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# Psychosocial and physical factors that influence instrumental activities of daily living of people living with human immune-deficiency virus in Blantyre, Malawi

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# PSYCHOSOCIAL AND PHYSICAL FACTORS THAT INFLUENCE INSTRUMENTAL ACTIVITIES OF DAILY LIVING OF PEOPLE LIVING WITH HUMAN IMMUNE-DEFICIENCY VIRUS IN BLANTYRE, MALAWI

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**A Research Report Submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfillment of the requirements for the degree Master of Science in Physiotherapy**

**Johannesburg, 2021**

## DECLARATION

I, Talumba Mercy Mankhokwe, declare that the work contained in this research report is my work, except to the extent indicated in the acknowledgment sections.

This research report is being submitted for a degree of Master of Science in Physiotherapy, at the University of the Witwatersrand, Johannesburg, South Africa.

This work has not been submitted for any other degree or examination in this or any other university.



Talumba Mercy Mankhokwe

24 November, 2021

Date

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## List of Abbreviations

| | |
|---|---|
| **3TC** | Lamivudine |
| **ART** | Anti-Retroviral Therapy |
| **ALHIV** | Adolescence living with HIV |
| **CPT** | Cotrimoxazole |
| **COMREC** | College of Medicine Research Ethics Committee |
| **DTG** | Dolutegravir |
| **EFV** | Efavirenz |
| **HIV** | Human Immune- Deficiency Virus |
| **HREC** | Human Research Ethics Committee |
| **IADLs** | Instrumental activities of daily living |
| **PLWH** | People living with HIV |
| **PCP** | Pneumocystis Carini pneumonia |
| **PN** | Peripheral neuropathy |
| **QECH** | Queen Elizabeth Central Hospital |
| **TB** | Tuberculosis |
| **TDF** | Tenofovir Disoprixil Fumarate |
| **WHO** | World health organisation |

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# CHAPTER 1: BACKGROUND AND NEED

## 1.1 Introduction

Malawi is a landlocked country situated in South-East Africa and is bordered by Mozambique, Zambia, and Tanzania (The World Bank Group, 2019). It has a population of about 18.7 million people, of which one million are living with HIV (National AIDS Commission (NAC), 2020). The southern region of Malawi has the highest population of 7.7 million people, seconded by the central region with a population of 7.5 million and the northern region with a population of 2.2 million (Malawi Government, 2019).

In the southern region, Blantyre is the commercial capital city and it has a population of 800,264, representing 2.6% of the total population of Malawi (Malawi Government, 2019). The prevalence of HIV is high in the cities and highest in the southern region of Malawi, with 15% prevalence of HIV in the south of the country (National AIDS Commission (NAC), 2020). The prevalence of HIV among adults over 15 years and above is 9.3% and young women have the highest HIV prevalence of 10.8% compared to men 6.4%(National AIDS Commission (NAC), 2020).

Young people are particularly at risk due to early sexual activity, and early child marriages, with 50% of new HIV infections affecting the age groups of (15 to 49 years) (UNICEF, 2019; UNAIDS, 2020). By 2019 about 850,000 people living with HIV were receiving antiretroviral therapy (ART) representing 85% coverage (National AIDS Commission (NAC), 2020; UNAIDS, 2020).

People Living with HIV (PLWH) encounter several challenges ranging from being sick due to HIV/AIDS, experiencing many side effects on antiretroviral Therapy (ART), continuous hospitalization, stigma, and discrimination from friends and relatives in the community (Renju *et al.*, 2017; Kiplagat *et al.*, 2019). These challenges may have an impact on their mental stability, social interaction, and physical activity in their daily life (Chisati, Constantinou, and Lampiao, 2018). For one to be able to perform fully during their day-to-

day life, they need mental stability, physical health, and assurance that they are safe in their community.

In Malawi, PLWH reported physical side effects such as dizziness, nausea, vomiting, nightmares, skin rash, increase in viral load, tuberculosis and hallucinations during ART clinics (Kim *et al.*, 2016; Renju *et al.*, 2017; Kaunda-Khangamwa *et al.*, 2020). These physical problems rendered them unable to participate in activities of daily living such as basic household chores, for example taking care of family and themselves. The participation limitations were attributed to weakness, dizziness, and severe headaches after taking antiretroviral drugs (Kim *et al.*, 2016; Renju *et al.*, 2017).

Muscle weakness is associated with fatigue and physical inactivity in PLWH, being HIV and receiving ART lower the physical level of PLWH which is more predominant in women than men (Chisati *et al.*, 2020). Chisati and Vasseljen (2015) in their study found that HIV-positive individuals had markedly lower aerobic endurance measured by maximal oxygen uptake than HIV-negative individuals, therefore adults who are in the early stages of HIV infection have reduced aerobic endurance level compared to HIV negative young adults. Literature shows that aerobic exercises improve upper and lower body strength in PLWH (Zech *et al.*, 2019). Muscle strengthening is important for minimizing physical and functional limitations (Germain *et al.*, 2016).

Shortage of food in the house has a direct implication on the adherence to ART in PLWH (Kim *et al.*, 2016). Wamoyi *et al.*, (2017) in their study found that those who were unable to eat a sufficient amount of food reported that dizziness intensified, forcing them to take the ART before sleep to reduce the effects of dizziness. This was supported by Kim *et al.*, (2016) who reported that PLWH complained of worsening of side effects when they take ART without food and they stopped taking ART occasionally when they did not have enough food. Low energy levels due to lack of food intake before and after taking ART results in general body weakness (Kim *et al.*, 2016; Renju *et al.*, 2017).

People living with HIV complain of physical symptoms such as pain, numbness, tingling sensation, pins and needles, body weakness that commonly presents in the lower limbs also

known as peripheral neuropathy (PN), these may present in the first or third stage of HIV infection or as a result of the effects of ART (Gunasekaran and Sivakumar, 2018). People living with HIV not only do they experience physical challenges but also face many psychological and social challenges in their communities and workplaces (Kim *et al.*, 2016; AVERT, 2019). They also face community-level stigma and discrimination towards PLWH has forced them to leave their homes and change their daily living (AVERT, 2019).

Reports of stigma, discrimination towards PLWH have been documented in many parts of Malawi (Kim *et al.*, 2016). People living with HIV are hesitant to disclose their HIV status to community members, partners, and relatives for fear of being talked about, mostly as gossip (Kim *et al.*, 2016; Chirambo *et al.*, 2019). In Malawi stigma has forced many PLWH to access ART clinics far away from home due to fear of disclosing their HIV status to friends and family members (Chirambo *et al.*, 2019). Meanwhile, some have stopped taking ART due to lack of partner support, attributed to fear of disclosure of their HIV status to their spouses which may lead to divorce (Kim *et al.*, 2016; Chirambo *et al.*, 2019).

In workplaces, PLWH may experience stigma from their co-workers and employers, such as social isolation and ridicule, or experience discriminatory practices such as termination or refusal of work, this results in loss of prospective employees and creates hostile working environments (Twinomugisha, Ottem and Daniel, 2020). The isolation that social rejection brings can lead to low self-esteem, depression, and even thoughts of suicide among PLWH (AVERT, 2019).

The psychosocial and physical problems that PLWH faces may interfere with the performance of instrumental activities of daily living (IADLs). Instrumental activities of daily living are defined as "those activities that allow an individual to live independently in a community" these include cooking, cleaning, transportation, laundry, and managing finances (Guo and Sapra, 2020). The problems faced by PLWH could interfere with performance and participation in activities that result in dependence on others hence affecting the quality of life of an individual.

## 1.2 Problem Statement

Although evidence of stigma, discrimination, depression, and physical problems of side effects of ART in people living with HIV exists in Malawi (Renju *et al.*, 2017; Chirambo *et al.*, 2019). There is limited information in the literature on how performance and participation in cooking, cleaning, laundry, transportation, and managing finances is interfered in PLWH considering the physical and psychosocial problems that they face. This study aimed at exploring how psychosocial and physical factors influence instrumental activities of daily living of PLWH in Blantyre, Malawi.

## 1.3 Research Question

How do psychosocial and physical factors influence instrumental activities of daily living of PLWH in Blantyre, Malawi?

## 1.4 Aim of the Study

The study aimed at exploring how psychosocial and physical factors influence instrumental activities of daily living of PLWH in Blantyre, Malawi.

## 1.5 Specific objectives

*1.5.1* To identify psychosocial and physical challenges faced by PLWH in Blantyre, Malawi.

*1.5.2* To assess how experienced psychosocial and physical factors influence instrumental activities of daily living of PLWH in Blantyre, Malawi.

## 1.6 Significance of the Study

This study adds more knowledge to the general public on how psychosocial and physical challenges faced by PLWH, influence their IADLs. It will help identify areas that need therapeutic or psychosocial intervention to improve the functional independence of PLWH.

## 1.7 Outline of the research report

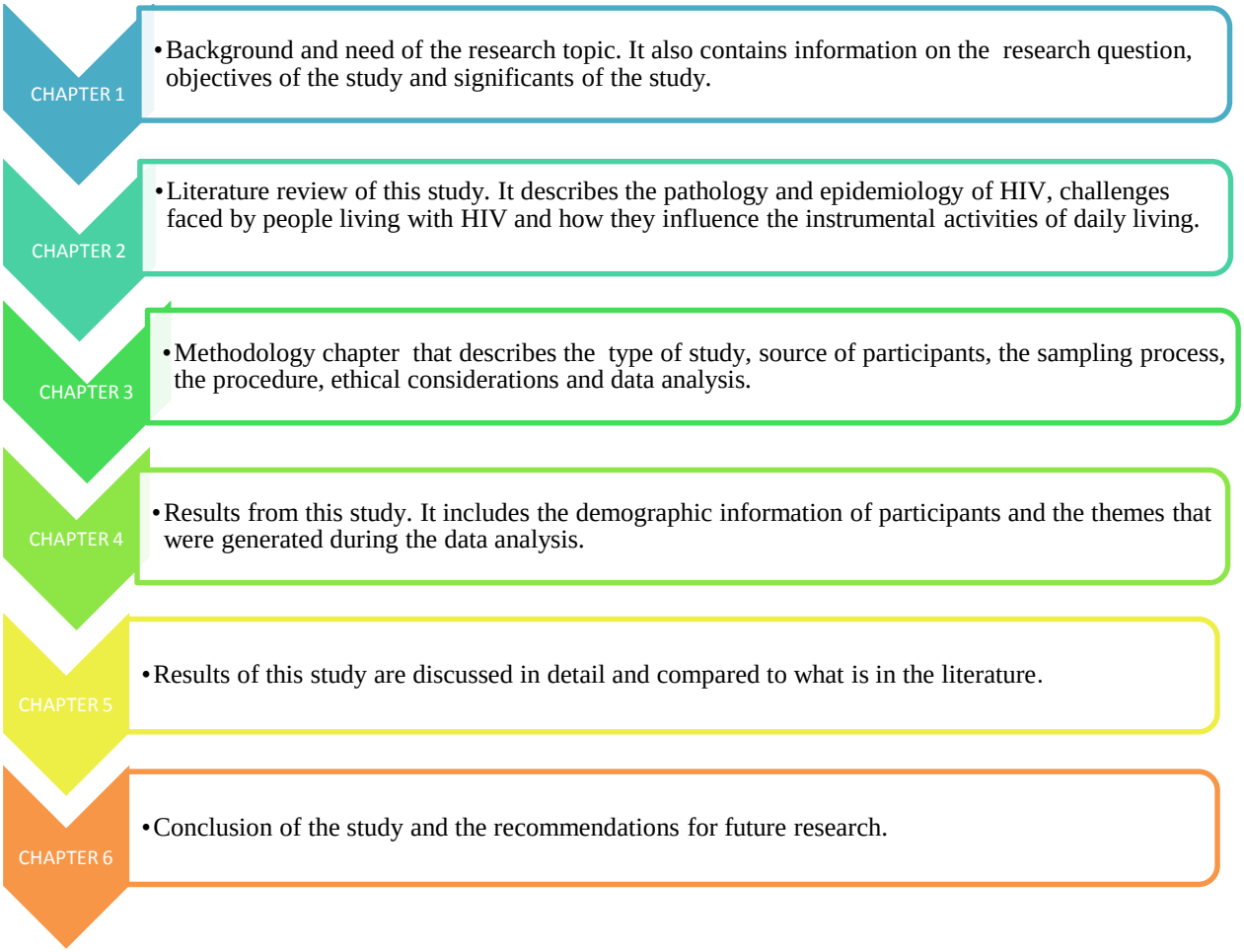



Figure 1.1 Outline of the research report

# CHAPTER 2: LITERATURE REVIEW

## 2.1 Introduction

This literature review describes the pathology of HIV including its definition and the virus progression in terms of its clinical phases. It contains an overview of the epidemiology of HIV in the world, Africa and Malawi. It further highlights the issue of the quality of life of people living with HIV and the impact of ART on Quality of life (QOL). It further describes the challenges that are faced by PLWH focusing on psychosocial and physical challenges and how these may influence instrumental activities of daily living.

To attain this literature review the following databases were consulted: PubMed, Clinical keys, Google Scholar, Wiley online Library, Springer link and Plos one, BMC, and BMJ open. The keywords used in the literature review search included: HIV, ART, discrimination, stigma, physical symptoms, psychosocial factors, leg pain, peripheral neuropathy, depression, and anxiety.

The literature review will follow the following format to present an overview of the research topic. This includes pathology of HIV, epidemiology of HIV, ART regimen, psychosocial challenges faced by PLWH, physical challenges face by PLWH, instrumental activities of daily living (IADLs), and influence of psychosocial challenges on IADLs, the influence of physical challenges on IADLs and quality of life of PLWH.

## 2.2 Pathology of HIV

HIV stands for Human Immunodeficiency Virus, which refers to a pathogen that attacks the body's immune system specifically CD4 cells weakening a person's ability to fight off infection and illness (Klatt, 2020). Weakening of the immune system makes a person prone to infections of the upper respiratory system such as tuberculosis (Majigo *et al.*, 2020). HIV infects many cells in the body which results in the spread of the virus to many organs in the body such as the brain, lungs, spinal cord, and liver (Klatt, 2020). This is general information on the pathology of HIV which is similar for all people in the world.

HIV infection has three phases, the acute, chronic, and AIDS stages, the acute phase is associated with a drop in the CD4+ T cell and an increase in the HIV virema it lasts for six

to nine weeks (Munawwar and Singh, 2020). This phase is characterized by WHO as clinical stage one, this stage is asymptomatic but there is persistent generalized lympodenopathy (WHO, 2005; Klatt, 2020). Phase two is the chronic phase also known as the clinical latency stage two, the infected individual may remain asymptomatic for a long period and others may experience progression and develop symptoms related to HIV infection (Munawwar and Singh, 2020).

In the third stage, the person infected experiences mild symptoms or severe symptoms of AIDS, these symptoms may include progressive weight loss prolonged unexplained diarrhoea, pulmonary tuberculosis, and other opportunistic infections such as Kaposi sarcoma (Klatt, 2020; Munawwar and Singh, 2020). The WHO clinical staging of HIV infection has been adapted by many countries in Africa to classify HIV infection, the same classification is being used in Malawi as a clinical guideline in the management of HIV (Ministry of health and population, 2018).

