25, 26, 34, 35], community agencies and medical clinics [32], and infectious disease clinics [28, 30], and through advertisement using channels such as social media, agency websites and community organizations [27, 33]. Participant sample sizes varied considerably, ranging from 40 [27, 28] to 460 participants [31].

The mean age of participants was reported in seven studies [24, 26, 28, 29, 32, 34, 35] and ranged from 32.43 years [34] to 51 years [28]. Gender was reported in all except two studies [27, 29]. One study only included female participants [26] and another only male participant [33]. Overall, most of the studies included in the review comprised more male than female participants.

The intervention period ranged from three weeks [27, 33] to 36 months [35], while the measurement period of outcomes ranged from eight weeks [33] to 27 weeks [35]. None of the included studies reported continuing the intervention beyond the final measurement point. The completion rate of participants was reported in all except two studies [25, 27]. This ranged from 51% [29] to 99% [28]. Baseline assessment was made for all included participants, and the finding was compared with post-intervention findings. An intention-to-treat approach was reported in half of the included studies [24, 26, 28, 29, 31, 35]; in the remaining studies, this was unclear or not defined.

Review findings

Intervention strategies. The studies included in the review employed varied intervention strategies. Half of the studies involved skills training intervention [24–27, 29, 30, 32, 34]. Others included phone counselling [25, 28, 30, 34], peer-based intervention [26, 31], provision of an HIV symptom management manual [25, 29, 34] and technology-assisted intervention (phone calling, text messaging and computer-based) [24, 25, 28, 34]. Table 4 summarizes the

Table 3. Characteristics of included studies—quasi-experimental study.

Authors	Country and setting/context	Participant characteristics	Design and groups	The main description of results
Côté, et al., [24]	**Canada** **Setting/context** Two University hospitals	A total of 179 participants recruited from age group 18 years and older and on ART for at least 6months.	**Quasi-experimental** **Intervention** (n = 99) Participants received virtual follow up which was technology-assisted teaching focusing on self-assessment skills, reinforcing and motivational skills, managing side effects, emotional management/coping skills, problem-solving process, establishing, maintaining, and strengthening social relation. Around 140 virtual nurse video clips presented. Four intervention sessions carried out over 6 to 8 weeks, and measurement took place at 6 months of follow up. **Control** (n = 80): usual care that covered medication, symptoms, and problems encountered	The analysis used an intention-to-treat approach and the completion rate of the intervention was 74% (73/99). The mean age of the participants was 48 years with SD of 8.4 and a range of 23–73 years. The mean duration of HIV diagnosis and treatment was 14 and 11 years respectively. Adherence was improved in the intervention group compared to the traditional follow-up. The interventions improved symptom-related discomfort ($P<0.05$) and mobilization of social support ($p<0.05$). The intervention group had a better CD4 count compared to the control group ($P < .05$). However, there was no change in self-efficacy.
Chiou et al. 2006 [25]	**Taiwan** **Setting/context** The outpatient department for infectious diseases of a Taipei medical Centre, and an AIDS social service agency	67 participants with HIV and on ART were recruited based on the inclusion criteria of being diagnosed as HIV-positive and a CD4 count >200/mm3	**Quasi-experimental** **Intervention(n = 45)** Symptom management instructions such as self-care of symptoms, skills training, and telephone counseling were applied to two experimental groups. Both individuals and groups were given self-care/self-management instructions and skills training once a week for 60–90 minutes for a consecutive period of three weeks. **Control (n = 22): usual care** Offered comprehensive symptom management instructions.	Most of the participants were male (n = 63), 4 were female. The average duration of HIV diagnosis was 27.39 ± 23.38 months. Median differences in adherence, CD4 count, and quality of life in both experimental groups were statistically significantly better than in the control group ($p<0.05$). The difference in drug adherence between pre- and post-testing was significant ($P<0.01$) in experimental groups compared to the control group. After the intervention, the quality of life in the experimental group was better than the control group.
Kalichman et al. 2011 [28]	USA	A sample of 40 participants aged 18 years and older were recruited among adults on ART with a self-reported adherence less than 95% in the last month of therapy.	**RCT, blinded**	The approach of analysis was intention-to-treat and the self-management counseling session and the completion rate was 99%. 26 participants were male and 14 were female. The mean age of the participants was 51 (SD, 4.7) years. The self-regulation counseling delivered by phone call demonstrated significant improvements in adherence compared to the control on the four follow up assessment measures ($p < 0.01$). Gains in adherence were paralleled with increased self-efficacy ($p < 0.05$). The behavioral self-management counseling condition demonstrated greater self-efficacy for medication adherence at the follow-up ($P<0.05$). Overall, participants who received behavioral self-management counseling reported a greater number of adherence strategies at the 4 months to follow up than the control condition.
	Setting/context Infectious disease clinics in Atlanta, Georgia		**Intervention (n = 21)** Behavioral counseling and cell phone counseling grounded in the self-management model. Contacted by phone called and received a 45-minute counseling session after pill counts that were used as feedback for self-regulation counseling twice a week. The intervention was provided for the four-month duration, and a measurement took place after 4 months. **Control (n = 19):** Usual care, the participants received a phone call for pill count, but the call was not used for feedback on adherence or counseling.	

(*Continued*)

Table 3. (Continued)

Authors	Country and setting/context	Participant characteristics	Design and groups	The main description of results
Miles et al. 2003 [29]	USA **Setting/context** Two tertiary care University-based infectious disease clinics in the Southeast Carolina state, with nine recruited from HIV care agencies.	Women (n = 109) were recruited from home to participate in maternal self-care symptom management interventions.	**RCT: Blinded** **Intervention (n = 59)** Cognitive reframing training on HIV self-care symptom management and provision of symptom management modules. The follow-up period was for six months. The cognitive reframing training involved teaching, interactive discussion, role-play, and problem-solving, and the intervention was embedded in therapeutic communication. **Control (n = 50):** usual care/ focus on health problems rather than self-care symptom management	The analysis approach was intention-to-treat and the completion rate was 51% (30/59). The mean age of the participants was 37 (SD, 9.5) years. Findings indicated a statistically significant effect of self-care symptom management interventions on the perception of stigma and physical health function (P<0.05). The mothers in the intervention group had lower stigma scores and higher physical function. For the intervention group, there were improvements in both emotional distress and health outcomes. For the control group, there was a significant decline in physical function and overall role function. Overall, interventions reduced emotional distress especially on HIV stigma and improved general health status including quality of life (P<0.05)
Webel. 2010 [26]	USA **Setting/context** San Francisco Bay Area HIV outpatient clinics, HIV/AIDS specific housing, and HIV/AIDS-related community-based care	The sample comprised 89 eligible HIV infected adult participants who self-identified as female and spoke fluent English.	RCT **Intervention(n = 43)** HIV-infected women followed over 14 weeks. The intervention tested peer-based, HIV symptom management using the curriculum of the Positive Self-Management Program (PSMP) as the content of the sessions. Seven, 2-hour sessions were delivered in-group behavioral skills training. **Control (n = 46):** usual care	The analysis approach was intention-to-treat. All participants were females with a mean age of 47 years (SD 8.16). The peer-based symptom management intervention did not increase medication adherence or symptom management but did improve some aspects of quality of life (HIV mastery, p<0.01 and disclosure worries, p<0.01).
Smith et al. 2003 [30]	USA **Setting/context** North Carolina University Hospital	Forty-three participants were recruited through referrals made at the discretion of staff clinicians, based on age (18 years or older) and willingness.	RCT **Interventions (n = 22)** Participants in the self-management program received individualized patient education and assistance with medication self-management and skills training by a registered pharmacist or nurse. The medication self-management program consisted of information exchange, skills training, counseling, and mobilization of social support. The intervention group followed for 12 weeks. **Control (n = 21):** Usual care/ medication education	The completion rate of the trial was 96%. The average age of the participants' was 37 years. Self-management training with the feedback of performance improved adherence to care. The study found also on-going medication counseling and regular consultations that helped to build confidence (better self-efficacy for self-management) and understanding of treatment plan. The adherence level in experimental groups was higher all the time than the control group (P<0.001).
Johnson et al. 2010 [32]	USA **Setting/context** Community agencies and medical clinics	HIV-infected individuals (n = 249), both male and female aged over 18 years included.	RCT **Interventions(n = 128)** Coping skills for self-management of ART side effects, adherence, and social support. A 60-minute individual counseling session and five problem-solving skills training sessions were conducted. **Control(n = 121):** Usual care/control condition received no active psycho-social interventions	The completion rate of all five sessions was 88%. Most participants were male (n = 226) and 23 were female. The mean age of participants was 46 years (SD 7.9). The mean duration of HIV diagnosis was 14 years and ART treatment 10 years. The intervention was effective in influencing individuals' efforts to access information (p<0.01) and social support for coping with HIV treatment side effects (p<0.01). Improved coping skills related to HIV treatment side effects had a protective effect on treatment adherence (P<0.05). Interventions focusing on skills related to ART side-effects management showed a promising effect (p<0.001). Odds of non-adherence decreased by 6% per month for the intervention group (p<0.05). A significant overall difference was observed between control and intervention groups regarding coping with side effects. Overall, the intervention improved mobilization of social support (p<0.001), coping with side effects (p<0.05) and adherence to medication.

(Continued)

Table 3. (Continued)

Authors	Country and setting/context	Participant characteristics	Design and groups	The main description of results
Inouye et al. 2001 [27]	USA, New York **Setting/context** Participants were recruited through advertisements in newspapers, private physicians, hospital flyer, and AIDS organizations	40 men and women with a diagnosis of HIV participants were recruited, aged 18 years and over.	RCT **Intervention (n = 20)** Received a 7-week individual self-management and coping skills training, which included a 14-session individual intervention for 60–90 minutes on skills training, and problem-solving. **Control (n = 20):** usual care/ waitlist who received standard care.	Self-management training improved coping. Psychosocial Health showed a significant improvement in mood and coping strategies (P<0.05) and the training significantly improved participants' mood (p<0.05). The intervention group demonstrated better self-management (p<0.05). However, no significant change was observed in the CD4 count.
Millard et al. 2016 [33]	Australia **Setting/context** HIV-positive gay men recruited through advertisements on social media, community organization websites and print media, AIDS council offices, and primary care clinics.	A total of 132 homosexual men with HIV were eligible for participation if they self-identified, homosexual were 18 years or older, living in Australia, had adequate English to enable participation and had access to a computer with internet.	RCT **Intervention (n = 68)** A training session was focusing on managing the emotional impact of HIV, disclosing HIV status to family and friends, maintaining social connectedness, and disclosure to partners. Seven weeks of intervention for 90 minutes per week **Control(n = 64):** Usual care/ primary health and community-based services and supports without any other additional intervention	The completion rate was 52% (35/68). The study indicated significant improvement in the intervention group on HIV-related quality of life (p< 0.05); social relationships (p<0.05); health-directed activity (p<0.05); skill and technique acquisition (p<0.05) and health service navigation (p<0.01); Positive Outlook Self-Efficacy (p<0.05) and social participation (p <0.01).
Chiou et al. 2004 [34]	Taiwan **Setting/context** A medical center and a Catholic AIDS support group in Taipei.	Sixty-seven patients with HIV/AIDS who were receiving ART during the study period and in the past four months and had a CD4 count >200/mm^3.	RCT **Intervention (n = 45)** Participants randomly assigned to a 60-minute individual (n = 23) or 90-minute group (n = 22) program on side effects self-care education and skills training once per week for 3 weeks; received telephone counseling and side effects self-care education manual. The intervention lasted for three months. **Control (n = 22):** Usual care. No intervention applied to the control group other than telephone counseling.	The completion rate was 86%. The mean age of the participants was 32.43 years (SD 6.68). 63 participants were male and 4 were female. Median differences in the customized adherence and quality of life in both interventional groups were statistically significantly improved compared to the control group (P<0.05). Drug adherence in the experimental groups was better than in the control group CD4 in the experimental groups (P <0.01) was better than in the control group (p>0.05. Quality of life in both interventional groups was better (p<0.05) than in the control group, as was self-care ability in managing medication side effects (p<0.05). Overall, the educational program with written manuals helped HIV-positive patients in increasing their self-care knowledge.
Webel et al. 2018 [35]	USA **Setting/context** Participants were recruited from 3 urban clinical sites specializing in the care of HIV patients.	179 participants aged 18 years and older, English speaking, and with at least one chronic condition with HIV were recruited from their home and/or clinic or other community sites according to participant preferences and availability.	**Randomized clinical trial** **Intervention(n = 90)** HIV Navigation Program intervention (Positive Self-management program). Comprehensive palliative care programs, particularly focusing on symptom management through home visits by social workers or nurses and phone calls The intervention was followed for 36 months. **Control (n = 89):** Usual care including medication adherence, general well-being, and hospital use	The analysis approach was intention-to-treat. The completion rate of the intervention was 52/90 (58%). The navigator program showed variable improvement in outcomes over time: self-blame, as a domain of coping, was lower (p<0.02). Understanding of the chronic nature of HIV self-management showed a positive effect (p<0.01). However, the program did not improve the overall quality of life or social support.

(Continued)

Table 3. (Continued)

Authors	Country and setting/context	Participant characteristics	Design and groups	The main description of results
Giordano et al. 2016 [31]	USA **Setting/context** Houston's Harris Health System	460 participants aged 18 years and above and able to speak English or Spanish were included in a study.	**Randomized clinical trial** **Intervention (n = 225)** Peer mentoring and encouragement for self-management. The intervention consisted of 2 in-person sessions in hospital and five telephone calls after discharge over 10 weeks. **Control(n = 235): Usual care;** no focus on retention in care or HIV treatment	Intention-to-treat was the approach of analysis and the completion rate was 90%. The study consisted of 305 males and 155 females. Peer mentoring did not increase re-engagement in outpatient care or effect CD4 count (P>0.05). Mentored participants with a service linkage worker visit and length of stay <7 days had a 1.58 relative risk (95% CI, 1.10, 2.27) of improvement at 6 months compared with other participants.

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type of interventions applied, mode of delivery, outcomes, and effectiveness of the intervention in the included studies.

Intervention outcomes. Outcomes were categorized under physical health, psychosocial and behavioral outcomes [12, 13] in line with the Individual and Family Self-Management Theory [17]. The physical health outcomes included symptom management and CD4 counts. Behavioral outcomes focused on medication adherence and psychosocial outcomes included self-efficacy, quality of life, coping, and social support. The interventions were summarised as per the Template for Intervention Description and Replication (TIDieR) reporting checklist and guide[36].

Interventions and outcomes. The studies included in this review consisted of complex, multi-component interventions that made it difficult to link specific interventions to specific outcomes. The complex nature of the problem requires multiple intervention strategies to improve self-management of ALWHIV on ART. Most of the studies consisted of some form of training interventions in conjunction with counseling or other forms of interventions to improve self-management outcomes. Adherence was the most frequently improved self-management outcome followed by symptom management, coping, and quality of life. The least improved self-management outcome was self-efficacy for self-management (Table 5). To provide additional clarity, the findings of the review are summarized under physical, psychosocial, and behavioral outcomes.

Physical health outcomes. Physical health self-management outcomes include symptom management and CD4 count [12]. Changes in physical health outcomes were evaluated in four papers [24, 26, 27, 34] and two of the four studies demonstrated significant improvements in the intervention groups. A quasi-experimental study conducted by Côté et al. [24] found better symptom management among participants who received virtual follow up (when involved in a technology-assisted teaching session with a virtual nurse) in the experimental group compared to the control group ($p < 0.05$). An RCT study conducted by Webel [26] reported that a peer-based symptom management program did not significantly improve symptom management. Another quasi-experimental study found that symptom management programs increased self-care ability through multiple teaching sessions and providing written manuals for people living with HIV [34]. An RCT conducted by Inouye et al. [27] found no significant difference between the intervention group who received individualized self-management and coping skills training for seven weeks and the control group about CD4 count ($p>0.05$). However, an RCT study conducted by Chiou et al. [34] evaluating skills training found a statistically significant improvement in CD4 count in the intervention group ($p<0.01$). Overall, therefore, the findings relating to the impact of self-management interventions on physical health outcomes are inconclusive.

Behavioural health outcomes. Maintaining medication adherence is the main behavioral outcome targeted by HIV self-management interventions [12]. Adherence to medication was reported in seven studies [24–26, 28, 31, 32, 34]. A study conducted by Côté et al. [24] found that adherence was significantly improved among participants who received virtual follow up through technology-assisted teaching. Chiou et al. [25] also found a statistically significant ($p<0.01$) pre/post-test difference amongst participants who received instructions on self-care of symptoms through skills training and phone counseling. An RCT conducted by Kalichman et al. [28] demonstrated that phone counseling intervention significantly improved adherence ($p<0.01$). In contrast, Webel [26] found that a peer-supported symptom management intervention did not increase adherence. Chiou et al. [34] found a statistically significant difference in adherence amongst an experimental group who received self-care training. Another RCT study conducted by Johnson et al. [32] also found that an intervention focusing on skills of ART side- effect management significantly improved medication self-management ($p<0.05$). In summary, interventions to improve medication adherence appear to be generally effective, although less so when delivered via peer mentoring.

Psychosocial outcomes. Psychosocial outcomes (quality of life, social support, self-efficacy, and coping) were reported in many of the papers. Quality of life was reported in eight studies [25–27, 29, 31, 33–35]. Of these, Chiou et al. [34] found a statistically significant improvement in the quality of life among the intervention group who received education about side effects and skills training once per week for 3 weeks and a 3-month symptom management intervention ($P<0.05$). An RCT conducted by Millard et al. [33] also indicated a significant improvement with regards to the quality of life amongst the experimental group who received self-management education ($p<0.05$).

Similarly, Miles et al. [29] reported that symptom management training interventions improved the quality of life. Chiou et al. [25] also found the quality of life improved in an experimental group provided with symptom management support, skills training and phone counseling ($P< 0.05$). However, Webel [26] found no improvement in the quality of life amongst participants who received a peer-based self-management intervention. Overall, the interventions studied appear to have a positive impact on the quality of life with the exception of those delivered via peers.

Three studies included interventions to improve the mobilization of social support as part of self-management [24, 33, 35]. A quasi-experimental study conducted by Côté et al. [24] found that social support mobilization was improved among an experimental group that received technology-assisted teaching (virtual follow up) on coping and establishing, maintaining, and strengthening social relationships ($p<0.05$). Millard et al. [33] conducted an RCT that involved providing an information module on social connectedness, emotional management, and the need for disclosure and reported a significant improvement in social relationships ($p<0.01$) among the intervention group. However, an RCT conducted by Webel et al. [35] using a Positive Self-Management Program reported no improvement in social support mobilization amongst the experimental group.

Four of the included studies reported that there were changes in self-efficacy for self-management [24, 28, 30, 33]. In one study [24], technology-assisted intervention to improve self-efficacy for symptom management was not significant ($p> 0.05$). However, in a different study, Kalichman et al. [28] reported that a phone counseling intervention did significantly improve self-efficacy for self-management ($p<0.05$). Similarly, Smith et al. [30] concluded that ongoing phone counseling and regular consultation improved confidence/self-efficacy for self-

Table 4. Summary of the main interventions, mode of delivery, outcomes and effectiveness.

Authors	Intervention/s	Mode of delivery	Outcomes	Effectiveness of the intervention and statistical significance
Côté, et al. 2015[24]	Technology-assisted teaching focused on skills and social support was carried out in two university hospitals.	**Online:** 4 sessions each 20–30 minutes long, offered over 8 weeks provided using a virtual nurse who acted as a coach interacting with the user.	Physical health Outcome • Symptom management • CD4 count Psychosocial Health Outcome • Self-efficacy • Social support mobilization Behavioral Health Outcome • Adherence	The interventions improved: • Symptom management ($p<0.05$) • CD4 count ($p<0.05$). • Mobilization of social support ($p<0.05$) • Adherence No difference in self-efficacy
Chiou et al.2006 [25]	Symptom management instructions, skills training and phone counseling	**Face-to-face and phone counseling:** one-on-one and group teaching on symptom management by HIV care professionals provided once a week for 60–90 minutes, followed by 3 weeks of phone calls.	Physical health Outcome • CD4 count Psychosocial Health Outcome • Quality of life Behavioral Health Outcome • Adherence	The interventions improved: • CD4 count in both intervention groups (one-on-one and group teaching) ($P<0.05$) • Quality of life in both intervention groups ($P<0.05$). • Adherence in both intervention groups ($P<0.01$)
Webel. 2010 [26]	Peer-based HIV symptom management and skills training using the Positive Self-management Program (PSMP) as content for the sessions	**Face-to-face and then phone calls:** 7 sessions each of two hours, led by a trained peer using PSMP in the community through face-to-face sessions and phone calls over 14 weeks.	Physical health Outcome • Symptom management Psychosocial Health Outcome • Quality of life Behavioral Health Outcome • Adherence	The intervention improved: • Some components of quality of life, namely, HIV mastery [sense of self-control] ($p<0.01$) and disclosure worries ($p<0.01$). No significant differences in medication adherence or symptom management capacity
Inouye et al. 2001 [27]	Individualized self-management and coping skills training	**Face-to-face:** the intervention was run over seven weeks for 60–90 minutes per session. Two trained clinicians delivered a total of 14 sessions.	Physical health Outcome • Symptom management • CD4 count Psychological outcomes • Coping skills	The intervention improved: • Coping and coping strategies ($P<0.05$). • Coping skills training resulted in better symptom self-management ($p<0.05$). No significant change was observed in the CD4 count.
Kalichman et al. 2011 [28]	Behavioral self-regulation counseling and cell phone counseling grounded in self-management model	**Initial face-to-face, then telephone calls for follow up:** After initial adherence counseling, participants received 45 minutes of phone counseling per session, 2 times per week for four months from an adherence counselor.	Psychological outcomes • Medication adherence self-efficacy Behavioral Health Outcome • Adherence	The intervention improved: • ART adherence ($p<0.01$). • Medication adherence self-efficacy ($p<0.05$)
Miles et al. 2003 [29]	Cognitive reframing training and symptom management modules	**Face-to-face with follow-up telephone calls:** The intervention was carried out in the homes of adults living with HIV (six home visits over 3 months by registered nurses), followed by phone calls.	Physical health outcome • Physical health function Psychosocial Health Outcomes • HIV related stigma • Quality of life	The intervention improved: • Physical health function ($p<0.01$). • HIV related stigma scores ($p<0.001$). No significant difference in health-related quality-of-life

(*Continued*)

Table 4. (Continued)

Authors	Intervention/s	Mode of delivery	Outcomes	Effectiveness of the intervention and statistical significance
Smith et al. 2003 [30]	Individualized medication self-management education by registered health care professionals. The interventions consisted of information exchange, skills training, and social support enlistment	**Face-to-face counseling:** 6-month intervention, including three monthly visits for medication consultations and monthly feedback of adherence performance, delivered by trained nurse or pharmacist.	Psychosocial Health Outcome • Self-efficacy Behavioral Health Outcome • Adherence • Self-management adherence	The intervention improved: • Self-management adherence ($p<0.05$) • Adherence ($p<0.005$) No significant difference in self-efficacy ($P>0.05$)
Giordano et al. 2016 [31]	Peer monitoring training interventions.	**Face-to-face training and phone calls after discharge:** Seven volunteer mentors provided two training interventions in hospital, each lasting between 20 and 45 minutes, and then five follow-up phone calls in the 10 weeks after discharge.	Physical health outcome • CD4 count Psychosocial Health Outcome • Quality of life Behavioral Health Outcome • Adherence	The intervention improved: • Mentored participants with a service linkage worker visited had a 1.58 relative risk (95% CI: 1.10, 2.27) improved adherence level and quality of life at 6 months compared with other participants ($p<0.05$). The interventions found no change; • Re-engagement in HIV care. • CD4 count ($P>0.05$)
Johnson et al. 2010 [32]	Individualized counseling and skills training	**Face-to-face:** Five counseling and skills training sessions individually delivered for 60 minutes with a focus on HIV treatment side effects and coping skills by the experienced clinician on HIV care over 3 months.	Psychosocial Health Outcome • Coping skills • Social support mobilization Behavioral Health Outcome • Adherence	The intervention improved: • Adherence ($p<0.05$) • Coping with side effects ($p<0.001$) • Providing adequate information improved coping with side effects and adhered to medication($p<0.05$) • Social support mobilization($p<0.001$)
Millard et al. 2016 [33]	Online peer-based programs delivered via a community-based peer support officer.	**Online:** 7-week program delivered for 90 minutes per week in closed groups with 15 participants per group, comprising information modules and weekly peer-facilitated live chats.	Psychosocial Health Outcome • Self-efficacy • Social support mobilization • Quality of life • Coping ability/ adjustment	The intervention improved: • HIV-related quality of life ($p<0.05$) • Social relationships ($p<0.05$) • Decreased emotional distress or coping ($p<0.05$) • Health service navigation ($p<0.01$) • Positive Outlook Self-Efficacy ($p<0.05$) • Social participation ($p<0.01$). • Quality of life ($p<0.05$)
Chiou et al. 2004 [34]	Individualized self-care education/ group skills training, symptom management manual and phone counseling	**Face-to-face education and skill training with phone counseling to support the face-to-face interaction:** 3 sessions of 60 to 90 minutes each on side effects, self-care education/skills training once per week over 3 weeks. Delivered by HIV care professionals and followed by phone counseling.	Physical Health Outcome • Symptom self-care Psychosocial Health Outcome • Knowledge of self-care Behavioral Health Outcome • Adherence	The intervention improved; • Self-care knowledge ($p<0.001$). • Adherence ($P<0.01$) • Symptom self-care ability ($P<0.05$).
Webel et al. 2018 [35]	Individualized navigator program intervention for HIV patients Comprehensive palliative care programs: home visits by social workers or nurses Phone calls	**Home visit and phone calls by nurses or social workers:** Advanced Practice Nurses and Social Workers delivered the intervention and trained volunteers over 3 years, depending on the need of the participant.	Physical health Outcome • Symptom management Psychosocial Health Outcome • Quality of life • Coping ability • Social support mobilization Behavioral Health Outcome • Living with chronic HIV and Self-management	The intervention improved; • Coping ($p<0.02$). • Symptom management ($P<0.01$) • Life satisfaction ($p<0.01$) and friendship ($P<0.05$) • Understanding of the chronic nature of HIV self-management showed a positive effect ($p<0.01$). No change in overall quality of life or social support mobilization

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Table 5. Summary of the main interventions and improved self-management outcomes.

Interventions	Self-management outcome improved
Technology-assisted interventions [24], Individualized symptom self-management and coping skills training[27], Cognitive reframing training and symptom management modules with phone calls [29], Individualized self-care education/ group skill training, symptom management manual and phone counseling [34], Individualized navigator program intervention for HIV patients with phone calls [35]	Symptom management
Symptom management manuals, Skills training and phone counseling [25], Peer-based HIV symptom management program and skill training [26], Peer monitoring training interventions with follow up phone calls [31], Online peer-based programs [33], Individualized self-care education/ group skill training, symptom management manual and phone counseling [34].	Quality of life
Technology-assisted interventions [24], Symptom management manuals, Skills training, and phone counseling [25], Behavioral self-regulation counseling and cell phone counseling grounded in self-management model [28], Individualized medication self-management education [30], Peer monitoring training interventions with follow up phone calls [31], Individualized counseling and skill training [32], Individualized self-care education/ group skill training, symptom management manual and phone counseling [34]	Maintaining Adherence
Technology-assisted interventions [24], Individualized counseling and skill training [32], Online peer-based programs [33]	Social support mobilization
Individualized symptom self-management and coping skills training[27], Cognitive reframing training and symptom management modules with phone calls [29], Individualized counseling and skill training [32], Online peer-based programs [33], Individualized navigator program intervention for HIV patients with phone calls [35].	Coping skills
Behavioral self-regulation counseling and cell phone counseling grounded in self-management model[28], Online peer-based programs[33]	Self-efficacy for self-management

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management, while Millard et al. [33] also demonstrated that self-management education significantly improved self-efficacy in the intervention groups ($p<0.05$). These findings suggest that self-efficacy for self-management improvement depends on continuous counseling and education.

Coping with HIV conditions was reported in four studies [27, 32, 33, 35]. A seven-week individual self-management coping skills training intervention found significant improvement in coping and coping strategies ($p<0.05$) in the experimental group [27]. Johnson et al. [32], also reported that providing information on self-management improved coping with side effects($p<0.001$). An online peer-based intervention program demonstrated decreased emotional distress after eight weeks of intervention ($p<0.05$) [33], whilst an RCT conducted by Webel et al. [35] found that understanding the nature of HIV self-management showed a positive effect on accepting and living with a chronic HIV condition ($p<0.01$)and lowered self-blame among the intervention group ($p<0.05$). Therefore, it is possible to conclude that interventions to improve coping were generally useful.

Discussion

This systematic review narratively synthesized evidence on interventions to improve self-management outcomes, including quality of life, self-efficacy, coping, symptom management, maintaining medication adherence, and mobilizing social support. However, the interventions studied are complex, often multi-component, and highly variable in terms of intensity, duration, and mode of delivery. This heterogeneity makes it difficult to attribute specific outcomes to specific interventions as factors related to intervention design, methods of implementing, and the context in which implementation takes place could all influence the study outcomes. This has implications for future interventional studies, which could be strengthened by including an embedded process evaluation to provide a more comprehensive understanding of what works, for whom, in what circumstances, how, and why[36].

From the evidence to date, it appears that skills training delivered in conjunction with other forms of interventions to enable self-management is a widely used intervention for ALWHIV on ART and is generally effective. Skills training with phone counseling interventions were applied in three studies and was effective [25, 32, 34]. Although the intervention period varied across these studies (Table 3), skills training with phone counseling interventions demonstrated effectiveness in improving many components of self-management. Peer-based HIV symptom management and skills training was another interventional approach to improve self-management, and in this case, significant improvement in the quality of life was reported [26]. This finding supported by three studies [31, 33, 35]. However, there was no change in adherence and symptom management with peer-based HIV symptom management programs and skills training. This suggests that peer-based interventions with skills training or other forms of intervention could be useful in improving some aspects of self-management but not others. Individualized skills training/educational sessions demonstrated significant improvement in many components of self-management other than CD4 count [27] and self-efficacy [30]. Overall, it appears that whilst approaches to skills training vary, they are generally effective, particularly in terms of improving psychosocial outcomes. Peer-based delivery of skills training appears less effective in improving physical and behavioral health outcomes.

The second most commonly applied intervention in the included studies was counseling (phone or general counseling) combined with different forms of interventions (for example skills training, symptom management manual, or education) with the intervention period lasting for 45 minutes to 90 minutes per session [25, 28, 30, 32, 34]. The counseling interventions were effective across all studies for most outcomes except self-efficacy [30] even though the mode of delivery varied across the included studies. Therefore, counseling with skill training, education, or symptom management manuals could be an essential intervention for improving the different aspects of self-management outcomes. However, self-efficacy for self-management remained unchanged in two studies [24, 30]. Improving self-efficacy for self-management may require more psychological and behavioral interventions with continuous phone counseling or online peer support.

Technology-assisted (via phone and website) interventions, in conjunction with other forms of interventions, were consistently found to be effective in improving self-management behaviors such as maintaining medication adherence, coping with HIV conditions and management of side effects [24]. Most of the interventions included in the review included phone calls as a means of follow-up or as a primary intervention to improve self-management and were effective [25, 26, 28, 29, 31, 34, 35]. All interventions that included phone calls for counseling were effective in improving many outcomes of self-management. The exception was quality of life and mobilizing social support, which were not significantly improved in one reported study [35]. Technology-assisted interventions such as phone calls and website- based interventions facilitate the sharing of information with ALWHIV efficiently and cost-effectively. The effectiveness of these types of intervention supported by the study conducted by Millard et al. [33]. In many parts of the world, ALWHIV may have access to cell phones, which allows information exchanges through calling, text messaging and the internet. Therefore, this type of intervention allows for remote access and timely information exchange. It also facilitates the connection between health providers, among peers and patients in resource-limited settings, by minimizing the cost of travel, saving time, and allowing privacy. These benefits may encourage the use of technology for improving self-management behaviors.

Interventions mainly targeting social support for improving self-management were effective in strengthening social relationships and social participation concerning their HIV conditions [24, 33]. However, Webel et al. [35] found no improvement in social support mobilization for self-management among the intervention group. The variability of effectiveness may be related to the mode of delivery. It could also be due to the common practice of searching for information from technology sources or the internet rather than seeking social support for self-managing HIV conditions. Although there were relatively few included studies that assessed social support, based on the current findings, it is possible to infer that social support may improve self-management.

A previous systematic review on a specific self-management education program [13], found that interventions focused on coping and symptom management improved the engagement of people living with HIV in self-management programs and the current review supports this finding. Interventions to improve self-management behaviors that focused on symptom management guidelines or coping behaviors were more effective than usual care [25–27, 34]. However, in two studies [26, 27], the intervention did not show a direct improvement in symptom management, although there were changes in quality of life and CD4 count. The possible explanation for this finding could be differences in the mode of delivery, duration, and type of intervention.

Whilst interventions designed to improve the self-management outcomes were generally found to be more effective than usual care [25, 27, 29, 31, 33–35], there was evidence of variability of effectiveness that could be related to a mix of contextual factors, intervention design features and implementation of the interventions. As the theory indicates [17], there is a complex inter-relationship between contextual factors and the process of self-management that influences a range of proximal and distal outcomes. Few studies provide a sufficiently detailed description of the intervention and its implementation in context to examine these relationships in detail. In particular, there is a lack of contextual grounding of the interventions, for example, in terms of the physical and social environment of study participants, or specific individual and family characteristics. The complex nature of self-management suggests that a multi-faceted, context-sensitive approach to intervention is required and there is unlikely to be a 'one-size-fits-all' solution. Equally, interventions designed to improve self-management need to be accessible and straightforward for users, particularly in resource-constrained settings.

Limitations

The review has some limitations. The search did not include grey literature, with the potential that some relevant studies may have been missed. It was not possible to generate a single estimated effect size due to the heterogeneity of interventions and outcomes evaluated in different studies. Behind a simple description of an intervention such as 'skills training', there was a considerable variation related to the length and frequency of the intervention, how it was delivered, and by whom.

Furthermore, many of the studies involved multi-component interventions, for example, skills training plus counseling. This combination of the complexity of the interventions studied, and inconsistencies with outcome measurement made narrative synthesis and interpretation of the evidence challenging. The review attempted to deal with the complexity and resulting limitations by presenting evidence from both the intervention and outcomes perspective and providing summary tables of individual studies. Overall, many of the interventions studied produced positive benefits; however, it is not possible to make definitive recommendations regarding the most evidence-based way of designing self-management interventions for ALWHIV on ART in terms of which are the best interventions to combine, how to deliver the interventions and over what time. The lack of economic analyses within the included studies is an additional limitation in this regard. Another potential limitation of the review is the fact that the included studies were from high-income countries, mostly North America. No studies were included from Africa or other low and middle-income countries. This may affect the generalizability and applicability of the review to these countries where HIV prevalence is the highest.

Conclusions

This review has synthesized evidence on interventions to improve the self-management of ALWHIV on ART. The evidence indicates that interventions that include components of skills training, counseling, symptom management instructions or manuals, technology-assisted teaching, and social support interventions were generally effective in improving physical, behavioral, and psychosocial self-management outcomes. Different forms of training combined with other modalities of interventions found to be effective in improving self-management outcomes, especially adherence to medication, quality of life, and symptom management. However, peer-based interventions seem less effective in improving different components of self-management. Further studies are required to give more attention to study design, description of interventions, and cost-effectiveness.

Recommendations for practice

Based on the evidence in this review, health professionals are recommended to offer self-management skills training and counseling programs to ALWHIV on ART. There could be a benefit in providing resources such as a symptom management manual and encouraging the use of technology, for example, cell phone messaging and internet applications to enable fast and easy access to information.

Supporting information

S1 Checklist. PRISMA checklists filled.
(DOC)

S1 Table. Summary of evidence findings.
(DOCX)

S1 Appendix. Search strategy.
(DOCX)

S2 Appendix. Data extraction instrument.
(DOCX)

S1 File.
(DOCX)

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Author Contributions

Conceptualization: Habtamu Abera Areri.

Data curation: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

Formal analysis: Habtamu Abera Areri.

Investigation: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

Methodology: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

Project administration: Habtamu Abera Areri.

Resources: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

Software: Habtamu Abera Areri.

Supervision: Amy Marshall, Gillian Harvey.

Validation: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

Writing – original draft: Habtamu Abera Areri.

Writing – review & editing: Habtamu Abera Areri, Amy Marshall, Gillian Harvey.

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Additional files for this published article are attached at the end as an appendix 2: supplementary files and consisted of PRISMA checklist, Summary of evidence findings, Search strategy, and critical appraisal checklist.

Chapter 4: Methodology

4.1 Introduction

Chapters 1, 2 and 3 have provided the background, literature review and presented a systematic review on interventions to improve SM behaviour. This chapter outlines the researcher's ontological and epistemological position, methodology, and the sequential explanatory mixed methods employed to address the research aim and objectives. A survey followed by in-depth interview were conducted and analysed sequentially and the findings from both studies were integrated to better understand the SM behaviour of adults living with HIV in Ethiopia. The study also aimed to synthesize evidence on interventions to enhance SM behaviours. The study aim was addressed through the following objectives:

1. Determine the daily self-management behaviours of ALWHIV on ART
2. Identify factors influencing the self-management behaviours of ALWHIV on ART
3. Make evidence-informed recommendations for improving the SM behaviours of ALWHIV in Ethiopia.

4.2 Ontological and epistemological position of the researcher

Ontology refers to the study of the nature of reality and human knowledge. Reality is relative and depends on how individuals experience it at any given time and place (Moon & Blackman 2014). Epistemology refers to the process of gathering knowledge to understand reality. It is concerned with all aspects of validity, scope, and methods of acquiring knowledge. Epistemology is important because it influences "how the researcher frames their research in an attempt to discover knowledge" (Moon & Blackman 2014:p5). Stemming from ontology and epistemology are philosophical perspectives, generalized views of the world, which form beliefs that guide action. Epistemology influences the way the researcher phrases the research question and conducts the study, and also guides the selection of an appropriate research methodology and methods (Moon & Blackman 2014). The researcher's ontological and epistemological position helps readers understand the relationship between the researcher and the phenomena under investigation.

The phenomena under investigation in this study is SM behaviour and its influencing factors among ALWHIV on ART in Ethiopia. The researcher is qualified in Adult Health Nursing with a strong background in chronic care for long-term diseases and is interested in investigating the SM behaviour of people living with chronic conditions. The researcher also has extensive experience in HIV patient care and treatment. The researcher has engaged in an ART follow-up program, has had the opportunity to discuss chronic HIV care with ALWHIV on ART, and has observed the continued existence of HIV-related illness and frequent hospital visits. The researcher also assumed a trainer position on antiretroviral therapy for HIV care providers and preservice health professionals. In the preservice training program, practical engagement with ALWHIV helped the researcher observe issues of implementing effective SM behaviour. The researcher was also involved in monitoring and evaluating people living with HIV and on a treatment program for six months.

Engagement in service, training and monitoring the HIV program provided the researcher with an opportunity to observe ALWHIV on ART who are self-managing their HIV condition for an extended period, with follow-up visits at three to six-month intervals. During this extended period, ALWHIV were expected to engage in a self-management program. However, the researcher started questioning how successful ALWHIV were at self-management, what problems they were facing related to their HIV SM and how to enhance the engagement of ALWHIV in SM behaviours. The researcher observed irregularities in executing medical recommendations among ALWHIV while monitoring the ART program. This indicated to the researcher that there were gaps in knowledge about SM behaviours and related factors influencing ALWHIV on ART. The researcher has been engaged in teaching and research roles for the past 6–8 years. In addition, the researcher has conducted and published several studies using a quantitative approach. He also has experience and training in qualitative research methodology.

Engagement in the HIV follow-up program, training HIV care providers, involvement in monitoring and evaluating the ART program, and the experience of conducting studies helped the researcher to create a mind map about current HIV care in Ethiopia. The researcher's clinical and educational background in HIV care highlighted the complexity of the issues involved in achieving effective SM and the need for appropriate research methodologies. The researcher's background experiences have informed the researcher's ontological and epistemological position and the choice of mixed-methods research to answer the research questions. In the next section, the study's research methodology will be discussed in detail.

4.3 Methodology

The absence of a comprehensive study on SM behaviour, combined with the researcher's background and ontological and epistemological position, informed the choice of methodology. A sequential explanatory mixed methods design was applied to investigate the factors influencing the SM behaviours of ALWHIV on ART. Mixed methods is a design with "a philosophical assumption as well as the use of multiple methods of inquiry" (Creswell 2014:p4). As a methodology, it involves "philosophical assumptions" that guide the data collection and analysis and the mixture of quantitative and qualitative data in a single study. Mixed-methods research involves a pragmatic philosophical assumption that allows the researcher to use whatever methods will best help the researcher to address the research problem under study. Mixed-methods research addresses different but related research questions and provides diverse data that helps improve understanding of the research problem under study (Creswell 2014). A mixed methods approach also allows the use of different study methods to answer the same question to validate the findings. The next section will discuss the application of a mixed-methods approach to this study.

