



COLLEGE OF MEDICINE

**Factors that are related to Adherence and Care Seeking for Hypertension treatments in
Individuals on Antiretroviral Therapy in Central Malawi.**

By

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DECLARATION

I, Khumbo Phiri hereby declare that this dissertation is my original work and has not been presented for any other awards at the University of Malawi or any other University.

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ABSTRACT

Background: Hypertension which occurs in 1 out of 3 adults is the most common non-communicable disease (NCD) in Malawi. Despite its high prevalence, treatment coverage for hypertension is low. Low rates of health seeking behavior, unhealthy lifestyles and poor access to health care remain key challenges to the prevention, control and management of hypertension.

Objectives: The objective of the study is to identify the factors related to care seeking for hypertension among adults on antiretroviral therapy (ART).

Methods: We conducted in-depth interviews with 30 individuals who are 18 years or older, on ART who also have hypertension. Interview questions focused on challenges and enablers to care seeking for hypertension and patients' perceived risks and benefits to health care utilization for hypertension. Andersen's behavior model for health services utilization (BMHU) was used as an organizing framework. Data were analyzed through constant comparison methods using Atlas.ti 8, applying both deductive and inductive techniques using a modified grounded theory approach. The results are presented based on common themes within the BMHU framework.

Results: The most common barriers for care seeking, adherence to medication and general management of hypertension included financial challenges due to poor health and weakened physical ability and medication side effects. At the health system level, lack of integrated care, lack of available hypertension medications, long wait times, and poor quality of care were the major challenges to care seeking. Respondents perceived risks of hypertension influenced their decision to start or stay on hypertension treatment. Knowledge about the benefits of treating hypertension encouraged individuals to properly manage their hypertension, despite barriers to care.

Conclusion: Among our participants on ART with hypertension there was a high level of knowledge about the risks of hypertension and high motivation for treatment, but individuals faced significant challenges to care seeking. Patient barriers could be reduced through integration of hypertension treatment within ART clinics, free or low cost access to antihypertensives, improvements in the supply chain for hypertension medication, and support services (counseling or other) for patients with multi-morbidity.

Contents

CERTIFICATE OF APPROVAL	II
DECLARATION	III
ACKNOWLEDGEMENTS	IV
ABSTRACT	V
LIST OF TABLES	IX
ABBREVIATIONS AND ACRONYMS	X
CHAPTER 1: INTRODUCTION	2
1.1 BACKGROUND	2
1.2 PROBLEM STATEMENT	3
1.3 LITERATURE REVIEW	4
1.4 JUSTIFICATION OF PROJECT.....	7
1.5 OBJECTIVES	8
1.5.1 <i>Broad</i>	8
1.5.2 <i>Specific</i>	8
CHAPTER 2: METHODS	9
2.1 TYPE OF STUDY.....	9
2.1.1 <i>Conceptual framework</i>	9
2.2 STUDY PLACE	9
2.3 STUDY POPULATION	10
2.4 SAMPLE SIZE	10
2.5 DATA COLLECTION.....	10

2.6 DATA ANALYSIS	12
2.7 LIMITATIONS	12
2.8 ETHICAL REVIEW	13
CHAPTER 3: RESULTS	14
3.1 HEALTH STATUS OF RESPONDENTS	16
3.1.1 <i>Blood pressure</i>	16
3.1.2 <i>Hypertension medication</i>	16
3.1.3 <i>Adherence to medication</i>	16
3.1.4 <i>Perceived quality of care received at health facility</i>	17
QUALITATIVE RESULTS	18
3.2 ENABLING/BARRING FACTORS: INDIVIDUAL-LEVEL ENABLERS	18
3.2.1 <i>Financial constraints due to poor health and weakened physical ability</i>	18
3.2.2 <i>Fear of side effects</i>	19
3.2.3 <i>Challenges with stress reduction</i>	19
3.3 ENABLING/BARRING FACTORS: SYSTEM-LEVEL ENABLERS	20
3.3.1 <i>Long wait times</i>	20
3.3.2 <i>Lack of availability and high cost of hypertension medication</i>	20
3.3.3 <i>Lack of integrated care</i>	21
3.3.4 <i>Perceived acceptability of quality of care</i>	22
3.4 NEEDS: PERCEIVED RISK	23
3.4.1 <i>Feeling healthy</i>	23
3.4.2 <i>Feeling that hypertension is not their main health problem</i>	24
3.4.3 <i>Knowledge on dangers of hypertension</i>	24
CHAPTER 4: DISCUSSION	26
CHAPTER 5: CONCLUSION AND RECOMMENDATIONS	31

REFERENCES	32
APPENDICES	38
APPENDIX 1: INTERVIEW GUIDE	38
APPENDIX 2: CERTIFICATE OF ETHICAL APPROVAL	42
APPENDIX 3: AMENDMENT APPROVAL	44
APPENDIX 4: AMENDMENT APPROVAL	46

LIST OF TABLES

Table 1: Characteristics of respondents	15
Table 2: Blood pressure measurement at most recent clinic visit.....	16
Table 3: Reported Missed doses for ART Vs hypertension in a month	17
Table 4: Quality of care for hypertension services received.....	17

ABBREVIATIONS AND ACRONYMS

ART	Antiretroviral Therapy
BMHU	Behavior Model for Health Services Utilization
BP	Blood Pressure
CHAM	Christian Health Association of Malawi
COMREC	College of Medicine Research and Ethics Committee
HBP	High Blood Pressure
HIV	Human Immunodeficiency Virus
LMICs	Low and Middle Income Countries
NCD	Non- Communicable Disease
PEPFAR	President's Emergency Plan For AIDS Relief
SSA	Sub Saharan Africa
UHC	Universal Health Coverage
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

1.1 Background

Hypertension, one of the most common non communicable diseases (NCDs), is a global public health challenge and a leading risk factor for cardiovascular morbidity and mortality [1] with 7% of deaths attributable to it [2]. An estimated 1.13 billion people worldwide have hypertension, most (two-thirds) living in Low and Middle-Income Countries (LMICs) [3]. A worldwide data analysis on the global burden of hypertension predicted that the number of adults with hypertension in 2025 will increase by about 60% to a total of 1.56 billion[4]. Furthermore, the global economic burden of NCDs is huge, estimated at US\$6.3 trillion in 2010, and projected to rise to \$13 trillion in 2030. The global community adopted a Global Action Plan for the Prevention and Control of NCDs with the aim of “25 by 25,” i.e., a 25% reduction in premature mortality from NCDs by the year 2025 [5].

