THE EFFECT OF PLHIV SUPPORT GROUPS AND INCOME GENERATION ACTIVITIES ON ART ADHERENCE AND RETENTION IN CARE IN MAGU DISTRICT, MWANZA REGION

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By

Amos Haki Nsheha

A Dissertation Submitted in (Partial) Fulfilment of the Requirements for the Degree of Masters of Public Health of Muhimbili University of Health and Allied Sciences October, 2021

CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by the Muhimbili university of health and allied sciences a dissertation entitled *"the effect of PLHIV support groups and income generation activities on ART adherence and retention in care in Magu District, Mwanza region"* in (partial) fulfilment of the requirements for the degree of masters of public health of Muhimbili University of Health and Allied Sciences.

Prof: Angwara Denis Kiwara

(Supervisor)

Date

DECLARATION AND COPYRIGHT

I, **AMOS HAKI NSHEHA** declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

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Last but not least, I would like to extend my sincere appreciation to my lovely family, for their prayers, tolerance, support, encouragement while I was away and their mutual understanding without which it would have been difficult for me to accomplish the mission.

DEDICATION

This work is dedicated to the memory of my beloved late father Mr. Haki Nsheha and my late mother Elika Iswelo for their guidance and norms when I was growing up.

ABSTRACT

Background: Poor adherence to ART medication is influenced by many factors including non-disclosure of a positive HIV status and HIV-related stigma. For optimal adherence to ART medicines, implementation of community interventions such as PLHIV support groups is critical in reducing stigma and enhancing disclosure of a positive HIV status. Additionally, income generation activities (IGA) being among the activities done by support groups have a positive link with the level of adherence. Despite the fact that PLHIV support groups have been formulated at both hospital and community settings in Tanzania as well as engagement of group members in income generation activities there is limited information on the effect of PLHIV support groups to ART adherence and retention in care among people living with HIV.

Aims of study: This study aimed at determining the effect of PLHIV support group interventions on ART adherence and retention in Care in Magu District, Mwanza Region.

Methodology: A cross-sectional study was designed to compare ART adherence rates and retention in care among PLHIV who participate in PLHIV support groups and those who do not. Study population included 252 HIV positive adults on ART receiving care at Magu District Hospital. Study respondents were obtained through systematic random sampling. Data was collected using structured questionnaire with close ended questions. The collected data was processed and analysed using SPSS version 16.

Results: The study enrolled 252 participants where majority of them were female (73%), aged above 40 years (53.2%), married (47.6%), had primary education (71%), disclosed HIV status (88.1%), not participating in PLHIV support group (53.6%), engaged in Income Generation activities (73.8%) and kept clinic appointments (90.1%). Respondents aged above 40 years, females, primary school leavers, married, disclosed their HIV status, engaged in income generation activities were more likely to participate in PLHIV support groups which was statistically significant (p=0.000; 0.034; 0.038; 0.002; 0.000 and 0.000) respectively. All clients participated in PLHIV support groups kept their clinic appointments which was statistically significant (p=0.000). Respondents participated in PLHIV support groups, engaged in Income generation activities (OR: 2.36(1.05-5.30 and p<0.05)) and disclosed HIV status (aOR: 5.62 (1.01-31.06 and p<0.05) were more adherent to ART and retained in care.

Conclusion: The study suggests that there is an association between PLHIV support group activities and Income generation activities and adherence to ART and retention in care: PLHIV who participate in PLHIV support group activities, engage in income generation activities and disclosed HIV status are more likely to adhere to ART and retained in care than those who do not participate.

Recommendation: This observation rationalizes investments in strengthening and scaling up the formulation of PLHIV support groups as one of the strategy for promoting social support and enhancing ART adherence and continuity of treatment among People Living with HIV.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-retroviral
CHAC	Council HIV and AIDS Coordinator
CTC	Care and Treatment Clinic
CTC 1	Care and Treatment Card number 1
DACC	District AIDS Control Coordinator
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
IGA	Income Generating Activities
PLHIV	People Living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
WHO	World Health Organization

DEFINITIONS OF TERMS

Adherence: Adherence to ART is taking all ARV pills in the correctly prescribed doses at the right time and in the right way (WHO, 2003)

Adherence using a three- day self- report: report over the last three days on how client took the pills. If taken throughout the month or missed one dose is good adherence and if missed two or more doses in a month then it is poor adherence (Nabukeera et al 2007)

Adherence using pill count: pill will be counted where the interview will be taking place, good adherence is considered when pills left coincides with prescribed dose and poor adherence will be considered when pills left over the prescribed dose (Nabukeera et al 2007)

ART: refers to provision of ARVs, Cotrimoxazole, management of opportunistic infections, nutritional support and palliative care as part of care (Aids Info Jan 2018)

ARVs: refers medications that suppress HIV replication and therefore restore client's immune system to prevent disease progression (Aids Info Jan 2018)

Good adherence: proportion of those who take their medication \geq 95% of the prescribed dose (National guideline for management of HIV and AIDS 2008)

Income generating activities: refers to activities (IGAs) consisting of small businesses managed by a group of people or individual to increase their household income through livelihood diversification such as gardening, piggery keeping, poultry keeping, money savings, transportation and grains business (Bassem, 2018).

Membership in PLHIV support group: refers to voluntarily joining to PLHIV support groups for all HIV positive individuals once he/she understood the purpose of a particular support group (Fanelli and Moyo, 2008)

Participation in PLHIV support group: refers to meaningfully participation in all aspects of support group formation and operation (Fanelli and Moyo, 2008)

Participation in PLHIV support group with IGA: refers to meaningfully participation in all aspects of establishment/initiation of any type of income of generating activity and its operation in the group (Bassem, 2018).

Poor adherence: proportion of those who take their medication <95% of the prescribed dose (Tanzania guideline for management of HIV and AIDS 2017)

PLHIV support group: refers to an association of PLHIV who come together to share challenges and experiences of living with HIV at community level (Fanelli and Moyo, 2008)

Viral suppression: refers to amount of HIV viral load in the blood of people living with HIV. Viral load below 1000 copies per microliter or undetectable level is considered to be good viral suppression and above 1000 copies per microliter is considered poor viral suppression (Tanzania guideline for management of HIV and AIDS 2017)

CHAPTER ONE

INTRODUCTION

1.1 Background

Over the decades the world has witnessed a negative impact of Acquired Immuno Deficiency Syndrome (AIDS) (Sibhatu, 2012). Globally, by 2017, the disease had affected more than 37 million people and almost two third of these lived in sub-Saharan Africa (UNAIDS, 2017). In addressing the burden, the Highly Active Antiretroviral Therapy (HAART) have proved to delay disease progression to AIDS resulting to optimal and more sustained virologic and immunologic response (Zulu et al, 2009) and increase survival (Birungi et al 2011). In sub-Saharan Africa the number of HIV and AIDS patients on Anti-Retroviral Therapy (ART) has increased substantially from 53% in 2015 to 67% in 2018 (UNAIDS, 2019). Increased access to ART for people living with HIV and AIDS requires extra efforts to support adherence to drugs and retention in care (Lawrence, 2018). To meet the treatment goals, People Living with HIV (PLHIV) are required to attain a good adherence to ART.

Adherence to prescribed daily dosing of ARV medicines among PLHIV is critical to appreciate the public health impact of ART in reducing HIV transmission and enhancing treatment outcomes (UNAIDS 2013). According to WHO, adherence to ARV medicines refers to the extent to which individual's drug-taking behaviour coincides with the prescribed treatment and for optimal viral suppression adherence of > 95% is required (WHO, 2013). Globally, an ART adherence rate was at 62% at the end of 2011 (Ortego et al, 2011). On the other hand, adherence in sub-Saharan African patients was at 77% (Mills et al, 2006). In Tanzania adherence rate was at 81% in Dar es Salaam (Aisa et al, 2014), Nyamagana District Council in Mwanza Region was at 54.9% (Samuel et al 2018) and that of Iringa was at 83% (Mosha et al, 2019).

Poor adherence to ART has been linked to increased hospital admissions, low productivity, and disease progression to AIDS and death in both developed and developing countries (Bajunirwe et al, 2009). Moreover, poor adherence can lead to treatment failure due to emergence of drug-resistant viral strains limiting future options and increased transmission of resistant strains of HIV to the public (Harries et al, 2001).

There are a number of known factors behind poor adherence of ART among PLHIV. Chiefly, include, non-disclosure of a positive HIV status and HIV-related stigma (UNAIDS 2013). HIV-Related stigma and nondisclosure of a positive HIV statuses are linked with poor ART adherence and increase HIV transmission (UNAIDS 2013). A person not disclosing his/her positive HIV status has negative inner feelings towards him/her because of HIV positive status. Because of stigma some PLHIV abstain from access to healthcare services since they tend to isolate themselves from others and not willing to be enrolled or not expose their ARV drugs to others even when they fall very sick (Overstreet et al, 2012). A study done in rural Nigeria proved that low level of stigma is associated with good adherence to ARV medication (Omosanya, 2013). Patients in sub-Saharan Africa have similar or higher adherence levels compared to those of developed countries and predictors for ART adherence included factors related to patients and their families, medication related factors (taste, pill size, drug formulation and drug side effects), healthcare systems, stigma and discrimination factors and socioeconomic factors (Ayalu and Sibhatu, 2012).