### 2.3 Epidemiology of HIV

About 37.7 million people are living with HIV in the world (UNAIDS, 2021). In East and southern of Africa about 20.7 million people are living with HIV, with 6.7% adult HIV prevalence, and about 73% of adults living with HIV are receiving ART (AVERT, 2021). Globally 53% of all people living with HIV are women and girls (UNAIDS, 2021).

In Malawi about 1 million plus people are living with HIV, overall, 8.8% of Malawian adults age 15-49 are HIV positive, with a prevalence of 5.7% of HIV and 87% of adults living with HIV are receiving ART (National AIDS Commission (NAC), 2020). The southern region of Malawi has the highest HIV prevalence and Blantyre is among the districts with higher HIV prevalence of 15.7% (Nutor *et al.*, 2020).

In Malawi, the HIV prevalence is higher among women 10.8% than among men 6.4% (National AIDS Commission (NAC), 2020). Similarly to Malawi, other African countries such also have HIV prevalence higher among women than among men (Girum *et al.*, 2018; National AIDS Commission (NAC), 2020; Nutor *et al.*, 2020).

## 2.4 ART regimen

Antiretroviral therapy (ART) drugs refer to the use of a combination of three or more Antiretroviral (ARV) drugs for treating HIV infections (WHO, 2021). In Malawi the standard protocol followed when initiating ART includes: all patients start ART if they have a confirmed HIV infection, they have received counselling, and benefits of ART and prevention of transmission has been explained, patients are given time to reflect and discuss with family if they do not want to start ART immediately (Ministry of health and population, 2018).

Similarly to other African countries where the same procedure is followed and patients are also screened for TB and they start ART immediately or within seven day of diagnosis (Ministry of Health, 2018; South African National Department of Health, 2019). ART are grouped according to regimes, these are first, second, and third-line regimes, this is similar in most of the African countries the only difference is the regime names and numbers that are used in these countries (Ministry of Health, 2018; Ministry of health and population, 2018; South African National Department of Health, 2019).

In Malawi, the following regime names are used regimes zero, two, five, six, seven, eight, nine, ten, twelve, thirteen, fourteen and fifteen (Ministry of health and population, 2018; Ministry of Health and Population, 2019). Dolutegravir (DTG) is a first line drug that is used in the regimes 13A, 14A, and 15A, the 'A' stands for adult, it is used in women who may get pregnant while on ART, it increases viral suppression, lowers the risk of maternal deaths, reduces HIV transmission to sexual partners and it lowers the risk of potential neural tube defects (Ministry of Health and Population, 2019).

DTG is used as first-line regimen in Uganda and South Africa respectively, the drug is used for all HIV infected clients, children, adolescents, men and women, including pregnant women (Ministry of Health, 2018; South African National Department of Health, 2019). DTG has the following potential side effects: insomnia, headaches, central nervous system(CNS) effects, gastrointestinal such as diarrhoea, agitation, weight gain, and skin rash (Ministry of Health and Population, 2019; South African National Department of Health, 2019).

In Malawi, DTG based regimens are standard first-line regimens for all patients 20kg+ including girls and women who may get pregnant and five-A is used as the alternative standard first- line regime for girls who may get pregnant while on ART (Ministry of Health and Population, 2019). Regimen five-A contains the following drugs, Tenofovir Disoproxil Fumarate (TDF), Lamivudine (3TC), and Efavirenz (EFV), the potential side effects are renal failure, hepatitis, rash, psychosis, persistent dizziness, and visual disturbance (Ministry of health and population, 2018).

Regime 13A is the standard first-line regimen for males 30kg or above and women who may get pregnant while on ART, it contains TDF,3TC, and DGT, the potential side effects include insomnia, fever, body pains, vomiting, cough, headaches, nauseas and diarrhoea (Ministry of health and population, 2018; Ministry of Health and Population, 2019).

In some cases HIV infected individuals are initiated on a drug called Cotrimoxazole Prevention Therapy (CPT). CPT is used to prevent Pneumocystis Carini Pneumonia (PCP), diarrhoea, malaria and other HIV-related diseases (Ministry of Health and Population, 2019). CPT is used in all children under the age of one year irrespective of their CD4 % or clinical stage, may also be used in adults with CD4 of more than or equal to 200 who are in WHO stage two, three and four clinical stage (South African National Department of Health, 2019). The potential side effects of CPT are not documented in the guidelines, both from Malawi and South Africa, which means there is need to identify if any side effects are experienced by PLWH from this drug.

These side effects of ART affect PLWH physically, emotionally and psychosocial wellbeing hence impact on the quality of life (de los Rios *et al.*, 2021). Poor adherence to ART has been shown to lower the quality of life, promoted poor health outcomes, and limit day-to-day life among PLWH (Desta, Biru, and Kefale, 2020; de los Rios *et al.*, 2021).

### 2.5 Psychosocial challenges faced by PLWH

PLWH experience many psychosocial reactions that come as a result of discovering their HIV status, effects of medications, uncertainties regarding how the disease is going to affect their life, jobs, and social life, the fear of physical deterioration and death (Basha *et al.*, 2019;

Adeniyi *et al.,* 2021). PLWH may experience psychological or mental distress and may present with psychiatric symptoms such as anxiety, depression, stress, hallucinations and confusion (Basha *et al.,* 2019). Similar reports of depression have been reported by PLWH in Malawi, women living with HIV reported that depression was associated with HIV diagnosis, marital problems, and worries about how to raise children alone (LeMasters *et al.,* 2020). Adolescence living with HIV (ALHIV) also reported that they felt angry and depressed as they were living with HIV in the community (Kaunda-Khangamwa *et al.,* 2020).

The prevalence of psychological distress was high in PLWH and was associated with being female and perceived stigma (Basha *et al.,* 2019). Fear of stigma and discrimination has been perceived by PLWH and it is associated with non-disclosure behaviours among PLWH in the world (Adeniyi *et al.,* 2021; de los Rios *et al.,* 2021). PLWH are afraid of disclosing their HIV status to their close friends, partners, family, co-workers and people around them, because they are not ready to disclose of their status due to fear of rejection, relationship break up and receiving judgmental attitudes from partners (Carbone *et al.,* 2019; Adeniyi *et al.,* 2021; de los Rios *et al.,* 2021).

Similarly in Malawi, PLWH expressed that they could not disclose their HIV status to partners due to fear of the reaction from the partner and they were afraid that they will end their relationship and tell other people of their status (Hino *et al.,* 2018). It was noted that ALHIV in Malawi were avoiding disclosing their HIV status to boyfriends as a way of avoiding emotional stress that comes as a result of disclosing HIV status (Kaunda-Khangamwa *et al.,* 2020).

Stigma and discrimination have been reported by many people living with HIV in Africa including Malawi (Trócaire and ZNNP+, 2019). HIV-related stigma is defined as discounting, discrediting, and discrimination directed towards people living with HIV in the community, families, and individual groups (U *et al.,* 2015). Due to stigma, PLWH will disconnect themselves from the world, withdraw from society in fear of being stigmatized (Basha *et al.,* 2019). In work places employees are afraid of disclosing their status due to fear of being stigmatised and discriminated by co-workers, stigma has created hostile work

environment filled with rumours and gossips leading to loneliness and isolation (Twinomugisha, Ottem and Daniel, 2020).

In Malawi, stigma and discrimination has been perceived by PLWH from relatives, friends, partners and people in the community. Women living with HIV have reported that they felt stigmatized and unsupported by their partners after disclosing their HIV status and others were afraid of taking ART due to fear that their partner will know of their status as such they could stigmatise them (Chirambo *et al.*, 2019; LeMasters *et al.*, 2020). ALHIV have also reported that they felt stigmatised and discriminated by family and friends as such they were excluded from interacting with relatives and others opted of living alone because they were afraid of being stigmatised by friends (Kaunda-Khangamwa *et al.*, 2020).

PLWH are involved in different types of work it could either be paid employment or self-employment. The paid employment involved may be permanent, fixed term, short-term or casual, part-time and paid apprentices, trainees and internships (Development, 2015). In the world of work, PLWH experience many challenges, they have reported of having difficulties with getting a job and disruption in career progression after being infected with HIV (Norbalkish *et al.*, 2021).

PLWH felt uncomfortable to be around colleagues due to changes in physical appearances after being infected with HIV, other felt they were being isolated by other as such they isolated themselves which later made them develop inferiority complex (Moyo, 2019; Norbalkish *et al.*, 2021). Stigma and discrimination was reported by PLWH in workplace, they felt that their colleagues speculated about their health and avoided them in fear of contracting HIV/AIDS (Moyo, 2019).

On HIV-related workplace stigma, not much has been document in Malawi. A policy was developed in 2010 that protects the rights of PLWH in workplaces but it was not implemented, the current HIV/AIDS strategic plan is aiming at strengthen and protecting the rights of PLWH in workplaces and involvement into programs that support PLWH (National AIDS Commission (NAC), 2020). There is need for identification of challenges that PLWH

face in workplace in Malawi and if there any policies that employers are using to protect the rights of PLWH in their workplace.

### 2.6 Physical challenges faced by PLWH

There are many physical symptoms that PLWH presents with at the ART clinics symptoms present are either directly or indirectly associated with HIV infection. PLWH may experience side effects of HIV medication such as dementia, neurological disorders, gastrointestinal disorder ( stomach upset, pain or diarrhoea) and difficulties with swallowing pills (De Los Rios *et al.*, 2021).

In Malawi the following are some of the side effects of HIV medication that have been reported by PLWH includes: dizziness, nausea, vomiting, night mares and hallucination (Kim *et al.*, 2016). The side effects of ART experienced are different for every individual depending on the regimen that they are on and compatibility of the ART with their body.

Pain and dizziness has also been reported in other countries in Africa including Malawi, the pain may present as headaches, gastrointestinal, musculoskeletal, and peripheral neuropathy (Wilson *et al.*, 2016; Renju *et al.*, 2017). Headaches are common potential side effect for most of the ART regimens that are used in Malawi for example 13A and neuropathy is a side effect of 12A regimen which is the second-line regimen used (Ministry of health and population, 2018).

Dizziness presents as direct or indirect effects of HIV on the vestibular system and as a side effect of ART (Wilson *et al.*, 2016; Khoza-shangase and Rie, 2017; Renju *et al.*, 2017). Dizziness is a possible adverse reaction of five-A regimen that is used as a standard first – line regimen for girls and women who may get pregnant while on ART in Malawi (Ministry of health and population, 2018).

Fatigue is the most common symptom in PLWH (Gebreyesus *et al.*, 2020). It is defined as a "subjective unpleasant potentially disabling symptom characterized by physical or psychological exhaustion experienced both acutely and chronically, results impaired function" (Joseph Perazzo, Allison Webel, Joachim Voss, 2018). It is mostly associated with stage two to four of HIV infection WHO classification (Gebreyesus *et al.*, 2020). Depression

and anxiety are the main factors associated with fatigue (Joseph Perazzo, Allison Webel, Joachim Voss, 2018; Baye *et al.*, 2020; Gebreyesus *et al.*, 2020).

In Malawi fatigue is one of the potential symptom that PLWH may experience while taking ART but it is associated with other symptoms such as muscle ache or joint pains, headaches, dizziness, numbness, nausea or vomiting, blurred vision, body weakness, skin rashes (Ministry of health and population, 2018). Reports of fatigue have been raised by PLWH in Malawi, the fatigue is associated with being tired of taking ART labelled as ART fatigue (Chirambo *et al.*, 2019). There is limited information on how fatigue presents and is experienced by PLWH in Malawi, creating a gap to identify if indeed PLWH experience fatigue.

Peripheral neuropathy (PN) is another symptom reported by PLWH (Puplampu *et al.*, 2019). It manifests as numbness of feet, tingling or burning pain, and muscle weakness (Armstead, 2019). Patients who report these symptoms are more likely to report having fatigue (Gebreyesus *et al.*, 2020). Numbness in the feet is one of the side effects reported by women living with HIV in Malawi (Phiri *et al.*, 2018). PLWH may experience HIV-co infections such as tuberculosis (TB) due to the weakened immunity, in Malawi, 48% of TB cases are HIV- related (National AIDS Commission (NAC), 2020).

### 2.7 Instrumental activities of daily living (IADLs)

The description below will give a general overview of the definition of IADLs and its components. These components can be affected in all people being it HIV positive or HIV negative.

Instrumental activities of daily (IADLs) living are defines as "activities that allow an individual to live independently in a community", the major domains of IADLs include cooking, cleaning, transportation, laundry, and managing finances (Guo and Sapra, 2020). People living with HIV are living longer and may experience the processes of normal aging just as the HIV-negative individuals. They may experience problems with their cognition associated with aging which may affect the IDALs of PLWH (Johs *et al.*, 2017).

Housework, laundry, transportation, and shopping are the most common reported difficulties that PLWH reports upon assessment of IADLs impairments (Johs *et al.*, 2017; Siegler, Moxley, and Glesby, 2021). Lower physical activity, neurocognition impairments, fatigue, frailty, and weight loss are associated with impaired IADLs in middle- age and older individuals living with HIV (Johs *et al.*, 2017; Siegler, Moxley, and Glesby, 2021).

### 2.8 Influence of Psychosocial challenges on IADLs

People living with HIV experience many psychosocial challenges that includes discrimination, stigma, anxiety, and depression. Discrimination affects people's relations as such family and friends tend to change how they relate to each other when they discover a person's HIV status (Mhode and Nyamhanga, 2016). Discrimination has an impact on a person's health since it leads to poor adherence to ART (Fatoki, 2016).

People living with HIV may experience stigmatization and discrimination from people which results in low self-esteem and social isolation (Turan *et al.*, 2018). Stigma makes people feel inferior and lose value in the communities (Fatoki, 2016). In Malawi, stigma has affected people living with HIV negatively as such it inflates the spirit of fear to seek medical help (Chirambo *et al.*, 2019). HIV- related stigma has led to the development of depression in women living with HIV in Malawi and it has led to adolescences being lonely due to stigma (Kaunda-Khangamwa *et al.*, 2020; LeMasters *et al.*, 2020).

PLWH isolated themselves in workplaces due to fear of stigma and discrimination this lead to developing inferiority complex (Moyo, 2019; Norbalkish *et al.*, 2021). Failure to get support in workplace has led to deterioration of health of PLWH and has caused psychosocial distress and depression (Moyo, 2019). In workplaces, stigma is the cause of the deprivation of job opportunities and it creates a hostile environment for employees and has led to the loss of potential employees (Twinomugisha, Ottem, and Daniel, 2020). Literature is lacking from Malawi describing how stigma has impacted PLWH in the workplaces.

Anxiety and depression are common mental disorders that PLWH encounter and it has direct and indirect effects on the adherence of medication and health (Camara *et al.*, 2019). It affects the emotional, sexual relationships, and social interaction among PLWH which

results in withdraw from social activities (Tran *et al.*, 2019). Depression increases the chances of unemployment among PLWH (Bernard *et al.*, 2020).

PLWH who have reported having psychological distress such as anxiety and depression have reported that they have challenges taking their HIV medication daily and this lead to poor health outcomes and limits their day-to day life (de los Rios *et al.*, 2021). In Malawi literature on how these psychological distressing factors interferes with one's day-to-day is missing and there is need to identify the link.