Around 9 million people in LMICs are on antiretroviral treatment (ART). Antiretroviral therapy extends life and this leads to a remarkable improvement in quality of life. With near-normal life expectancy, HIV-positive individuals are at risk for comorbidities of aging, such as hypertension, diabetes, and cardiovascular disease. Studies have highlighted factors, including urbanization, an aging population, physical inactivity, obesity, increasing alcohol consumption, and high salt intake as contributing to the increasing rates of hypertension in LMICs [6]. Access to health care would contribute to reduced burden of NCDs [7, 8]

There is high and increasing burden of hypertension in Malawi in the general population and specifically among people living with HIV[4]. In Malawi, 32% of the adult population have hypertension and 94% of these are unaware of their condition and therefore untreated [9]. Poor access to health care services contributes to the burden of NCDs including hypertension. The

World Health Organization's (WHO) Innovative Care for Chronic Conditions framework which is relevant for both prevention and disease-management in health care settings recommends that ministries of health should work on improving the quality of patient interactions, organization of health care, community involvement, policy, and financing systems [10]. Any lack in the mentioned areas which has direct influence on the prevention and disease management is expected to contribute the prevalence and also lack of diagnosis of hypertension cases in the general population.

1.2 Problem statement

Hypertension control rates are low worldwide [11], and delay in seeking care is associated with increased mortality, particularly among the HIV-positive population [12]. Currently, 71% of HIV-positive Malawian adults receive ART [13] and therefore come into regular contact with the health system, but little work has been done to address hypertension in this population despite clear opportunities. Preliminary results from an observational cohort study conducted at a health facility in central Malawi shows that one-third of participants reported missing antihypertensive medication 2 or more times per week, versus no participants missing 2 or more doses of ART per week [14]. It is of high importance to note that individuals are managing the two conditions concurrently, yet face different barriers and report different levels of adherence to medications for HIV versus hypertension. Many studies have been conducted to examine barriers to HIV care but there has been very little work focusing on understanding barriers to NCD care, especially for hypertension. A better understanding of these barriers will help outline patient preferences for hypertension care and help in supporting individuals to manage hypertension. Furthermore, it is

critical to understand barriers to care, to ensure adequate utilization of health services and achieve optimal health outcomes for hypertension.

1.3 Literature review

Countries in Sub Saharan Africa (SSA) are facing a challenge of coping with rising numbers of patients with chronic diseases. This is causing a growing attention for chronic conditions in SSA. There is a strong advocacy for managing NCDs appropriately, many of which are life-long. Numerous barriers impede care seeking behavior for NCDs including the contextual factors such as the environment and the health system. This study adapts the Andersen's Behavioral Model of Health Services Utilization (BMHU), a model which was established in the late 1960', and it suggests that people's use of health services is a function of their predisposing factors which influence them to use health services, factors which enable or inhibit use, and their need for care [15, 16]. In this model, Andersen defined use of health services as a function of 3 main elements: need, enabling, and predisposing factors. Literature has so far shown the need factors, as accounting for the majority of reasons why individuals seek health care services. This has mainly focused on theory that the individuals' perceived health care needs and other indicators of health status influence one's care seeking behavior. Studies have reported factors such as self-reported symptoms, self-perceived health, number of days they spend in bed not feeling well, limitation in their physical activity, and activities of daily living as part of the patient's perceived need of health care [17-19]. Enabling factors according to the BMHU include items such as the individual's income, health insurance status, and access to a source of regular care [17-19]. Finally, the model also talks about predisposing factors which includes demographic variables, socioeconomic status, attitudes, and beliefs as influencing individuals care seeking behavior as well [17-19]. Much as

Andersen's model explain the three factors as predicting health services utilization by individuals, studies have shown that the enabling and needs factors are the ones that have shown to be potentially responsive to interventions [20]. Enabling factors may include factors at an individual level as well as at a health system level.

The World Health Organization proposed a framework describing health systems in terms of six core components including service delivery, health workforce, health information systems, access to essential medicines, financing, and leadership/governance. Several factors within the health system have been reported within the BMHU as influencing health care seeking behavior for individuals with hypertension. Recently a more general focus on health systems strengthening has catalyzed attention for chronic care [21, 22]. Under the weak health system, a commonly reported factor influencing care seeking behavior is lack of available medication for NCDs in public health facilities. A study of six LMICs found that the highest contribution to out-of-pocket expenditure in patients with multimorbidity was on medications [23, 24]. This spending is compounded by limited public sector provision of medicines and the fact that these medications are for chronic conditions that require lifelong treatment. Due to significant funding from mechanisms like Presidential Emergency Plan For AIDS Relief (PEPFAR), health organizations can provide free and equitable access to HIV medications for their patients, easing the financial burden on them and their households. However, just 1% of Malawi's healthcare funding is directed towards NCD care compared to 51% for HIV [25] and thus, patients are often left to procure essential medications for other non-HIV chronic conditions and comorbidities on their own. This clearly shows that there are gaps in the health system as a whole hence the need for the Malawi ministry of health to come up with strategies that might help fill up the gaps.

Countries including Malawi have adopted health system reforms which aim at achieving Universal Health Coverage (UHC) [26-28]. Such reforms were designed to introduce or expand public health care financing systems that helps to pool resources together for a prepaid financing source. This strategy is mainly intended to replace out-of-pocket payments [28, 29]. With UHC, health systems are ensured that they will be able to provide the needed health services adequately to the general population. [27, 29]

Apart from health systems, studies have reported on other aspects that determine usage of health care services as outlined within the BMHU, individual level factors have also been mentioned as attributing to the individual's health care seeking behavior. For efficient disease control and management, the individual's care seeking behavior needs to be understood as it influences the duration of symptoms and the probability of morbidity and risky health outcomes [30]. Several factors have been reported to influence care seeking behavior at individual level within the BMHU including accessibility of the health care services source, type of illness and its severity, as well as the individual's level of education [31]. Higher levels of education were mostly associated with care seeking behavior as individuals in this category are mostly exposed to knowledge about importance of seeking care if they are aware of their health condition.

