College of Medicine

ASSESSMENT OF FACTORS ASSOCIATED WITH LINKAGE TO CARE AMONGST ADULTS ACCESSING HIV SERVICES AT BWAILA HOSPITAL, LILONGWE DISTRICT, MALAWI.

By:

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Certificate of Approval

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Declaration

I, Clifton Muvwala Gondwe declare that this dissertation ***"Assessment of factors associated with linkage to care amongst adults accessing HIV services at Bwaila hospital, Lilongwe district"*** is my original work and has been done as part of the partial fulfillment of the requirements for the award of Master's Degree in Public Health. The work has not been presented for any other awards at the University of Malawi or any other university. All the sources I have used or quoted have been acknowledged as references.

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Date March, 2020

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Abstract

Introduction:

Despite the policy progress made in Malawi about HIV and AIDS, the prevalence rate remains among the highest in the world. Despite many people being tested HIV positive not all have been linked to HIV care. Linkage to care is a crucial early step in successful HIV treatment. Linkage to HIV care is still a challenge in Malawi as 32% is not yet linked to care. This group may pose a threat of transmitting the infection to the population. Currently the country is striving to meet the 90.90.90 UNAIDS target.

Objectives: The main objective of the study was to assess factors associated with linkage to care amongst adults accessing HIV services at Bwaila Hospital in Lilongwe District.

Methods: This was a descriptive cross-sectional study which employed qualitative methods. Eighteen in-depth interviews were conducted with clients above 18 years old and 2 focus group discussions with Health Providers at Bwaila Hospital. Purposive sampling method was used to recruit study participants. Thematic analysis was used to analyze data.

Results: Findings indicate that linkage to care is affected by one's perception towards Antiretroviral Therapy initiation, physical escort of clients by providers, integration of services, existence of support partners, shortage of staff leading to high workload, poor coordination of services at the facility and distance to the facility.

Conclusion: Interventions aimed at improving linkage to care in HIV services should focus on integration of health services. In addition, additional human resource and ease of access to health services should also be considered.

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Abbreviations and Acronyms

AIDS Acquired Immune Deficiency Syndrome

ART Anti-retroviral Therapy

CBHTS Community Based HIV Testing Services

COMREC College of Medicine Research Ethics Committee

DALYs Disability-adjusted life year

FGDs Focus Group Discussions

HIV Human Immune Deficiency Virus

HTS HIV Testing Services

PITC Provider Initiated Counseling

VCT Voluntary Counseling and Testing

IQR Interquartile Range

CHAPTER 1: Introduction and objectives of the study

1.1.Background

Human Immune Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) continue to be a major health challenge worldwide. Globally there are 36.1 million people living with HIV [1]. Out of these, 2.1 million are children (<15 years old). HIV remains the number one cause of disability adjusted life years lost for women aged between 25 and 45 years and also men aged between 30 and 45years. Globally in 2017, about 20.9 million people of those affected were linked to ART up from 15.8 million people in 2015,7.5 million in 2010 [1].

Sub Saharan Africa is home to the largest number of people living with HIV. As of 2017, about 19.4 million people were living with HIV in the region while 61% of these were accessing ART services [1]. South Africa accounted for one third of the region's HIV infection followed by Mozambique, Kenya and Zambia [2].

The prevalence of HIV amongst adults aged 15-64 in Malawi remains at 9.2% which remains one of the highest in the world [1]. Annual incidence of HIV infection among adults in the country is 0.39% [3]. Those infected with HIV are at 1.0 million and only 68% are linked to care [1]. The consequences of these are escalation of HIV transmission and high rates of mortality and morbidity [3].

1.2.Statement of the problem

Despite many people being tested HIV positive, not all have been linked to ART care. Globally out of the 30.7 million that are HIV infected, only 20.1 million are accessing Antiretroviral Therapy (ART) care. In sub - Saharan Africa, out of 19.4 million people who are HIV infected, only 11.7 million are linked to ART. Similarly, in Malawi out of 932,000 positive individuals, only 660,117 are accessing ART care. Realizing this gap, this study assessed factors associated with linkage to ART care among adults accessing HIV services at

Bwaila Hospital in Lilongwe Malawi. The results will inform policy makers on factors surrounding test and treatment strategies which Malawi Government adopted in 2016 as one way of improving linkage to care.

1.3. Literature review

1.3.1. HIV Testing

HIV testing is the gateway to HIV prevention, treatment, care and other support services [4] and it is the first step in continuum of care. Peoples' knowledge of their HIV status through HIV testing services (HTS) is crucial to the success of the HIV response [5]. Worldwide, only half of the people infected with HIV are aware of their status. In low and medium income countries only 20% know about their serostatus [6]. In sub- Saharan Africa, about 76% of the people are aware of their status while in Malawi, about 70% of the people are aware of their status [1].

In Malawi, challenges encountered with HTS include inadequate and limited space which compromises privacy and confidentiality [4]. There is no proper trainining for service providers hence no registration by regulatory bodies. There is no recognition and remuration for lay counsellors and yet they are heavily burdened with HIV counselling [4]. Another quality challenge is high work load in testing centers leading to long waiting times for HIV test results[4].Inadequate human resource which results into taskshifting[4].

1.3.2. Models of testing

Provider Iniative Testing and Counselling

Provider Iniative Testing and Counselling is the routine offer of HTS to anyone accessing services at a health facility, and is one of the most effective models for identifying HIV positive clients [4]. In PITC, HTS services are streamlined and focus on the provision of

pretest information and accurate results. All patients/clients accessing PITC provide consent for testing since PITC is neither mandatory nor compulsory, and those being offered are informed of their right to decline [6]. With this model many people are expected to refuse the results and less likey to be linked to care.

Voluntary Counselling and Testing

Voluntary Counselling and Testing occurs when the client voluntarily makes a decision to learn his or her HIV status and seeks HTS at a site providing the service [6]. VCT includes pre-test and post test counselling. Verbal informed consent is always sought from the client before testing. This model will make more people to be tested and accept the results hence more to be linked to care[6].

Community Based HIV Testing Services

Community Based HIV Testing Services is conducted in various modes including campaign, home-based, door to door, workplace, mobile, outreach and school/educational institution modes [5].This model focusess on key and priority populations with higher risk behaviour or access challenges [5]. CBHTS is also used to target high risk male populations who normally would neither access VCT or PITC[5].

1.3.3. Benefits of HIV testing

Early detection of HIV can facilitate early access to intervention and support services hence prolonging somebody's life [7]. There is promotion of prevention messages through education which is provided during pre and post-test counselling. HIV testing effectively link individuals and their families to appropriate HIV treatment, care and support, as well as HIV prevention services, based on their status [1].

1.3.4. Linkage to HIV care

Linkage to care is a crucial early step in successful HIV treatment and is typically defined as the completion of a first medical clinic visit after an HIV diagnosis [8]. Linkage to care plays a crucial role in the HIV care continuum because it is a necessary pre-cursor to retention in care, antiretroviral therapy initiation, and viral suppression. HIV treatment cascade covers four stages and linkage to care falls between stages one and four. Stage one covers the interval from receiving an HIV positive diagnosis to receiving CD4 count results [2]. Patients may be lost at this stage between an HIV test and enrolment to care. Stage two covers the interval from enrollment to ART eligibility, when patients who are not yet eligible for ART must make regular monitoring visits until they meet prevailing eligibility criteria. Under treat all policy this ceases to exist for vast majority of patient's linkage to care and ART initiation should be synonymous. Stage three of the current cascade last from determination of eligibility to ART initiation. Loses to this stage may relate to health system barriers such as multiple clinic visits and longer delays in getting laboratory results [9] and patient factors such as time constraints or reluctance to commit to lifelong treatment. Stage four covers the interval from retention after ART initiation which is a critical in the cascade of care

1.3.5. Benefits of Early Linkage to Care

Early linkage to care leads clients to experience full health and prevention benefits [7]. An individual is likely to have viral load reduction when put on ART as well as reduction in HIV transmission [6]. Early linkages minimize serious HIV related illnesses such as bacterial disease, TB because ART reduces the amount of the virus in a patient's body, it reduces the transmission of infection to sexual partners [6]. It is expected that less people will present with infection at a health facility, hence reduction in work load to the service providers. As less people will be coming for treatment, less expenditure on resources to be incurred [7].