Income generation activities (IGA) contributing to socioeconomic status of an individual have fundamental role in setting up enabling factors such as food, transport, water and good housing for a client to access HIV care, treatment and support services. Therefore, adherence to ART medication is linked with socioeconomic status of an individual (Beth et al, 2011). Economic constraints, perceived stigma and discrimination and poor healthcare services are barriers to ART adherence whereas disclosure of HIV status, social support and having long lived projects had positively supported adherence to ART (Woldesellassie et al, 2014). A good thing is that many of these factors can be changed through deploying interventions which improve adherence (Simpson et al, 2015).

Optimization of ART adherence needs to deploy community interventions that are geared to reduce stigma and enhance disclosure of a positive HIV status. Social support interventions are among the proposed community strategies to address HIV related stigma and discrimination (Bolton, 2003). Social support can improve psychosocial status on people with increased stress due to chronic illness such as HIV and AIDS (Turner-Cobb et al, 2002. Studies in Nigeria revealed that PLHIV support groups have been widely used as an intervention of providing social support for PLHIV (Simpson, 2015).

PLHIV support group refers to an association of PLHIV who come together to share challenges and experiences of living with HIV. Further, a HIV positive person participating in PLHIV support group activities is exposed to both individual and group benefits. Individual benefits include general supportive counselling, ART adherence counselling, and peer support for addressing other HIV-related needs. Group benefits include

education/information on HIV/AIDS management, group psychotherapy and experience sharing (Fanelli and Moyo, 2008)

PLHIV support groups are recommended as a strategy to address retention in HIV care and adherence among PLHIV getting ART (WHO, 2013). PLHIV support groups assist group members to cope with stressful events, alleviate stigma and engaging in new actions which promote a healthy life (Kalichman & Sikkema, 1996; Visser & Mundell, 2008; Wood, 2007). Further, support groups have shown to be an effective, useful and supportive intervention (Spirig, 1998) and participation in support groups' increases self-esteem, social belonging, enhance quality of life, reduce stigma and improve medication compliance (Lennon-Dearing, 2008). Despite the fact that PLHIV support groups have been formulated at both hospital and community settings in Tanzania as well engagement of group members in income generation activities there is limited information on the contribution of PLHIV support groups to ART adherence among people living with HIV to enable formulation of more support groups at the communities

1.2 Statement of the problem

Adherence to prescribed daily dosing of ARV medicines among PLHIV is critical to appreciate the public health impact of ART in reducing HIV transmission and enhancing treatment outcomes (UNAIDS 2013). According to WHO, adherence to ARV medicines refers to the extent to which individual's drug-taking behaviour coincides with the prescribed treatment and for optimal and durable viral suppression adherence of > 95% is required (WHO, 2013).

Research findings have shown that there is poor adherence to ART medication among PLHIV on ART (UNAIDS, 2013). Globally, an ART adherence rate was at 62% at the end of 2011 (Ortego et al, 2011). Further, in developed countries ART adherence rates were below 75% and that of developing countries was above 75% at the end of 2008 (Vreeman et al, 2008). On the other hand, adherence in sub-Saharan African patients was at 77% (Mills et al, 2006), while in West Africa adherence rate in Nigeria was at 85% (Okoronkwo et al, 2013) and in Ghana 38% (Obirikorang, 2013). In Tanzania adherence rate was at 81% in Dar es Salaam (Aisa et al, 2014) and that of Nyamagana District Council in Mwanza Region was at 54.9% (Samuel et al 2018).

Poor adherence to ART medication is influenced by many factors including non-disclosure of a positive HIV status and HIV-related stigma (UNAIDS 2013) and poor adherence to

ART has been linked to increased hospital admissions, low productivity, and disease progression to AIDS and death in both developed and developing countries (Bajunirwe et al, 2009). Therefore, for optimal adherence to ART medicines, implementation of community interventions such as PLHIV support groups is critical in reducing stigma and enhancing disclosure which in turn will improve adherence on ART (Sphiwe, 2012).

However, there is limited information on the contribution of PLHIV support group activities in improving ART adherence among people living with HIV (Simpson, 2015). Therefore, there is a dire need to explore whether PLHIV who participate in PLHIV support group activities have better adherence to ARV medication than those who do not. This study aims at examining the contribution of PLHIV support groups and income generation activities on ART adherence and retention in care in Magu District, Mwanza Region

1.3 Conceptual framework.

The conceptual framework for various factors influencing adherence to ART therapy and retention in care among People Living with HIV and AIDS (PLHIV) in Magu District, Mwanza Region described below is based on the Information Motivation Behaviour Skill (IMB) model proposed by Fisher et al (2006). In regard to ART the model holds that People Living with HIV who are well informed, motivated to act and possess the behavioural skills that enable them to act effectively, will adhere to the ART treatment plan (Fisher et al 2006).

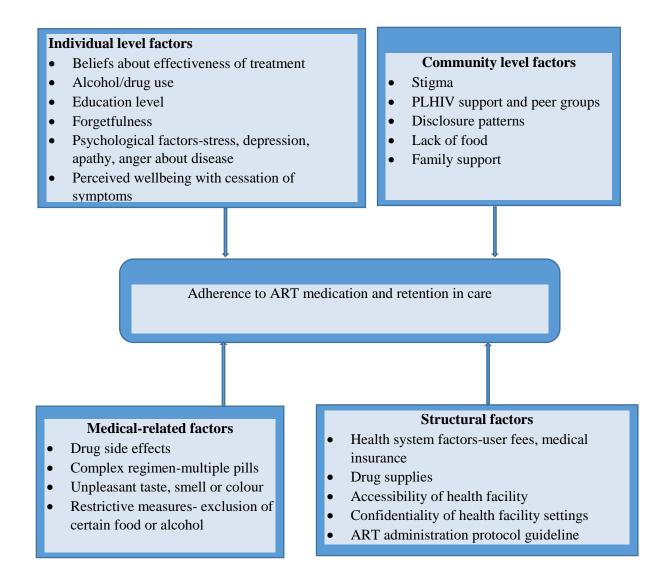


Figure 1: Factors influencing adherence to ART (adopted and modified from Wekesa, 2007)

This conceptual framework describes the association between various variables and their contribution to adherence on ART therapy and retention in care that an investigator sees that they are relevant to answer the research question. Adherence to ART depend on a number of various factors which are interlinked. Individual factors, Community factors, Medication related factors and structural related factors such as level of stigma, disclosure of a positive HIV status, participation in PLHIV support group & IGA, drug side effects, distance to the clinic, education level, family support and accessibility to ART services can influence ART adherence and retention in care either negatively or positively (Ayalu and Sibhatu, 2012). A person who has disclosed a positive HIV status to the family or friends, participates in PLHIV support groups and gets family support will have none or low level of stigma which

creates conducive environment for good adherence (Omosanya, 2013). Whereas a person who has not disclosed a positive HIV status to friends or family members will neither get support from the family members nor participate in PLHIV support groups leading to poor adherence (Overstreet et al, 2012). On the other hand, income generation activities improve household income to afford transport costs, medical costs and access to ART services at Care and Treatment clinics which is associated with good adherence and retention. A person not participating in income generation activities has unreliable household income to afford transport costs and access to ART services at Care and access to ART services and this is associated with good adherence and retention. A person not participating in income generation activities has unreliable household income to afford transport costs and access to ART services and this is associated with poor adherence to ART (Beth et al, 2011).

1.4 Rationale

The study findings will add knowledge to the existing body of knowledge on the value of social support groups in reducing HIV related stigma and enhancing disclosure of HIV status which in turn will improve adherence to ARV medication. Success of ART program is directly connected with improved adherence and with this PLHIV will have immune reconstitution, improved survival and decreased HIV transmission to the public. In addition, gained knowledge will act as catalyst to policy makers and program managers to emphasize on the formulation/establishment of PLHIV support groups for PLHIV in different settings.

1.5 Research questions

1.5.1 General research question

• What is the effect of PLHIV support groups and IGA on ART adherence and retention in care in Magu District?

1.5.2 Specific research questions

- 1. What is the association between PLHIV support groups and adherence on ART in Magu District?
- 2. What is the association between income generation activities (IGA) and adherence on ART in Magu Districts?
- 3. What is the association between PLHIV support groups and retention in HIV care in Magu District?
- 4. What is the association between income generation activities (IGA) and retention in HIV care in Magu District?

1.6 Objectives

1.6.1 Broad Objective

To determine the contribution of PLHIV support groups and IGA on ART adherence and retention in Care in Magu District, Mwanza Region

1.6.2 Specific objectives:

- To examine the association between PLHIV support groups and adherence on ART in Magu District.
- 2. To find out the association between income generation activities (IGA) and adherence on ART in Magu Districts?
- 3. To explore the association between PLHIV support groups and retention in HIV care in Magu District?
- 4. To examine the association between income generation activities (IGA) and retention in HIV care in Magu District?

CHAPTER TWO

LITERATURE REVIEW

World Health Organization (WHO) promotes peer support groups as a means of addressing special needs of their companion and thus such groups create an avenue for experience sharing, encouraging disclosure, reducing stigma and discrimination, improving self-confidence, improving patient's coping skills and psychosocial functioning and assisting medication compliance (WHO, 2014). Therefore, PLHIV support groups have a great role to play in HIV care and treatment programs particularly in improving adherence on ART and retaining HIV positive participants in care (Moses et al, 2015).