It is clear that most factors that influence care seeking behavior for health services utilization that have been presented in different studies do revolve around an individual. This being the case, patient centredness approach has been proposed as one of a framework that is ideal as it provides opportunities for support for patient's self-management which includes efforts to bring in patient participation in their care and a joint goal-setting and planning of their treatment with a health care provider[32]. Studies have indicated patient centredness approach as contributing to improvements in adherence to treatment for hypertension [33]. This has been achieved by understanding the

patients' perspective of their illness. Patient centredness approach incorporates all needs of the patient[34]. Furthermore, patient centredness has the potential of integration of management of chronic diseases like HIV and hypertension as involving the patients themselves in managing their disease might bring in opportunity to the patients to plan management of both conditions concurrently. As such, use of the BMHU for this study is appropriate as it will help in better understanding and identifying what it is that matters as regards management of hypertension treatment and most of all the overall care seeking behavior of individuals who have hypertension in the face of HIV which is yet another chronic disease, individuals are managing.

This research focussed on identifying what matters for the medical management of chronic hypertension among adults on HIV treatment in a resource-limited health system, in order to be able to enhance our understanding of how to provide effective health services to address hypertension within the context of HIV care. We believe this has a potential of informing interventions that aim to increase treatment coverage for hypertension and decrease burden of NCDs.

1.4 Justification of project

Resource-constrained health systems now offer care for people living with HIV, but struggle to provide health services for people with NCDs (diagnosis, lifelong medications and regular clinical monitoring) [35-37]. In Malawi, ART is recommended for all individuals living with HIV [38] with the goal of 90% treatment coverage by 2020 [39]. Currently, 71% of HIV-positive Malawian adults receive ART[40] and therefore come into regular contact with the health system, but little work has been done to address NCDs in this population despite clear opportunities. Much as there is a very set and well-coordinated framework in managing HIV a chronic disease, individuals still

struggle to manage other chronic diseases like hypertension. It is important to identify synergies between care for infectious diseases and chronic disease [41].

There are repeated calls for “patient-/people-centred” models of health care [42, 43], but what does this mean for people with multiple chronic conditions in low-resource settings? Patients care-seeking behaviours are not well-understood [41, 44] particularly in fragmented (“vertical”) care systems where disease management is particularly for that one disease. This framework of managing one disease at a time, HIV program in Malawi being an example, presents enormous transaction and opportunity costs [45, 46]. Consequently, research to understand barriers and facilitators for care seeking among HIV-positive individuals with NCDs is of high interest. It is critical to understand barriers to care, to ensure adequate utilization of health services and achieve optimal health outcomes for hypertension.

1.5 Objectives

1.5.1 Broad

The broad objective of this study was to identify the factors related to care seeking and adherence for hypertension treatment among individuals receiving HIV treatment in central Malawi

1.5.2 Specific

1. To identify patient individual-level factors that are associated with adherence and care seeking for hypertension treatment.
2. To identify system-level factors that affect a patient’s adherence and care seeking for hypertension treatment.

CHAPTER 2: METHODS

2.1 Type of study

This research used qualitative methods, to understand the factors that are related to, and shape care-seeking and adherence for hypertension among the population of HIV-positive adults in selected health facilities in Central Malawi.

2.1.1 Conceptual framework

The research design was guided by the Behavioural Model of Health Services Use [47, 48], a seminal theory that has been used extensively in health services research worldwide [49, 50]. Determinants of utilization were organized into domains that are informed by contextual factors like the environment and health system. These domains shape, where, and how often care is sought. This research focused on the constructs of “need” and “enabling/barring” factors, as these are potentially most pliable to intervention.

2.2 Study Place

In depth interviews (IDIs) were conducted with individuals at three health facilities: Kasungu District Hospital, Kabudula Rural Hospital and Daeyang Luke mission hospital which in this report will be referred to as a CHAM facility, (Christian Health Association of Malawi). These 3 health facilities are located in two of the districts in Central Malawi. The health facilities were purposively selected to participate in the study based on the fact that they offer HIV treatment, offer other health services including care for hypertension, and the size of the ART cohort is over 1500 patients. All the participating facilities provided hypertension care via the outpatient department i.e. separate from HIV care.

2.3 Study population

The study captured adults who are 18 years of age and older, HIV positive, on ART at least for one year, and have hypertension and have been on hypertension medication for at least 6 months.

2.4 Sample size

Using convenience sampling, consecutive patients presenting for care at the ART clinic were approached for participation. Thirty IDIs were conducted across the 3 study sites. By the time we were interviewing the 30th participant, we were no longer finding any new concepts and recurrent themes were similar across all interviews. At this point we assumed that saturation had been reached and we stopped data collection.

2.5 Data collection

In-depth interviews were conducted in local language (Chichewa) by local research assistants led by the principal investigator. The IDI guide (Appendix 1) was designed basing on the conceptual framework, BMHU. Clients basic demographic data were collected to help address the predisposing factors as stipulated by the conceptual framework.

We also collected clinical information about date when they initiated ART, date when a diagnosis for their hypertension was made, ART medication they are taking, and hypertension medication they were prescribed for. We also collected information about their adherence for hypertension and ART medication in terms missed doses per month.

The IDI guide included questions to identify ‘needs’ related to health care use. Questions about how they perceive their health status and those focusing on the immediate cause of healthcare use

were asked. To assess objective 1 and 2, questions around access to health care in terms of availability of medication, availability of health workers, wait times to access care, distance to access the health facility were asked. Questions around the individual's physical ability and involvement in income generating activities were asked to assess the financial capacity which would contribute to access of health care in one way or another. All these were meant to capture the barriers or enablers of care seeking as stipulated by our conceptual frame work the BMHU. We also asked questions about whether they collect their HIV medication together with the hypertension medication at the same facility, how often they come to facility for hypertension and ART, and if they get all of their medication for free. The IDI guide was first developed in English, and translated into the local language (Chichewa) by research assistants. Interviews were completed between January and April 2019.

1.5.1. Participant recruitment process

On an ART clinic day, research assistants screened potential participants on the queue as they were waiting to go into the consultation room. Screening involved checking the clients' master cards {checked Age (18 and above) and duration on ART (at least 1 year)}. Those who qualified through this check were asked if they have you been diagnosed with High Blood pressure. If the client answered 'Yes' to this screening question, the study staff kindly asked the client to meet with them at a private space to conduct a full screening to ascertain if the client was eligible to participate. Full eligibility screening was done after clients finalize everything for that day's clinic visit. Clients were eligible to participate if they were 18 years and older, been on ART for at least one year and been on hypertension medication for at least six months. Once they.