### 2.9 Influence of physical challenges on IADLS

Fatigue has a direct or indirect impact on the activities of the daily life of PLWH (Gebreyesus *et al.*, 2020). It limits activity by restricting the performance of physical exercise and involvement in leisure activities (Joseph Perazzo, Allison Webel, Joachim Voss, 2018; Gebreyesus *et al.*, 2020). It affects motivation and leads to self-isolate from social activities (Baye *et al.*, 2020). There is a gap in information on how fatigue influenced day-to day life of PLWH in Malawi, hence need for identifying how it impact on their lives.

Dizziness interferes with the participation of PLWH at work, in social activities and it leads to difficulties with walking and reduces physical activity levels (Khoza-shangase and Rie, 2017). In African countries including Malawi, it has been documented that PLWH experience dizziness, headaches, and pain which limits participation in outdoor activities and self-care or caring for family members (Renju *et al.*, 2017). While neuropathies such as pain, numbness, burning sensation affect the lower extremities which result in reduced sensation that impairs a person's ability to walk (Puplampu *et al.*, 2019). The pain reported limits an individual to participate in activities.

In Malawi, the side effects of ART has made PLWH to feel weak which makes them unable to do basic household chores which are a major component IADLs. Not much has been documents how these side effects interferes with the day-to-day life of PLWH.

### 2.10 Quality of life of PLWH

Quality of life (QOL) has four main domains that include Mental and Physical health, communication, and functional autonomy (Ghiasvand *et al.*, 2019). PLWH present with

problems in the QOL in line with the general functioning of the body and satisfaction with life (Sharifi *et al.*, 2019). HIV-affected patients suffer from physical problems that range from side effects of ART to opportunistic diseases. Not only do they experience this they also face challenges of stigma, discrimination, misjudgement from the society that may negatively impact their QOL (Ghiasvand *et al.*, 2019).

ART has shown a positive impact on PLWH, it has been shown to improve their QOL through many ways, for example, living a healthy life without being sick and fewer chances of getting opportunistic infections if the medications are adhered to (Yaya *et al.*, 2019). The above information gives a general outlook of quality of life of PLWH in African as well as other countries in the world.

### 2.11 Conclusion of literature review

The literature review identified psychosocial and physical challenges that PLWH experiences such as discrimination, stigma, anxiety, fatigue, pain, dizziness, and peripheral neuropathy. These challenges experienced have an effect on household chores, work, mobility, and social interaction which affects the quality of life of PLWH.

The literature review has shown that PLWH do experience psychosocial and physical challenges regardless of the continent that they belong to. It has highlighted that there are gaps in literature that show how the challenges experienced interfere with lives of PLWH in Africa as well as in Malawi. Therefore there is a need to identify if similar or new challenges experienced by PLWH in Malawi.

The review has shown that work, mobility, and social interaction are IDALs that are affected in PLWH in Africa as well as Malawi. There is need to identify how these challenges experienced interferes with other components of IADLs such as transportation, handling finances, cooking, and laundry, and identify if there other aspects of daily living that are affected by the lived experienced. Therefore this study will help with filling the gap that is not known in literature on how psychosocial and physical factors influence IADLs of PLWH in Malawi.

# CHAPTER 3: METHODOLOGY

## 3.1 Introduction

In this chapter, the methods of the study will be described in detail. This will include the study design, study population, study setting, sample size selection, inclusion and exclusion criteria, data collection tools, a procedure that includes the preliminary study and main study, and ethical consideration. The interviews were done in the participant's home language which is Chichewa. The process of transcription and translation was done by a colleague who is a physiotherapist working as a lecture at University of Malawi, College of Medicine, who has Chichewa social linguistic abilities.

## 3.2 Study design

This was a qualitative study that used a pre-interview questionnaire and semi-structured interviews.

## 3.3 Study population

Study participants were men and women living with HIV and receiving ART at the lighthouse ART clinic.

## 3.4 Study setting

The study participants were sourced from the lighthouse ART clinic, located at Queen Elizabeth Central Hospital, in Blantyre. This is the main referring hospital and it has a major ART outpatient clinic that services all residents of Blantyre and all districts in the southern region of Malawi.

## 3.5 Sample Selection

Purposive sampling was used to select participants in the study based on the three stages of HIV (WHO, 2005). This technique was used to identify and select information-rich participants with experience related to the research (Palinkas *et al.*, 2016). Semi-structured interviews were done until data saturation was reached. The aim was to get an understanding of their experiences within a homogeneous group of people.

Fourteen semi-structured interviews were aimed at until data saturation was reached. Guest and Johnson (2006) and Turner-bowker *et al.*, (2018) recommended 10 to 12 interviews to

be sufficient to reach saturation for a qualitative study that has a relatively homogeneous population that is sampled purposively.

Guest and Johnson (2006) defined saturation as the point at which no new information or themes are observed in the data from the completion of additional interviews or cases. They further said that the more similar participants in a sample are in their experiences concerning the research domain, the sooner they would expect to reach saturation. In qualitative, with practical research, it has been illustrated that a sample size of 12 may be cases where theoretical data saturation occurs among a relatively homogeneous population (Sim *et al.*, 2018).

### 3.5.1 Inclusion Criteria

- PLWH on ART from Lighthouse ART clinic located at Queen Elizabeth Central Hospital Blantyre, Malawi.
- Individuals/people between the age of 18 and 60 years
- PLWH in any of the following HIV infection stages: stage one, two, three and four clinical stage of HIV infection based on World Health Organisation (WHO) classification. WHO stage one: asymptomatic stage: the infected individual is asymptomatic but the HIV virus continues to replicate in the blood and the immunity fights it and patient presents with generalised lympodenopathy (Ministry of health and population, 2018). WHO stage two: mild symptoms: the infected individual has mild symptoms and presents with recurrent respiratory tract infections such as sinusitis, herpes zoster, oral ulcerations and unexplained moderate weight loss. WHO stage three: advanced symptoms: the immunity become weak and patient presents with persistent and unexplained fevers, pulmonary tuberculosis, unexplained anaemia, severe weight loss, chronic diarrhoea, severe bacterial infections such as pneumonia and meningitis. WHO stage four: the immune system has weaken and opportunistic infections are manifesting: infected individual presents with pneumocystis pneumonia, candidiasis of oesophagus, trachea, bronchi or lungs, extra pulmonary tuberculosis, Kaposi's sarcoma, HIV encephalopathy, Cryptococci meningitis, and HIV wasting syndrome (Ministry of health and population, 2018).

The age range helped identify participants that were mature, independent and had experience living with HIV. This group of participants provided key information on their experience and how they had coped living with HIV.

### 3.5.2 Exclusion Criteria

- Those who had conditions that may affect IADLs other than HIV/AIDS for example stroke, Parkinson's disease.
- Those that were hospitalized for any reason during the time of the study.

## 3.6 Data collection tool

A Pre-interview questionnaire (Appendix A) was established to collect demographic data of participants for example age, gender, marital status, HIV duration, ART duration, occupation. The HIV duration is defined as the period from the initial diagnosis of HIV to the current date and ART duration is defined as the period between the initial start of taking ART to present date. The interview guide (Appendix B) was developed in English based on the objectives of the study then translated from English to Chichewa (with the help of a person with Chichewa social linguistic abilities).

Content validation of the interview questions was done by two researchers with experience in HIV-related research, one from the University of Malawi and one from Lighthouse research Centre, Queen Elizabeth Central Hospital, Blantyre Malawi. Two experienced researchers were consulted to assess and validate each question against the aims and objectives of the study.

Questions were rearranged to provide clarity and flow and were sent to the supervisor for final endorsement. The semi-structured interviews were tape-recorded using a cell phone application and notes were taken for all tape-recorded interviews.

## 3.7 Procedure

### 3.7.1 Preliminary study

A preliminary small-scale study was done before the main study to test the research questions and the researcher to obtain experience in conducting interviews (Aliff *et al.*, 2017). To establish how long it took to conduct one interview and identify any problems or

limitations within the interview design that allow necessary modifications and determine if indeed the participants would answer the questions (Castillo-Montoya, 2016).

Permission to access the participants for both preliminary and main studies was obtained from the Hospital Director of Queen Elizabeth Central Hospital (Appendix C). Two PLWH on ART that was within the three stages of HIV infection (stage 1, 2, and 3) and was between the ages of 18 to 60 years and was receiving care at Lighthouse ART clinic, were recruited in the preliminary study.

One male and female who met the inclusion criteria were purposively selected for the study. Participants were given information documents about the research, aims, and what to expect during the study. Two people who were willing to participate in the study were given a consent form (Appendix D) for interviews and tape recording (Appendix E) to sign. For confidentiality the participants were identified by a number, the key to where these numbers were stored was kept by the researcher.

The participants were interviewed in a quiet room at the Physiotherapy department within Queen Elizabeth Central Hospital at their convenient time. The researcher recorded the participant's demographic data using the pre-interview questionnaire and conducted the semi-structured interviews using the interview schedule questions in the participant's home language.

The research assistant (Nurse) was taking down notes of the interview and observations noted from the participants during the interview process. The interviews were tape-recorded and notes were taken for the tape-recorded interviews. Interview notes were read out to them to check if what was written was what they said.

Data were analyzed using thematic content analysis, which used inductive data processing. The data analysis was done manually by the principal investigator using Microsoft word. Audio files were transcribed and combined with notes, then translated from Chichewa to English and translated from English to Chichewa. The interview transcripts were cleaned by listening to check if all information was captured correctly.

The principal investigator read the individual transcripts many times to get an understanding of the information and immersed it into the information, word by word. Similar words were identified and grouped according to similarities. Codes were developed from words that had a similar meaning. The themes were searched from the coded data by sorting different codes into potential themes. Themes were interpreted to give meaning. The process of data analysis was done manually using Microsoft word by the principal investigator.

From the preliminary study, the researcher gained experience in conducting an interview. Participants were able to understand the questions since they were in their home language and were able to answer. It took about 30 minutes to conduct one interview. No limitations were identified from the interview guide and questions hence no changes were made to the procedure and the data was used in the main study.

### 3.7.2 Main Study

One research assistant was recruited and appointed, she was responsible for taking down notes and observing the participant's behaviour during the interview, identifying participants at the Lighthouse ART clinic, and determining if they met the inclusion criteria. The data were collected for four months, from 23$^{rd}$ March to 15$^{th}$ June 2020. The same procedure that was used to recruit participants in the preliminary study was followed in the main study.

### 3.7.3 Trustworthiness

These are processes that are followed to ensure that the findings of a qualitative research study are trustworthy (Korstjens and Moser, 2018). Korstjens and Moser, (2018) described the following criteria to ensure the trustworthiness of results; credibility, transferability, dependability, and confirmability.

To ensure the credibility of the results, member checks were done. Participants were called on the phone to check if the codes were developed from the transcripts matched with their own words and they reflected what they intended to say and their experiences. This ensured that the results were accurate. The study process was described in detail to ensure that it is easy to follow and could be done in other settings.

For confirmability and dependability, the research steps that were followed from the start through to the development and reporting of the findings were described (Korstjens and Moser, 2018). Audio files, interview notes, transcribed transcripts, translated transcripts, analysing notes (similar color notes, groupings), and coding notes, theme developing notes, and interpretation notes. The codes were given to a person with experience in HIV research to confirm them.

These notes were provided to the supervisor for an audit trail, to ensure that the results are originating from the raw data. A diary was kept to record reflective notes, thus everything that was happening starting from the contact with the participant, to the interview process, to all decisions that were taken during transcribing of the audio files, to analysing of the transcripts. All decisions were taken during the development of codes, themes, and interpretation of results. The diary was sent to the supervisor along with the raw data.

### 3.8 Ethical Considerations

Ethical clearance was granted from the Human Research Ethics Committee of the University of the Witwatersrand (M190976) (Appendix F) and the University of Malawi, College of Medicine, Research Ethical committee (P.11/19/2888) (Appendix G). Permission to access the participants was obtained from the Hospital Director, Queen Elizabeth Central Hospital. Information documents (Appendix H) were available for participants, explaining the study.

Informed consent was obtained from participants before the interviews. Participation in the study was voluntary as such participants were free to withdraw from the study at any time and there were no consequences. The information obtained during interviews was used only for the study. There were no benefits and risks to participating in the study.

Participant's information was kept confidential as such names were not used. A letter was assigned to the participant and the key to the letter was stored by the researcher. Audio files were stored in a locked file in a password-protected computer. Transcripts were stored in a locked cabinet in the Physiotherapy department located at Queen Elizabeth Central Hospital, Blantyre, Malawi.

### 3.9 Data Analysis

Data were analyzed manually using a thematic analysis process which involved identifying, analysing, and reporting patterns/themes within data (Braun and Clarke, 2006). Thematic analysis is the realist method that reports experiences, meanings, and reality of participants, and it examines how events realities, meanings, experiences, and so on are the effects of a range of disclosure operating within society (Braun and Clarke, 2006). Themes or patterns were identified using an inductive approach where the identified themes were strongly linked to the data themselves (Braun and Clarke, 2006).

Audio files were transcribed and translated from Chichewa into English and translated back from English to Chichewa by help of a person with Chichewa social linguistic abilities. The interview transcripts were cleaned by listening to check that all the information had been captured correctly. Individual transcripts were read many times to familiarize with the data and to get an understanding of the information and immersed into the information, word for word. All the transcripts were checked if the information provided had reached saturation or not.

Notes were made from each transcript, data was broken down into chunks of information, and those with similar words were grouped and labelled with a similar color. Similar words were identified and grouped according to the similarities. Codes were developed from words that had a similar meaning.

For validation of the codes, raw transcripts were sent to an experienced researcher in the field of HIV to develop codes and themes without any influence from the primary investigator. The transcripts with codes and themes were sent directly to the supervisor and the codes developed by the primary investigator were also sent to the supervisor.

The supervisor compared the codes and check for similarities within the codes. The validated codes were compiled and sent back to the primary investigator to develop themes. Themes were developed from the validated codes and interpreted to give meaning.

### 3.7 Conclusion of the methodology

This chapter described all the processes that were taken to conduct this study. It has highlighted how participants were recruited, how interviews were conducted and how long it took to conduct an interview, and how the raw data was processed until the themes were developed.

## CHAPTER 4: RESULTS

### 4.1 Introduction

The demographic details of the study participants and themes that emerged from data analysis of the fourteen interviews are presented in this chapter. Themes and categories will be presented based on the objectives of the study and the interview questions. The quotes provided are interpreted to give clarity and meaning to what the participant was trying to communicate.

### 4.2 Participants Demographic information

A total of fourteen people participated in this study representing seven males and seven females. Figures 4.1 to 4.4 presents the profile of the participants based on age group, gender, relationship status, occupation, HIV, and ART duration in years. Figure 4.1 shows the participant's age groups to gender.