4.3.1 Mixed-methods research

Mixed-methods research allows the researcher to utilize and integrate different forms of data in one study. It also allows the researcher to integrate the findings of two study designs to refine and clarify the interpretation of the findings. Mixed-methods research can include the utilization of quantitative data supported by in-depth qualitative interviews, observations, focus group discussion, etc. to better understand the phenomena under study through integrated analysis of all sets of findings (Creswell 2014; Polit & Beck 2012). Usually, mixed-methods studies incorporate quantitative and qualitative studies undertaken for breadth and depth of understanding of the phenomena under study. The quantitative methods allow the identification of variance, whereas qualitative methods help to generate a more in-depth and meaningful explanation of the variance and allow a better understanding of the whole picture of the phenomena under study. Therefore, it involves utilizing multiple methods (like a survey and in-depth interviews) and integrating the results of the studies to get better outcomes (Creswell 2014).

There are two types of mixed-methods research based on the time and type of data collection. These are sequential and concurrent mixed-methods research. A concurrent mixed-methods study, also called concurrent parallel mixed methods, uses different research methods on the same dimension at the same time to complement each other. The results are compared and confirmed at the discussion of the study. A sequential mixed-methods study consists of explanatory and exploratory mixed methods. Exploratory mixed-methods research is applicable for research in new fields to explore the important issues of the topic under study, usually starting with a qualitative study. In contrast, explanatory sequential mixed-methods research is the most common mixed-methods research design and involves quantitative data collection and analysis followed by in-depth qualitative data collection and analysis. The initial quantitative study can be used to broadly understand and describe the phenomena under study, followed by a qualitative study design to further explain the initial study (Creswell 2014). This thesis used explanatory sequential mixed methods. In the first phase of the study, a quantitative study was carried out for broad understanding of the SM behaviours and then the key findings followed up qualitatively. The reason for first conducting the quantitative research was to get the broad understanding of the SM behaviours among ALWHIV since there was no study so far in the country. Then second phase built on significant findings from phase one. Then, the findings of both phases were integrated during interpretation to broadly describe and explain the SM behaviours of ALWHIV in the study area.

4.3.2 Quantitative methodology

Quantitative methods are applied in order to generate numerical values that can be analysed by statistical procedures. Quantitative research uses quantitative data collection and statistical analysis to describe and explain the phenomena under study. Researchers using quantitative methods are interested in an objective description of the research findings to examine the relationship between variables (Babbie 2014). Quantitative research adheres to rigorous scientific methods to collect and analyse data and strives for generalizability of the findings beyond the study setting (Polit & Beck 2012).

Quantitative research involves deductive reasoning to generate a prediction that is tested in the real world. It involves a systematic approach from the problem to the solution of the problem. It is interested in gathering empirical evidence that is rooted in objective reality. Quantitative research usually has its roots in positivist epistemology which emphasizes a preference for ‘objective’ truth and reality. However, quantitative research has been criticized for its lack of emphasis on complex human experiences and “inflexibility of vision that does not capture the full breadth of human experience” (Polit & Beck 2012: p14). This drawback of a quantitative design can be minimized by mixing the design with a qualitative study.

Descriptive quantitative study designs are common research approaches designed to observe, describe and document aspects of existing phenomena and sometimes serve as a starting point for hypothesis generation or theory development. They could use a survey approach that involves data collection at a specified point in time. A cross-sectional survey approach can be used to estimate the levels of certain health behaviours, for instance, disease prevalence, level of health-related behaviour and the like at a particular point in a time. A survey is appropriate for describing the status of phenomena under study at a fixed point in time (Polit & Beck 2012). A survey research method is probably the best method available to researchers interested in collecting original data to describe a population too large to observe directly” (Babbie 2014:p283). It allows a researcher to generate a real picture of individuals’ behaviour. For the current study, a survey was an appropriate research method for data collection, for generating a description of a population, generalizing from the study sample to the general population, and generating statistical inferences on variables in the study in a cost-effective way (Babbie 2014). Hence, this study used a quantitative survey as an initial way to examine the SM behaviours of ALWHIV on ART and gain a broad view of the topic of inquiry.

4.3.3 Qualitative methodology

This approach is based on naturalistic inquiry and “emphasizes the inherent complexity of humans, their ability to shape and create their own experiences, and the idea that truth is a composite of realities” (Polit & Beck 2012:p14). As such, qualitative research involves non-numeric examination and interpretation of the phenomena under study to discover underlying meanings and patterns of relationships (Babbie 2014). Through careful data collection and analysis (that could involve narrative, subjective interpretation….), qualitative researchers try to understand human experience. The methodology uses a flexible and inductive processes to develop a description of the phenomena under study. These process of data management helps to “capitalize on findings that emerge from a study and it yields rich, in-depth information that can elucidate varied dimensions of complicated phenomena” (Polit & Beck 2012:p14).

The qualitative descriptive approach allows the choice of various theoretical approaches, purposive sampling, and provision of a descriptive summary of the data in a way that best fits with the collected data (Neergaard et al. 2009; Sandelowski 2000; Sandelowski 2010). It is essential when the researcher aims to gain first-hand knowledge of participants’ life experiences in resource- and time-limited settings (Neergaard et al. 2009). Therefore, the researcher conducting a qualitative descriptive study seeks descriptive validity of the events that most participants agree is an interpretively valid or accurate account of meanings (Sandelowski 2000; Sandelowski 2010). The next section will discuss in detail the research design.

4.4 Research design: A sequential explanatory mixed-methods study

A sequential mixed-methods research design was applied to conduct a quantitative study, followed by a qualitative study to explain the key findings from the quantitative study. The reason a sequential explanatory mixed methods was used in the current study was to get the full picture of the SM behaviours among ALWHIV since there has been no study on this so far in the country. As there is a lack of evidence on the SM of ALWHIV in Ethiopia, it was assumed that the quantitative study’s findings would provide an overview of the SM behaviours of ALWHIV on ART. A qualitative study was used to explain the key findings of the quantitative study. Therefore, the research design consisted of two phases. Phase one involved quantitative data collection and analysis. Phase two involved qualitative in-depth interviews and analysis based on the key findings from phase one. Then the findings of both phases were integrated during interpretation (Figure 2 and data integration detailed in section 4.6).

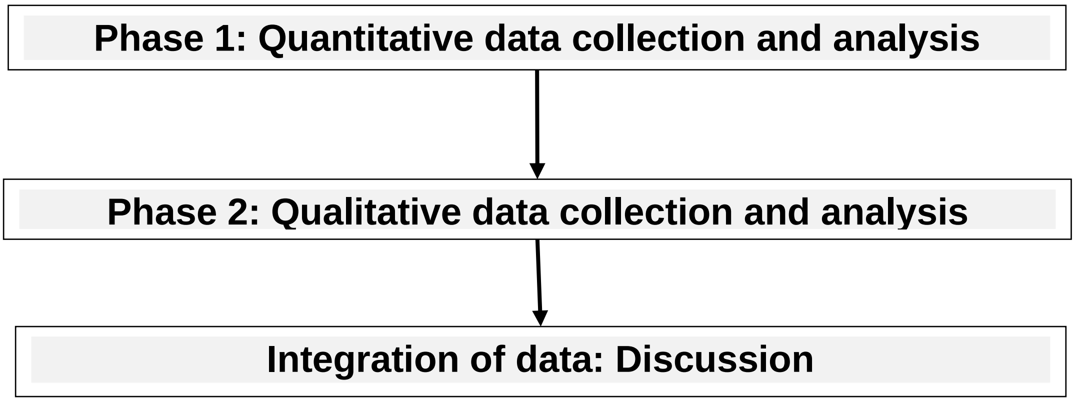

Figure 2. Sequential explanatory mixed-methods research design (Creswell 2014)

Phase one was designed to identify daily SM behaviours and factors influencing them and then key findings from phase one were followed up in the qualitative study to explain key factors influencing SM behaviours (phase two). A mixed-methods approach was chosen because of its strength of simultaneously providing quantitative and qualitative data and minimizing the limitations of both designs (Polit & Beck 2012). Thus, an explanatory sequential mixed-method design helped to examine the SM behaviours and their influencing factors among adults with HIV in the study area. Therefore, the two study designs provided rich data for the conclusion and recommendations (see Figure 3).

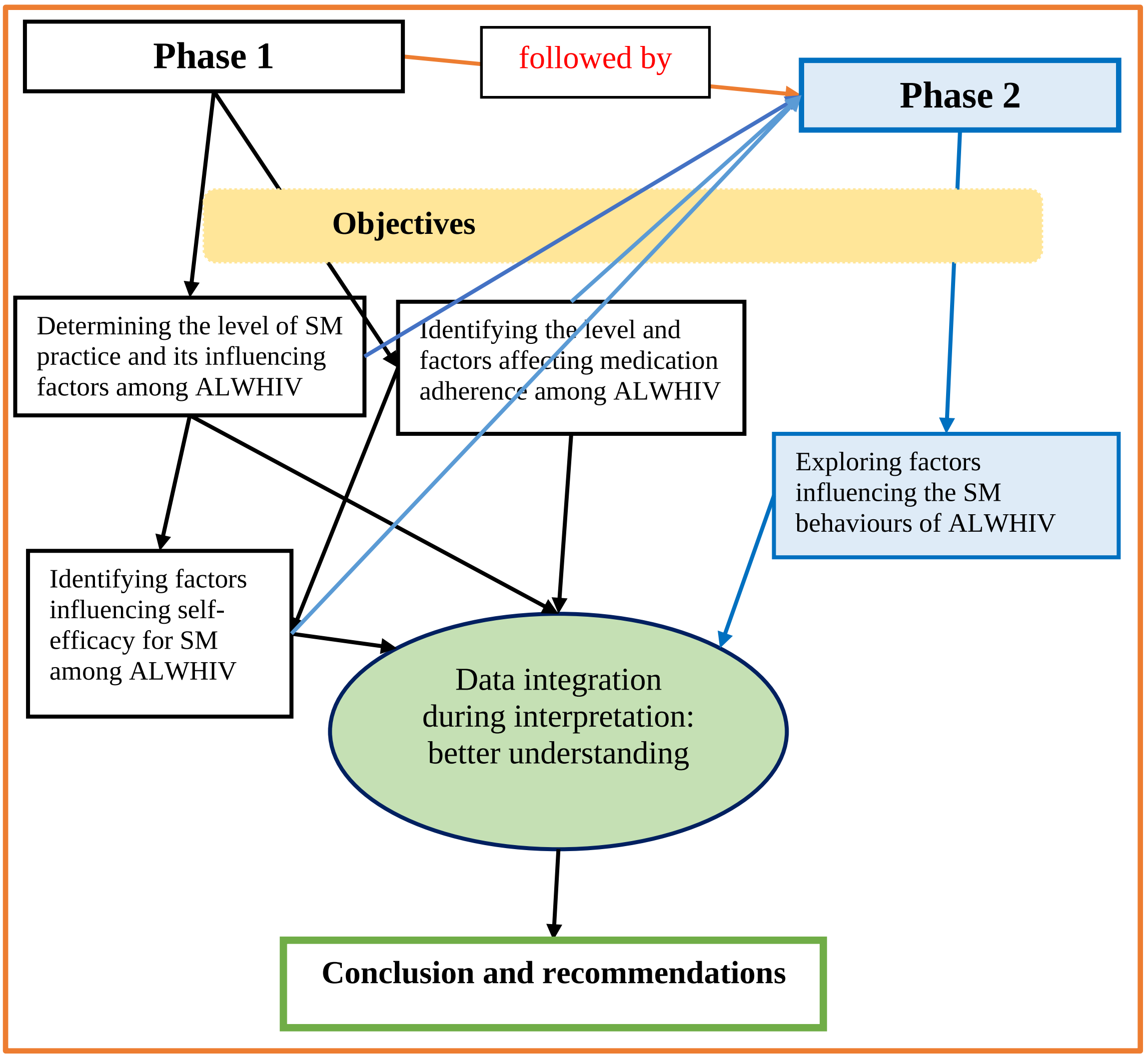

Figure 3. The study design and purpose

In phase one, a cross-sectional survey was used to gain a broad understanding of SM practice, medication adherence and self-efficacy for SM. Then key findings from the survey phase were examined through in-depth interviews in the follow-up phase. The survey phase and qualitative phase were conducted sequentially, and the findings of both phases were integrated, concept by concept under each variable to provide a holistic picture of the current SM behaviours among ALWHIV on ART.

4.5 Research methods

4.5.1 Phase one

4.5.1.1 Study population

The study population in the quantitative study were all ALWHIV and enrolled in ART care in Debre Markos Referral Hospital (DMRH), from which study participants were accessed and selected during the study period. At the time of the study, the hospital was providing care for 3802 ALWHIV on ART, of which 2243 were female, and 1559 were male (DMRH 2019). DMRH was selected as it is a major referral hospital serving a population of over 3.6 million. All adults (≥ 18years**)** living with HIV on therapy for at least six months in DMRH were invited to participate in the study. The study excluded those unable to respond for any reason like illness or being unable to communicate, and those who did not volunteer to sign to indicate their informed consent.

4.5.1.2 Sampling methods

Representativeness can be enhanced through careful planning of the sampling process like sample size, sampling method, and procedures for recruiting participants. The sample size refers to the number of study participants to be included (Polit & Beck 2012). The sample size was calculated using Daniel's (2010) "single population proportion formula" as follows:

$$n = \frac{Z^2 p(1-p)}{d^2}$$

where n = the final sample size from the finite population; Z = a standard score of 95% (1.96); d = the sampling error or marginal error = 5%, and p = the expected proportion of SM practice in the population, which was estimated at 50% since no previous study had been undertaken in Ethiopia. Thus, $N = (1.96^2 \times 0.5(1-0.5))/0.05^2 = 384$ respondents were required for this study. Therefore, this study's final quantitative sample size allowing for a 10% non-response rate was 422 (that is, 384 + 384*10% = 422). Participants were selected from those who came for their quarterly ART appointment. After requesting volunteer participation, convenience sampling was applied to interview 12–15 attendants from the average 30 attendants of the hospital per day during the study period (from 1 April to 30 May 2019). The connivence sampling allowed maximum access to the study participant in a cost effective and short time period.

4.5.1.3 Data collection tool

Phase one used a combination of a face-to-face survey tool developed to measure HIV SM practice (Webel et al. 2012), medication adherence (using a self-report tool developed for low- and middle-income settings) (Patel et al. 2010; Steel, Nwokike & Joshi 2007) and self-efficacy for SM (Wallston et al. 2011). Permission to use the existing validated HIV SM tool was obtained from the developer of the tool through email (Webel, email: arw72@case.edu, 03 November 2018). The tool used to gather data on HIV SM practice was developed in line with the theoretical framework that guided the overall study, namely Individual and Family Self-Management Theory (IFSMT).

The face-to-face administered survey tool was used to explore SM practice, medication adherence and self-efficacy of ALWHIV on ART. This approach had advantages over a self-administered tool. As no reading skill is required and ambiguous items can be clarified, the administered tool was expected to increase the response rate (Polit & Beck 2012). Before use, the tool was reviewed by supervisors and colleagues for clarity. After final agreement on the tool to be used, the survey tool was translated into the local language (Amharic) by registered language experts. The tool was then pre-tested, and feedback from the pre-test process was incorporated and administered face to face by data collectors. The quantitative questionnaire consisted of three sections: sociodemographic and clinical characteristics, the process of SM, and SM practice and self-reported medication adherence (Table 3 and Appendices 3 and 4).

Table 3. Summary of the survey instruments

Theoretical constructs	**Details of research instrument/s used**
Contextual factors	21-item questionnaire developed for this research:
Sociodemographic: individual factors	5 items
Sociodemographic: physical and social environment	7 items
Clinical: Condition-specific factors	9 items
Process of SM	
Knowledge of ART	Existing 10-item questionnaire (Olowookere, Fatiregun & Adewole 2012)
Self-efficacy for SM	Existing 8-item questionnaire (Wallston et al. 2011)
Self-regulation skills	3-item questionnaire developed for this research
Social facilitation	5-item questionnaire developed for this research
SM interventions	3-item questionnaire developed for this research
Outcome: SM behaviours	
SM practice (20 items)	Existing 20-item questionnaire (Webel et al. 2012)
Medication adherence (4 items)	Existing 4-item questionnaire (Patel et al. 2010; Steel, Nwokike & Joshi 2007) and reasons for nonadherence were assessed using the 14-item Revised AIDS Clinical Trial Group Reasons for Missed Medications(Chesney et al. 2000).

4.5.1.4 Measurement

Knowledge of ART. *Knowledge of ART* was measured using an existing instrument. The tool consisted of ten items answered as 'yes' or 'no' responses. Based on the responses, knowledge level was categorized as adequate (6–10) or inadequate (0–5) (Horvath, Smolenski & Amico 2014; Olowookere, Fatiregun & Adewole 2012).

Self-efficacy for SM. *Self-efficacy* was measured using an existing perceived medical condition SM scale. Overall scores were calculated by obtaining the mean of the 8 items scored over a 3-point Likert scale (1 = disagree, 2 = neutral, and 3 = agree). Final scores ranged from 8 to 24, with higher scores reflecting greater self-efficacy (Wallston et al. 2011).

Self-regulation skills. Based on IFSMT and existing literature, three survey items were developed to assess *self-regulation skills* such as goal setting, planning and symptom management. These items were answered as 'yes' or 'no' responses.

Social facilitation. Based on IFSMT and existing literature, five survey items were developed to assess *social facilitation*, which consisted of social influence and support from HIV care providers, family, peers, and social networking. The items were answered as 'yes' or 'no' responses.

SM interventions. SM interventions are strategies used by HIV care providers to enhance the SM practice of ALWHIV. Supportive interventions include information on drug management, symptom management, self-regulation enhancement and social networking. The study used different items to measure SM interventions related to counselling, encouragement to disclose HIV status and adherence support (answered by a yes/no response).

Self-management practice. SM was measured using the HIV SM scale, originally developed in the USA to measure the SM of women living with HIV (Webel et al. 2012). The scale consists of 20 items that focus on daily physical health practices, activating social support and living with HIV as a chronic condition. Each item is scored on a 4-point Likert scale ranging from 0 to 3 (0 = not applicable, 1 = none of the time, 2 = some of the time, and 3 = all the time). A higher score indicates better SM. Cronbach's alpha ranges from 0.62 to 0.77 in the current study, which is slightly lower than the original study's alpha value of 0.72–0.86 (Webel et al. 2012).

Medication adherence. An existing 4-item questionnaire was used and three correct responses out of four items were considered to demonstrate medication adherence (Patel et al. 2010; Steel, Nwokike & Joshi 2007). Additionally, reasons for nonadherence were assessed using the 14-item Revised AIDS Clinical Trial Group Reasons for Missed Medications (Chesney et al. 2000).

4.5.1.5 Validity and reliability

Validity. Content and construct validity are appropriate for assessing the validity of the tool. Researchers can ensure the content validity of a tool through the careful formulation of the research instrument in line with the theoretical framework (IFSMT) and research objectives, which can be verified by experts in the field. This study used an already validated tool (HIV SM Scale, Medication adherence, and Self-efficacy Scale) after pre-testing in Ethiopia. Construct validity refers to the adequacy of an instrument in measuring the core construct it is intended to measure. It also measures the instrument's quality against the theoretical framework (Polit & Beck 2012). Therefore, this study's construct validity was ensured by using tools developed based on the literature and theoretical framework guiding the study.

Reliability. According to Grove, Burns and Gray (2013) and Babbie (2014), reliability stands for the consistency of the measures obtained from the items in a study. In this study, a tool tested in other contexts for its reliability was used after pre-testing the instrument in Ethiopia to enhance its reliability. The reliability of the tool was measured at 0.62–0.77 which is slightly lower than the original study's alpha value of 0.72–0.86 (Webel et al. 2012).

4.5.1.6 Training data collectors and piloting

Two data collectors who have the educational level of BSc, have been trained on ART and have experience in data collection were recruited and employed for the data collection. Training was given to ensure the standardization of the data collection procedure. The training session included how to conduct interviews ethically and with scientific integrity. A practical session followed the training until they mastered the data collection process (Polit & Beck 2012). The data collectors were then sent to pilot the tool on a group of respondents amounting to 5% of the required number of study participants in a different hospital (F/Selam General Hospital). This was done not to include the participants from pilot in the study sample, one month before the actual data collection. After the pilot test, discussion was carried out with the data collectors to assess the tool’s clarity and the time required to complete the face-to-face survey. Some minor revisions were made to reduce the time required to complete the questions on educational level and job status.

4.5.1.7 Data collection procedure

Nurses working in the ART clinic were contacted to arrange data collection after obtaining ethics clearance and permission from the responsible body. An invitation letter and information sheet were posted during the survey data collection period to invite participants to take part in the study (Appendices 5 and 6). For those who could not read and understand the letter, the team read it for them in the waiting area and gave them time to decide whether to participate. A face-to-face request for participation was carried out during the initial contact since the next follow-up appointment would be three months away or more. Then, selected participants were asked to sign a consent form before starting the face-to-face survey in a private room. The consent form could also be signed using a fingerprint (a common practice in Ethiopia) for those who could not read and write after fully understanding the project. After the study’s aim was clarified, the trained data collectors delivered a face-to-face survey with consenting participants during the survey’s data collection period (1 April to 30 May 2019). The data collection times were in the morning and afternoon while the participants were sitting in the waiting areas after registration. The survey was carried out in the adherence counselling room (a natural environment) where they usually received a counselling service. To maintain the respondents' anonymity and privacy, their name or any identifier were not used on the data collection tool.

4.5.1.8 Data analysis

The quantitative study consisted of three stages of quantitative analysis depending on the nature of the outcome after the data was entered into the software SPSS version 25.0. The analysis was carried out using SPSS software, and the output included descriptive statistics like the mean, frequency, percentages and graphic representation, and inferential statistics like hierarchical multiple regression, multiple linear regression and logistic regression depending on the nature of outcome variables.

Based on the objective of the study, two separate primary analyses were carried out. The first analysis focused on SM practice, and the responses were scored over 4-point Likert scales. The outcome was then summarized using mean and standard deviation, while categorical items were described using frequencies and percentages. The difference in mean of SM practice was assessed using an independent *t-test* and one-way *ANOVA*. Associations between selected factors and the outcome were assessed using Pearson and Spearman rank correlations. Variables that were statistically significant in bivariate analysis were used as covariates. Hierarchical multiple regression analysis was then used to identify factors influencing SM practice based on IFSMT (see Chapter 5).

The second quantitative analysis focused on medication adherence as a key SM behavioural outcome and its influencing factors. Descriptive analysis such as frequency, percentage, mean and standard deviation were used. Associations between selected factors and the outcome were assessed using Spearman rank correlations and logistic regression. Variables that were statistically significant on bivariate analysis were used as covariates. A logistic regression model was used for the analysis of factors associated with medication adherence (see Chapter 6).

A third quantitative analysis was required as self-efficacy for SM remains a powerful predictor for both SM behaviour outcomes, namely SM practice and medication adherence. Descriptive statistics such as mean, frequency, percentage and standard deviation were used to summarize the data. An independent *t-test* and one-way *ANOVA* were performed to identify the differences in self-efficacy for SM scores according to the demographic, clinical and intervention characteristics. Correlation analysis was carried out for self-efficacy for SM and independent variables. Based on the findings from the bivariate analysis, linear regression analysis was performed to identify factors influencing self-efficacy for SM among ALWHIV on ART based on IFSMT. A *p*-value less than 0.05 was considered statistically significant. Text and tables were used for presentation of the findings (see Chapter 7).

4.5.2 Phase two

4.5.2.1 Participant recruitment

Participants were given an opportunity (an invitation letter with an additional information sheet for the in-depth interview was posted) to participate in the in-depth interview during survey data collection and then, volunteer participants were contacted through their contact details for in-depth interview (Appendix 5 and 7). A total of twenty participants showed interest to be interviewed. From this pool, participants were purposively selected to ensure balanced representation. A final sample size was achieved after the first 11 interviews, which was determined based on the a criterion of data saturation (Polit & Beck 2012).

4.5.2.2 Data collection

An interview guide was developed in line with Individual and Family Self-Management Theory (IFSMT) and key survey findings (Appendix 8). Before starting the in-depth interview, the purpose of the study, procedure, and the need to use audio tape were explained to participants. Then, participants requested to sign consent for their participation and for the use of audio recordings. The researcher used an interview guide to ensure consistency. During the in-depth interview, the researcher tried to keep participants comfortable as much as possible to make them express their feeling. A probing technique was used for deep understanding of the variable of study. The details of the data collection are discussed in Chapter 8.

4.5.2.3 Data analysis

The interview was conducted in the local language (Amharic). Each interview was transcribed and checked against the audio recordings by principal investigator. The interview data were then translated from the local language to English by a language expert before the final analysis. Cross checking for accuracy was conducted. Then, the interview transcription was read multiple times to get a sense of the important themes. This helped with the coding of the data before importing it into NVivo 12 software for analysis. During the process of reading and coding, the researcher kept memos for later checking and use. Rigour was ensured by the principal investigator and two supervisors coding and data checking independently. The researcher initially coded the data, and then discussed the emerging codes and themes with the research supervisors. Frequent discussions among project members were carried out during the analysis to improve the findings' credibility and dependability. Braun and Clark's six-step thematic analysis approach was followed for the final qualitative data analysis (Braun & Clarke 2006). The steps involve:

- **Step 1: Familiarization with the data.** At this stage, the researcher immersed himself into the data to become familiar with the collected data through repeated reading in an active way, searching for meanings and patterns. This involved transcription and prolonged engagement in the process of analysis to enhance the credibility of the findings.
- **Step 2: Generating initial codes.** Inductively the interview data were coded with as many codes as possible. Initial coding was carried by three investigators who then met and briefed each other on the coding, which enhanced the credibility of the findings.
- **Step 3: Searching for themes.** In this step, the codes were sorted into themes. Codes were visually represented to help the sorting of different codes into themes. At this time the researcher thought about the relationship between codes and themes. Some initial codes formed main themes while others were considered as sub-themes.
- **Step 4: Reviewing the themes.** The formulated themes were reviewed and revised so that they could be refined. Then some codes were merged due to the diverse meaning of the supporting data while others were deleted due to insufficient data to support the theme, while different themes could also be merged into one theme. Themes were checked in relation to the coded extracts and generated thematic map. The final coding map is included in Chapter 8.
- **Step 5: Defining and renaming the themes.** This step helped the researcher to identify the story that each theme told. Ongoing analysis refined the theme and the story the analysis told, generate a clear definitions and names for each theme. Then, the formulated themes were shared among the team, and discussion carried out to identify the name that best described the theme. For each theme, a detailed analysis was carried out.

- **Step 6: Producing the final report.** Finally, a scholarly report is produced in accordance with the research question and literature. Then, the findings were interpreted and presented in the text under each theme. Frequently used expressions of the participants were used in italics.

4.5.2.4 Trustworthiness

Trustworthiness is a scientific approach by which qualitative researchers ensure the quality of data. It also refers to the validity the researchers try to achieve by ensuring specific criteria like *credibility, dependability, transferability* and *confirmability* (Polit & Beck 2012).

Credibility was ensured by allocating adequate time for the in-depth interviews, using the participants' own words during analysis, and keeping all interview records and notes for review whenever necessary. The *dependability* of the study was ensured through the use of an inquiry audit which is the process of validating the data by reviewing the recorded data, audios and the relevant data collection processes. Therefore, all audio records, transcribed texts and field notes will be kept for five years to check whether the findings, interpretations and conclusions are accurately supported by the data (Pandey & Patnaik 2014). Keeping the interview documents is also helpful for ensuring *confirmability*. Therefore, to ensure the confirmability of the findings, the researcher worked with the supervisors to check and recheck the collected data. Finally, *transferability* is "the extent to which the findings can be applied to other similar settings" (Polit & Beck 2012). Transferability is established through thick description and purposive sampling. Describing the process of data collection in detail helps the evaluation of the extent to which the conclusion is transferable to other settings (Pandey & Patnaik 2014).

4.6 Data integration

Mixed-methods research can only achieve better understanding when integration is carried out to mix both data sets during the interpretation of the results (Creswell 2014). The integration of quantitative and qualitative data can enhance the value of mixed methods research as either data set can be used to assess the validity of the other data set. Integration at the interpretation and reporting level was done through a narrative integration approach. The study findings were discussed when reviewing the qualitative and quantitative findings in a series of reports, theme-by-theme, or concept-by-concept (Fetters, Curry & Creswell 2013). In this thesis, the findings from both phases were narratively integrated and discussed concept-by-concept.

4.7 Ethics approval

The study was approved by the Human Research Ethics Committee at the University of Adelaide (Approval number: H-2018-243) (Appendix 9) and the Amhara Regional Health Bureau Research Office (Approval number: APHHRTD/03/264/2019) (Appendix 10). A letter of support was obtained from the Amhara Regional Health Bureau Research Office (Appendix 11). Then, permission was obtained from DMRH to get access to the study participants. Potential participants were not under any external influence to participate or not in the research. The participants of this study had the right to withdraw at any time from the research project without any negative consequences. The right to privacy is another crucial aspect of research ethics, and therefore the data was collected in private rooms and always kept private. Participants' identities were not recorded on the survey tool to maintain confidentiality and anonymity.

There were no immediate individual benefits or direct risks to participants in the study. However, participants were informed that the research findings could help to improve SM by identifying the barriers and recommending ways to address them. There was minimal risk related to social discomfort for participants during data collection and this was minimized by conducting the interviews in private ‘adherence’ counselling rooms. Informed consent (Appendix 12) was obtained from the study participants voluntarily after they received adequate information about the proposed research (Grove, Burns & Gray 2013). Consent was also obtained for participation in the interviews and the use of audio recording before data collection (Appendix 13). The study’s data files were entered into password-protected files. Once the digital recordings were transferred to a password-protected file on a computer, the interview was deleted from the recorder.

4.8 Summary

This chapter has outlined the methodology and associated quantitative and qualitative methods that were applied to generate, analyse, and interpret survey and interview data. The following chapters will present the findings of survey study in journal publication format. Four published articles and one manuscript submitted for possible journal publication were included in the next chapters.

Chapter 5: Paper 2

Factors influencing self-management of adults living with HIV on antiretroviral therapy in north-west Ethiopia: A cross-sectional study

5.1 Preface

This chapter reports the quantitative findings from phase one of the study relating to the first outcome of interest, SM practice among ALWHIV on ART. This involved assessing the level of SM practice amongst the study population in north-west Ethiopia using a validated survey tool and the factors that influenced their SM practice. The resulting article was published in *BMC Infectious Diseases*. The overall level of SM practice was low relative to international comparisons and multiple, intersecting factors were found to affect SM practice. The findings were applied to inform subsequent quantitative analyses and the design of the interview schedules for the qualitative study in the second phase of the research to better explore the key factors influencing SM behaviours.

5.2 Publication

Areri, H, Marshall, A & Harvey, G 2020, ‘Factors influencing self-management of adults living with HIV on antiretroviral therapy in northwest Ethiopia: a cross-sectional study’, *BMC Infect Dis.*, vol. 20, no. 1, art. 879, <https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-020-05618-y>.

Statement of Authorship

Title of Paper	Factors influencing self-management of adults living with HIV on Antiretroviral Therapy in Northwest Ethiopia: A cross-sectional study
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Principal Author

Name of Principal Author (Candidate)	Habtamu Abera Areri		
Contribution to the Paper	Conceived the study, designed the study, conducted data analysis, interpreted the findings and drafted the manuscript		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	May 20, 2020

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Name of Co-Author	Dr Amy Marshall		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation, and reviewed the manuscript.		
Signature		Date	May 26, 2020

Name of Co-Author	Professor Gillian Harvey		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	May 26, 2020

Please cut and paste additional co-author panels here as required

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BMC Infectious Diseases

RESEARCH ARTICLE

Open Access

Factors influencing self-management of adults living with HIV on antiretroviral therapy in Northwest Ethiopia: a cross-sectional study

Habtamu Areri[1,2*†], Amy Marshall[1†] and Gillian Harvey[1†]

Abstract

Background: Effective self-management is an important consideration for adults living with HIV on therapy to enable people to maintain their health and well-being whilst living with chronic HIV. Although numerous attempts have been made to implement and improve HIV self-management practice, there is limited evidence on effective self-management strategies, particularly in sub-Saharan Africa. This study aimed to identify the level and factors influencing the self-management practice of adults living with HIV on antiretroviral therapy.

Methods: A cross-sectional survey was conducted on a sample of 415 adults living with HIV on antiretroviral therapy at a major referral hospital in Northwest Ethiopia using convenience sampling. A theory of self-management – the Individual and Family Self-Management Theory - guided the study design, analysis and presentation of the data. A face-to-face survey tool was administered for data collection, and the data were entered and analyzed using SPSS version 25.0.

Results: Over half (58.1%) of the respondents were female. Many of the respondents did not know their HIV stage (76.9%) but reported adequate knowledge of their treatment (79.5%). The mean self-management score was 1.94– 0.22 out of a total score of 3. Female gender was associated with decreased self-management. Contextual factors (gender, educational level, job status, income, living in a rural area, and awareness of HIV stage) explained 8.2% of the variance in self-management. The explanatory power increased by 9.2% when self-management process variables (self-efficacy, setting a goal, knowledge of antiretroviral therapy, HIV disclosure, and use of reminders) were added. Intervention-focused variables (encouraging disclosure and adherence support) increased the proportion of explained variance by 2.3%.

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* Correspondence: habtamu.abera64@gmail.com;
habtamu.areri@adelaide.edu.au

†These authors contributed to the study design and preparation of the manuscript equally. All authors approved the final version for submission.

†Habtamu Areri, Amy Marshall and Gillian Harvey contributed equally to this work.

[1]Adelaide Nursing School, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, SA 5005, Australia
[2]School of Nursing and Midwifery, College of Health Sciences, Addis Ababa University, 4412 Addis Ababa, Ethiopia

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Conclusions: The findings of the study indicate that the level of self-management practice amongst the population studied was low compared to international literature. Our study findings support the theoretical model and previously identified factors influencing HIV self-management. The most important predictors of lower self-management practice in Ethiopia were female gender, illiteracy, lack of awareness of HIV stage, low self-efficacy, absence of reminders, lack of encouragement to disclose and absence of adherence support. HIV care providers should seek ways to empower and support adults living with HIV to self-manage, particularly through enhancing self-efficacy and encouraging the use of reminders.

Keywords: Adults living with HIV, Antiretroviral therapy, HIV/AIDS, Individual and family self-management theory, Knowledge of HIV treatment, Self-efficacy, Self-management

Background

Globally, since the start of the HIV epidemic, it is estimated that over 70 million people have been infected and 32 million have died of AIDS-related illnesses. About 38 million people are currently living with HIV, most of whom are adults (36.2 million) [1]. This figure includes around 25.7 million individuals in Africa [2], of whom 690,000 are living in Ethiopia. Women are disproportionately represented in Ethiopia, with approximately 410,000 out of the 690,000 being women. Even though rates of new HIV infection declined by 79% from 2010 to 2018, 11,000 people died from AIDS-related complications in Ethiopia in the year 2018. The national Antiretroviral Therapy (ART) coverage is 66%, meaning around a third of the population currently lack access to ART [3].

Recently, there has been an emphasis on self-management outcomes to achieve optimal benefits from HIV interventions in Ethiopia [4]. Self-management refers to managing illness need (managing medication, daily physical health), activating social support (family, peers, and HIV care providers), and living with chronic illness [5, 6]. Successful ART programs depend on effective and prolonged SM programs to ensure optimal uptake of medical, physical, emotional, and psychological recommendations [5]. Health care providers can help identify the unique SM needs of patients and guide a patient-centred approach to enable patients to be the self-manager of their health conditions [6–8].

Studies on HIV SM in high-income and upper-middle-income countries focus on three domains of SM, namely daily physical health practice, social support, and living with HIV [6, 9, 10]. Daily physical health practice refers to physical exercise, diet management, reducing stress, symptom management, managing drug side effects and implementing other recommended physical health activities. Activating social support refers to the use of families, health care providers and social networking for effective SM. Living with HIV refers to accepting and adjusting to HIV, dealing with stigma and giving meaning to life with existing conditions [5, 6, 10]. A survey conducted among women living with HIV in the United States of America (USA) reported mean scores of daily physical health practice 2.19 ± 0.53, activating social support 2.0 ± 0.88, living with chronic HIV 2.64 ± 0.43 and an overall mean SM score of 2.28 ± 0.61 out of a maximum score of 3, which was interpreted by the authors as a moderate level of SM [11]. A similar study using the same scale and conducted in China indicated lower mean scores: daily physical health practice, 1.80 ± 0.42, activating social support, 1.47 ± 0.63, living with chronic HIV, 2.46 ± 0.43 and an overall mean SM score of 1.91 ± 0.36, which was interpreted as low [12]. A third study conducted in Korea using the same scale reported an overall SM mean score of 2.00 ± 0.49, again interpreted as low [9]. These findings demonstrate variable levels of SM across different international settings.

The factors influencing SM will be discussed through the theoretical lens of the Individual and Family Self-management Theory (IFSMT) which was developed to frame the management of chronic conditions including HIV [13]. This middle-range theory is descriptive and comprises dynamic and interrelated constructs defined as the context, the process of SM, SM interventions and SM outcomes. The contextual factors focus on “risk and protective factors”, including condition-specific factors, the physical and social environment, and individual factors. The “process of SM” encompasses knowledge of ART, self-efficacy, self-regulation abilities, and social facilitation. Self-regulation is a process of individuals setting an engagement to achieve a change in health behaviours. Social facilitation is a means of social influence, support, and negotiated collaboration. Social influence can be exerted by HIV care providers, family, and peer networks with the explicit goal of facilitating engagement in recommended behaviours. SM interventions are interventions intended to enhance both the process and outcomes of SM [13]. SM outcomes are concerned with different aspects of practicing SM and include daily physical practice, activating social support, and managing medication whilst living with chronic HIV [5, 6, 9, 11, 12, 14] (see Fig. 1).

Few studies have addressed all the domains of SM in a comprehensive way, as outlined in the IFSMT [9, 11, 12]. Rather, individual studies tend to focus on specific

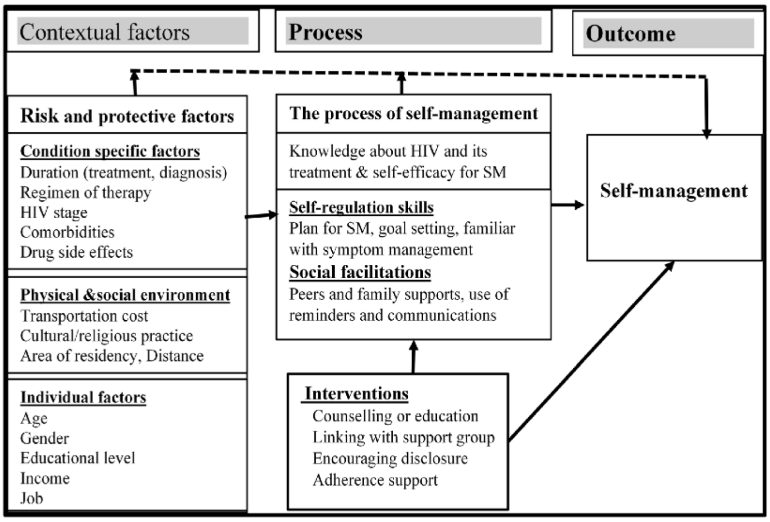

Fig. 1 Conceptual framework of self-management of ALWHIV developed from IFSMT

aspects of SM and the factors that affect this, such as treatment duration [15], regimen complexity [16, 17], comorbidities [16, 18–20], and drug side effects [21], which can be categorized as condition-specific factors under the contextual factors in IFSMT. Other contextual factors studied that influence SM of ALWHIV correspond with the physical and social environment domains of the IFSMT. These include the cost of travel [22], area of residence and distance from health facilities [12], and religious practices such as fasting or using holy water [23]. In the IFSMT, individual characteristics are also viewed as responsible for enhancing or inhibiting engagement in SM behaviours. Individual factors influencing SM identified in previous research include age, gender, educational level [11] and income [11, 12, 24].

According to the IFSMT, the process of SM can be influenced by factors such as knowledge, self-efficacy, self-regulation abilities, and social facilitation. Russell et al. [5, 25] and WHO [26] reported that adequate knowledge of HIV treatment enhances SM. Self-efficacy, namely a person's perception of their ability to self-manage, is another factor that influences SM [27], with studies demonstrating that a higher self-efficacy is associated with improved utilization of recommended health behaviours [28, 29]. The presence of social support [12, 30], reminders and a good relationship with HIV care providers have been shown to facilitate engagement in care [31, 32]. However, barriers to mobilizing existing community resources for SM include non-disclosure of HIV status, inadequate information, and negative community perceptions towards people living with HIV. Therefore, interventions are required to overcome the barriers and enhance SM practice [30, 32]. Examples of such interventions include counselling, adherence support and encouraging disclosure [30, 31]. Overall, patient-centred interventions are seen to be the most effective in fostering engagement in SM practice [13, 31–33].