2.6 Data analysis

Audio recordings of interviews were transcribed and imported to Atlas.ti v8. Interviews were analyzed using inductive thematic analysis to identify key themes and patterns within the data [51]. Verbatim transcripts were independently coded by two members of the research team (KP and CM). After the initial set of codes were generated, members of the research team compared and discussed codes, identified points of concurrence or divergence, and developed a preliminary codebook based on the IDI guide. The results are presented based on common themes within the BMHU framework, with a focus on the “need” and “enabling/barring” factors, to care seeking behaviour. The enabling/barring factors were either arising from individuals or the health system, while the needs factors were mostly individuals perceived risks of the disease.

2.7 Limitations

Some limitations should be noted. First, there may be response bias including recall bias. In some cases, respondents were asked to recall some incidences around their life being diagnosed with hypertension and scenarios around care they receive for hypertension vis a vis ART. We might have also been faced with social desirability bias where respondents would provide us with responses they feel, are what we are looking for and not necessarily the truth of the matter. We mitigated this by using well-trained and experienced research assistants. Another limitation was that we anticipated to have equal numbers of respondents for males and females as well as per facility but this was not achieved. Finally, these data were collected at only three health facilities in urban and rural Malawi, as such they cannot be used to generalize the results to the general population.

2.8 Ethical review

All respondents who met the eligibility criteria were given an introduction to the study, and taken through the consenting process and provided an opportunity to ask questions before providing written consent to participate. The study was reviewed and approved by the College of Medicine Research Ethics Committee.

CHAPTER 3: RESULTS

Between January and April 2019, we conducted 30 IDIs with males and females receiving hypertension and HIV treatment at our 3 study sites. Nearly one third of the interviewed clients (n= 9) were males and about two thirds (n=22) were females. The mean age of females in our sample of respondents was 56 years, indicating a slightly younger age than males in the sample (58 years). The Median duration on ART was 5 years for males (IQR 4-10 years) versus 8 years for females (IQR 5-11 years). Males had been on hypertension medication for slightly longer period of time, median 5 years (IQR 3-9) compared to women being on hypertension medication for 3 years (IQR 2-7 years). All males reported having attended formal education at either primary, secondary or tertiary level. Slightly above half of the respondents were working either formally (full-time job) or informally (business and subsistence farming) with majority of males (55%), being actively involved in business, subsistence farming (self-employed), or being on a salary/wage work. All males in the sample were married and 66% of females were divorced or widowed. Socio-demographic and clinical data are summarized in Table 1.

Table 1: Characteristics of respondents (n=30)

Variable	Male (n=9)	Female (n=21)	Total n
Years on ART, median(IQR)	5(4-10)	8(5-11)	8(4-11)
Period on hypertension meds, median(IQR)	5(3-9)	3(2-7)	4(2-9)
Age, Mean(IQR)	58.3(61-63)	56.1(51-62)	57.5(52-63)
Education level completed			
No school	0	2	2
Primary	2	11	13
Secondary	3	5	8
Tertiary	4	3	7
Occupation			
Unemployed	4	14	17
wage work	3	1	3
Business	2	1	5
Subsistence farming	0	5	5
Marital status			
Married	9	7	16
Divorced	0	4	4
Widowed	0	10	10

3.1 Health status of respondents

3.1.1 Blood pressure

Based on records (respondents' health passports or ART master-cards), 3 of the respondents' blood pressure measures indicated that they had severe hypertension on their most recent clinic visit, 4 had moderate hypertension, 10 had mild hypertension and 7 had a normal blood pressure measure. Data were missing in 5 respondents (Table 2).

Table 2: Blood pressure measurement at most recent clinic visit (n=25*)

BP classification		Number of clients		Degree of hypertension based on Malawi National Guidelines [38]
Systolic	Diastolic	Male	Female	
120-139	60-89	3	4	Normal
140-159	90-99	3	7	Mild
160-179	100-109	1	3	Moderate
>180	>110	1	2	Severe

*data missing on 5 participants

3.1.2 Hypertension medication

Approximately half of participants (n=15) were taking first-line hypertension therapy (hydrochlorothiazide), 3 respondents were taking amlodipine, 2 were taking nifedipine and 2 were taking propranolol. Four respondents were taking at least two medications.

3.1.3 Adherence to medication

About 40% (n=12) of the respondents reported to have missed more than three hypertension medication dose in the last month, and some (n=4) missed 2 or 3 doses in the last month. On the other hand, only 10% of respondents reported to have missed ART doses in the last month. Data on missed ART doses in the last month were missing for 5 respondents (Table 3).

Table 3: Reported Missed doses for ART Vs hypertension in a month (n=30)

Missed doses per month	Number of clients for ART	Number of clients for hypertension
None	22	12
1	1	2
2	0	2
3	2	2
>3	0	12

3.1.4 Perceived quality of care received at health facility

Table 4 below indicates respondents' experience with the quality of care they receive for hypertension at their respective health facilities. Above 80% of clients at the CHAM facility and rural hospital indicated that when receiving care for hypertension, they feel listened to, are given a chance to state their problems and ask questions, are treated with respect by providers for hypertension and have privacy while talking to health workers. However, about 44% of respondents at the district hospital expressed concern about their consultation with their health care worker as not being private and not being given a chance to state their problems and ask questions.

Table 4: Quality of care for hypertension services received

When you receive care for hypertension:	Yes responses form sites		
	CHAM facility, n=16(%)	district hospital, n=9(%)	rural hospital n=6(%)
Do you feel listened to?	14(88%)	8(89%)	5(83%)
Are you given the chance to state your problems and ask questions?	13(81%)	5(56%)	4(67%)
Do you feel you can trust the health workers?	3(81%)	7(78%)	5(83%)
Are you treated with respect?	16(100%)	6(67%)	5(83%)
Do you have privacy while you talk to the health workers?	14(88%)	5(56%)	5(83%)

Qualitative Results

Our findings are presented using the two main constructs of the BMHU namely (1) enabling/barring factors relating to treatment management/care seeking for hypertension and (2) needs factors related to treatment management/care seeking for hypertension.

3.2 Enabling/barring factors: Individual-level enablers

In our study, individual-level enablers emerged as an important influence over care-seeking behavior and hypertension treatment adherence for respondents. Several sub-themes emerged under individual-level factors including: (1) financial constraints due to poor health and weakened physical ability; (2) concerns about medication side effects; (3) concerns about adhering to lifestyle/dietary recommendations for hypertension; and (4) challenges with stress reduction.

3.2.1 Financial constraints due to poor health and weakened physical ability

Some clients mentioned that being sick and feeling weak due to hypertension prevented them from having the time and focus for income-generating work. They complained that having hypertension has made it hard for them to work, and instead they are recuperating at home.