The subsections below review the impact of support groups' activities including income generating activities and those not participating in support group activities as a way of addressing HIV- related stigma and disclosure as among the factors influencing adherence to ART.

Association between PLHIV support groups and ART adherence

In regard to PLHIV support groups and ART adherence, a systematic review study reveals that HIV positive patients who are participating in PLHIV support groups and peer groups have increased adherence on ART as compared to those who do not participate in support groups (Moses et al, 2015). Additionally, Wouters and colleagues found that 89.9% of support group members reported that support group meetings formed an avenue of knowledge and experience sharing on how to take ARV medications (Wouters et al, 2009). This has been documented following a study in Mozambique which shows that participation in PLHIV support groups has increased adherence to ART among group members (Decroo et al, 2011).

HIV positive patients participating in PLHIV support groups have good adherence of about 95% as compared to 92% of their counterparts and this suggest that HIV positive patients who participate in PLHIV support groups have higher chances of being adherent than those who do not participate (Simpson, 2015). Also participation in PLHIV support groups improves adherence to medication, practice safer sex to prevent re-infection and self-efficacy (Lennon-Dearing, 2008).

Studies done in Uganda, Mozambique and Nigeria have shown the association between participation in PLHIV support groups and adherence to ART (Decroo et al, 2011, Simpson, 2015, Moses et al, 2015). However, the association is not so direct since it is the function of

reduced stigma and enhanced disclosure of HIV status among PLHIV. Stigma alleviation facilitates easy disclosure of a positive HIV status, enhances self-efficacy, resilience, getting support from peers, family and community members and subsequently creates conducive environment for accessing ART services. Accessing ART means being able to collect ARV drugs, afford transportation to ART clinics, access food and keeping clinic appointments.

Association between PLHIV support groups and retention in HIV care

For successful ART programs, retention in HIV care has a big role to play in ensuring continuous provision of HIV care and treatment services leading to improved adherence. HIV positive participants on ART participating in support groups had low rates of lost to follow up as compared to their counterparts (Wouters, 2009) and on the other hand in Mozambique 97.5% patients remained in care for almost one year among PLHIV participating in PLHIV support groups (Decroo et al, 2011).

Community-based model like peer support groups assist in improving maternal enrolment and retention in care for option B+ sites (Sam et al, 2017). This is in support with the study findings by Erica and colleagues in Iringa which showed that support groups for PLHIV are among the community interventions for improving adherence to ART and retention in HIV care (Erica et al, 2014). Furthermore, systematic review study on community-based adherence group by Amy and colleagues has shown that HIV positive patients who are members of community-based adherence group were retained in care approximately 60 months (Amy et al, 2018). In Uganda, it was learnt that peer support groups have helped adolescent to adhere to ARV medication and 94% of adolescent remained in HIV care after one year post enrolment (Nabukeera Barungi et al, 2015).

Therefore it is evident that support groups for PLHIV have great role in ensuring continuity in receiving HIV care and treatment services among PLHIV since stigma and discrimination would be at minimal level and hence free access to aforementioned services. Our study needs to substantiate that evidence or come with different results for the Tanzanian context.

Association between income generation activities and ART adherence

Income generating activities (IGAs) consist of small businesses managed by a group of people to increase their household income through livelihood diversification also can be defined as the support to the vulnerable people and their host communities to have increased revenues in order to reinforce their food security and livelihoods (Bassem, 2018). Adherence on ART medication is linked with socioeconomic status of an individual which explains

individual's access to resources like food, water, education, health facilities and good housing (Beth et al, 2011). Hence, it includes individual's capability to afford transportation costs to attend ART clinic appointments, pharmacy drug collection, financial needs for treating illnesses, access to food and good housing (Sibhatu, 2012). In order to cater for the costs and needs, an individual is forced to engage in income generating activities to have good access to the mentioned resources. Socioeconomic factors that include income, education, occupation or employment status have a positive link with the level of adherence though it depends on the culture, economic and geographical contexts where the study is taking place (Karl & Supa, 2013). Furthermore, financial problems and the need to use available money for other social needs like shelter are associated with poor adherence to ART (Beth et al, 2011). Poverty, unemployment and lack of food impact negatively ARV medication compliance since lack of income reduces individual's purchasing power (Kaal and Brian, 2019) and lack of money prevents access to health facility to collect ARV drugs (Ankomah et al, 2016).

Many studies conducted in low and middle income countries have shown that there is a connection between economic strengths and compliance to antiretroviral therapy (Lankowski et al, 2014; Peltzer & Pengpid, 2013; Reda & Biadgilign, 2012). Recently conducted longitudinal studies in high income countries aimed at examining the association between socioeconomic indicators and virologic suppression revealed that low household income has negatively affected virologic suppression and retention in care (McFall et al, 2013). Also poor socioeconomic status is linked to poor adherence on ART especially in settings where there is no access to universal free healthcare services (Lisa et al, 2016). A study in Australia aiming at examining the influence of socioeconomic and psychosocial issues to virologic suppression found that financial hardships in meeting travel costs to attend ART clinic, cost share and cost barriers to access health services was linked to poor adherence and retention in care (Krista et al, 2019).

Inadequate food is associated with decreased compliance to ART and therefore food security has connection to good adherence to both ART and continuum of care (Sera et al, 2014). This is in support with the randomized control study findings in Shinyanga which addressed food insecurity among PLHIV newly initiated on ART that food security has connection with good adherence to ART (McCoy et al, 2015). Further, study findings in Iringa-Tanzania shown that income generating activities and community mobilization activities for PLHIV played a great role in adhering to ART medication (Erica et al, 2014).

A randomized trial of food and cash incentives for people living with HIV infection in Shinyanga revealed that intrinsic motivation for ART compliance increased considerably both in control group and within the food and cash incentive groups (Nancy et al, 2018). However, the study did not explain the role of other factors such as PLHIV support groups which contribute to intrinsic motivation for ART adherence and the long effect (more than one year) to ART adherence after cessation of incentives. Therefore, there is still a gap in understanding other factors that influence intrinsic motivation for ART adherence and long term adherence to ART post cessation of incentives.

Income generating activities are geared to improve household economy in the sense that families with HIV positive participants will provide economic and psychosocial support to their fellows in accessing care and treatment services, access to nutritious food and decreased incidences of recurrent illness leading to increased quality of life and decreased hospitalizations. Improved health has a direct link with increased productivity at household level and this contributes to ART program success particularly retention in care. So, our study examined the contribution of PLHIV support groups and self-initiated income generating activities to ART adherence.

Association between income generation activities and retention in HIV care

In an effort to improve economic status at household level, individuals are obliged to engage in income generating activities to have access to health services, food and good housing. Improved household economy facilitates and ensures food security; afford transportation costs and hence enhancing retention in care. Recently conducted longitudinal studies in high income countries aimed at examining the association between socioeconomic indicators and virologic suppression revealed that low household income has negatively affected virologic suppression and retention in care (McFall et al, 2013). In addition, poor socioeconomic status is linked to poor adherence to ART and retention in care (Lisa et al, 2016) and financial hardships in meeting travel costs to attend ART clinic, cost share and cost barriers to access health services is linked to poor adherence and retention in care (Krista et al, 2019).

Inadequate food is associated with decreased compliance to ART and retention in care and therefore food security has connection to good adherence to both ART and continuum of care (Sera et al, 2014). In addition, income generating activities and community mobilization activities for PLHIV play a great role in retaining patients to HIV care (Erica et al, 2014).

Therefore, income generating activities are geared to improve household economy in the sense that families with HIV positive participants will provide economic and psychosocial support to their fellows in accessing care and treatment services, access to nutritious food and decreased incidences of recurrent illness leading to increased quality of life and decreased hospitalizations. Improved health has a direct link with increased productivity at household level and this contributes to ART program success particularly retention in care. So, our study will examine the contribution of income generating activities in improving participants retention in care and the results will be utilized to inform policy makers and partners working on ART program across the country.

CHAPTER THREE

MATHEDOLOGY

3.1 Introduction

This chapter describes the methods that were used in the study. It shows study area, study design, study population, sample size estimation, sampling technique, inclusion and exclusion criteria, how data was collected, analysed, and disseminated as well as ethical consideration.

3.2 Study area

The study was conducted in Magu District Council of Mwanza Region. The district has a prevalence of 4.9%, 14,136 current on care with the retention rate of 99%, viral load coverage of 76.9% and viral suppression of 97.2% according to the local data for the period of April-June from DHIS. Magu district was selected because of the community PLHIV support groups' activities that are being conducted including income generation activities following the exposure to the knowledge and awareness on income generating activities done by different partners in the past and this can be an avenue of assessing their long term impacts in relation to ART adherence and retention in care.

Explanation of the PLHIV support groups: To enhance ART adherence and retention in care, Adherence counsellors sensitize ART patients about the benefits of PLHIV support groups and encourage them to become members so as to benefit from continuous adherence support and care services. Membership to join PLHIV support groups is voluntary to all HIV positive individuals receiving care at care and treatment and membership is defined as being formally registered with a particular PLHIV support group. Participation in PLHIV support group activities include attending support group meetings and group activities (Simpson et al, 2015). Group members meet at PLHIV cluster office or at chairperson's home on weekly or monthly basis depending on what they are engaged on. Group members do the following: conduct discussion on adherence (experience sharing), discussion on ways to reduce stigma and discrimination in the community, counselling, building relationship, discussion on how to deal with psychosocial challenges such as overcoming anxiety, coping with stress, identification of treatment supporter, tracking of lost to follow ups, providing testimonies regarding their health and home visits among PLHIV group members and engaging in income generation activities (Fanelli and Moyo, 2008).