In Ethiopia, it has proved difficult to avoid HIV related complications, which are a cause of frequent hospital visits [34, 35]. Sub-optimal levels of adherence, fear of stigma and disclosure, and opportunistic infection treatment costs remain a major challenge for ALWHIV in Ethiopia [36–38]. Although the chronic care model has been incorporated and implemented in the HIV program of the country, there is a lack of evidence about the practice of SM for ALWHIV on ART. Therefore, this study aimed to identify the level and factors influencing the SM of ALWHIV on ART in a regional area of Ethiopia. The study aimed to address two specific objectives, namely: 1) to determine the level of SM practice and 2) to identify factors influencing SM practice of ALWHIV on ART in the study area.

Methods

Study design, setting, participants and sampling

In order to address the research question, a survey was conducted at a referral hospital in Northwest Ethiopia. The study sample was selected from ALWHIV (18 years plus), enrolled in ART care for at least six months and visiting the referral hospital during the study period (April 1 to May 30, 2019). The study area had 3802 adults on ART (2243 females and 1559 males) in the year 2018 [39]. Daniel's [40] "single population proportion formula" was used to estimate the sample size. The estimation was based on an assumption of the standard score of 95% (1.96), the sampling error 0.05, and a 50%

of SM practice among ALWHIV since no previous study had been conducted in the study area. This indicated a required sample size of 384. To allow for a 10% non-response rate, the final sample size was set at 422. Convenience sampling was used to identify 12–15 volunteer participants per day attending the HIV clinic.

Variables and measurement

The survey tool comprised a combination of existing instruments and additional survey questions that were designed for the study based on the constructs of IFSMT and relevant literature (Table 1 and Additional file 2).

Contextual factors

Sociodemographic and clinical data from the participants were collected using a 21-item questionnaire developed for the purposes of the study, based on the IFSMT and variables identified in the literature. Sociodemographic questions encompassed the individual, physical and social environment. Clinical factors influencing the patient's health status included duration of HIV diagnosis, duration of ART, HIV stage, treatment changes, comorbidities, other treatments, number of drugs taken, and drug side effects.

The process of SM

The process of SM was assessed across 4 areas, namely knowledge of ART, self-efficacy, self-regulation abilities, and social facilitation, using a combination of existing instruments and additional questionnaires developed specifically for the study.

The *knowledge of ART* was measured using an existing instrument. The tool consisted of ten items answered as 'yes' or 'no' responses. Based on the responses, knowledge level was categorized as adequate (6–10) or inadequate (0–5) [41, 42]. The *self-efficacy* was measured using an existing perceived medical condition SM scale. Overall scores were calculated by obtaining the mean of the 8 items scored over a 3-point Likert scale *(1 = disagree, 2 = neutral, and 3 = agree).* Final scores ranged from 8 to 24, with higher scores reflecting greater self-efficacy [27]. Based on the IFSMT and existing literature, three survey items were developed to assess *self-regulation skills* such as goal setting, planning, and symptom management. These items were answered as "yes" or "no" responses. Similarly, based on the IFSMT and existing literature, five survey items were developed to assess *social facilitation*, which consisted of social influence and support from HIV care providers, family, peers and social networking. The items were answered as 'yes' or 'no' responses.

SM interventions

SM interventions are strategies used by HIV care providers to enhance the SM practice of ALWHIV. Supportive interventions include information on drug management, symptom management, self-regulation enhancement and social networking. The study used different items to measure SM interventions related to counselling, encouragement to disclose HIV status and adherence support (answered by a yes/no response).

Self-management

SM practice was measured using the HIV SM scale, originally developed in the USA to measure SM of women living with HIV [10]. The scale consists of 20 items that focus on daily physical health practice, activating social support and living with chronic HIV conditions. Each item is scored on a four-point Likert scale ranging from 0 to 3 (0 = *not applicable*, 1 = *none of the time*, 2 = *some of the time*, and 3 = *all the time)*. A higher score indicating better SM. Cronbach's alpha ranges from 0.62–0.77 in the current study, which is slightly lower than the original study's alpha value of 0.72–0.86 [10].

The current study translated the above existing tool [10] into the local language (Amharic) to combine them

Table 1 Summary of the survey instruments

Theoretical constructs	Details of research instrument/s used
Contextual factors	21 item questionnaire developed for this research:
Sociodemographic: individual factors	5 items
Sociodemographic: physical and social environment	7 items
Clinical: Conditions specific factors	9 items
Process of SM	
Knowledge of ART	Existing 10 item questionnaire [41]
Self-efficacy for SM	Existing 8 item questionnaire [27]
Self-regulation skills	3 item questionnaire developed for this research
Social facilitation	5 item questionnaire developed for this research
SM interventions	3 Item questionnaire developed for this research
Outcome	
SM practice (20 items)	Existing 20 item questionnaire [10]

with the other sections created specifically for this study in Amharic. The locally translated data collection tool was pretested on 5% of the total sample size one month before the main data collection commenced, and some minor revisions were made. The data collection was conducted by degree qualified nurses with experience in research and HIV care. The survey was administered via a face-to-face interview in a private room with consented participants.

Statistical methods

The SM score out of a maximum of 60 was calculated and changed to mean score within SPSS version 25.0. There were no identified missing data. Continuously measured variables were summarized using the mean and standard deviation, while categorical items were described using frequencies and percentages. The difference in mean of SM was assessed using an Independent *t-test* and *one-way* ANO VA. Associations between selected factors and the outcome were assessed using Pearson and Spearman rank correlations, and Hierarchical multiple regression for binary and continuous outcomes, respectively. Variables that were statistically significant in bivariate analysis were used as covariates. Hierarchical multiple regression analysis was then used to identify factors influencing SM based on the IFSMT. Variables from contextual factors were entered at model 1.Variables from the process of SM were then added to the model at model 2, and finally, variables from SM interventions were added at model 3. A *p*-value of less than 0.05 was considered statistically significant.

Results

The response rate to the survey was 98.34% ($n = 415$). The results are presented according to the key constructs of the IFSMT, namely: contextual factors (sociodemographic and clinical characteristics), the process of SM, SM interventions and SM outcomes. Findings from the inferential analysis are then presented to describe the factors influencing SM.

Contextual factors

Sociodemographic: individual factors, physical and social environment

Over half, 58.1% ($n = 241$), of respondents were female, which is representative of the proportion of women living with HIV in Ethiopia. The mean age of the respondents was 41.05 ± 10.54 years. Over one-third of the respondents, 34.9% ($n = 145$) were illiterate, and over half, 51.3% ($n = 213$) were employed privately. The mean monthly income of the respondents was 100 ± 96.52USD. The mean distance travelled to the ART facility was 31.75 ± 41.11 km, and the cost of transportation was reported as a challenge for 29.6% ($n = 123$) of respondents. There was a difference in the mean of SM in terms of gender (males better in SM), educational level (higher educational level increased SM), job categories (those who were employed in government jobs were better in SM), and place of dwelling (urban dwellers had better SM than rural) (see Table 2).

Clinical characteristics: condition-specific factors

The mean duration of HIV diagnosis and therapy was 8.69 ± 3.89 and 7.99 ± 3.66 years, respectively. Over three-quarters, 76.4% ($n = 317$) of the respondents did not know their HIV stage. Respondents who knew their HIV stage had a higher mean SM score (see Table 2).

The process of SM

Knowledge, self-efficacy, self-regulation skills, and social facilitation

The majority, 79.5% ($n = 330$), of the respondents reported adequate knowledge of their HIV treatment. The mean self-efficacy score was 19.76 ± 0.12 (out of a possible total of 24). Most of the respondents, 93.0% ($n = 386$), reported that they got information on ART from health care providers, and over half, 51.6% ($n = 214$), received reminders about SM. A higher mean SM score was observed among respondents who had adequate knowledge, set a plan for emotional distress, were familiar with how to manage HIV-related symptoms, had set goals in relation to their treatment program, who received information on ART and who used reminders for SM. The majority, 74.2% ($n = 308$), of respondents did not have support either from family or peers (see Table 3). One fifth, 20.7% ($n = 86$) of the participants did not disclose their HIV status to the community for reasons relating to fear of stigma (47.3%; $n = 79$), fear of discrimination (46.7%; $n = 78$), or because they did not consider it to be important (6.0%; $n = 10$).

Self-management interventions

The majority, 80.7% ($n = 335$), of respondents considered the counselling they received was adequate for their next step of HIV treatment. Most of the respondents, 92.3% ($n = 383$), were encouraged to disclose their HIV status. Almost three-quarters of the respondents, 73.0% ($n = 303$), were not linked to social networks. A higher mean SM score was reported among respondents who were encouraged to disclose their HIV status and those who received adherence support (see Table 3).

Outcome: self-management practice

The overall SM score (out of 60) was converted to a score out of 3, in line with the Likert scale used and in order to make comparison with reported from other studies using the same instrument. The overall mean of the HIV SM item score was 1.94 ± 0.22 out of maximum 3. About 47% ($n = 195$) of the participants scored below the mean value whereas the rest, 53%($n = 220$) scored

Table 2 Mean SM according to demographic and clinical characteristics ($n = 415$)

Variables	*n* (%)	Mean (SD)	t or F	*p*
Gender				
Male	174 (41.9)	39.54 (4.49)	2.829	0.005
Female	241 (58.1)	38.32 (4.32)		
Educational level				
Illiterate	145 (34.9)	37.72 (4.15)	6.279	< 0.001
Primary education	103 (24.8)	38.83 (4.40)		
High school [a]	100 (24.1)	39.65 (4.21)	(a < b)	
College and above education [b]	67 (16.1)	40.06 (4.58)		
Job-status				
Governmental employed [a]	73 (17.6)	40.47 (4.17)	7.446	0.001
Privately employed [b]	213 (51.3)	38.76 (4.28)		
No regular job	129 (31.1)	38.04 (4.44)	(a > b)	
Religion				
Orthodox Christian	396 (95.4)	38.87 (4.39)	0.621	0.538
Protestant Christian	6 (1.4)	39.33 (5.13)		
Muslim	13 (3.1)	37.54 (3.67)		
Marital status				
Never married	26 (6.3)	38.73 (4.15)	1.765	0.173
Married	208 (50.1)	39.23 (4.29)		
Live separated/Divorced/Widowed	181 (43.6)	38.40 (4.50)		
Living arrangement				
Lives alone	91 (21.9)	39.13 (4.56)	0.728	0.467
Lives with families/parents	324 (78.1)	38.75 (4.33)		
Area of residency				
Rural	106 (25.5)	38.00 (3.94)	−2.289	0.023
Urban	308 (74.5)	39.12 (4.49)		
HIV Stage				
I know it	98 (23.6)	40.47 (4.47)	4.312	< 0.001
I do not know it	317 (76.4)	38.33 (4.23)		
Treatment changed				
Yes	110 (26.5)	39.13 (4.20)	0.813	0.417
No	305 (73.5)	38.73 (4.45)		
Comorbidities				
Yes	45 (10.8)	38.76 (4.54)	−0.131	0.896
No	370 (89.2)	38.85 (4.37)		
Treatment for comorbidities				
Yes	40 (9.6)	38.83 (4.59)	−0.017	0.987
No	375 (90.4)	38.84 (4.36)		
Number of drugs				
One type	312 (75.2)	38.84 (4.37)	0.345	0.709
Two types	68 (16.4)	39.09 (4.88)		
More than two types	35 (8.4)	38.32 (3.34)		
Drug side effects				
Yes	38 (9.2)	38.53 (4.27)	−0.457	0.648
No	377 (90.8)	38.87 (4.40)		

[a & b] post hoc analysis significant mean difference

Table 3 Mean SM according to process of SM and SM interventions (*n* = 415)

Variables	*n* (%)	Mean (SD)	t or F	*p*
The process of SM				
Knowledge of ART				
Inadequate	85 (20.5)	37.73 (3.81)	2.631	0.009
Adequate	330 (79.5)	39.12 (4.48)		
Self-efficacy for SM, Mean (SD)	19.76 ± 0.12			
Have a plan for emotional distress				
Yes	358 (86.3)	39.04 (4.38)	2.379	0.018
No	57 (13.7)	37.56 (4.18)		
Familiar with how to manage HIV illness-related symptoms				
Yes	165 (39.8)	39.38 (4.59)	2.070	0.039
No	250 (60.2)	38.48 (4.21)		
Set a goal in the process of HIV therapy				
Yes	395 (95.2)	38.94 (4.35)	2.193	0.029
No	20 (4.8)	36.75 (4.59)		
Got support from family/peers				
Yes	107 (25.8)	39.48 (4.81)	2.380	0.018
No	308 (74.2)	38.56 (4.22)		
Got information on ART from health care providers				
Yes	386 (93.0)	38.96 (4.39)	2.041	0.042
No	29 (7.0)	37.24 (4.02)		
Used reminders for HIV management				
Yes	214 (51.6)	39.51 (4.37)	3.268	< 0.001
No	201 (48.4)	38.12 (4.29)		
HIV disclosure				
Yes	329 (79.3)	39.05 (4.31)	1.967	0.050
No	86 (20.7)	38.01 (4.55)		
SM interventions				
Counselling was adequate for the next steps of treatment				
Yes	335 (80.7)	38.91 (4.45)	0.678	0.498
No	80 (19.3)	38.54 (4.08)		
Adequately linked to social networks				
Yes	112 (27.0)	39.48 (4.40)	1.949	0.052
No	303 (73.0)	38.56 (4.35)		
Got support from adherence supporters				
Yes	94 (22.7)	39.78 (4.81)	2.380	0.018
No	321 (77.3)	38.56 (4.22)		
Encouraged to disclose HIV status				
Yes	383 (92.3)	39.00 (4.34)	2.785	0.006
No	32 (7.7)	36.78 (4.39)		

above the mean value of total SM practice. The mean level of SM outcomes varied across the domains as follows: daily physical health practice mean score was 1.95 ± 0.23; activating social support mean score was 1.64 ± 0.45; living with chronic HIV mean score was 2.11 ± 0.56.

Correlational analysis

Variables positively related to SM scores were educational level, job status, income, knowledge of ART, self-efficacy, setting goals, use of reminders, encouragement to disclose HIV status, receipt of adherence support, and disclosure of HIV status. Gender and living area were negatively associated with SM (see supplementary file 1).

Factors influencing self-management practice

Hierarchical multiple regression analysis was used to identify factors influencing SM based on the theoretical model after testing for fitness. In step 1, statistically significant contextual variables identified in the bivariate analysis were entered (see supplementary file 1). Step 1 revealed that the statistically significant contextual factors influencing SM explained 8.2% of the variance in SM. Self-awareness of HIV stage was a contributor to the prediction ($\beta = 0.14, p = 0.008$). In step 2, statistically significant SM process variables were added, and explanatory power increased by 9.2%. Self-efficacy and the use of reminders were the most significant variables in predicting SM. In step 3, statistically significant intervention-focused variables were added, and explanatory power increased by 2.2%. The final model explained 19.7% of the variance in SM of ALWHIV on ART and was statistically significant, adjusted $R^2 = 17.1\%$ $F\ (13, 401) = 7.552$, $p < 0.0005$). Self-efficacy ($\beta = 0.20, p < 0.0005$) and the use of reminders ($\beta = 0.15, p = 0.002$) were the strongest predictors of SM (Table 4).

Discussion

Several international studies on SM of ALWHIV have been conducted using the same measure of SM practice that was applied in this research [9, 11, 12]. However, evidence to date has been lacking on SM and influencing factors amongst ALWHIV in low-income countries such as Ethiopia. Table 5 summarises the level of SM at an overall level and by each of the three-domain scores in the Ethiopian sample compared to results from studies in the United States of America (USA, female-only sample), Korea and China.

Similar patterns of scores are apparent across all four countries, with activating social support being the lowest of the domain scores and living with chronic HIV the highest score. However, overall SM scores are notably lower in the Ethiopian and Chinese studies, when compared to the USA [11] and Korea [9]. In these latter two study areas, the implementation of the SM model was earlier compared to the current study area, where it is relatively new. (Table 5).

The components of social support are multiple and require the input of different groups, including families, health care providers and peer supporters [13, 43]. Social support also depends on the availability of social services

Table 4 Hierarchical multiple regression of factors influencing SM of ALWHIV on ART

	Self-management								
Variables	***Model 1***			***Model 2***			***Model 3***		
	B	**β**	***t(p)***	**B**	**β**	***t(p)***	***B***	***β***	***t(p)***
(Constant)	38.26		71.45 (0.000)	27.95		14.52 (0.000)	25.93		13.10 (0.000)
Gender (female)	−0.79	−0.09	−1.81 (0.071)	− 0.74	− 0.08	− 1.75 (0.081)	− 0.90	− 0.10	− 2.13 (0.034)
Educational level (formal)	0.83	0.09	1.76 (0.089)	0.90	0.10	1.89 (0.059)	0.95	0.10	2.02 (0.044)
Income (mean)	6.11^{e-5}	0.04	0.65 (0.52)	-8.82^{e-6}	−0.01	−0.10(.923)	3.97^{e-5}	0.02	0.44 (0.662)
Job status (employed)	0.84	0.07	1.30 (0.196)	0.85	0.07	1.37 (0.172)	1.01	0.09	1.64 (0.101)
Living area (rural)	−0.65	−0.06	−1.31 (0.190)	−0.33	− 0.03	−0.70 (0.487)	0.00	0.00	−0.01 (0.999)
Knowledge of HIV stage	1.40	0.14	2.66 (0.008)	1.14	0.11	2.24 (0.026)	1.00	0.10	1.99 (0.047)
Knowledge of ART				0.42	0.04	0.82 (0.414)	0.49	0.05	0.97 (0.334)
Self-efficacy				0.38	0.21	4.55 (0.000)	0.37	0.20	4.43 (< 0.001)
Disclosed HIV status				1.14	0.11	2.26 (0.024)	0.98	0.09	1.97 (0.049)
Set goal for SM				1.52	0.07	1.63 (0.103)	1.51	0.07	1.62 (0.105)
Use of reminder				1.41	0.16	3.46 (0.001)	1.30	0.15	3.20 (0.002)
Encouraged to disclose HIV status							1.64	0.10	2.15 (0.032)
Adherence support							1.13	0.11	2.31 (0.022)
R^2 (Adjusted R^2)	0.082 (0.069)			0.175 (0.152)			0.197 (0.171)		
F *(df)*	6.110 (6408)			7.764 (11,404)			7.552 (13,401)		
p	< 0.0005			< 0.0005			< 0.0005		
ΔR^2	0.082			0.092			0.022		
F *(df)*	6.110 (6408)			9.027 (5403)			5.446 (2400)		
P	< 0.0005			< 0.0005			0.005		

Durbin-Watson statistic = 1.799.

and the acceptance of the individual to receive support [10]. The findings of this study also show that the use of reminders can be an enabling factor for SM. These findings are consistent with surveys conducted in the USA [11] and China [12]. Both a systematic review [32] and the IFSMT [13] have identified the importance of social facilitation in SM. The level of daily physical health practice in this study is consistent with the Korean [9] study but lower than the study conducted in the USA [11] and higher than the study conducted in China [12]. In terms of daily physical health practice, a review on interventions to improve SM showed improvement amongst individuals who received skills training and education on the importance of daily physical health practice [32]. The mean score of living with chronic HIV in the study area is lower than studies conducted in the USA [11], Korea [9] and China [12] (Table 5), which may reflect the later implementation of the chronic care model in Ethiopia.

The study identified different factors influencing overall SM of ALWHIV on ART. Some of the variables are modifiable, whereas others are not, for example, gender and age. In this study, there was no age-related difference in SM, similar to the studies conducted in Korea [9] and China [12]. The study also identified potentially modifiable factors influencing SM. These included the educational level of ALWHIV, as higher educational levels showed an association with increased SM, a finding that is consistent with surveys conducted in the USA [11] and China [12]. This study showed a mean difference in SM between participants from rural and urban areas, with urban-dwelling participants having a higher level of SM. This could be because stigma and discrimination towards people living with HIV in rural communities remains a problem [36]. As a result of these fears, ALWHIV may not be willing to expose themselves to the community and not ready to mobilize the available supports.

SM is higher amongst ALWHIV who are aware of their HIV stage. This is consistent with previous literature that suggests a basic awareness of the HIV condition and its treatment helps in improving SM [5, 26]. A higher score of self-efficacy was associated with an increased level of SM, again in line with previous studies [29, 44, 45]. Overall, enhanced self-efficacy is an enabling factor in terms of retention in an HIV care program and success of HIV management [31]. However, evidence is lacking on the specific factors that determine self-efficacy for SM. This is an important area for future investigation as it is a key factor in the process of enhancing SM.

In this study, respondents who received adherence support, used reminders and were encouraged to disclose their HIV status reported higher levels of SM. These findings support the propositions of the Individual and Family Self-management Theory [13]. Previous research also supports the use of reminders and social support as important enabling factors for SM [12, 13, 31]. ALWHIV are in different social situations, and they need situation-specific support for successful engagement in care and treatment. In summary, SM requires strong social facilitation and SM interventions. Interventions to improve SM in Ethiopia should seek to address the most significant modifiable factors, for example, through framing practice with the IFSMT theoretical model and using the constructs of the theory as an 'aide-memoire' or checklist during follow up visits of patients.

Limitations of the study

Despite the contribution, there were some limitations to the study. The respondents were from one referral hospital only, and the sampling technique used was convenience sampling. This could potentially limit the generalizability of the study findings to other settings, although the large sample size and high response rate enhance the level of confidence in the findings. Finally, the study findings could be subject to social desirability bias, as data collection involved the use of an interviewer-administered, self-report survey.

Conclusions

The study found a relatively low level of SM amongst ALWHIV in Ethiopia. Factors influencing the level of SM were consistent with previous literature. The most important predictors of low SM in Ethiopia were female gender, illiteracy, lack of awareness of HIV stage, low self-efficacy, absence of reminders, lack of encouragement to disclose and absence of adherence support. Self-efficacy and the use of reminders were the most significant contributors to the prediction of SM scores. HIV care providers should evaluate the SM behaviours of ALWHIV and develop person-centred care plans and

Table 5 Level of self-management in this study and different literature

	Ethiopia	USA (females only) [11]	Korea [9]	Chin a[12]
Sample size	415	260	203	322
Overall SM score	1.94	2.28	2.00	1.91
Daily physical health practice	1.95	2.19	1.92	1.80
Mobilising social support	1.64	2.00	1.66	1.47
Living with chronic HIV	2.11	2.64	2.42	2.46

interventions that take account of important contextual and process-related influencing factors. This would facilitate the development of more tailored approaches, for example, to enhance self-efficacy and the appropriate use of reminders. Future qualitative research is recommended to develop a more in-depth understanding of the barriers and enablers of effective SM of ALWHIV in the study area and help inform the design of future tailored interventions.

Implications for practice

The study is the first of its kind in Africa, where HIV prevalence is high, and health care access and infrastructure are limited. Therefore, this study could be a baseline for policymakers, implementers and researchers in the region. It highlights to policymakers the importance of addressing SM in chronic HIV. Many of the factors are modifiable, although addressing them will require input from both HIV care providers and patients. HIV care providers should work on enhancing self-efficacy, as it is a crucial factor in HIV care and treatment. HIV care providers should also motivate and help patients to build self-belief and confidence to practice SM. Increased self-efficacy could help ALWHIV to mobilize existing support, manage symptoms, and cope with the illness. It is also important to devise a mechanism for enhancing the use of reminders, for example, through use of technology-assisted solutions such as phone calls, text messaging and online support, and other social facilitation approaches for improving the SM of ALWHIV on ART. HIV care providers should identify the target population based on contextual and process factors in the design and delivery of SM programs. This could be enhanced by considering the constructs of the IFSMT when working with ALWHIV on ART.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12879 020 05618 y.

Additional file 1 : **S1 Table 5**. correlational analysis between different predictors and self-management outcomes

Additional file 2 : **S2**. Survey tool

Abbreviations

AIDS: Acquired Immunodeficiency Virus; ART: Antiretroviral therapy; ALWHIV: Adults Living with HIV; HIV: Human Immunodeficiency Virus; IFSMT: Individual and Family Self-Management Theory; SM: Self-Management; WHO: World Health Organization

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Authors' contributions

HA designed the study, collected data, analyzed and interpreted data, wrote and revised the manuscript. AM advised in developing the study, interpreting the data, and critically revising the manuscript. GH advised in designing the study, interpreting the data, and critically revising the manuscript. All authors read and approved the final version of the paper.

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Availability of data and materials

The datasets used and/or zanalyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

To conform with the Declaration of Helsinki (1964) and Population Screening Act, ethical approval for the study was obtained from the Human Research Ethics Committee at the University of Adelaide (H-2018-243) and Amhara Regional Health Bureau Research Office (APHHRTD/03/264/2019). Permission was obtained from the hospital management. Participation was determined by the person without any external influence to participate or not. Written consent was obtained from the individual participant. Participants of this study had the right to withdraw anytime from the research project without any negative consequences. Information was collected in private rooms and kept confidential and secure at all times.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Chapter 6: Paper 3

Medication adherence as a key behavioural outcome of self-management and associated factors among adults living with HIV on antiretroviral therapy: A cross-sectional study

6.1 Preface

This chapter reports the quantitative findings from the first phase of the study relating to the second outcome of interest, medication adherence. This involved assessing the level of medication adherence amongst the study population using an existing validated tool and examining the factors that influenced medication adherence. The manuscript has been submitted to a journal for possible publication. The overall level of self-reported medication adherence was moderate. Self-efficacy, duration of ART and educational level were identified as the main influencing factors. The findings were applied to inform subsequent quantitative analyses and the design of the interview schedules for the qualitative study in the second phase of the research to better explore the key factors influencing SM behaviours.

6.2 Manuscript

Statement of Authorship

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Principal Author

Name of Principal Author (Candidate)	Habtamu Abera Areri		
Contribution to the Paper	Conceived the study, designed the study, conducted data extraction and analysis, and drafted the manuscript		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	22/8/2021

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Amy Marshall

Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	22/8/2021

Name of Co-Author	Professor Gillian Harvey		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	22/8/2021

Please cut and paste additional co-author panels here as required.

Original article

Medication adherence as a key behavioural outcome of self-management and associated factors among adults living with HIV on antiretroviral therapy: A cross-sectional study

Habtamu Abera Areri[a, b]*, Amy Marshall[a, c], and Gillian Harvey[a]

[a] *Adelaide Nursing School, The University of Adelaide, Adelaide, Australia;* [b] *School of Nursing and Midwifery, Addis Ababa University, Addis Ababa, Ethiopia;* [c] *College of Nursing and Health Sciences, Flinders University, Adelaide, Australia.*

*Corresponding author: Habtamu Abera Areri

E-mail: habtamu.areri@adelaide.edu.au

Phone: +61478211554

ORICD: 0000-0002-7165-922X

Abstract

Introduction: Medication adherence is a key task in the self-management of HIV, but little is known about which contextual and process factors are key drivers of adherence in Ethiopia. This study aimed to identify factors affecting medication adherence among adults living with HIV on antiretroviral therapy (ART).

Methods: A survey was carried out on a sample of 415 adults living with HIV on therapy in Debre Markos Referral Hospital from 1 April to 30 May 2019. Data was collected using an existing tool developed for resource-limited settings and analysed using SPSS version 25.0. The analysis considered variables identified in Individual Family Self-Management Theory during bivariate analysis, followed by a multivariate logistic regression analysis with a statistical significance at $p < 0.05$.

Results: The overall adherence level was 81% ($n = 336$). Near to half of the respondents, 45.3% ($n = 188$) and 43.1% ($n = 179$) had been on this treatment for the duration of 3–8 and 9–14 years, respectively. Illiteracy was reported in over one-third of the study participants, and they were 41% less likely to adhere than their literate counterparts (*AOR: 0.59; 95% CI: 0.35, 0.98; p = 0.043*). A higher self-efficacy score was associated with a better adherence (*AOR:* 1.12*; 95% CI: 1.01, 1.25; p =* 036). The odds of medication adherence for those with a duration on ART of less than or equal to two years was almost six times greater than the odds for those with greater than 2 years duration on therapy (*AOR: 5.92; 95% CI: 1.02, 35.55; p = 0.038*).

Conclusions: The medication adherence was below the optimal level. Self-efficacy, educational level and duration on therapy were associated with self-reported adherence. Medication adherence should be monitored and evaluated as one key self-management behaviour of HIV therapy. To enhance medication adherence, it is recommended that health care providers identify and closely monitor or support those with low education, on ART for a longer time and those with low self-efficacy.

Keywords: a*dherence, self-efficacy, self-management, HIV, ART*

Introduction

Over two-thirds (67.8%) of people living with HIV are living in Africa (WHO 2019). In Ethiopia, the rate of new HIV infection is decreasing, and the existence of ART has improved the life expectancy of people living with HIV in the country. Even though many people living with HIV are without antiretroviral therapy (ART) access, the coverage is improving (71%) (UNAIDS 2019). The HIV treatment program has proven effects on the clinical outcomes of people living with HIV; however, its effectiveness depends on medication adherence (Legesse & Reta 2019; Molla et al. 2018).

Medication therapy has transformed HIV from an acute to a chronic condition and requires optimal medication adherence (≥ 95%) to enhance well-being (Belayihun & Negus 2015; WHO 2016). The program of HIV care and treatment calls for self-management of the complex drug regimen, so it is important to improve well-being by enhancing medication adherence (Modi et al. 2012; Smith et al. 2003). Medication adherence is a required behaviour in chronic illness self-management. Nonadherence to the recommended behaviours in self-management is pervasive and remains the leading cause of poor health outcomes and increased cost of health care (Phillips et al. 2016). That is why maintaining medication adherence should be a critical focus of any HIV treatment program (Grey et al. 2015).

Individual and Family Self-Management Theory (IFSMT) framed the development of the study. Maintaining medication adherence is one of the key tasks of self-management behaviour (Elzarrad, Eckstein & Glasgow 2013; Martin et al. 2013; Swendeman, Ingram & Rotheram-Borus 2009). The theoretical framework's proximal outcomes include medication adherence as one self-management (SM) behaviour (Ryan & Sawin 2009). This concept is also supported by different literature sources (Johnston, Liddy & Ives 2011; Martin et al. 2013; Russell et al. 2016; Schulman-Green et al. 2012; Swendeman, Ingram & Rotheram-Borus 2009). The theoretical framework guiding this study has interrelated constructs: contextual factors, process, intervention, and outcome. The contextual factors consist of condition-specific factors, individual factors, and the physical and social environment. Previous studies identified that the condition-specific factors affecting medication adherence are treatment duration (Houston & Fominaya 2015), regimen complexity (Almodovar 2014; Edelman et al. 2013), and side effects (Monroe et al. 2013). The physical and social environment factors affecting medication adherence reported in different studies include; the area of residence (Tegegne, Ndlovu & Zewotir 2018), fasting (Wasti et al. 2012), and using holy water (Bezabhe et al. 2014). Individual factors like age, gender, education (Wolf et al. 2007), and income are also considered factors influencing medication adherence (Modi et al. 2012; Sunil & McGehee 2007). Inadequate knowledge about HIV treatment (Russell et al. 2016; WHO 2016) and low self-efficacy (Adefolalua et al. 2014; Modi et al. 2012; Wallston et al. 2011) are commonly identified factors influencing medication adherence in the process of SM. Finally, better medication adherence could be achieved through encouraging disclosure, and counselling/education about the disease, and its treatment and outcomes (Cummings et al. 2014; Holtzman, Brady & Yehia 2015; Legesse & Reta 2019).

Identifying the factors that influence medication adherence in SM behaviour could provide insight into medication adherence’s dynamic nature and help address SM behaviours in a comprehensive way (Okonsky et al. 2015). It is crucial to develop and integrate medication adherence with other SM behaviours (Holtzman, Brady & Yehia 2015; Martin et al. 2013). Therefore, understanding the level of medication adherence as one key component of SM behaviour and its influencing factors is so important to enhance the SM behaviour of ALWHIV on ART. However, different studies have showed variable levels of medication adherence and different influencing factors globally. A study conducted in Vietnam identified an optimal level of adherence among 74.1% of respondents, and the barriers for adherence were being busy working, forgetfulness, running out of pills, being asleep during dosing and travel away from home. On the other hand, a higher score for self-efficacy and the use of reminders were associated with optimal adherence (Tran et al. 2013). In China, the level of adherence was 85.5%, and those who had not disclosed their HIV status were at higher risk of poor medication adherence (Yu et al. 2018).

In Ethiopia, regional differences in medication adherence and influencing factors have previously been identified. A study in Harar showed below the optimal level of medication adherence at 87% with forgetfulness, being away from home, and being busy were the main reasons for nonadherence (Mitiku, Abdosh & Teklemariam 2013). A similar study in Gondar showed below the optimal level of adherence at 88.2%, and factors associated with better adherence were living in an urban environment, better knowledge of HIV treatment, and disclosure of HIV status (Molla et al. 2018). A Dubti Hospital study also identified a low level of adherence at 81.1%, while therapy duration was a factor affecting medication adherence; the longer the therapy time, the lower the adherence (Belayihun & Negus 2015). The adherence of people living with HIV in the Jimma hospital was 63.8% while its influencing factors were educational level, area of residence and occupation status (Abera et al. 2015). Sub-optimal adherence was also reported in in Harar and Dire Dawa health facilities at 85% (Letta et al. 2015a). From this, it is possible to conclude that different studies conducted in Ethiopia have found varied medication adherence levels and influencing factors. However, to the best of our knowledge there is no theoretically framed study that examined the factors affecting medication adherence as a behavioural outcome within the self-management model. This could provide local policymakers with contextualized and theoretically grounded evidence to inform HIV care and treatment policy and practice. Therefore, this study aimed to identify the level of medication adherence as a key SM behavioural outcome and its influencing factors among ALWHIV on therapy.

Methods

Study setting, design and participants

A cross-sectional survey was conducted from 1 April to 30 May 2019 involving 415 ALWHIV who had been on therapy for at least six months in Debre Markos Referral Hospital in north-west Ethiopia. After inviting voluntary participation from those coming for their quarterly ART appointment, convenience sampling of 12–15 people were carried out from the average 30 attendants at the hospital per day in the ART clinic.

Data collection and measurement

The study was approved by the Human Research Ethics Committee at the University of Adelaide (H-2018-243) and the Amhara Regional Health Bureau Research Office (APHHRTD/03/264/2019). Two data collectors with an educational level of Bachelor of Science, have been trained in ART and have experience conducting data collection were recruited and employed for the data collection. They received training for the study, including how to conduct interviews ethically and with scientific integrity. Practical sessions followed the training until they mastered the data collection process (Polit & Beck 2012). The data collectors were then sent to pilot the tool on a group of respondents amounting to 5% of the desired number of study participants in a different hospital one month before the actual data collection. In the lead up to data collection, information sheets were posted in the ART clinic area. A face-to-face request for participation was carried out during the initial contact. After clarifying the aim of the study, the trained data collectors delivered a survey tool with consenting participants in a private counselling room. The tool used for the data collection consisted of four existing items measuring medication adherence in resource-limited settings. Three correct responses out of four items was considered indicative of medication adherence (Patel et al. 2010; Steel, Nwokike & Joshi 2007). Additionally, nonadherence was assessed using the 14-item Revised AIDS Clinical Trial Group Reasons for Missed Medications (Chesney et al. 2000) .

Statistical methods

The constructs included in the Individual and Family Self-Management Theory (IFSMT) guided the data analysis, interpretation, and the data presentation. Continuous data were summarized using mean and standard deviations, while categorical data were summarized using frequency and percentage descriptions. The association between selected factors and the outcome variable was assessed by using a logistic regression model. Text, tables, and charts are utilized for data presentation.

Results

Sociodemographic and medical characteristics

The response rate was 98.34%. Near to one-third of the respondents did not have a regular job, 31.1% (n = 129). Near to half, 45.3% (n = 188), of the respondents had been on ART for 3–8 years. Treatment had changed for a quarter of the study participants, 26.5% (n = 110). The main reason for the drug change was drug resistance, 9.6% (n = 40). The majority of the respondents, 75.2% (n = 312), received one type of ART drug (see Table 1).

Table 1: Sociodemographic and medical characteristics (n = 415)

Variables	N	%
Gender		
Male	174	41.9
Female	241	58.1
Age		
≤ 50 years	116	28.0
> 50 years	299	72.0
Educational level		
Illiterate	145	34.9
Attended education	270	65.1
Job-status		
Employed	286	68.9
No regular job	129	31.1
Religion		
Orthodox Christian	396	95.4
Others	19	4.6
Marital status		
Never married	26	6.3
Married	389	93.7
Living area		
Rural	106	25.5
Urban	308	74.5
Duration of ART		
≤ 2 years	37	8.9
3–8 years	188	45.3
9–14 years	179	43.1
15+ years	11	2.7
Treatment changed		
Yes	110	26.5
No	305	73.5
Reason for drug change		
Drug side effects	18	4.3
Did not take properly	18	4.3
Did not know the reason	34	8.2
Drug resistance	40	9.6
Number of drugs		
One type	312	75.2
Two types	68	16.4
More than two types	35	8.4
Drug side effects		
Yes	38	9.2
No	377	90.8

The process of adherence self-management

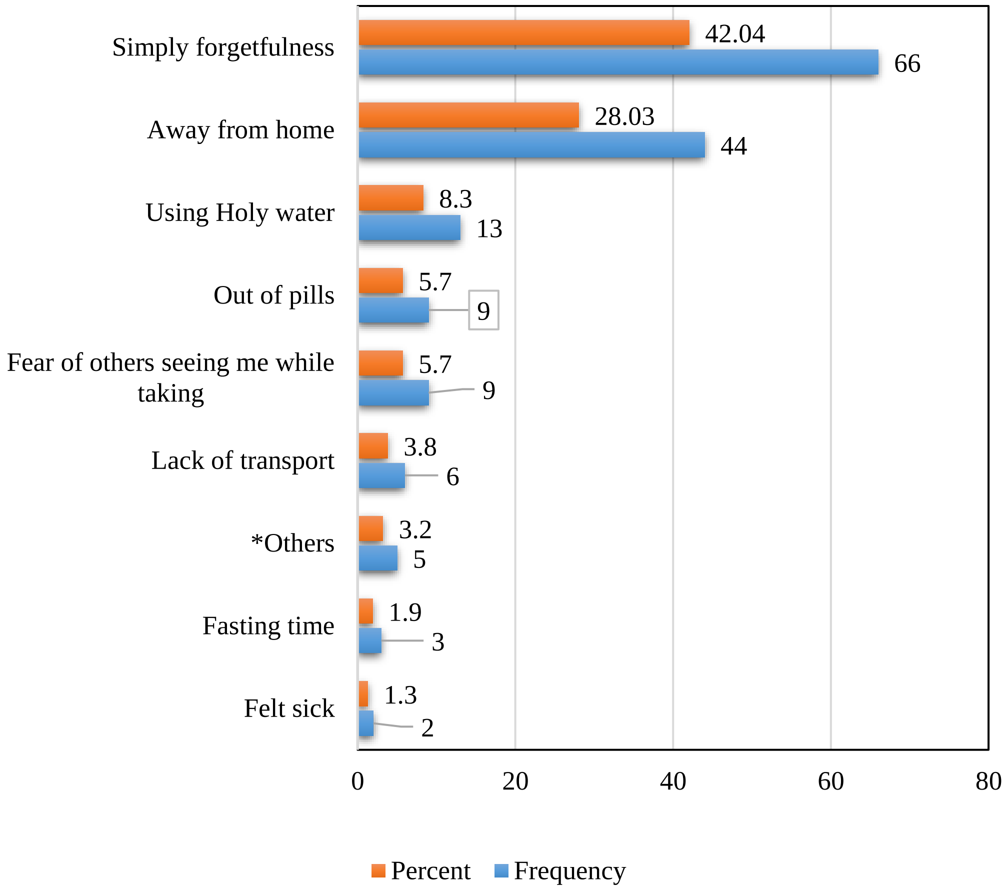
A moderate level of self-efficacy was scored, 19.76 ± 0.12. However, over one-fifth of the study participants, 20.7% (n = 86), remain with a non-disclosed status, and the main causes for nondisclosure were fear of stigma 47.3% (n=79) and discrimination 46.7% (n=78). The majority, 77.3% (n = 321), did not get adherence support from HIV care providers. However, most respondents, 80.7% (n = 335), reported that they got adequate counselling for the next step of their HIV care (see Table 2).

Table 2: The process of adherence self-management (n = 415)

Variables	**n**	%
Knowledge of ART		
Inadequate	85	20.5
Adequate	330	79.5
Self-efficacy for SM, Mean (SD)	19.76 ± 0.12	
Used reminders for adherence		
Yes	214	51.6
No	201	48.4
Disclosed HIV status		
Yes	329	79.3
No	86	20.7
Reasons for nondisclosure (n = 167, multiple response)		
Fear of stigma	79	47.3
Fear of discrimination	78	46.7
Thinking it is not important	10	6.0
Adequate counselling		
Yes	335	80.7
No	80	19.3
Linked to social networks		
Yes	112	27.0
No	303	73.0
Support from adherence supporters		
Yes	94	22.7
No	321	77.3

Level of medication adherence

The medication adherence was assessed based on the self-report of the respondents to four items. Therefore, the respondents' adherence level in the previous month was 81.0% (n = 336). The primary reasons for non-adherence were forgetfulness, 42.0% (n = 66), being away from home, 28.0% (n = 44), and using holy water, 8.3% (n = 13) (see Figure 1).



