When The Blood Runs Too Fast

People's health literacy, behaviour, perspectives and experiences on hypertension and hypertension treatment in Ekwendeni area, Malawi.

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WHEN THE BLOOD RUNS TOO FAST

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health

by

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Declaration: Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements. The thesis 'When The Blood Runs Too Fast' is my own work.

Signature:

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LIST OF FIGURES AND TABLES

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
BP	Blood Pressure
CCC	Chronic Care Clinics
CHAM	Christian Health Association of Malawi
CVD	Cardio Vascular Diseases
DHO	District Health Officers
EHP	Essential Health Care Package
EMH	Ekwendeni Mission Hospital
FDG	Focus Group Discussion
GZB	Gereformeerde Zendings Bond
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistances
ICHOM	International Consortium for Health Outcomes Measurement
IC	Informed Consent
IDI	In-Depth Interview
INGO	International Non-Governmental Organization
LMIC	Low and Middle Income Countries
MMR	Maternal Mortality Rate
MOH	Ministry of Health
NAP	National Action Plan
NCD	Non Communicable Diseases
NHSRC	National Health Sciences Research Committee
OPD	Out Patient Department
PCHS	People Centres Health Services
PFP	Private for Profit
PNFP	Private not for Profit
SLA	Service Level Agreement
SSA	Sub Saharan Africa
TA	Traditional Authorities
TBA	Traditional Birth Authorities
TH	Traditional Healer
WHO	World Health Organization

GLOSSARY

Definitions used by the WHO

Adherence	The extent to which a person's behaviour— taking medication, following a diet and/or executing lifestyle changes—corresponds with agreed recommendations from a healthcare provider(1)
Health literacy	The degree to which individuals are able to obtain, process, and understand basic health information and services needed to make appropriate health care decisions(2)
Literacy	A person is considered literate if he or she was reported to be able to read and write a simple sentence in any language(3)
Traditional Medicine	The sum total of the knowledge, skill, and practices based on theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in prevention, diagnosis, improvement or treatment of physical and mental illness(4)

ABSTRACT

Background: Hypertension in Malawi affects 33,2 % adults above 25. Whereby 94% of people living with hypertension are unaware of their condition. Upon records, interventions like Chronic Care Clinics (CCC) show low uptakes on hypertension treatment and only a fraction of patients have the blood pressure under control.

Objective: This research is particularly aims to explore people's health literacy, behaviour, perspectives and experiences around hypertension and hypertension treatment from ages 25-64 in Ekwendeni, Malawi, in order to advise the CCC in Ekwendeni on how to improve hypertension prevention and treatment from a people-centred perspective**.**

Method: This thesis contains an explorative qualitative research whereby the data was collected via 9 Focus Group Discussions (FGD) in the communities and 18 In-depth Interviews (IDI) with patients at the CCC, supplemented with 7 interviews with stakeholders such as HSA and the staff of the clinic. Also 4 FDG were held with the village headmen of the communities. The model on hypertension in LMIC of ICHOM was adopted to guide the study.

Results: Findings show that people's health literacy and health behaviour on hypertension and hypertension treatment are influenced by physical distance to health education and their educational level. The furthest communities had the least knowledge and revealed uncommon ideas on the risk factors and local beliefs like witchcraft, chemicals and stress. They also related possible consequences like heart attacks or strokes to witchcraft. In communities closer to the hospital, sudden deaths were often related to hypertension and as such it was seen as threatening. The perceived ability to control hypertension was found to be influenced by the accessibility, affordability and the acceptability of the services and in their absence often traditional healers are consulted. People's needs and preferences on hypertension and hypertension treatment are continuous education on the primary prevention and early detection of hypertension and improvement of the accessibility, acceptability, affordability and availability of services via community based programs. Participants commented to include local traditional and health care stakeholders and referred to the set-up and structure of other programs like those for HIV. CCC participants commented on the queuing, charged fees and health education at the clinic in Ekwendeni.

Conclusion and Recommendations: Primary prevention on hypertension needs to be addressed via repeated education and campaigning within the communities, including local cultural- and health stakeholders, preferably integrated in other health programs like those for HIV. Treatment of hypertension needs to be part of community based programming by including early detection, repeated education and free access to recommended medication. Recommendations given to the organization of the clinic include reduction of the medication fees, time management and improved health education.

Key words: hypertension, treatment, people-centred health care services, Malawi

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INTRODUCTION

Non-Communicable Diseases (NCD) are the leading worldwide causes of death, accounting for almost 68% of the world's deaths(5). While it is often presumed that NCDs afflict mostly high-income populations, reality shows a very different story. Nearly 80% of NCD deaths occur in the lower-income countries(5).

Let me introduce myself; I am a community nurse by profession and worked in that capacity for 1,5 year in Malawi in the field of Home Based Care (HBC). In the HBC program many patients suffered from hypertension and its complications. Patients had a hard time to receive appropriate care and treatment in a low recourse environment. Consequently burdening the relatives to provide adequate care.
This inspired me to choose hypertension as the subject for this thesis. In the process of defining the exact topic and formulating objectives I came across the Chronic Care Clinic (CCC) as part of the Mission Hospital in Ekwendeni (EMH). The service providers were eager to learn why many patients in their program did not come for check-ups or did not adhere to the treatment. Whereas health care in the Netherlands gradually changes from the focus on care and cure to the prevention of diseases; called positive health, many patients at EMH only receive health care assistance once they show severe symptoms and are in need of costly treatment. Meanwhile, I came across the WHO's vision on People-centred Health Services (PCHS). In this approach, health care services start from the perspective of the people which also brings in the idea of positive health. This made me decide to conduct an explorative research using the principles of PCHS as I believe that if we involve people's knowledge, perspectives, experiences and behaviour in the provisions of hypertension treatment we can achieve better health outcomes.

To achieve the objectives of this study, 13 focus group discussion where held in five villages within the catchment area of EMH. Males and females were interviewed in separate groups and additionally four FDGs were held with village headmen. In addition, four health surveillance assistances (HSA) were interviewed as well as 16 patients and three service providers at the CCC.