3.3 Study design:

A cross-sectional study was designed to compare ART adherence rates and retention in care among PLHIV who participate in PLHIV support groups and those who do not. This design was deployed to gather information on the association between dependent and independent variables. The design was preferred because it was easy to carry out and cost conscious which allowed data collection in an environment with limited resources.

3.4 Study population:

Study participants included adult PLHIV receiving ARV medication at Magu District Hospital. The district hospital has a total of 3,856 client receiving ART services and about 74% (2,853) of clients are on multi-months scription and 1,003 clients were on monthly prescription. The reason of selecting Magu District hospital is that district hospital receives clients from different places and hence a representative sample was obtained from district hospital. Participants on ARVs have different status as far as PLHIV support groups are concerned, so we have participants who have not joined PLHIV support group activities and those who joined support group activities. The study gathered information from both PLHIV who participate in PLHIV support groups activities and those who do not.

3.5 Sample size estimation

The sample size was calculated by using WHO formula for sample size estimation for a proportion under the following assumptions; from the previous study the proportion of adherence to ART among PLHIV was at 83% (Mosha et al, 2019) and 95% confidence level with the margin error of 5%.

$$N = (\underline{Z})^2 P (1-P)$$
$$E^2$$

Where,

N is the estimated sample size

Z is taken as 1.96, equivalent to a confidence interval level of 95%

P is the proportion/ prevalence of level of adherence (83% Mosha et al, 2019)

E is the maximum likely error. For this study will allow study error of 5% \pm

$$N = \underline{1.96^2 \times 0.83(1-0.83)}_{0.05^2} = 217$$

N=217 as the minimum sample size of this study

3.6 Sampling technique:

Study participants were obtained through systematic random sampling. The sampling frame was obtained from the Facility ART register of Magu district hospital and thereafter calculated sampling interval k (k=N/n) based on the clients on monthly ARV prescription which was 5 and then selected the first element at random using simple random sampling from the first k units. Number 4 was the first element and from there included every kth unit from the frame into the sample (4, 9, 14, 19, 24.....) until we reached the required sample size of 252. The researcher provided the ID numbers of all expected and eligible respondents to the triage person at CTC. The triage person identified clients on sample list during the clinic day by comparing the numbers on the patient file and requested them to meet with the researcher. Thereafter, all recruited participants were provided with baseline information including filling out the consent form. The status of PLHIV support group participation was established during the interview.

3.7 Inclusion criteria

The inclusion criteria were all adults who tested positive for HIV, are enrolled into Care and Treatment Clinics, receive ARV drugs, physically and mentally fit, willing to participate in the study and residents of the Magu District Council.

3.8 Exclusion criteria

The exclusion criteria were newly diagnosed to have HIV infection, participants with other chronic diseases such as diabetes, cancers and psychiatric disorders.

3.9 Study variables

According to the nature of the study, the primary outcome or dependent variables was the rate of adherence to ARV medication and retention in care. This was measured through unannounced pill counts and keeping clinic appointments. The main exposure variable was participation in PLHIV support group activities. Other independent variables included socio-demographic characteristics such as sex, age, education and marital status. These were measured through observation and posing questions to respondents to ascertain the age (in years), marital status and education level; socio-economic characteristics including occupation and medical related factors including hospital admission, medication related factors (drug side effect, pill burden, taste), family support, HIV status disclosure, distance to the clinic, transport cost and education level through posing questions to respondents.

3.10 Data collection methods:

In an effort to achieve the desired goal of the study quantitative method was applied. This method objectively measured adherence levels, retention in care, study participants characteristics, PLHIV support group participation status, status of HIV disclosure and socio-demographic characteristics.

Structured questionnaire developed by the investigator and used to collect data. The investigator prepared questionnaire in English and later translated in Kiswahili for easy follow up and better understanding among respondents. The structured questionnaire consisted of sections regarding socio-demographic characteristics (age, sex, education, marital status and HIV status of the family member or spouse), socio-economic status (occupation, income, assets, food uptake), socio-cultural information (disclosure, stigma, opinion and benefits of ART therapy), Information regarding participation in PLHIV support groups (membership status, schedule of the meeting, attendance, opinion and benefits of support groups) and income generating activities (small business, poultry or piggery keeping, money savings, SACCOS, farming, transportation and bee keeping). Questions to ask the respondents were developed following the proposed sections mentioned above to have the right information which assisted in answering the research question of this study.

Prior to data collection, the questionnaire was piloted to a maximum of 10 people with similar characteristics (HIV positive, Receiving ART, participating in PLHIV support groups-) as study participants to determine its applicability and appropriateness in getting the required information but were not included in the final sample. The process of pre-testing of developed questionnaire involved one to one discussion to 10 PLHIV to get the real feedback. Thereafter, the questionnaire was reviewed and updated to accommodate comments and feedback from the pilot. The questionnaire was then printed and interviewer administered the structured questionnaire through one to one discussion with the respondents.

To ascertain PLHIV support group participation status, respondents were asked questions regarding their participation in PLHIV support group activities by answering Yes or No and if the answer is yes then other questions followed to further understand their participation and observed benefits.

3.11 Adherence measurements:

Researchers across the globe have established different subjective and objective modalities for measuring adherence to ARV among different populations. Subjective measurement of adherence to ARV medication include: self-report and visual analogue scale. Pharmacy refill logs and pill count are objective ways of measuring adherence to medication since there is physical count of remaining pills after one month supply of ARV drugs (Sibhatu, 2012)

For this study, adherence to ARV medication was obtained by using both self-report and pill count along with viral load quantification. Self-report concentrated on 3-day self-report whereby client were asked how he/she has been taking medication in the past three days prior to the interview and pill count was done at the time of interview whereas viral load results was checked from CTC 1 card or traced in patient's file at the clinic. For this study adherence was measured using unannounced pill count.

For once daily dosing of ARV drugs: taking all the medication as prescribed or missing one dose per month was considered as good adherence (\geq 95%) and missing 2 or more doses was considered as poor adherence (<95%). For twice daily dosing ARV drugs: taking all the medication as prescribed or missing three doses per month was considered as good adherence (\geq 95%) and missing 4 or more doses per month was considered as poor adherence (<95%). Whereas good viral suppression is plasma viral load below 1000/ml copies or undetectable level and poor viral suppression is viral load above 1000/ml copies.

3.12 Data management:

Data were gathered into developed questionnaire and transferred to computer for further cleaning and processing. To ensure quality of data, the questionnaire was tested before the actual data collection and after data collection, before entering in the computer data were cleaned and checked for completeness and consistency. The questionnaire was first piloted by interviewing PLHIV with the same characteristics of intended respondents to see applicability of the set questions in terms of ethical issues, relevance and acceptability. And thereafter the questionnaire was refined to suit the comments given and utilized the refined questionnaires to collect data.

For the viral load quantification, CTC ID unique number was used to follow HIV Viral Load for an individual results documented in the client file. All the interviews was conducted by principal investigator and this ensured consistency in administering the questionnaire, viral load quantification and pill count for adherence measurement.

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3.13 Data analysis

Data entry and analysis carried out using Statistical Package for the Social Science (SPSS) software version 16.0. Analysis was conducted using both descriptive statistics and logistic regression analyses. Descriptive statistics was carried out to characterize PLHIV in Magu district hospital. Bivariate analysis was used to examine the association between the exposure variable, and other independent variables with ART adherence and retention in care. To control the effect of confounding variables, stepwise logistic regression was deployed to examine the independent association between PLHIV support group and their ART adherence and retention in care. Any association was considered statistically significant if the association reached a p-value of <0.05 at a 95% confidence interval.

3.14 Reliability

To ensure reliability of the study findings, investigator used the validated tools for measuring adherence on ART and registers to ascertain for clinic appointments which can reproduced when the research is repeated under the same conditions.

3.15 Ethical Issues

Ethical issues were observed throughout data collection, data analysis and reporting. Since data collection involved PLHIV, they needed to be equipped with the right information regarding the study in order for them to make an informed consent on their participation.

To maintain confidentiality throughout data collection process, the names of respondents were de-identified and given code numbers. Because of the nature of the problem under study, there was no harm inflicted to the respondents such as discomfort, harassment, invasion of privacy since the information required was easy to share with someone else. Further, data was not collected from a respondent who was sick or has mental problem and no any incentives were given prior to data collection. In addition, before conducting study, ethical clearance was sought from Ethical Research Committee and Institutional Review Board.

3.16 Dissemination of the Research Findings

The final dissertation findings of the study is planned to be disseminated through submission of copies to the office of the Director of postgraduate studies at MUHAS. One copy will be sent to the DMO office in Magu. Efforts will be made to present the dissertation findings during the World AIDS day forum where different stakeholders including policy and decision makers convene for strategic planning.

CHAPTER FOUR

RESULTS

4.1 Introduction

This section has two parts; part 1 of the results shows descriptive statistics of the respondents and part 2 shows how different variables affect adherence on ART and retention in care among People Living with HIV.