Because when the BP [blood pressure] is high you don't do any form of business that can get you money. I sell vegetables, but when my BP is high I can't do that. I am sick and tired... (female, 57, district hospital)

Back then, I had the energy to make several businesses and find money, but now that I am sick from BP I am too weak to go around and look for money. That's a very big problem. (male, 61, district hospital)

3.2.2 Fear of side effects

A few respondents expressed their concerns about the side effects of hypertension medication based on reports from others with hypertension. Some respondents raised concerns about experiencing dizziness and heart palpitations from some hypertension medication. One respondent mentioned that HTCZ, if taken for longer periods, would cause diabetes.

These medications that we take have their side effects. Those who take propanol or HCTZ, more especially HCTZ eventually develop diabetes when you take them for a long time... [HCTZ] activates diabetes inside the body of a person. (male, 62, CHAM facility)

The drugs I was taking made me feel dizzy, the heart rate speeds up or at times you just feel like sleeping. (female, 35, CHAM)

3.2.3 Challenges with stress reduction

Some respondents mentioned that having hypertension has made them change the way they approach social interactions, especially conflict with others, in order to avoid stress. One respondent mentioned that since their hypertension diagnosis, they have learnt to be calm and avoid stress.

Socially, well I should not think a lot, I should not be at a noisy place, when someone wants to tell me something they should not tell me in a loud frightening way (female, 49, rural hospital).

3.3 Enabling/barring factors: System-level enablers

Under the overarching theme of health system related factors, we found four sub-themes that influence care-seeking behavior for hypertension: (1) Long wait times at the hospital (2) lack of availability of hypertension medications and cost of buying medication; (3) lack of integrated care for hypertension and HIV; (4) quality of care for hypertension

3.3.1 Long wait times

Most clients reported long wait times to be assisted for hypertension care. Clients mentioned that the ART clinic is less congested as compared to where they access hypertension care; and that ART visits are more predictable in duration. This played a key role in clients' care seeking behavior for hypertension.

Where we receive BP medication it is usually crowded and when we arrive around past seven you may end up leaving at 12. (female, 54years, district hospital)

At the BP doctor, there are a lot more people and I wait. But for the ARV [ART clinic] I do not wait a long time (female, 48, CHAM facility)

3.3.2 Lack of availability and high cost of hypertension medication

Several respondents mentioned that hypertension medications, unlike ART, were sometimes not available at the hospital (where they could be acquired for free). Clients therefore must buy their

medication from private hospitals or pharmacies. This added cost, is one reported reason why respondents miss doses of hypertension medication as they look for money to purchase their medications.

Sometimes we find that there are no drugs...That is the big problem that I face, to look for money so that you can buy the drugs at the pharmacy. (male, 61, district hospital)

Right now I am remaining with meds for two days and I wanted to get them here for two months but they told me that they don't have [meds] meaning I will have to buy from the pharmacy. (male, 63, CHAM facility)

3.3.3 Lack of integrated care

The majority of respondents reported that they do not collect their hypertension medication together with their ARVs. Clients mentioned that they usually have different appointment dates for ARVs and hypertension: they usually receive a 3-month supply of ARVs but a 1-month supply of antihypertensive medications.

When I want to access BP medication, I do not use the same room, I get ARVs directly from the doctor who is working on that day. (female, 52, rural hospital)

Because I get ART drugs which are for a long period like three months... while as for the HBP [high blood pressure meds] I get them frequently. Because I live far, the distance plus frequency [of visiting the facility] poses to be a problem. (male, 53, CHAM facility)

3.3.4 Perceived acceptability of quality of care

Many clients mentioned that for the last few years, their BP is checked during their ART refill visits, however, most said that they are not told the results. When asked if ART providers ever talk about how they are managing their hypertension treatment, about half of the clients reported that there was limited discussion or mention of hypertension.

No they don't, the only time they asked me was last month that was when they checked my BP but they never even told me the results. Most of the times I expect them to ask me or tell me my BP results but they don't say anything. They just test me and give me drugs for HIV. (female, 46, CHAM facility)

They have never asked me before [how I manage my BP treatment]. They only ask me about ARV, like what time I am taking the ARVs and how do I feel. (female, 55, district hospital)

The majority of clients reported that they have never missed an ART appointment day but have missed at least one hypertension appointment though both hypertension care and ART care are outpatient services. Most clients mentioned that one needs to give the ART provider a very good reason for missing an appointment, unlike the outpatient department providers where clients usually receive their hypertension care, who do not hold them accountable for attendance. Participants perceived missing an ART appointment to have more serious health consequences.

No I have never missed [ART appointment dates] since the beginning. If I don't come, I have a guardian who comes to get them[ARVs] for me. If I am away, I leave the book with them so they come and get the ARVs for me (female, 48, CHAM)

No I never missed [ART appointment date] before, when they say come on such date I make sure I am here. (female, 49, rural hospital)

3.4 Needs: Perceived risk

‘Need’ represents both perceived and actual need for health care services. It represents health outcome factors that entail potential needs of health service use, such as self-perceived health, chronic conditions, and restricted activity. The commonly observed sub-themes under this theme were: (1) Feeling healthy; (2) feeling that hypertension is not their priority health problem; (3) severity and knowledge of the dangers of hypertension. The sub-themes illustrate challenges to care-seeking behavior for hypertension and provide insights into participants’ attitudes and beliefs about being hypertensive.

3.4.1 Feeling healthy

Some respondents reported that they would take hypertension medication for a short time, and would discontinue once they felt better. Some respondents perceive that when one is not experiencing the signs and symptoms of hypertension, then they can stop taking the medication until the symptoms return.

At first I used to take them every day until I finished the dosage that they gave me. Then I saw that I was not having problems with my BP as before, so I stopped. Then I got measured and saw that it had spiked a bit so I started taking them again. I have not been taking them this entire time I was diagnosed. (male, 62, CHAM facility)

[I stop taking medication for BP] because I see that I am doing fine. I am not seeing any symptoms in relation to the BP. (male, 62, CHAM hospital)

I stopped [taking BP medication] after I felt better and after 2 years in 2018 December I started having BP again so I went back on the medication. (female, 52, rural hospital)

3.4.2 Feeling that hypertension is not their main health problem

Some respondents mentioned that HIV was their main problem, and not hypertension. The sentiments were mainly reported by respondents who indicated that they were diagnosed with hypertension prior to an HIV diagnosis. Most of them felt that they had continuous health problems, but after an HIV diagnosis and initiating ART, they felt better and so they stopped taking hypertension medication, which they interpreted as meaning that hypertension was not their problem, but rather HIV.