The findings of this research are meant to assist the CCC of EMH to improve their approach in hypertension prevention and treatment. As such, the target audience include: the management and service providers of the CCC at EMH, programme managers or planners at the Gereformeerde Zendingsbond (GZB) whose missionaries have been implementing the CCC, the district health officer (DHO) in Mzimba and the Ministry of Health (MOH) since the findings may also be applicable to other areas in Malawi.

Chapter 1. BACKGROUND OF THE STUDY

1.1 Socio Demographics

Malawi, also called 'the warm heart of Africa,' or in earlier days 'Maravi; reflecting lights,' is a sub-Saharan, small, landlocked country in South-Eastern Africa situated within the Great Rift Valley system.
Malawi has been able to reduce the proportion of the ultra-poor from 24,5 to 20,1 percent between 2011 and 2017. However, Malawi remains as one of the poorest nations in the world with a poverty headcount of 71,5 % of the total population living below US$1,25 per person per day(6).
The country is seen as one of the least developed countries in the world in which 85% percent of the population lives in rural areas dependent on farming.
Between 2008 and 2018 the population of Malawi had increased by 35 percent to over 17 million people(7). Making Malawi's population density one of the highest in Africa with 173 people per square kilometre(8).
This rapid population growth, as well as reduced plot sizes, flooding and droughts, deforestation, and water pollution from agricultural runoff is worsening food shortages. Other major problems include corruption, and the scourge of Human Immunodeficiency Virus(HIV)(6).

Thirty percent of Malawi's population is in the age category between 25-64 years (the target group in this research)(9).
Malawi faces an aging population in which the projected number of persons over 60 will be > 1 million by 2030 and > 2 million by 2050(10).

Malawi has a current literacy rate of 62% with primary school education being on average 5.6 years for women and 6.6 years for men. The median number of years of schooling is higher in urban areas than in rural areas with 6.7 years versus 2.7 years among women and 7.6 versus 3.4 years among men(11).

1.2 Malawi, Mzimba, Ekwendeni

Malawi is divided into three regions namely; Northern, Central and Southern. The regions are divided in districts that are administratively subdivided into Traditional Authorities (TA). The TA's represent the local village headmen. The village is the smallest administrative unit and each village is under a village headman(12).

This study was conducted in the area surrounding the town of Ekwendeni in Mzimba District in Northern Malawi, 20 kilometres from the district city Mzuzu from where a public central hospital operates (Figure 1). Main tribes in Mzimba are the Tumbuka and Ngoni who merged their cultural habitats(13). With 90 persons per square kilometre, the population density is much lower than in other regions within Malawi(7). In addition, Mzimba, as part of the Northern region, is more literate compared to other regions with a 79% literacy rate(7). With a polygyny of 18%, the region ranks high compared to the 11% in the Southern region of Malawi(11). Over 60% of the population in North Malawi is physically active in agriculture(14). It is found that being overweight and smoking are uncommon in the Northern region(11)(14), althoughfor men drinking beer is part of Ngoni culture(15). Over 86% of the people are Christian, often combining the church practice with the practice of African beliefs(16).

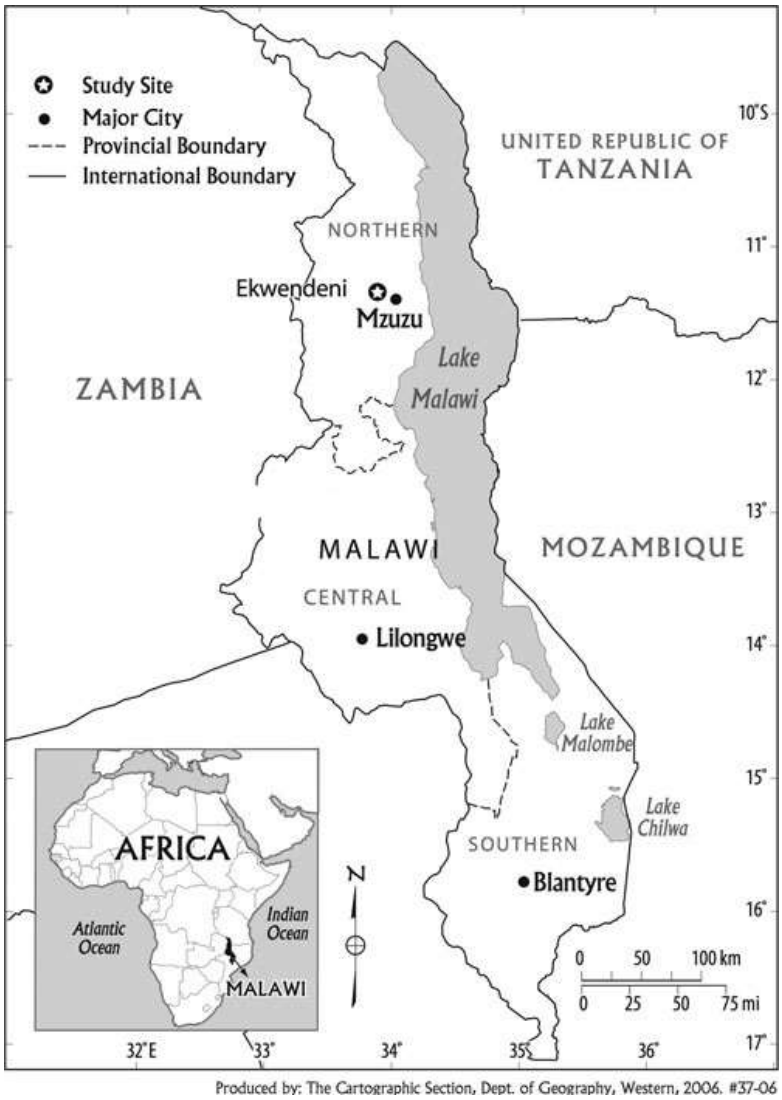

Figure 1. Study Site

1.3 The Health Care System

Health services in Malawi are provided by the public, the private and not for profit (PNFP) and private for profit (PFP(17)) sectors. Delivery of the free at point of care occurs at three levels: health centres at the local level, district hospitals at regional level and central hospitals at the highest level.