*Conflict, death of children, funeral ceremony, imprisoned, and intention to stop

Figure 1: Reasons for medication nonadherence

Factors associated with medication adherence

The study applied binary logistic regression to ascertain the effects of age, educational level, duration of ART, self-efficacy, treatment change and the number of drugs on the likelihood of the participants' medication adherence (all variables with $p < 0.2$ were added to the regression model). The model was statistically significant, χ^2 (8) = 21.856, $p = 0.005$, explained 8.2% (Nagelkerke R^2) of the variance in medication adherence and correctly classified 81.2% of cases. Only three variables were statistically significant from the included predictors: educational level, duration of ART and self-efficacy. Illiterate respondents were 41% less likely to adhere compared to their counterparts (*AOR: 0.59; 95% CI: 0.35, 0.98; p = 0.043*). A better score of self-efficacy was associated with an increased likelihood of adherence (*AOR:* 1.12*; 95% CI: 1.01, 1.25; p = 0.036*). The odds of adherence for those with a duration on ART less than or equal to two years were almost six times greater than the odds for those with more than two years (*AOR: 5.92; 95% CI: 1.02, 35.55; p = 0.038*) (see Table 4).

Table 4: Factors associated with medication adherence among adults living with HIV on ART

	B	*SE*	Wald	*df*	*p*	Odds ratio	95% CI	
							Lower	Upper
Age								
≤ 50 years	-0.34	0.29	1.42	1	0.234	0.71	0.40	1.25
> 50 years								
Educational status								
Illiterate	-0.53	0.26	4.10	1	0.043	0.59	0.35	0.98
Attended education								
Duration of ART								
</= 2 years	1.78	0.90	3.91	1	0.048	5.92	1.02	34.55
3–8 years	0.84	0.68	1.51	1	0.220	2.31	0.61	8.79
9–14 years	0.84	0.68	1.55	1	0.213	2.32	0.62	8.71
15+ years								
Change of drug therapy								
No	0.46	0.61	0.57	1	0.452	1.59	0.48	5.27
Yes								
Number of drugs								
One	0.17	0.62	0.07	1	0.787	1.18	0.35	3.98
Two/more								
Self-efficacy score	0.11	0.06	4.39	1	0.036	1.12	1.01	1.25

Discussion

The study aimed to identify factors affecting medication adherence in HIV SM behaviour. Medication adherence was assessed using SM theory as one integral but self-standing component of SM behaviour. A study of the full range of HIV SM behaviour should consider both SM practice and medication adherence. Self-management practice is inadequate without medication adherence (Martin et al. 2013; Schulman-Green et al. 2012; Swendeman, Ingram & Rotheram-Borus 2009). Therefore, this study investigated medication adherence through the lens of Individual and Family Self-Management Theory to provide contextualized evidence for HIV care providers and policymakers in the study area.

The study found that medication adherence in the sample population is low (81%) compared to the expected optimal level of medication adherence (≥ 95%) (WHO 2016). This finding is consistent with a study conducted in Dubti Hospital, Afar region, eastern Ethiopia (Belayihun & Negus 2015). However, the finding in this study is higher than in the study conducted in Jimma University teaching hospital (Abera et al. 2015). The difference might be due to sociodemographic characteristics (such as educational status, social cultural practice…) and data collection methods. The reasons for nonadherence in this study were consistent with the study conducted in the Harar region of Ethiopia (Abera et al. 2015; Mitiku, Abdosh & Teklemariam 2013).

Enhancing medication adherence is one way of improving the SM of HIV as a chronic condition. Forgetfulness was the most common reason for nonadherence, and this might call for technology-assisted interventions and reminder strategies such as text messages, phone calls or setting alarms and online support (Areri, Marshall & Harvey 2020c). Our previous systematic review identified interventions that effectively enhanced medication adherence, which consisted of technology-assisted interventions, symptom management instructions, individualized counselling and skills training (Areri, Marshall & Harvey 2020c). Therefore, it is essential to focus on strict medication adherence by providing continuous medication information using a symptom management manual. It is also useful to consider technology-assisted approaches for counselling, education and reminders.

Nevertheless, the medication adherence level found in this study is lower than in the study conducted in Harar and Dire Dawa (Letta et al. 2015a) and Gondar University hospital (Molla et al. 2018). This gap might be related to a difference in measurement methods and even the study population. In the study area, some ALWHIV are taking their medication flexibly due to physical and social environmental factors such as religious practices which included fasting and the use of holy water for healing, while others are affected by social factors like fear of stigma and discrimination. The perceived fear of stigma and discrimination may also lead to nondisclosure of HIV status, which could lead to a decrease in the level of medication adherence. The absence of disclosure may affect the use of social support and may also lead to missing doses while in a social environment or living with others. The theoretical framework guiding the study (IFSMT) proposes that lack of social support can lead to poor medication adherence (Ryan & Sawin 2009). Our systematic review also showed that the presence of social support enhances medication adherence (Areri, Marshall & Harvey 2020c). HIV care providers, therefore, should focus on how to minimize the effect of stigma and discrimination on medication adherence. Importantly, encouraging disclosure of HIV status is one way to decrease stigma and discrimination in the community over time and enhance taking medication on time at any time. Additionally, working with religious leaders may support the strict taking of HIV medication side by side with spiritual practice.

A lesser duration on ART improves medication adherence compared to those on therapy for a longer duration in this study, which is consistent with studies conducted in the Harar region and in Dubti Hospital in Ethiopia (Belayihun & Negus 2015; Mitiku, Abdosh & Teklemariam 2013). The finding implies that, as the duration of therapy increases, the patient is likely losing knowledge about taking their medication strictly or becoming tired of routinely taking medication. Another reason could be taking medication longer might improve health status and might lead to a sense of being cured from the disease. This indicates that, as therapy duration increases, the need for adherence support, counselling and education should increase. In the continuum of HIV care and treatment, taking medication is a lifelong process, and it needs to be persistent to be effective. However, maintaining medication adherence is challenging and needs continuous support (Holtzman, Brady & Yehia 2015; WHO 2016). HIV care providers should integrate and implement the full range of the SM model in ART programs across the life span.

Respondents who had attended some forms of education had higher rates of medication adherence than those who were illiterate. This finding is consistent with studies conducted in the USA (Wolf et al. 2007), Thailand (Hansana et al. 2013) and a systematic review of studies in Asian developing countries (Wasti et al. 2012). Illiteracy might create difficulty in getting information from different sources like searching for information and reading. Lack of education might also lead to difficulty in forecasting the outcomes of poor medication adherence. Educated people might have better awareness that might improve their engagement in treatment programs. Therefore, greater attention should be given to ALWHIV with a low education level during drug refills. They may need updating on their medical condition and on how to lead their lives while strictly taking medication. Adherence supporters (expert patients) are also important resources who could be further resourced and utilized to share their lived experience on how to lead life while taking medication strictly (Areri, Marshall & Harvey 2020c).

Our findings showed a higher score for self-efficacy was associated with increased medication adherence. This finding is consistent with studies conducted in Vietnam (Tran et al. 2013), Thailand (Hansana et al. 2013) and Asian developing countries (Wasti et al. 2012) . Patients with strong self-efficacy are highly adherent to medication (Adefolalua et al. 2014). Their beliefs in their own capacity to execute medical recommendations generally influence their medication use behaviour. Thus, HIV care providers should assess the self-efficacy level of ALWHIV to identify a gap in adherence related to the problem of self-efficacy and provide feedback to enhance it. It is also essential to support ALWHIV on therapy to believe in themselves and their abilities to strictly take their medication. Thus, adherence interventions need to incorporate self-efficacy-enhancing approaches to improve medication adherence (Adefolalua et al. 2014; Wasti et al. 2012).

Limitations of the study

The study has some limitations. First, the study participants were included from one hospital, and convenience sampling was used to access a maximum sample size in the shortest possible time. The sampling process applied may limit its generalizability to ALWHIV on ART in other settings. Second, the findings may be subjected to social desirability bias and poor recall as it used a self-report data collection approach (Polit & Beck 2012). Despite the limitations, our findings are useful for policymakers and implementers in the area of HIV care and treatment. It helps to address the SM behaviour in a comprehensive way.

Conclusions

The study found a sub-optimal medication adherence level compared to set standards of medication adherence and to other studies. The level of medication adherence was strongly associated with educational level, duration of ART and self-efficacy. Taking medication for HIV therapy is a lifelong process and needs optimal medication adherence to get maximum treatment benefits. Enhancing medication adherence could be achieved through identifying and closely supporting those with a low academic level, those on ART for a longer duration and those with low self-efficacy for medication adherence. Helping ALWHIV to understand the nature of the disease, its treatment and its consequences is essential. HIV care providers should evaluate the full package of SM behaviours of ALWHIV and should develop a plan to enhance medication adherence as a key SM behaviour.

Implications for practice

The findings of the study provide evidence for policymakers and clinical practice. The association between self-efficacy and medication adherence provides support for developing self-efficacy-enhancing interventions. For instance, identifying reasons for nondisclosure and encouraging disclosure may help to build self-efficacy to maintain medication adherence. A low level of education might affect the confidence and decision-making capacity of ALWHIV. Therefore, HIV care providers need to consider the components of Individual and Family Self-Management Theory while planning to enhance medication adherence. They should consider encouraging disclosure to others, linking with peer support groups (expert patients) and social networks. Across studies conducted in Ethiopia, including this one, forgetfulness is the most common reason for medication nonadherence. Therefore, this calls for implementing reminder strategies like text messages, online support and phone calls.

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Conflicts of interest

All authors declare that they have no conflict of interest to declare.

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The University of Adelaide provided a PhD stipend for the primary investigator. The university had no role in designing the study, data collection, analysis and interpretation of the study.

Authors' contributions

HAA designed the study, collected data, analysed and interpreted data, and wrote and revised the manuscript. AM advised in developing the study, interpreted the data, and critically revised the manuscript. GH advised in designing the study, interpreted the data, and critically revised the manuscript. All authors read and approved the final version of the paper.

Chapter 7: Paper 4

Self-efficacy for self-management and its influencing factors among adults living with HIV on antiretroviral therapy in north-west Ethiopia

7.1 Preface

This chapter presents an analysis of self-efficacy for SM amongst the study population. Self-efficacy was identified as a significant factor that influenced both SM outcomes of interest, namely SM practice and medication adherence. Hence, this additional analysis was undertaken to further understand the level of self-efficacy and influencing factors among adults living with HIV on ART in north-west Ethiopia, which also helps clinicians and policymakers to enhance overall self-management behaviours. The manuscript has been published on *AIDS Care*.

A validated survey tool was used to assess the level of self-efficacy. This was found to be at a moderate level compared to other studies. Income level, area of residence and the experience of side effects were identified as the key factors influencing self-efficacy for SM. These findings further informed the design of the qualitative study in phase two of the research.

7.2 Publication

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Principal Author

Name of Principal Author (Candidate)	Habtamu Abera Areri		
Contribution to the Paper	Conceived the study, designed the study, conducted data analysis and interpretation, and drafted the manuscript		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	08/11/2020

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Amy Marshall		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	08/11/2020

Name of Co-Author	Professor Gillian Harvey		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	08/11/2020

Please cut and paste additional co-author panels here as required

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Self-efficacy for self-management and its influencing factors among adults living with HIV on antiretroviral therapy in northwest Ethiopia

Habtamu Abera Areri, Amy Marshall & Gillian Harvey

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Self-efficacy for self-management and its influencing factors among adults living with HIV on antiretroviral therapy in northwest Ethiopia

Habtamu Abera Areri [a,b], Amy Marshall[a,c] and Gillian Harvey [c]

[a]Adelaide Nursing School, The University of Adelaide, Adelaide, Australia; [b]School of Nursing and Midwifery, Addis Ababa University, Addis Ababa, Ethiopia; [c]College of Nursing and Health Sciences, Flinders University, Adelaide, Australia

ABSTRACT
Previous research has identified that self-efficacy is an essential factor in the process of self-management; however, the evidence is lacking concerning factors influencing self-efficacy in low-income countries. Therefore, this study examined factors influencing self-efficacy. A validated survey tool was orally administered to 415 adults living with HIV. Many of the respondents, 82.4%, do not have a regular job while one-fourth (25.5%) of the respondents were from a rural area. A mean self-efficacy score, 19.76 ± 0.12 out of a maximum of 24 was identified. This self-efficacy score was positively correlated with age, educational level, income and job status, but negatively correlated with gender, residency and drug side effects. Income, residency in rural, and experiencing drug side effects were significant predictors of self-efficacy and explained 5.4% of the variance. Better income ($\beta = 0.514$, $p = 0.029$) was associated with a higher self-efficacy score but living in rural areas ($\beta = -0.520$, $p = 0.043$) and experiencing drug side effects ($\beta = -1.246$, $p = 0.001$) were associated with a lower self-efficacy score. The use of Individual and Family Self-Management Theory helps clinician and patients to work together to identify factors influencing self-efficacy and to intervene.

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Self-efficacy; adults living with HIV; self-management

Introduction

Globally, over 70 million people have been infected, and over 36.2 million adults are living with HIV (UNAIDS 2020). Worldwide, 1.6 million new infections and 67,000 adult deaths were reported in 2018 (WHO 2018). In Ethiopia, over 690,000 people are living with HIV (EMOH 2019), the national antiretroviral therapy (ART) coverage is improving, although there are still many people without access. As the number of adults living with HIV as a chronic condition is growing (EMOH 2019), effective self-management is so important. Self-management enhances daily lived experience, empowers individuals and reduces the cost of care and the burden on the healthcare system (Ryan & Sawin 2009). The ability to self-manage is influenced by a range of factors including how an individual with HIV feels about the disease, its treatment and their degree of self-efficacy (Foster et al. 2015; Johnson et al. 2006; Johnson et al. 2007). Self-efficacy for self-management (SM) refers to an individuals' belief in their ability to perform tasks essential to obtain the desired level of SM (Bandura 2004; Wallston et al. 2011).

Self-efficacy has been shown to have a positive impact on overall SM for those living with HIV (Adefolalua et al. 2014; Tran et al. 2013; Wasti et al. 2012). Higher levels of self-efficacy appear to be correlated with improved adherence to treatment (Huang et al. 2013) and lower symptom prevalence (Berg et al. 2009). Other studies have also demonstrated a positive association between higher self-efficacy scores and improved SM (Cha et al. 2008; Colbert, Sereika & Erlen 2013; Weng et al. 2010; Xu et al. 2008). Similarly, a higher level of self-efficacy correlates with better SM experiences (Weng et al. 2010; Xu et al. 2008) and, as such, it is important to understand factors that influence an individual's self-efficacy for SM to tailor appropriate support (Foster et al. 2015). Studies have demonstrated that enhancing the self-efficacy of adults living with HIV (ALWHIV) can help them to mobilize resources, manage illness-related symptoms, and better cope with discomfort (Cha et al. 2008; Wolf et al. 2007).

However, identifying what affects the self-efficacy of ALWHIV on therapy is complex, as a mix of demographic, psychological and emotional factors require careful investigation to identify appropriate self-efficacy-enhancing strategies (Gallagher et al. 2008; Sarkar, Fisher & Schillinger 2006; Wallston, Rothman & Cherrington 2007; Yoo et al. 2011).

Studies have been conducted in a several countries to determine the level and influencing factors of self-efficacy for chronic condition SM with a similar instrument. The findings related to the level of self-efficacy for chronic condition SM look consistent across different contexts. A moderate level of self-efficacy was reported in Korea (Yoo et al. 2011), China (Huang et al. 2013) , and the USA (Berg et al. 2009; Colbert, Sereika & Erlen 2013). However, the factors observed to influence self-efficacy for SM varied across the studies. For instance, sociodemographic variables including gender and socioeconomic status, the complexity of the disease and treatment-related factors such as experiencing side effects and illness perception are all known to influence self-efficacy (Foster et al. 2015). A positive correlation between educational level, social support and a higher degree of self-efficacy was reported from a study undertaken in China (Xu et al. 2008). Low levels of literacy were identified as a risk factor for lower self-efficacy in a survey conducted in the USA (Wolf et al. 2007). Similarly, a study conducted in Korea identified statistically significant differences in self-efficacy related to age, occupation and educational level (Yoo et al. 2011). Males appear to be higher in self-efficacy for SM than females (Foster et al. 2015; Wallston et al. 2011; Wallston, Rothman & Cherrington 2007), whilst the presence of drug-related side effects negatively influences self-efficacy for SM (Zhang et al. 2016).

Our previous study investigating the SM of ALWHIV in Ethiopia demonstrated that the level of self-efficacy is a significant predictor of SM practice (Areri, Marshall & Harvey 2020b) . However, evidence is lacking in the Ethiopian context related to the factors affecting self-efficacy. This prompted further research to explore the determinants of self-efficacy in order to inform contextually relevant strategies that could be implemented to enhance self-efficacy for SM. In Ethiopia, many efforts have been made to address chronic HIV care and treatment. However, HIV-related complications are still prevalent in the country, resulting in frequent hospital visits (Alemayehu et al. 2017; Mitiku, Weldegebreal & Teklemariam 2015). Although there is a policy of a patient-centred model of HIV care and treatment in the country, there is no established evidence on the level of patients' self-efficacy to self-manage their HIV condition. A better understanding of issues relating to self-efficacy would enable HIV care providers, particularly nurses who are the primary care providers of chronic disease management, to identify potential areas of deficit and plan care interventions accordingly (Colbert, Sereika & Erlen 2013). For instance, contextual factors such as age and homelessness were predictors of self-efficacy of HIV patients in a study conducted in Canada (Lee et al. 2019). The study was guided by Individual and Family Self-Management Theory (IFSMT), which proposes a causal relationship between contextual factors, the process of SM and subsequent outcomes (self-management). Contextual factors are seen as predictors that influence the process of SM, in this case, self-efficacy for SM (see Figure 1) (Ryan & Sawin 2009).

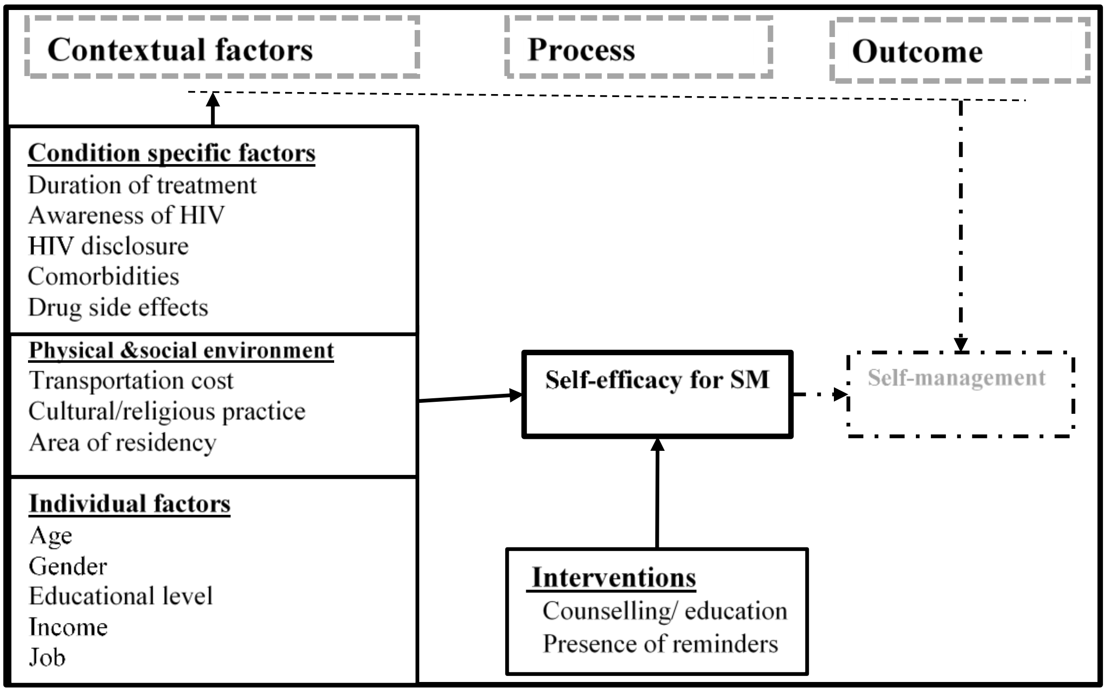

Figure 1: Conceptual framework of self-efficacy for self-management of ALWHIV

Methods

Design, population, and sampling

A cross-sectional study was conducted amongst ALWHIV on ART northwest Ethiopia. The study included adults (≥ 18years**)** living with HIV on therapy. The study excluded those unable to respond and not volunteer to sign a consent form. An estimate sample size (N = 422) and convenience sampling was used to select study participants. Participants invited to participate in the study during a routine clinic appointment. Trained data collectors orally administered the survey tool to consenting participants in private adherence counselling rooms.

Data collection tool, procedure and measurement

An existing self-efficacy survey instrument, with a Cronbach alpha of 0.78, was used for data collection (Wallston et al. 2011). Participants rated their self-efficacy for SM over eight self-efficacy items, each scored using a three-point Likert scale. This resulted in a total self-efficacy score from 8 to 24, where a higher score indicated better self-efficacy for SM. Ethics approval for the study was obtained from the Human Research Ethics Committee at the University of Adelaide (H-2018-243) and Amhara Regional Health Bureau Research Office (APHHRTD/03/264/2019). Data collection took place from 1 April to 30 May 2019.

Data analysis

Coded data were entered and analysed using SPSS version 25.0. Respondents' characteristics were summarized using frequency and mean. To assess the differences in self-efficacy scores according to demographic, clinical and intervention characteristics, an *independent t-test* and *one-way ANOVA* were performed. Correlational analysis between self-efficacy and selected variables was undertaken using Spearman correlation coefficients. Based on the findings from the bivariate analysis, linear regression analysis was performed to identify self-efficacy influencing factors. A statistical significance level was set at a p-value of less than 0.05.

Results

Sociodemographic and medical characteristics

The self-efficacy survey was administered to 415 ALWHIV on ART. Participant characteristics are summarized in Table 1. Almost two-thirds of the respondents, 65.1% (n = 270), had attended formal education; however, most 82.4 %, (n = 342) did not have a regular job. A quarter of the respondents were from a rural area 25.5%, (n = 106). A mean difference in self-efficacy was identified in relation to gender (t = 2.244, p = 0.025), educational level (t = -2.103, p = 0.036), job status (t = 2.209, p = 0.028) and dwelling area (t = 2.081, p = 0.038). The majority, 75.2% (n = 312), of the respondents took one type of ART drug and, of the total sample, 9.2% (n = 38) reported experiencing drug side effects. A difference in self-efficacy was apparent between respondents with and without drug side effects (t = -3.111, p = 0.002).

Table 1: Sociodemographic, medical characteristics, interventions, and univariate analysis (n = 415; 100%)

Variables	N	%	Mean ± SD
Gender			
Male	174	41.9	20.07±2.44*
Female	241	58.1	19.54±2.40
Mean age (SD)	41.05 (10.54)		
Educational level			
Illiterate	145	34.9	19.42±2.394
Literate	270	65.1	19.94±2.431*
Job status			
Government employed	73	17.6	20.33±2.404*
Do not have a constant job	342	82.4	19.64±2.420
Religion			
Orthodox Christian	396	95.4	19.81±2.441
Others	19	4.6	18.84±1.979
Marital status			
Never married	26	6.3	19.54±2.642
Married	389	93.7	19.78±2.416
Residency			
Rural	106	25.5	19.34±2.19
Urban	308	74.5	19.91±2.49*
Number of drugs for HIV Rx			
One type	312	75.2	19.84±2.45
Two or more types	103	24.8	19.51±2.34
Presence of drug side effects			
Yes	38	9.2	18.61±2.320
No	377	90.8	19.88±2.411
Disclosed HIV status			
Yes	329	79.3	19.83 ±2.48
No**	86	20.7	19.49 ±2.22
**Reason for nondisclosure			
Fear of stigma and discrimination	86	20.7	
Use of reminders			
Yes	214	51.6	19.71±2.89
No	201	48.1	19.81±2.37

**Mean difference **All nondisclosure was due to fear of stigma and discrimination*

Self-efficacy for SM and its correlates

The overall self-efficacy mean (SD) score was 19.76 (0.12) out of a total score of 24, indicating an above-average level of self-efficacy for SM. However, over half of the respondents, 52.3% (n = 217), agreed that it is difficult for them to find an effective solution for problems with managing their HIV infection and the majority, 73.7% (n = 306), disagreed with the statement: no matter how hard I try, managing my HIV infection does not turn out the way I would like. This implies they felt that they had achieved their desired level of HIV management (Table 2).

Table 2: Respondents' scores on self-efficacy for HIV SM

	Items	**Responses**			
		Agree	***Neutral***	***Disagree***	***Total***
		n (%)	***n (%)***	***n (%)***	***n (%)***
1	It is difficult for me to find effective solutions for problems with managing my HIV infection.	217(52.3)	14(3.4)	184(44.3)	415(100)
2	I find my efforts to change things I don't like about my HIV infection are ineffective.	189(45.5)	23(5.5)	203(48.9)	415(100)
3	I handle myself well with respect to my HIV infection.	315(75.9)	37(8.9)	63(15.2)	415(100)
4	I succeed in the projects I undertake to manage my HIV infection.	306(73.7)	74(17.8)	35(4.8)	415(100)
5	I am able to manage things related to my HIV infection as well as most other people.	310(74.7)	35(8.4)	70(16.9)	415(100)
6	Typically, my plans for managing my HIV infection don't work out well.	44(10.6)	56(13.5)	315(75.9)	415(100)
7	No matter how hard I try, managing my HIV infection doesn't turn out the way I would like.	57(13.7)	52(12.5)	306(73.7)	415(100)
8	I'm generally able to accomplish my goals with respect to my HIV infection.	322(77.6)	68(16.4)	25(6.0)	415(100)
	Mean total score	**19.76±0.12**			

Self-efficacy for SM scores were positively correlated with age (r = 0.128, p = 0.009), educational level (r = 0.105, p = 0.033), income (r = 0.156, p = 0.001) and having a job (r = 0.099, p = 0.043). They were negatively correlated with female gender (r = -0.106, p = 0.031), area of residency (r = -0.114, p = 0.020) and experience of drug side effects (r = -0.144, p = 0.003) (Table 3).

Table 3: Significant correlation between self-efficacy for SM and related variables

Variables	Self-efficacy	
	r	*P*
Age	0.128	0.009
Educational level	0.105	0.033
Gender (female)	-0.106	0.031
Income	0.156	0.001
Address: rural	-0.114	0.020
Job: employed	0.099	0.043
Drug side effects	-0.144	0.003

Factors influencing self-efficacy for SM

To identify the factors influencing self-efficacy for SM among ALWHIV on ART, we conducted multiple linear regression analysis. Variables were entered based on the constructs of IFSMT and a p-value less than 0.05 on a bivariate analysis (correlation and simple linear regression). Of the proposed predictors, income, rural area residency and the presence of drug side effects significantly predicted self-efficacy for SM, explaining 5.4% of the variance in self-efficacy for SM ($F = 4.401$, $p < 0.001$, Adjusted $R^2 = 0.054$). The results indicated that a higher income ($\beta = 0.514$, $p = 0.029$) was associated with higher self-efficacy for SM, whilst living in a rural area ($\beta = -0.520$, $p = 0.043$) and presence of drug side effects ($\beta = -1.246$, $p = 0.001$) were associated with lower self-efficacy for SM (see Table 4). The fitness of the model was assessed, and the findings showed that the linear regression model was fit for the data. Tests confirming the model's fitness consisted of Shapiro-Wilk's tests ($p = 0.058$), Durbin-Watson statistic of 1.853 and visual plot inspection.

Table 4: Linear regression analysis of factors influencing self-efficacy for SM

Model	B	SEE	T	p-value
Constant	19.398	0.323	60.023	<0.001
Age	0.429	0.233	1.847	0.066
Income	0.514	0.234	2.195	0.029*
Gender (ref: male)	-0.183	0.241	-0.756	0.450
Rural (ref: urban)	-0.520	0.256	-2.028	0.043*
Drug side effects (yes)	-1.246	0.382	-3.264	0.001**
Job (ref: no constant job)	0.167	0.319	0.524	0.600
Educational level (ref: no formal education)	0.129	0.250	0.516	0.606
R^2 (Adjusted R^2)				0.070(0.054)
F(df)				4.401(7,407)
p				< 0.001

*p-value less than 0.05 and **p-value less than 0.01

Discussion

To knowledge of the investigator, this is the first study in Ethiopia to evaluate factors influencing self-efficacy for SM amongst ALWHIV on ART. Overall, the findings showed above average self-efficacy for SM. The self-efficacy level reported in our sample is similar to studies conducted in Korea (Yoo et al. 2011) and China (Huang et al. 2013) , whereas studies from the USA have reported variable levels of self-efficacy for SM (Berg et al. 2009; Wallston et al. 2011). Currently, living with HIV is considered as easy as living with other chronic diseases. However, there is a gap between how confident participants feel and the actual level of SM, which is low (Areri, Marshall & Harvey 2020b). Stigma and discrimination remain a problem, with a significant proportion of participants (20.7%) remains undisclosed due to a fear of stigma and discrimination, which may limit their confidence to mobilize and use available community recourses. More importantly, over 51.6% of the study participants depend on different types of reminders to execute their SM. This implies that ALWHIV in the study area are executing SM with some limitations. Working on the prevention of stigma and discrimination could be essential to improve self-efficacy for SM.

Our study identified a positive correlation of age, attending education and employment with self-efficacy for SM, which is consistent with a study conducted in Korea (Yoo et al. 2011). ALWHIV who have attained some level of education might have some awareness about living with HIV that might help to build self-efficacy for SM. Those who attended some form of education could be able to search for and update their knowledge on side effects management and coping with stigma and discrimination. Similarly, employed participants might have a better income for fulfilling basic needs, which in turn could enhance self-efficacy for SM.

Multivariate linear regression analysis showed that income, living in rural areas, and experiencing drug side effects remained significant predictors of self-efficacy for SM. Among these, experiencing drug side effects was the most modifiable risk factor associated with low self-efficacy for SM. The finding is consistent with a study conducted in China (Zhang et al. 2016). The findings imply that the presence of drug side effects appears to affect the confidence of adults living with HIV on ART. HIV care providers should focus on assessing the presence of side effects and provide appropriate support for the prevailing side effects. Teaching patients about medication side effects and their management could enhance self-efficacy for SM. Lack of side effect interpretation and management capabilities could be another reason influencing self-efficacy for SM (Jones 2006; Zhang et al. 2016). Therefore, it is vitally important to use a structured SM model (such as IFSMT) at each point of care. This would help HIV care providers to assess the presence of side effects and discuss the possible causes and the possible interventions. This may enhance their patients' self-efficacy for SM of health outcomes.

Better income was associated with increased self-efficacy for SM in our findings. This finding is consistent with the result of other studies that reported low socioeconomic status is an influencing factor for self-efficacy for SM (Foster et al. 2015; Wallston, Rothman &

Cherrington 2007). However, many of the participants in the study area do not have a regular job, which could be a possible reason for low income. Modifying the income level of ALWHIV could help enhance self-efficacy for SM, but this is not easy and achievable in the short term. However, creating job opportunities for ALWHIV could be a vital strategy by governments and policymakers to improve their income in the long term, which, in turn, may improve self-efficacy for SM.

Living in a rural area is another factor associated with low self-efficacy scores. The finding is not reflected in other studies (Zhang et al. 2016) and may be specific to the Ethiopian context. The rural community is characterized by low literacy, inadequate awareness of HIV treatment, unfavourable infrastructure for communication and low socioeconomic status. At the same time, the limited access to information in rural communities could also be linked to fear of stigma and discrimination. These all could affect the self-efficacy for SM of member of rural communities. However, this could be a slightly modifiable factor by using a SM model during the provision of feedback to ALWHIV. Continuous provision of awareness-enhancing HIV education to rural communities could also reduce stigma and discrimination.

Overall, the current findings call for interventions to enhance the self-efficacy of this population across the modifiable factors influencing self-efficacy. The regular and systematized use of a model based on IFSMT as a check and balance criteria during follow-up visits could help to identify and address problems related to experiencing drug side effects. However, long-term intervention by policymakers is required to change community perceptions of HIV, income and educational level.

This study has some limitations. First, the measurement of self-efficacy was based on an interviewer-administered self-report tool, and self-efficacy could have been overestimated due to a possibility of social desirability bias. Secondly, the validity of the translated tool was not tested in the Ethiopian context, although it has been tested and reported to be valid in other settings. Thirdly, the research focused on one hospital, and it is challenging to generalize the findings to ALWHIV on ART in other areas since the context is not the same. A further study consisting of multiple study sites is recommended to generalize the study findings to all ALWHIV on ART in Ethiopia.

Conclusions

Being female, living in a rural area and experiencing medication side effects were negatively correlated with self-efficacy. Age, attendance at education, having a job and a higher income level were positively correlated with self-efficacy for SM. The study confirmed that three contextual factors – the area of residence, income and drug side effects – were significant predictors of self-efficacy for SM among ALWHIV on ART. Factors that influence self-efficacy for chronic HIV management are multiple and, as such, require different strategies to address them. HIV care providers should consider the components of Individual and Family Self-Management Theory during discussions with patients so as to identify factors and choose interventions to enhance self-efficacy. Targeting the complex cognitive and personal factors that influence self-efficacy for SM may optimize not only self-efficacy but also broader health-related outcomes

Implications for practice

HIV care providers should assess self-efficacy for SM regularly, provide feedback and motivate ALWHIV to enhance their self-efficacy for SM. HIV care providers should provide education on possible side effects of HIV medication and their possible management. To enhance the self-efficacy for SM of ALWHIV, it might be helpful to use the IFSMT during follow-up visits to guide the clinical decision making using the constructs of the model. Working with patients to increase their belief in their own ability to perform SM is also worthy. As there is a high risk of perceived stigma and discrimination, HIV care providers should work on enhancing individual patients' and rural communities' awareness. Policymakers should consider focusing on job opportunities for ALWHIV to enable them to earn an adequate income which in turn would enhance self-efficacy.

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Declaration of conflicts of interests

The authors reported no potential competing interest.

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Authors' contributions

HAA design the study, collected data, analysed and interpreted data, and wrote and revised the manuscript. AM advised in developing the study, interpreted the data, and critically revised the manuscript. GH advised in designing the study, interpreted the data, and critically revised the manuscript. All authors read and approved the final version of the paper.

Chapter 8: Paper 5

Exploring self-management of adults living with HIV on antiretroviral therapy in north-west Ethiopia: Qualitative study

8.1 Preface

This chapter presents the qualitative findings from the second phase of the mixed-methods study. This involved exploring the key factors identified from the quantitative analyses of SM practice, medication adherence and self-efficacy in greater depth. The manuscript was published in the journal *HIV/AIDS – Research and Palliative Care*. The findings present a more in-depth understanding of the barriers and enablers of SM of ALWHIV on ART in Ethiopia, providing nuance and detail that could not be identified in the survey, as well as giving voice to ALWHIV and their experiences and perspectives. While many of the findings were consistent with the survey findings, there were some contradictory and some new findings. In particular, the qualitative findings highlighted the interconnected and reinforcing effect of factors that influence SM within a resource-constrained country such as Ethiopia. In turn, this emphasizes the need for context-relevant, multifaceted approaches to address the barriers to SM, requiring collaborative action from HIV care providers, policymakers and community networks.

8.2 Publication

Areri, H, Marshall, A & Harvey, G 2020, 'Exploring self-management of adults living with HIV on antiretroviral therapy in north-west Ethiopia: qualitative study', *HIV AIDS (Auckl)*, vol. 12, pp. 809-820, <https://pubmed.ncbi.nlm.nih.gov/33312002/>.

Statement of Authorship

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Principal Author

Name of Principal Author (Candidate)	Habtamu Abera Areri		
Contribution to the Paper	Conceived the study, designed the study, conducted data collection and analysis, and drafted the manuscript.		
Overall percentage (%)	70-80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	09 September 2020

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Amy Marshall		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	09 September 2020

Name of Co-Author	Professor Gillian Harvey		
Contribution to the Paper	Contributed to the design of the study, validated the data analysis and interpretation of the findings, and reviewed the manuscript.		
Signature		Date	09 September 2020

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ORIGINAL RESEARCH

Exploring Self-Management of Adults Living with HIV on Antiretroviral Therapy in North-West Ethiopia: Qualitative Study

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HIV/AIDS - Research and Palliative Care

Habtamu Areri[1,2]
Amy Marshall[1]
Gillian Harvey[1]

[1]Adelaide Nursing School, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, SA 5005, Australia; [2]School of Nursing and Midwifery, College of Health Sciences, Addis Ababa University, Addis Ababa 4412, Ethiopia

Background: The changing nature of HIV from an acute to chronic illness requires adults living with HIV to self-manage. Self-management enables individuals with HIV to maintain physical health, medication adherence and live with HIV-related conditions. This study aimed to explore self-management experiences of adults living with HIV on antiretroviral therapy in Ethiopia.

Methods: A qualitative descriptive study framed by the Individual and Family Self-Management Theory was carried out to explore the self-management experience of adults living with HIV in Northwest Ethiopia. Eleven semi-structured, in-depth interviews were conducted. The recruitment involved participants who volunteered to be contacted during a preceding quantitative study. The interview data were coded inductively and subject to thematic analysis.

Results: The main themes identified, each with a number of sub-themes, related to perceptions and experience of self-management, barriers and facilitators of self-management. Factors influencing self-management behaviour were inter-connected and particularly influenced by spiritual practices, low levels of income and experiences of stigma and discrimination.

Conclusion: The study highlights barriers to self-management among individuals living with HIV on antiretroviral therapy in a resource-constrained country. Interventions to address modifiable barriers and build on identified facilitators of self-management include working with the broader community to minimise HIV-related stigma and discrimination and engaging with religious leaders to tackle the observed conflict between spiritual practice and effective self-management behaviour.

Keywords: self-management, barriers, facilitators, antiretroviral therapy, stigma ; discrimination

Introduction

In Eastern and Southern Africa, over 20.6 million people were living with HIV in 2018, including 690 000 people living with HIV in Ethiopia.[1] The government of Ethiopia has a clear policy to improve access to medication, and the national Antiretroviral Therapy (ART) coverage has increased. However, living with HIV remains a challenging condition due to stigma, discrimination, poverty, and a low educational literacy rate.[2]

Improvements in HIV treatment have changed the experience of living with HIV from an acute to a chronic condition, which requires the individual with HIV to learn to live with and manage their condition. This implies that adults living with HIV (ALWHIV) should practice self-management (SM) to address the unique symptoms, medical challenges, and psycho-social stressors that they face daily.[3] Effective SM requires the individual to routinely take care of themselves and

Correspondence: Habtamu Areri
Tel +251 910218513
Email habera76@gmail.com

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illness-specific concerns, supported by families, social networks, and HIV care providers.[4–6] This can help to optimise the physiological, psychological, and social functioning of ALWHIV and enables them to take an active role in their health care decision-making.

In order to support ALWHIV, interventions aimed at enhancing SM are viewed as essential.[7] According to Holtzman, Brady and Yehia,[8] the most common interventions to improve SM are counselling about the benefits of medication adherence and how to live with HIV. Our systematic review also identified common effective interventions to enhance SM which consisted of SM skills training, counselling, provision of symptom management manuals, and technology-assisted support through phone calls, text messaging and online support.[7] As such, support from HIV care providers is crucially important in improving the wellbeing of ALWHIV.[9,10] HIV disclosure is another key aspect of HIV care and treatment, as it helps to initiate and mobilise support, decrease fear of stigma and discrimination and improve self-efficacy.[11]

Despite the literature recommending various strategies to promote SM, there is relatively little empirical research examining the SM experiences of ALWHIV on therapy. Where studies have been undertaken, it appears that self-management experiences and the factors that influence SM are variable.[9] A survey conducted in the USA indicated that ALWHIV used sleeping and support groups to enhance SM, as well as paying attention to diet management and physical activities.[12] In comparison, a study conducted in Uganda identified that ALWHIV depended on health system resources to improve their knowledge of the disease and coping skills for better self-management.[9] Evidence is lacking to better understand the SM experiences of ALWHIV on therapy in Ethiopia. This is particularly important given the additional challenges faced by ALWHIV in resource-limited settings, where the health system infrastructure is less developed, literacy levels are low, and individuals are more likely to face financial difficulties.[9,13,14] Skipping medication for religious reasons is another challenge that has been identified in some studies.[15,16] These are all factors that could impact on self-efficacy[17,18] and the individual's ability to self-manage.[11,12,19–21] This study set out to explore these issues and other related factors, building upon a prior survey undertaken in a region of Ethiopia to assess SM amongst ALWHIV. The survey findings revealed low levels of SM amongst the population studied. Predictors of SM included gender, literacy, living area, awareness of own HIV condition, self-efficacy, the use of reminder strategies, and encouragement to disclose HIV status.[22]

Methods

Design and Study Setting

As the second phase of a sequential explanatory mixed-methods study, a qualitative descriptive approach was applied to gain an in-depth understanding of the survey findings.[22] The study was conducted in Debre Markos referral hospital, which is the only referral hospital in East Gojjam of Amhara regional state, from September 1 to October 30 2019. The setting was selected as it is the major referral hospital serving a population of over 3.6 million.