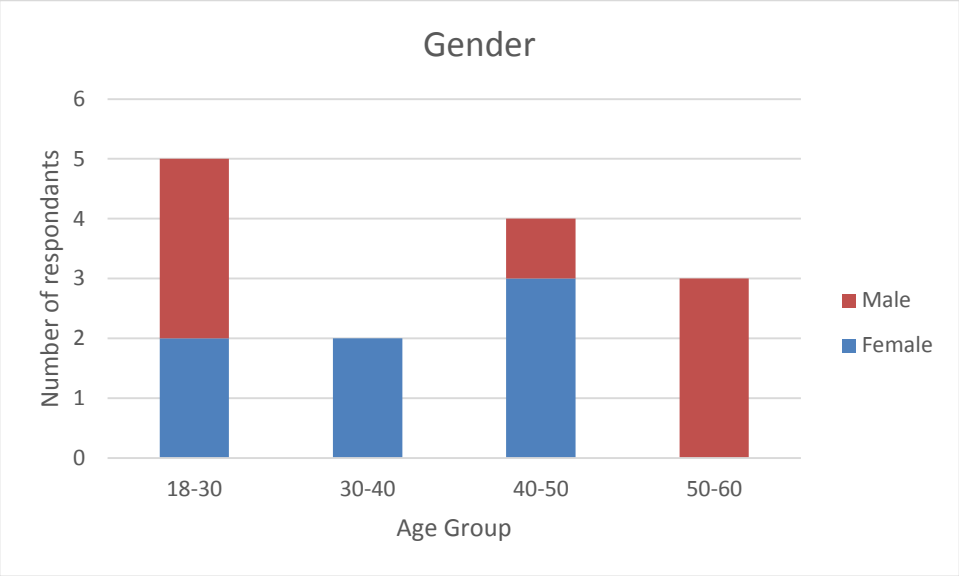



Figure 4.1 - Age group by Gender (N=14)

The majority of the females were in the 40 to 50 years age group and there was an equal number of male participants in the 18 to 30 and 50 to 60 age groups respectively. The age group 30 to 40 years have female participants only. The relationship status of the participants is presented in figure 4.2.

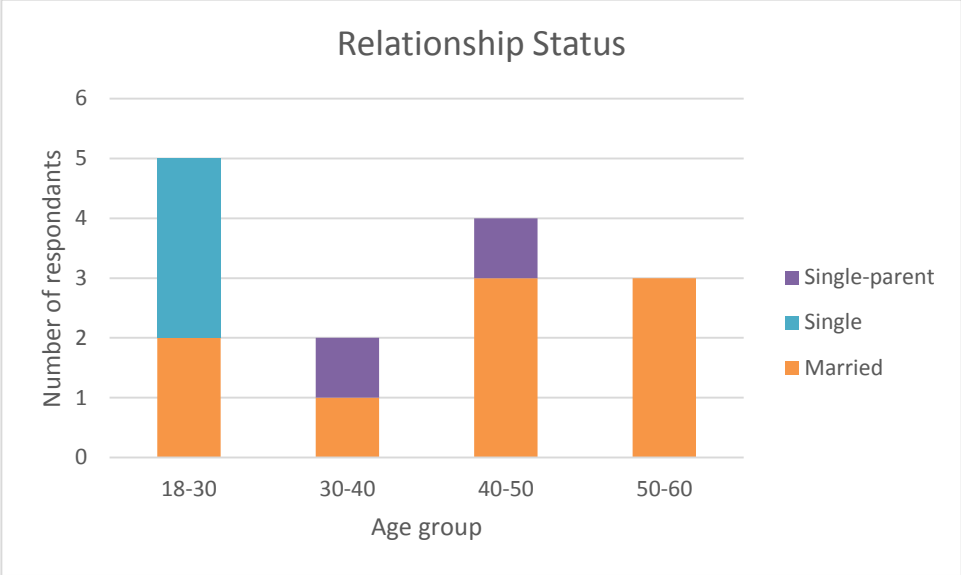



Figure 4.2 - Age group by Relationship status (N=14)

The majority of the participants were married and two of the participants were single-parent presented in the age groups 30 to 40 years and 40 to 50 years and four participants were single in the age group 18 to 30 years. Figure 4.3 presents the occupation of participants.




Figure 4.3 - Age group by occupation (N=14)

The majority of the participants were employed as shown in all the age groups and four of the participants were unemployed. Figure 4.4 shows the type of employment of participants.

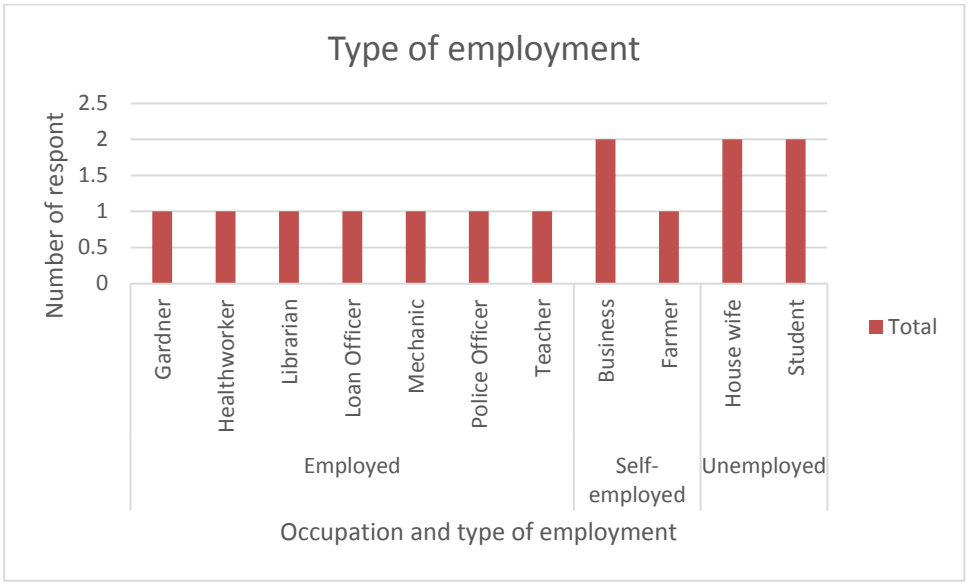



Figure 4.4 – Occupation by type of employment (N=14)

There was a diversity in the type of employment that participants were involved in in the employed category. Two of the participants in the category of unemployed were housewives and two were students and in the category of self-employed two were doing business and one was a farmer. Figure 4.5 the HIV and ART duration for the participants.

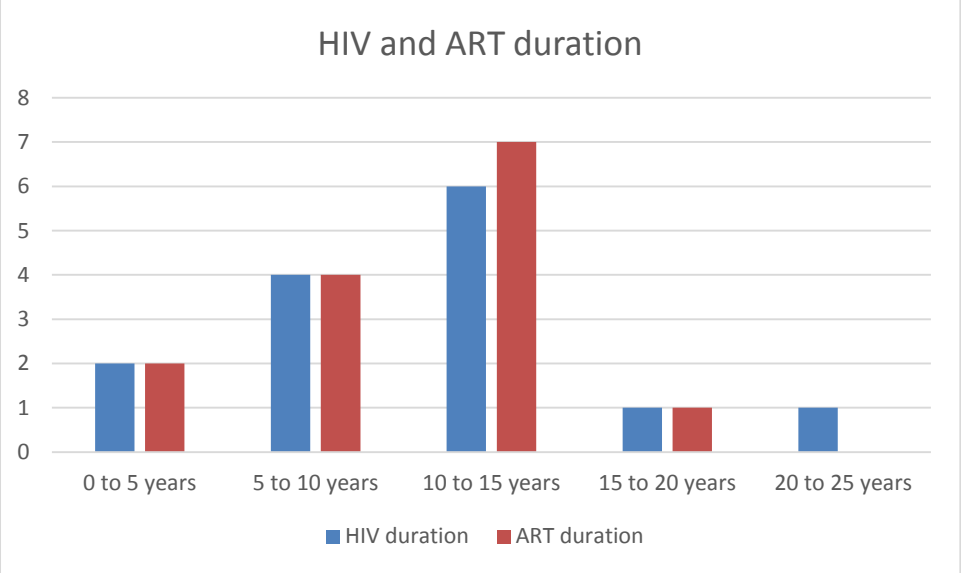



Figure 4.5 –HIV and ART duration (N=14)

The HIV and ART duration was the same for most of the participants except in 10 to 15 years, which shows seven of the participants had an ART duration of 10 to 15 years. One participant had an HIV duration of 20 to 25 years but with a lower ART duration.

### 4.3 Psychosocial challenges

Table 4.1 shows the themes, categories, and subcategories under the psychological challenges faced by PLWH.

*Table 4.1 Psychological Challenges*

| Themes | Categories | Subcategories |
|---|---|---|
| 1. Discrimination | a. From relatives<br>b. From people<br>c. From secondary school<br>d. From home<br>e. Self-discrimination<br>f. Consequences of discrimination | a. Depression |
| 2. Acceptance of HIV status | a. Own acceptance<br>b. Someone else acceptance | |
| 3. Stigma | a. From people<br>b. Due to yellow eyes | |
| 4. Anxiety and Worries | a. Anxious about living with HIV<br>b. Anxious about being sickness<br>c. Anxious because of stigma<br>d. Worried about life<br>e. Relatives worried for you | |
| 5. Memory loss and mental problems | a. Forgetting | a. At work<br>b. At home |
| 6. Loss of hope | a. HIV is a punishment for sin<br>b. Being unhappy due to HIV<br>c. HIV is the end of life<br>d. Feeling ashamed | |

### 4.3.1 Discrimination

Discrimination was one of the major themes that emerged from the transcripts. Discrimination was perceived by people and relatives once they knew the participants' HIV status. Fear of discrimination in secondary school led to not taking ART and depression and self- discrimination were also reported.

*"Ok in terms of my relatives and family members, it was my step-grandmother and step-brother who showed that they were discriminating against me" Participant X*

*"Upon knowing my HIV status, my relatives gave me cooking utensils to be using, it seems that they had a miss-conception of HIV" Participant E*

*"Another problem was being afraid of discrimination, at that time I was in boarding school. I did not want people to know that I take ART because if they knew, they would be discriminating me… this affected me, I was depressed" Participant E*

*".....in the group of those that are not HIV positive, you start discriminating yourself while your friends are not discrimination you" Participant M.*

### 4.3.2 Acceptance of HIV status

Acceptance of own HIV status was easier for most of the participants, about four of the participants had difficulties in accepting their status. Three of the participants were able to accept their status but faced problems with their partners who refused to go get tested and four reported that relatives accepted their status.

*" I did not have any problems accepting my HIV status, I went home and told my family members…but my husband did not accept that I was HIV positive and up to now I do not know his HIV status" Participant W*

*"The first problem was to accept that I am HIV positive and start HIV medication" Participant M*

*"I told my husband and my family members that I have HIV. It was difficult for my husband to accept that I have HIV" Participant D*

*"…your body looks good since you started taking ART, one of my relatives said. Since my relatives accepted my HIV status, I was able to accept my own HIV status" Participant B*

### 4.3.3 Stigma

Stigma was perceived by people in the community and at work.

*"Now I just accepted myself, even when people talk behind my back, I would let them talk since they are not God, I have already accepted my status" Participant C*

*"After I was found with HIV, I had side effects from the ART I was getting, they just changed it to 8A. 8A made my eyes yellow, so at work when my colleagues noticed the change in the color of my eyes, they knew that I was taking ART thus when they started talking behind my back" Participant D*

### 4.3.4 Anxiety and Worries

One participant was anxious about living with HIV due to financial problems, she also felt anxious due to sickness and her relatives were worried for her when she was sick. One participant was worried when people talked about their HIV status, even though they were born with it (perinatal acquired HIV).

*"I have met a lot of problems as I live my day-to-day life. I live an anxious life because of my current status. This life needs one to be doing some business to support the change that I am experiencing… my relatives become worried if they see that my body is changing, they become anxious, saying what is happening with our sister, this makes me anxious and worried" Participant B.*

*"Ok it was affecting me because it was like people were treating me as if I wanted to have HIV, but I was born with it. So I was worried because of the way people treated me." Participant E*

### 4.3.5 Memory loss and mental problems

Memory loss was reported by two of the participants, this was in the form of forgetting what they were supposed to do either at home or work. One participant felt mentally not ok with how they were behaving.

*"When I get into the office, I forget where I was supposed to start from … at home I would miss-match activities that I would do in the evening I ended up doing them in the morning, mentally I was not ok " Participant M*

*"What bothered me was for getting up to now I still forget. I would go to my bedroom to get something once I open the door to the bedroom had already forgotten what I was supposed to get from the room" Participant K*

### 4.3.6 Loss of hope

Three of the participants lost hope in life and felt that having HIV was like being punished for sin and it was the end of life.

*"At first it was very difficult for me to accept my status, I accepted because I got tested. I thought about my life, I will be taking drugs daily, I felt like it was a punishment" Participant T*

*"Knowing my status affected my work, I could not prepare to go to work in good time. Sometimes I will be in my room sleeping or thinking about life and I thought being HIV positive was the end of life" Participant Z*

*"At home when they told me I have the virus (Perinatal acquired HIV), for few days I was not happy but accepted it and they told me that it was not the end of life, then I removed all the thoughts and I started living a happy life." Participant E*

## 4.4 Social challenges

Table 4.2 shows the themes, categories, and subcategories under the psychosocial challenges by PLWH.

*Table 4.2 social challenges*

| Themes | Categories | Subcategories |
|---|---|---|
| 1. Experiences in the community and family | a. Coping mechanisms | a. Cope from worries by chatting and laughing with friends and reading<br>b. Coped with discrimination through the help of friends<br>c. Forgetting by delegating at work<br>d. Coped with discrimination by joining a support group<br>e. Coped with effects of ART by taking drugs and resting<br>f. Coped with stigma by trusting God |
| | b. Support | a. Supported at work by employer<br>b. Supported by friends<br>c. Joined a support group<br>d. Supported by wife at home<br>e. Supported by relatives at home<br>f. Self-support |
| | c. Encouragement | a. Encouraged to be taking ART<br>b. Encouraged to get tested<br>c. Being encouraged by people about life<br>d. Encouraged to go to the hospital when sick<br>e. Not assisted to get ART<br>f. Encouraged by friends to disclose the status |
| | d. Social interaction | a. Difficulty to use condoms in the family<br>b. Living properly without being discriminated by relatives after discovering your status<br>c. Living in the community without problems<br>d. Denied of job |
| | e. Disclosure | a. Disclosed status to children<br>b. Disclosed status to a partner<br>c. Disclosed status to parents<br>d. Disclosed status to relatives<br>e. Disclosed status to people in the community<br>f. Disclosed status at work<br>g. Did not disclose status to children<br>h. Did not disclose status to other people<br>i. Violation of the human right to information |

| | | |
|---|---|---|
| | f. Food security problems | a. Lack of food to support changed diet due to HIV |

### 4.4.1 Experiences in the community and family

Another theme that emerged during the analysis was the experiences in the community and family. From this theme, five categories and their subcategories emerged under the experiences of PLWH in the community and family.

#### 4.4.1.1 Coping mechanisms

Participants explained that they were able to cope with discrimination, stigma, worries, and many things while living in the community. One participant coped with worries which hindered them from interacting with other people by listening to music, reading, and laughing with friends, while one participant coped with discrimination by chatting with friends.

*"When I am worried or I have thoughts in my head, I would go home and explain to my parents, so they told me that to avoid that I should love to listen to music or watching a movie or reading a book." Participant N*

One participant coped with forgetting by delegating his duties to juniors, this increased work on his colleagues and it was not effective because some work was left undone. One participant coped with discrimination from family members and the community by joining a support group.