1.3.6. Disadvantages of delayed linkage to care

Health Consequences

Failure to initiate timely HIV care after diagnosis is common [7]. Poor linkages prevent people from acting on their test results [6]. Presenting more risks of ongoing HIV transmission amongst the population. Massive viral replication , transmission and high levels of opportunistic infection makes an individual sicker resulting into higher mortality rate [11]. Without timely entry into care, individuals with HIV infection miss an opportunity to benefit from HIV treatment at the earliest stage feasible [7].

Health System Consequences

The facility experiences increased work load as more people get sick and visit the facility. The system will be over burdened with sick people presenting with opportunistic infections. As more people come for treatment, resources will become scarce [11]. The country will fail to meet the 90-90-90 target [11].

1.3.7. Trends in Linkage to care

It has been discovered globally that not all who are tested HIV positive are immediately linked to care [6] Despite impressive advances in the provision of antiretroviral therapy (ART) for HIV-infected individuals in resource poor settings based on current treatment guidelines, approximately only one third of the 15 million individuals who are eligible for treatment are currently receiving it [2]

In sub- Saharan Africa, it is estimated that as much as 40% of the people who are diagnosed through HIV testing services are not linked to care [12–14]. Linkage to care has varied across countries and in USA, 64% of individuals with newly diagnosed HIV infection initiated care within 3 months and 83% within 4 years [15]. A study done in Ukraine recruit HIV positive patients and conducted in-depth interviews to the group. It was found that only 56% of those

tested positive were linked to care [16]. It is seen that linkage to care is an issue in most of the countries[14]. A lot of work has to been done if we are to successfully eradicate AIDS by 2030. A national testing program in South Africa reported successfully testing of 1.7 million individuals between April and July 2010 but, of 300,000 HIV-positive subjects, only half were referred to any related health services and only an additional 3000 initiated ART during the first two months of the program [13,17] A study done in Uganda where among newly HIV-diagnosed patients, only 53.0 % were linked to care within 1 week [14,15]. Of these, 83.7% were linked within a month. WHO estimates that only 50% of HIV-positive individuals in Africa are linked to care and this figure rises to 80% in some countries [18]. Among those tested positive, there is substantial attrition between receipt of HIV test and engagement in HIV care.

In Malawi, the number of people receiving treatment amongst those that are HIV infected has increased from 46 % in 2013 to 68 % in 2017. This still falls short of the 90% that is targeted to achieve 90% of people on treatment [1]. It was estimated that in 2010, 48% of the men and 27% of the women had never tested for HIV [19]. Limited studies have been done in the country about linkage to care. A study done in rural Malawi indicated that out of those newly diagnosed through home based testing; only 47.5 % were linked to care within 3 months [19]. As in the most countries in sub-Saharan Africa, diagnosis and linkage to care remain the main gaps in the cascade of care in the country [14].

1.3.8. Barriers to linkage to care

Literature describes several factors that hinder linkage to care. According to studies done in Uganda, factors that hinder or delay linkage to HIV treatment include financial, geographical/accessibility, disclosure decisions and health system factors [20].

Financial factors

This refers to transportation costs one incurs in accessing care. Some facilities offering care are very far from an individual, so there is need for an individual to have money to reach that end in order to access services [15]. If one has inadequate money it will be difficult to travel to the facility and access care. As a result there is poor linkage to care leading to massive replication of viral load in that individual who later becomes sicker, hence high chances of dying [21]. With enough money, one will be able to travel to the facility and access care hence improving survival and quality of life [15].

Geographical Factors

Some facilities are very far and people have to travel longer distances in order to access care and other facilities are hard to reach [11]. As a result, people are hindered to go and access care because transport cost to be incurred will be high.

Disclosure

Some people fear to disclose their status because they feel that they will be discriminated and stigmatized [6,11]. They tend to suffer silently and may not start treatment hence being hindered to be linked to care. A study in America reveals that patients more often reported psychosocial issues (fear of people knowing their diagnosis, concern about medication side effects, stigma and shame) as the important barrier to care [17].

Health Systems

Health systems include long waiting times, shortage of staff at a facility and lack of proper structure for provision of services [11]. People get bored if they wait for long time to access services a result they lose hope and leave the facility without being linked to care. This is usually the case where a facility has few staff providing services [11]. A study in Kenya reveals that lack of proper structure compromises confidentiality and privacy in provision of services hence making people not to go for the services [17]. A recent South African study

indicated that only 12 % of people receiving an HIV diagnosis through home-based diagnostic testing were linked to HIV/AIDS care, including ART [22].

1.3.9. Strategies for linking people to care

The following are the possible strategies for linking people to care: designated staff person to re-engage patients in care through systematically identifying poorly engaged patients, call to check in scheduled appointments and coordinate with Centre manager [13]. Take referrals from providers and center manager for outreach. If the clinic has the capacity, consider setting up special procedures for the hardest-to-reach patients through walk-in care and intensive case management and outreach support.

1.3.10. Enablers to linkage to care

The factors that facilitate linkage to care include structural, integrated services, active referral, dedicated case management team and individual level factors. Structural factors such as mobile outreach enables people to have easy access to care and at no cost as they don't travel long distances [20]. Where HIV and primary care are integrated, one expects that a greater proportion of individuals will easily be linked to care [20].

Studies done in South Africa, Kenya, Botswana, Malawi indicate that support from close family members, friends and peers from within one's community encourages HIV infected individuals to enter into care [23]. The studies also reveal that positive interaction with health workers and case managers have a positive impact of trusting relationships with providers hence enabling somebody to enter into care [23].

1.3.11. Conclusion

In conclusion, the literature has revealed that smooth linkage to care is fundamental in ensuring that services are accessed with ease when individuals are found positive. Factors

such as financial, health systems setup and geographical locations may hinder the access of services by individuals hence delay in linkage to care.

1.3.12. Conceptual framework

Andersen's framework of health services utilization

The study was guided by Andersen's framework of health utilization. This framework is aimed at demonstrating the factors that lead to the use of health services. In the past it has been used to discover conditions that either facilitate or impede utilization of health services [23].

The main concepts of the framework are predisposing, need and enabling factors.

Predisposing factors

These are social cultural characteristics that exist among individuals prior to their illness. These are issues like social structure such as education, health beliefs such as attitude, religious beliefs and demographics such as gender, marital status and age. These play important role in utilization of health services for example one who is educated will understand the importance of seeking health services hence adequate utilization of services while someone with low education may be hindered from utilization of health services due to poor understanding of seeking health services[23].

Enabling Factors

These are logistical aspect of obtaining care in other words factors facilitating to use health services for example finances, availability of health personnel, availability of ART, facility and waiting time. For example, availability of health personnel will facilitate provision of services to those who seek them [24].

Need factors

These are perceptions people have about their health. The way how people perceive their own general health and experience symptom of illness, pain, worries about their health. If somebody feels sick he/she is going to seek services. ‘

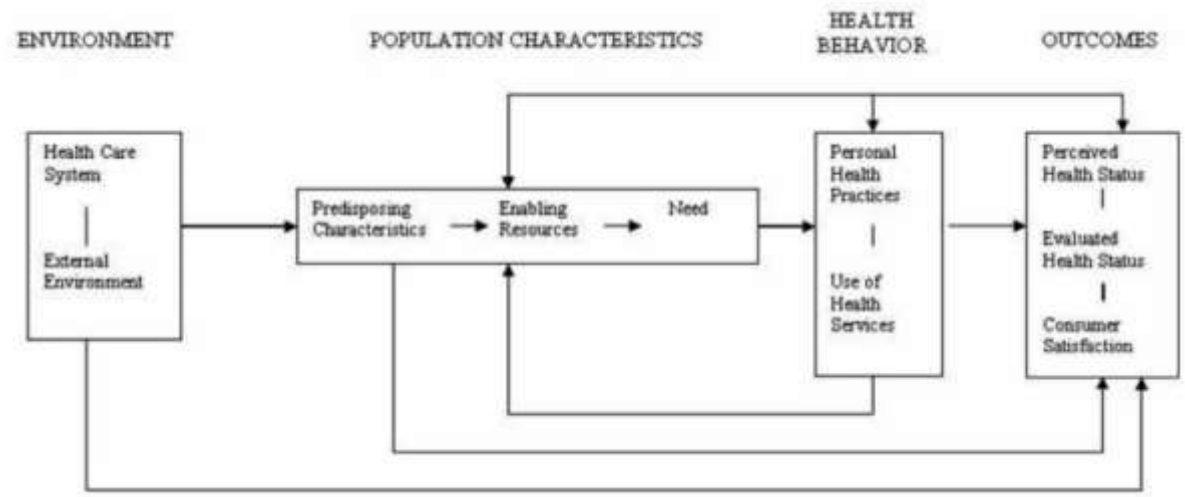

Figure 1: Andersen and Newman Framework of Health Utilisation

(Source: Adapted from Andersen’s theory of health utilisation)