Participant Recruitment

The study included adults (≥18years) living with HIV on ART for at least 6 months. The study excluded those unable to respond for any reasons such as illness or inability to communicate, and those who did not volunteer to participate. An invitation letter was posted during the survey data collection to invite participants to take part in an in-depth interview. Twenty participants showed interest and contacted the first author [HA] to register their willingness to be interviewed. From the potential pool of 20 interviewees, participants were purposively selected to ensure balanced representation, for example, in terms of gender and area of residence (urban-rural). A criterion of data saturation was applied to determine the final sample size.[23] This was achieved after the first eleven interviews, at which point no new data were identified, and it was deemed that data saturation had been reached.

Data Collection

A semi-structured interview guide was developed, informed by the survey findings and the theoretical framework that guided the overall study, namely the Individual and Family Self-Management Theory (IFSMT). The IFSMT is a descriptive middle-range theory, comprising interrelated dimensions defined as contextual factors, the process of SM, SM interventions and SM outcomes. The contextual factors include condition-specific factors, physical and social environment, and individual factors. The process of self-management is influenced by the individual's knowledge and self-efficacy, self-regulation abilities, and social facilitation, such as support and collaboration. SM interventions are actions that enable the process of SM and SM outcomes and include counselling, education and training, encouraging disclosure of HIV status and linking to support groups. SM outcomes encompass physical health, engagement in medication management, mobilisation of resources, coping and living with HIV.[5]

The interview guide was constructed in line with the theoretical domains of the IFSMT and then pre-tested before the main data collection began. The interviewer (HA) had prior experience of undertaking qualitative research and conducted the pre-test on two purposively selected ALWHIV to check the clarity of the interview guide. Minor changes were made to the interview guide following these interviews (Table 1). The pre-test data were not included in the analysis. The purpose of the study, the procedure of the in-depth interview and a request to audio-tape the interview were explained to the participants before beginning the interview process. The participants were then asked to sign a written consent for their participation and the use of the audio recording. The first author [HA] conducted face-to-face interviews using the semi-structured interview guide to ensure consistency. The interview was carried out in private in the adherence counselling room, where participants received their usual counselling service, in the local language (Amharic).

Eleven participants (six females and five males) were interviewed and included in the final analysis. One participant stopped the interview and withdrew without justifying a reason, and the data were not used in the analysis. The interview time ranged from 25 to 45 minutes. Upon completion of the interview, the conversation was summarised for the participant to confirm the content of the discussion. At the end of the interview, participants were compensated for their time with 60ETB. The audio-recorded interview was transcribed verbatim and read while listening to the audio recording to check the accuracy of the data.

Data Analysis

The interview data were translated from local Amharic language to English by a language expert before the final analysis. Interview data were imported into the qualitative analysis package QSR Software NVIVO 12. Respondents were coded as participant/P1, 2, 3, through to 11 to maintain anonymity. The process of analysis was conducted according to Braun and Clark's thematic analysis approach,[24] namely: 1) Familiarisation with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing the themes; 5) Defining and renaming the themes; 6) Producing the final report. The first author read and immersed himself in the data before preliminary analysis, keeping memos for later checking and use. To enhance the trustworthiness of the findings, three interview transcripts were coded independently by all three authors and discussed to identify and resolve any discrepancies in coding. After reaching an agreement, the first author [HA] completed the initial coding of the remaining transcripts. Emerging codes and themes were critically discussed and confirmed through regular meetings of the project team [HA, AM and GH].

Results

Most of the participants were aged 35 to 60 years (see Table 2), and around half had completed some level of education. All of the participants were Orthodox Christian by religion, which is a dominant religious practice in Ethiopia. Their monthly income ranged from 120–6360ETB (4.30–227USD). All participants had been receiving ART for between 5 and 15 years. Three main themes, with related sub-themes, were

Table 1 Semi-Structured Interview Guide: Short Form

#	Interview Guide
1	Sociodemographic characteristics
2	What does the term self-management (SM) mean to you?
3	What factors are hindering/facilitating your SM?
4	Is this health facility convenient for your HIV care and treatment?
5	How do you rate your self-efficacy/confidence for the SM program?
6	What kind of social facilitation/support have you received for your HIV-related SM?
7	How do you see your overall self-regulation abilities? How do you manage your HIV illness-related symptoms? What is your goal of HIV treatment?
8	Can you tell me about the interventions provided to you to support/enhance your SM?
9	**SM behaviour**
	a. Can you tell me how, on a daily basis, you self-manage your physical health? Symptoms? Side effects? Diet? Stress? What helps/prevents you from performing your HIV related physical health practice?
	b. Have you mobilised existing support (families, HIV networks, and health care providers) around you for your SM?
	c. What do you feel about living with chronic HIV conditions? What do you think could be the impact of ART on your life? Are you taking medication for HIV as recommended?
10	What do you think is the biggest challenge in your ART program and/or SM overall? What has worked well? What do you suggest as a solution to improve SM of ALWHIV on ART?
11	Any additional points?

Table 2 Demographic Characteristics

Demographic		Number of Participants
Age group (in years)	35–60 >60	9 2
Gender	Male Female	5 6
Marital status	Never married Married Divorced Widowed	1 4 2 4
Living area	Rural Urban	5 6
Educational level	No education Grade 1–12 Diploma Degree	5 4 1 1

identified from the inductive analysis, namely; Perceptions and experience of SM; Facilitators of SM; and Barriers to SM (see Table 3 and Figure 1).

Perception and Experiences of Self-Management

Participants typically described SM as a process of maintaining their health, with a particular focus on staying healthy, symptom management, reducing stress and medication taking behaviour. The SM perceptions and experiences of respondents were summarised under four sub-themes.

Table 3 Main Themes and Sub-Themes

#	Themes	Sub-Themes
1	Perceptions and experience of self-management	Staying healthy Symptom management Reducing stress Medication taking behaviour
2	Facilitators of self-management	Support mechanisms Reliance on HIV care providers Acceptance of HIV Availability of free HIV medication
3	Barriers to self-management	Financial difficulties Fear of stigma and discrimination Spiritual practice Lack of trust in HIV care providers

Staying Healthy

Participants largely associated SM with a desire to stay healthy. This involved keeping themselves protected from disease and staying healthy, for example, by eating a proper diet, undertaking physical activity, performing personal hygiene and the use of a condom. Diet management and physical activity were the most commonly referred to practice by the respondents:

> I eat my meal properly and on time. [P1]

> I try to make my diet, fresh and complete. I am doing this to prevent infections. [P4]

> I am trying to eat cooked food from different sources. [P2]

However, although participants were trying to eat a balanced diet, financial difficulties presented a challenge for many of them.

> Inadequate income is affecting my diet management. [P1]

Participants of the study also reported engaging in different forms of physical activity to stay healthy, although this was often undertaken as part of a daily routine such as getting to and from work and involvement in manual labour:

> I do physical exercise on a regular basis that makes me active and healthier. [P4]

> Every day, I always walk for more than 20 minutes to work on foot. However, I do not have a planned schedule to do physical exercise. [P1]

However, around half of the interviewees [P 1, 2, 3, 6 and 10] noted that a lack of motivation and awareness was preventing them from performing planned physical activities.

Symptom Management

Most participants reported seeking medical advice when they experienced symptoms such as side effects of medication and tiredness. For less complicated issues, many of the participants described managing their symptoms by taking rest, sleeping or going to church to be baptised with Holy water.

> When I felt a symptom of disease, I went to a health institution, but if the symptom is simple, I took a rest/sleep. When I felt tired, I also took a rest. I also go to the monastery church for baptising through Holy water for headache and feeling sick. [P9]

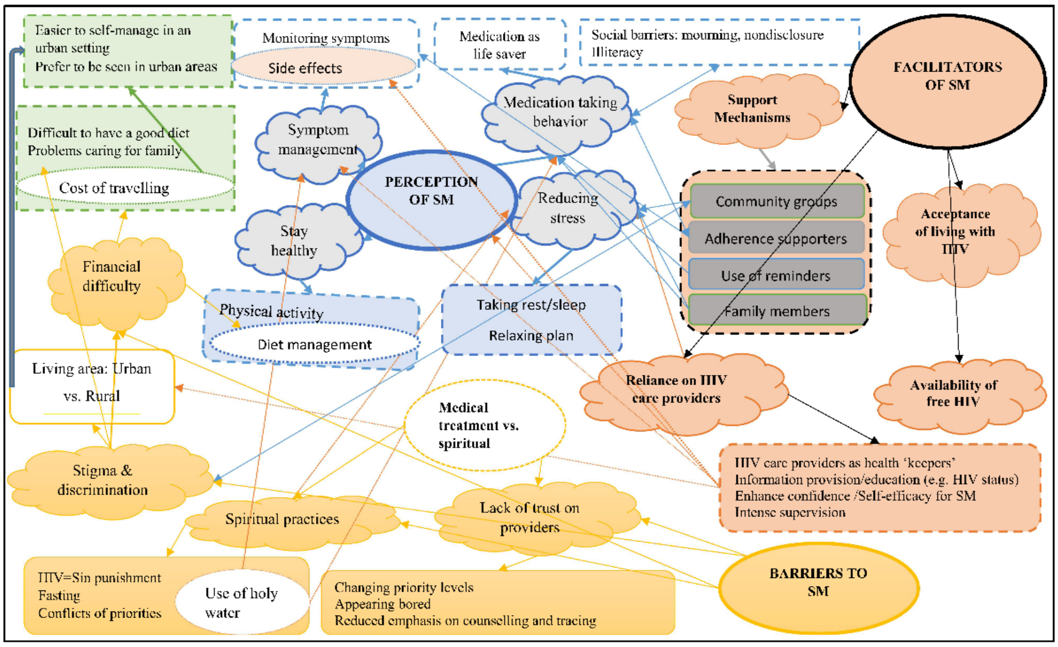

Figure 1 Concept coding.

> Since I acclimatise with the disease, I try to find a remedy for mild disease symptoms … I have sometimes got a headache problem, and for its management, I took coffee, but if not relieved, I contacted health care providers. Nevertheless, if the symptom of the disease seems complex, I go to health care organisations. I gave due attention to disease symptoms primarily. [P1]

In relation to medication, only two participants reported experiencing side effects [P4 & 5], and both said they made use of adherence supporters and HIV care providers:

> I had a side effect of drugs. For which, I consulted HIV care providers … I frequently came here to get support from HIV care providers and adherence supporters of the hospital. [P4]

Reducing Stress

Most of the participants described experiencing some form of stress or worry related to their current situation. Various stress-reducing strategies were reported. These included seeking support from family and friends:

> I am trying to relax sometimes with friends. [P6]

> … because of stress, I am losing weight. I am worried about my child. I tried to relax, but it works for a short time. Sometimes, I share my stress with my friends and my families. [P1]

Other participants used sleeping or taking a rest as a strategy for reducing their experience of stress. However, the inadequacy of income posed a challenge for some participants in terms of relaxation time as they were forced to keep working and could not afford to take time off work.

Medication Taking Behavior

Participants agreed that taking their medication routinely was essential for improved health status and leading a productive life. As a result, most stated that they had not missed their medication in the last month. However, a number of the participants did not strictly follow the schedule of taking medication at the set time. This was for a number of reasons, particularly social and religious issues, such as fear of other people seeing them taking medication, fasting, forgetting and mourning.

> Oh! I miss medication sometimes for different reasons—fear of others and forgetting to take medication. Sometimes, I leave the drug at home. Moreover, I do not have any person to remind me of taking medication. [P1]

> I did not take the drug one day because of mourning. The families did not allow me to return home, and I remained without medication for that night. [P7]

While in most cases taking medication was considered as "a deadly struggle for saving a life" [P2, 4,5,6,7 and 10], it was considered that medication should be appropriately taken to the end of life. Participants commented that taking medication on the days of fasting was challenging [P1, 8 and 9].

Facilitators of Self-Management

Four main facilitators of SM were reported by the participants related to their support mechanisms, a reliance on HIV care providers, acceptance of HIV, and the availability of free HIV medication.

Support Mechanisms

Adherence supporters [expert patients] are people living with HIV on ART who are trained and employed to support other people living with HIV. The presence of these supporters in HIV care and treatment clinics helps to enhance the sharing of experience and clarify potential misconceptions of other individuals living with HIV on ART. Adherence supporters were described as a lifesaver by many of the participants.

> Adherence supporters were life-saving people from the starting time. They were helping me in providing information on when to come, how to manage if symptoms happen and clarifying my confusions. [P8]

Social networking and community groups were also seen to be helpful through enhancing engagement in treatment, sharing experiences, and providing psychological and economic support. For example, three participants [P1, 3 and 6] reported that the support they received from the "association of Bezawit people living with HIV" helped them to disclose their HIV status after hearing shared experiences from peers in the association. They also commented that the support they got from the association changed their lives, both financially and in terms of reducing stigma and discrimination. However, other participants did not see a need for involvement in social networking for self-management, for example, viewing it as a waste of time because members lacked appropriate knowledge.

Another critical source of support came from friends and family members. Four of the eleven participants were entirely dependent on support from family members to carry out their medical recommendations.

> Family members were helping in reducing my stress, reminding medication time and general discussion about my conditions. [P2]

Nine of the eleven participants used different strategies in the process of SM to avoid forgetting their medications, particularly reminder approaches. Some used families or friends as reminders, while others used their phone alarm. Two participants commented on the challenge of not being able to use a watch due to illiteracy, which meant they had to depend on other family members or friends to remind them of the timing of their treatment [P3 & 8].

> I am using my families as a reminder for my drug. I could not take on time my medications if they were not with me. [P10]

> My friend with whom I am living helped me to cope with the HIV condition and self-manage. She always reminds me of what to do and not to do. [P3]

Reliance on HIV Care Providers

The majority of participants acknowledged the support they got from HIV care providers, particularly around health information and HIV medication, which were seen to enhance SM. The support they got from HIV care providers allowed most participants to lead a productive and healthy life; one person referring to the HIV care providers as 'my health keepers' [P4]. Notably, the information that care providers gave on participants' HIV status helped them to focus attention on SM.

> Knowing my current HIV condition motivated me more to self-manage. [P3]

> Knowing the condition of the disease helped me to plan for better self-management. [P11]

> They told me about my CD4, whether it improved or needed improvement. It helped me to identify the problem of my self-management. Overall, knowing self-HIV status is essential for determining the focus area of weakness and strength. [P5]

However, whilst most participants thought it is essential to know their HIV status, many of them were, in fact, unaware of their specific HIV disease status, for example, concerning their CD4 level.

> I do not know the level of my condition now; I forgot it; however, if I knew the level of the disease, it helps me to

> treat myself well. They [HIV care providers] better remind us every time we come, it might motivate me. [P4]

> I do not know the status of my disease. [P8]

Many participants reported increased confidence to carry out SM through the process of HIV therapy. However, they also acknowledged the need for intense supervision from HIV care providers to enhance their SM. This helped to improve health status, retention in care and adherence to treatment. This was seen to be particularly important for adults living in rural communities.

> Intense supervision on self-management is essential because many adults on ART do not correctly take their medication for different reasons. [P1]

Acceptance of HIV

As treatment started and their health status improved, many participants realised that accepting and living with HIV was the only option open to them. Some described living with HIV as their destiny or fate, whilst others thought that living with HIV on therapy was not that different from those who were not HIV positive.

> Living with HIV does not have a new feeling. I am living as any other person is living. Now, I am delighted and leading a stable health condition. It is a sin punishment for our bad behaviour … I must accept living with HIV as part of life and be able to carry out my self-management. [P10]

The confidence developed once they started on HIV therapy enhanced the ability of participants to self-manage.

> It is a matter of convincing myself. I have the confidence and power to treat myself. My self-efficacy is increasing from time to time". [P3]

Availability of Free HIV Medication

All participants described HIV medication as a lifesaver that allowed them to cope. Without the therapy, it was unimaginable to live the life they were living. Many participants reported that it had significantly impacted on their health status from a state of being bedridden to now leading productive lives. The free HIV medication enhanced engagement in SM programs.

> Thanks to the free HIV treatment I got from health care providers. This support is very decisive in engaging in the treatment program. [P3]

> The treatment program is for free for all, which is great support for self-managing. [P6, 7and9]

However, whilst most of the participants were motivated by the beneficial effects of the treatment program, a minority had contradictory feelings:

> On one side, I thank God for keeping me healthy; on the other side life with HIV is difficult because of taking HIV medication always. [P2]

Barriers to Self-Management

From the interview data, several barriers to SM were also identified. These included financial difficulties, fear of stigma and discrimination, spiritual practice, and lack of trust in HIV care providers.

Financial Difficulties

As described in relation to attempts to remain healthy as part of SM, many participants faced financial challenges, with 8 of the 11 participants stating that their income was not sufficient to cover the cost of living. Six of the participants reported a monthly average income within the range of 120–2500ETB (equivalent to 4.30–89 USD), which is also reported insufficient to fulfil basic SM needs. Such financial hardship presents challenges in relation to supporting families, refilling medications for the treatment of opportunistic infection, costs of transportation for hospital visits and diet. As one participant commented:

> It is difficult to say that I am performing my self-management due to inadequate income … my focus is on my work to generate income. Inadequate income is affecting my diet. Sometimes, I feel hungry due to a lack of food. [P1]

Another participant commented that her child was living with other family members because her income was inadequate. [P3]

Fear of Stigma and Discrimination

Many of the participants reported that they incurred additional transportation costs to receive HIV treatment from health facilities further away from where they lived even though an HIV care facility was available in their local community. This was because they did not want to be treated in their local health facilities due to fear of stigma and discrimination. This created an additional financial burden and a potential risk factor for poor SM.

> This hospital is convenient for me. I do not want to be treated in my area even though I have a difficulty of

> covering my cost of transportation. I do not want to go and get treated in my area due to the presence of stigma and discrimination. [P11]

> I was told to go to a health facility in my area, but I insisted on remaining here for my HIV follow up and treatment despite the challenge of the increased cost of transportation and living cost. In my community, there is a perception problem regarding the disease [HIV]. [P2]

Stigma and discrimination, especially in the rural community, were the main obstacles in the process of HIV therapy that made ALWHIV travel to distant health facilities to get treatment. Participants from rural locations claimed that the perception of the rural community was significantly influencing their SM, for example, in preferring not to disclose their HIV status or receiving treatment in their local area. Some even chose to move to live in an urban setting, although this could create further financial difficulty as they needed to rent a house to live in. The perceived fear of stigma and discrimination meant that disclosure was difficult even though participants were advised to do so.

> HIV care providers told me many times to disclose my status and get treatment in nearby health facilities. I rejected this many times due to fear of stigma in my community. In the same way, working on community perception may be necessary. [P5]

> Living in a rural area is challenging because of society's perception of HIV… stigma and stigmatisation. I am thinking of living in town, and this may help me to follow my treatment. I will rent a house in a town. I am not comfortable in my living area, and I want to change to the urban area. I am getting sick from time to time. In rural areas, society thinks that the disease will be transferred through contact. [P9]

Consequently, the presence of HIV care centres in the local community has not fully solved the burden of transportation costs and access issues for all ALWHIV.

Spiritual Practice

Another self-management challenge was related to spiritual practices such as the use of holy water and fasting. For example, even if participants themselves were not fasting, their SM could be affected by the family's fasting time and practice, causing them to skip medication and diet.

> The reason for not performing my self-management is my mother's fasting time; I am waiting for my mother till the end of her fasting time to eat food with her… If my medication is in the morning, it could be difficult for me. [P1]

Another participant added:

> For the interest of family, I am also fasting and using holy water, and the fasting time has influenced my self-management. [P7]

The study findings demonstrate a potential conflict of priorities, with participants worried about practising spiritual life and SM together.

> Today is fasting day, so how can I take medication? I commented many times for missing drugs on fasting days. Spirituality is part of my life; I must think of my future spiritual life. In my age, not fasting is a sin. That is why I am not taking medications in the morning during fasting days. [P8]

Lack of Trust in HIV Care Providers

Whilst HIV care providers were identified as a key enabler of good SM, challenges were also identified, such as a sense of decreasing attention from the health care system.

> Preventing the progression and stopping HIV spread has got less attention compared to the past and made me hopeless. Many of my friends are leaving their medication. Strong counselling and tracing should be in place. [P5]

Other participants commented that their HIV care providers looked bored, which affected their level of trust in the treatment program [P5 & 7]. It was also reported that the emphasis on counselling and tracing had reduced, which impacted on SM.

> I got counselling services from HIV care providers regarding my HIV treatment and on the importance of joining peers. However, I do not believe that the counselling service is enough. [P1]

Summary of Findings

Participants mostly associated SM with taking medication and staying healthy through the practice of physical activities and diet management. SM was enhanced by systems such as adherence supporters, social networking, and family supports, supervision from HIV care providers and availability of free medication. Major barriers to effective SM included financial difficulties, fear of stigma and discrimination, spiritual beliefs and practice and, in some instances, a lack of trust in HIV care providers. These issues are explored further in the discussion.

Discussion

This study examined the SM experience and influencing factors among ALWHIV on ART in Northwest Ethiopia. In line with the IFSMT, the findings reveal a number of interconnected and often reinforcing factors that pose challenges to maintaining effective self-management amongst ALWHIV on therapy. These relate to the potential conflict between the requirements of SM and spiritual beliefs and practice, the difficulties of maintaining a healthy lifestyle on low levels of income and the impacts of experiencing stigma and discrimination.

Orthodox Christianity is the dominant religion in Ethiopia and one that involves regular fasting to fulfil religious obligations. This involves fasting until lunchtime on Wednesday and Friday every week and a full 15 to 56-day block of fasting during the fasting seasons. Similarly, going to monasteries to fast and use holy water is a major reason for skipping medication and diet or even stopping medical treatment. As a result, skipping medication and diet during fasting time and the use of holy water was common, supporting the findings from a previous study conducted in Ethiopia.[15] From the perspective of the IFSMT, the conflict between spiritual practice and taking treatment offers a specific example of goal incongruence and highlights an important area for action, namely working with religious leaders to educate ALWHIV on ways of reconciling medical recommendations and religious practice.

Financial difficulties, related to low levels of income, created a number of challenges, including the ability to maintain a healthy diet and a pressure to work, which limited the ability to get adequate rest and relaxation. In turn, these factors could add to feelings of stress. Financial difficulty is globally recognised as a major challenge affecting SM.[12,14,18,19,25] However, in our study, issues related to stigma and discrimination added another layer of stress and financial burden. For example, in rural areas, stigma and discrimination forced some people to travel outside their community for treatment, creating additional transportation costs and exacerbating financial difficulties. The fear of stigma and discrimination also affected the willingness to disclose HIV status, thus limiting the potential to share experiences with others and mobilise existing resources from the community. This affected the involvement of ALWHIV in community networking in our study area, which is recognised as an important support strategy in existing literature.[11,14,21] Working to minimise the perception of stigma and discrimination, particularly in rural areas, is an essential aspect of HIV care and an important pre-requisite to encouraging disclosure of HIV status.

Despite the challenges and barriers, the study identified various strategies that could help to enhance self-management. Consulting with HIV care providers, sharing experiences within social networks and being familiar with symptom management enhanced the experience of SM, a finding that is consistent with other studies,[6,26] including research conducted in Uganda and the USA.[4,9] Participation in social networking can help ALWHIV to get access to health information, resources and share lived experience with individuals with the same condition. As such, establishing networks of ALWHIV and promoting their engagement in networking could be helpful. Along similar lines, the findings also identified that the presence of adherence supporters facilitated SM behaviours, which is consistent with a study conducted in Uganda.[10] The use of adherence supporters in resource-limited settings can serve a dual purpose. Firstly, it helps to support the sharing of lived experiences, for example, how to cope with medication side effects, symptom management and the need to follow a strict medication regime, since adherence supporters are also ALWHIV on therapy. Secondly, it represents a job opportunity for ALWHIV on therapy and can motivate others to engage in SM behaviours more actively. However, the feasibility and effectiveness of these type of enabling strategies is dependent upon prior attention to the previously identified barriers to disclosure. This poses an important question about where to start in terms of strategies to facilitate and support more effective SM, for example, by considering which of the identified barriers are potentially the most modifiable and how best to address them.

Of the previously discussed barriers, namely the conflict between spiritual practice and SM activities, financial constraints and stigma and discrimination, tackling issues relating to stigma and discrimination could help to alleviate some of the other problems experienced and would seem to be an appropriate starting point. For example, if ALWHIV felt comfortable to receive care closer to home, they would not incur the additional transportation costs associated with visiting an HIV clinic further away. They might also feel able to more openly discuss the tensions they experience between maintaining established spiritual practice, such as fasting, and the need to follow a strict medication regimen.

HIV providers are an important group to consider in terms of addressing the barriers presented by stigma and discrimination. Consistent with a study conducted in Uganda,[9] HIV care providers were considered as important health keepers, acting as a resource for health information, providing practical advice on SM, encouraging disclosure and linking with other support groups. On the contrary, however, some participants expressed negative views, perceiving some care providers to be less engaged or attentive, suggesting a possible need to invest in staff education and resources. Specific activities that health care providers could undertake include increasing the individual's own awareness of their HIV status, such as their CD4 count, as this type of feedback could reinforce the motivation to self-manage. However, more intensive information provision and support on an individualised basis during follow-up visits could have implications for the number of HIV care providers required to staff the HIV clinics.

Our study identified the significance of supervision to enhance engagement in the SM program, especially for those with low educational literacy and those living in rural communities. The finding is supported by previous research.[8,9] Low literacy and living in rural communities could be linked to poor SM behaviour due to various reasons, including the inadequacy of health information, poor communication infrastructure, and fear of stigma and discrimination. As a result, ALWHIV require persistent supervision from HIV care providers could help them to keep doing what is recommended.

In summary, the study highlights the complexities involved in attempting to improve the SM behaviour of ALWHIV in Ethiopia, influenced by specific economic, social and cultural factors. A number of key findings emerge that require the critical attention of HIV care providers and policymakers. Firstly, the interconnectedness of the various contextual factors adds to the complexity of improving SM experience. For example, those living in a rural community are more likely to experience stigma and discrimination and so choose to travel further away for treatment. However, the costs associated with this exacerbate their financial difficulties and could have a knock-on effect in terms of the ability to maintain a healthy diet and managing stress, consequently making SM even more difficult to achieve. Fear of stigma and discrimination is also an issue influencing attitudes to disclosure, in turn affecting resource mobilisation and poorer SM. Therefore, decreasing fear of stigma and discrimination should be a primary area for interventions to enhance SM of ALWHIV. However, encouraging individual disclosure alone is not a solution; rather, working on the community's broader perception about HIV is essential. This includes taking account of the prevailing religious culture and the potential conflict between spiritual beliefs and effective SM behaviour, an area where local religious leaders may have an important role to play in community education and support. Finally, the role played by HIV care providers and adherence supporters in the provision of health information, supervision, and coping is vital and one that should be intensified and developed moving forward.

In terms of limitations, it is important to note that the study was conducted on participants from one regional area in Ethiopia and all shared the same cultural and religious background. This might affect the transferability of the findings beyond the immediate study setting.

Conclusions

This study highlights the particular challenges faced by individuals living with HIV on antiretroviral therapy in a resource-constrained country. Whilst some barriers to effective SM require long-term solutions, for example, poverty and low levels of literacy, the study also identifies a number of modifiable barriers where actions in the short to medium term could enhance SM practice. This will require a collaborative effort from a range of stakeholders, including HIV care providers, policymakers, and health system and religious leaders.

Abbreviations

ALWHIV, adults living with HIV; HIV, human immunodeficiency virus; IFSMT, Individual and Family Self-Management Theory; SM, self-management.

Data Sharing Statement

Data supporting the findings of this study are available from the corresponding author [HA] on request.

Ethical Considerations

All procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval for the study was obtained from the University of Adelaide (H-2018-243) and Amhara Regional Health Bureau Research Office (APHHRTD/03/264/2019). Written informed consent was obtained from all individuals participants included in the study.

Consent for Publication

Consent for publication was obtained from all participants, including consent to publish anonymized quotes from the interview in published material.

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Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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Chapter 9: Discussion and conclusion

9.1 Introduction

This study set out to assess the factors influencing the self-management of ALWHIV on ART in Debre Markos Referral Hospital through addressing the following research objectives:

- Determine the daily self-management behaviours of ALWHIV on ART
- Identify the factors influencing the self-management behaviours of ALWHIV on ART
- Make evidence-informed recommendations for improving the SM behaviours of ALWHIV in Ethiopia.

The chapter starts by discussing the key findings in connection with the research aim and questions, integrating the results of quantitative and qualitative studies, and considers the implications of the results from practice and policy perspectives. Study limitations and areas for future research are highlighted.

9.2 Self-management behaviours of ALWHIV on ART

In addressing the first research question, the study investigated the self-management behaviours of ALWHIV in terms of daily SM practice and medication adherence. Participants described self-management as a process of maintaining health through engagement in different behaviours such as symptom management, physical health practices, reducing stress and taking medication properly. In particular, ALWHIV mostly associated SM with a desire to stay healthy. This finding is somewhat consistent with studies conducted in Uganda (Russell et al. 2016) and China (Wang et al. 2016). However, the survey findings indicated a relatively low level of self-management practice compared to studies conducted in other countries (Korea and USA) using the same self-management measure (Kim et al. 2015; Webel et al. 2013). This suggests that, although participants could define what SM meant to them, their ability to practise it was restricted or limited. The reasons for this are examined in detail in the following section. However, it is important to note that the application of a chronic disease management approach to HIV care is relatively recent in the study context (Ethiopia), which, in turn, means that strategies to develop and implement SM programs are in the early stages of development.

Similarly, medication adherence was low (81%) compared to research conducted in other parts of Ethiopia (Letta et al. 2015a; Tegegne, Ndlovu & Zewotir 2018). The difference might be related to the difference in the study population. In this study area, almost all of the population is Orthodox Christian, and fasting is common. The finding is also low compared to the World Health Organization optimal level of medication adherence of $\geq 95\%$ (WHO 2016). Participants in the qualitative interviews reported that taking medication for their HIV treatment was considered a "deadly struggle to save a life". However, they did not deny that taking medication strictly is challenging. This suggests there is a problem of medication-taking by adults living with HIV.

9.3 Factors influencing SM behaviours of ALWHIV on ART

The SM practice of ALWHIV on ART in the study sample was relatively low, even though participants could define what SM meant to them. This section examines the possible reasons for the gap between ideal and actual SM practice. The findings reveal many factors that influenced SM behaviours, both in terms of SM practice and medication adherence. These factors operate at different levels, which has implications for the strategies and interventions that will be required to improve the SM of ALWHIV on ART.

9.3.1 Individual and socio-demographic factors

Key individual and socio-demographic factors influenced the engagement of ALWHIV on ART in SM behaviours, including educational status, employment status, income, area of residence, self-efficacy, and spiritual beliefs and practices.

Both the quantitative and qualitative findings indicated that a higher level of education was associated with better engagement in the two SM behaviours: SM practice and medication adherence, particularly compared to those who were illiterate. Participants in the in-depth interviews reported that an inability to read and use a timer watch as a reminder leads them to depend on family members as a reminder for SM behaviours. The findings are congruent with the literature on the relationship between educational attainment and SM behaviours (Ellis 2015b; Marc et al. 2007). Low educational attainment could influence independent engagement in SM behaviours. Illiteracy could lead to an inability to critically analyse the importance of engaging in SM behaviours and affect confidence to be involved in decision making about one’s own health conditions. Overall, illiteracy might be responsible for poor engagement in SM behaviours and requires person-centred interventions to enhance engagement in SM behaviours. Special attention should be given to illiterate individuals to keep them informed and then proactively engage them in SM behaviours.

Employed participants were better in SM practice compared to those who were unemployed. Employment could enhance the financial capability of ALWHIV on ART to engage in SM practice. This is supported by the finding that participants with a higher income had a higher average SM practice score. Lack of a regular job affected participants’ ability to focus on engaging in SM behaviours (Areri, Marshall & Harvey 2020a; Areri, Marshall & Harvey 2020b). This finding is consistent with studies globally (Arns, Martin & Chernoff 2004; Brooks et al. 2004; Gaden 2017; Russell et al. 2016). The interviews revealed that looking for a job influences the time needed for relaxation and creates further stress in daily life. In the study population, financial difficulties remained a major challenge for SM especially by limiting the ability to maintain a healthy diet (Areri, Marshall & Harvey 2020a). Creating employment opportunities for ALWHIV might generate regular and higher income, which would help individuals to allocate adequate time for SM practice. On the other hand, employment status was not associated with the other SM behaviour, medication adherence. The possible reason could be HIV medication is available for free. The finding is consistent with a study conducted in Gondar, Ethiopia on medication adherence behaviour (Bezabhe et al. 2014).

Area of residence was another factor influencing the SM behaviours of ALWHIV in the study population. ALWHIV on ART from a rural community were associated with lower SM practice. The participants from rural communities were much more likely not to disclose their HIV status due to fear of stigma and discrimination. This remained a barrier to engaging in SM behaviour fully (Areri, Marshall & Harvey 2020a). This finding is congruent with a study conducted in Iran (Oskouie et al. 2017) and a local study in other parts of Ethiopia (Bezabhe et al. 2014). In the rural community, there is evidence of a low level of educational status, poor communication infrastructure and low access to health care. As a result, individuals living in rural communities are forced to travel long distances to access HIV medication, which exacerbates their financial difficulties.

The quantitative study did not show the effect of spiritual beliefs and practices on SM behaviours. However, the in-depth interviews revealed a conflict of priority between spiritual practices and SM management behaviours such as diet management and medication-taking behaviour. The interviewed participants worried about engaging in both spiritual practices and the recommended SM behaviours. Taking medication flexibly due to physical and social environmental factors such as religious practices that included fasting and using holy water for healing is becoming a norm. Skipping medication and giving up one’s healthy diet during fasting and using holy water for healing were commonly reported in the study population, which is consistent with a study conducted in Gondar teaching hospital, Ethiopia (Bezabhe et al. 2014). The findings imply a clear conflict of priority between strictly following medical recommendations and spiritual practice. Besides, it is argued that there is a clear lack of context-relevant guidance on managing these competing priorities. This conflict affected the belief and self-confidence (the so-called self-efficacy) of ALWHIV on ART (Areri, Marshall & Harvey 2020a).

Self-efficacy for SM was found to be a key influential factor across both SM behaviours (SM practice and medication adherence). A moderate level of self-efficacy was identified in the study population, a finding that is comparable with a study in China (Huang et al. 2013). A higher self-efficacy for SM was associated with better SM behaviours. However, there is a clear gap between how confident the study participants feel and their actual engagement in SM, which is low (Areri, Marshall & Harvey 2020b). Living area, drug side effects and income affected the study population’s self-efficacy (Areri, Marshall & Harvey 2021). This finding is consistent with a study conducted in China with respect to reduced self-efficacy in the presence of drug side effects (Zhang et al. 2016). This implies ALWHIV on ART with drug side effects lose confidence in engaging in self-management behaviours. Additionally, the interview participants stressed the need for intense supervision by HIV care providers of the SM behaviours of ALWHIV on ART. Hence, teaching about medication side effects and their management could enhance self-efficacy for SM. Therefore, it is vitally important to use a structured SM model (such as one based on IFSMT) at each care point. This would help HIV care providers to assess the presence of side effects and discuss the possible causes and interventions.

In line with other literature (Foster et al. 2015; Wallston, Rothman & Cherrington 2007), financial difficulty was also linked to reduced self-efficacy for SM. Most of the study participants had no regular job, and this, in turn, could affect their self-efficacy for SM behaviours. Another factor that influenced self-efficacy for SM was living in a rural area. However, this finding is not reflected in the literature (Zhang et al. 2016) and may be specific to the Ethiopian context. This needs further investigation. However, in the study population low literacy, inadequate awareness of HIV treatment, and unfavourable communication infrastructure remain major problems. These limitations in rural communities could also be linked to stigma and discrimination from the community, which could further reduce the level of self-efficacy for SM.

9.3.2 Disease-related factors

The disease-related factors that influenced the engagement of ALWHIV on ART in SM behaviours included awareness of HIV status, disclosure, drug side effects, and fear of stigma and discrimination. Awareness of self-HIV status, especially CD4 level and staging, was statistically associated with higher SM practice but not medication adherence. Better awareness of self-HIV status was associated with better engagement in SM practice. However, the participants from rural areas and the illiterate were less likely to be sure about their status, including their CD4, and they wanted continuing information sessions. This finding is in support of reports in the literature (Kim et al. 2015; Russell et al. 2016; WHO 2016). Revision of individual case conditions during each clinical visit is important to remind each individual of the HIV status of their case. Updating each individual on their HIV status, especially those coming from rural communities and those with low educational status, could be considered routine components of motivation and feedback.

Contradictory findings were observed with respect to HIV disclosure status. The reported level of disclosure in the study population was high (79.3%), but the in-depth interviews showed that, even though participants were encouraged to disclose, they did not find it easy, and many remain undisclosed with their HIV status. Interview participants indicated the main reasons were social factors such as stigma and discrimination. Nondisclosure meant that missing medication doses while in a particular social environment or living with others was inevitable. Stigma and discrimination were also considered social obstacles to getting a job. Consistent with the literature (Ellis 2015b), it was also be a reason to be unemployed. This is a very concerning issue, especially for those coming from rural communities. It calls for evaluating and revising the existing guidelines regarding stigma and discrimination, emphasizing rural communities and illiteracy. It is essential to examine what is working and what is not working with regard to stigma and discrimination in community. It is worth considering motivational communication to encourage disclosure, which, in turn, enhances engagement in SM behaviours (CDC 2017). Even though disclosure is the choice of the clients, it is important to encourage them to disclose as it helps them to activate existing resources in the community, including social support and networking. Social networking is recognized as a key support strategy in literature (Gaden 2017; McDonald et al. 2016; Wang et al. 2016).

9.3.3 Factors related to health care and support

Support obtained from HIV care providers such as medication adherence support, free medication and reminders remains a key influential factor that influences the engagement of ALWHIV on ART in SM behaviours. The presence of adherence supports in HIV clinics and the support they provide enhances SM practice (Areri, Marshall & Harvey 2020a; Areri, Marshall & Harvey 2020b). Adherence support is given by adherence supporters who are ALWHIV who have been trained and employed to help people living with HIV with coping, side effects or symptom management, medication adherence and provision of information on HIV care and treatment (Hussen et al. 2014). The adherence supporters in the ART clinic helped with the sharing of experiences, clarified potential misconceptions and were considered ‘a lifesaver’, especially at the start of ART (Areri, Marshall & Harvey 2020a). This finding is congruent with several studies (Holtzman, Brady & Yehia 2015; Igumbor et al. 2011; Nakamanya et al. 2019; Wang et al. 2016). The finding implies that the presence of adherence supporters in HIV clinics is important for both SM behaviours (SM practice and medication adherence), although the use of adherence supporters did not have a statistically significant effect on medication adherence. This may need further study by including multiple sites.

The use of reminder strategies was associated with a higher SM practice. However, many participants reported difficulty using a watch, phone, or readable materials as a reminder. Those who disclosed their HIV status were entirely depended on the support of family or friends to remind them of what to do in the process of their SM. This finding of the study is supported by other literature, and the use of reminder strategies in the process of HIV therapy is associated with better engagement in treatment programs (Holtzman, Brady & Yehia 2015; Wang & Wu 2007). It was observed that taking medication strictly on schedule was difficult for a number of participants for different reasons such as religious practices, social reasons and forgetting (Areri, Marshall & Harvey 2020a). This finding means the cause of reduced engagement in SM behaviours could be multifactorial and this implies that multiple strategies are needed to tackle the problems. The next section will discuss the identified evidence-informed interventions.

9.4 Evidence-informed interventions

Individual and sociodemographic factors, disease-related factors, and health care and support related factors were all identified as affecting the SM behaviours of ALWHIV on ART in the study population. A number of key influencing factors were identified across both the survey and the interviews: financial difficulty, low education, living area, nondisclosure status, presence of drug side effects, conflict between spiritual practices and medical treatment, and stigma and discrimination. Evidence on interventions to improve the SM of ALWHIV on ART using experimental studies conducted globally was also synthesized in a systematic review as part of this study (Areri, Marshall & Harvey 2020c). While none of the included studies were conducted in low-income countries, many of the interventions are applicable in developing countries.

The synthesis of the most common and successful interventions identified in the systematic review could be useful for resource-limited settings like Ethiopia. It is possible to identify which interventions may be most appropriate and effective in addressing the identified key influencing factors, as presented in Table 4. The factors that influence SM that were identified in this study are interrelated and reinforce each other. ALWHIV living in rural areas suffer from stigma and discrimination and, as a result, are forced to pay to travel to access HIV medication. Additionally, the low educational level, stigma and discrimination cause employment difficulties. All these factors exacerbate the existing financial difficulty. As a result, the pressure to spend more time looking for work and working reduces the time available for engaging in SM programs. Overall, living in a rural area and low educational status result in reduced access to healthcare information, which, in turn, leads to reduced motivation to engage in SM activities. Therefore, interventions designed to enhance SM behaviours should consist of different modalities to promote engagement of ALWHIV on ART in the recommended SM behaviours. The rest of this section discusses applicable interventions for the key influencing factors in the context of the study population.