When I started taking ART I did stop BP drugs... Since I started taking ART I have strength, so I thought BP wasn't that necessary to be taking drugs so I did stop. (female, 57, district hospital)

3.4.3 Knowledge on dangers of hypertension

When asked about the dangers of hypertension, the majority of clients understood the dangers of hypertension and most of them mentioned that hypertension can easily cause death or serious health complications and disability.

BP disturbs me psychologically because after the heart races I start seeing dizziness, and I get confused that I don't know what to do (female, 60, district hospital).

BP is dangerous because if people have not gone to the hospital they may suffer a stroke or lose the use of some limbs or even die. Sometimes we hear of people just dying without getting sick. (male, 58, district hospital)

Some respondents also mentioned that their experience with life threatening symptoms of hypertension made them start or in other cases take their hypertension treatment seriously.

I fell unconscious, I was at the farm, then I just fell and had a stroke. This made me to start receiving treatment for BP. I was getting weak and couldn't talk. I was just drooling and one side of my body was not working. (female, 70, rural hospital)

Most clients were also quick to say the best way to avoid the dangers of hypertension would be to always follow recommendations from doctors regarding both medication and lifestyle

By following what the doctor is saying, always taking the medication, avoiding the food we are not supposed to take. Doing physical exercises. (female, 55, CHAM facility)

CHAPTER 4: DISCUSSION

Our study identified several factors that affect care-seeking for hypertension. Clients reported that poor health because of hypertension affects their physical ability to work, which limits their ability to engage in income generating activities, which limits individuals' ability to purchase medications. This puts the individuals at a disadvantage as it leads to less money being generated at house hold level due to illness from hypertension. These findings are consistent with other studies which have also reported decrease in income-earning opportunities for people with NCDs [52] due to poor physical status which leads to lost time and limited productivity [53].

It is important to note that the nature of hypertension treatment requires repeated visits to health facilities, as such lack of financial stability may affect patients' ability to cover costs (out of pocket expenses) for these frequent visits especially for those that live far from the health facilities.

Secondly clients are affected in terms of covering medical costs particularly since non-public sector facilities including mission hospitals and drug shops require consultation fees and purchase of medications. Studies have reported that individuals with diabetes, cervical cancer, and mental illnesses face reduction in their personal income due to illness [54-57] though no studies have specifically reported on hypertension, to date

Fear of medication adverse effects was another concern mentioned by some respondents as affecting care-seeking and hypertension medication adherence. Other studies have similarly indicated that side effects are an important determinant of adherence in hypertension patients [58, 59]. Some respondents specifically had concerns about long-term side effects from HCTZ, such as diabetes. This finding raises the importance of counseling about medications for hypertension and allowing clients to understand the risks and benefits of treatment.

We found that clients faced major challenges in accessing hypertension care especially when compared to their HIV care. Although blood pressure is now frequently checked during ART visits, respondents did not often get the results and if they required additional hypertension-related care, they were referred to a different doctor at the facility (usually in the outpatient department, which is often congested). The additional wait time for a separate hypertension visit, after queuing for HIV care, was reported as a challenge. Other studies from SSA about people receiving both HIV and NCD care have reported similar challenges around seeing multiple providers and long wait times [67-69]. Although the Malawi clinical HIV management guidelines encourage the management of hypertension for clients in the ART program[38],our data suggest that these services are not well-integrated. Integration offers an opportunity to improve the efficiency of care and likelihood of adherence to care for HIV-positive clients. Vertically-delivered (and funded) programs currently serve as a major barrier to integration of NCD and HIV service delivery. Successful models of integration have often been piloted at well-funded centers of excellence in southern Africa [70, 71] although those lessons learned are difficult to generalize to the more resource-constrained public sector. More research is needed to identify feasible integration models.

Lack of availability of hypertension medication was commonly reported by respondents at all 3 sites in our study; this was starkly different to reports of ART availability, which was reported as always available at these same facilities. Clients are sometimes told that there is no hypertension medication especially at the district and rural hospitals (where medication would be free), and therefore must buy medication from private hospitals or pharmacies. This adds cost (both for medications and other costs related to time and cost of seeking medications at a different facility), which causes some clients to miss their hypertension doses, resulting in poor health outcomes as

has been noted in other studies [72]. A recent systematic review similarly found an association between multi-morbidity and out-of-pocket expenditure on medicines [73]. Malawi has prioritized NCDs in its essential health package [28] in an attempt to move towards UHC. Our findings demonstrate clear implementation challenges in NCD service provision given health system constraints, which may lead to care-seeking in the private sector and therefore higher out-of-pocket costs for patients. In contrast, our respondents said they had not encountered a stock out of ART, suggesting that these challenges can be overcome with sufficient resources and attention. Funders should consider the prevalence of co-morbidities like hypertension, and what this means for ensuring management (including availability of medications) of all illnesses during HIV care [74].

Most respondents are satisfied with the quality of hypertension care they receive: they are listened to by their providers, respected when receiving care, and they trust their providers. Privacy during care-seeking was a more common quality of care concern. Respondents felt that some clinics were not private enough to allow them to freely express themselves on issues about their diseases. This concern was more common at the district hospital where clients complained that measuring of vitals would be done at an open common place where everyone could see them. The Malawi health sector strategic plan II has noted factors that hamper overall quality of care, including inadequate human resources for health, uncoordinated and weak social accountability mechanisms, poor clinical practices, insufficient client safety systems as well as lack of patient feedback mechanisms on the quality of care received in both public and private facilities [28] and these likely also affect hypertension services. Quality improvement activities are essential.

Feeling healthy was an important factor that influenced hypertension medication adherence decisions. We found that clients would stop or skip their hypertension medication when they felt healthy. Many clients reported that they would restart their medications only after experiencing

signs and symptoms of hypertension. Our findings echo existing literature that feeling ill, and perceiving clear and immediate benefits from treatment (improving health status and allowing people to return to a sense of normalcy) may affect treatment adherence [75-79]. An important point to note is that our findings clearly shows that people understand the risks of hypertension including death but still feel that HIV is their main problem. This complexity deserves further research.