4.2 Part 1. Descriptive statistics

4.2.1 Social demographics (Table 1)

The study enrolled 252 participants where majority of them were female (73%), aged above 40 years (53.2%), married (47.6%), had primary education (71%), disclosed HIV status (88.1%), not participating in PLHIV support group (53.6%) and majority of them were engaging in Income Generation activities (73.8%) and not missed their clinic appointments (90.1%)

Characteristics	Frequency	Percentage %
Age:		
21-40	97	38.5
41-60	134	53.2
61-80	21	8.3
Sex:		
Male	68	27
Female	184	73
Education:		
None	59	23.4
Primary School	179	71
Secondary School	11	4.4
College	3	1.2
Marital status:		
Single	29	11.5
Married	120	47.6
Separated	49	19.4
Widowed	48	19
Cohabiting	6	2.4
Disclosure:		
Yes	222	88.1
No	30	11.9
Engage PLHIV Group:		
Yes	117	46.4
No	135	53.6
Engagement in IGA:		
Yes	186	73.8
No	66	26.2
MISSAP		
Yes	25	9.9
No	227	90.1
Pill count		
>95%	224	88.9
<95%	28	11.1

Table 1: Sociodemographic Characteristics of Respondents (n=252)

4.2.2 Social demographics of respondents by Support Group Participation Status (Table 2)

Respondents aged above 40 years, females, primary school leavers, married, disclosed their HIV status, engaging in income generation activities were more likely to participate in PLHIV support groups which was statistically significant (p=0.000; 0.034; 0.038; 0.002; 0.000 and 0.000) respectively. All clients participating in PLHIV support groups kept their clinic appointments which was statistically significant (p=0.000).

	Support Group Participation			n	P-value
Variable	NO		YES		
	Frequency	%	Frequency	%	1
Age:					
21-40	70	51.85	27	23.08	
41-60	54	40	80	68.38	0.000
61-80	11	8.15	10	8.55	
Sex:					
Male	44	32.59	24	20.51	0.034
Female	91	67.41	93	79.49	0.034
Education:					
None	40	29.63	19	16.24	
Primary School	87	64.44	92	78.63	0.038
Secondary School	7	5.19	4	3.42	0.050
College	1	0.74	2	1.71	
Marital status:					
Single	22	16.3	7	5.98	
Married	69	51.11	51	43.59	
Separated	26	19.26	23	19.66	0.002
Widowed	17	12.59	31	26.5	
Cohabiting	1	0.74	5	4.27	
Disclosure:					
Yes	107	79.26	115	98.29	0.000
No	28	20.74	2	1.71	
Engage-IGA:					
Yes	74	54.81	112	95.73	0.000
No	61	45.19	5	4.27	
MISSAP					
Yes	25	18.52	0	0	0.000
No	110	81.48	117	100	0.000

 Table 2: Sociodemographic of respondents by Support Group Participation Status

 (252)

4.3 Part 2. Association of variables with adherence to ART and Retention in care4.3.1 Association between sociodemographic, IGA, PLHIV support group

participation and ART Adherence

Participants aged 41-60 were more adherent to ART which was statistically significant (OR: 2.83 (1.24-6.43) and p<0.05). Females were more adherent to ART but was not statistically significant (OR: 1.09(0.46-2.61). Respondents who disclosed their HIV status were more adherent to ART which was statistically significant (aOR: 5.62 (1.01-31.06 and p<0.05). Participants participated in PLHIV support groups and engaged in Income generation activities were more adherent to ART which was statistically significant (OR: 2.36(1.05-

5.30) and p<0.05. Respondents who missed clinic appointment were less likely to adhere on ART which was statistically significant (aOR: 0.02 (0.005-0.102).

Table 3: Association between sociodemographic, IGA, PLHIV support groupparticipation and ART Adherence

Variable		Adhe	erence			
	YES		NO		COR (95%CI)	AOR(95% CI)
	n	%	n	%		
Age:						
21-40	79	35.27	18	64.29	ref	ref
41-60	124	55.36	10	35.71	2.83(1.24-6.43)**	1.54 (0.38-6.33)
61-80	21	9.38	0	0.00		
Sex:						
Male	60	26.79	8	28.57	ref	
Female	164	73.21	20	71.43	1.09(0.46-2.61)	
Education:						
None	55	24.55	4	14.29	ref	
Primary School	155	69.2	24	85.71	0.47(0.16-1.41)	
Secondary School	11	4.91	0	0.00		
College	3	1.34	0	0.00		
Marital status:						
Single	26	11.61	3	10.71	ref	
Married	105	46.88	15	53.57	0.81(0.22-3.0)	
Separated	40	17.86	9	32.14	0.51(0.13-2.07)	
Widowed	47	20.98	1	3.57	5.42(0.54-54.82)	
Cohabiting	6	2.68	0	0.00		
Disclosure:						
Yes	201	89.73	21	75.00	2.91(1.12-7.59) **	5.62 (1.01- 31.06)**
No	23	10.27	7	25.00	ref	ref
Participation in PLHIV Group:						
Yes	117	52.23	0	0.00		
No	107	47.77	28	100		
Engagement in IGA:						
Yes	170	75.89	16	57.14	2.36(1.05-5.30) **	
No	54	24.11	12	42.86	ref	
MISSAP						
Yes	10	4.46	15	53.57	ref	ref
No	214	95.54	13	46.43	0.04(0.02-0.11)**	0.02 (0.005- 0.102)**

4.3.2 Association between sociodemographic, IGA, PLHIV support group participation and Retention in care

Respondents aged above 40 years (OR: 1.89(0.82-4.36), engaging in income generation activities (OR: 2.04(0.87-4.79)), Participated in PLHIV support groups and disclosed their HIV status (OR: 1.47(0.47-4.63) were associated with high odds of high retention in care. Respondents who had poor adherence to ART were associated with low odds of being retained in care (aOR: 0.03(0.01-0.10).

	R	etention	in care		COD (050/	
Variable	NO MISSAP		MISSAP		COR (95%	AOR (95% CI)
	n	%	n	%	CI)	
Age:						
21-40	83	36.56	14	56	ref	
41-60	123	54.19	11	44	1.89(0.82-4.36)	
61-80	21	9.25	0	0.00		
Sex:						
Male	58	25.55	10	40	ref	
Female	169	74.45	15	60	1.94(0.83-4.56)	
Education:						
None	55	24.23	4	16	ref	ref
Primary School	160	70.48	19	76	0.61(0.20-1.88)	0.90(0.25-3.31)
Secondary School	10	4.41	1	4	0.73(0.07-7.20)	0.37(0.03-3.98)
College	2	0.88	1	4	0.15(0.01-1.97)	0.07(0.01-1.08)
Marital status:						
Single	25	11.01	4	16	ref	
Married	107	47.14	13	52	1.32(0.40-4.38)	
Separated	41	18.06	8	32	0.82(0.22-3.01)	
Widowed	48	21.15	0	0		
Cohabiting	6	2.64	0	0		
Disclosure:						
Yes	201	88.55	4	16	1.47(0.47-4.63)	
No	26	11.45	21	84	ref	
PLHIV Group						
Yes	117	51.54	0	0		
No	110	48.46	25	100		
Engage IGA:						
Yes	171	75.33	15	60	2.04(0.87-4.79)	
No	56	24.67	10	40	ref	
Pill counts						
>95%	214	94.27	10	40	ref	ref
					0.04(0.02-	
<95%	13	5.73	15	60	0.11)**	0.03(0.01-0.10)**

Table 4: Association between sociodemographic, IGA, PLHIV support groupparticipation and Retention in Care.

Abbreviations: AOR- adjusted odd ratio; COR- Crude odd ratio; CI- Confidence interval

CHAPTER FIVE

DISCUSSION 5.1 Introduction

This chapter discusses study findings and it compares with other related studies conducted prior to this. This study measured different variables which might influence participants' adherence on ARV medication and retention in care. Participant's participation in PLHIV support groups and socio-demographic characteristics of people living with HIV were assessed to determine the adherence rates and retention in care.

5.2 Adherence to Antiretroviral therapy in People living with HIV

Adherence to ARV medication requires dedication to consistently follow treatment recommendations and not only do patient needs to be committed to treatment, but a variety of other factors may also complicate ART adherence among adult population. Overall, 224 (88.9) of the respondents were found adherent and 28 (11.1%) not adherent using unannounced pill count.

5.2.1 Association between PLHIV support groups and Adherence on ART

Participation in support groups offers the opportunity for the PLHIV to participate in their care at both facility and community level. In this study 46% of the respondents were members of PLHIV support groups which is slightly higher than that from earlier studies in Nigeria and Uganda which was at 33% and 30% respectively. Adherence on ART among PLHIV who participated in PLHIV support groups was reported by 117/117 (100%) respondents while adherence among PLHIV who never participated in PLHIV support groups was reported by 107/135 (79.3%). These findings advocate that PLHIV who participate in support groups are more likely to adhere to ART than those who do not participate similar to the findings reported by Moses et al.(2015 and Decroo et al. (2011) and a bit higher than the findings reported by Wouters et al.(2009) and Simpson et al. (2015). Respondents aged above 40 years, female and disclosed their HIV status were more adherent to ART similar to the previous findings in Nigeria (Simpson et al, 2015).