According to this conceptual framework, different studies on association of variables have been done on predisposing, enabling, and need factors. Three studies looked at an association between gender/sex and utilization of health care services and it was reported that women were more likely to visit a physician than men [23,25]. Predictor variables were classified as factors that predispose or enable the individual to obtain those services. Those who obtained general practitioner care were more likely to be female, to have been or be undertaking higher education and to be living with children. They were also identified by their having poorer physical health, more chronic diseases, higher levels of suicidal ideation and by their regularly using marijuana. General practitioners need to be aware of the potential mental health and substance use problems experienced by consumers in these females. Other studies looked at an association between education and utilization of health care services and it was found that education was significantly associated with utilization of health care services [23].

One study showed that African American men with lowest education had the lowest odds of scheduling a routine health examination [25].

On enabling factors for example on finance, associations identified between income and service use varied, US adults with lower income had lower likelihoods of doctor contacts [24] and less access to alcohol, drug and mental health care [25].

On need factors studies found that that those with chronic conditions were more likely to have physicians visits than other [26].

Justification of the Conceptual Framework

This conceptual framework was very appropriate for this study as it was looking at how people utilize ART services especially after being tested positive. It helps answer our questions of interest- if people are tested positive, are they starting ART immediately or they do differ, if they start the treatment, how do they perceive to be on treatment, what has enabled them to seek the services? Andersen's conceptual framework does highlight all these important concepts which have effects on utilization of HTS and ART services hence its appropriateness for this study. This framework informed the tools of my study. The tools included questions that discussed predisposing factors, (for example education level, marital status and demographic factors), enabling factors (financial, geographical/accessibility, availability of health personnel) and need factors looking perceptions of people towards initiation of ART.

1.4. Justification for the research project

Despite Malawi making positive strides in both HIV testing and initiation of ART, 32% of HIV infected people are not yet linked to ART care [1]. Currently at Bwaila hospital only 80% of those who have been tested positive are accessing ART and this falls below the target of reaching 90% of HIV infected people initiated on ARVs [27]. Failure to reach the desired

targets has likelihood of increasing the HIV and AIDS morbidity and mortality [27]. Poor linkage to care may result to an increase in transmission rates. Given the importance of linking newly diagnosed HIV infected people to care, this study assessed factors that are associated with linkage to ART care among HIV-infected adult men and women at Bwaila Hospital in Lilongwe District. This information will be critical in strengthening systems for ART linkage**.**

1.5. Objectives

1.5.1. Broad objective of the study

The broad objective was to assess factors that are associated with linkage to ART care amongst adults accessing HIV services at Bwaila Hospital in Lilongwe District.

1.5.2. Specific objectives

The specific objectives of the study were:

1. To explore perceptions of adults accessing HIV testing services towards initiation of ART at Bwaila Hospital.
2. To explore enabling factors to linkage to ART care amongst adults at Bwaila Hospital
3. To identify challenges for health workers and participants associated with linkage to ART care.

CHAPTER 2: Methods

The chapter describes the methodology that was adopted to conduct the study.

2.1. Type of the Research

This was a descriptive cross-sectional study which utilized qualitative methods. Qualitative methods chosen were for their ability to allow the investigator to establish the meaning of a phenomenon from the views of participants. Thus, the design enabled the researcher to investigate participants' social realities by exploring complex lived experiences. Further, this method provided a chance for respondents to give their views and experiences freely, hence enabling the researcher to collect rich data on perceptions, beliefs, and experiences on the study topic[9].

2.2 Study place

The study was conducted at Bwaila Hospital in Lilongwe District from 2nd to 30th April 2019. Bwaila hospital is the hub of health services for Lilongwe District which has a population of 2.6 million. The HIV prevalence for Lilongwe District is 7.5%. The population comprise rural and urban with composition of people with poor and good economic status. In other words the hospital caters for mixed population. Bwaila acts as a referral center for over 55 health centers of Lilongwe district and provides a range of services including HIV testing and ART delivery. Conducting the study at this hospital therefore broadened the scope of the study giving true picture of Lilongwe as a district.

2.3. Study population

The population for this study was ART health care workers at Bwaila Hospital and HIV infected clients accessing HIV services at Bwaila.

2.3.1. Inclusion criteria

Participants aged 18 and above seeking HIV care services and tested positive at the hospital (Bwaila) and were willing to participate in the study. For health workers, we included those working at the HIV care services department at least for a year or more and were willing to participate in the discussions.

2.3.2. Exclusion criteria

For health care seekers, we excluded all those below 18, pregnant women, mentally ill individuals. For health workers we excluded those not working in the HIV department, those who were not willing to participate, and those who had less than a year' working experience in the HIV department.

2.3.4. Enrolment of study participants

In order to ensure that participation in the study was voluntary, potential study participants were presented with a written informed consent form in Chichewa. Depending on the preferred language of the potential participant, consent forms were read and explained in either English or Chichewa to allow the participant to make an informed decision. Explanation of the consent form included but was not limited to the purpose of the study, risks and benefits of taking part and that participation was voluntary and free. Furthermore, participants were informed of their universal right to withdraw even after they had already given consent to participate. Participants who were literate endorsed a signature indicating their willingness to participate in the study. For those who were not able to write, the consent form was read in presence of an impartial witness and a thumbprint was used indicating willingness to participate in the study. Those who participated in the study were the people who were coming for the services so there no need of reimbursement.

2.4. Study Period

The study was conducted from May 2018 to August 2019 from protocol development to write-up.

2.5. Sample size

The study sample included adult clients of 18 years and above. It also included trained Health Diagnostic Assistants (HDA) and health care providers involved with provision of HIV services. Participants were selected through purposive sampling because these were the ones who had come to seek HIV services and they were all ready to accept the results. This saved time for the researcher. Participants were identified as having HIV after being tested positive. So far all potential participants participated in the study. Health workers were selected using convenience sampling because they were contacted, willing and able to participate. Those who were available and willing were approached to participate in the study.

In total 34 participants were recruited, 18 participants for in-depth interviews (IDIs) with health seekers and 16 for focus group discussions (FGDs) with health workers. Since this was a qualitative study, the specified sample study was adequate enough to generate rich and thick information and also reach the saturation point. When IDI number 16 was being interviewed, he was giving same information as IDIs numbers 12, 13, 14 and 15. Then the researcher noticed that saturation point has been reached. Saturation in qualitative research refers to a point when there is enough information to answer the research question [9]. Each FGD comprised of 8 participants. The researcher had also conducted some observations during data collection. The researcher could observe all the processes of testing thus pre, during and post in a testing room. The focus was on a decision made by a client after being tested positive. Then the researcher could record the responses on whether the client is going to start the treatment or not and reasons why in his writing pad. These responses have been presented in the result section.

2.6 Data collection process

We conducted IDIs using a semi-structured interview guide [appendix 1]. IDIs are used when seeking information on individual or personal experiences. A semi-structured interview guide with open-ended questions was used in order to get valuable information based on the participants own experiences [appendix 1].

Interview guide was used to induce themes and discussions, some of which were then probed in IDIs. FGDs also served to increase study credibility through source triangulation. The two FGDs were conducted with 8 health care workers (for each group), one with ART providers and one with HIV diagnostic assistants.

The researcher also conducted non-participatory observations using observation guide [appendix 4] to clients who had been tested positive. Prior to everything the researcher approached the hospital and got permission and thereafter got consent from the participants after being explained. The researcher sat in a testing room and observed the whole process of testing. The observation was centered on decision made after positive result. This enabled the researcher to see the reaction made towards initiation of ART thereby addressing the issue of participant's perception towards ART.