The Essential Health Package (EHP) includes interventions addressing the main morbidity and mortality patterns of the country and is supposed to be provided free of charge at point of care in all public facilities and at selected Christian Health Association of Malawi (CHAM) facilities(18). CHAM, as a major PNFP, provides approximately 30% of all health services in Malawi(19).
While in principal CHAM hospitals are paying hospitals via the EHP in the form of Service Level Agreements (SLAs) selected services are for free including maternal, neonatal and child health care. Delivered services within these SLA are for free(19). CHAM hospitals charge fees for all other services including NCD. Exact figures on the out of pocket expenditures for NCD services in NFPF are not reported, but studies indicated that for those consulting public health facilities, the amount of out of pocket expenditure on NCDs comprised 22% of their monthly per capita household expenditure(16). Since public facilities often fall short in providing all the services formally included in the EHP, patients are often sent to PNFP providers for specific diagnostics or drugs(20).

At primary level, health services are provided by health surveillance assistants (HSAs) whom are responsible for about 1,000 people. HSAs mainly provide promotive and preventive health care, often working together with volunteers within the community(17). Community volunteers often act as a conduit for community engagement.
The secondary level of care consists of district public hospitals and CHAM hospitals. They provide referral services to health centres and also provide their surrounding populations with both outpatient and inpatient services. From this secondary level patients can be referred to the central hospitals in Mzuzu, Lilongwe and Blantyre(21).

In the delivery of health care, Malawi is for over 60% dependent on external financing(19). In 2016, health expenditure as a share of GDP for Malawi was 9.8%(22).

As such, the health care financing in Malawi remains unpredictable and instable. Because of low resources, investigations are limited and diagnosis is largely based on clinical presentation. Malawi has very few doctors; therefore, clinical officers (trained for four years) and medical assistants (trained for three years) are the main healthcare cadre(21).

In 2016, the proportion of the population living within an eight kilometre radius of a health facility was 76%, which indicates that still a significant proportion of the population is underserved, especially those residing in the rural and hard to reach areas(10).
Although Malawi made substantial health gains by the reduction of 72% of deaths related to AIDS and a reduction of over 40% of deaths related to Malaria; deaths rates related to Cardio Vascular Diseases (CVD) increased up to 30%(19). The **Chronic Care Clinics (CCC)** are invented by MOH to address these amongst other NCDs(23). At those clinics, care and treatment for NCD (mainly hypertension) is provided by trained medical officers and nurses in order to prevent hypertensive patients from life-threatening consequences(2). Some CCC are initiated by hospitals themselves like as in Ekwendeni. Since they found that one third visiting the Out Patient Department (OPD) had hypertension, Ekwendeni Mission Hospital (EMH), with the support of the *Gereformeerde Zendingsbond* (GZB)[1], established a CCC in 2013. After patients have been found to be hypertensive, while often coming for other reasons, they are referred to the CCC to follow up the treatment of hypertension. The aim of the clinic is to manage the blood pressure of their patients to prevent the life-threatening consequences of hypertension. The CCC as part of a referral hospital serves the catchment area of EMH and reports to MOH.

[1] The GZB is a mission organization that supports the EMH in different ways, e.g. sending medical personal and financial support www.gzb.nl

CHAPTER 2. PROBLEM STATEMENT

2.1 The Problem of Hypertension in Malawi

In the last decade, age-standardised studies revealed that 32,2% of Malawi's adult population above 25 is hypertensive(5)(24). Those are at major risk for cardiovascular diseases (CVD). For example, hypertension accounts for 52,5% of all strokes in Africa (25). In Malawi, stroke and ischaemic heart diseases take 7th and 8th place in the list of causes of death. In most of these cases, hypertension is viewed as the main driver(25)(26).
Hypertension in Malawi is likely to increase due to effects related to urbanization, ageing population and life-style changes(5)(14). In addition, HIV is also considered a risk factor: it is estimated that 46% of people living with HIV have hypertension(27). Current country reports show 8.8 % of HIV in adults(28)(29).

The World Health Organization (WHO) indicates that by 2030, CVD will overtake infectious diseases as leading cause of death in Africa(30).
The large majority of these deaths occur among those aged 25–59 years in their productive ages. Consequently, this has a negative economic impact which is directly felt by the individuals and the health care system in threatening complications, and indirectly through the loss of household incomes (31).

A range of cost effective interventions could prevent many premature deaths, such as early detection, pharmacological interventions upon diagnosis and lifestyle modification(32)(33).

While in earlier days most attention was given to interventions for infectious diseases, NCD were first introduced in 2011 as part of the Essential Health Package in Malawi (EHP)(34). A National Action Plan (NAP) was developed. After this, different interventions on hypertension in Malawi were implemented via local campaigning and mass screening, including the roll out of CCC (see par 1.3) (23)(35). Despite these interventions, only a fraction of people with hypertension in Malawi receive treatment, and the majority do not have their blood pressure under control(23)(36)Documented causes of this are unawareness, poor implementation of screening programs, inadequate recourses and low treatment adherence(27).
A country wide survey showed that 94% of people living with hypertension are unaware of their condition and therefore remain untreated(24). In addition, those who are aware may not have access to treatment due to inadequate recourses including human capital, finances, supplies and transportation(34). On top of that, many people diagnosed with hypertension do not follow medical or lifestyle recommendations.

According to a report of the CCC in Lilongwe, 49% of their patients came late to collect medication which made it difficult to manage the hypertensions: only 30% had their blood pressure controlled and 20% failed to follow up (6). Another clinic in Blantyre also reported a treatment adherence of 33% and only 6% who had their blood pressure controlled(2). In addition, health education at the CCC failed in Mzuzu whereby 85% of the patients failed to mention complication of hypertension and 65% did not have knowledge on the recommended lifestyle and as such did not adjust their lifestyle (3).

The CCC at EMH also reports many defaulters, especially after the first visit, unless the clinic counsels on adherence.
According to the clinic's reports, between 2013 and 2018, 381 patients are registered. Of these, 113 come for follow ups and only 41 of those have their blood pressure under control; which is 10% of the total registered. This is significantly lower compared to other CCCs in the country with an average of 25-30% control of registered patients (36)(23). Out of the 113 patients only 37 are male.