*"At the offices due to the problem of forgetting, I would tell someone to do the things on my behalf. So I would tell them that this is what I want you to do, is there a question they would say that no we can do it." Participant M*

*"I had coped up and joined an organization, Malawi National Association of young people living with HIV that organization helped me understand that being HIV positive is not the end of everything." Participant E*

Two participants reported that they coped with the effects of ART by taking the drugs and going to bed immediately and dealt with stigma by trusting God respectively.

*"But what was needed was I should take the drugs (ART) and I should immediately go to bed so that the power of the drugs will not be felt as I sleep" Participant C*

*"So you know that people are talking about me, but I will just say God knows better" Participant B*

#### 4.4.1.2 Support

Most of the participants received support from their relatives, workplaces, spouses, support groups, and friends. One participant received financial support at work from his employer when he was sick.

*"When I was diagnosed with HIV, then I was working with my boss who was a good person. I was sick for a longer period but my boss did not deduct my salary even though he knew that I had HIV, up until I recovered and went back to work" Participant T*

One participant received support from their partner to deal with stigma and one participant was able to support themselves through farming.

*"I can do farming on my own so that I should not reach the point where I am panicking because of lack of food" Participant T*

#### 4.4.1.3 Encouragement

Most of the participants experienced encouragement within the family as well as the community. Parents and spouses played a big role in encouraging the uptake of ART. Participants reported that they positively benefited from living in the communities even though their HIV status was known to people and were encouraged to disclose their status to people in the community.

*"My parents encouraged me to be taking the medication without forgetting." Participant A*

*"So my parents encouraged and reminded me to be taking medication (ART)"*

*Participant C*

*"So what is important is encouraging each other to be taking medication so that we do not forget thus what my husband said" Participant D*

*"You look the same just as the way you looked before you started receiving the HIV medication. So I feel like they encourage me to keep telling people about my condition" Participant T*

One participant reported that their partner encouraged them to seek medical help and to use condoms for protection to prevent the increase of the virus in their body. One participant was encouraged by their sibling after they were told that they went for HIV testing.

*"So what is important is encouraging each other to be taking medication so that we do not forget. Also, we should be using condoms so that we don't add more viruses to our bodies." Participant D*

*"My husband will say you look like you are not feeling well in your body when he notices that I am not eating well. He would say yo need to go to the hospital you should meet a doctor" Participant B*

*"He encouraged me, he said my brother you did well because things would have been worse if you didn't get tested. So he became another person who encouraged me a lot and was always available for me." Participant T*

**4.4.1.4 Social interaction**

Participants were generally able to live with their families and relatives without being discriminated against even though they knew about their HIV status. Many participants had a positive experience living in the community.

*"There few relatives that knew but I was living with them properly" Participant N*

*"There are some people in the community who know my status. I protect myself like maybe I am using a razor blade or needle I will keep those things safe other than to share with other people" Participant D*

*"Now when I came back from the village and relocated to the town, there were no problems here in town. I was chatting with people and we could do everything together in the community, for example at the funeral or doing community work" Participant F*

*"Like my close friends and close relatives, I won't say that they discriminated me, or even now if I happen to tell my friends about my HIV status I live with them without problems" Participant W*

Though participants had positive experiences living in the community, some participants experienced negative responses from the community after knowing their HIV status. One participant was denied work because of how they looked as a result of changes in their body (body wasting) due to sickness.

*"Some people, since they knew they will be pointing at you, look at him he has it (HIV), you need to be careful with him. So you would see that even for them to come to your house they could not, that time people were not understanding, they thought that I will infect them… at that time after recovering from my sickness, I went job hunting and I was rejected in many jobs because of my body appearance" Participant F*

**4.4.1.5 Disclosure**

Another category that emerged under the theme of experiences in the community and family was disclosure. It was shown that most of the participants were free to disclose their status to their relatives, friends, children, and at work. However, one participant did not feel free to disclose their status to their children and other people.

Others disclosed their HIV status to their parents:

*"First of all, I told my mother that I went for HIV testing because of the way I was feeling and also the rashes that I had, and I have been found HIV positive." Participant D*

*"I told my parents that I went to the hospital for antenatal check-ups and I was tested for HIV and I have been found HIV positive, I am informing you so that you are not surprised since we will be together most of the time" Participant C*

Some disclosed their status to relatives without any problems:
*"After I got tested I told my relatives but at first the problem was to accept but after counselling here and there I accepted "Participant Z*

*"At home, I explained properly to my relatives and they encouraged me that I should not worry." Participant A*

Disclosing their status to partners was easier to some while to others it was not:
*"So as I was saying I was pregnant and when I was coming from the antenatal clinic in the evening I told him (husband) and that I have been found with HIV." Participant A*

*"As for my husband, when I told him that I am HIV positive, he just said maybe I might also be positive, but I do not think of leaving you because you are positive." Participant B*

Some partners went for the test when they found out that their spouse/partner tested positive:

*"What I did was I told my wife that she should go and get tested, she also has the virus." Participant G*

While some participants told their spouses and they welcomed the idea of also getting tested, some spouses did not accept to go get tested after their partner tested positive.

*"Ok after I knew that I have HIV, I told my husband and my family members that I have HIV. My husband found it difficult for him to accept it, then when people from the hospital told me to bring my partner for HIV testing he too was found HIV positive." Participant D*

*"I went home and told my husband and he did not accept it and he did not go with me to the hospital. Up to now, I don't know his status" Participant W*

It was also noted that two participants were able to disclose their status to other people in the community, while others could not disclose it to other people.

*"Like my close friends and close relatives, I won't say that they discriminated against me, or even now if I happen to tell my friends about my status I live with them properly." Participant W*

*"I don't hide, even at home people knew because I told them." Participant T*

*"Towards my relatives, I did not tell anyone but I helped someone like I am not HIV positive" Participant K*

Disclosing status to children seems to be easier to some of the participants, one participant did not disclose his status to children for fear of the children disclosing to their friends if they find out that their parent is on ART.

*"So I told him with a heavy heart when he was still in school, so he was disappointed for some time, but now I know that he has accepted it." Participant Z*

*"My mother and my relatives and my elder son were the ones that I told." Participant T*

*"We just told the children that the sickness we were having we went for testing and were found with HIV." Participant G*

*"To the children, I did not tell them like their father because they are children, we assumed that when they go and chat with their friends, maybe out of excitement they would tell their friends that our father is receiving ART" Participant M*

Three of the participants were able to disclose their HIV status at work. Reasons for disclosing their status at work were for them to be permitted to go get ART and to explain frequent absence from work to employer.

*"At work, I told my boss of my HIV status, so that when I ask for permission that I want to go somewhere they know where I was going." Participant G*

One of the participants indicated that she felt that her husband violated her right to information because she only found out about his status after she told him about her status. She realized that her husband was not surprised because he already knew his HIV status but never told her.

*"I told my husband that I went for antenatal clinic and I have tested HIV positive, it was not a surprise to him, it was like he already knew but he did not tell me." Participant C*

#### 4.4.1.6 Food security problems

One participant reported that he had problems finding food so that he meets his dietary needs for a person with HIV. He experienced a lack of food to support the diet change due to HIV.

*"I do a lot of farming, yes challenges are always there. Here in the village, it happens that we do not afford the required amount of food which is recommended for a person with HIV" Participant T*

### 4.5 Physical challenges

The summary of the themes and categories under physical challenges faced by PLWH are presented in table 4.3.

*Table 4.3 Physical challenges*

| Themes | Categories |
|---|---|
| 1. Physical impairments | a. Dizziness<br>b. Leg pain<br>c. Darkness in the eyes<br>d. Yellow eyes<br>e. Skin rashes and black spots<br>f. Vomiting, nausea, and increased heartbeat<br>g. Fatigue and increased viral load<br>h. Weight loss, fever, and sweats<br>i. Weakness |
| 2. Opportunistic infections | a. Tuberculosis |

| | |
|---|---|
| | b. Pneumonia |

### 4.5.1 Physical impairments

Physical impairments were the major theme that emerged under the physical challenges that PLWH faced. The theme had categories that will be described below.

#### 4.5.1.1 Dizziness

Dizziness was one of the major physical impairments that participants reported. It showed to influence many aspects of the life of participants. Generally, participants experienced dizziness as a result of the ART they were taking as well as any change in their ART regime.

*"But now I am crocking two months, for the things that I was told I will be experiencing once I start taking these drugs, I have experienced them but dizziness has been persistent" Participant B*

*"The first drug that I was given was 5A. With 5A I was experiencing dizziness when I am walking, I felt like falling, and sometimes I would just sit down" Participant D.*

Dizziness also affected the ability to take care of household chores such as cooking and washing clothes.

*"At home, I was failing to wash, I was failing to cook due to dizziness" Participant D*

*"When I felt dizzy I would not wash children's clothes, I would not cook, I would not manage to do any activity, what I wanted was to sit down or just sleep" Participant A*

#### 4.5.1.2 Leg pain

One participant reported having experienced leg problems such as leg pain, burning sensation since they started taking ART.

*"When they changed the ART, the ones we are receiving now, the problems of burning sensation in my legs ended but I would have episodes of muscles spasms" Participant F*

The challenges experienced also affected the ability to go to work. In addition to leg pain, one participant reported other symptoms such as cold feet, burning sensation of the legs, and numbness.

*"The problems were the same like numbness, having cold feet when sleeping, and having leg pains." Participant F*

One of the participants experienced leg pain due to twisting of her ankle. She indicated that she started experiencing a leg twist when she started taking ART, this made her fail to walk.

*"When I twist my leg it will be swollen to a point that I stopped walking and I will be staying at home. This meant that I had to stop business as well" Participant C*

Leg pain also affected the ability to sleep:

*"Sometimes when you sleep, you get leg pains, like I don't know what." Participant B*

#### 4.5.1.3 Darkness in the eyes

One of the participants reported that they experienced temporary vision loss in the form of darkness in the eye. When this happens they need to hold on to something or sit down until it clears out.

*"But now the dizziness will stay longer and also it is mixed with nausea, urge for vomiting, and the darkness is there and it happens frequently, sometimes when you sleep, you get leg pains" Participant B*

#### 4.5.1.4 Yellow eyes

Two of the participants experienced a physical change in the color of their eyes. Their eyes turned yellow (or jaundice).

*"The side effects were my eyes turned yellow and people who knew about ART they would recognize me and at work, they would know that I am taking ART by looking at my eyes" Participant D*

*"Also there was a time when they changed my medication, I had jaundice of which my eyes still haven't cleared out. But now I am better my eyes are clear but then they were very yellow" Participant W*

#### 4.5.1.5 Skin rashes and black spots

Skin changes such as developing skin rashes and shingles that resulted in stigmatization and discrimination were reported as one of the challenges experienced.

*"At first I did not know that I have HIV that time I was having rashes in my whole body and people were laughing at me, saying what kind of rashes are these, I also had shingles. People were discriminating against me and others were mocking me saying go and get tested you are going to die" participant D*

Other skin problems included black spots on the skin that made people know that one was sick.

*"When I started taking Bactrim I was not compatible with it. The drug was making me have black spots on my skin, these spots made people notice me as I was walking and I had many things on my skin but now they have disappeared because I stopped taking that drug" Participant W*

#### 4.5.1.6 Vomiting and nausea, increased heartbeat

Nausea after taking medication and vomiting after taking food were reported problems and in some cases, this did not change even after they changed the drugs.

*"The problem of nausea associated with ARTs was persisting, it does not completely stop, but the problems with dizziness stopped" Participant K*

*"They changed and gave me the second ones (ART), but I was vomiting every day so I lost a lot of weight." Participant Z*

Vomiting affected appetite as reported by one participant who indicated that:
*"It was like if I am vomiting it means that I would not be eating as well, so my children will be sad." Participant B*

One participant reported that she experienced an increase in heartbeat soon after taking her ART.

*"When I take the medication my heart will be beating fast*" *Participant K*

#### 4.5.1.7 Fatigue and increase in viral load

Fatigue was reported by one of the participants she said that she was always late for work due to fatigue. Being tired every day made her depend on others to help her with activities at home.

*"At work, it was difficult for me to carry books, I felt tired and sometimes I was late to work due to the tiredness... For the household chores, it meant that I needed help from a person to do them" Participant W*

An increase in viral load was reported as a challenge by two of the participants. This was a result of incompatibility of ART or non-adherence to ART.

*"The viral load was increasing because I was incompatible with the drugs" Participant N*

*"Because I was afraid of discrimination I was not taking my medication(ART)...it ended up destroying my health and the viral load increased because the medication was not working" Participant E*

#### 4.5.1.8 Weight loss, fever, and sweats

Weight loss, fevers, and sweats were reported by some of the participants. Weight loss led to the loss of body energy which was later gained after taking ART.

*"I was having fevers and I was sweating in the evening…now my weight has increased compared to then and also my energy levels has also improved than before." Participant N*

Another participant said that they lost weight due to sickness that was before they knew their HIV status. They gained the weight back after taking ART.

*"Let's start with health. My life changed like that time I was very sick and I lost weight…Now my life is good, I am fine even weight now has increased I was most of the time within the weight range of 55 to 60kg, but now it has increased and today I was 73kg" Participant W*

#### 4.5.1.9 Weakness

One participant reported that he was not allowed to do any activities at home such as doing home chores. The physical inactivity resulted in his body being weak.

*"So it was affecting me because I was receiving ART but they made my body become weak" Participant E*

### 4.5.2 Opportunistic infections

Two of the participants reported that they experienced opportunistic infections due to the suppressed immunity. This led to frequent hospital admissions, before starting to take ART.

*"By then every three months I was admitted with pneumonia" Participant W*

*"I had TB, I was having fevers while I already have the virus. So it was like the HIV made me have the TB" Participant F*

### 4.6 Influence of psychosocial and physical challenges instrumental activities of daily living

Table 4.4 shows a summary of the themes under the influence of psychosocial and physical challenges on IADLs.

*Table 4.4 Influence of psychosocial and physical challenges on IADLs*

| Themes | Categories |
|---|---|
| 1. Influence of discrimination on IADLs | a. Discrimination made one feel that there is no love<br>b. Fear of discrimination leads to not taking ART.<br>c. Depression as a result of discrimination<br>d. Discrimination affected school which resulted in poor performance and health<br>e. Fear of discrimination resulted in being sick which in return made one miss classes |
| 2. Influence of stigma on IADLs | a. Stigma resulted in low self-esteem |
| 3. Influence of not disclosing HIV status on IADLS | a. Not disclosing HIV status to children due to fear that they will be bullied by friends |
| 4. Influence of dizziness on IADLs | a. Dizziness affected walking which resulted in affecting work<br>b. Not going to work due to dizziness resulted in losing money<br>c. Dizziness disturbed business<br>d. Dizziness affected life or mobility<br>e. Dizziness affected doing household chores<br>f. Dizziness affected social interaction |
| 5. Influence of leg pain on IADLS | a. Leg problems lead to not going to work<br>b. Numbness affected work: could not stand and teach<br>c. Leg pains led to lack of sleep at night |
| 6. Influence of leg twisting on IADLs | a. Twisting of legs lead to difficulties walking which lead to not doing business |
| 7. Influence of burning sensation on IADLs | a. The burning sensation made it difficult to wear shoes |
| 8. Influence of fatigue IADLs | a. Fatigue affected the ability to take care of children<br>b. Fatigue disturbed work<br>c. Fatigue lead one to need help to do household chores |

| | |
|---|---|
| 9. Influence of darkness in the eyes on IADLs | a. Darkness in the eyes makes one fail to do anything at home |
| 10. Influence of sickness on IADLs | a. Drop-in performance at school due to being sick |
| 11. Influence of increased heartbeat on IADLs | a. Fast heartbeat disturbs mobility at home |
| 12. Influence of ART on IADLs | a. Taking ART led to decreased diseases<br>b. ART led to an increase in weight and improved energy<br>c. After taking ART was ok and went back to work<br>d. No abnormal body changes due to ART<br>e. Increased viral load due to not taking ART<br>f. ART resulted in forgetfulness at work<br>g. Sleeping during work hours due to ART |
| 13. Influence of not eating IADLs | a. Not eating and taking ART led to poor quality farming |
| 14. Influence of vomiting on IADLs | a. Vomiting lead to one not eating |
| 15. Influence of lack of home activities on IADLs | a. Lack of activity at home resulted in body weakness |

### 4.6.1 Influence of discrimination on IADLs

Discrimination was one of the major psychosocial challenges that most of the participants reported having experienced. It was shown to have an effect on secondary school performance, adherence to ART and it has made others feel pain and not loved.