Credibility refers to confidence in the truth of data in its interpretations [9]. In this study, credibility was ensured by prolonged engagement in data collection and interpretation. The researcher dedicated sufficient time for data collection activities. The researcher took his time during interview. He could not rush in interviewing the participant. This was to help participants unfold naturally. The researcher dedicated the whole of the month to data collection. The researcher established a good rapport with participants at the beginning of the interview to allow for participants' free expression. Confidentiality was maintained

throughout the study and unintended disclosure was avoided. This means all audio recorded data was put in a password protected computer.

2.7. Data analysis

Data collected from IDIs and FGDs were audio recorded then transcribed verbatim in the same language as recorded (Chichewa). The researcher audio recorded and transcribed the IDIs and FGDs himself. Thereafter data were analyzed using thematic analysis approach. Thematic analysis enabled us to transcribe and interpret various aspects of data in detail, thereby providing a comprehensive meaning to the data. Qualitative data which had been captured through IDIs, FGDs and observations were coded, and themes induced (thematic analysis). The following steps were applied in analyzing the data. First step was becoming familiar with the data; the researcher did repeated readings of the transcripts to familiarize himself with the data, trying to get sense out of it. During the reading the researcher was looking for data meaning and its patterns thereby marking ideas for coding. A list of ideas about data was made. Then second step was initial generation of codes by the researcher after going through the data again. After identifying so many of the codes then a list was made.

The data were then organized in a meaningful and systematic way. The third step was searching for themes. The researcher captured something significant and interesting from the data and made themes from the captured data. The fourth step was reviewing themes. The researcher reviewed, modified and developed the preliminary themes and found out whether they made sense and gathered the data which was relevant to each theme and made subthemes and themes within the data. The fifth step was defining themes where the researcher was going to identify the essence of what each theme was about, how sub theme interacted and related to the main theme. The sixth step was writing-up where the researcher was finally going to write the report, journal and published it.

2.8 Ethical considerations

Approval to conduct this study was obtained from College of Medicine Research and Ethics Committee (COMREC - P.10/18/2511-) and permission was sought from Bwaila Hospital Management. In order to ensure that the principle of voluntary participation was adhered to, participants were provided a written informed consent to participate in the study after thorough information was given regarding the study. The consent was read to participants to make an informed decision then endorse signature indicating their willingness to participate. For those who were not able to write, were consented in the presence of impartial witness In order to maintain confidentiality and anonymity of respondents, serial numbers were used on the interview notes instead of names. Participants were free to withdraw at any time they wished. Data is kept in a password protected computer and it will be there for two years. The researcher is responsible for data safety.

CHAPTER 3: Results

This chapter presents findings of the study from 18 in-depth interviews conducted with clients accessing HIV testing services and two (2) focus group discussions done with health care workers including nurses, clinicians and HIV Diagnostics Assistants(HDAs) at Bwaila Hospital in Lilongwe. Furthermore, it includes findings from eighteen observations conducted to HIV infected clients on the process of linking them to care. The chapter has been divided into two sections. The first part presents the participants' demographic characteristics and the second part presents themes that emerged from narrated experiences of study participants and reactions made during observation towards starting of ART.

3.1. Participants' demographic characteristics

A majority of the participants were married and their median age was 30 years and Interquartile Range (IQR) 24-33.

Table 1: Background characteristics for IDI participants (n=18)

Characteristic	Frequency
Age	
18- 20	1
21-30	7
31-40	7
41 and above	3
Education	
None	3
Primary	6
Secondary	9
Marital Status	
Married	13
Single	5
Employment	
Employed	8
Not employed	10
Gender	
Male	11
Female	7

3.2. Demographic characteristics of the health care workers

We conducted 2 focus group discussions with 16 health care workers and each group had 8 members thus 8 ART providers and 8 HDAs. The age range was from 21 to 52years with median age of 24 years and IQR of 24-33

Out of the total participants 8 had attained tertiary education thus nurses and clinicians while the rest had secondary school education with certificate obtained from in-service training.

3.3. Emerging Themes

Table 2: Summary of the emerged themes and sub-themes

THEMES	SUB THEMES
Knowledge on HIV Testing Services	Testing location
	Testing procedure
	Motivators to get tested for HIV
Linkage to care	Perceptions
	Facilitators
	Challenges

3.4. Theme 1: Knowledge of HIV testing services

3.4.1 Testing location

The majority of the participants interviewed mentioned that HIV testing is offered at hospitals only; some participants expressed knowledge about community testing services that are offered by other partners who visit clients in their localities.

"mostly the testing is done at a hospital setting in most of the circumstances as this one". (Respondent 16)

"Some come in the communities, they test and one is able to know the results right away in the communities" (Respondent 5).

3.4.2. Testing procedure

All participants expressed knowledge on how the testing procedure is conducted. Two participants were able to explain where the sample is collected and how the results are interpreted.

"I came for HIV testing last year. They took blood on this finger and told me that if 2 lines appear on the test kit then it means am positive..." (Respondent 17)

"In terms of testing, they pierce your finger and take your blood and send it to the laboratory. Then you are told to go out and wait for the results. Then when the results are ready they call you and inform you whether you are positive or negative." (Respondent 2)

3.4.3. Motivators to get tested for HIV

3.4.3.1 Knowing one's HIV status

Some participants expressed that the decision to get tested was personal and were motivated to just know their status.

"I just want to know my health status whether I am HIV positive or negative….Thereafter I should know what next step to take." (Respondent 10)

3/4/3/2 Encouragement by significant persons in your life

One participant stated that he was encouraged to test by his wife who got tested earlier.

"I have come because in the first place I brought my wife, now I think it's my turn…" **(Respondent 7)**

3.4.3.3 Desire to maintain positive health

Further, knowing one's status was equated to empowering oneself to take care of your own health.

"Moyo ndi mpamba (life is precious) and one has to take care of himself or herself in order to live longer." (Respondent 4)

"*Everybody needs to take care of his or her life these days. It's easier to help oneself earlier on than wait until you become sick."* (Respondent 5)

3.4.3.*4 Pushed to test by one's own risky behavior*

Another participant indicated that he opted for testing because he has multiple sexual partners and feels it is important to undergo the test.

"I had two girlfriends. I ended the relationship with one of the girlfriends. I'm still in a relationship with the other one. So I'd like to know my status considering I have a girlfriend…" (Respondent 3)

3.4.3.5 Experience of ill-health

Furthermore, other participants highlighted that they seek the service after noting something strange about their body.

"I have a skin rash on my skin. When I met with the doctor, he advised me to get tested." (Respondent 19)

I feel pain when I am passing urine. This prompted me to come for testing" (Respondent 16)

"I get this pain on the lower abdomen…I feel like I would want to go to the toilet but once I go there nothing happens. This is one of the things that have made me to come for testing because I don't have to keep guessing what the pain is." (Respondent 14)

3.5 Theme 2: Linkage to HIV care

Participants had varied views regarding linkage and hesitancy and readiness to initiate ARVs.

3.5.1 Perceptions on linkage to care

Some participants expressed willingness to initiate ART immediately once found positive.

3.5.1.2 Readiness to initiate ARVs

a. Influence by their position as family caretakers

Some participants said that they felt that as bread winners of their families, they have to take care of their families hence to start treatment instantly.

"*I am also looking into the future. Our parents passed away. And we are having children, so the children are depending on us, so there is need to take caution*". (Respondent 8)

b. Acceptance of status quo to avoid stress and depression

They went further saying that they want to avoid stress and depression because not accepting one's status is mentally challenging.

"In my thinking, I'll accept to be taking medication so that I avoid any stress or feeling of depression. I'll just follow the instructions given at the hospital concerning the medication." (Respondent 15).

c. Boost one's health

One participant said that she wants to boost body immunity through suppression of viral load by ARVs.

"*By taking ARVs I will be able to live longer life because I will have strong immunity.*" (Respondent 18)

On the aspect of observation especially on the reaction made after tested positive, participants reacted differently. Others had views of starting ARVs instantly while others opted for deferment.

3.5.1.3Hesitancy to initiate ARVs

a. Fear of side effects of ARV's

Some participants expressed worry that most people change their moods, body structures when they have started taking ARVs.