Several reasons causing the low uptake at CCC in the control of hypertension are identified. A research at Blantyre CCC revealed that the long waiting times at the hospital to collect medication and lack of transportation to the hospital would delay coming to the hospital(36). In addition, because hypertension can remain without symptoms people do not prioritize uptake of the treatment(11)(13).

Another research found that instead of travelling to the clinic, people give priority to maintain daily business and the care at home(11). It has also been identified that there was a knowledge-behaviour gap about adherence to medication and life style recommendations(37).

A higher uptake of females has also been reported in other studies in Malawi(14)(35). Some suggest that females live under greater pressure and as such are more vulnerable to hypertension, others believe that men are less involved in health related issues and are not motivated to participate in studies(36)(35).

2.2. Justification

Upon request of the CCC in Ekwendeni, this research was done to get in-depth understanding regarding people's health literacy, behaviour, perspectives and experiences around hypertension and hypertension treatment. Despite the efforts of the implementation of their CCC, little progress has been made to control hypertension and, as such, it remains a major public health problem with huge consequences(11).

The identified barriers concerning hypertension control in Malawi are mostly based on patients who visited CCC. More research is needed to get more and comprehensive in-depth understanding of the factors leading to these poor outcomes.
Especially patients failing to go for medical services or the communities around them may have the information behind these poor health outcomes and have suggestions to improve it.

This research is specifically interested in the way people perceive hypertension and its treatment. This is in line with the emerging understanding in public health that local people need to be involved in the design and implementation of local health services.
WHO calls it People-centred Health Services (PCHS) and although there is still limited evidence, it's proven to be a promising approach in addressing public health care challenges such as unawareness, poor access, underutilization of services and poor health outcomes(38)(39).
PCHS focusses on the perspectives, needs and preferences of individuals, families and communities, strongly believing that the involvement and empowerment of local people will remarkably improve health outcomes and prevention (38).
In Malawi, as in many other countries, needs and preferences of patients and populations, personal values, and belief systems are often overlooked in medical practice(39).
This research was implied in the area of EHM involving the people living there in the age category between 25-64, regarding the fact that hypertension mostly occurs in this age group(1).

2.3 Objectives

2.3.1 General Objective

To explore people's health literacy, behaviour, perspectives and experiences around hypertension and hypertension treatment from ages 25-64 in Ekwendeni, Malawi, in order to advise the 'Chronic Care Clinic' in Ekwendeni on how to improve hypertension prevention and treatment from a people-centred perspective.

2.3.2 Specific Objectives

- To explore people's health literacy and behaviour regarding hypertension.
- To explore people's perspectives on the impact of hypertension on the health status in terms of complications, control of hypertension and their quality of life.
- To explore people's experiences related to clinical hypertension treatment in terms of burden and satisfaction.
- To make recommendations to the clinic on how to improve their approach, including PCHS, in relation to the findings in their provision of hypertensive treatment.

2.4. Method

2.4.1 Study Type

An explorative, qualitative approach was adopted for which the International Consortium of Health Outcome (ICHOM) standard on hypertension in Low and Middle Income Countries (LMIC) served as guide to collect comprehensive information about hypertension. ICHOM, founded in 2012, develops standards for different regions and different diseases based on what matters most to people in relation to a certain disease. While relatively new in health research, it works with health systems and measurement bodies all over the world in clinical practice and in clinical studies(40). Also in SSA including the region of Malawi (Mozambique)(88). The categories in the ICHOM standard on hypertension are defined by teams of patients, physicians and researchers. The first three objectives in this study (par 2.3.2) and figure two reflect these categories. Different variables under the categories are listed in the so called 'ICHOM reference guides' and are adjusted to qualitative themes in this research.

2.4.2 Institution and Study Setting

This research was conducted in communities of the catchment area of EMH and the CCC.
The hospital, associated with CHAM, serving approximately 140.000 inhabitants, is a paying hospital.

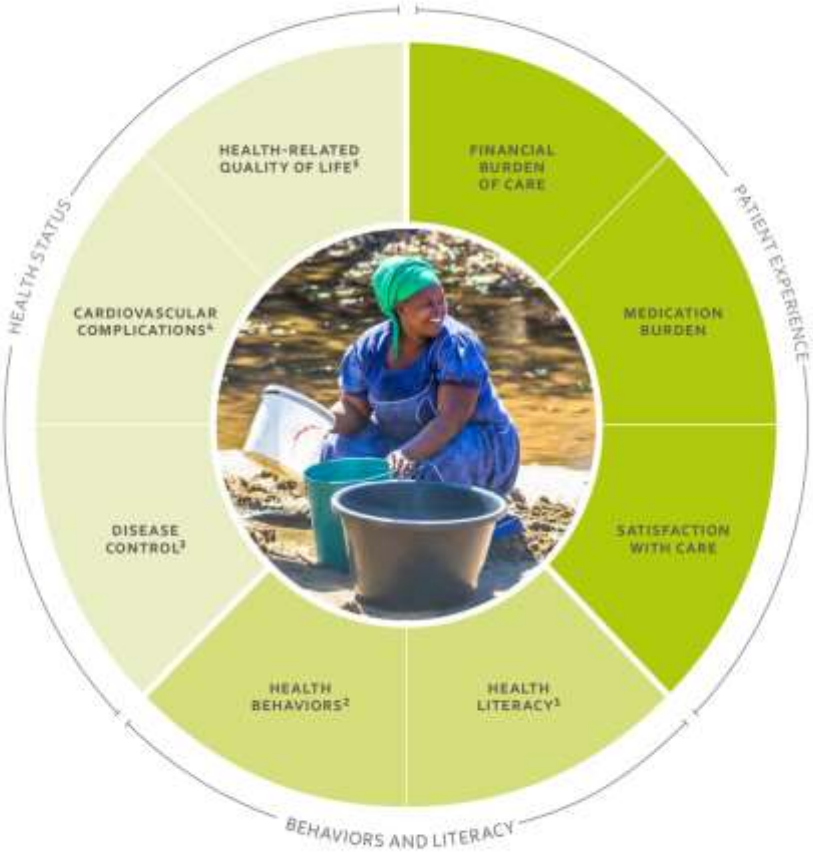

Figure 2. ICHOM on hypertension in LMIC (www.ichom.org)

2.4.3 Study Population and Sampling

The main participants were Tumbuka and Ngoni with a mixed cultural habitat and using the same language; Tumbuka(13). Cultural habits include patrilineality[2], polygamy, a healing dance called 'Vimbuza' and consumption of alcohol and meat(41). They often combine church, traditional healers (TH) and medical approaches(13).