There are several possibilities regarding the differences in observation. First, the evolution and advancement of HIV management across the globe and the proven efficacy of ARV drugs in viral suppression has made HIV positive participants to be more adherent to stay healthy and productive (Zulu et al, 2009). Second, promotion of peer support groups by

WHO as a means of addressing special needs, creating an avenue for experience sharing, encouraging disclosure, reducing stigma and discrimination, improving self-confidence, improving patient's coping skills and psychosocial functioning and assisting medication compliance have improved overtime to impact positively ART adherence (WHO,2013; Kalichman&Sikkema,1996; Visser &Mundell, 2008; Wood,2007) . Third, PLHIV participating in support groups are open to disclose their HIV status, have low levels of stigma and discrimination, self-confidence which in turn increase compliance to prescribed medications (Lennon-Dearing, 2008). Fourth, older age were more likely to participate in PLHIV support group activities than the younger age because African norms stigmatize young people and inhibit their health seeking behaviour and this can explain why young PLHIV avoid PLHIV support groups which are run by older people (Simpson et al, 2021). Fifth, participation in PLHIV support groups enhance disclosure of HIV status, reduce stigma and enhance support from peers, family members or health care workers which in turn enhance ART adherence (Simpson et al, 2015).

5.2.2 Association between Income generation activities (IGA) and adherence on ART

This study found that, engaging in income generation activities was positively associated with adherence to antiretroviral therapy (OR: 2.36(1.05-5.30 and p = <0.05) similar to the findings reported by Beth et al. (2011), Sibhatu (2012), Lankowski et al. (2014); Peltzer & Pengpid (2013); Reda & Biadgilign (2012) and Erica et al. (2014).

The possible explanations for the similarities is that; income generating activities are geared to improve household economy of the individual participants and have access to care and treatment services, nutritious food and decreased incidences of recurrent illness leading to increased quality of life and decreased hospitalizations (Beth et al. 2011). This include individual capability to afford transportation, cost to attend ART clinic appointments, pharmacy drug refills, financial needs for treating illnesses, access to food and good housing (Sibhatu, 2012). On the other hand poverty, unemployment and lack of food impact negatively ART adherence since lack of income reduces individual's purchasing power (Kaal and Brian, 2019) and lack of money prevents access to health facility to collect ARV drugs (Ankomah et al, 2016).

5.3 Retention in care among PLHIV

Retention in care requires dedication to consistently follow clinic appointments and attend the scheduled visits regularly and patient's commitment is highly needed. Overall, 227 (90.1) of the respondents were found retained in care and 25 (9.9) not retained in care.

5.3.1 Association between PLHIV support groups and retention in care

In this study, we found that participation in PLHIV support groups was positively associated with retention in care (100% p=0.000) similar to the findings reported by Wouters et al. (2009); Decroo et al.(2011), Erica et al. (2014); Nabukeera Barungi et al.(2015);Sam et al.(2017) and Amy et al.(2018). These findings suggest that PLHIV who participate in PLHIV support group are more likely to be retained in care than PLHIV who do not participate.

The possible explanation for the observed similarities is that, support groups assist group members to cope with stressful events, alleviate stigma and engaging in new actions which promote a healthy life, increases self-esteem, social belonging, enhance quality of life, reduce stigma and improve medication compliance (WHO,2013; Kalichman&Sikkema,1996; Visser &Mundell, 2008; Wood,2007). In addition, support groups ensure continuity in receiving HIV care and treatment services among PLHIV since stigma and discrimination would be at minimal level and hence free access to services (Moses et al, 2015, Decroo et al, 2011).

Respondents aged above 40 years (OR: 1.89(0.82-4.36) and disclosed their HIV status (OR: 1.47(0.47-4.63) were positively associated with being retained in care. This could be explained by the fact that participants above 40 years of age are socially stable and mature enough to understand what is needed in life and their responsibilities in taking care of their children promotes good adherence to ART and hence retained in care to live healthy life.

5.3.2 Association between Income generation activities (IGA) and retention in care

This study found that, engaging in income generation activities was positively associated with retention in care (OR: 2.04(0.87-4.79) similar to the findings reported by Erica et al. (2014); Lisa et al. (2016) and Krista et al. (2019). The possible explanation for the observed similarities is that, improved household economy increases purchasing power and facilitates meeting travel costs to attend ART clinics, costs to meet food security, cost share and other costs for health services and hence enhancing retention in care (Sibhatu, 2012). Additionally, Improved household economy facilitates and ensures food security; afford transportation costs and hence enhancing continuity of treatment and on the other hand low household income is linked to poor adherence on ART and retention in care (McFall et al, 2013; Lisa et al, 2016) and financial hardships in meeting travel costs to attend ART clinic, cost share and cost barriers to access health services is linked to poor retention in care (Krista et al, 2019).

5.4 Limitations and strength of the study

The main limitation to this study is not explored the reasons for none participation in PLHIV support groups. However, this study used unannounced pill count for adherence assessment which is more objective.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The study suggests that there is an association between PLHIV support group activities and Income generation activities and adherence to ART and retention in care: PLHIV who participate in PLHIV support group activities, engage in income generation activities and disclosed HIV status are more likely to adhere to ART and retained in care than those who do not participate.

6.2 Recommendations

This observation rationalizes investments in strengthening and scale up the formulation of PLHIV support groups as one of the strategy for promoting social support and enhancing ART adherence and continuity among People Living with HIV.

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APPENDICES

Appendix I: STRUCTURED QUESTIONNAIRE (DATA COLLECTION TOOL) A) BASIC INFORMATION

- 1. Date of interview_____
- 2. Study site_____
- 3. District-----
- 4. Code number of the interviewee_____

B) SOCIO-DEMOGRAPHIC CHARACTERISTICS

- 5. Sex (1) Male (2) Female
- 6. Age :-----
- 7. Educational level
- 1. None
- 2. Primary school
- 3. Secondary school
- 4. College
- 8. Have you ever been admitted before 1) Yes 2) No
- 9. Marital status
- 1. Single
- 2. Married
- 3. Separated
- 4. Widowed
- 5. Cohabiting
- 10. HIV status of the spouse
- 1. Positive ART status: Yes..... No.....
- 2. Negative
- 11. Is there any family member with HIV? 1) Yes..... 2) No.....
- 12. If the answer is yes, are they using ART 1) Yes..... 2) No.....

C) SOCIO-ECONOMIC STATUS

- 13. What is your main occupation
- 1. Unemployed
- 2. Employed
- 3. Business/self employed
- 4. Farming
- 5. Others
- 14. Monthly household income (TZS)
- 1. Less than 50,000
- 2. 50,000/= to 100,000
- 3. 100,001/= to 200,000
- 4. Above 200,000
- 15. What is the main source of food for your household
- 1. Purchase
- 2. NGO support
- 3. Household farm/garden
- 4. Relative/ friends
- 16. Is the food you are able to get enough for your family?1) Yes 2) No
- 17. How many meals do you afford to take in a day

1). One 2) Two 3) Three

18. How much do you have to pay to cover your travel expenses when you visit the clinic? (TZS) 1) <1000 2) 1000-5000 3) 5001- 10000 4) >11000

If yes;

- 1) Land
- 2) Livestock
- 3) Bicycle, Motorcycles, car
- 4) Others (specify)

D) SOCIO-CULTURAL INFORMATION

20. Have you disclosed your HIV status to someone else? 1) Yes...... 2) No...... If yes to who 1) Spouse 2) Family member 3) Friends 4) Other 21. Do you avoid relatives or friends because of your HIV status? 1. Yes 2. No

.....

- 22. What is your opinion regarding ART therapy
 - 1. Approve
 - 2. Disapprove
 - 3. Undecided
- 23. Do you think that ARV drugs have a positive effect on your health? 1) Yes 2) No
- 24. What benefits have you gained from using ARV Drugs?
 - 1. No more frequent sickness
 - 2. Increased productivity
 - 3. Improved quality of life

E) INFORMATION REGARDING PLHIV SUPPORT GROUPS

25. Do you participate in PLHIV support groups? 1) Yes...... 2) No and if the answer

- is Yes then respond to below questions
- 26. How often do you meet? 1) Weekly 2) Bi-weekly 3) Monthly
- 27. Do you attend the scheduled meeting? 1) Yes regularly 2) Yes occasionally 3) No
- 28. When did you join the group?
- 1) < 6 months ago
- 2) 1 year ago
- 3) 2 years ago
- 3) > 2 years ago
- 29. Where did you get information about PLHIV groups?
- 1) Friends 2) Health worker 3) PLHIV group members 4) PLHIV group leaders
- 30. What is your opinion regarding PLHIV support groups?
- 1) Approve
- 2) Disapprove
- 3) Undecided
- 31. What benefits have you gained from participating in PLHIV support groups?
- 1) Assisted in HIV disclosure
- 2) Reduce stigma and discrimination
- 3) Improved adherence to medication
- 4) Freedom of expression
- 5) Gained self-confidence (reduce anxiety)

6) Make friends

- 7) Share experience
- 8) Retained in HIV care
- 9) Happiness and peace

32. What activities are being conducted when PLHIV group members meet?

- 1) Discussion on adherence (experience sharing)
- 2) Discussion on ways to reduce stigma and discrimination in the community
- 3) Counselling
- 4) How to build relationship
- 5) Discussion on how to deal with psychosocial challenges such as overcoming anxiety, coping with stress.
- 6) Identification of treatment supporter
- 7) Tracking of lost to follow ups
- 8) Providing testimonies regarding their Health
- 9) Home visits among PLHIV group members
- 10) Others (mention)

F) INCOME GENERATING ACTIVITIES.