> *"I acknowledged ARVs lengthen people's lives, but they also bring problems. Others get stomach ulcers; others change body shape."* (Respondent 15)

b. Fear of long life treatment

Some participants went further saying that they want to inform their spouses first since the drug will be taken for the rest of their lives.

"Our partners have to be informed first, if they are ready to start taking the medication then I will also follow suit, but if they are not ready then we will also not take the drugs." (Respondent 11)

Some health workers were concerned with the process of linking clients to HIV care and stated that clients are rushed to make a decision about initiation on ARVs and rarely are they given time given time to make informed decisions as per WHO guidelines.

*"It's just that clients need enough time to digest and understand the situation. Looking at how test and treat is initiated, it's like despite that we have put this person on ART, the person may still have unanswered questions because due to limitation of time, it is not possible for the person to ask the entire question he might have had and understand things instantly. Hence there was need for this person to be given the chance to understand what is really happening considering this is a lifelong treatment." (*Focus Group Discussion *2)*

c. Limited health provider/client engagement

During observation it was noted that at one point clients were not given time to ask questions during the process and sometimes the provider could not give proper explanation on the importance of taking or not the drugs. In some instances, clients were not given time to decide because providers could do things in a hurry.

3.5.1.4 Knowledge on linkage to care

During FGDs, all the cadres were able to discuss what linkage into ART care meant.

"Linking people to the right assistance, in this context we mean if a person has been found positive, we assist that person to start taking ARV medication." (Focus Group Discussion 1)

Further, another health provider related that linking one into care may also mean the partner as well.

> *"If someone tested HIV positive, he/she should be taken to a relevant person who can take care of him or her by giving necessary treatment. If this person has got a spouse, he/she should also be taken care of so that everyone should be linked to care...."* (Focus Group Discussion 2)

Some members in FGD2 showed inadequate knowledge on how the linkage is done even though they explained some ideas in linkage.

> *"Sometimes it can be done voluntary where somebody is sick then he come, then he goes for an HIV test. Then when he's positive he goes for the treatment he came for and HIV treatment…"* (Focus Group Discussion2)

One member in FGD 1 explained in detail how the linkage is done.

> *"As a person has been found positive, we firstly counsel him. We do everything about counseling, telling him about the side effects of the drugs which he/she is about to start using and that she will use it for the whole life. Now we document all the information and initiate treatment or provide referral letter if she/he don't want to start the ARV's from this facility… so when they go the facility of their choice, the ART providers know the person has been diagnosed with HIV…no need of again testing its only confirmatory test."* (Focus Group Discussion 2)

All the groups indicated that the linkage is done immediately after one is found positive.

3.5.2.Facilitators to linkage to HIV care

Factors that facilitated linkage into care were physical escort of clients by health providres, intergration of services and support from HIV programme implementing partners.

3.5.2.1 Physical escort by health providers

The providers expressed satisfaction with the introduction of health promoters and linkage providers who personally escort clients to specific service areas within the facility because it helps ensure proper linkage of clients.

"For Bwaila we have a system which we formulated to say that linkage to care should involve physical escort of the person who is about to start medication from point A to point B,(from testing site to ART clinic) not just sending the clients on their own. This has facilitated our linkage into ART care." (Focus Group Discussion 1)

Participants expressed satisfaction with this approach noting it shortens the time newly tested clients wait to be assisted.

The researcher observed this and saw a provider escorting a client from HTS clinic to ART clinic.

3.5.2.2 Integration of services

The health workers applauded the issue of integration of services (STI, family planning, HTS, ART) which has taken shape at Bwaila is being the main contributor to successful linkage to HIV care as most services are provided in one area hence reducing the time to access services.

> *"I feel this is helpful because even management of STI's, TB, family planning are done right here. Even medical conditions such as malaria are managed right here. So integration to services has really helped linkage to care"* (Focus Group Discussion 1)

The researcher went around and observed STI, family planning, HTS, ART, OPD services in place and running. Clients could be referred from STI to HTS then to ART.

3.5.2.3 Existence of support from HIV program implementing partner

The health workers applauded existence of Nurse led Community ART Program (NCAP) and Moonlight projects which has facilitated the linkage to care at the facility.

> *"NCAP is a community project where by health workers treat or serve ART patients at their door step. So this reduces pressure of work here at the facility and at the same time it helps reduce high numbers of defaulters."* (Focus group discussion 2)

> *"As Moonlight, we operate during the night in the communities… we also go to beer drinking places… test people…. those testing are also linked to care. We also have community testing, we can also go to some place say a school and put some poster that here at the school we are testing for HIV and we have people flocking to this place. People get tested, once they have been diagnosed with HIV they are linked to care to any facility of their choice, we give them a referral letters* (Focus group discussion 2)

HDAs expressed happiness with community outreach by supporting partners. Many clients have been linked to care because of these support partners since some said they feel shy to come to the hospital to get tested but felt comfortable to test at home or drinking places.

3.5.3. Challenges to linkage to HIV Care

The challenges encountered with linkage to HIV care as stated from FGDs and IDIs included shortage of staff leading high work load, poor coordination of health services, and long distance to the health facility.

3.5.3.1 Shortage of staff leading to high workload

Health workers indicated that shortage of staff is impacting the service delivery at their facility as they have so many clients to be attended to. Such being the case most of the times they miss steps in provision of services. This is affecting the quality of care of the surrounding communities.

> *"It's a challenge but we try to mitigate it through shifts. So some clients prefer to be assisted in the morning while some are assisted in the afternoon and evening, that's up to 7 o'clock. But still this Bwaila as a facility, it has a large cohort of patients so that poses pressure of work to the service providers."* (Focus Group Discussion 2)

> *There is heavy workload, I would say that one for the health workers, there is an* increase *in defaulter rate…clients are not given enough time to think about the whole process. They start medication but it's like they have been forced so when they notice some side effects and the challenges they face at home, they decide to stop taking the medication increasing the defaulter rate.* (Focus group discussion 1)

Some participants expressed concern on the way how the services are being run at the facility considering pressure of work. Some of them arrived in the morning and only to be helped in the afternoon because there was only one person providing the services. As a result they could not finish the process of the services.

> *"The work here is just too much…we come in the morning but are assisted late in the afternoon."* (Respondent 3)

> *The government needs to put more staff at the facility to help us on time considering the large number of clients who come here for assistance* (Respondent 6)

This researcher observed the challenge as one health worker could be seen attending to so many clients. In some instances the provider could be seen missing some steps for example

explanation of the test procedure, clinical benefits of HIV testing, risk of transmitting HIV to others in testing process thereby comprising result outcome. In addition it was observed that providers had late lunch in order to assist clients and also worked up to two o'clock in the afternoon instead of 12 noon. The researcher also observed that the counselor could allow three clients to be tested at once in order to finish the long queue.

3.5.1.2 *Poor coordination of services at the facility*

Poor coordination of services also affected services negatively. Since some of services are not integrated, some clients tend to miss out on other services because they do not know the direction of the place they are referred to.

> *"As health workers have a task of giving proper direction to our clients as to where they can get services. Especially here where services are scattered. So there is need for proper coordination amongst us in order to carry out the task."(*Focus Group Discussion 1)

3.5.1.3 Distance to health facility

The majority of participants bemoaned the long distances to access health facilities and HTS and ART services citing economic challenges.

> *"We have to board a bus from …about eleven kilometers and drop off right here…. Of course we have problems financially and sometimes walk on foot to save money. Otherwise, it would have cost us K500 per person so we have financial problems…"* (Respondent 2)

> *" I am feeling tired now, I walked from …seventeen kilometers to here and will* walk *back on foot yet am sick I couldn't find money for transport. Moreover I am not employed" (*Respondent 3)

3.6. Observations

The researcher conducted eighteen observations using the participant observation guide thus pre testing during testing and post testing but out of these only fourteen were done following the guide. The counselor followed all the steps in the guide. In the six observations conducted, there was no confidentiality of clients as the counselor allowed three clients to be tested at once since there was shortage of staff. It was also observed that there was high traffic flow during testing as the door was not locked. At one point there was no opportunity for the client to ask the health care worker questions as she was in a hurry so to serve everyone in the queue as there were too many clients to be attended to. This depicted high work load at the facility. Clients went home with unanswered questions. The provider at the one point could not talk to clients while giving out results as he was busy writing.