For this study communities were selected that are known to have a high prevalence of hypertension. Those communities are more likely to have experience and knowledge about hypertension and hypertension treatment, which is useful for the study.

Another criteria was the distance to the hospital, assuming that those living closer have less difficulties with consulting the hospital. Four communities were selected determined upon records of the HSA and the CCC and upon discussion with both institutions. These were two communities about 10 kilometres and two others about 25 kilometres outside Ekwendeni town in hard to access places (See figure 3). An extra community was included for pilot testing.

[2] Meaning: inheriting or determining descent through the male line.

A range of participants were included; male and female; of different ages between 25 and 64, self-employed in farming, received on average five years primary education and the average age of participants was between 45-50 years(24). This suggests that the youngsters were occupied or not interested. In regard of power balances, women and men met in different groups. The investigator and translator were not in any formal relationship with the participants.
The study also included patients visiting the CCC in the same age range. Key informants, like village headmen, HSAs and service providers of the CCC, were included to provide more insights on the study topics.

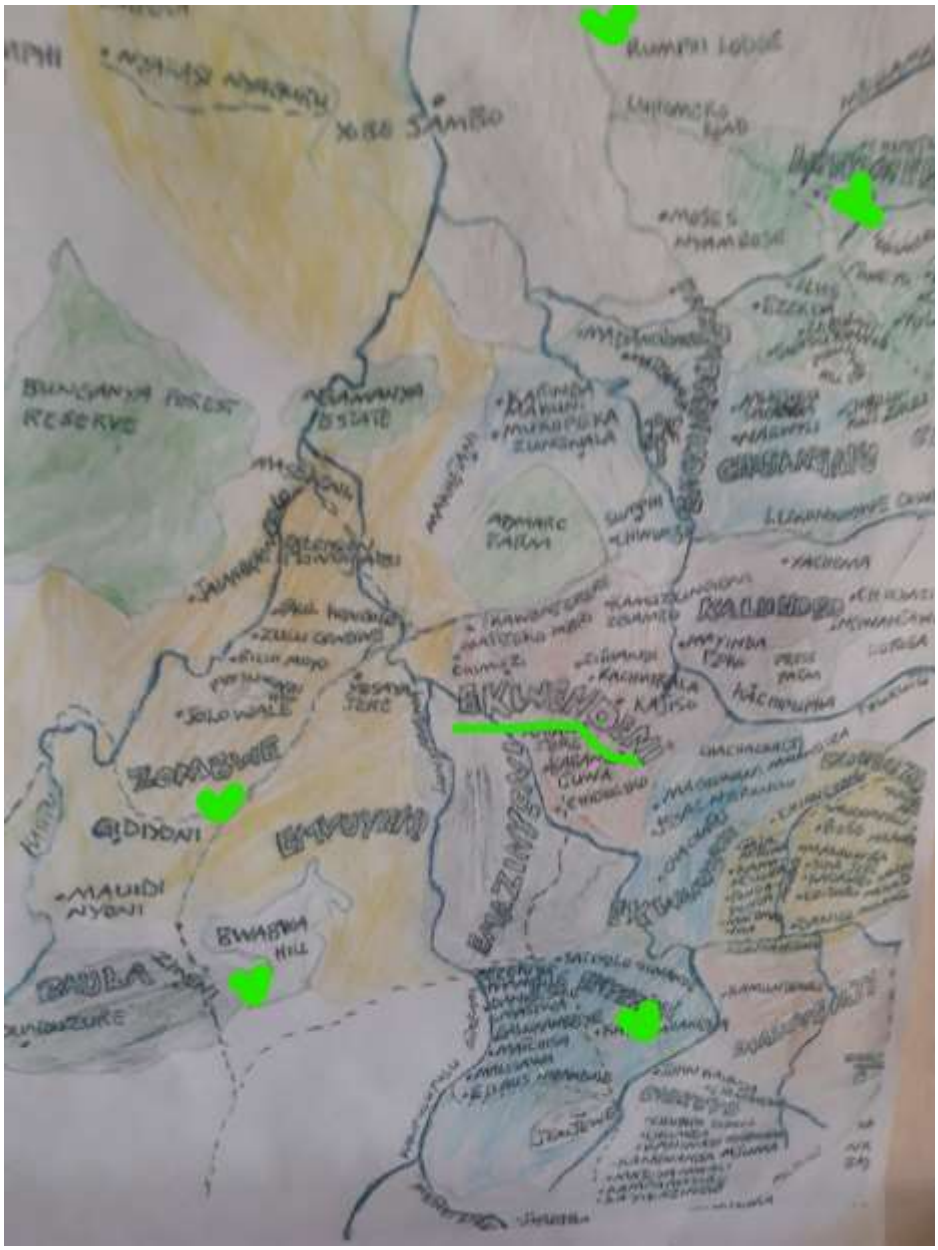

Figure 3. Villages within the study. Map; source CCC Ekwendeni Mission Hospital.

2.4.4 Recruitment

The selected communities were verbally informed in advance by the HSA. Upon arrival in the community, the HSA assisted in recruiting participants the study was looking for. For interviews at the CCC, the clients who came to the CCC were informed by the staff. Those willing to participate received information about the study and an informed consent form (IC) by the translator and investigator (TP). After participants had signed the IC they were included in the study.

2.4.5 Data Collection

Interviews and discussions contained open ended questions guided by ICHOM, as explained earlier, but were open to any other themes as it is an exploratory study. New themes were added in the instrument when they were useful in answering to the objectives.