It is also of paramount importance for guidelines to encourage health workers about counseling patients on the importance of remaining on medication even when one is feeling healthy and free from signs and symptoms of hypertension. Poor adherence to medication results in worse health outcomes, reduced quality of life, and wasted health care resources [80]. No respondents reported skipping their HIV medication, suggesting that such messaging has been successful for that disease and providing an example to learn from for hypertension. Other studies have suggested that it will be critical to improve NCD patients' education and the relationship or the attention clients received from their health care providers [81-83]. It is also important for such counseling to be sensitive to patients' multi-morbid status, and to help them understand the importance of being fully adherent to all medications prescribed [84].

Despite these various adherence- and engagement-related challenges, most respondents showed a clear understanding of hypertension health risks and serious health complications such as death. Respondents who had experienced life threatening symptoms clearly indicated that they took their hypertension medication seriously and mentioned that they adhered to their hypertension medication. Other studies have similarly found that patients who experience severe symptoms of a given disease are more likely to seek medical care compared to those who experience mild symptoms [85]. Education strategies should aim to help patients understand the importance of

hypertension medication adherence and care-seeking even when they experience mild or no symptoms at all.

Much as the prevalence of hypertension is reported at 30% in Malawi, it was very difficult to enroll within this population at the district and rural hospitals. This shows us that there might not be enough screening for hypertension happening at these facilities. We also noticed that it was not easy to enroll male respondents as opposed to female respondents. This might also be attributed to several factors including low screening rates.

Finally, based on the findings, this study suggests the importance of theory based health promotion models. Our findings clearly show that, it is important to assess the needs of the patients in the process of providing hypertension services for patients who also have HIV and are also in the ART program. This study to some extent showed that the needs factors as stipulated by Andersen's BMHU as well as other health promotion theories like the health belief model were important factors explaining health services utilization [86]. It is also necessary to pay attention to the general factors that would hinder usage of health services at individual level or at the health system level. Our study finding clearly identified several barriers at individual and health system level which hindered access to health services, factors that are also outlined in the BMHU as potential influencers of health services utilization [50].

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

Poor adherence and care seeking behaviors for hypertension were noted among our study participants, who were on both HIV and hypertension treatment. This was influenced by a number of client-related and health system factors. Strategies to improve hypertension management and control are needed in this population. For example, strategies that tackle messaging about management of hypertension should be strengthened among providers who manage this population. Also, improvements in the supply chain of hypertension medication should be considered. Integration of hypertension treatment with ART clinics, low cost access to antihypertensives, and support services (counseling or other) for patients with multi-morbidity would also greatly help reduce patient barriers at the health system level. It is important that the perceived benefits to care seeking behavior for patients be used to improve care seeking for hypertension.

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APPENDICES

Appendix 1: Interview guide

Participant study ID# _____

Date of Interview: _____

Full Name of Interviewer: _____

District where Client Lives: _____

DEMOGRAPHICS:

A1. Sex	<input type="checkbox"/> Male (1) <input type="checkbox"/> Female (2)
A2. What is your current age in years?	Age in Completed Years <input type="text"/> <input type="text"/>
A4. Have you ever attended formal education?	<input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) IF NO, skip to A5
A4b. What is the highest level of school you attended?	<input type="checkbox"/> Primary (1) <input type="checkbox"/> Secondary (2) <input type="checkbox"/> Higher (3)
A5. Are you currently married	<input type="checkbox"/> No, Single (1) <input type="checkbox"/> Married, monogamous (2) <input type="checkbox"/> Married, polygamous (3) <input type="checkbox"/> Separated (4) <input type="checkbox"/> Divorced (5) <input type="checkbox"/> Widow/er (6)
How many children do you have	
Did you work for pay anytime in the last six months?	<input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0)
How many days do you work in in a week?	<input type="checkbox"/> ≥ 5 days a week (3) <input type="checkbox"/> 2-4 days a week (2)

	<input type="checkbox"/> Less than 2 days a week (1) <input type="checkbox"/> Not working at all (0)
Medical records	
Date ART initiated (Day/Month/Year)	____/____/____
ART Adherence at current or most recent visit if current visit is not for ART refill (<i>Doses missed</i>)	
ART Supply given at 3 most recent appointments prior to today (From most recent)	<ul style="list-style-type: none"> ▪ Visit #1): ____Days ▪ Visit #2): ____Days ▪ Visit #3): ____Days
Are you currently on High bold pressure medications?	<input type="checkbox"/> Yes <input type="checkbox"/> No
If on High Blood Pressure medication fill out the section below	
Blood pressure	_____/_____mm/hg
Date started on hypertension treatment <i>*should be at least 12 months to be eligible and if record is not available it can be self-reported</i>	____/____/____
Current hypertension Medications	<input type="checkbox"/> Hydrochlorothiazide (HCTZ) <input type="checkbox"/> Propranolol <input type="checkbox"/> Amlodipine <input type="checkbox"/> Enalapril <input type="checkbox"/> Atenolol <input type="checkbox"/> Nifedipine

Open- Ended Questions

Note: The in-depth interview will be open-ended and guided by the respondent's answers. This outline reflects a general guide for the in-depth interviews.

The interviews are meant to help us understand barriers to care for hypertension. We are particularly interested in those factors that enable or pose as challenged to care seeking for Hypertension and the perceived needs factors for care seeking for hypertension. The following questions are meant to guide interviewers. Actual questions asked during the interview will vary basing on participant responses.

SCRIPT: Now I'd like to talk to you about your experience with management of your hypertension and things that have made it difficult for you to use or access high blood pressure care, as well as things that make you think about using the treatment.

Now I would like to talk to you about your experience accessing care for your HIV and hypertension

1. What are your positive and negative experiences of accessing healthcare for HBP?
2. Have you ever found it difficult to see a doctor and gain care for your hypertension?
 - a. If no, can you describe to me why you don't have difficulties seeing a doctor for help for your hypertension?
 - b. If yes, why was it difficult? What was the problem? Were there other problems? *Eg Medicines, transport availability or cost, distance to travel, accessibility or availability of the service required, lack of resources within hospital, waiting times for services.*
3. Have you had difficulties accessing care for HIV? Please explain.
4. Are there any other services or people you access your hypertension from? E.g. Pharmacy?
 - a. What makes it easier or difficult for you to access a pharmacy for your hypertension care

Now I am going to ask you questions about your experience taking medication for hypertension

5. Do you collect your ARVs together with your hypertension medication? If No, what makes it difficult for you to get all the meds together within one clinic visit

6. How much time has it taken you to get assisted today from the time you arrived at the clinic to the time you left to return home?
7. Do you take your medication exactly as required?
 - a. Have you ever missed doses for your hypertension treatment? How many pills would you guess you miss each week (or month?)?
 - b. What makes it difficult or not difficult for you to take your medications as required?
8. Have you ever been unable to get your hypertension medicines refilled on time for any reason? Please explain.
9. Have you ever stopped, or thought about stopping, your hypertension medicines? If yes, when and why?