CHAPTER 4: Discussion

4.1. Introduction

The main purpose of this study was to assess the factors associated with linkage to Antiretroviral Therapy (ART) care amongst adults accessing HIV services at Bwaila Hospital. The factors that are associated with linkage to HIV care are physical escort of the clients by providers, integration of services at the facility and support from other HIV programme implementing partners. The challenges faced by health workers and participants with linkage to HIV care are shortage of staff leading to high workload and distance to the health facility, poor coordination of services at the facility.

4.2. Perceptions with linkage to care

Our findings on readiness to start ARVs are similar to other studies done in Mozambique which revealed that most people feel that once found positive they should immediately start [28,29] ART . This explains Andersen's theory about how an individual perceives his own health and how he seeks and utilizes health services [23]. If an individual feels that he is sick he will seek for testing services and if found positive, then decides to go for ART considering its benefits. By being on ART an individual will have reduced frequency of illness [6]. In addition ARVs will slow the escalation of HIV [29]. Therefore there is need to encourage people to start ART once found positive as this will promote healthy living and prolong peoples life [30]. According to START trials ARVs increase CD4 count in an individual thereby boosting the immunity and ARVs reduce the risk of sexual transmission of HIV [31].

Our findings on hesitancy on ARV initiation secondary to side effects remains consistent with a study done in South Africa which revealed that people hesitate to be initiated on ART when tested positive because they fear the ART side- effects [32]. Another study in Cape

Town found that sixty percent of infected people could not disclose to their colleagues of being HIV infected because of fear of being rebuked [33]. To avoid these fears people need to be health educated on importance of being on ART when found positive so as to lengthen their life and be told that current regime has few side effects [30,33]. Furthermore, participants in our study expressed the need to discuss the result with a spouse before initiating on ARVs which resonates with an earlier study where HIV infected clients opted for discussion with their partners first before starting ART [34], The option to discuss with a partner first, delayed initiation of the treatment thereby putting their lives at risk [35]. Denial of an HIV infected status may also be expressed as the need to discuss with partner [36]. This is consistent with findings from another study where denial of HIV status has been cited as a major barrier to entry into HIV care [37]. The longer the denial process the longer for them to link to care. Fagan et al argued that change in client's perceptions may be an additional step to acceptance of HIV status for clients to enter into care [38].

Our findings on knowledge to linkage to HIV care is consistent with a South African study which found that other people have adequate knowledge while others have inadequate knowledge about perceptions with linkage to care [8]. This explains why some people who are linked to care while others are not. Adequate knowledge is an important factor for one to be effectively linked to care. Having adequate knowledge an individual will be able to know the importance of being of linked to care and consequences of not being linked to care [39]. Individuals with inadequate knowledge will have problems in uptake of HIV services thereby compromising linkage to care [39].

4.3. Facilitators to linkage to HIV care

Our findings on why individuals go for HIV testing are similar to an earlier Malawian study which indicates that the decision to undertake HIV testing services by most individuals is strongly influenced on by their awareness of their ailing health, knowing one's status and

their knowledge of the potential benefits of ART treatment [40]. This is in line with Andersen's theory which says that an individual who believes health services are an effective treatment for an ailment is more likely to seek care. A study in Uganda further found that people take HIV testing because they know that if found positive they will benefit from ART [41].

The study found that integration of services has promoted linkage to care at Bwaila Hospital. The findings are similar to a study done in South Africa which showed that integration of health services facilitates the proper linkage to care for clients [42]. The study showed that where services are offered in one area, clients are easily assisted and this promotes acceptance as it reduces long waiting times [42]. Integration of ART services with other primary health care services like immunization clinics are motivators to clients to initiate on ART instantly [42]. Another study done in the same country South Africa has also found similar results on the significance of integration of services in HIV care, where there is integration of HIV services into existing health services like family planning, antenatal care, STI and general OPD has tremendous potential for health system strengthening [43]. Studies done by Partners in Health in Uganda found that integration of ART services into TB care improved health outcome for patients [44]. A systematic review found that where ART was integrated with ANC, initiation of ARVs greatly improved while another study found that there was little difference in the outcome [45]. A study in rural Kenya found that where HIV and Sexual and Reproductive Health services were integrated, there was increased patient burden, inadequate staffing and resistance from existing health care workers. The study further found that there was lower utilization of HIV services and reduced patient satisfaction [43].

Physical escort by the provider from HIV testing center to ART clinic enhances individuals to have quick linkage to HIV care. This is consistent with a study done in Tanzania which

found that linking a client to ART the same day increases chances of that person of continuing to receive HIV services especially when a service provider personally escorted the client [46]. In Malawian setting this is not feasible as the country is hit by shortage of staff [47]. Most rural facilities have only one nurse and one clinician who apart from running HIV service them also run other services for example OPD, ANC, family planning. So it is difficult to carry out this method in such situations but if it can be carried out, large proportion will be linked to HIV care. This will be good for the country as the world strives to have zero infection by 2030 [48]. A study done in Uganda found that physical escort becomes a barrier to seeking care especially in instances where one needs to disclose their sero-status to family members including their partner [49].

The other factor which makes Bwaila unique in terms of facilitation to linkage to HIV care is the existence of an HIV program support partner and availability of Moonlight services which brings HIV services to the client's homes, drinking places where clients are offered testing services and linking to HIV care to those who have been tested positive. Moonlight services are done during night time. This has resulted to a number of people including vulnerable groups being tested and linked to care if found positive. These findings are similar to a study done in Mombasa, Kenya where a large number of people have been tested and linked to HIV care because of moonlight services [50]. But since this is a project run by an NGO once its term expires, it stops existing and the services stop

4.4. Challenges associated with linkage to HIV care

Shortage of staff at the facility affects the processes of linking clients to HIV care. This finding is in line with what a systematic review reported that HIV infected were not linked properly to care because of shortage of staff and service accessibility [51]. Similarly a Tanzania study revealed that inadequate human resource has negatively affected HIV care services [46]. Specifically to Malawi, McPherson et al has reported that inadequate human

resource affected progression of continuum of care [40]. But adequate personnel according to Andersen's theory facilitates provision of services to those who seek them [25].If the facility has adequate personnel one is assured of maximum utilization of the services. The recruitment policy put in place by government is contributing to this problem as there is no routine recruitment of health workers in Malawi as has been the case in the last five years [52]. Because of this there is a high vacancy rate of 33% in the health system [47]. As a result of inadequate staff, the health workers experience increased work load due to a large volume of clients. This compromise the quality of services rendered as the provider to patient ratio is very high. hence failure to properly link clients to HIV care [40]. A study done in sub-Saharan Africa has found that the more health workers are overstretched hence compromising the quality work [53]. The HTS/ART clinics are overwhelmed with clients leading to excessive workload on the already understaffed health personnel especially in Malawi [53,54]. This has led to task shifting where duties have been delegated to lower cadres who are providing HIV services [47]. The pros of this system are: there is relatively low investment and it uses already existing healthcare workforce. The cons are: health care workers require training and investment, need for change in clinical guidelines which they may understand better. They need license for them to practice legally [55].

Distance to health facility poses a challenge in accessing HIV services [40]. This is in tandem with this study on assessment of factors with linkage to HIV care where participants expressed long distance to access health services as a challenge as they require to have transport money to reach Bwaila Hospital. This is in line with Tanzanian study where eighty clients could not be linked to HIV care because of long distance to the facility [46]. Instead they remain at home or seek services from traditional healer despite potential effects. So scaling up of mobile and outreach HTS/ ART clinics could ease the problem of accessing HIV services since clients would walk shorter distance [46].

Poor coordination of facility services has posed a challenge in linkage services. This has led to poor coordination among health workers resulting into misdirecting clients for linkage to HIV care. The findings are similar to a study done in Lilongwe where inadequate coordination of maternal and infant HIV services affected early infant diagnosis of HIV outcome [30]. Some mothers could not test HIV on their infants because of being misdirected. Coordination of services at any facility is very crucial as this enhances proper delivery of quality services [56]. Proper coordination ensures that all levels of services are coherent so as to support service delivery. This enables health system goals to be achieved [30,56]. A study done in USA revealed that good coordination improved performance in service of elderly care. The study further revealed that good coordination of services resulted in minimizing delays and maximised the responsiveness to clients' needs [57]. Another study done by Partners in Health in Malawi revealed that case management and support by dedicated community health worker created a longitudinal continuum of care in the prevention of mother to child cascade and resulted in improved outcome [58].