33. Do you engage in Income generating activities?

- 1) Yes 2) No
- 2)

34. If the answer is yes above (engaged in Income generating activities) what type of IGA?

- 1) Farming
- 2) Piggery farming
- 3) Poultry keeping
- 4) Savings group (SACCOS, small interest loans)
- 5) Transportation (Boda boda)
- 6) Small business
- 7) Grains business 8) Bee keeping

35. What benefits have you gained from engaging in Income generating activities?

- 1) Can afford transport cost to attend CTC clinic
- 2) Managed to keep clinic appointments
- 3) Can cover other medical expenses

4) Can afford to buy food
5) Managed to pay for house rent
6) Manage to build my own house
7) Reduce stigma and discrimination
8) Reduce dependency
36. Who provided support of Income generating activities?
1) From group members contribution
2) Support council level (loan)
3) Support from NGOs
4) Support from faith based organization
5) Financial institutions
6) Others (specify)
37. What is your recommendation on IGA for PLHIV?
1) Recommended
2) Not recommended
38. What are the challenges on IGA for PLHIV?
1) Difficult in getting capital
2) Long process in getting money from the council
3) High interest
4) Other (specify)
39. What aspects of Income generating activities need to be improved?

1)..... 2) 3).....

40. Will you advice your friend or family member to join PLHIV group with IGA

1) Yes 2) No

THANK YOU FOR YOUR TIME

Appendix II: Adherence measuring tools

- 1. Date of interview_____ _____
- 2. Study site_
- 3. Code number of the interview_____

Instructions to the study participants

Investigator introduces him/herself to the participants,

Explanation of the exercise to be done: "I know you have come here to get your ARV drugs or attend PLHIV support group. Now I would like to ask questions on how you have been taking the drugs in the past three days. We know that it is very difficult to take this medication, and we are doing some research to find out whether adults manage to take their medicine correctly. Be assured that this information will neither change the way you get ARV drugs from the treatment center- Would you have a few minutes to answer some questions?"

A) Cost consideration

4. Do you afford to come to the clinic?

1) Yes 2) No

5. Do you incur any other costs as a result of your taking ART?

1) Yes 2) No

B) Treatment and adherence issues.

6. How long have you been on ART? 1) 1 year 2)2-3 years 3)4-5 years 4) >5 years

7. Have you experienced any side effects with your ARV drugs? 1) Yes 2) No

8. If the answer is yes above, has this made you to skip your medication at any time?

1) Yes 2) No

9. Has distance to the clinic ever been a reason for you to skip your medication at any time?1) Yes2) No

10. Has cost ever been a reason for you to skip your medication at any time?

1) Yes 2) No

11. Does lack of food ever made you skip medication? 1) Yes 2) No

12. Do you have anyone to remind you to give/take your medication? 1) Yes 2) No

13. If yes, who was the person who supported you (specify) 1) family member 2) Friend

14. Have you have ever missed an appointment at your ART clinic? 1) Yes 2) No

15. Have you ever missed taking your tablets 1) yes 2) No

16. If the answer is yes above how many doses 1) below 6 2) above 6 doses

17. What was the reason of missing the dose 1) forgetfulness 2) Travelling 3) Fatigue 4) stigma?

18. Have you ever had to skip a dose because you felt you had to hide your Medication from others around you? 1) Yes 2) No

- 19. Tell me how did you take your medicines three days ago?
- 1) Took medicine prescribed dose in the last three days
- 2) Missed one dose in the last three days
- 3) Missed two doses in the last three days

THANK YOU FOR YOUR TIME

Appendix II: DODOSO LA KUKUSANYA TAARIFA KUHUSU MATUMIZI YA DAWA ZA KUFUBAZA VVU NA USHIRIKI KATIKA VIKUNDI VYA WAVIU

Appendix I: Habari za jumla kuhusu matumizi ya ARVs

G) TAARIFA MUHIMU

- 18. Tarehe ya mahojiano _____
- 19. Sehemu ya mahojiano _____
- 20. Wilaya -----
- 21. Namba ya siri ya mshiriki _____

H) HABARI KUHUSU SIFA ZA KIJAMII

- 22. Jinsia (1) Kiume (2) Kike
- 23. Umri :-----
- 24. Kiwango cha elimu
- 5. Hajasoma
- 6. Elimu ya msingi
- 7. Elimu ya sekondari
- 8. Chuo
- 25. Je umewahi kulazwa hospitalini 1) Ndio 2) Hapana
- 26. Hali ya mahusiano
- 6. Sijaoa/sijaolewa
- 7. Nimeolewa/nimeoa
- 8. Tumeachana
- 9. Mjane
- 10. Naishi na mwenzi bila ndoa
- 27. Hali ya maambukizi ya Mwenza
- 3. Ana maambukizi ya VVU Matumizi ya dawa: 1) Ndio 2) Hapana
- 4. Hana maambukizi ya VVU
- 28. Je kuna mwanafamilia anayeishi na VVU? 1) Ndio 2) Hapana
- 29. Kama jibu ni ndio hapo juu, je anatumia dawa 1) Ndio 2) Hapana

I) HABARI KUHUSU HALI YA KIJAMII NA UCHUMI

- 30. Je unajishughulisha na nini?
- 6. Sijaajiriwa

- 7. Nimeajiriwa
- 8. Biashara/nimejiajiri
- 9. Kilimo
- 10. Shughuli nyingine
- 31. Kipato chako kwa mwezi (TZS)
- 5. Chini ya 50,000
- 6. 50,000/= to 100,000
- 7. 100,001/= to 200,000
- 8. Zaidi ya 200,000
- 32. Chakula cha nyumbani kwako kinapatikana wapi?
- 5. Kununua
- 6. Msaada kutoka kwa asasi za kiraia
- 7. Kutoka shambani/bustani ya familia
- 8. Kutoka kwa ndugu/rafikia
- 33. Je chakula unachopata kinatosha kwa familia yako?1) Ndio 2) Hapana
- 34. Je ni milo mingapi unamudu kwa siku 1) Mmoja 2) Miwili 3) Mitatu
 - 18. Je ni kiasi gani cha pesa unatumia kwa usafiri kwenda kliniki ya tiba na matunzo? (TZS)
 - 1) <1000 2) 1000-5000 3) 5001- 10000 4) >11000
 - 19. Je una rasilimali yoyote? 1) Ndio 2) Hapana
 - Kama ni ndio hapo juu, taja rasilimali hizo;
- 5) Ardhi
- 6) Mifugo
- 7) Baiskeli, Pikipiki, Gari
- 8) Nyinginezo (taja)

J) HABARI KUHUSU UTAMADUNI WA KIJAMII

20. Je umekuwa wazi kuhusu hali yako ya maambukizi ya VVU kwa mtu mwingine? 1)Ndio 2) Hapana

Kama ni ndio hapo juu, umekuwa wazi kwa nani 1) Mwenza 2) Mwanafamilia 3) Rafiki 4) Wengineo

21. Je kuna wakati unawakwepa ndugu zako kwa sababu una maambukizi ya VVU?1. Ndio 2. Hapana

- 22. Je nini maoni yako kuhusu Tiba na matunzo ya huduma za VVU na UKIMWI?
 - 1. Nakubaliana nazo

- 2. Sikubaliani nazo
- 3. Sina maoni yoyote
- 23. Je unafikiri dawa za ARVs (za kufubaza VVU) zina faida kwenye afya yako? 1) Ndio
- 2) Hapana
- 24. Je ni faida gani umepata kwa kutumia dawa za ARVs?
 - 1. Siugui mara kwa mara
 - 2. Kuongezeka kwa utendaji wangu wa kazi
 - 3 Maisha yangu yameboreka zaidi

K) HABARI KUHUSU VIKUNDI VYA WAVIU

25. Je unashiriki kwenye vikundi vya WAVIU? 1) Ndio 2) Hapana. Kama jibu ni ndio, jibu maswali yanayofuata hapo chini

26. Je ni mara ngapi mnakutana? 1) Kila wiki 2) Kila baada ya wiki mbili 3) Kila mwezi

27. Je unahudhuria vikao vilivyopangwa? 1) Ndio kila wakati 2) Ndio mara chache 3) Hapana

- 28. Je ni lini umejiunga na kikundi?
 - 1. chini ya miezi sita iliyopita
 - 2. Mwaka mmoja uliopita
 - 3. Miaka miwili iliyopita
 - 4. Zaidi ya miaka miwili iliyopita

29. Je ulipata wapi habari kuhusu vikundi vya WAVIU?

 Rafiki 2) Mhudumu wa afya 3) Wanachama wa vikundi 4) Kiongozi wa kikundi cha WAVIU

30. Je ni nini maoni yako kuhusu vikundi vya WAVIU?

- 1. Nakubaliana navyo
- 2. Sikubaliani navyo
- 3. Sina maoni yoyote

31. Je ni faida gani umezipata kwa wewe kushiriki kwenye vikundi vya WAVIU?

- 1. Imenisaidia kuwa wazi kuhusu hali ya maambukizi ya VVU
- 2. Imepunguza unyanyapaa na ubaguzi
- 3. Imeongeza ufuasi mzuri wa dawa
- 4. Uhuru wa kujieleza
- 5. Kujiamini na kuondoa uoga
- 6. Kupata marafiki

- 7. Kubadilishana uzoefu
- 8. Kuendelea kupata huduma za tiba na matunzo
- 9. Furaha na amani
- 32. Je ni shughuli gani zinafanywa wakati wanakikundi wamekutana?
 - 1. Majadiliano kuhusu ufuasi wa dawa
 - 2. Majadiliano kuhusu njia za kupunguza unyanyapaa na ubaguzi katika jamii
 - 3. Ushauri nasaha
 - 4. Namna ya kujenga urafiki
 - 5. Majadiliano kuhusu njia bora za kutatua changamoto za kisaikolojia kama kuondoa

hofu, uoga na kuondoa msongo wa mawazo.