Table 1. number of FDG and Participants
V=village headman, M=Male, F= Female, H=HSA, S=Service Providers

Participants and Technique	Village A				Village B				Village C				Village D				Test FDG village E	CCC		S	FDG	Sub Total of part.
	V	M	F	H	V	M	F	H	V	M	F	H	V	M	F	H		M	F			
Focus group discussion + No of part	1 (6)	1 (6)	1 (6)		1 (6)	1 (9)	1 (9)		1 (10)	1 (6)	1 (6)		1 (9)	1 (9)	1 (6)		1 (6M) (6F) (1V)				13	105
In-depth Interview				1				1				1				1		6	12	3		25
Total FDG																						
Total Participants																					**13**	**130**

2.4.5.1 Focus Group Discussion (FGD)
Three FDGs were held in each selected community; male, female and the village headman as key informant. One test FDG included male, female and village headman. A total of 13 FDGs were held at the communities using a topic guide and an approximate time of one and half hours was used for each FGD.

2.4.5.2 In-depth Interviews (IDI)
With the assistance of an interview guide, IDI were done with patients of the CCC. Saturation was reached at a number of 18 IDIs. Key informants included four HSAs of the targeted villages and the three service providers at the clinic. An approximate time of an hour was used during each interview.

2.4.6 Data Processing and Literature Review

All interviews and discussions were audio recorded. Discussions were held in Tumbuka and translated into English and vice versa. All English was transcribed the same week. Coding and clustering themes and sub themes was done in an Excel sheet and subsequently analysed to present the findings. Case histories and actual quotes have been used to illustrate these. Differences in opinion were documented in order to reflect reality. Databases such as PubMed, The library of Vrije Universiteit and Google scholar were searched for relevant literature within Africa related to the findings, over the last 10 years. Findings were compared and discussed with the found literature before reaching conclusions.

2.4.7 Quality Assurance

Data collection was done by the initiator of the research (TP) in collaboration with the translator. The translator was a trained nurse with a good understanding of Tumbuka and English. Prior to the data collection the guide was pre-tested at an FDG by the researcher and the translator in Village A. The type of questions were discussed as well as the interaction with the translator and the way she translates; exactly the words of the respondents.

The translator and investigator evaluated every meeting, focussing in particular on cultural implications which could have been missed by the investigator due to being an outsider. No new information came in after having conducted the FDG and IDI as planned: saturation was reached.

2.4.8 Dissemination of the Results

The written output will be shared to KIT, MOH of Malawi, CCC clinic of EMH including the people and patients who are interested in it. The CCC staff and supervisors are encouraged to discuss the findings and to look for ways how and where to implement the recommendations.

2.4.9 Ethical Considerations

Ethical approval was obtained from KIT in Amsterdam, Netherlands, and the National Health Sciences Research Committee (NHSRC) in Lilongwe, Malawi.

CHAPTER 3 FINDINGS

The findings as described below are clustered by the ICHOM categories (par 2.4.1) and in line with the specific objectives (par 2.3.2).

3.1 Health Literacy and Behaviour Related to Hypertension

This paragraph clarifies people's health literacy; clustered around their knowledge about the concept of hypertension, the signs and symptoms of hypertension and the causes of hypertension. Secondly, it clarifies what action people undertake when experiencing health problems related to hypertension followed by what people have to consider before going for medical help.

3.1.1 Health Literacy Related to Hypertension

3.1.1.1 The Concept of Hypertension

Hypertension was seen as an upcoming and fatal disease by many participants in the community. They learn at funerals that the hospital has confirmed someone's death to be because of hypertension.

The term BP as an abbreviation of blood pressure was familiar to most participants, but most often hypertension was connected with the Tombuka term; '*kuchimbira kwa ndopa'*.

Translated to 'when *the blood moves to fast'* or '*when the heart beats very fast'.* Most participants also seemed to regard the fast heart beat synonymous to hypertension, not knowing that the heart can beat fast without having hypertension as a condition.

This was confirmed by the finding that many participants at the community and CCC think that someone who experiences a stressful event is at high risk of hypertension and as such may faint or even die. Given examples of such stressful situations were '*when someone disappoints us,'* '*because of funerals'* or '*when we hear bad news*'.

> *"BP comes in when somebody is stressed up or maybe frightened. Maybe someone went to a stream to drink water. Then it meets a snake on the way he gets frightened. The heart beats faster, he can faint due to raised BP"* (Community C / Village headman*)*

Participants in the community related hypertension to the spiritual healing dance 'Vimbuza': while dancing the heartbeat goes up which to them means that the spirit is knocking.

Those traditional beliefs were hardly found in participants at the CCC although they said that *'those in the village'* still believe it. Anyone presenting heart palpitations at the traditional healer will hear it is Vimbuza, meaning that it also occurs outside dancing ceremonies.

> *"When my heart beats faster means that the spirit is coming to me"(* Community D/Male)

Apart from these beliefs, some community participants related hypertension to anaemia and as such with low blood levels and heart palpitations. Others mentioned Asthma regarding the shortness of breath.

Most CCC participants could describe the signs, symptoms and risks related to hypertension. However, some were unknowledgeable. One even did not know to be hypertensive herself. Upon asking why she had an CCC appointment she answered '*Because of the stroke I went through'*.

In one community (furthest from the hospital), none of the females had knowledge on hypertension: although they went for antenatal or family planning clinics they did not know what the BP machine was meant for.

All others in the CCC and the villages knew relatives or community members with hypertension**.** Some even knew numerous, saying; '*My wife has it, my mom, my stepmother. My father's young brother and aunt'.*

3.1.1.2 Knowledge on the Signs and Symptoms

Many community participants were unable to relate possible symptoms to hypertension. One said 'I'm overworked'. Others said 'it's Vimbuza'. Others said '*someone is jealous of me*' or *'it's due to witchcraft*'. Others suggested that shouting on top of their voice is a symptom of hypertension. Explanation given by a hypertensive participant about the symptoms led a young man attending the discussion to realize he had the same symptoms, saying *'I may also have it'*. Service providers acknowledged the lack of knowledge in the community.

> "*They don't have knowledge. The blood is running fast that is what they know*"
> (Service provider)

However, some participants closely related to hypertensive patients were a bit more knowledgeable.