#### 4.6.1.1 Influence of discrimination on school performance

Fear of discrimination influenced secondary school performance as indicated by this quote: *"This affected me because I was afraid of being discriminated and I could not take medication. I frequently got sick and I was missing classes and school was disturbed. Most of the time I was either at the hospital or sleeping in the hostels" Participant E.*

#### 4.6.1.2 Influence of discrimination on mental status

The following quotes show the influence of discrimination on mental status:

*"Discrimination was affecting me because I was depressed as everything was not ok with me. School and health were not ok and most of the time I was sad and was thinking why are things happening to me like this" Participant E*

*"When I was taking this other HIV medication it came to appoint that I would say to myself no, I was not like this. I was losing myself and I came back to the hospital I told them that I am experiencing these signs, that somehow I am not ok mentally." Participant M*

#### 4.6.1.3 Influence of discrimination on life

One participant reported that people were discriminating against her and she was blaming God and asking what sin did she commit to having HIV. This resulted in her feeling that there was no love in the world. While another participant felt so much pain as a result of the discrimination because his relatives did not want to escort him to the hospital to get ART just because he was HIV positive.

*"Ok the challenges that I was facing was that I felt that there is no love in this world, I was being discriminated and I was blaming God that, what sin did I commit so that I should face this, and why are people mocking me like this as if I am the only one, a lot of people have HIV but people are only mocking me" Participant D*

*"When I was young I would ask my relatives to escort me to the hospital to get ART, they refused this was hurtful to me but I had to stay strong" Participant X*

### 4.6.2 Influence of stigma on IADLs

One participant reported that she was being mocked by people due to the skin rashes and shingles that she had on her body. This led to stigmatization from people which resulted in low self-esteem that affected her social interaction.

*"Why are people mocking me like this since I am not the only one, a lot of people have HIV but people are only mocking me. This made me have low self-esteem, I could feel that I am behind." Participant D*

### 4.6.3 Influence of not disclosing HIV status on IADLs

It was noted that many participants reported that they told their children about their HIV status. Only one of the participants reported that he did not tell his children about his status and had no intentions of telling them. He said this is because he thought that when he tells his children they might tell their friends who would, later on, bully them. After all, their parents are taking ART.

*"My fears are on that a child is a child, I have already said, he might in chatting say my dad is taking ART. They might also say my dad is not doing well to me, maybe it is because of the medication that he is taking saying that to his friends. So the reflection of his friends on me, they will say bad things back to him saying that you are also doing crazy things like your dad because he is taking ART, are you also taking them" Participant M*

### 4.6.4 Influence of dizziness on IADLs

Participants reported that dizziness affected their work, mobility, household chores, and social interaction.

#### 4.6.4.1 Influence of dizziness on work

Participants reported that they experienced dizziness which affected walking which affected their ability to work. One participant reported that she felt dizzy when she was walking to her work as such she had to stop at some stage to wait for the dizziness to stop. She also said she had to take leave from work because of dizziness. Thus dizziness resulted in the loss of income.

*"Dizziness affected my work a lot, I could not go to work due to dizziness, instead of them promoting me at work because I have collected a lot of arrears instead they did not add the bonus to my account since I was not meeting targets" Participant D*

#### 4.6.4.2 Influence of dizziness on business

One participant reported that she had dizziness throughout the day as such when she experiences dizziness while she is with a customer she had to stop and go and rest, this meant

that the customer will be waiting long for her until she feels better. Dizziness disturbed her business because she was not attending to many customers in a day.

*"If I experienced dizziness when I am working and I have a customer, it meant that I had to leave the customer and get some rest. It means the customer needs to wait for me, as a result, I ended up losing customers" Participant B*

#### 4.6.4.3 Influence of dizziness on mobility

Two participants said dizziness affected their mobility as such they had problems with standing and they felt like they will fall.

*"If I have taken the drugs but I haven't slept yet, I was experiencing dizziness sometimes I would fall" Participant C*

*If I was walking and I experience dizziness while I am walking on the road, I am supposed to stop which means I need to hold on to a person who is closer to me and should help me sit down which means I will wait until it stops" Participant B*

#### 4.6.4.4 Influence of dizziness on household chores

Two participants reported that dizziness made them fail to do household activities at home. One felt dizzy that she could not wash her children's clothes, cook, and would not manage to do anything she just need to sit down or just sleep. While the other felt dizzy that she could not wash and cook as such she needed help with home activities from her relatives.

*"I was very much affected because when I felt dizzy, then I would not wash my children clothes, I would not cook, I would not manage to do any activity, it means I need to sit down or just sleep" Participant A*

*"At home, I was failing to wash, I was failing to cook, my husband will be going to work, so I would find someone to help me wash or my relatives will come they would help me wash or cook" Participant D*

#### 4.6.4.5 Influence of dizziness on social interaction

One participant reported that he was taking ART at night and whenever he is watching television and he feels dizzy, he will just start and go to bed and could not continue chatting with his relatives.

*"If you are watching television and you feel dizziness, you will just start and go to bed. Thus how I was living and it's not that it was affecting me that much" Participant X*

### 4.6.5 Influence of leg pain on IADLs

Leg pain was reported by some participants and it was shown to be affecting work and sleep.

#### 4.6.5.1 Influence of leg pain on work

One participant reported that she had leg pains and numbness that lead her not going to work. As such she stayed home without going to work, but when she returned she could not work the way she used to.

*"I stayed home without going to work because of leg pain. When I started going to work, I was going but I was not working the way I used to be working. Because for me to stand, I was failing as such I was teaching while seated" Participant Z.*

#### 4.6.5.2 Influence of leg pain on sleep

Two participants experienced leg pain which disturbed sleep at night. As such one of them could not find peace at night when sleeping.

*"... because if I feel too much pain especially in my leg when I wanted to sleep I did not find peace due to leg pains and I had to stretch the legs to get a relief, it was really bad" Participant B*

*"The problems were the same like numbness, having cold feet when sleeping and having leg pains" Participant F*

### 4.6.6 Influence of leg twisting on IADLs

One participant reported that she twisted her leg (spasticity) and this lead to difficulties with walking which lead to not doing business.

*"when I twist my leg it become swollen and I could not walk and I had to stay at home. This meant that I had to stop doing business until I was fully recovered" Participant C*

### 4.6.7 Influence of burning sensation on IADLs

One participant reported that he could not wear shoes due to the burning sensation that he was feeling in his feet.

*"When they changed the ART the problems of burning sensation in my legs stopped but I had muscles spasms here and there. But it is different from before because then I could not even wear a slipper." Participant F*

### 4.6.8 Influence of fatigue on IADLs

Fatigue was shown to influence child care, work, and household chores.

#### 4.6.8.1 Influence fatigue on child care

One participant reported that she was feeling tired every morning as such found it hard to prepare her child for school in good time. She felt that she needed more time to sleep because she was tired.

*" I woke up tired and I could not prepare my child for school in good time" Participant W*

#### 4.6.8.2 Influence of fatigue on work

Participant W continued to say that her work was affected, she was failing to carry books because she felt tired. She also said that she felt weak as such she could not wake up early to prepare for work as she was always late to work. This continued and she was off and on at work.

*"At work, it was difficult for me to carry the books because I was always tired and I was always late to work due to my tiredness, this affected my work" Participant W*

#### 4.6.8.3 Influence of fatigue on household chores

Participant W reported that due to the fatigue that she had, she needed someone to help her with managing the household chores. Sometimes she could do the chores but at her free will. But since most chores are done in the morning and she could not wake up in the morning she needed someone to help her with it.

*"I need someone to help me with home activities because I could not since I was always tired" Participant W*

### 4.6.9 Influence of darkness in the eyes

One participant reported that whenever she takes ART she experienced darkness in her eyes as such she had to sit or hold on to something wherever she is.

*"When I experience darkness in my eyes if I was standing I need to find something to hold on to or I should just sit down" Participant B.*

### 4.6.10 Influence of sickness on IADLs

One of the participants reported that his performance at school dropped because he was sick most of the time and this was because he was not taking his ART. He could miss classes due to the sickness which in return resulted in dropped performance.

*"...it is like you frequently get sick and school was not going on well because most of the time I was not in class, I was either at the hospital or sleeping in the hostels." Participant E*

### 4.6.11 Influence of Increased heartbeat on IADLS

One participant said that when she experiences a fast heartbeat, she needs to stop everything that she was doing at home and she needs to lie down until she feels better.

*"At home when my heart is beating fast, I would just go in my room and choose a cool place and lay down and I don't need noise and I should stay there for some time then my heart will normalize and I would go and work." Participant K*

### 4.6.12 Influence of ART on IADLs

ART had positive and negative effects on the IADLs of the participants.

#### 4.6.12.1 Positive influence of ART on IADLs

Some of the participants reported that they benefited positively from the effects of ART. Being on ART resulted in living a life without diseases.

*"....it was like we were coming from another world going into the new world. The new world without diseases while the old world was like now and again we are down, with headaches" Participant M*

One participant said that after he started taking ART he went back to his work and he did not experience any problems. Another participant was able to do all household chores without any problem since they started taking ART and two did not experience any side effects such as body changes.

*"...on household chores, I did not have problems" Participant X*

*"I am thankful because none of those side effects did I experience since I started taking medication up to today I did not get any side effects of ART" Participant E*

*"I get ARVs daily and people say, it's only yourself who knows that you receive HIV medication, but people don't see that because of how you look" Participant T*

#### 4.6.12.2 Negative influence of ART on IADLs

One participant was negatively affected by ART as such he was so forgetful this affected his work because he could not do important tasks. He was also sleeping during working hours which he never did before he started taking ART.

*"When I get into the office, I forget, I do not know where I am supposed to start from in the office until someone should remind me" Participant M*

### 4.6.13 Influence of not eating on IADLs

One participant reported that whenever he did not eat and also took ART his performance at the farm was poor as such he had poor quality farming.

*"And it happens that sometimes, I sleep without eating and being on medication, you go to the field to do some farming activities. You end up doing a poor quality job in the field." Participant T*

### 4.6.14 Influence of vomiting on IADLs

One participant said that whenever she took her medication she was vomiting, this lead her to avoid eating and it made her children sad.

### 4.6.15 Influence of lack of activity on IADLs

One participant reported that his body was becoming weak due to a lack of activity at home. This was because when his relatives discovered that he was HIV positive they could not let him do any activity at home this meant that he will just be seated. This in return made his body to be weak.

*"Ok, it was affecting me very much because, sometimes we say household chores are physical exercises that every child need to be doing so that they have a strong body, but that time it was like I was not allowed, you should not do this, you should not do that, almost everything I was not doing, that means I was just staying idol. So it was affecting me because yes I was receiving ART but what they were doing to me, the body was becoming weak." Participant E*

### 4.7 Conclusion of the results

In conclusion, the following psychosocial challenges were commonly reported by the majority of the participants: discrimination, stigma, anxiety and worries, and loss of hope. The participant also reported coping mechanisms, support, encouragement, social interaction, and disclosure as they lived in the community. Memory loss and mental problems, and food security problems were unique psychosocial challenges that were reported by a minor group of participants.

While physical challenges commonly experienced were dizziness, leg pain, burning sensation darkness in the eyes, yellow eye, skin rashes, and black spots, increase heartbeat, increase in viral load, vomiting and nausea, leg twisting, and weight loss. The following were unique physical challenges that were presented by participants, these include opportunistic infections such as tuberculosis and pneumonia, weakness, sweats and fevers, and fatigue. These challenges have been shown to influence mobility, work, household chores, social interaction, child care, secondary school performance, and adherence to ART.

# CHAPTER 5: DISCUSSION

## 5.1 Introduction

The study aimed at exploring the psychosocial and physical challenges that people living with HIV encounter and how it influences the instrumental activities of daily living. The following psychosocial challenges emerged: discrimination, acceptance of HIV, stigma, anxiety, and worries, memory loss and mental problems, loss of hope, and experiences in the community.

Under physical challenges, the following themes emerged: physical impairments and opportunistic infections. Lastly on the influence of psychosocial and physical challenges on IADLs, these challenges showed to affect life, social interaction, and adherence to ART, walking, work, farming, household chores, and business. In this chapter, the profile of study participants and the challenges listed above will be discussed.

## 5.2 Profile of study participants

The study found that majority of the women who were married were between the ages of 18 and 50 years. In Malawi the marriage age for girls is 18 years of age, the results are in conjunction with the national guidelines for the marriage age (National Statistical Office, 2015). However, Malawi has registered the highest child marriage rate in Africa which means that many girls are married by the age of 18 years. They are involved in early sexual activities which puts them at high risk of getting infected with HIV (UNICEF, 2019).

The findings show that there were fewer men in the age group of 50 to 60 years. This could be as a result of reduced sexual activity by men at this age. Similarly with literature which reports that there is a decline in sexual activity among men and women as they get to 50 years and older (Freeman and Anglewicz, 2012). The rate of being infected with HIV is lower in this age group, however, there is an aging group of people living with HIV that are reaching this age. In the 30 to 40 years age group there were no men presented, this is the economically active age group who are involved in different jobs and businesses to earn a living and they did not have time to access ART clinics during the working hours. The reason why men do not attend clinics is being committed to working or feeling delayed by long queues at the clinics (Kunutsor *et al.*, 2010).

The study found that ART and HIV duration were similar among some of the participants. The standard protocol of initiation of ART soon after diagnosis was followed for these individuals. The findings concur with the standard treatment protocol for Malawi where all people diagnosed with HIV are put on ART as early as possible (National AIDS Commission (NAC), 2020). This is in line also with the standard protocol used in South Africa for pregnant mothers who are initiated on ART as soon as they are diagnosed with HIV (National Department of Health, 2015).

The results also show that there are some of the participants who did not start ART immediately after being diagnosed with HIV which made them at risk of developing opportunistic infections which could affect their health. This shows that these participants were in the third phase of HIV infection where the immunity has been suppressed and they become prone to other infections such as tuberculosis (Klatt, 2020; Munawwar and Singh, 2020).