- 6. Kupatikana kwa msaidizi wa matibabu
- 7. Kuwafuatilia WAVIU waliopotea kwenye dawa
- 8. Kutoa ushuhuda juu ya afya ya mwanachama
- 9. Kutembelea wanakikundi majumbani kwao
- 10. Mengineyo (taja) -----

L) HABARI KUHUSU SHUGHULI ZA UJASILIAMALI.

- 33. Je unajishughulisha na shughuli za ujasiliamli? 1) Ndio 2) Hapana
- 34. Kama jibu ni ndio hapo juu, je unajishughulisha na nini?
 - 1. Kilimo
 - 2. Kufuga ngurumwe
 - 3. Kufuga kuku
 - 4. Kikundi cha kuweka na kukopeshana (SACCOS)
 - 5. Usafiri (Boda boda)
 - 6. Biashara ndogondogo
 - 7. Biashara ya mazao na nafaka
 - 8. Kufuga nyuki
- 35. Je ni faida gani umezipata kwa wewe kushiriki kwenye shughuli za ujasiliamali?
 - 1. Naweza kumudu gharama za kuhudhuria kliniki ya tiba na matunzo
 - 2. Naweza kuhudhuria miadi ya kwenda kliniki kama ilivyopangwa
 - 3. Naweza kugharamia gharama zingine za matibabu
 - 4. Namudu kununua chakula cha familia yangu
 - 5. Nimeweza kulipia kodi ya nyumba
 - 6. Nimeweza kujenga nyumba yangu mwenyewe

- 7. Imepunguza unyanyapaa na ubaguzi
- 8. Imepunguza utegemezi

36. Nani ametoa msaada wa shughuli za ujasiliamali?

- 1. Kutoka kwenye michango ya wanachama
- 2. Mkopo toka Halmashauri
- 3. Msaada kutoka asasi za kiraia
- 4. Msaada kutoka mashirika ya dini
- 5. Taasisi za Fedha
- 6. Kwingineko (taja).....

37. Je ni nini ushauri wako kuhusu shughuli za ujasiliamali kwenye vikundi vya WAVIU?

- 1. Nina shauri vikundi vya WAVIU vijishughulishe na shughuli za ujasiliamali
- 2. Si shauri MVIU ajihusishe na shughuli za ujasiliamali

38. Je ni nini changamoto za shughuli za ujasiliamali kwa WAVIU?

- 1. Ugumu wa kupata mitaji
- 2. Mlolongo mrefu kupata mkopo kutoka halmashauri
- 3. Riba kubwa
- 4. Changamoto zingine (zitaje).....

39. Je ni maeneo gani ya shughuli za ujasiliamali yanahitajika kuboreshwa?

1.

2.

3.

40. Je utamshauri rafiki yako au mwanafamilia kujiunga na vikundi vya WAVIU vinavyoshughulika na ujasiliamali?

1) Ndio 2) Hapana

Appendix II: Zana za kupima ufuasi wa dawa

- 1. Tarehe ya mahojiano_____
- 2. Sehemu ya mahojiano_____
- 3. Alama ya siri ya mshiriki_____

A) Gharama za kupata matibabu

4. Je unaweza kuhudhuria kliniki? 1) Ndio 2) Hapana

5. Je unalazimika kutoa gharama zingine kwa kupata huduma za tiba na matunzo? 1) Ndio

2) Hapana

B) Tiba na Ufuasi wa dawa.

6. Umekuwa ukitumiwa dawa za ARVs kwa muda gani ? 1) Mwaka 1 2)Miaka 2-3 3) Miaka4-5 4) zaidi ya miaka 5

 Je umeshawahi kupata madhara yoyote yatokanayo na dawa za ARVs? 1) Ndio 2) Hapana

8. Kama jibu ni ndio hapo juu, je hali hii ilikufanya usimeze dawa zako kwa muda fulani?1) Ndio 2) hapana

9. Je umbali wa kwenda kliniki umewahi kuwa sababu ya wewe kutotumia dawa zako kwa muda fulani?1) Ndio2) Hapana

10. Je gharama zimewahi kuwa sababu za wewe kutotumia dawa zako muda Fulani?1) Yes 2) No

11. Je kukosekana kwa chakula kumewahi kukufanya usitumie dawa? 1) Ndio 2) Hapana

12. Je una mtu anayekukumbusha kumeza dawa? 1) Ndio 2) Hapana

13. Kama jibu ni ndio hapo juu, je ni nani anayekusaidia) 1) mwanafamilia 2) rafiki

14. Je umewahi kukosa miadi ya siku ya kliniki yako? 1) Ndio 2) Hapana

15. Je umewahi acha kumeza dawa zako? 1) Ndio 2) Hapana

16. Kama jibu ni ndio hapo juu, je vidonge vingapi ngapi?1) chini ya vidonge 6 (au chini ya dozi 3 2) zaidi ya vidonge 6 (au zaidi ya dose 3)

17. Je nini ilikuwa sababu ya kutomeza dawa?1) Kusahau 2) Kusafiri 3) Kuchoka 4)Unyanyapaa

18. Je umewahi kutokumeza dawa kwa sababu ya kujificha kutoka kwa watu waliokuzunguka muda wa kunywa dawa? 1) Ndio 2) Hapana

19. Embu nambie namna ulivyotumia dawa zako siku tatu zilizopita?

1) Nilimeza dawa siku zote tatu kama nilivyoelekezwa

2) Nilikosa dozi moja ya dawa katika kipindi cha siku tatu zilizopita

3) Nimekosa dozi mbili kwa kipindi cha siku tatu zilizopita

Appendix III: Consent form

My name is Amos Nsheha, I am here today doing research to find out the association between PLHIV support groups and income generation activities and adherence to ARV drugs and retention in HIV care. Be assured that you will be identified by code numbers (no names) and the information given will not be shared to someone else and neither will it change the way you participate in PLHIV support groups and get ARV drugs nor denied getting required services at Care and Treatment Clinic (CTC). The exercise include people living with HIV in treatment and who participate in PLHIV support groups and income generation activities and who do not.

You are free whether to participate in this research or not. Do you agree to participate in the study Yes \Box No \Box If the answer is Yes above then sign below,

Signature.....

Date.....

Thank you for your time and cooperation

Appendix IV: Fomu ya Idhini/Kibali cha kushiriki kwenye utafiti

Jina langu ni Amos Nsheha, nipo hapa leo kufanya utafiti kuhusu kuangalia uhusiano baina ya ushiriki wa WAVIU katika vikundi vya WAVIU na shughuli za ujasiliamali na ufuasi wa dawa za ARVs na muendelezo wa huduma za tiba na matunzo. Nipende kukuhakikishia kwamba utatambulika kwa namba na sitatumia jina wakati wa kukusanya taarifa na taarifa itakayotolewa haitamuhusisha mtu mwingine na wala haitabadilisha ushiriki wako kwenye vikundi na kupata dawa zako na huduma zingine za tiba na matunzo katika kituo cha huduma. Zoezi hili litawahusisha WAVIU wanaotumia dawa ambao wamejiunga na vikundi na wanashiriki katika shughuli za ujasiliamali na wale ambao hawajajiunga na vikundi na wala hawajishughulishi na shughuli za ujasiliamali.

Una uhuru wa kuchagua kushiriki au kutokushiriki katika utafiti huu.

Je unakubali kushiriki kwenye utafiti huu Ndio 🗆 Hapana 🗆

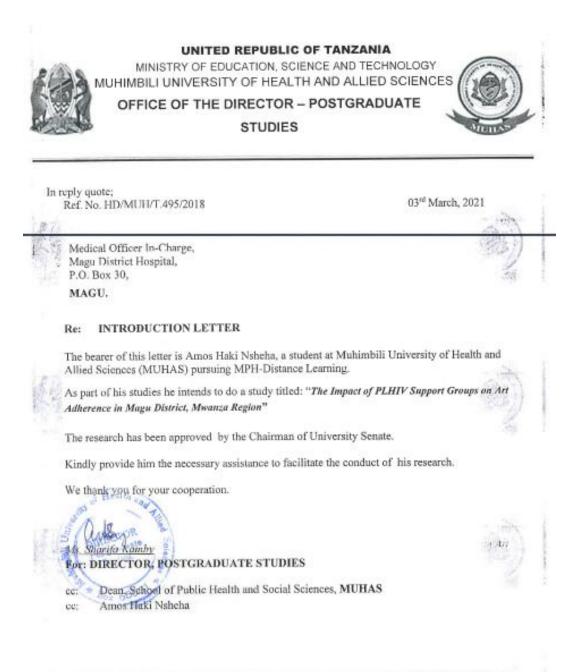
Kama jibu ni ndio hapo juu, basi saini hapo chini,

Saini

Tarehe.....

Asante kushiriki na kwa muda wako

Appendix V: Ethical clearance letter



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