> *"I have a mother who is suffering from BP. I know the signs and symptoms of my mother.*"
> (Community D/Village headman)

Most diagnosed hypertensive participants in the community and the CCC described signs and symptoms; headache, dizziness, heart palpitations, shortness of breath, tiredness, swollen legs and numbness of the legs. They learned this after they were diagnosed. The few who considered themselves as hypertensive before being diagnosed were teachers or nurses, meaning that they were educated and living within Ekwendeni.

All of the HSAs were not trained in NCDs such as hypertension, and had gained their limited knowledge by working with hypertensive patients in the community who were diagnosed by the hospital.

3.1.1.3 Knowledge on the Causes

Prolonged stress as a leading cause to 'fast heartbeat' was mentioned in almost all discussions with all different participants acknowledging that community members live stressful lives.

Men and women agreed that especially women are burdened. Family relations, explicitly polygamy and affairs, are seen as leading causes. Some men also revealed that women are more stressed regarding polygamy now then in earlier days.

> *"If a wife find out that he is with another they don't accept it"* (Community A/Male)

Men and women agreed that polygamy became problematic due to poverty causing difficulties in taking care of multiple wives and many children. According to them; hypertension comes in by *'thinking too much'* on how to solve these problems.

> *"If they have four or five wives how are they going to take care of them? Because you think a lot that causes stress then hypertension comes in"* (Community B/Female)

Many also related stress to *generation gaps*, saying that if nothing changes in the attitude and behaviour or their children they don't see future for the next generations. Especially chiefs were concerned about losing traditions in the community.

Some argued that the frustrated youngsters' parents, in comparison to earlier days, have more demands like school fees and clothes that the parents cannot afford to buy. Others believed that the exposure to other lifestyles via media and traveling to Mzuzu leads youngsters to disrespect their parents and traditions.

> "*Now there is media (--) they don't want to listen to their parents it is old fashion what you are thinking"* (CCC/Male)

Some added that smoking 'Chamba' (cannabis TP) and alcohol at young ages contributes to cheeky behaviour.

> *"Chamba at 8-10 years. (---) It effects their brain when they come home they feel like the boss of the house. When they* (the parents TP) *think about their future it becomes stress full"* (CCC/ Female*)*

Some empathized with the adolescents, saying that the little future perspectives are frustrating them.

Many participants saw *envy* as a major factor behind psychosocial problems, citing that back in the day everybody was at the same level of poverty for example; '*everyone had a grass rooftop and no one had fertilizer, now you see your neighbour with an iron rooftop and with a great harvest*'.
Participants explained that these unfulfilled desires cause stress.
Also *dependency on fertilizer* was said to increase stress. In earlier days they could harvest without fertilizer, but nowadays you can's harvest without it, while fertilizer became more and more expensive over the years.
Finally, stress coming from *chronical diseases* like hypertension itself, HIV and cancer were mentioned at times.

Almost everybody in the community saw the consumption of **fertilizer and chemicals (pesticides)** as a major problem behind hypertension. Especially men were sure that the use of fertilizer and chemicals in the crops and the chemicals in meat are life threatening and cause hypertension, saying that the pesticides are abundantly added to many crops like tomatoes, banana's and maize to avoid diseases and parasites and to make them ready to harvest faster.
Many showed concerns on the use of medication in chickens, given by the vet, to grow them fat in only six weeks. Others explained that pigs were given ARVs for the same reason. The rise of fertilizer and chemicals and the increase of hypertension made the community conclude that there must be a direct link; a conclusion that they also got confirmed from external sources like health workers.
One HSA and one service provider suggested a relation between hypertension and the saltiness of fertilizer.

Regarding the **diet** most participants at the CCC were aware of the threat of oil and salt. Community participants had less knowledge on these risk factors. Some at the CCC said that this was the only information they received from the service providers at the CCC; '*don't eat fat and salt*'.

Most participants agreed that even the poorest can afford buying salt and oil of doubtful quality, using it plentiful; '*we use the oil like water*'.

> *"When you ask the patient how much salt are you allowed to take they will respond; little little. If you ask; what is little little? They will show a hand full"* (Service provider)

Asking whether knowledgeable participants are motivated to reduce salt and oil as a preventive measure some responded: '*No we cannot, we like it too much'*, seeing it as an obtained development. In contrast, some hypertensive participants, having experienced the severity of hypertension, argued that it's easy to adapt while it effectively reduced the complaints. Additionally, participants explained that if a random community member tells them to reduce these foods, the community thinks that this person is poor and unable to buy it.
Often adding '*If the hospital tells us, we will change,'* believing that '*There is power in the word of the doctor*.'

Nevertheless, especially in the communities further from the hospital, people explained hypertension, convulsions, strokes and sudden deaths to happen because of **witchcraft** even when officially diagnosed by the hospital. The belief being that witchcraft uses diseases like hypertension to sicken someone.
Other community participants saw witchcraft as an explanation in the absence of medical reasons. Someone said that while hypertension was expected to be in the obese, finding it in the thin, that must be a reason for witchcraft.
Many more said that they only look for spiritual causes when the hospital failed to diagnose or treat.

> *"We will think I suffer all along. How come it is so persistent even the hospital cannot cure it. It must be bewitching"* (Community D/Female)

Talking about witchcraft came often with laughs and often only after directly asking.

In a few discussions, participants believed that hypertension is caused by multiple sexual partners: '*Your blood get mixed with others and as such it causes hypertension'.* Few had the knowledge that hypertension can be a side effect to medical **family planning** methods.

Some would relate hypertension to **genetics**.

A minimal number said that hypertension is caused by **lack of exercise***,* but one immediately elaborated by saying: '*this doesn't apply to us since we plow and walk so much*'. In contrast, a service provider commented that she sees hypertensive patients to be often overweight with a sedentary lifestyle, hence they use their car wherever they go.

3.1.2 Health Seeking Behaviour

3.1.2.1 Solutions at Homes
After having discussed the possible symptoms related to hypertension participants explained to *wait and observe at home* in case of any of these symptoms. Other participants explained to take Panadol from the local shops.

Other participants, especially in the community mentioned taking local *herbs and fruits* like pear leaves, mango leaves, banana leaves, moringa, wild lemon, lemon, ginger and garlic to lessen the complaints.