CHAPTER 5 Conclusions and Recommendations

5.1. Conclusion

The study has provided an insight on what needs to be done in order to improve linkage systems at the facility and in other hospitals. HIV linkage to care interventions is increasingly important in order to achieve the UNAIDS 90–90–90 as larger numbers of individuals receive testing and enter the continuum of care. Our findings provide a number of policy-relevant suggestions for the design and implementation of linkage to care programs. Interventions aimed at improving linkage to care in HIV services should focus on overcoming health system barriers and integration of health services. For linkage to work properly there is need to consider additional human resource and ease of access to health services.

5.2. Recommendations

- **Support through supervision: providing consistent and ongoing support and supervision to the linkage officers.**

There is need to ensure that the person who is supervising the linkage health workers receive support and proper training so as to discharge his duties effectively.

- **Post-project continuation of partner HIV projects.**

  The Malawi Ministry of Health should ensure that projects that are being implemented by HIV support partners like Moonlight are sustained for continuity of services

  1. The government health workers should always be involved in the running of the projects for the sake of continuity in case it phases out.

- **Integration of HIV Care within Primary Health Care Services**

Integration can offer several potential advantages to HIV clients when it comes to linkage [59]. This will ensure that there is sharing of services and resources within the facility.

- **Review of recruitment policy of health care workers**

  There is need to review this policy so as to enable The Ministry of Health to recruit more staff who will fill the gap of the existing vacancy .

5.3. Strengths and Limitation of the study

The inclusion of adult clients and health care workers in this qualitative study facilitated deeper understanding of perceptions of people towards initiation of ART, factors facilitating and impeding linkage to H.IV care. We also noted that community based Moonlight testing services and linkage programs enhance linkage to care. These interventions decreased the travel barriers that often prevent prompt linkage to care.

Several limitations should be considered in the interpretation of these findings. Firstly we did not identify any linkage to care interventions specifically focused on men who are known to have poor health seeking behavior. This has been noted in the literature as well and underlines the need for greater programs focused on serving men. Secondly, all data was cross-sectional. Thirdly this study was done at one place so results could not be generalized.

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APPENDICES

Appendix 1: In-depth interview guide (English version)

Study Title: Assessment of factors associated with linkage to ART care at Bwaila Hospital, Lilongwe District.

Good day, I am Clifton Gondwe, a student at College of Medicine of Malawi. I welcome you to this discussion. I am conducting a study on assessment factors associated with linkage to ART care. I will interview you and the session will audio recorded so that everything should be captured. Shall we proceed. Once the participant agrees, the proceedings will be as follows:

PART I: Social Demographic

A1 Gender	Male Female
A2 What is your current age in years?	Age in completed years
A3 Have you attended any formal education?	Yes (1) No (1) If no skip to 5
A4 What is your highest level of education?	Primary (1) Secondary(2) Tertiary (3)

A5 Are you married?	Yes (1) No (1)
A6 How far do you live?	
A7 Where are you working?	

PART 2: Knowledge of HIV transmission and its prevention strategies

Now we will talk about HIV transmission and prevention strategies.

What do you know about HIV and AIDS?

How is it transmitted?

What are the prevention strategies?

PART 3: Knowledge of HIV testing and treatment

We have talked about HIV transmission and prevention strategies; now let's talk about testing and treatment,

Tell me about what you know about HIV testing?

What do you know about HIV testing and treatment?

PART 4: Enabling factors to linkage to care

What prompted you to come for testing?

Have you been forced to come for testing?

What do you expect of the outcome of the testing? Are you ready of any outcome?

Suppose you are found positive, what would be your next step? Probe more

Any barriers encountered with? Explain

PART 5: Perceived views towards ART

Now let's talk about your perception and your views on ART.

What are your perceptions regarding ART?

PART 6: Areas of improvement

What could be the government of Malawi do to improve the linkage to ART care after one is tested positive so as to reduce transmission?

Anything more to inform policy makers?

Thank you very much for sparing your time and giving your information.

END OF DISCUSSION

Appendix 2: In-depth interview guide (Chichewa version)

Ndakulandiran manja awiri. Khalani omasuka. Ine ndine Clifton Gondwe wophunzira ku sukulu ya college of medicine. Tifunsanapo mafunso angapo okhuzana ndi kafukufuku wathu umene tifuna kudziwa zimene zimachitika kwa munthu amene apezeka ndi matenda koma safuna kuyamba mankhwala. Titepa chilli chonse chimene tikambirana pano koma mmene ndinanenera kale zikhala za chinsinsi. Kodi tipitilire? Ngati avomereza tipitilira motere:

Gawo loyamba: Social demographic

A1 Gender	Mwamuna Mkazi
A2 Muli ndi zaka zingati?	
A3 Munayamba mwaphunzirapo?	Primary (1) Sekondale (2) Ukachendede (3)
A4 Ndinu wokwatiwa?	Inde (1) Ayi (2)
A5 Mukhalira kuti?	
A6 Mugwira kuti ntchito?	

Gawo Lachiwiri: Zomwe mukudziwa pa matenda a HIV mmene imafalikira ndimmenenso timatetezera.

1. Kodi mukudziwapo chani za HIV?
2. HIV imafala bwanji?
3. Nanga ndi njira ziti zimene tingapewere matenda a HIV kuti asafalikire?

Gawo lachitatu: Kuyezetsa ndi kuyamba mankhwala nthawi yomweyo.

1. Kodi mungathe kutiuza zimene mumadziwa pa nkhani yakuyezetsa HIV?
2. Kodi mukudziwapo chani pa nkhani ya kuyezetsa ndi kuyamba mankhwala nthawi yomweyo?

Gawo la Chinayi: Zomwe zimapangitsa kuti munthu ayambe kulandira chithandizo nthawi yomweyo atayezedwa.

1. Ndichani chakupangitsani kuti muzayezetse?
2. Kodi mwakamizidwa kuti muzayetzedwe?
3. Mudzivomera bwanji zotsatira zake?
4. Ngati zotsatira zake zionetsa kuti mwapezeka ndi kachirombo **,** muyamba mankhwala nthawi yomweyo, ngati ayi chifukwa chiyani? Fufuzani mokwanira.
5. Pali zophwinja zili zonse? Fotokozani

Gawo la Chisanu: Malingaliro anu pa ndondomeko ya mankhwala(ART)

Tiyeni tsopano tikambepo za malingaliro anu pakamwedwe ka mankhwala a matenda a HIV.

Tsopano ngati mwayamba kumwa mankhwala malingaliro anu ndiwotani ndiponso amene akumwa mankhwalawo?

Gawo la chisanu ndi chimodzi: Zoyenera kufuna kukonzedwa

1. Ndiziti zimene ziyenera zitakonzedwa ndi boma la Malawi kuti nkhani yakuyezedwa ndi kuyamba mankhwala nthawi yomweyo iziyenda bwino
2. .Pali zina zoti mutha kuwonjezera pa nkhani imeneyi kuti oyendetsa mapologiramu ndi malamulo atayiziwa?

Zokambirana zathu zathera pamenepa.

Zikomo kwambiri chifukwa chokhala ndi nthawi kuti tikambirane

Appendix 3: Focus Group Discussion Guide with Health Workers

1. Good day. Welcome to this session where we will have discussion as a group. As you know that I am looking at assessment of factors associated with linkage to ART care right here at Bwaila Hospital. Feel relaxed. You may agree with me that so many people are found HIV positive but not all are linked to care, even here at this hospital. What do you think are the problems or challenges associated with it? The flow is open. The researcher will record the responses. Thereafter the researcher is going to ask another question., What do you think the program manager or policy makers should do to alleviate the problems? After recording the responses, the researcher will ask for additional comments.

2. Thank you very much for sparing your time and attend this discussion.

Appendix 4: Observation guide

1. **Study title: Assessment of factors associated with linkage to ART care at Bwaila Hospital, Lilongwe District.**

2. Good day. My name is Clifton Gondwe, a student of College of Medicine. I am conducting a study on assessment of factors associated with linkage to care. In order to achieve I need to observe pre-testing, during testing and post testing services. I will use a checklist to capture information. Shall we proceed?