Table 4 Summary of key SM influencing factors and possible interventions

Factors (Areri, Marshall & Harvey 2020a; Areri, Marshall & Harvey 2020b)	**Interventions** (Areri, Marshall & Harvey 2020c)	**Expected SM outcomes**
Educational status: low educational level	SM skills training Counselling: phone/face-to-face Use of reminders Symptom management manuals Individualized SM education Adherence supporter visits	**Enhances:** Symptom management Medication adherence Self-efficacy and coping

Financial difficulty	Creating job opportunities	Helps patients to get adequate time for SM programs Improves income, which helps patients to engage in physical health activities
Living area: rural	SM skills training/continuous education session during each follow-up visit Counselling: phone/face-to-face Encourage disclosure Symptom SM manuals Adherence supporter visits	Reduces the risk of stigma and discrimination in the community Helps patients to use locally available resources: healthcare access, social networking and social support Reduces travel costs
Disclosure status: undisclosed	Counselling Phone calls Adherence support Sending text reminders Encourage disclosure	Reduces the risk of stigma and discrimination Helps to mobilize existing resources for SM like social support, experience sharing from peers Improves medication-taking behaviour in any social environment
Stigma and discrimination	Counselling SM skills training Text messages Adherence supporter visits	Reduces the fear of stigma and discrimination Enhances coping with societal perceptions Improves self-efficacy for SM
Drug side effects	Symptom management instruction SM skills training Counselling: phone calls and text messages Adherence support	Enhances medication adherence Improves self-efficacy for SM
Conflict between medical treatment and spiritual practices	Counselling SM skills training/continuous education session during each follow-up visit.	Improves self-efficacy for SM Enhances medication adherence

Low educational status of ALWHIV on ART was responsible for the decreased level of engagement in SM behaviours in the study population, which indicates person-centred interventions may be more impactful due to their individualized and relational nature.

Assessment of literacy level should be done on HIV diagnosis and special attention should be given to illiterate individuals to keep them informed and then proactively engage them in SM behaviours. More ‘relational’ care via greater interpersonal interaction with HIV care providers and adherence supporters would increase HIV literacy/knowledge and enable and empower ALWHIV to engage in SM behaviours. Provision of individualized SM instructions in the form of skills training, counselling through phone calls and use of reminders would enhance engagement in SM behaviours (Areri, Marshall & Harvey 2020c). Routine counselling for those coming from rural areas and those with a low educational status is essential and should include different effective approaches like SM skills training and phone calls. Sending text message reminders and providing updates through phone calls could help ALWHIV to engage in SM programs due to their higher frequency, instead of more traditional periodic evaluation. The healthcare system could collaborate with telecom service providers to set reminder strategies (reminder text messages, free follow-up calls and counselling) for SM behaviours There should be confidentiality agreements between the health care and telecom providers on the matter of personal information of ALWHIV.

Provision of counselling with other resources like symptom management instruction is another possible way of informing and encouraging engagement in SM (Areri, Marshall & Harvey 2020c). Engagement in SM behaviours is enhanced by the support obtained from HIV care providers like adherence support, encouraging disclosure of HIV status and free HIV medication (Areri, Marshall & Harvey 2020a; Areri, Marshall & Harvey 2020b). These findings are consistent with the systematic review findings (Areri, Marshall & Harvey 2020c). This indicates that strengthening the existing support system is essential to enhance the SM behaviours of ALWHIV on ART in the study population. Hence, the use of adherence supporters for SM skills training on how to live with HIV as a chronic condition, sharing experiences, encouraging disclosure, and providing symptom management instruction to

ALWHIV on ART could have paramount benefits in enhancing engagement in SM behaviours. Adherence supporters working in ART clinics were considered “a lifesaver” by ALWHIV in the study population. Adherence supporters are ALWHIV on ART who are trained and employed to clarify misconceptions, share lived experiences, and suggest recommended behavioural modifications. Therefore, strengthening the existing training and employment of adherence supporters in ART clinics should be emphasized for two major reasons. Firstly, it would create job opportunities for ALWHIV on ART, and secondly, the employed adherence supporters could be a greater source of support for ALWHIV on ART.

9.5 Contribution of the thesis

This thesis has made a number of contributions in the field. First, this thesis is the first of its kind in investigating factors influencing SM behaviours using mixed methods in the Ethiopian context. The use of mixed methods helps to better understand the overall SM behaviours and explain the factors that influence SM behaviours in the study population. The findings broaden the understanding of SM behaviours, and by synthesizing evidence from published studies the study is able to identify and recommend effective interventions to enhance SM behaviours in this context. Second, the thesis used a well-established theoretical framework called Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin 2009) to design the research methods, which have not been used before in resource-limited settings. HIV care providers can implement this theoretical framework in the provision of routine clinical practice with no limitation to enhance SM behaviours. Thus, the thesis has contributed new knowledge on the application of IFSMT in resource-limited settings, in this instance in Ethiopia. This theoretical framework helped to identify and understand various interrelated and reinforcing factors influencing SM behaviours in the study population. Third, this study has proposed IFSMT to guide HIV care providers and future research. It is a relevant model that could be useful in framing management of chronic HIV. This theory sets assumptions that include contextual, process and interventions related factors that could direct engagement in SM behaviours. Therefore, it helps in identifying the factors influencing SM behaviour across various domains. Fourth, the thesis has contributed by generating evidence that can be used by stakeholders in a resource-limited setting to enhance the engagement of ALWHIV on ART in SM behaviours. It has identified interventions that may be suitable in resource-limited settings to enhance engagement in SM and identified barriers and enablers within the individual, context and process of SM that can be capitalized on or addressed to support the SM of ALWHIV. In this way, this research could reduce the impact of poorly managed HIV-related complications on the health system. Finally, the study established a number of evidence-based recommendations that can be actioned in the Ethiopian context and elsewhere by policymakers, HIV care providers and researchers. These recommendations are listed in detail in the next section.

9.6 Implications

This study is the first of its kind in Ethiopia, where HIV prevalence is high and healthcare access and infrastructure are limited. The study used an established theoretical framework (IFSMT) and a mixture of methods, which helped to better understand factors influencing SM behaviours. The study also comprehensively presented factors influencing the SM of ALWHIV on ART and evidence-informed effective interventions to enhance SM behaviours. Therefore, this study could be a baseline for policymakers, implementers and researchers in the region.

9.6.1 Policy

The current HIV care policy in Ethiopia gives due attention to the prevention and pandemic control with less emphasis on chronic care (EMOH 2019). However, more emphasis should be given to chronic HIV care to enhance SM of people living with HIV that helps to improve the quality of life and at the same time reduces the burden on the healthcare system. The finding of this study helps to revisit the existing national HIV policy of Ethiopia on the identified key influencing factors. This thesis identified various factors influencing the engagement of ALWHIV on ART in SM behaviours and highlights to policymakers the importance of addressing these factors in Ethiopia. Policymakers need to intervene to change community perceptions of HIV, access to adequate income, educational status, stigma and discrimination, and religious influence in order to enhance SM behaviour in Ethiopia.

The study identified that the community's perception of HIV remains a problem, especially in rural communities, and creates various interrelated problems like fear of attending nearby health facilities. This leads to costs associated with travel to health facilities further removed from the local community, which exacerbates financial difficulty, which remains a significant challenge for SM in the study population and requires policymakers' attention (Areri, Marshall & Harvey 2020a). Revisiting the existing prevention guidelines for stigma and discrimination is essential to identify the gaps and take corrective action to improve community perceptions of ALWHIV in Ethiopia. Sending community text messaging and awareness-raising campaigns could also help in reducing stigma and discrimination. In addition, creating employment opportunities for ALWHIV on ART would generate regular and increased income. Due attention should be given to training and employing more adherence supporters and basing them in HIV clinics. The existence of adherence supporters in the care system could help to enhance the SM behaviour of ALWHIV by sharing experiences, providing counselling, encouraging disclosure and conducting regular home visits. Technology-assisted interventions are becoming an area of interest for both HIV care providers and clients. A policy should be in placed on a free and easily accessible communication platform.

9.6.2 Practice

It is speculated that reduced emphasis on strict implementation of chronic HIV management approaches has influenced SM behaviours. The findings show the use of a range of different support mechanisms is required to enhance SM behaviours. Strong support mechanisms should be in place to strengthen the utilization of adherence supporters in HIV care and treatment clinics. It is also important to devise a mechanism for enhancing the use of reminders, for example, through the use of technology-assisted solutions such as phone calls, text messaging and online support, and other social facilitation approaches for improving the SM of ALWHIV on ART.

HIV care providers should identify the target population based on the factors influencing SM behaviours to design and deliver SM programs. Considering the constructs of the IFSMT (contextual, process and interventional factors) when working with ALWHIV on ART could help HIV care providers to empower and support ALWHIV to self-manage. HIV care providers should develop person-centred care plans and interventions that consider important contextual and process-related influencing factors. Overall, HIV care providers should be familiar with each individual context. This would facilitate the development of more tailored approaches for the factors influencing SM behaviours. HIV care providers should also offer self-management skills training and counselling programs to ALWHIV on ART. There could also be a benefit in providing resources such as symptom management instructions. Audio and visual symptom management instructions should be prepared to benefit both illiterate and literate ALWHIV. HIV care providers should emphasize the use of adherence supporters to train, counsel and share their experiences with ALWHIV on ART during follow-up visits.

Enhancing the self-efficacy of ALWHIV on ART is a crucial factor to build self-belief and confidence to engage in recommended SM behaviours. Enhanced self-efficacy has a positive impact on overall engagement in SM behaviours and well-being. It is essential to identify and implement self-efficacy-enhancing interventions such as motivational communication, feedback on performance and enabling self-trust in one’s own self-efficacy for therapeutic programs. In the systematic review included in this thesis, interventions identified to enhance self-efficacy for SM were phone counselling and online peer-based support programs (Areri, Marshall & Harvey 2020c). HIV care providers should assess the level of self-efficacy for SM behaviours and design a means of enhancing it. The regular and systematized use of IFSMT as a check and balance during follow-up visits could help to identify and address the factors affecting the self-efficacy of ALWHIV. Additionally, conflict of priority between religious practices and following medical recommendations was identified as having a significant impact on SM behaviours and particularly medication adherence. It would be impactful to involve religious and community leaders in the HIV treatment program to address these perceptions and enhance SM behaviours.

9.6.3 Research

This thesis suggests several areas of future research. A large-scale study, including different hospitals from different parts of the country, is recommended to better understand factors influencing SM behaviours across different settings. It is considered essential to explore the SM experiences of ALWHIV on ART from different socio-cultural backgrounds. Future research should also include HIV service providers. It would be meritorious to explore the perspectives and experiences of HIV care providers on SM programs to consolidate the findings and provide a more practice-focused understanding of the SM of ALWHIV on ART. Studies are recommended to empirically test whether the interventions identified in this thesis enhance the SM behaviour of the study population in the Ethiopian context. Future qualitative research with adherence supporters is also recommended to develop a more in-depth understanding of the barriers and enablers of effective SM of ALWHIV in the study area and help inform future tailored interventions.

9.7 Self-reflection on the PhD process

Improved ART coverage has resulted in increased longevity of ALWHIV, which brought about the need to understand SM behaviours. Understanding the complex nature of SM behaviours and designing an appropriate research methodology was a key personal motivation for the last few years. The SM behaviour of ALWHIV on ART remains complex and requires an advanced research methodology and theoretical underpinning to better understand it. The opportunity to pursue this PhD has helped the researcher to learn how to investigate complex SM behaviours and to synthesize evidence from different sources. The PhD process also equipped the researcher with a variety of research approaches and theoretical applications to design research methods. Sequential explanatory mixed methods helped the researcher see the factors influencing self-management from a different perspective. The researcher comes from a quantitative background and has had an opportunity to learn a variety of research approaches such as qualitative and mixed methods approaches and systematic reviews to generate evidence. This PhD thesis helped the researcher to investigate SM behaviour in various ways to better understand the phenomenon under study. To this end, the thesis deeply investigated factors that influence SM behaviours and provided a synthesis of available evidence for possible application in the Ethiopian context to enhance engagement in SM behaviours.

The theoretical framework used in the study also provided the researcher the opportunity to set the structure of the variables of the study. Individual and Family Self-Management Theory consists of well-structured constructs and assumptions that aided better understanding of the SM behaviours of ALWHIV on ART. The researcher also learned using the theoretical domains of Individual and Family Self-Management Theory could be used as check and balance criteria during day-to-day individual case management.

9.8 Limitations of the study

Specific limitations to this study were presented in each paper. However, in this section, the overall limitations are presented. First, the study used one referral hospital that could limit the study findings' generalizability to other settings, although the large sample size and high response rate in both the quantitative and qualitative phases enhance the level of confidence in the findings. Second, the study tool involved self-reports, but the tool was orally administered in person by the data collectors due to a low literacy rate in the study population. While this increased accessibility, it may have induced some social desirability bias.

9.9 Conclusions

Following the successful introduction of ART, HIV is now considered a chronic condition requiring long-term treatment. As such, effective SM has become an increasingly important component of HIV care. This was recognized in Ethiopia with the introduction of a chronic care model to the ART guidelines in 2014. Yet levels of SM amongst ALWHIV on ART in Ethiopia remain sub-optimal, both in terms of reported SM practice and medication adherence. This study set out to add to the understanding of SM of ALWHIV in the Ethiopian context and to identify feasible interventions that could be implemented to address known barriers to SM. Adopting a mixed-methods study design, underpinned by Individual and Family Self-Management Theory, the research has elucidated the complex, interrelated factors at the individual, socio-demographic, disease-related and healthcare level that influence an individual's ability to self-manage their HIV. The barriers have been mapped to contextually appropriate, evidence-informed interventions to generate policy and practice recommendations that could help to address the SM challenges faced by ALWHIV in Ethiopia.

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Appendixes

Appendix 1: Supplementary information

Supplement 1: S1 PRISMA 2009 checklist

https://doi.org/10.1371/journal.pone.0232709.s001

Section/topic	**#**	**Checklist item**	**Reported on page #**
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Supplement 2: S2 table-summary of evidence findings

https://doi.org/10.1371/journal.pone.0232709.s002

Interventions to improve self-management include training, counselling, peer-mentoring, social support, providing self-management manuals, and encouraging active self-management compared to usual/standard care

Patient or population: Adults living with HIV on ART.
Intervention: interventions to improve self-management include training and or counselling and or peer-mentoring and or providing social support and or providing self-management manuals, and or encouraging active self-management
Comparison: usual/standard care.

Outcomes	**Anticipated absolute effects**[*] (95% CI)		Relative effect (95% CI)	№ of participants (studies)	Certainty of the evidence (GRADE)
	Risk with usual care	**Risk with interventions**			
Self-efficacy	not estimable	not estimable	not estimable	394 (4 RCTs)	⊕⊕⊕◯ MODERATE [a]
Social support mobilization	not estimable	not estimable	not estimable	490 (3 RCTs)	⊕⊕◯◯ LOW [b, c, d]
Adherence to ART	not estimable	not estimable	not estimable	1151 (7 RCTs)	⊕⊕⊕◯ MODERATE [b, c, d]
Symptom management	not estimable	not estimable	not estimable	335 (3 RCTs)	⊕⊕◯◯ LOW [a, b, c, d]
Quality of life	not estimable	not estimable	not estimable	1143 (8 RCTs)	⊕⊕⊕◯ MODERATE [a, b, c, d]
Coping	not estimable	not estimable	not estimable	468 (3 RCTs)	⊕⊕⊕◯ MODERATE [a, b, c, d]

***The risk in the intervention group** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).

CI: Confidence interval

GRADE Working Group grades of evidence
High certainty: We are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.
Very low certainty: We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

Explanations: [a] small sample size, [b] Inconsistency in methods, [c] Difference in participants, [d] Difference in tool

Supplement 3: S1 appendix-search strategy

https://doi.org/10.1371/journal.pone.0232709.s003

Database(s): Pub Med from 2001 to 30 March 2019 with daily updates

Number	Searches	Items found
#6	Search (AND #2 AND #3); Full text; Publication date	205
#5	Search (AND #2 AND #3) Filters: Full text	210
#4	Search (AND #2 AND #3)	216
#3	Search (Interventions[mh] OR Strategies[mh] OR Intervention[sh] OR Interventions*[tiab])	37,966
#2	Search (Self-management[mh] OR Self-management*[tiab] OR self-care[mh] OR self-care*[tiab])	66,656
#1	Search (HIV [mh] OR HIV [tiab] OR HIV-1*[tiab] OR HIV-2*[tiab] OR Human Immunodeficiency Virus*[tiab] OR AIDS virus*[tiab] OR Acquired Immune Deficiency Syndrome Virus*[tiab] OR Acquired Immunodeficiency Syndrome Virus*[tiab])	313,514

Database(s): CINAHL from 2001 to 30 March 2019 with daily updates

Number	Searches	Items found
S3	(MH Human Immunodeficiency Virus OR TI Human Immunodeficiency Virus* OR AB Human Immunodeficiency Virus* TI HIV OR AB HIV OR TI “Human Immunodeficiency Virus” OR AB “Human Immunodeficiency Virus”) AND (MH self-management OR TI self-management OR AB self-management OR TI “self-care” OR AB “self-care”) AND (MW Interventions* OR TI Interventions* OR AB Interventions*) Full Text; Abstract Available; Published Date, Narrow by Language: - English	**32**
S2	(MH Human Immunodeficiency Virus OR TI Human Immunodeficiency Virus* OR AB Human Immunodeficiency Virus* TI HIV OR AB HIV OR TI “Human Immunodeficiency Virus” OR AB “Human Immunodeficiency Virus”) AND (MH self-management OR TI self-management OR AB self-management OR TI “self-care” OR AB “self-care”) AND (MW Interventions* OR TI Interventions* OR AB Interventions*) Published Date and English	101
S1	(MH Human Immunodeficiency Virus OR TI Human Immunodeficiency Virus* OR AB Human Immunodeficiency Virus* TI HIV OR AB HIV OR TI “Human Immunodeficiency Virus” OR AB “Human Immunodeficiency Virus”) AND (	104

	MH self-management OR TI self-management OR AB self-management OR TI “ self-care” OR AB “self-care”) AND (MW Interventions* OR TI Interventions* OR AB Interventions*)	

Database(s): Embase from 2001 to 30 March 2019 with daily updates

Number	Searches	Item found
#5	#1 AND #2 AND #3 AND #4	**86**
#4	#3 AND ('clinical trial'/de OR 'controlled study'/de OR 'human'/de OR 'randomized controlled trial'/de) AND 'human immunodeficiency virus infection'/de AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py) AND ('article'/it OR 'conference abstract'/it) AND ([adult]/lim OR [aged]/lim OR [middle aged]/lim OR [young adult]/lim)	5,406
#3	('mw interventions' OR ti) AND 'interventions' OR 'intervention’: ti,ab	748,281
#2	'self-care'/de OR 'self-management’: ti,ab OR 'self-care*':ti,ab OR 'selfcare':ti,ab	64,103
#1	'human immunodeficiency virus'/exp OR hiv:ti,ab OR 'hiv 1':ti,ab OR 'hiv 2':ti,ab OR 'human immunodeficiency virus':ti,ab OR 'aids virus':ti,ab OR 'acquired immune deficiency syndrome virus':ti,ab OR 'acquired immunodeficiency syndrome virus':ti,ab	408,109

Search from other sources found: **10 articles**

Supplement 4: S2 appendix- critical appraisal checklists

https://doi.org/10.1371/journal.pone.0232709.s004

JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Reviewer_____________________________________Date______________________
Author ____________________________________Year___Record Number ______

	Yes	No	Unclear	Not applicable
1. Is it clear in the study what is the "cause' and what is the 'effect' (i.e., there is no confusion about which variable comes first)?	☐	☐	☐	☐
2. Were the participants included in any comparisons similar?	☐	☐	☐	☐
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	☐	☐	☐	☐
4. Was there a control group?	☐	☐	☐	☐
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	☐	☐	☐	☐
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	☐	☐	☐	☐
7. Were the outcomes of participants included in any comparisons measured in the same way?	☐	☐	☐	☐
8. Were outcomes measured in a reliable way?	☐	☐	☐	☐
9. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Reviewer_____________________________________Date______________________

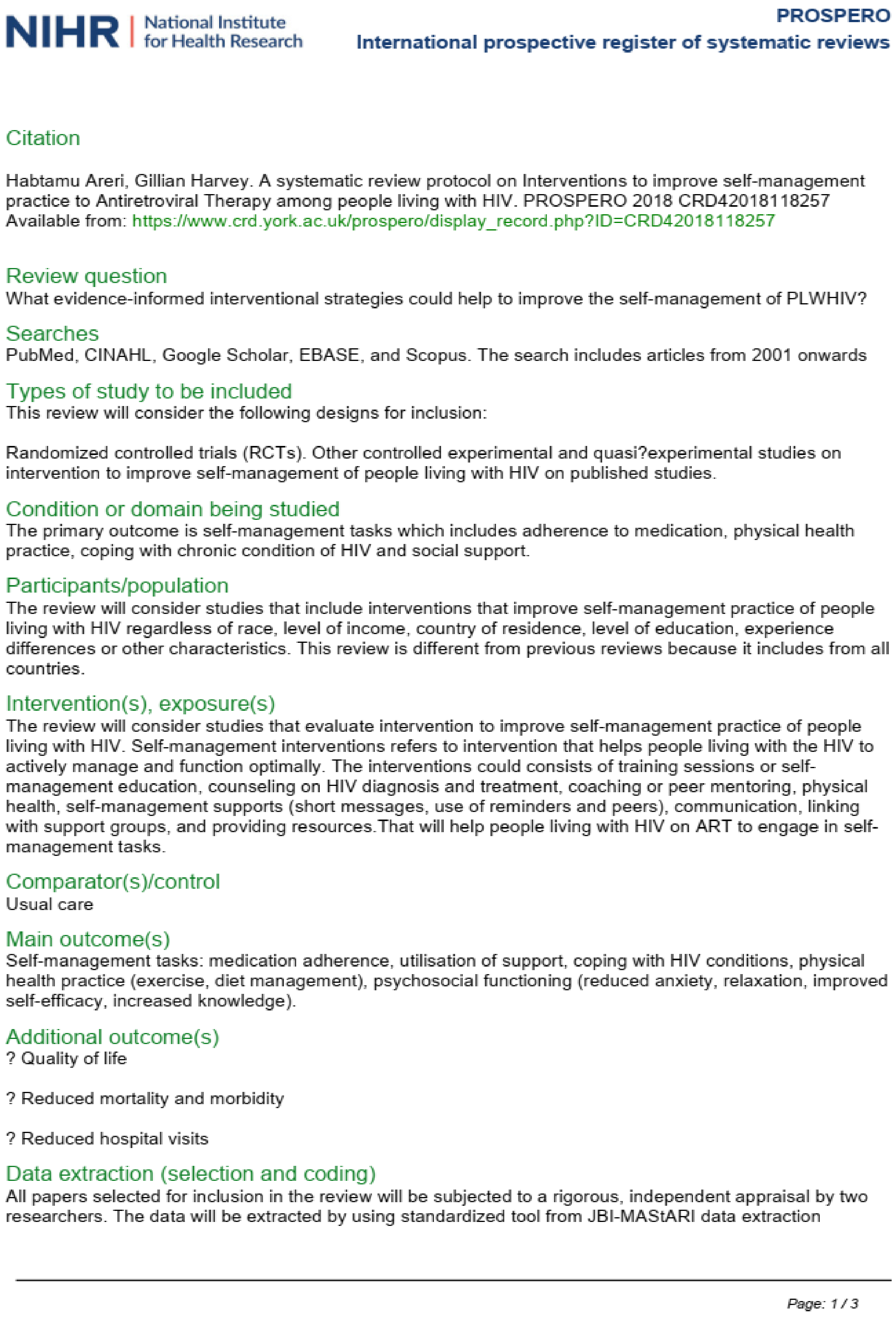
Author _______________________________Year_________Record Number ______

	Yes	No	Unclear	NA
1. Was true randomization used for assignment of participants to treatment groups?	☐	☐	☐	☐
2. Was allocation to treatment groups concealed?	☐	☐	☐	☐
3. Were treatment groups similar at the baseline?	☐	☐	☐	☐
4. Were participants blind to treatment assignment?	☐	☐	☐	☐
5. Were those delivering treatment blind to treatment assignment?	☐	☐	☐	☐
6. Were outcomes assessors blind to treatment assignment?	☐	☐	☐	☐
7. Were treatment groups treated identically other than the intervention of interest?	☐	☐	☐	☐
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	☐	☐	☐	☐
9. Were participants analysed in the groups to which they were randomized?	☐	☐	☐	☐
10. Were outcomes measured in the same way for treatment groups?	☐	☐	☐	☐
11. Were outcomes measured in a reliable way?	☐	☐	☐	☐
12. Was appropriate statistical analysis used?	☐	☐	☐	☐
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Supplement 5: PROSPERO registration



NIHR | National Institute for Health Research

PROSPERO
International prospective register of systematic reviews

Citation

Habtamu Areri, Gillian Harvey. A systematic review protocol on Interventions to improve self-management practice to Antiretroviral Therapy among people living with HIV. PROSPERO 2018 CRD42018118257 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42018118257

Review question

What evidence-informed interventional strategies could help to improve the self-management of PLWHIV?

Searches

PubMed, CINAHL, Google Scholar, EBASE, and Scopus. The search includes articles from 2001 onwards

Types of study to be included

This review will consider the following designs for inclusion:

Randomized controlled trials (RCTs). Other controlled experimental and quasi?experimental studies on intervention to improve self-management of people living with HIV on published studies.

Condition or domain being studied

The primary outcome is self-management tasks which includes adherence to medication, physical health practice, coping with chronic condition of HIV and social support.

Participants/population

The review will consider studies that include interventions that improve self-management practice of people living with HIV regardless of race, level of income, country of residence, level of education, experience differences or other characteristics. This review is different from previous reviews because it includes from all countries.

Intervention(s), exposure(s)

The review will consider studies that evaluate intervention to improve self-management practice of people living with HIV. Self-management interventions refers to intervention that helps people living with the HIV to actively manage and function optimally. The interventions could consists of training sessions or self-management education, counseling on HIV diagnosis and treatment, coaching or peer mentoring, physical health, self-management supports (short messages, use of reminders and peers), communication, linking with support groups, and providing resources.That will help people living with HIV on ART to engage in self-management tasks.

Comparator(s)/control

Usual care

Main outcome(s)

Self-management tasks: medication adherence, utilisation of support, coping with HIV conditions, physical health practice (exercise, diet management), psychosocial functioning (reduced anxiety, relaxation, improved self-efficacy, increased knowledge).

Additional outcome(s)

? Quality of life

? Reduced mortality and morbidity

? Reduced hospital visits

Data extraction (selection and coding)

All papers selected for inclusion in the review will be subjected to a rigorous, independent appraisal by two researchers. The data will be extracted by using standardized tool from JBI-MAStARI data extraction checklists will be used. In the data extraction includes the authors, publication year, the study area, study design, sample size, response rate and interventions to improve self-management. The data extraction will be done by two independent reviewers using a standardized JBI review format (Munn 2016). Any disagreements that arise between the reviewers will be resolved through discussions.

Risk of bias (quality) assessment

Two authors independently will screen the title, abstract and full articles to consider the paper for review using the criteria of Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (JBI 2017). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Screen all reference lists for possible inclusion of articles in review process. The selection process will be based on the inclusion criteria, outcome measurements, study area and appropriate statistical analysis. The Preferred Reporting of Systematic Reviews and Meta-Analysis (PRISMA) guidelines will be used (Liberati et al. 2009).

Strategy for data synthesis

To analyze the data, the JBI SUMARI software will be used. Pooled level of self- management practice will be considered. Association effect sizes for odds ratio (for categorical data), weighted mean difference (for continuous data) and their 95% confidence intervals will be calculated. Where statistical pooling or summarizing is not possible the findings will be presented in narrative form. A weighted inverse variance random-effects model will be used to estimate the strategies to improve self-management practice (Tufanaru et al. 2015).

Analysis of subgroups or subsets

Heterogeneity among reported prevalence will be assessed by using I^2 test, standard $?^2$-Q and also explored using subgroup analysis based of the study design and study area included in the study. A Funnel plot will be used to check publication bias.

Contact details for further information

Habtamu Areri
habtamu.areri@adelaide.edu.au

Organisational affiliation of the review

University of Adelaide

Review team members and their organisational affiliations

Mr Habtamu Areri. University of Adelaide
Professor Gillian Harvey. The University of Adelaide, School of Nursing

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Stage	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.
The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

21 December 2018

Appendix 3: English version of data collection tool

Date of interview: ______________________________ Code: ____________

Instruction 1: ***Circle the response for the closed-ended questions and write responses on the space for the open-ended questions. The tool has six parts.***

Part I: Questions on the contextual factors in self-management of adults living with HIV			
A	**Sociodemographic characteristics/individual factors**		
S.no.	**Questions**	**Responses**	**Code**
1	Gender	1. Male 2. Female	
2	Age	………………. years	
3	Your educational level	1. No formal education attended 2. Primary education 3. Secondary education (9–10th grade) 4. Preparatory school (11–12th grade) 5. College education 6. University education	
4	Your job status l	1. Governmental employed 2. NGO employed 3. Private employed 4. Daily labourer 5. I do not have job	
5	What is your income?	……………. Ethiopian Birr	
B	**Sociodemographic characteristics/physical and social environment**		
S.no.	**Questions**	**Responses**	**Code**
6	What is your religion?	1. Orthodox Christian 2. Protestant Christian 3. Muslim 4. Other……………	
7	With whom you are living?	1. Lives alone 2. With family 3. With parents 4. With friends	
8	Your marital status	1. Never married 2. Married 3. Live separated 4. Divorced 5. Widowed	
9	Did you use traditional treatment for your HIV management	1. Yes 2. No	
10	Where is your residency?	1. Rural 2. Urban	

11	How far is your residence from this hospital?	………………. kilometres	
12	Do you think the cost of transportation affects your HIV therapy program?	1. Yes 2. No	
C	**Condition-specific factors**		
S.no.	**Questions**	**Responses**	**Code/ skip**
13	When were you diagnosed as HIV positive?	…………………………year	
14	For how long you have been on antiretroviral therapy?	…………………………months	
15	Your stage of HIV?	1. Stage I 2. Stage II 3. Stage III 4. Stage IV 5. I do not know	
16	Has your treatment changed?	1. Yes 2. No	If no, skip to Q18
17	If yes to Q 16, why was your drug changed?	1. the drug's side effect 2. I do not know 3. Not taken properly 4. Other (please specify) …………	
18	Do you have any comorbidities?	1. Yes 2. No	
19	Do you take treatment other than antiretroviral therapy?	1. Yes 2. No	
20	How many drugs you are taking for your HIV treatment?	1. One type 2. Two types 3. Three types	
21	Do you have drug side effects?	1. Yes 2. No	
Part II: Questionnaire on the process of self-management			
A. Knowledge about HIV and antiretroviral therapy			
S.no	**Variables**	**Responses**	
		Yes	**No**
22	Are you familiar with your HIV medications?		
23	If you miss your medication dose, do you know what to do?		
24	Are you familiar with the side effects of your medications?		
25	HIV medications can eradicate the virus from your body.		
26	If you feel better, it is ok for you to miss some doses.		
27	Do you know that HIV medications can interact with alcohol?		
28	Do you know skipping HIV medications would really hurt others?		
29	Do you know how HIV medication works in your body to fight HIV?		
30	Do you know if you did not take your HIV medication as ordered, they may not be effective in the future?		
31	Do you know that taking HIV medication as prescribed helps you live longer?		
B. Self-efficacy for HIV self-management			
	Items	**Response**	

S/no		Agree = 3, Neutral = 2 and Disagree = 1		
		Agree	**Neutral**	**Disagree**
32	It is not difficult for me to find effective solutions for managing my HIV condition.			
33	I can easily change things I do not want related to my HIV condition.			
34	I am managing my HIV condition well.			
35	I was successful in performing HIV-related recommendations.			
36	It is possible for me to manage my HIV-related conditions and other people.			
37	My plan for managing HIV did not work for me well.			
38*	Even if I am trying hard to manage my HIV, it was not achieved as I wish.			
39	In general, I am able to achieve my HIV-related goals.			
C	**Self-regulation abilities**	**Responses**	**Code/skip**	
40	Do you have plan for self-management of emotional distress?	1. Yes 2. No		
41	Are you familiar with how to manage your HIV illness related symptoms?	1. Yes 2. No		
42	Have you set a goal in the process of your HIV therapy?	1. Yes 2. No		
D	**Social facilitations and interventions**			
43	Have you joined networks of people living with HIV?	1. Yes 2. No		
44	Are you supported by an adherence support group?	1. Yes 2. No		
45	Did the healthcare providers provide you information on ART?	1. Yes 2. No		
46	Do you think the counselling you got was adequate for your next steps in your HIV treatment?	1. Yes 2. No		
47	Do you think you have adequately linked to social/ peer networks?	1. Yes 2. No		
48	Have you been encouraged to disclose your HIV status?	1. Yes 2. No		
49	Do you have reminders for your HIV management?	1. Yes 2. No		
50	Have you disclosed your HIV status?	3. Yes 4. No		
51	If “No” to question 50, what is the reason/s for not disclosing? (More than one is possible)	2. Fear of stigma 3. Fear of discrimination 4. Considered not important 5. Other (specify) …		
Part III: Tasks of self-management of adults living with HIV				
Instruction 2: *(3 = all of the time, 2 = some of the time, 1 = none of the time, 0 = not applicable, and mark* ***“X”*** *where appropriate.*				
	Questions		**Responses**	

S/no		**3**	**2**	**1**	**0**	**code**
A	**Domain 1: Daily health practice**					
52	Staying physically active (exercising) is an important part of my HIV management strategy					
53	I have been successful at staying physically active (walking, exercising, stretching, weightlifting, physical work)					
54	Spirituality/religion is my motivator to manage HIV					
55	I have been changing some aspect of my health to better manage HIV (ex: taking medication, exercising, reducing stress)					
56	I have been successful at achieving my health goals					
57	I modified my diet to better manage HIV (vegetables, fruits, natural ingredients)					
58	Even with all of my family responsibilities I had have enough time to take care of my health needs					
59	I set aside personal time to do things I enjoy					
60	My job responsibilities help me to take care of my health					
61	Educating others about HIV helps me stay in control of HIV (working as a counsellor, advocating for safe sex)					
62	When I was stressed out I did positive things to relieve the stress (exercising OR journaling OR joining a group)					
63	I was able to control (or manage) HIV symptoms and medication side effects					
B	**Domain 2: Resource mobilization for HIV self-management**					
64	When I feel overwhelmed, I find that talking to my counsellor or attending support groups is very helpful.					
65	Attending support groups is an important part of HIV management strategy.					
66	I have been attending support groups because I found that listening to someone's testimony or personal story motivates me to take better care of myself.					
C	**Domain 3: Chronic nature of HIV and self-management**					
67	I have accepted that HIV is a chronic (or life-long) condition that can be managed					
68	Managing HIV is the number one priority for me					
69	HIV has been my motivator to take better care of myself					
70	I call to make appointments with my HIV doctor when I need to (change in symptoms, problems with meds, new health concern)					
71	My HIV doctor and I have a good relationship					

D.	**Questions on medication adherence**			
S/n	Questions	**Responses**		**Code**
		Yes	No	
72	Have you ever felt worse because of taking medication and stopped taking them without talking to your health provider?			
73	Sometimes, when you feel your symptoms controlled, did you stop taking your drugs?			
74	How often do you feel that you have difficulty taking your medication for not more than 2 hours delay? A. Never B. Once in a while	A = "Yes"	the rest is "No"	

	C. Sometimes D. Usually E. All the time			
75	Have you missed your HIV medications in the past 30 days?			
76	If your response to question 75 is “Yes” indicate your reason for the missed dose. More than one answer is possible			
	1. Away from home			
	2. simply forgot			
	3. side effects			
	4. fear of others seeing me while taking			
	5. Having many pills to take			
	6. Fasting			
	7. Using holy water/religious reasons			
	8. felt depressed			
	9. out of pills			
	10. felt good or controlled symptoms			
	11. felt sick			
	12. lack of transport			
	13. lack of food			
	14. others, please specify			

Thank you for your time contribution.

Name of the interviewer: ___________________ Signature: _________ Date: _________

Appendix 4: Amharic version of data collection tool

የመረጃ መሰብሰቢያ ቅጽ የቃለ መጠይቅ ቀን: ______________________________ ኮድ: _____________

መመሪያ: ለሚቀጥሉ ጥያቄዎች ምላሾች ይምረጡ እንዲሁም ክፍት ለሆኑ ጥያቄዎች በቦታው ላይ መልስ ያስቀምጡ።ቅጹ *ሶስት ክፍሎች አሉት*::

	ክፍል 1: ከኤች አይ ቪ ጋር ለሚኖሩ አዋቂዎች ራስን በራስ መከባከብ ጋር ሊያያዙ የሚችሉ ጉዳዮች		
A	**የማህበረሰባዊ ባህርያት ወይም ግለሰባዊ ምክንያቶች ለመዳሰስ የቀረበ ጥያቄ**		
ተ/	**ጥያቄዎች**	**ምላሽ**	**ኮድ**
1	ፆታ	1. ወንድ 2. ሴት	
2	ዕድሜዎ ስንት ይሆናል?	………………. አመት	
3	የትምህርት ደረጃዎ?	1. መደበኛ ትምህርት አልተሳተፈም 2. የመጀመሪያ ደረጃ ትምህርት 3. ሁለተኛ ደረጃ ትምህርት (9-10) 4. መሰናዶ ደረጃ ትምህርት(11-12) 5. ኮሌጅ ትምህርት 6. ዩኒቨርሲቲ ትምህርት	
4	የስራ ሁኔታዎ	1. የመንግስት ሰራተኛ 2. መንግስታዊ ያልሆነ 3. የግል ሰራተኛ 4. የቀን ሰራተኛ 5. ጡረታ 6. ሥራ የለኝም	
5	ገቢዎ ምን ያህል ነው?	……………. ኢትዮጵያ ብር	
ለ	**አካላዊ፤ ማህበራዊ እና አካባቢዊ ምክንያቶች**		
ተ/	**ጥያቄዎች**	**ምላሽ**	**ኮድ**
6	ሃይማኖትዎ ምንድን ነው?	1. ኦርቶዶክስ ክርስቲያን 2. የፕሮቴስታንት ክርስቲያን 3. ሙስሊም 4. ሌላ (ይግለጹ)…………	
7	አብረዎ የሚኖር?	1. ብቻውን የሚኖሩ 2. ከቤተሰብ ጋር 3. ከወላጆች ጋር 4. ከጓደኞች ጋር	
8	የጋብቻ ሁኔታዎ	1. ያላገባ 2. ያገባ 3. ተለያይቶ የሚኖር 4. የተፋታ 5. የሞተባት/በት	
9	ለኤች አይ ቪ ባህላዊ ህክምናን ተጠቅመው ያውቃሉ?	1. አዎ 2. አይደለም	
10	ነዋሪዎ የት ነው?	1. ገጠር 2. ከተማ	

11	ይህ ሆስፒታል ምን ያህል ርቀት ይኖረዋል?	………………. ኪሎ ሜትር	
12	የትራንስፖርት ወጪዎ ውደ ህክምና ለመምጣት ተጽዕኖ ያሳድርብኛል ብለው ያስባሉ?	1. አዎ 2. አይደለም	
ሐ	**ከጉዳዩ ጋር ተያያዝ የሆኑ ምክንያቶች**		
ተ/	**ጥያቄዎች**	**ምላሽ**	**ኮድ**
13	ኤች አይ ቪ እንዳለበዎት የተነገሩት መቼ ነው?	………………………አመት	
14	በፀረ ኤች አይ ቪ መድሃኒቶች ህክምና ላይ የቆየዎት ለምን ያህል ጊዜ ነው?	……………………… አመት	
15	የእርስዎ የኤችአይቪ ደረጃ?	1. ደረጃ I 2. ደረጃ II 3. ደረጃ III 4. ደረጃ IV 5. አላውቅም	
16	መድሃኒቶዎ ተቀይሮ ያውቃል?	3. አዎ 2. አይደለም	የለም ከሆነ ወደ <ጥያቄ 18> ይለፉ
17	16 ኛው ጥያቄዎ አዎ ከሆነ ለምን መድሃኒትዎ ተቀየረ?	1. የመድሃኒት የጎንዮሽ ጉዳት 2. እኔ አላውቅም 3. መድሃኒት በትክክል ስላልውሰድኩ 4. ሌላ (ይግለጹ)…………	
18	ሌላ ተጨማሪ በሽታ አለበዎት?	1. አዎ 2. አይደለም	
19	ከፀረ ኤች አይ ቪ ሕክምና ውጭ ሌላ ህክምና ይወስዳሉ?	1. አዎ 2. አይደለም	
20	ለኤች ኣይ ቪ ህክምናዎ ምን ያህል መድሃኒት እየወሰዱ ነው?	1. አንድ ዓይነት 2. ሁለት ዓይነት 3. ከሁለት በላይ	
21	የመድኃኒት የጎንዮሽ ጉዳቶች አለብዎት?	1. አዎ 2. አይደለም	

ክፍል ሁለት: ራስን የማስተዳደር ሂደትን በተመለከተ መጠይቅ			
ሐ. ስለ ኤች አይ ቪ ህክምና ያለዎትን እውቀት ስለመዳሰስ			
ተ/ ቁ	**ጥያቄዎች**	**መልስ**	
		አዎ	**አይ**
22	የኤችአይቪ መድሃኒቶችዎን በደንብ ያውቁታል?		
23	የታዘዘሎትን መድሃኒት ሳይውስዱ ቢቀሩ ምን ማድረግ እንዳለብዎት ያውቃሉ?		
24	የእርስዎ መድሃኒቶች የጎንዮሽ ጉዳቶች ያውቃሉን?		
25	ኤች አይ ቪ መድሃኒቶች ቫይረሱን ከሰውነትዎ ሊያነጹ ይችላሉ?		
26	የመሻል ስሜት ከተሰማዎት አንዳንድ ጊዜ መድሃኒቶችን አለመውሰዱ ብዙ ችግር የለሁም ብሎ ያስባሉ?		
27	የኤች አይ ቪ መድሃኒቶች ከአልኮል ጋር ሊጋጩ እንደሚችሉ ያውቃሉ?		
28	የኤችአይቪ መድሃኒቶችን በተባለው ጊዜ አለመውስድ ሌሎችን እንደሚጎዳ ያውቃሉ?		