### 5.3 Psychosocial challenges of PLWH

Discrimination, stigma, acceptance of HIV status were some of the psychosocial challenges that were reported by participants in this study. Discrimination and stigma were perceived from family members, secondary schoolmates, and people from the community and workmates upon disclosure of one's HIV status to others. This implies that the mental well-being of PLWH is affected and it leads to depression, social isolation, and low self-esteem (Ashaba *et al.*, 2017; Kimera *et al.*, 2019; Abdisa, Tolesa, and Abadiga, 2021).

The study found that participants experienced stigma in workplaces which emanated from workmates and employers as a result of body changes due to the side effects of ART and disclosure of one's status. The results highlight the burden of HIV-related stigma in workplaces which could affect an individual's ability to participate in work and become productive (Mahamboro *et al.*, 2020; Twinomugisha, Ottem, and Daniel, 2020). It also shows that workplaces do not have policies that protect PLWH. There is a need to strengthen workplace policies that aim at promoting equality and non-discrimination between all people (National AIDS Commission (NAC), 2020).

Disclosure of one's status to others needs one to be able to accept their status. This study found that participants who were able to accept their HIV status were able to disclose to others easily. However, disclosing their status had its consequences; partners refuse to get tested and others were labelled unfaithful and judged after being found HIV positive (Albright and Fair, 2018; Bilardi *et al.*, 2019). Disclosing HIV status to partners made one at risk of being divorced as they are labelled unfaithful (Bilardi *et al.*, 2019). Unique to this study it was noted that one woman felt violated of her human right to information by her partner, they discovered that their partner already knew her HIV status but did not disclose it to them. It could have been that the woman was deliberately infected with HIV by her partner since he did not disclose his status to her before they were married.

Literature has shown that some parents are reluctant to disclose to children of their HIV status due to fear of stigmatization, discrimination, negative social interactions, and fear of child's reactions when they find out about their HIV status (Hayfron-Benjamin *et al.*, 2018; Madiba, 2020). This concurs with these study findings which highlighted that some parents could not disclose their HIV status to children as a way of protecting them from stigma and discrimination that they could receive after disclosing their parents' status to others.

The current study findings show that participants faced psychological or mental problems such as anxiety, worries, and mental disturbance, due to worries about living in the community and financial constraints to support dietary changes, leading to feelings of hopelessness and self-judgments for being HIV positive (Albright and Fair, 2018). There is a need of intensifying the provision of psychological interventions to manage the common mental health problems that PLWH may experience with time (Nakimuli-mpungu *et al.*, 2021).

Literature has shown that mental problems that PLWH face are a result of the side effects of ART or HIV infection. The mental problems present in form of impaired cognition which in turn affect the quality of life of PLWH (Desta, Biru, and Kefale, 2020; de los Rios *et al.*, 2021). The study findings show that participants were faced with issues of memory loss in the form of forgetting, which had an impact on the performance of household chores and

participation in work. Similarly, literature shows that PLWH experience memory loss which makes them dependent on others to adhere to HIV medication (Kiplagat *et al.*, 2019).

Meanwhile, the study has shown that participants were able to cope with these psychosocial challenges faced in day-to-day life. To cope with worries, forgetting, and side effects of ART, they were encouraged to be chatting with friends, delegate some duties to their juniors in case they forget, and others opted for joining support groups that could help them deal with discrimination from the community, and to sleep soon after taking HIV medication to avoid the effects of ART.

The study findings are different from the coping mechanisms that are documented in the literature that reports that PLWH copes with living in the community by self-acceptance and writing down to cope with memory loss and prayers to deal with stigma, taking other medication to deal with the side effects of ART (Parikh *et al.*, 2016; Olusola *et al.*, 2017; Anima-korang, 2018; Gelaw *et al.*, 2018; Tavares *et al.*, 2018). This study has shown unique ways on how PLWH cope with worries, memory loss, and side effects of ART.

People living with HIV survive in the community through the support received from family members, spouses, and friends. The study results show that participants were able to adhere to their ART uptake due to the encouragement that they receive from those around them. Family support and encouragement improved ART adherence, social and emotional support among PLWH hence improving their health outcomes and quality of life (Pedrosa *et al.*, 2016; Anima-korang, 2018; Tavares *et al.*, 2018).

For one to be able to take ART without problems they need to eat diet food that will give their body energy. Most individuals living with HIV lack micronutrients in their diet such as organic meat and dark vegetables which provide more energy and proteins (Khatri, Amatya, and Shrestha, 2020). The study found that participants had problems finding food to support their dietary changes for a person with HIV because of a shortage of food and lack of financial support to access food (Moyo *et al.*, 2017). There is a need for PLWH to get food supplements from the hospitals and also be joining support groups that teach how to use locally available food to support their dietary needs as they are taking ART.

### 5.4 Physical challenges of PLWH

People living with HIV may experience dizziness with the change of ART regime and commencement of ART (Khoza-shangase and Rie, 2017; Khoza-shangase, 2018). Taking ART without food intensifies the dizziness symptoms hence affecting the performance of day-to-day activities in PLWH (Moyo *et al.*, 2017). The study findings show that participants indeed experienced dizziness with start and change in regimes of ART which is consistent with the literature.

Vomiting, nausea, increased heartbeat, and increased viral load were reported by participants in the study. Nausea and vomiting were stimulated by the intake of ART attributed to the smell and test of the drugs. These symptoms were associated with an increased heartbeat which was experienced soon after taking ARTs. Literature reports that PLWH experience nausea and vomiting as side effects of ART (Wilson *et al.*, 2016; Zhu, Zhao, and Hu, 2019). However, increased heartbeat was not among the commonly reported effects of ART reported by PLWH in literature. An increase in viral load as a result of incompatibility with the ART as such there is reduced viral suppression that was noted.

Leg pain, burning sensation, leg twisting, temporary vision loss or darkness in the eyes, and changes in eye color to yellow were reported as physical impairments experienced by participants in this study. Wilson *et al.*, 2016 in their study reported that leg pain and burning sensation were reported by PLWH in the ART clinic which is similar to the study findings.

Tan, Liu, and Jiang, 2009 in their study found that PLWH experience vision loss due to the effects of HIV on the optic nerve which causes temporary vision loss. Similar to these study findings the participants reported having darkness in the eyes for a short period during the day. The changes in eye color are due to the effects of ART on the liver which stimulates overproduction of bilirubin which changes the eye color to yellow (Nsobya *et al.*, 2015).

Skin rashes, black spots, and shingles were skin problems that were reported in this study. The participants reported that they noticed the skin change before they knew their HIV status. This encouraged them to get HIV tests. Skin rashes are one of the first signs of

immunosuppression by HIV which is commonly manifested in the third stage of HIV infection (Altman and Westergaard, 2015).

Fatigue has been a commonly reported symptom that has burden the lives of PLWH in the world. It is most persistent and could be there throughout the day (Wilson *et al.*, 2016; Ven *et al.*, 2019; Zhu, Zhao, and Hu, 2019). Fatigue in the form of tiredness during morning hours and the day was reported by participants in this study. Antiretroviral therapy drugs affect the muscle as it stimulates the production of lactic acid which has an exhaustive effect on the muscles hence the feeling of tiredness. Fatigue is also associated with increased CD4 count, anaemia, depression, lack of sleep, and physical inactivity among PLWH (Gebreyesus *et al.*, 2020).

Weakness and weight loss are associated with fatigue, these symptoms were reported by study participants. As the body tries to fight the HIV infection, there is an increase in the body metabolism which takes up a lot of energy from the muscular proteins which results in wasting of the musculature resulting in generalized weight loss (Grinspoon *et al.*, 2003). This makes the body weak due to loss of body mass and reduced physical activity.

Pneumonia and tuberculosis were the opportunistic infections reported by participants in this study. These infections manifest due to the immunosuppression of the body by the virus and the body becomes prone to infections of the upper respiratory tract. The HIV infection may rapidly progress into stage three of HIV infection characterized by WHO in individuals who do not start ART immediately after diagnosis. They may present with weight loss and pulmonary tuberculosis (Weinberg and Kovarik, 2010). Pneumonia and tuberculosis are the most common upper respiratory tract infections in PLWH (Bhuvana, Hema, and Patil, 2015; Solomon *et al.*, 2018).

### 5.5 Influence of psychosocial and physical factors on IADLs

The study findings show that discrimination harms the life of PLWH. It results in poor secondary school performance, poor ART adherence, and causes depression. Kimera *et al.*, 2019 in their study found that discrimination leads to poor academic performance and increased school drop-out among youth living with HIV. It is also associated with non-adherence to ART which impacts the health of PLWH (Kheswa, 2017). Discrimination has

a strong association with depression, anxiety, and psychological distress (Williams *et al.*, 2019).

Therefore, discrimination has been shown to have an influence on the education of youth living with HIV. It promotes poor health outcomes among PLWH and promotes psychological distress. This highlights the need for mental health and physical support to promote good health outcomes which results in improved quality of life of PLWH.

Parents are afraid of disclosing their HIV status to their children because they are afraid that children do not keep secrets, how they will react and to protect them from discrimination and stigma (Hayfron-Benjamin *et al.*, 2018; Madiba, 2020). Parents are afraid of disclosing their HIV status to children to protect them from the consequences such as abuse after disclosing their parent's status to others.

Dizziness, leg pain, fatigue were physical impairments reported by participants in the study that influenced the IADLs of PLWH. These impairments influenced work, business, mobility/walking, household chores, child care, and social interaction. The household chore was the common impaired activity in the IADLs which was influenced by all three factors. Literature shows that housework, laundry, transportation are the commonly reported difficulties that PLWH reports upon assessment of the IADLs impairment this is similar to the study findings (Johs *et al.*, 2017; Siegler, Moxley, and Glesby, 2021).

Dizziness, leg pain, fatigue influence the person's ability to handle finances through interfering with mobility and balance hence limits the participation of a person in income-generating activities such as work and business (Khoza-shangase and Rie, 2017). The study also shows that social interaction was affected due to limited mobility.

Furthermore, leg pain was reported to affect sleep and such participants reported that they could not sleep at night due to the pain. Continuous disturbance in sleep leads to chronic fatigue which affects a person's ability to function and participate in activities of daily living (Ownby, 2007). Among the physical impairments, fatigue showed to influence child care. It

limits the activity of PLWH and is associated with limitations in IADLs and mobility performance (Gebreyesus *et al.*, 2020).

Overall, ART was beneficial to PLWH as they did not get sick and were able to participate in household and work-related activities. For PLWH who had experienced ART side effects such as vomiting and nausea, not eating, their IADLs were affected and they could not participate in family, community, work-related activities. These are unique findings reported by PLWH who participated in this study.

# CHAPTER 6: CONCLUSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

## 6.1 Conclusions

People living with HIV are thriving to walk and participate in IADLs even though they are being physically and psychologically challenged every day to successfully engage in functional activities. This study aimed at exploring how psychosocial and physical factors influence IADLs in PLWH. The results of this study identified the following psychosocial challenges that participants experienced: discrimination, stigma, anxiety, worries, and memory loss, disclosure and loss of hope.

They coped with these psychosocial challenges through chatting with friends, trusting God, laughing, resting, delegating duties, and joining support groups. The support and encouragement they received from their parents, spouses, relatives, and friends helped them to deal with the psychosocial and physical challenges that they faced. The participants further identified physical challenges in form of physical impairments that included: fatigue, dizziness, leg pain, yellow eye, vomiting and nausea, weakness, weight loss, sickness, numbness, burning sensation, increased viral load, and heartbeat.

These challenges influence the following IADLs: mobility, work, farming, household chores sleep, business, secondary school performance, child care, and social interaction. Identification of physical, mental, and social challenges that PLWH experiences may provide valuable insight for developing psycho-social programs, and physical interventions to promote positive everyday functioning and health outcome. Therefore there is a need for further studies to identify interventions that are given to PLWH who are dealing with physical and psychosocial challenges such as dizziness, leg pain, and discrimination.

## 6.2 Strengths of this study

The data collection methods used are detailed as such they could be adapted and modified to suit the research question to produce desirable results.

### 6.3 Limitations of this study

It would be hard to generalize the results because the study was only done in Blantyre and did not cover the whole country. The sample size was small to capture all the IADLs that PLWH would be involved in.

### 6.4 Clinical Recommendations

There is a need for PLWH to receive treatment to help with physical challenges such as numbness, leg pain, muscle weakness, and fatigue. Mental health interventions are required for PLWH even if they might seem to be coping well after diagnosis.

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**Appendix A: Pre-interview Questionnaire**

Please tick where necessary

1. Age: 18-30 yrs. ☐ 30-40 yrs. ☐ 40-50 yrs. ☐ 50 -60 yrs. ☐

2. Gender: Male ☐ Female: ☐

3. Marital Status: Single ☐ Married ☐ Widowed ☐

   Single Parent ☐

4. Occupation: Employed ☐ Unemployed ☐ Self-employed/Business ☐

If employed mention your type of employment ……..

If unemployed mention what you do every day ……

If self-employed mention what you do ……

5. HIV Duration: 0-5yrs ☐ 5- 10 yrs. ☐ 10- 15yrs ☐ 15-20 yrs. ☐
   20-25 years ☐

6. ART Duration: 0-5yrs ☐ 5- 10 yrs. ☐ 10- 15yrs ☐
   15-20 yrs. ☐ 20-25yrs ☐

**Appendix B: Interview Guide**

Interview Schedule Questions

**Instructions**

Please answer all these questions, I will be asking for clarification during the interview, to get a better understanding of your experiences.

## Section A: Challenges faced by people living with HIV/AIDS

1. What are the challenges that you have been experiencing since you were diagnosed with HIV?

### Sub Question:

1) How have you been coping to live in the community since you were diagnosed with HIV?

2) How have you been interacting with your family and friends since you were diagnosed with HIV?

3) Have you told your family about your HIV status and how did they react?

4) What has been your experience since you started taking ART?

## Section B- How challenges affect instrumental activities of daily living

2. Please tell me what has been your experience taking ART and how it has been influencing your work/business/ Household chores/farming/ caring for the family?

3. Please tell me what has been your experience interacting with people in the community since you discovered your HIV status and how it has been influencing your work/ business/ household chores/farming/ care for the family?

4. Please tell me your experience on how you have been interacting with your partner and family since you discovered your HIV status and how it has been influencing your work/ business/ household chores/farming/ care for the family?

## Appendix C: Permission letter QECH

Telephone: (265)874 333/877 333
*Facsimile: (265)874 603*
Email: queenshospital@malawi.net

All *Communications should be addressed to:*
*The Hospital Director*



*In reply please quote No.* ..
QUEEN ELIZABETH CENTRAL HOSPITAL
MINISTRY OF HEALTH
P. O. BOX 95
BLANTYRE
MALAWI

25th July 2019

The Chairpersons of Research and Ethics Committees
College of Medicine, Malawi and the University of Witswatersrand

Dear Sir/Madam,

**Psychosocial and physical factors that influence instrumental activities of daily living of people living with HIV in Blantyre, Malawi.**

I write to support the conduct of the above proposed student research to be done in this hospital by Ms Talumba Mankhokwe. As a hospital we believe that the findings from this study will go some way in addressing the quality of life challenges in this patient population.