3. Once the participants agree, then proceed using checklist.

4. **PRE TEST SERVICE**			
1.	6.STEP (Check if the following is explained)	7/DONE 8 YES / NO	1.COMMENTS
9	1.Explanation of the service to be provided		
12	1.Reasons why HIV testing and counseling is being recommended		
14	1.The clinical and prevention		

	benefits of HIV testing		
16	1.Risk of transmitting HIV to others		
18	1.Availability of HIV services for negative or positive results		
20	1.Observed confidentiality		
22	1.In event of an HIV positive test result encouragement of disclosure to their partners		
24	1.An opportunity to ask the health care provider questions		
26.**GENERAL COMMENTS**			
1.**H I V**	28,**T E S T I N G**		

1	30.Seek consent to perform an HIV test		
1	32.Explanation of the steps during the process		
1	34.Talking to the clients while results are reading		
1	36.Interpretation of the results		
1,**P O S TEST**			
39	1.Education on risk reduction measures to one who is tested negative		
41	1.Somebody with positive test result-psychological support - Need to start ant retroviral treatment		
1	44.Decision made by the positive client		

1	44.If client defers treatment- should explain reasons why?		
1.**GEN E R A L COMMENTS**			

Appendix 5: Participants information sheet

Study Title: **Assessment of Factors associated with Linkage to ART Care at Bwaila Hospital**

Investigator: Clifton Muvwala Gondwe

I am a student pursuing a Master of Public Health Degree at the College of Medicine. I am conducting this study to find out factors which are associated with linkage to ART care as part of academic fulfillment. I will ask questions and conduct focus group discussions with you as well as health care workers.

What you need to do for this study?

If you decide to participate in the study, you will be required to give your personal data and answer questions which will be recorded or written.

How will your privacy be maintained?

I will be the only person to gain access to your personal details and all recorded information will be kept safe. Codes will be used instead of names. After the study, your records will be destroyed.

Voluntary Participation and your right to refuse

Participation into this study is voluntary. You have the right to withdraw from the study at any point if you wish to do so without being penalized, however, your participation into this study is very important as your responses will assist in improving adolescent health issues within your area.

Are there any risks involved in the study?

There are no known risks in taking part into this study that I am aware of.

Whom to contact if you have any questions about the study?

Clifton Muvwala Gondwe

Medical Council of Malawi

P O Box 30787, Lilongwe 3

Cell: 0888866004/ or 0993042045

Dr Linda Mipando

University of Malawi, College of Medicine

P/Bag 360, Chichiri

Blantyre 3.

Cell: 0994412212

You can also visit me at the Medical Council of Malawi, Professional Department.

Who has given permission for me to go ahead with the study?

The College of Medicine Research and Ethics Committee and Lilongwe District Health Office. If you have any worries or queries, contact the Chairperson of the Research and Ethics Committee, College of Medicine, P.O Box 360, Chichiri, Blantyre3 or you can call using telephone number 01871911, extension No 334. You can also contact the District Health Officer for Lilongwe District.

Clifton Muvwala Gondwe

[Researcher]

Name of participant/Witness …….

Agree to Participate [Yes] / [No]

Date …….. Signature/thumb print …….

Please give participant/witness two forms to sign and leave one form with the participant.

Thank you very much for taking your time reading/listening to the study information.

Appendix 6: Informed Consent for Participants and Health workers (English)

Study Title: Assessment of factors associated with linkage to ART care at Bwaila Hospital

Principal Investigator: Mr Clifton Gondwe, Master of Public Health Student, College of Medicine

Research Supervisor: Dr Linda Nyondo- Mipando, Lecturer, College of Medicine

PI Version Date: October 2018

What should you know about this study?

You are being asked to participate in a research study. You will find explanations of research study in this consent form and you are supposed to read it carefully and understand the part you are to play in this research study. Make sure you take much time as you need. Take note that your participation in this study is voluntary and you are free not to participate. Any time you decide to withdraw you are free to do so without any consequences. In the course of study, you may be notified if we learn new information that may affect your participation.

The research is being conducted to learn factors associated with linkage to ART care among adults. The investigator is Mr Clifton Gondwe, Master of Public Health Student at College of Medicine. Be free to ask him any question concerning the study any time before or during the study. Before you decide to take part in the study or not, we want you to know the purpose of the study, the possible benefits and risk to you and what is expected during the study. After you have understood the information you may decide to participate or not. You will be asked to sign the consent form after you have decided to participate in the study. You will be given this consent form and you will keep it.

Purpose of the Study

The purpose of the study is to assess factors associated with linkage to ART care after being tested positive. Why do some people don't start taking medication immediately after being tested positive. How does one perceive to be on anti-Retroviral therapy drug for the rest of his life after being tested positive? What could be the enabling factors and challenges associated with ART uptake. Understanding of these issues will help programme managers and policy makers on how best to improve HIV care services amongst adults.

Study Procedures

About 20 participants will participate in depth interview and 20 health care workers in focus group discussion. Health care workers include 12 nurses who are involved in dispensing drugs and testing participants as well as 8 diagnostic assistants. In addition, observation will be done to these 20 participants as they are being pre tested, tested and decision made after being tested positive.

The researcher will ask you to sign the consent form if you agree to participate in the study and ask some information about nature of your work and challenges you face in delivery of HIV services. This will also be done to participants on how they feel being tested and to be on medication after being found positive.

Risk or discomforts

The risks for participating in the study are very minimal. However, there might some experiences you might not share with us you are free to do so, otherwise your views are very important to understand issues surrounding HIV testing and treatment. We will respect your privacy and confidentiality while you are in the study and your name will not be used in the summaries. The interviews will be conducted in privacy and responses will not be known to others.

Potential benefits for the study

There may be no benefits from the study however the information gained will help programme managers and policy makers on how best to improve on HIV testing and treatments services so as to reduce transmission amongst the population thereby keep them healthy.

Reasons you may be withdrawn from your study without your consent

Your participation from the study may be terminated without your consent if:

- The study is stopped by College of Medicine Research Ethics Committee (COMREC)

or

- If there is a possibility that staying in the study will be harmful to you.

Cost and Compensation

There is no cost associated with the study. No money will be received. You are free to participate or not. This will not affect you in any way.

Confidentiality

Your information as participant will be kept confidential. The interviews will be conducted in a private place and nobody is going to hear conversation. The interview records will be signed codes and not your name. The recorded interviews will be used for the purpose of this research and they will be erased once requirements are met. The consent forms will be kept according COMREC guidelines and will be destroyed once requirements of the study are met. Only the researcher will access the records which will be kept in lockable cabinet. Your name will not appear on any of research reports. Only the research team will have information, thus the study supervisor and College of Medicine Research Ethics committee.

Research Related Injury

There are minimal chances of getting injured in participating in this study. In case you get injured because of taking part in this study you will be directed where to get treatment. You will not be compensated for in any form for getting injured.

Problems or questions

If you have any question about this study or any related injury, please contact:

- Clifton Gondwe working at Medical Council of Malawi on cell no's 088866004/ 0993042045
- The research supervisor, Dr Linda Nyondo Mipando working at College of Medicine under the Department of Health Systems and Policy. Cell phone number: 0994412212
- COMREC secretariat, P/Bag 360 Chichiri Blantyre 3. Tel.No 01871911 ext.334

If you have any question or concerns about your rights as a study subject, please contact

SIGNATURE PAGE

Study version 1.0: October 2018

If you have read the consent form or somebody has read for you and you have understood the information. You want to participate in this study voluntarily, please sign your name below

---------- ----------

Participants Name/Thumb Print Participants Signature /Thumb Print

---------- ----------

Researcher Name (PRINT) Researcher Signature and Date

--- ---

Witness NAME (PRINT) Witness Signature and Date

Appendix 7: Study Area Map

Appendix 8: Certificate of Ethics Approval

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.10/18/2511 - Assessment of factors associated with linkage to ART care at Bwaila Hospital, Lilongwe District. Version 2.0 dated 27 November 2018 by Cliff Gondwe

On 22-Dec-18

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

Mlombe

22-Dec-18

Dr. YB. Mlombe - Chairperson (COMREC)

Date