29	ኤች አይ ቪን መጠኑን ለመቀነስ በሰውነትዎ ውስጥ የኤችአይቪ መድሃኒት እንዴት እንደሚሠራ ያውቃሉ?			
30	የኤች አይ ቪ መድሃኒትዎን እንደ ታዘዘው ካልወሰዱ ለወደፊት መድሃንትዎ ውጤታማ ላይሆን እንደማይችል ያውቃሉ?			
31	የታዘዘልዎትን የኤች አይ ቪ መድሃኒት መውሰድ ረዘም ላለ ጊዜ ለመኖር እንደሚረዳዎ ያውቃሉ?			
C.	**ለኤችአይቪ ራስ-ማስተዳደር ራስን የመቻል ብቃት**			
ተ/ ቁ	**ጥያቄዎች**	**መልስ**		
		እስ	**ገለ**	**አልስ**
32	ኤች አይ ቪዎን ለመቆጣጠር ውጤታማ መፍትሄ ለማግኘት አልተቸገሩም፡፡			
33	ከኤች አይ ቪ ሁነታዎ ጋር እንዳይዛመድ ይፈልጉዋቸው የነበሩ ነገሮችን በቀላሉ መለወጥ ይችላለሁ			
34	የኤች አይ ቪ ሁኔታዎን በደንብ እየተከባከቡ ነው፡፡			
35	ከኤች አይ ቪዎ ጋር የተያያዙ ምክሮችን በመፈጸም ረገድ ተሳክቶለዎታል፡፡			
36	ኤች አይ ቪዎ እና የሌሎች ሰዎችን ሁኔታ መረዳት እና መከባከብ ይችላለሁ፡፡			
37	የኤች አይ ቪ ሁኔታዎን ለመከባከብ የነበረዎት እቅድ አልሰራም፡፡			
38*	ኤች አይ ቪ ሁኔታዎን ለመከባከብ ከፍተኛ ጥረት ቢያደርጉም፤ እንደፈለጉት አልሆነም፡፡			
39	በአጠቃላይ ኤች አይ ቪዎ ጋር ተያያዝ የሆኑ ግቦችን ለማሳካት ችለዋል፡፡			
ሐ	**ራስን ስለመቆጣር ችሎታዎች**	መልስ		
		አዎ	አይ	
40	ከጭንቀት ራስን ለመከላከል እቅድ አለዎት?			
41	የኤች አይ ቪ በሽታ ምልክቶች እንዴት እንደሚታከሙ ያውቃሉ?			
42	ሰለ ኤች አይ ቪ ህክምናዎ ግብ አለዎት?			
መ	**ማህበረሰባዊ እርዳታዎችን በተመለከተ**			
43	ከኤችአይቪ ጋር የሚኖሩ ሰዎች ማህበር ውስጥ ገብተዋ?			
44	ከኤች አይ ቪ ድጋፍ ቡድን ድጋፍ አግኝተዋል?			
45	የጤና ባለሙያዎች ስለህክምናዎ በሚመለከት መረጃ ይሰጡዎታል?			
46	በኤች አይ ቪ ህክምናዎ ለቀጣይ እርምጃዎች የተሰጠዎ ምክር በቂ እንደሆነ ያስባሉ?			
47	ከማኅበራዊ / የአቻ አውታረመረብ ጋር በበቂ ሁኔታ የተገናኙ ይመስለዎታል?			
48	የኤች አይ ቪዎን ሁኔታ እንዲገልፅ ተበረታተዋል?			
49	ለኤች አይ ቪ ሕክምናዎ አስታዎሽ አለዎት?			
50	የኤች ኣይ ቪ ሁኔታዎን ኣሳውቀዋል?			
51	ጥያቄ 50 "አይደለም" ከሆነ, መግለፅ የማይፈቀድበት ምክንያት ምንድን ነው? (ከአንድ በላይ ሊሆን ይችላል)	1. መገለል መፍራት 2. መድልዎ መፍራት 1. አስፈላጊ አይደለም 2. ሌላ (ይግለጹ)		

	ክፍል 3: ከኤችአይቪ ጋር የሚኖሩ አዋቂዎች ራስን የማስተዳደር ተግባራት					
	መመሪያ 2: *(3: ሁሉም ጊዜ, 2: አንዳንድ ጊዜ, 1: ተፈጽሞ አያውቅም 0: ተፈፃሚ የማይሆን)*					
	ጥያቄዎች	**መልስ**				
		3	**2**	**1**	**0**	**ከ**

1	**ክፍል ሀ: ዕለታዊ ጤና አጠባበቅ**					
52	አካላዊ እንቅስቃሴ ማድረግ (ስፖርት መስራት) ለኤች አይ ቪ ህክምና አስፈላጊ ጉዳይ ስለሆኔ ምን ያህል እየሰሩ ነው?					
53	አካልዊ እንቅስቃሴ እየሰራሁ መቆየት ላይ ምን ያህል ስኬታማ ነበሩ (ክብደት ማንሳት፣ መቀሳቀስ፤ የእግር ጉዞ፤ ሰውነትን ማሳሳብ፡ ስራ መስራት)?					
54	መንፈሳዊነተዎ/ ሃይማኖተዎ የኤች አይ ቪ ሁኔታዎን ለመከባከብ ምን ያህል ያነሳሳዎታል?					
55	የኤች አይ ቪን ሁኔታዎን በጥሩ ለመጠበቅ የተወሰኑ የአኖኖር ዘየበ ምን ያህል ቀይረዋል (ለምሳሌ መድሃኒት መውሰድ, የሰውነት እንቅስቃሴ ማድረግ, ጭንቀትን መቀነስ)?					
56	የጤና ግብዎን ለማሳካት ምን ያህል ስኬታማ ነበሩ?					
57	የኤች አይ ቪ ሁነታ በተሻለ ለመከባከብ አመጋገብ ለወጠዋል (አትክልቶች፤ ፍራፍሬዎች ላይ ማተኮር)?					
58	ምንም እንኳ የቤተሰቤ ኃላፊነት ቢኖርብትም፤ የጤና ፍላጎት እንክብካቤ ለማርደግ በቂ ጊዜ አለዎት?					
59	የምደሰቱባቸውን ነገሮች ለማድረግ የግል ሰዓት ምን ያህል ይመድባለሁ?					
60	የሥራ ድርሻዎ ጤንነቶን ለመንከባከብ ምን ያህል ይረዶታል?					
61	ስለ ኤች አይ ቪ ለሌሎች ማሰተማረዎ ኤች አይ ቪን መቆጣጠር እንድችሉ ረድቶታል (እንደ አማካሪ መሥራት፤ ጤናማ ወሲብን በማስተማር)?					
62	ውጥረት ሲያጋጥመኝ ውጥረትን ለመቀነስ አዎንታዊ ነገሮችን ምን ያህል ያደርጋሉ (እንቅስቃቄ ማደርግ ወይም የቡድን አባላተን ማግኘት መሞከር)?					
63	የኤች አይ ቪ ምልክቶችን እና የመድሃኒት የጎንዮሽ ጉዳቶችን መቆጣጠር (ወይም መከባከብ) ምን ያህል ችሎው ነበር?					
2	**ክፍል ለ: ማህበራዊ ድጋፍ እና ከኤች አይ ቪ ጋር ራስን መከባከብ**					
64	በጭንቀት ውስጥ ሲሆን ወደ አማካሪዬ መሄድ ወይም የድጋፍ ሰጪ ቡድኖችን ማግኘት በጣም ጠቃሚ ሁኖ አግቼዋለሁ፡፡					
65	የድጋፍ ቡድኖችን መከታተል የኤችአይቪዬ ሁኔታ ዋና መንከባከቢያ አካል አደርገዋለሁ፡፡					
66	አጋዠ ቡድኖች ውስጥ እሳተፍ ነበር ምክንያቱም የአንድን ሰው ምስክርነት ወይም የግል ታሪክን ማዳመጥ እራሴን በተሻለ መንገድ ለመንከባከብ ያነሳሳኛል፡፡					
3	**ክፍል 3፡ ከኤች አይ ቪ ጋር ስለመኖር እና ራስ-መከባከብ ሁኔታ**					
67	ኤች አይ ቪ በሽታ ሊታከም የሚችል ረጅም ጊዜ(ህይውት ዘመኔ አብሮኝ የሚኖር) ህመም መሆኑን ተቀብለዋል፡፡					
68	የኤች አይ ቪ ሁነታን ለመከባከብ ምን ያህል ቅድሚያ ይሰጣሉ?					
69	ኤች አይ ቪው ለራዎ ጥሩ እንክብካቤ እንያድረጉ ምን ያህል ተነሳሽ እንድሆኑ ያደርጎታል?					
70	ሲያስፈልግ ከኤች አይ ቪ ህክምና ባለሙያ ጋር ቀጠሮ ለመያዝ ይደውሉላችዋል ወይም መሄድ እችላሉ (የሕመም ምልክቶችን ስኖሩኝ፤ የመድሃኒቶች ችግር፤ አዲስ ጤና ስጋት ስያጋጥመኝ)?					
71	ከእኔ የኤች አይ ቪ ህክምና ባለሙያ ጋር ጥሩ ግንኙነት አለዎት?					

**መ.	መዳሃኒትን በተገቢ ስለመውስድ መጠየቅ**

ተ/	ጥያቄዎች	**መልስ**	
		አዎ	**አይ**
72	መድሃኒት በመውሰዶዎ ምክንያት መጥፎ ስሜት ተሰምቶዎት ለጤና ባለሙያዎ ሳይነጋገሩ መውሰድዎን አቁሙው ያውቃሉ?		
73	አንዳንድ ጊዜ የህመም ሰሜት ስጠፋለዎት መድሃኒት መውሰድዎን ያቆማሉ		
74	የታዘዘለዎትነ መድሃኒት ከተባለው ጊዜ ሁለት ሰዓት ባልበለጠ ጊዜ ውስጥ ለመውሰድ ምን ያህል ይቸገራሉ? ሀ. በጭራሽ፣ ለ. ከትንሽ ጊዜ በኋላ ሐ. አንዳንድ ጊዜ፣ መ. በተለምዶ፣ ሠ. ሁልጊዜ	ሀ = “አዎ”	የተቀሩት አይ”
75	የኤችአይቪ መድሃኒት ባለፉት 30 ቀናት ውስጥ አልፈውታል?		
76	ለጥያቄ 75 መልስዎ "አዎ" ከሆነ መደሄንትዎ ያልወሰዱበት ምክንያት ምን ልሆን ይችላል? ከአንድ በላይ መልስ መስጠት ይችላል		
	1. ከቤት ወጥተው		
	2. ረስቸው		
	3. የጎንዮሽ ጉዳቶች ስላሉት		
	4. መድሃኒት ስውሰድ ሰዎች ስለሚያዩኝ በመፍራት		
	5. ብዙ ኪኒኖች መውሰድ		
	6. ጾም		
	7. ጸበል መጠቀም / ሃይማኖታዊ ምክንያቶችን		
	8. የተስፋ መቁረጥ ስሜት ተሰምቶኝ		
	9. መድኃኒት አልቆብኝ		
	10. በጥሩ ሁነታ ምልክቶች ስለተቆጣጠርኩኝ		
	11. ህመም ይሰማኛል		
	12. የመዳዳዣ እጥረት		
	13. ምግብ አለመኖር		
	14. ሌላ, እባክዎን ይግለጹ		

ስለ ሰጡን ጊዜ እናመሰግናለን፣ ቃለመጠየቁን ያደረገ ስም: ____________________ ፊርማ: __________

ቀን: __________

Appendix 5: Invitation letter

Participants needed for research project

Dear clients of ART clinics

I am a PhD candidate at The University of Adelaide, Australia. I am studying self-management of adults living with HIV on antiretroviral therapy in Debre Markos Referral Hospital.

The study is approved by The University of Adelaide Human Research Ethics Committee [Approval number: H-2018-243] and Amhara Regional Health Bureau Research Office [Approval number: APHHRTD/03/264/2019].

If you are attending Debre Markos referral Hospital ART clinics for the last six months, I would like to invite you to participate in this study. You are invited to participate in two phases of the study. Phase one of the study involves a survey interview about your self-management behaviours. After attending the survey interview, you will be invited to participate in the second phase of the study. Phase two of the study will explore in detail your self-management behaviours (self-management practice and medication adherence). Your participation is entirely voluntary and be assured that you may withdraw at any time without any consequences to your future treatment. We will not gather personal information that can identify you and your name will not be recorded. Be assured that your anonymity and confidentiality will be maintained. The phase one interview will take about 30 minutes and phase two may take 30-45 minutes. Your informed consent will be obtained before participating in both studies. More information is included in both studies' information sheets.

Your kind participation in this study is highly appreciated. If you are interested, please contact the data collectors or researcher.

Contacts:

Desta Yitayehu: 0913358417

Habtamu Abera: 0910218513; email: habtamu.abera64@gmail.com

Your sincerely,

Habtamu Abera Areri, PhD student

Appendix 6: Participant information sheet

PROJECT TITLE: ***Self-management of adults living with HIV on treatment in Debre Markos Referral Hospital***	**የምርምሩ ርዕስ፡** *በደብረ ማርቆስ ሪፈራል ሆስፒታል በኤች አይ ቪ ህክምና ክትትል ላይ ያሉት አዋቂዎች ራሳቸውን እንደት እንደሚከባከቡ ጥናት ስማድርግ።*
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-243	የሰው ምርምር ሰነምግባር ኮሚቴ ምርምሩን ያጸደቀበት ቁጥር፡ **H-2018-243 እና *APHIHRTD/03/264/2019***
Supervisor's Name: Professor Gillian Harvey and Dr Amy Marshall	የምርምሩ አማካሪ: ፕሮፌሰር ጊሊያን ሃርቬይ እና ዶክተር ኤሚ ማርሻል
PRINCIPAL INVESTIGATOR: Habtamu Abera Areri	ተመራማሪው: ሀብታሙ አበራ ›_]
STUDENT'S DEGREE: PhD	የተማሪው ዲግሪ: **PhD (ፒ. ኤች. ዲ. ዲግሪ)**
Dear Participant, You are invited to participate in the research project described below.	**ውድ ተሳታፊዎች፣** ከታች በተገለጸው የምርምር ፕሮጀክት ላይ እንዲሳተፉ ተጋብዘዋል:
What is the project about? This study is about self-management of adults living with HIV. The researcher aims to study the level and factors influencing self-management behaviours of adults living with HIV on follow up. Specifically, the aims of the study are assessing the health practice, support required for self-management, living with HIV, confidence for self-management and level of adherence. It is hoped that the result of the study will provide data on self-management and suggest ways of improving the self-management.	**ምርምሩ ምንድነው?** ይህ ጥናት ከኤች አይ ቪ ጋር የሚኖሩ አዋቂዎች ***ራሳቸውን እንደት እንደሚከባከቡ ማጥናት*** ነው። የጥናቱ አላማ የአካላዊ ጤንነትን፤ እራስ መቆጣጠርን፤ ኤችአይቪ ጋር ተላምዶ መኖርን፤ ራስን በራስ መከባከብ እና በራስ የመተማመን ደረጃ ላይ ጥናት ማድረግ ናቸው:: የጥናቱ ውጤት ከኤች አይ ቪ ጋር ለ ሚኖሩት ሰዎች ራሳቸውን እንዴት እንደሚከባከቡ ለማወቅ እና እንድት እደሻሻልም ለመጠቆም ነው። በመሆኑም ጠቀሜታው ለታካሚዎች እና ለጤና ተቋማት የላቀ ነው።
Who is undertaking the project? This project is being conducted by Habtamu Abera Areri. This research will form the basis for the degree of Doctor of Philosophy in nursing at the University of Adelaide, Australia, under the supervision of Professor Gillian Harvey and Dr Amy Marshall.	**ጥናቱን ማን ያካሂዳል?** ይህ ጥናት በአቶ ሃብታሙ አበራ ›_] እየተካሄደ ነው: ይህ ጥናት ነርስንግ የዶክትሬት ዲግሪ ማሚያ ስሆን በፕሮፌሰር ጊሊያን ሃርቬይ እና ዶ/ር ኤሚ ማርሻል አማካሪነት የሚሰራ ነው።
Why am I being invited to participate? You are being invited as you are a person living with HIV on treatment and you have been on therapy for at least six months. You are invited to participate in this survey, but your participation is completely voluntary.	**ለምን እንዲሳተፍ ተጋበዙኝ?** የHIVለህክምና በመከታተል ላይ ያሉትን ሰዎች በመጋበዝ ላይ እንገኛለን። እናም እርሰዎ ለአለፉት 6 ወራት ህክምና እየተከታተሉ ስለሆነ በጥናቱ እንዲሳተፉ ተጋብዘዋል። ይሁን እንጇ የእርስዎ ተሳትፎ ሙሉ በሙሉ በፈቃደኝነትዎ ላይ የተመሰረተ ነው።
What am I being invited to do? You are being invited to participate in a survey (study) about your self-management. The survey will be carried out by data collectors in adherence counselling rooms. Your participation is on a volunteer basis. If you agree to participate in the follow-up interview, you will be asked to provide your contact details to the researcher.	**ምን እንድሆን ተጋበዝኩኝ?** ስለ ራስዎ የህክምና እንክብካቤ በተመለከተ ጥናት ውስጥ እንዲሳተፉ እየተጋበዙ ነው። የጥናቱ መረጃ የሚሰበሰበው በምክር መስጫ ክፍሎች ውስጥ ስሆን ተሳትፎዎም በፈቃደኝነት ላይ የተመሰረተ ይሆናል:: በተጨማሪም በሁለተኛ ዙር ቃለ-መጠይቅ ላይ ለመሳተፍ ከፈለጉ የመገኛ አድራሻዎን ለተመራማሪው መስጠት ይችላሉ።
How much time will my involvement in the project take? The study involves a face-to-face survey which will take around 30 minutes. If you agree to participate in study 2, you will be invited to an interview which will take approximately 40 minutes. The interview will be carried out at a different time to the survey, and you will be paid 63 Ethiopian Birr (3AU$) for your time contribution. For the interview study you will be provided another information sheet for more information.	**በጥናቱ ውስጥ ተሳትፎዬ ምን ያህል ጊዜ ይወስዳል?** የመጀመሪያ ዙር ጥናት እስከ 30 ደቂቃዎች ልወስድ ይችላል። በሁለተኛ ዙር ጥናት ለመሳተፍ ከተስማሙ ወደ 40 ደቂቃ የሚወስድ ቃለ መጠይቅ ይደረግልዎታል።የሁለተኛው ዙር ጥናት በለላ ቀጠሮ የምካሄድ ይሆናል።በወቅቱም ላበረከቱት ጊዜ 63 የኢትዮጵያ ብር ይከፈለዎታል።ስለ ሁለተኛ ዙር ጥናትም ተጨማሪ መረጃ ለማግኘት የሚያስችል ሌላ የመረጃ መስጫ ወረቀት ይሰጥዎታል።

Are there any risks associated with participating in this project? The study may induce some anxiety related to the face-to-face survey and during the in-depth interview. To reduce any anxiety the data collection will be carried out privately in an adherence counselling room and your details will not be included in the data. You are also free not to respond to specific questions or to stop participation at any time. If you feel distressed, the data collectors will help you to get a counselling service in this hospital in private rooms.	**ፕናት ውስጥ መሳተፍ ጋር ተያይዘው የሚመጣ ችግር ይኖራል ወይ?** ጥናቱ በቃለ መጠየቅ የሚደረግ ስሆን ከዚህ ጋር ተያይዘው በአንዳንድ ተሳታፊዎች ላይ የመረበሽ ስሜት ሊታይ ይችላል። በመሆኑም ጭንቀትን ለመቀነስ መረጃ የሚሰበሰበው የምክር አግልግሎት መስጫ ክፍል ውስጥ ብቻ ለብቻ ስሆን፤ እንዲሁም የእርስዎ ስም ሆነ ካርድ ቁጥር መረጃ ውስጥ አይካተትም:: በተጨማሪም ለተወሰኑ ጥያቄዎች ብቻ መልስ መስጠት ወይም በማንኛውም ጊዜ ተሳትፎዎን ማቆም ይችላሉ:: የመጨነቅ ስሜት ከተሰማዎ መረጃ ሰብሳቢ ባለሙያዎች በሆስፒታሉ ውስጥ የምክር አገልግሎት እንዲያገኙ ይረዱዎታል::
What are the potential benefits of the research project? There may be no immediate individual benefit of the study. However, the research findings might be helpful to improve support for self-management through identifying the barriers and recommending ways to solve them. The research might provide knowledge on self-management in the study area that might help to improve HIV care services for people living with HIV. The findings of this study are important to generate evidence to improve the self-management of people attending HIV treatment.	**ጥናቱ ልያስገኝ የምችል ጥቅሞች ምን ምን ናቸው?** ጥናቱ ከኤች አይ ቪ ጋር የሚኖሩ ሰዎች ራሳቸውን እንዳይከባከቡ ልያደርጉ የምችሉ እንቅፋቶችን በመለየት መፍትሄ ልሆኑ የምችሉ መንገዶችን ይጠቁማል። በመሆኑም ወደፊት የጸረ-ኤች አይ ቪ ህክምና አግለግሎትን ለማሻሻል ከፍተኛ ሚና ልጫውት ይችላል።
Can I withdraw from the project? Participation in this project is completely voluntary. If you agree to participate, you can also withdraw from the study at any time. Your withdrawal from the study will not affect your current and future treatment.	**ከፕናቱ ለመውጣት እችላለሁ?** በዚህ ኘሮጀክት መሳተፍ በፈቃደኝነት ላይ የተመሠረተ እንዲሁም ለመሳተፍ ከተስማሙ በኃላ በማንኛውም ጊዜ ከጥናቱ ማቋረጥ ይችላሉ። ከጥናቱ በማቋረጠዎ አሁንም ሆነ ወደፊት ህክምናዎ ላይ ምንም ተጽእኖ አይኖረውም።
What will happen to my information? No personal identifier will be used during the survey, data processing, storage and publications. All data will be kept in password-protected folders and only the researchers will have access to the data. In the face-to face survey, no names will be collected with your data. Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.	**መረጃዬ እንደት ይያዛል?** መረጃ ስሰበስብ፤ ስደራጅ፤ ስከማች እና ስታተም ምንም አይነት የግል መለያ ስምዎ፤ቁጥረዎ አይካተትም።ሁሉም መረጃ በይለፍ ቃል ይታሰራል። የተሰበሰበውን መረጃ ዋናው ተመራማሪ እና የምርመሩ አማካሪዎች ብቻ የሚያቁት ሲሆን የተሳፊዎች መረጃ ከፈቃዳቸው ውጭ ለማንም ማሳየት አይቻልም።
Who do I contact if I have questions about the project? If you have any question about this study, please contact me, Habtamu Abera Areri, phone number +61478211554 or +251985063523, email: habtamu.areri@adelaide.edu.au. You may also contact my supervisors: Professor Gillian Harvey, email: gillian.harvey@adelaide.edu.au and Dr Amy Marshall, email: amy.marshall@adelaide.edu.au	**ስለ ፕናቱ ጥያቄ ቢኖረኝ ማንን ልጠይቅ ይችላለሁ?** ስለዚህ ጥናት ማንኛውም ጥያቄ ካለዎት እባክዎን ሀብታሙ አበራን በስልክ ቁጥር +61478211554 ወይም +251985063523፤ ኢሜል habtamu.areri@adelaide.edu.au ይደውሉ። ለጥናቱ አማካሪዎች: ፕሮፌሰር ግሊያን ሃርቬይ፤ ኢሜይል: gillian.harvey@adelaide.edu.au እና ዶክተር ኤሚ ማርሻል ፤ ኢሜል amy.marshall@adelaide.edu.au.
What if I have a complaint or any concerns? The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-243). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the university's policy on research involving	**ቅሬታ ወይም ሌላም ጉዳይ ቢኖረኝስ?** ጥናቱ በአድላይዴ ዩኒቨርሲቲ የሰው ምርምር ሰነምግባር ኮሚቴ (ፍቃድ ቁጥር H-2018-243) ጸድቋል። ይህ የምርምር ፕናት የሚካሄደው በአውስትራሊያ ብሔራዊ ምርምር ሰነምግባር (2007) መሰረት ነው። በፕሮጀክቱ ውስጥ ከተሳተፉዋቸው ተግባራዊ ጠቀሜታዎች ጋር የተዛመዱ ጥያቄዎች ወይም ችግሮች ካጋጠሙዎት ወይም ስለ ፕሮጀክቱ ጉዳይ ወይም አቤቱታ ለማቅረብ ከፈለጉ የፕሮጀክት ተመራመሪውን ያማክሩ።

human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:
Phone: +61 8 8313 6028; Email: hrec@adelaide.edu.au
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

For local contact

Regional Health Bureau: Health research and technology transfer core process owner
Phone: +251582201698

If I want to participate, what do I do?

If you want to participate, please inform the data collector in the clinic, or contact me, Habtamu Abera Areri, by phone number +251985063523 or email habtamu.areri@adelaide.edu.au. We will discuss the details of participation, consent, and any questions you have.

Yours sincerely,
Habtamu Abera Areri

ስለጉዳዩ ቅሬታ ካለዎት ነጻ ገለልተኛ ሰው ጋር ለመነጋገር ከፈለጉ የዩኒቨርሲቲው የሰዎች ተሳታፊዎች የሚያካሂደውን ምርምር በተመለከተ ወይም እንደ ተሳታፊ ባለዎት መብቶች ላይ ለመሳተፍ ከፈለጉ የሰብአዊ ምርምር ሥነ-ምግባር ኮሚቴ ጽ/ቤት
ስልክ፤ +61 8 8313 6028፤ ኢሜይል: hrec@adelaide.edu.au
ፖስት፤ ደረጃ 4፤ ራውደል ሞል ፕላዛ, 50 Rundle Mall, ADELAIDE SA 5000
ማንኛውም ቅሬታ ወይም ስጋት ካለዎት ቅረታዎ በሚስጥር ይያዛል ፤ ውጤቱን ያሳውቃሉ።

ለአካባቢያዊ ግንኙነት

የአማራ ክልል የማህበረሰብ ምርምር ማዕከል ስልክ: +251582263223/+251582220191

ለመሳተፍ ቢፈልግ ምን ማድረግ አለብኝ?

ለመሳተፍ ከፈለጉ በክሊኒኩ ውስጥ ለመረጃ ሰብሳቢዎች ያሳውቁ ወይም ሀብታሙ አበራን በስልክ ቁጥር +251910218513 ወይም በኢሜል habtamu.areri@adelaide.edu.au ያግኙትን:: ስተሳትፎ፤ ስለ ስምምነትዎ እና ማንኛውም ጥያቄዎች ካለዎ ማነጋገር ይችላሉ።

ከአክብሮት ጋር,
ሀብታሙ አበራ ›_]

Appendix 7: Participant information sheet for in-depth interview

PROJECT TITLE: ***Exploring self-management of adults living with HIV on treatment***	**የምርምሩ ርዕስ፡** *በኤች አይ ቪ ህክምና ክትትል ላይ ያሉት አዋቂዎች ራሳቸውን እንደት እንደሚከባከቡ ጥናት ስማድርግ*
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-243	የሰው ምርምር ሰነምግባር ኮሚቴ ምርምሩን ያጸደቀበት ቁጥር፡ **H-2018-243 እና** ***APHIHRTD/03/264/2019***
Supervisor's Name: Professor Gillian Harvey and Dr Amy Marshall	የምርምሩ አማካሪ: ፕሮፌሰር ጊሊያን ሃርቬይ እና ዶክተር ኤሚ ማርሻል
PRINCIPAL INVESTIGATOR: Habtamu Abera Areri	ተመራማሪው: ሀብታሙ አበራ
STUDENT'S DEGREE: PhD	የተማሪው ዲግሪ: **PhD (ፒ. ኤች. ዲ. ዲግሪ)**
Dear Participant, You are invited to participate in the research project described below.	**ውድ ተሳታፊዎች፣** ከታች በተገለጸው የምርምር ፕሮጀክት ላይ እንዲሳተፉ ተጋብዘዋል:
What is the project about? This study is about self-management of adults living with HIV. The researcher aims to explore key factors influencing self-management behaviours of adults living with HIV on follow up. It is hoped that the result of the study will provide data on self-management and suggest ways of improving the self-management.	**ምርምሩ ምንድነው?** ይህ ጥናት ከኤች አይ ቪ ጋር የሚኖሩ አዋቂዎች ***ራሳቸውን እንደት እንደሚከባከቡ ማጥናት*** ነውየጥናቱ ውጤት ከኤች አይ ቪ ጋር ለ ሚኖሩት ሰዎች ራሳቸውን እንዴት እንደሚከባከቡ ለማወቅ እና እንድት እደሻሻልም ለመጠቆም ነው። በመሆኑም ጠቀሜታው ለታካሚዎች እና ለጤና ተቋማት የላቀ ነው።
Who is undertaking the project? This project is being conducted by Habtamu Abera Areri. This research will form the basis for the degree of Doctor of Philosophy in nursing at the University of Adelaide Australia, under the supervision of Professor Gillian Harvey and Dr Amy Marshall.	**ጥናቱን ማን ያካሂዳል?** ይህ ጥናት በአቶ ሃብታሙ አበራ እየተካሄደ ነው: ይህ ጥናት ነርስንግ የዶክትሬት ዲግሪ ማሟያ ስሆን በፕሮፌሰር ጊሊያን ሃርቬይ እና ዶ/ር ኤሚ ማርሻል አማካሪነት የሚሰራ ነው።
Why am I being invited to participate? You are being invited as you are a person living with HIV on treatment and you have been on therapy for at least six months. You are invited to participate in this interview, but your participation is completely voluntary.	**ለምን እንዲሳተፍ ተጋበዙኝ?** የHIVለህክምና በመከታተል ላይ ያሉትን ሰዎች በመጋበዝ ላይ እንገኛለን። እናም እርሰዎ ለአለፉት 6 ወራት ህክምና እየተከታተሉ ስለሆነ በጥናቱ እንዲሳተፉ ተጋብዘዋል። ይሁን እንጂ የእርስዎ ተሳትፎ ሙሉ በሙሉ በፈቃደኝነትዎ ላይ የተመሰረተ ነው።
What am I being invited to do? You are being invited to participate in a second phase study to better understand your self-management. The in-depth interview will be carried out by principal investigator in adherence counselling rooms. Your participation is on a volunteer basis. If you agree to participate in the follow-up interview, you will be asked to provide your contact details to the researcher.	**ምን እንድሆን ተጋበዝኩኝ?** ስለ ራስዎ የህክምና እንክብካቤ በተመለከተ ጥናት ውስጥ እንዲሳተፉ እየተጋበዙ ነው። የጥናቱ መረጃ የሚሰበሰበው በምክር መስጫ ክፍሎች ውስጥ ስሆን ተሳትፎዎም በፈቃደኝነት ላይ የተመሰረተ ይሆናል::
How much time will my involvement in the project take? The study involves a face-to-face in-depth interview which will take around 25-50 minutes. You will be paid 63 Ethiopian Birr (3AU$) for your time contribution.	**በፕናቱ ውስጥ ተሳትፎዬ ምን ያህል ጊዜ ይወስዳል?** ጥና~ እስከ 25-50 ደቂቃዎች ልወስድ ይችላል። ላበረከቱት ጊዜ 63 የኢትዮጵያ ብር ይከፈለዎታል።
Are there any risks associated with participating in this project? The study may induce some anxiety during the in-depth interview. To reduce any anxiety the interview will be carried out privately in an adherence counselling room and your details will not be included in the data. You are also free not to respond to specific questions or to stop participation at any time. If you feel distressed, the data collectors will help you to get a counselling service in this hospital in private rooms.	**ፕናት ውስጥ መሳተፍ ጋር ተያይዘው የሚመጣ ችግር ይኖራል ወይ?** ጥናቱ በቃለ መጠየቅ የሚደረግ ስሆን ከዚህ ጋር ተያይዘው በአንዳንድ ተሳታፊዎች ላይ የመረበሽ ስሜት ሊታይ ይችላል። በመሆኑም ጭንቀትን ለመቀነስ መረጃ የሚሰበሰበው የምክር አግልግሎት መስጫ ክፍል ውስጥ ብቻ ለብቻ ስሆን፤ እንዲሁም የእርስዎ ስም ሆነ ካርድ ቁጥር መረጃ ውስጥ አይካተትም:: በተጨማሪም ለተወሰኑ ጥያቄዎች ብቻ መልስ መስጠት ወይም

	በማንኛውም ጊዜ ተሳትፎዎን ማቆም ይችላሉ:: የመጨነቅ ስሜት ከተሰማዎ መረጃ ሰብሳቢ ባለሙያዎች በሆስፒታሉ ውስጥ የምክር አገልግሎት እንዲያገኙ ይረዱዎታል::
What are the potential benefits of the research project? There may be no immediate individual benefit of the study. However, the research findings might be helpful to improve support for self-management through identifying the barriers and recommending ways to solve them. The research might provide knowledge on self-management in the study area that might help to improve HIV care services for people living with HIV. The findings of this study are important to generate evidence to improve the self-management of people attending HIV treatment.	**ጥናቱ ልያስገኝ የምችል ጥቅሞች ምን ምን ናቸው?** ጥናቱ ከኤች አይ ቪ ጋር የሚኖሩ ሰዎች ራሳቸውን እንዳይከባከቡ ልያደርጉ የምችሉ እንቅፋቶችን በመለየት መፍትሄ ልሆኑ የምችሉ መንገዶችን ይጠቁማል። በመሆኑም ወደፊት የጸረ-ኤች አይ ቪ ህክምና አግለግሎትን ለማሻሻል ከፍተኛ ሚና ልጫውት ይችላል።
Can I withdraw from the project? Participation in this project is completely voluntary. If you agree to participate, you can also withdraw from the study at any time. Your withdrawal from the study will not affect your current and future treatment.	**ከፕናቱ ለመውጣት እችላለሁ?** በዚህ ኘሮጀክት መሳተፍ በፈቃደኝነት ላይ የተመሠረተ እንዲሁም ለመሳተፍ ከተስማሙ በኃላ በማንኛውም ጊዜ ከጥናቱ ማቋረጥ ይችላሉ። ከጥናቱ በማቋረጠዎ አሁንም ሆነ ወደፊት ህክምናዎ ላይ ምንም ተጽእኖ አይኖረውም።
What will happen to my information? No personal identifier will be used during the survey, data processing, storage and publications. All data will be kept in password-protected folders and only the researchers will have access to the data. In the face-to face survey, no names will be collected with your data. Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.	**መረጃዬ እንደት ይያዛል?** መረጃ ስሰበስብ፤ ስደራጅ፤ ስከማች እና ስታተም ምንም አይነት የግል መለያ ስምዎ፤ቁጥረዎ አይካተትም።ሁሉም መረጃ በይለፍ ቃል ይታሰራል። የተሰበሰበውን መረጃ ዋናው ተመራማሪ እና የምርመሩ አማካሪዎች ብቻ የሚያቁት ሲሆን የተሳፊዎች መረጃ ከፈቃዳቸው ውጭ ለማንም ማሳየት አይቻልም።
Who do I contact if I have questions about the project? If you have any questions about this study, please contact me, Habtamu Abera Areri, phone number +61478211554 or +251985063523, email: habtamu.areri@adelaide.edu.au. You may also contact my supervisors: Professor Gillian Harvey, email: gillian.harvey@adelaide.edu.au and Dr Amy Marshall, email: amy.marshall@adelaide.edu.au	**ስለ ፕናቱ ጥያቄ ቢኖረኝ ማንን ልጠይቅ ይችላለሁ?** ስለዚህ ጥናት ማንኛውም ጥያቄ ካለዎት እባክዎን ሀብታሙ አበራን በስልክ ቁጥር +61478211554 ወይም +251985063523፤ ኢሜል habtamu.areri@adelaide.edu.au ይደውሉ። ለጥናቱ አማካሪዎች: ፕሮፌሰር ግሊያን ሃርቬይ፤ ኢሜይል: gillian.harvey@adelaide.edu.au እና ዶክተር ኤሚ ማርሻል ፤ ኢሜል amy.marshall@adelaide.edu.au.
What if I have a complaint or any concerns? The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-243). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the university's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on: Phone: +61 8 8313 6028; Email: hrec@adelaide.edu.au Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000 Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.	**ቅሬታ ወይም ሌላም ጉዳይ ቢኖረኝስ?** ጥናቱ በአድላይዴ ዩኒቨርሲቲ የሰው ምርምር ሰነምግባር ኮሚቴ (ፍቃድ ቁጥር H-2018-243) ጸድቋል። ይህ የምርምር ፕናት የሚካሄደው በአውስትራሊያ ብሔራዊ ምርምር ሰነምግባር (2007) መሰረት ነው። በፕሮጀክቱ ውስጥ ከተሳተፉዋቸው ተግባራዊ ጠቀሜታዎች ጋር የተዛመዱ ጥያቄዎች ወይም ችግሮች ካጋጠሙዎት ወይም ስለ ፕሮጀክቱ ጉዳይ ወይም አቤቱታ ለማቅረብ ከፈለጉ የፕሮጀክት ተመራመሪውን ያማክሩ። ስለጉዳዩ ቅሬታ ካለዎት ነጻ ገለልተኛ ሰው ጋር ለመነጋገር ከፈለጉ የዩኒቨርሲቲው የሰዎች ተሳታፊዎች የሚያካሂደውን ምርምር በተመለከተ ወይም እንደ ተሳታፊ ባለዎት መብቶች ላይ ለመሳተፍ ከፈለጉ የሰብአዊ ምርምር ሥነ-ምግባር ኮሚቴ ጽ/ቤት ስልክ፤ +61 8 8313 6028፤ ኢሜይል: hrec@adelaide.edu.au ፖስት፤ ደረጃ 4፤ ራውደል ሞል ፕላዛ, 50 Rundle Mall, ADELAIDE SA 5000 ማንኛውም ቅሬታ ወይም ስጋት ካለዎት ቅረታዎ በሚስጥር ይያዛል ፤ ውጤቱን ያሳውቃሉ።

For local contact
Regional Health Bureau: Health research and technology transfer core process owner
Phone: +251582201698

If I want to participate, what do I do?

If you want to participate, please inform the data collector in the clinic or contact me, Habtamu Abera Areri, by phone number +251985063523 or email habtamu.areri@adelaide.edu.au. We will discuss the details of participation, consent, and any questions you have.

Yours sincerely,
Habtamu Abera Areri

ለአካባቢያዊ ግንኙነት
የአማራ ክልል የማህበረሰብ ምርምር ማዕከል ስልክ: +251582263223/+251582220191

ለመሳተፍ ቢፈልግ ምን ማድረግ አለብኝ?