We request that the findings of the study be made available to the hospital and the relevant department.

We wish the Ms Mankhokwe success in her study.

Yours faithfully

**Dr Samson Mndolo**
**Acting Hospital Director**

The Hospital Director
Queen Elizabeth Central Hospital
2019 -07- 31
P.O. Box 95
Blantyre

**Appendix D: Consent form**

Participants consent form

I (full name and surname) _____ give permission to Talumba Mercy Mankhokwe to interview me to find out psychosocial and physical factors that influence instrumental activities of daily living of people living with HIV.

**I understand why this research is done and know that:**

- I can leave the research project any time when I want to
- Information that I will give will be treated with confidentiality
- I will have one interview for about 45 to 60 minutes.
- I will be called back to the study to check if the results are reflecting what was discussed during the interviews
- I will be allocated a code, which will be used in place of my name
- I will not be paid for taking part in this research
- Participating in the study does not have any consequences of any sort.

**Name & Signature: _____Date: ……**

**Name &Signature: _____Date……..**

**Researcher**

**Appendix E: Participants tape-recorder consent form**

I (full name and surname) _____ give permission to Talumba Mercy Mankhokwe to tape record the interview for the research to find out psychosocial and physical factors that influence instrumental activities of daily living of people living with HIV.

**I read and fully understand why this research is done and know that:**

- I can terminate the interview at any time
- Information that I will give will be treated with confidentiality
- The interview will take about 45 to 60 minutes long
- I will not be paid for taking part in this research

Name & Signature: _____ Date: ……
Participant

Name & Signature: _____ Date: ……
Researcher

## Appendix F: HREC Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Miss Talumba Mercy Mankhokwe

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**

**CLEARANCE CERTIFICATE NO. M190976 MED19-08-135**

| | |
|---|---|
| **NAME: (Principal Investigator)** | Miss Talumba Mercy Mankhokwe |
| **DEPARTMENT:** | Physiotherapy<br>Queen Elizabeth Central Hospital, Blantyre, Malawi |
| **PROJECT TITLE:** | Psychosocial and physical factors influencing instrumental activities of daily living of people living with Human Immunodeficiency Virus in Blantyre, Malawi |
| **DATE CONSIDERED:** | 27/09/2019 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | South African Human Research Ethics Committees (HRECs) have no standing outside South Africa. Ethics and site approval is also required from the local HREC and CEO of study site in the country in which research will be done. |
| **SUPERVISOR:** | Prof Veronica Ntsiea |
| **APPROVED BY:** | Dr C Penny, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 11/12/2019 |

**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.**

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed September and will therefore be due in the month of September each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**

**Appendix G: COMREC Certificate**

# CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.11/19/2888- PSYCHOSOCIAL AND PHYSICAL FACTORS INFLUENCING INSTRUMENTAL ACTIVITIES OF DAILY LIVING OF PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS IN BLANTYRE MALAWI. By Talumba Mankhokwe

On 07-Feb-20

As you proceed with the implementation of your study, we would like you to adhere to international ethical Guidelines, national guidelines and all requirements by COMREC some of which are indicated on the next page for Your study

07-Feb-20

Prof. E. -Chairperson Dat

Approved by College of Medicine 07Fe- (COMREC) Research and Ethics Committee

**Appendix H: Participant's information document**

Dear Participant,

I, Talumba Mercy Mankhokwe, am studying towards a master's degree at the University of the Witwatersrand. I am conducting a study to find out how psychosocial and physical factors influence instrumental activities of daily living of people living with HIV.

I will be most grateful if you will be willing to participate in this research project. Before agreeing to participate, it is important that you read and fully understand what is involved. Males and females living with HIV for more than five years, receiving ART care at Lighthouse ART clinic, should be within the three stages of HIV infection (stages one, two, and three) and are between the ages of 18 to 60 years will be included in this study.

Participation will include filling a pre-interview questionnaire that will capture your demographic data for example age, gender, occupation. There will be a face-to-face interview for 45 to 60 minutes long that will be aimed at getting an understanding of the psychosocial and physical challenges that people living with HIV face and how these challenges influence instrumental activities of daily living.

Semi structure interview schedule questions will be used and the process of the interview will be tape-recorded if you consent, probes will be used to get clarification on issues that will be arising. You will not be exposed to any risk during the interview and there are no benefits for taking part in this study. Efforts will be made to keep personal information confidential. To ensure the confidentiality of participants, each participant will be assigned a study number. The key to the study numbers assigned will be kept by the researcher only. Names of participants are only to be written on the consent form and not on the questionnaire. You will be called back to the study during data analysis to check if the findings of the study match your own words and your experiences.

All information will be used only for the purpose intended in this study. Participation is voluntary and refusal to participate will not involve any penalty. You may withdraw from this study at any time without suffering any consequences.

For further information, you are welcome to contact me on 0882878406 or send an email to tmankhokwe1@gmail.com.

Please let me know if you are willing to participate in this study by filling in and signing the consent form.

I will appreciate your help.

Kind Regards,

Talumba Mercy Mankhokwe, Cell: 0994493319, 0882878406

**Appendix I: Fomu ya mafunso**

Chonde chongani pomwe pakufunika kutero

1. Zaka : pakati pa zaka 18 ndi 30 ☐ pakati pa zaka 30 ndi 40 ☐ pakati pa zaka 40ndi 50 ☐

Pakati pazaka 50 ndi 60 ☐

2. Wam'muna/Wam'mkazi: Wam'muna ☐ Wam'mkazi ☐

3. Banja: Wosakwatiwa ☐ wokwatiwa ☐ woferedwa ☐ kholo limodzi ☐

4. Ntchito: wolembedwa pa ntchito ☐ wosalembedwa pa nchito ☐ wozilembe ntchito/Bizinezi ☐

Ngati munalembedwa ntchito fototkozani ntundu wantchito yanu ……

Ngati simunalembedwe ntchito nenani chomwe mumachita tsiku ndi tsiku ……..

Ngati munazilembe nokha ntchito nenani chomwe mumachita ……..

5. Kutalika kwa nthawi yokhala ndi kachilombo: zaka zero mpakana zisanu ☐

Zaka zisanu mpakana khumi ☐ zaka khumi mpaka khumi ndi zisanu ☐

Zaka khumi ndi zisanu mpaka makumi awiri ☐

zaka makumi awiri mpaka zaka makumi awiri ndi zinayi ☐

6. Kutalika Kwa nthawi yomwa mankhwala a kachilombo ka HIV:
7. zaka zero mpakana zisanu

Zaka zisanu mpakana khumi ☐ zaka khumi mpaka khumi ndi zisanu ☐

Zaka khumi ndi zisanu mpaka makumi awiri ☐

zaka makumi awiri mpaka zaka makumi awiri ndi zinayi 

**Appendix J: Fomu yamafunso a kafukufuku**

**Malangizo a kayankhidwe ka mafuso**

Chonde muyankhe mafunso onse, ndipo ndizifunsa mafunso enaowonjezera pomwe sindidakumvetsetseni, kuti ndimvetsetse zodutsamo/zokumana nazo zanu.

Gawo loyamba: Mavuto Okumana Nawo Chifukwa Chokhala ndi Kachilombo Kapena matenda HIV.

1. Kodi mwakumana ndi mavuto anji kuchokera pomwe mudapezeka ndi kachilombo ka HIV?

   Mafunso otsatila:

   1) Mwapirira motani pamene mukukhala ndi anthu kuchokera pa nthawi yomwe mudadziwa za kupezeka kwanu ndi kachilombo ka HIV?

   2) Munkakhala bwanji ndi banja lanu ndi anzanu pamubuyo pa kupezeka ndi kachilombo ka HIV?

   3) Mudaliwuza bwanji banja lanu kuti muli ndi kachilombo ndipo a m'banjamo anayilandira motani nkhaniyi?

   4) Mwakhala mukukumana ndi zotani chichokereni pomwe mudayamba kumwa mankhala a kachilomboka?

Gawo LachiwirI: Momwe mavuto odza chifukwa chokhala ndi kachilombo amakhudzira ntchito zofunika kwambiri za umoyo wa tsiku ndi tsiku.

2 Chonde ndiwuzeni zomwe mwakumana nazo kuyambira pomwe mudayamba kumwa mankhwala a kachiromboka ndi momwe zikukhuzila kagwiridwe kanu ka ntchito/kuchita bizinezi/kugwira ntchito zapakhomo/kulima/kusamalila banja?

3. Chonde ndiwuzeni momwe mukukhalira ndi anthu ena m'mudzi chidziwireni kuti muli ndi kachilombo ndi momwe zikukhuzila kagwiridwe kanu ka ntchito yanu/bizinesi yanu/ntchito zapakhomo/kulima/kusamalila banja?

4. Chonde ndiwuzeni momwe mukukhala ndi wokondedwa ndi banja lanu chidziwireni kuti muli ndi kachilombo ndi momwe zikhudzira ntchito yanu/bizinesi yanu/ntchito zapakhomo/kulima/kusamalila banja?

   Zikomo

**Appendix K: Fomu ya chilolezo cho tenga mbali kafukufuku**

Ine (Dzina ndi mfunda wanu) …… ndikumulola Talumba Mercy Mankhokwe kuti tikambirane kuzera munjira yo funsidwa mafunso, pomwe akufuna kudziwa mavuto omwe anthu omwe ali ndi kachilombo ka HIV amakumana nawo ndi momwe mavutowa amakhudzira moyo wawo wa tsiku ndi tsiku.

Ndawerenga ndi kumvetsetsa zolinga za kafukufukuyu ndipo ndikuziwa kuti:

- Nditha kusiya zokambiranazi nthawi ina iliyonse
- Kutalika kwa nthawi ya zokambilanazi zizakhala pakati pa phindi makumi anai ndi asanu ndi mphindi makumi asanu ndi chimodzi
- Ndizayitanidwaso mukafukufukuyu kuti akafufuze ngati zomwe tinakambirana nthawi ya nkambirano ndizomwe zapezeka kumapeto akafukufukuyu
- Mawu anga adzusingidwa mwachinsinsi
- Sindidzalipiridwa potenga nawo mbali mu kafukufukuyu

Kutenga nawo mbali mu kafukufuku ameneyi molibe chilango chilichonse.
Dzina ndi sayini…… Tsiku ……

Dzina ndi sayini……Tsiku……
Ofufuza

**Appendix L: Fomu ya chilolezo kutepa mau mu kafukufuku**

Ine (Dzina ndi mfunda wanu) …… ndikumulola Talumba Mercy Mankhokwe kuti atepa mawu anga pamene tizikambirana munjira yofunsidwa mafunso, pomwe akufuna kudziwa mavuto omwe anthu omwe ali ndi

kachilombo ka HIV amakumana nawo ndi momwe mavutowa amakhudzira moyo wawo wa tsiku ndi tsiku.

Ndawerenga ndi kumvetsetsa zolinga za kafukufukuyu ndipo ndikuziwa kuti:

- Nditha kusiya zokambiranazi nthawi ina iliyonse
- Kutalika kwa nthawi ya zokambilanazi zizakhala pakati pa phindi makumi anai ndi asanu ndi mphindi makumi asanu ndi chimodzi
- Mawu anga adzasungidwa mwachinsinsi
- Sindidzalipiridwa potenga nawo mbali mu kafukufukuyu
- Kutenga nawo mbali mu kafukufuku ameneyi mulibe chilango chilichonse.

Dzina ndi sayini…… Tsiku ……

Dzina ndi sayini…….Tsiku……
Ofufuza

**Appendix M: Chikalata cha uthenga wokhudza kafufukuyu**

Okondedwa otenga nawo mbali,
Dzina langa ndine Talumba mercy Mankhokwe. Ndine ophunzira wa sukulu ya ukachenjede ya University of the Witwatersrand ku South Africa. Ndikupanga kafukufuku yemwe

tikufuna kudziwa mavuto omwe anthu omwe ali ndi kachilombo ka HIV amakumana nawo ndi momwe mavutowa amakhudzira moyo wawo wa tsiku ndi tsiku.

Ndidzakhala oyamika kwambiri ngati mungalole kutenga nawo mbali mu kafukufukuyu. Musanavomere kutenga nawo mbali, n'kofunika kuti muwerenge ndi kumvetsetsa chomwe chidzachitike: Abambo ndi amayi omwe akukhala ndi kachilombo ka HIV kwa zaka zoposera zisanu omwe akulandila mankhwala otalikitsa moyo a ART ku kiliniki ya Light House, komanso a zaka za pakati pa khumi zisanu ndi zitatu, ndi makumi asanu ndi chimodzi atha kutenga nawo mbali mu kafukufukuyu.

Kuti mulowe nawo mukafukufukuyu, mudzafunika kuti mulembe mu fomu yomwe idzafufuza za mbiri yanu, zinthu monga zaka ndi ntchito yanu. Kudzakhala mafunso omwe tidzakambirane pamaso ndi pamaso.Zokambirana kuzera mu njira yamafunso zikuyembekezereka kuzakhala pakati pa phindi makumi anayi ndi phindi makumi asanu ndi chimodzi, pomwe tidzafune.

Kumvetsetsa movuto omwe anthu omwe ali ndi kachilombo ka HIV amakumana nawo ndi momwe mavutowa amakhuzira moyo wawo watsiku ndi tsiku. Ndondomeko yamafunso idzagwiritsidwa ntchito pokambirana ndipo zokambiranazi zidzatepedwa potsatira kulora kwanu. Moyo wanu suzakhala mu chiwopsezo chiri chonse komanso simudzalandila mphotho ina iliyonse Kamba kotenga nawo mbali mu kafukufukuyu.

Tidzapanga kuthekela kulikonse kuti mbili ya moyo wanu iriyonse isungidwe mwachinsi. Pofuna kusunga chinsisi, aliyenso otenga nawo mbali mu kafukufukuyu adzapasidwa nambala yachinsisi yomwe idzasungidwe ndi wofufuza. Mayina anu adzalembedwa pa fomu yopempha chirolezo yokha.

Mudzayitanidwanso mukafukufukuyu kuti tikafufuze ngati zomwe tinakambirana nthawi ya nkambirano ndizomwe zapezeka kumapeto akafukufukuyu tizakhala tikuyang'ana ngati zomwe zidzapezeke zidzafanana ndi mawu anu komanso zomwe inu mwakhala mukukumana nazo. Ndipo mbiri yonse yomwe idzatengedwe mukafukufukuyu idzagwiritsidwa ntchito kuthandizira kafukufukuyu basi.

Kutenga nawo mbali kwanu mu kafukufukuyu kutengela kufuna kwanu ndipo ngati mungakane kutenga mbali, palibe chilango chomwe mudzapatsidwe. Muthaso kusiya kutenga nawo mbali muzokambiranazi nthawi ina iliyonse opanda chilango chotsatila.
Ngati muli ndi mafunso, chonde ndiyimbireni pa nambala lamya pa 0882878406 kapena tumizireni uthega wa imelo ku tmankhokwe1@gmail.com .

Ngati mukufuna kutenga nawo mbali mukafukufukuyu, chonde lembani fomu yotenga chiloledzo.

Ndizakondwera kwambiri mukandithandiza.

Ndatha ine wanu,
Talumba Mankhokwe
Lamya: 0994493319, 0882878406

## Appendix N: Turnitin similarity report

Research Final - Talumba

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