Now I would like to ask you questions about your health care for your hypertension

10. For all the visits you make to the hospital for your ARV refills does the provider ask you about how you manage your HBP treatment? What exactly do they do?
11. In the last year, have you missed an appointment for your Hypertension? What kind of appointment? Why didn't you go?
12. In the last year, have you missed an appointment for your HIV? What kind of appointment? Why didn't you go?
13. Are you equally satisfied with the quality of care you receive for HIV as for your Hypertension? *(Prompt if needed: knowledge of providers, the way you are treated by providers, the overall experience in terms of wait times, distance from clinic)*. If no, please describe how the experiences are different.

Question	Yes/No	Any additional comments mentioned by respondent
When you receive care for Hypertension:		
Do you feel listened to?		
Are you given the chance to state your problems and ask questions?		
Do you feel you can trust the health workers?		
Are you treated with respect?		
Do you have privacy while you talk to the health workers?		

Now I am going to ask you questions about what you know as dangers of

hypertension.

14. In your own thinking do you think that hypertension is Dangerous? Why?

15. What are some of the problems you have had because you have hypertension in terms of:

- a. Your health
- b. Your finances
- c. your social life

16. Tell me how this disease has affected your life? Explain how it has changed the way you do things.

Please explain the good and bad effects

17. Tell me what you would do to avoid the dangers that could come with hypertension.

THANK YOU FOR YOUR PARTICIPATION IN THIS INTERVIEW. LET ME ENCOURAGE YOU THAT ARVS AND HIGH BLOOD PRESSURE MEDICATION CAN HELP YOU LIVE LONG AND HEALTHY.

Appendix 2: certificate of ethical 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.07/18/2441 - Factors that determine care seeking for hypertension and type two diabetes, in individuals on antiretroviral therapy in central Malawi version 1.1 dated 3 August 2018 by Khumbo Phiri Nyirenda

On 25-Aug-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 as indicated on the next page

A handwritten signature in blue ink, appearing to read "YB Mlomba".

Dr. YB. Mlomba - Chairperson (COMREC)

25-Aug-18

Date

Appendix 3: Amendment approval

COLLEGE OF MEDICINE RESEARCH AND ETHICS
COMMITTEE
Request for Amendment/Modification

Please complete the following:

COMREC REF. Number: 07/18/2441 (COMREC will not process requests without this number.)	Date of Request 15 March 2019
Principal Investigator Name Khumbo Phiri Nyirenda Phone # 0999840946 Email: khumbophiri@gmail.com	Contact Person (if other than PI) Phone # Email
Title of Study: Factors that are Related to Care Seeking for Hypertension in Individuals on Antiretroviral Therapy in Central Malawi	

- 1. Description of proposed changes:** (Note: Changes may not be implemented before COMREC approval)
- i. We would like to exclude a population of individual who were targeted for surveys. This is a population of individuals who are on ART and have hypertension but did not initiate hypertension treatment. This population was going to help in addressing the third objective in the protocol.
 - ii. We would like to use qualitative methods of data collection and analysis and not both qualitative and quantitative methods as initially indicated in our approved protocol.

Use attachments and additional pages, as needed. The proposed changes should be reflected in the approved protocol.

- 2. Reason for Amendment/Modification:** Two weeks of initiated data collection has shown that it will be very difficult to get the required sample size for this population as it is taking very long to get to the eligible individuals to be enrolled. Basing on our budget and tight timelines, a decision has been made to drop Objective three and concentrate on the other two objectives.
- 3.** We have also changed the design of the study to qualitative and not mixed methods as previously approved by the COMREC in our previous protocol.

Address: College of Medicine Research and Ethics Committee / Mahatma Gandhi Road, Chimutu Building Room # 822, P/Bag 360
Chichiri, Blantyre 3 Telephone: (265) 01 871 911/01 874 377 Fax (265) - 01 874 740 E-mail: comrec@medcol.mw

Version: #1:0 Effective date: 25th November, 2007

Page 1 of 2

3. Changes to Consent Form: Are changes required? No _____ Yes
___X___ (If Yes, attach new consent form)

	15 th March 2019
Signature of Principal Investigator	Date

Approval of Changes /Modifications by COMREC

COMREC Office Use only: Approval date: _____ Approved by: _____

Recommended : _____
Not recommended : _____

Signature Date 2 April 2019



IRB Chairperson or Authorized Signatory

Dr YB Mlombe

COMREC form 103

2. Reason for Amendment/Modification: we have increased our scope for the study such that we would like to collect data from form the population of individuals that have hypertension and on ART and not T2D as previously indicted in our approved protocol. To strengthen our understanding of the factors that are related to care seeking for hypertension especially for people that are on ART we would like to also

Address: College of Medicine Research and Ethics Committee / Mahatma Gandhi Road, Chimutu Building Room # 822, P/Bag 360 Chichiri, Blantyre 3 Telephone: (265) 01 871 911/01 874 377Fax (265) - 01 874 740 **E-mail:** comrec@medcol.mw

Version: #1:0 **Effective date: 25th November, 2007**

Page 1 of 2

include a population of individuals that are on ART and have hypertension but did not start hypertension treatment in addition to our previous scope which only looked at those that are on ART and have been on hypertension treatment for at least one year. We have also changed the design of the study to qualitative and quantitative mixed methods of data collection and analysis as opposed to our previous design in which we only used the qualitative methods of data collection and analysis

3. Changes to Consent Form: Are changes required? No _____ Yes X (If Yes, attach new consent form)

 _____ Signature of Principal Investigator	_____ 24 th October 2018 _____ Date
---	--

Approval of Changes /Modifications by COMREC

<p>COMREC Office Use only: Approval date: _____ Approved by: _____</p>

2018

Recommended : _____
Not recommended : _____

Signature *YB Mlombe*

Date 23 Nov

IRB Chairperson or Authorized Signatory

Dr YB Mlombe

COMREC form 103

Address: College of Medicine Research and Ethics Committee / Mahatma Gandhi Road, Chimutu Building Room # 822, P/Bag 360 Chichiri, Blantyre 3 Telephone: (265) 01 871 911/01 874 377 Fax (265) - 01 874 740 E-mail: comrec@medcol.mw

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Page 2 of 2