ለመሳተፍ ከፈለጉ በክሊኒኩ ውስጥ ለመረጃ ሰብሳቢዎች ያሳውቁ ወይም ሀብታሙ አበራን በስልክ ቁጥር +251910218513 ወይም በኢሜል habtamu.areri@adelaide.edu.au ያግኙትን:: ስተሳትፎ፤ ስለ ስምምነትዎ እና ማንኛውም ጥያቄዎች ካለዎ ማነጋገር ይችላሉ።

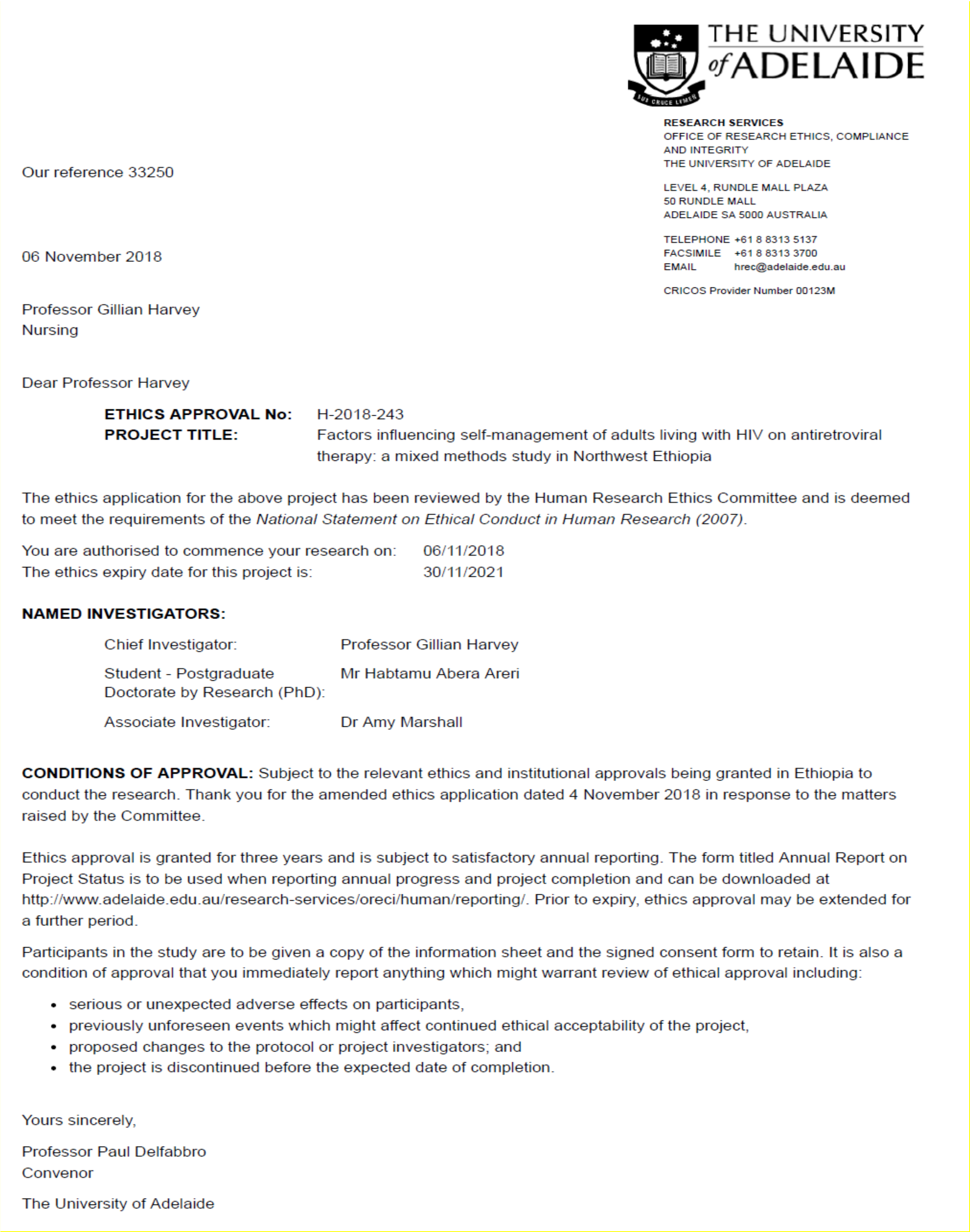
ከአክብሮት ጋር,
ሀብታሙ አበራ

Appendix 8: Interview guide for qualitative study

• Tell me about yourself (Age…., residency……, education……, income……………… etc.)	○ ስለ ራሰዎ ንገረኝ(ዕድሜ………………፧ መኖሪያ ቦታ………..፧ የት/ት ደረጃ……….፡ ገቢ………….፧ ወዘቴ)
• I am exploring the importance of self-management for adults living with HIV who are on ART. Can you tell me a bit about your condition and what the term 'self-management' means to you?	○ በኤች.አይ.ቪ. ቫይረስ ለተያዙ አዋቂዎች ራስን መንከባከብ አስፈላጊነት እያጠናሁ አገኛለሁ። ስለ ሁኔታህ እና ‹እራስ መንከባከብ› የሚለው ቃል ለእርሰዎ ምን ማለት እንደሆነ ይንገሩኝ?
• What factors are hindering/facilitating your self-management? Why? Your religion? Your monthly income? Your area of living (rural or urban)? Income? Your HIV stage?	○ ስዎትን እንዳይከባከቡ የሚያደናቅፉ ምክንያቶች/ የሚያመቻቹ ሁኔታዎች ምንምን ናቸው? ለምን? ሃይማኖትዎ? እንዴት? ወርሃዊ ገቢዎ? እንዴት? የመኖሪያ ቦታዎ (የገጠር ወይም የከተማ)? ለምን? ገቢ? ለምን? የኤችአይቪዎ ደረጃ? ለምን?
• Is this a convenient health facility for your HIV care and treatment? Why?	○ ይህ ሆስፒታል ለጸረ-ኤች-አይ-ቭ ህክምናዎ ምቹ ነው? ለምን?
• How do you see your self-efficacy (confidence) for the self-management program? Any success history related to your self-management?	○ ለራስ እንክብካቤ ፕሮግራምዎ በራስ መተማመኖን እንዴት ይመለከታሉ? ለምን? ከራስዎ መከባከብ ጋር የተገናኘ ማንኛውም የስኬት ታሪክ ካሉት ያጋሩን?
• What kind of social facilitations did you have for your HIV-related self-management?	○ ከኤች አይ ቪ ጋር የተዛመዱ ለራስ መንከባከብ እስካሁን ድረስ ምን አይነት ማህበራዊ ድጋፍ ተጠቀሙ?
• How do you see your overall self-regulation abilities? Why? How you manage your HIV illness-related symptoms? What is your goal of HIV treatment?	○ አጠቃላይ የራስ-መቆጣጣር ችሎታዎችዎን እንዴት ይመለከታሉ? ለምን? ከኤች አይ ቪ ህመም ጋር የተዛመዱ ምልክቶችን እንዴት እንደሚይዙ? የኤችአይቪ ሕክምና ዓላማዎ ምንድን ነው?
• Can you tell me about the interventions provided to you to support/enhance your self-management?	○ የራስዎን መንከባከብ እንዲደግፉ ለእርስዎ ስለተደረገለዎት እገዛዎች ሊነግሩኝ ይችላሉ? (የምክር አግልግሎት? በቡድን ወይም በእኩያዎት ለመታገዝ/ለመገናኘት?
• I want to see the outcomes of self-management: on daily physical health practice, resource mobilization and self-management, accepting and living with chronic HIV conditions, and managing medication adherence. Can you tell me how you are self-managing in these areas? ✓ **Daily physical health practice:** Symptom management? Side effect monitoring? Diet? Physical activities? Stress management? What helps/prevents you from performing your HIV-related physical health practice self-management? ✓ **Resource mobilization for self-management:** Do you think the presence of support is important for self-management? What kind of support helps you improve your self-management? Why? Have you mobilized existing support (families, HIV networks, and healthcare providers) around you? When? Why? ✓ **Living with chronic HIV conditions and self-management:** What do you feel regarding living with chronic HIV conditions? Why? What do you think	○ የራስን መንከባከብ ውጤቶችን ማየት እፈልጋለሁ-በየቀኑ የአካል ብቃት እንቅስቃሴ ፣ ማህበራዊ ድጋፍ እና ራስን መንከባከብ ፣ የኤች አይ ቪ ሁኔታን መቀበል እና አብሮ መኖር እና የመድኃኒት መመሪያን መከተል ። በእነዚህ አካባቢዎች እንዴት ራስዎን እንደሚከባከቡ ሊነግሩኝ ይችላሉ? ✓ ***አካልዊ:***-የህመም ምልክት መቆጣጠር? የጎንዮሽ ጉዳት ቁጥጥር? ከኤች አይ ቪ ጋር የተዛመደ የአካል ብቃት እንቅስቃሴ እና ራስን በራስ የመከባከብ ተግባር ለመፈፀም የሚረዳዎት / የሚከለክለዎት ምንድን ናቸው? ✓ ***ማህበራዊ ድጋፍ ማሰባሰብ:***-ለራስ መከባከብ የድጋፍ መኖር አስፈላጊ ነው ብለው ያስባሉ? የራስዎን አስተዳደር ለማሻሻል ምን ዓይነት ድጋፍ ነው? ለምን? በዙሪያዎት ያሉትን የድጋፍ አካለት (ቤተሰቦች ፣ የኤች አይ ቪ ጋር የሚኖሩ አቻዎች እና የጤና ባለሙያዎች) አሰባስበዋል? መቼ? ለምን? ✓ **ከኤች አይ ቪ በሽታ ጋር መኖር:-** የኤች አይ ቪ በሽታ መኖር ጋር በተያያዘ ምን ይሰማዎታል? ለምን? የኤች አይ ቪ መዳሄኒት በህይወትዎ ላይ ምን ተጽዕኖ አሳድረዋል?

could be the impact of ART on your life?	
• Are you taking medication for HIV as recommended? Why?	○ ለኤች.አይ.ቪ ህክምና እንደተመከሩ መድሃኒት እየወሰዱ ነው? ለምን?
• What do you think is the big challenge in your ART program self-management overall? What worked well? Please elaborate on this. What do you suggest as a solution to improve self-management of adults living with HIV on ART?	○ በኤች.አይ.ቪ ህክምና ፕሮግራም ላይ በአጠቃላይ ራስን ለመከባከብ ትልቁ ፈተና ምን ይመስልዎታል? በጥሩ ሁኔታ የሚገኝ ምንድን ነው? ያብራሩ። በኤች አይ ቪ በኤች አይ ቪ የተያዙ አዋቂዎችን ራስን መከባከብ ለማሻሻል እንደ መፍትሄ ምን ሃሳብ ያቀርባሉ?(መድሀኒትን በተገቢው መውስድ ፣ ዕለታዊ የጤና እንቅስቃሴ ፣ አጋዥ አካለትን ማሰባሰብ ፣የኤች አይ ቪ ሁኔታዎን መቀበል እና አብረው መኖር)።
• Any additional points that the ART service providers should consider for improving the self-management of adults living with HIV on ART?	○ የኤች.አይ.ቪ ህክምና አገልግሎት ሰጭዎች በኤች.አይ.ቪ በኤች አይ ቪ የተያዙ አዋቂዎችን ራስን መከባከብ ለማሻሻል ከግምት ውስጥ ማስገባት የሚኖርባቸው ማናቸውም ተጨማሪ ጉዳዮች?
Thank you for your time and for sharing your experience with us!	ስለ ጊዜዎ እና ተሞክሮዎን እናመሰግናለን!

Appendix 9: Human Research Ethics Committee ethics approval letter



THE UNIVERSITY
of ADELAIDE

RESEARCH SERVICES
OFFICE OF RESEARCH ETHICS, COMPLIANCE
AND INTEGRITY
THE UNIVERSITY OF ADELAIDE

LEVEL 4, RUNDLE MALL PLAZA
50 RUNDLE MALL
ADELAIDE SA 5000 AUSTRALIA

TELEPHONE +61 8 8313 5137
FACSIMILE +61 8 8313 3700
EMAIL hrec@adelaide.edu.au

CRICOS Provider Number 00123M

Our reference 33250

06 November 2018

Professor Gillian Harvey
Nursing

Dear Professor Harvey

ETHICS APPROVAL No: H-2018-243
PROJECT TITLE: Factors influencing self-management of adults living with HIV on antiretroviral therapy: a mixed methods study in Northwest Ethiopia

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)*.

You are authorised to commence your research on:	06/11/2018
The ethics expiry date for this project is:	30/11/2021

NAMED INVESTIGATORS:

Chief Investigator:	Professor Gillian Harvey
Student - Postgraduate Doctorate by Research (PhD):	Mr Habtamu Abera Areri
Associate Investigator:	Dr Amy Marshall

CONDITIONS OF APPROVAL: Subject to the relevant ethics and institutional approvals being granted in Ethiopia to conduct the research. Thank you for the amended ethics application dated 4 November 2018 in response to the matters raised by the Committee.

Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled Annual Report on Project Status is to be used when reporting annual progress and project completion and can be downloaded at http://www.adelaide.edu.au/research-services/oreci/human/reporting/. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the information sheet and the signed consent form to retain. It is also a condition of approval that you immediately report anything which might warrant review of ethical approval including:

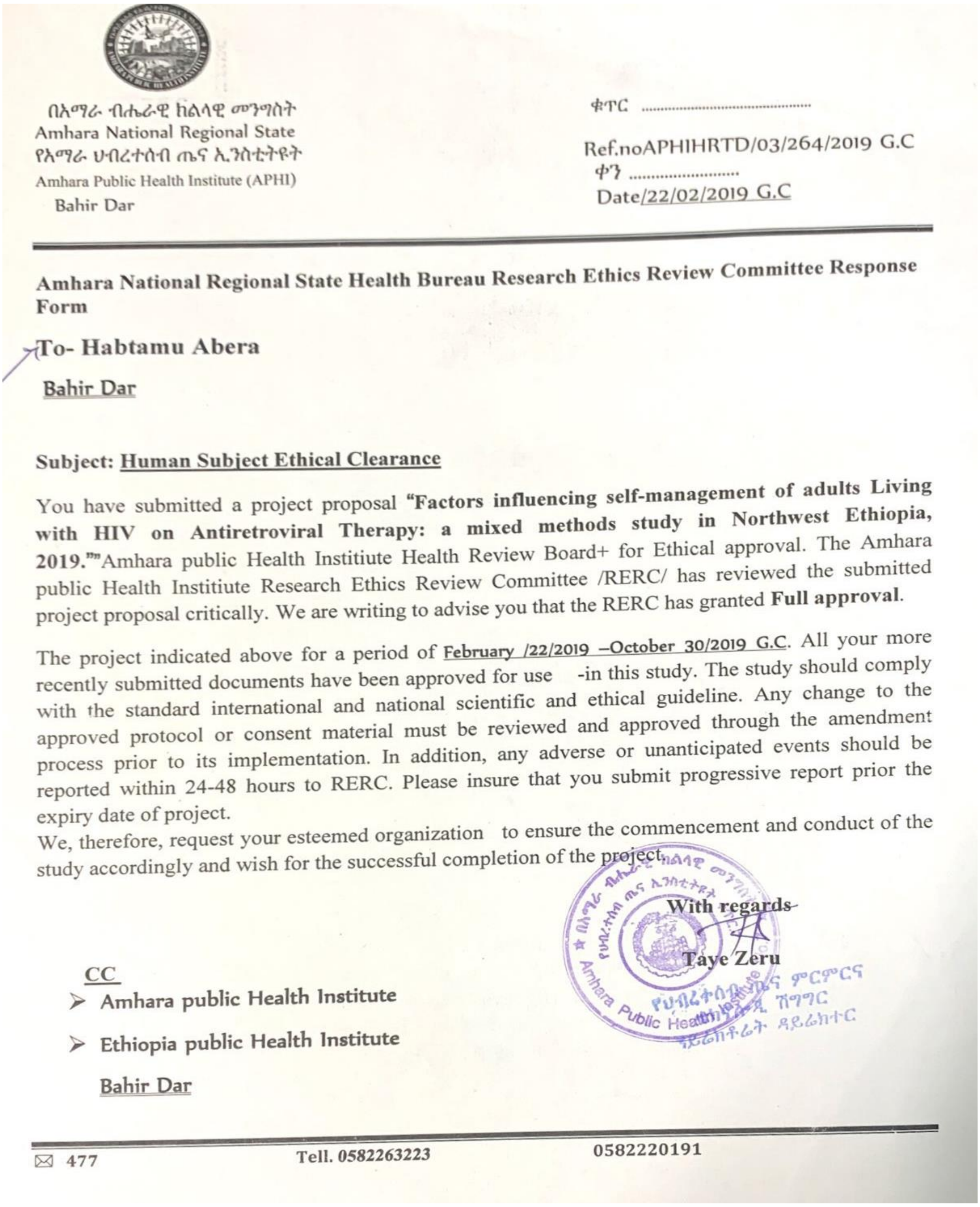
- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol or project investigators; and
- the project is discontinued before the expected date of completion.

Yours sincerely,

Professor Paul Delfabbro
Convenor

The University of Adelaide

Appendix 10: Amhara Regional Health Bureau Research Office ethics approval letter



በአማራ ብሔራዊ ክልላዊ መንግስት
Amhara National Regional State
የአማራ ህብረተሰብ ጤና ኢንስቲትዩት
Amhara Public Health Institute (APHI)
Bahir Dar

ቁጥር ....
Ref.noAPHIHRTD/03/264/2019 G.C
ቀን ....
Date/22/02/2019 G.C

Amhara National Regional State Health Bureau Research Ethics Review Committee Response Form

To- Habtamu Abera

Bahir Dar

Subject: **Human Subject Ethical Clearance**

You have submitted a project proposal **"Factors influencing self-management of adults Living with HIV on Antiretroviral Therapy: a mixed methods study in Northwest Ethiopia, 2019."**"Amhara public Health Institiute Health Review Board+ for Ethical approval. The Amhara public Health Institiute Research Ethics Review Committee /RERC/ has reviewed the submitted project proposal critically. We are writing to advise you that the RERC has granted **Full approval**.

The project indicated above for a period of February /22/2019 –October 30/2019 G.C. All your more recently submitted documents have been approved for use -in this study. The study should comply with the standard international and national scientific and ethical guideline. Any change to the approved protocol or consent material must be reviewed and approved through the amendment process prior to its implementation. In addition, any adverse or unanticipated events should be reported within 24-48 hours to RERC. Please insure that you submit progressive report prior the expiry date of project.
We, therefore, request your esteemed organization to ensure the commencement and conduct of the study accordingly and wish for the successful completion of the project.

With regards

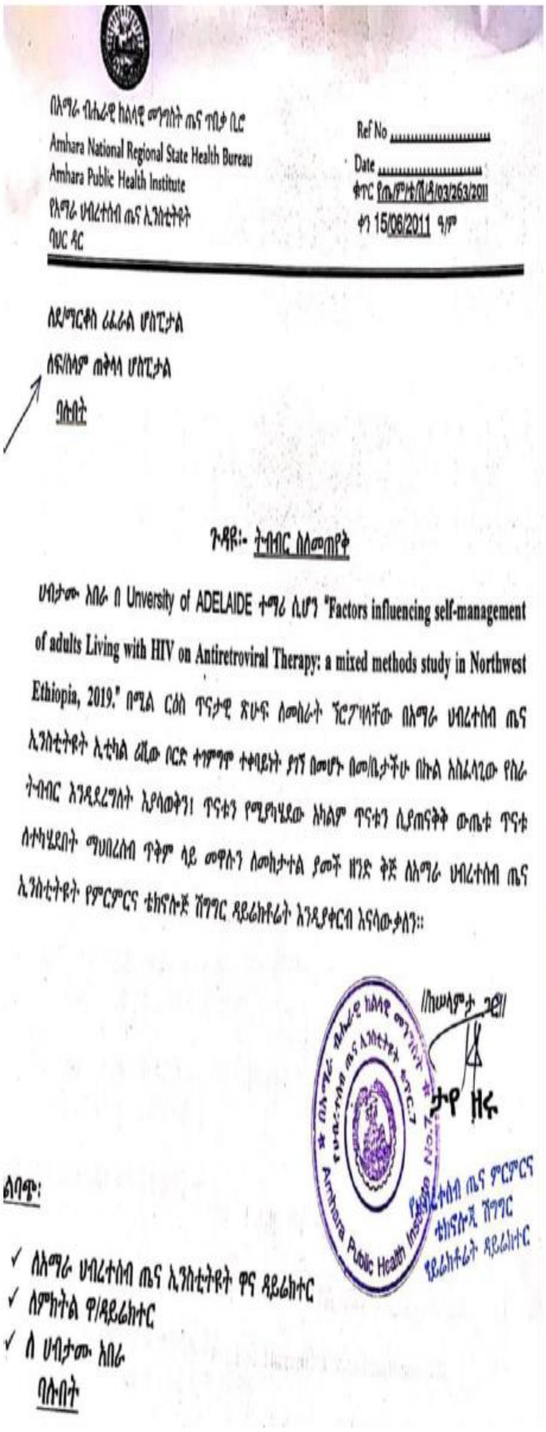
Taye Zeru

የህብረተሰብ ጤና ምርምርና
ሽግግር
ዳይሬክቶሬት ዳይሬክተር

CC
- Amhara public Health Institute
- Ethiopia public Health Institute

Bahir Dar

Appendix 11: Letter of support



በአማራ ብሔራዊ ክልላዊ መንግስት ጤና ጥበቃ ቢሮ
Amhara National Regional State Health Bureau
Amhara Public Health Institute
የአማራ ህብረተሰብ ጤና ኢንስቲትዩት
ባህር ዳር

Ref No ....
Date ....
ቁጥር የጤ/ም/ቴ/ሽ/ዳ/03/263/2011
ቀን 15/06/2011 ዓ/ም

ለደ/ማርቆስ ሪፈራል ሆስፒታል
ለፍ/ሰላም ጠቅላላ ሆስፒታል
ባሉበት

ጉዳዩ፡- ትብብር ስለመጠየቅ

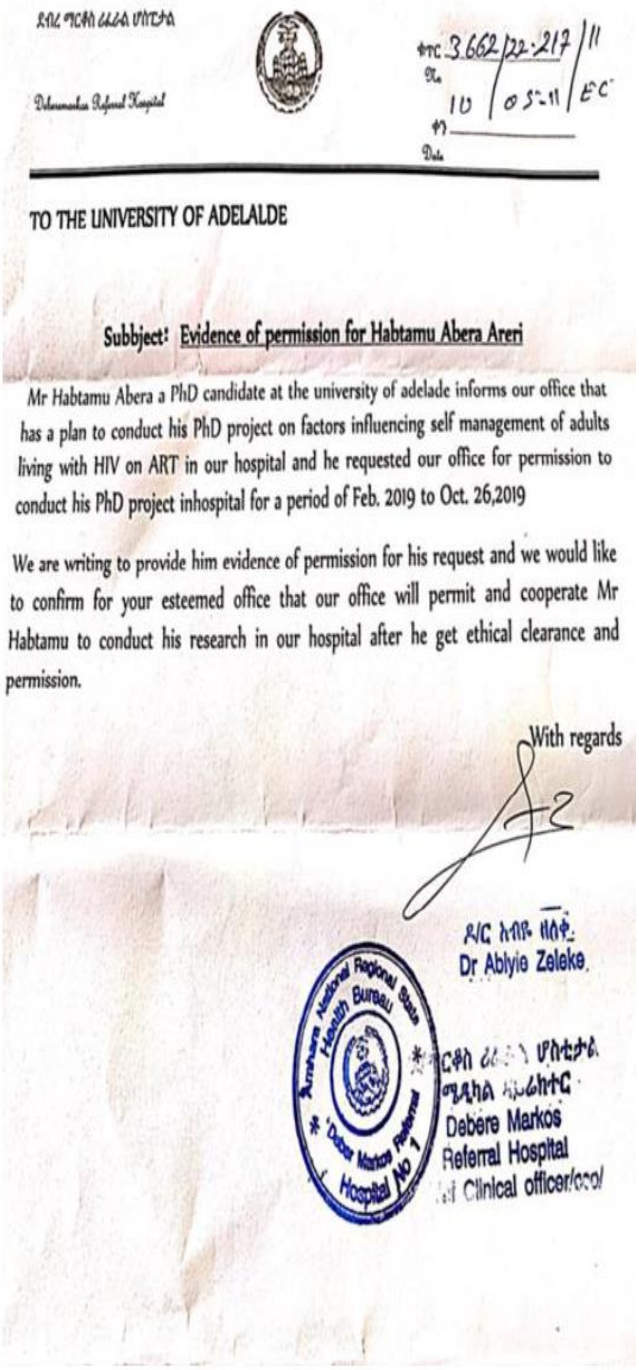
ሀብታሙ አበራ በ Unversity of ADELAIDE ተማሪ ሲሆን "Factors influencing self-management of adults Living with HIV on Antiretroviral Therapy: a mixed methods study in Northwest Ethiopia, 2019." በሚል ርዕስ ጥናታዊ ጽሁፍ ለመስራት ፕሮፖዛላቸው በአማራ ህብረተሰብ ጤና ኢንስቲትዩት ኢቲካል ሪቪው ቦርድ ተገምግሞ ተቀባይነት ያገኘ በመሆኑ በመ/ቤታችሁ በኩል አስፈላጊው የስራ ትብብር እንዲደረግለት እያሳወቅን! ጥናቱን የሚያካሂደው አካልም ጥናቱን ሲያጠናቅቅ ውጤቱ ጥናቱ ለተካሄደበት ማህበረሰብ ጥቅም ላይ መዋሉን ለመከታተል ያመች ዘንድ ቅጅ ለአማራ ህብረተሰብ ጤና ኢንስቲትዩት የምርምርና ቴክኖሎጂ ሽግግር ዳይሬክቶሬት እንዲያቀርብ እናሳውቃለን።

//ከሠላምታ ጋር//

ታየ ዘሩ
የህብረተሰብ ጤና ምርምርና ቴክኖሎጂ ሽግግር ዳይሬክቶሬት ዳይሬክተር

ልባጭ:

- ✓ ለአማራ ህብረተሰብ ጤና ኢንስቲትዩት ዋና ዳይሬክተር
- ✓ ለምክትል ዋ/ዳይሬክተር
- ✓ ለ ሀብታሙ አበራ
  ባሉበት



ደብረ ማርቆስ ሪፈራል ሆስፒታል
Debremarkos Referral Hospital

ቁጥር 3662/22-217/11
No.
10/05-11/EC
ቀን ____________
Date

TO THE UNIVERSITY OF ADELALDE

Subbject: Evidence of permission for Habtamu Abera Areri

Mr Habtamu Abera a PhD candidate at the university of adelade informs our office that has a plan to conduct his PhD project on factors influencing self management of adults living with HIV on ART in our hospital and he requested our office for permission to conduct his PhD project inhospital for a period of Feb. 2019 to Oct. 26,2019

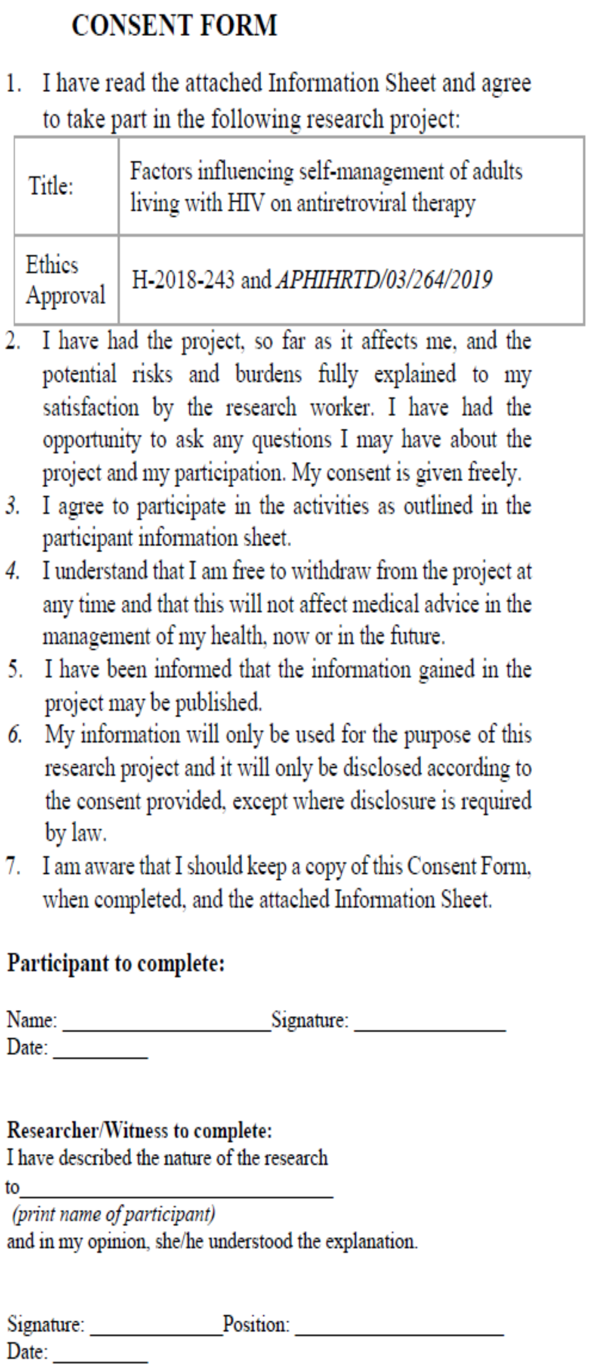
We are writing to provide him evidence of permission for his request and we would like to confirm for your esteemed office that our office will permit and cooperate Mr Habtamu to conduct his research in our hospital after he get ethical clearance and permission.

With regards

ዶ/ር አብዩ ዘለቀ
Dr Ablyie Zeleke
ርቆስ ሪፈ[illegible] ሆስፒታል
ሜዲካል ዳይሬክተር
Debere Markos
Referral Hospital
[illegible] Clinical officer/coo/

Appendix 12: Written informed consent for surveys

Human Research Ethics Committee (HREC)



CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	Factors influencing self-management of adults living with HIV on antiretroviral therapy
Ethics Approval	H-2018-243 and *APHIHRTD/03/264/2019*

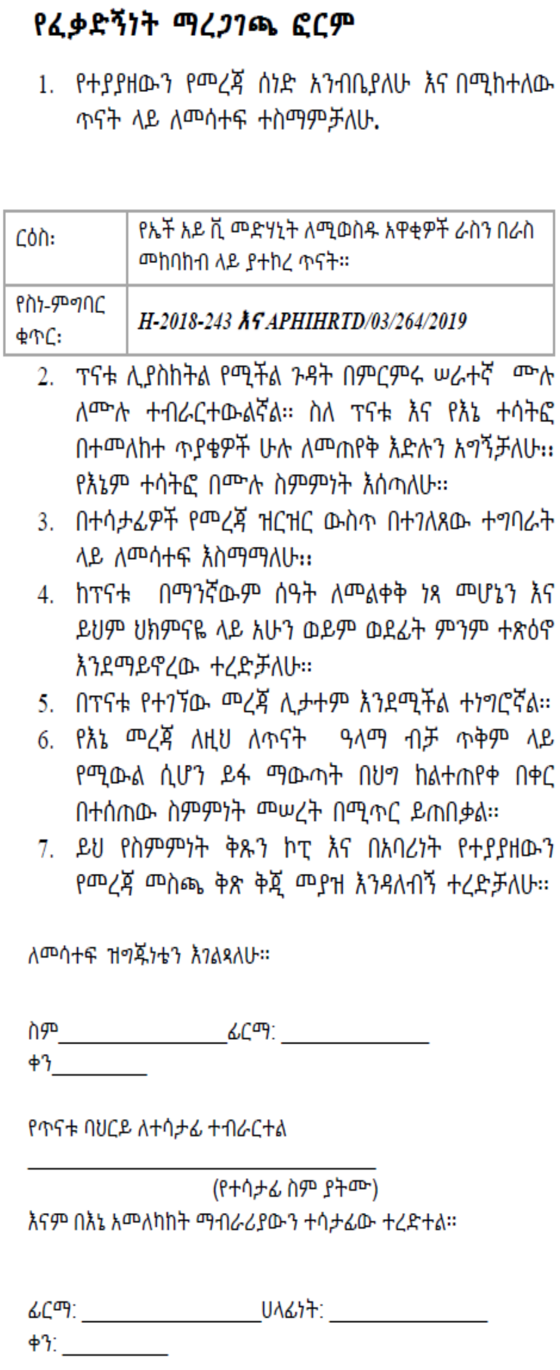
2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.
3. I agree to participate in the activities as outlined in the participant information sheet.
4. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
5. I have been informed that the information gained in the project may be published.
6. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.
7. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ____________________ Signature: ______________
Date: _________

Researcher/Witness to complete:
I have described the nature of the research
to____________________________
(print name of participant)
and in my opinion, she/he understood the explanation.

Signature: ____________ Position: ____________________
Date: _________



የፈቃድኝነት ማረጋገጫ ፎርም

1. የተያያዘውን የመረጃ ሰነድ አንብቤያለሁ እና በሚከተለው ጥናት ላይ ለመሳተፍ ተስማምቻለሁ.

ርዕስ፡	የኤች አይ ቪ መድሃኒት ለሚወስዱ አዋቂዎች ራስን በራስ መከባከብ ላይ ያተኮረ ጥናት።
የስነ-ምግባር ቁጥር፡	***H-2018-243 እና APHIHRTD/03/264/2019***

2. ጥናቱ ሊያስከትል የሚችል ጉዳት በምርምሩ ሠራተኛ ሙሉ ለሙሉ ተብራርተውልኛል። ስለ ጥናቱ እና የእኔ ተሳትፎ በተመለከተ ጥያቄዎች ሁሉ ለመጠየቅ እድሉን አግኝቻለሁ፡፡ የእኔም ተሳትፎ በሙሉ ስምምነት እሰጣለሁ።
3. በተሳታፊዎች የመረጃ ዝርዝር ውስጥ በተገለጸው ተግባራት ላይ ለመሳተፍ እስማማለሁ፡፡
4. ከጥናቱ በማንኛውም ሰዓት ለመልቀቅ ነጻ መሆኔን እና ይህም ህክምናዬ ላይ አሁን ወይም ወደፊት ምንም ተጽዕኖ እንደማይኖረው ተረድቻለሁ።
5. በጥናቱ የተገኘው መረጃ ሊታተም እንደሚችል ተነግሮኛል።
6. የእኔ መረጃ ለዚህ ለጥናት ዓላማ ብቻ ጥቅም ላይ የሚውል ሲሆን ይፋ ማውጣት በህግ ከልተጠየቀ በቀር በተሰጠው ስምምነት መሠረት በሚጥር ይጠበቃል።
7. ይህ የስምምነት ቅጹን ኮፒ እና በአባሪነት የተያያዘውን የመረጃ መስጫ ቅጽ ቅጂ መያዝ እንዳለብኝ ተረድቻለሁ።

ለመሳተፍ ዝግጁነቴን እገልጻለሁ።

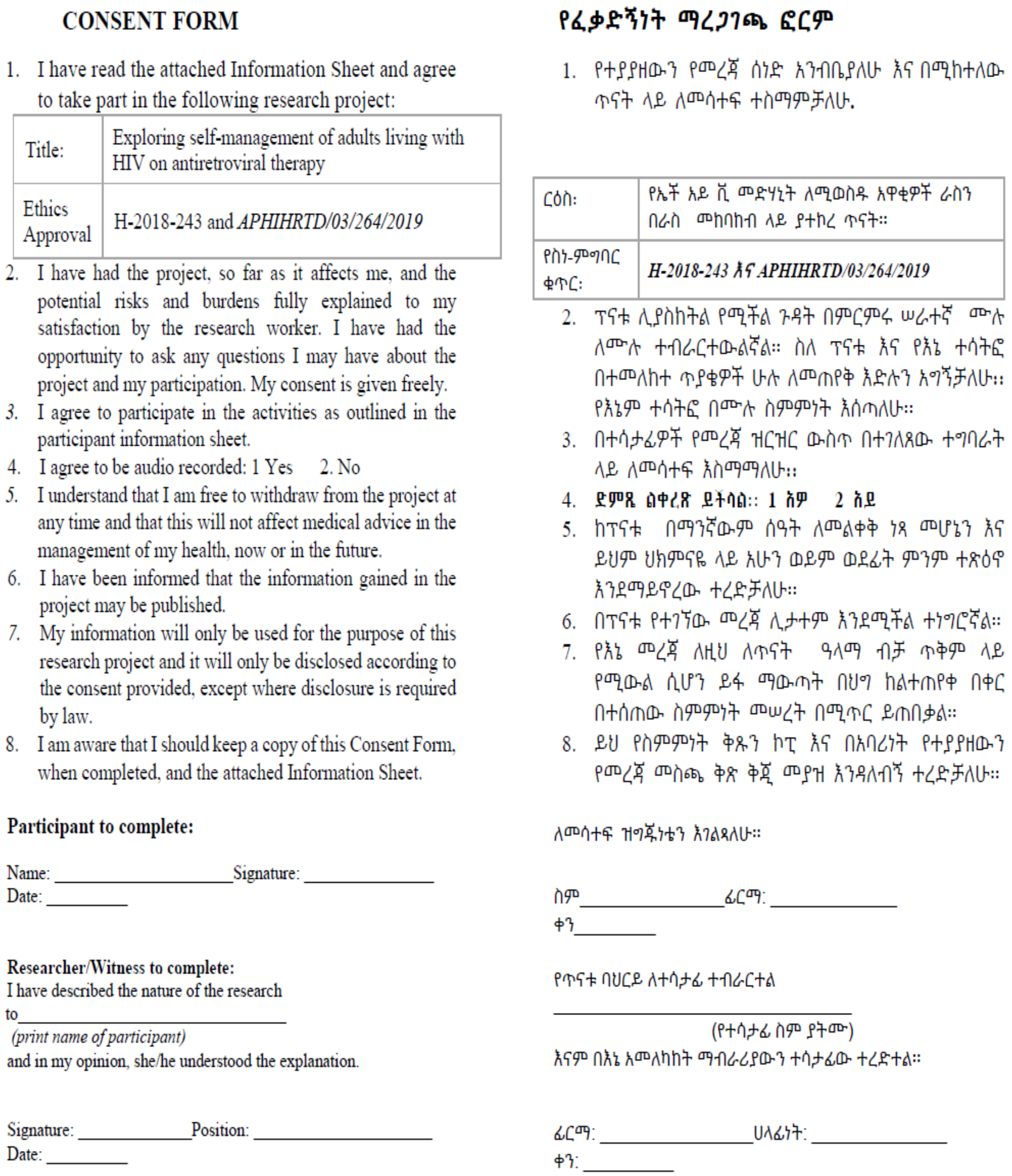
ስም________________ፊርማ: ______________
ቀን__________

የጥናቱ ባህርይ ለተሳታፊ ተብራርተል
____
(የተሳታፊ ስም ያትሙ)
እናም በእኔ አመለካከት ማብራሪያውን ተሳታፊው ተረድተል።

ፊርማ: _________________ሀላፊነት: _______________
ቀን: __________

Appendix 13: Written informed consent for in-depth interviews

Human Research Ethics Committee (HREC)



CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	Exploring self-management of adults living with HIV on antiretroviral therapy
Ethics Approval	H-2018-243 and *APHIHRTD/03/264/2019*

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.
3. I agree to participate in the activities as outlined in the participant information sheet.
4. I agree to be audio recorded: 1 Yes 2. No
5. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
6. I have been informed that the information gained in the project may be published.
7. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ____________________Signature: ______________
Date: _________

Researcher/Witness to complete:
I have described the nature of the research to______________________________
(print name of participant)
and in my opinion, she/he understood the explanation.

Signature: ____________Position: ____________________
Date: _________

የፈቃድኝነት ማረጋገጫ ፎርም

1. የተያያዘውን የመረጃ ሰነድ አንብቤያለሁ እና በሚከተለው ጥናት ላይ ለመሳተፍ ተስማምቻለሁ.

ርዕስ፡	የኤች አይ ቪ መድሃኒት ለሚወስዱ አዋቂዎች ራስን በራስ መከባከብ ላይ ያተኮረ ጥናት።
የስነ-ምግባር ቁጥር፡	***H-2018-243 እና APHIHRTD/03/264/2019***

2. ጥናቱ ሊያስከትል የሚችል ጉዳት በምርምሩ ሠራተኛ ሙሉ ለሙሉ ተብራርተውልኛል። ስለ ጥናቱ እና የእኔ ተሳትፎ በተመለከተ ጥያቄዎች ሁሉ ለመጠየቅ እድሉን አግኝቻለሁ፡፡ የእኔም ተሳትፎ በሙሉ ስምምነት እሰጣለሁ።
3. በተሳታፊዎች የመረጃ ዝርዝር ውስጥ በተገለጸው ተግባራት ላይ ለመሳተፍ እስማማለሁ፡፡
4. **ድምጼ ልቀረጽ ይችላል:: 1 አዎ 2 አይ**
5. ከጥናቱ በማንኛውም ሰዓት ለመልቀቅ ነጻ መሆኔን እና ይህም ህክምናዬ ላይ አሁን ወይም ወደፊት ምንም ተጽዕኖ እንደማይኖረው ተረድቻለሁ።
6. በጥናቱ የተገኘው መረጃ ሊታተም እንደሚችል ተነግሮኛል።
7. የእኔ መረጃ ለዚህ ለጥናት ዓላማ ብቻ ጥቅም ላይ የሚውል ሲሆን ይፋ ማውጣት በህግ ካልተጠየቀ በቀር በተሰጠው ስምምነት መሠረት በሚጥር ይጠበቃል።
8. ይህ የስምምነት ቅጹን ኮፒ እና በአባሪነት የተያያዘውን የመረጃ መስጫ ቅጽ ቅጇ መያዝ እንዳለብኝ ተረድቻለሁ።

ለመሳተፍ ዝግጁነቴን እገልጻለሁ።

ስም__________________ፊርማ: _______________
ቀን_________

የጥናቱ ባህርይ ለተሳታፊ ተብራርቷል

____
(የተሳታፊ ስም ያትሙ)
እናም በእኔ አመለካከት ማብራሪያውን ተሳታፊው ተረድቷል።

ፊርማ: __________________ሀላፊነት: ________________
ቀን: __________