Others said to *wipe with water* as first aid or in case of prolonged suffering.

3.1.2.2 Traditional Healer/ Sinanga
Although participants knew that Traditional Healers (TH) are banned by the government, some say that the function of TH cannot stop because their evil powers need to be passed on to next generations. Explaining that TH work secretly using herbs in combination with magic. Some rejected the TH finding their practisers awkward. Others believe them having powers coming from spirits of the dead bodies, snakes or the mountains.

Participants explained that when someone is, for example, jealous, this person consults the TH and pays him to send a disease, like hypertension, to the 'privileged' person (the person who is envied). Sick people, in turn, consult the TH to find out who sent the disease. Then a disease is bought by the patient to cause the person who 'did it' to to fall sick or die. Participants agreed that these beliefs and practices bring fear and distrust in relations while the TH can accuse anyone innocent.

> *"We believe that yesterday I had a quarrel with my neighbour. So today I don't feel well. So let's go to the healer. Maybe he can say who did witchcraft to me. (-) So you replace the bewitching to kill the one who bewitched you"* (Community D/Female)

The reasons for envy and as such for putting a spell on someone's life could be anything from a happy family to economic success or a desired position.

Almost all patients at the CCC explained that they would not go to a TH. They do not trust him and believe that he is mostly after money and causes stress.

3.1.2.3 The Prophet and the Church

Many participants explained about the recent coming of 'healing prophets'. Some said they replaced the 'banned' TH and work alone and isolated from the established churches. Some participants believed these prophets to be sent by God and having real powers. Others argued that they 'act exactly as the TH bringing fear and quarrels, making money by pretending to cure patients.'

Few found the actions of the 'healing prophets' threatening, even though patients who are 'proclaimed' to be healed are encouraged to stop medication.

> "*I'm sure many people have lost lives because of that. Because they don't take drugs now"* (CCC/Male)

Others go to church not to get healing but to find rest and peace in prayers which they believe to have a positive effect on their hypertension: *"The heart will cool down".*

Many just say: '*try and fail in order to pass'*. Meaning they try combining herbs, magic, prayers and medication, going back and forth depending on the available opportunities. .

3.1.2.4 The Health Centre and Hospital

It appeared that women tend to go more often to hospital explaining they to go there for maternal services or as guardians for patients. Additionally, some said that men are occupied with work and stay drinking at home after work.

Although most participants agreed that it is patients who need to go to hospital*,* only few patients go there in an early stage. And only a minority actually reaches it, often in a very severe stage.

> *"Only 20 % will go to the hospital. The others will neglect the symptoms"* (Community B/Male)

Findings behind these delays are presented in the following paragraph.

3.1.3 Consideration in Health Seeking

Findings in this study show that health seeking is influenced by people's knowledge on hypertension, the accessibility, availability, affordability and acceptability of the services. In addition, it is influenced by considerations regarding responsibilities at home.

3.1.3.1 Absence of Knowledge

Since community participants are often unknowledgeable on the signs and symptoms of hypertension, (although being selected as communities with a higher hypertension prevalence), , they are in many cases unable to recognize it as a medical disease. Because of this, they are not motivated to undertake a long journey to the hospital because they are not sure about medical treatment options related to their symptoms.

3.1.3.2 Accessibility

Almost all villages engaged in this research spoke of the problems they face in reaching medical services whether these are public or private. Some have to cross a river, others have to climb a mountain and some need to stay somewhere overnight before reaching the destination. Participants explained that they consult the traditional healer or the church because they are nearby. Most CCC participants appeared to live within the neighbourhood of the hospital. Whereby transport can be considered as an important enabling factor seeking CCC services.

3.1.3.3. Finances

Many communities and CCC participants explained that transport fees, consultation fees for the clinic and the payment for the medication are obstacles for people with symptoms to present themselves, especially stating that someone unemployed cannot buy the medication. Amongst the participants only a few nurses and teachers were found, the others were all unemployed.

I "*Even as a worker I have a point not even having a single tambala (*smallest monetary unit in Malawi/TP*) in my home. What more about someone coming from the community"* (Service provider)

Participants explained preferring alternatives like the TH and the prophet because often they are cheaper, for free or you can pay them in kind (e.g. with a chicken).

3.1.3.4. Responsibilities at Home

Participants often stated that potential hypertensive patients tend to neglect the symptoms because they have too many responsibilities to consider before being able to go to the hospital. These responsibilities are, for example, caring for little children and the elderly, daily duties or protection of properties. One participant said that hypertensive patients are a burden: "If they fall sick we have to leave our daily activities and take them to the hospital."

3.2 Considered Complications and Ability to Control the Disease

This paragraph presents findings on people's considerations about the threat of hypertension, the extent to which they feel the need and ability to control hypertension and how to sustain or improve the quality of life.

3.2.1 Considered Complications

Participants, at the CCC and nearby communities, recognized hypertension as a *threatening public health problem* and even as the current leading cause of too many deaths.

> *"We know that BP is a leading cause of death (----) Often when you go to the funeral they will say it is due to BP. (---) One was 43, another mama was 75, another man was 64. From 40 and above"*. (Community A/Female)

In the communities further from the hospital, people said that sudden deaths are caused by witchcraft. Some expressed discomfort in the knowledge of so many recent sudden deaths. In contrast with most patients at the CCC, very few participants in the villages linked hypertension to strokes.
Also the limited contribution in the community due to hypertension was considered saying; *'they don't play football,' 'standing in the kitchen for a long time is difficult*' and '*they just stay at home'.*

3.2.2 Ability to Control Hypertension

The ability to control hypertension is found to be influenced by some **misconceptions** on the treatment. Some community participants believed that they can stop the medication after their condition has improved. One community strongly believed that patients should stop the medication after a certain period to prevent getting used to it. Others said, on the contrary, (including the HSA) that you need to take medication continually so as not to create resistance.
Additionally, some CCC participants were not sure if hypertension can be cured.

For many CCC participants non-adherence lies in the **inability to buy the full prescribed medication**. Some may still go to check-ups to measure their blood pressure, others buy medication to last a couple of days or weeks, equivalent to the money they have.
One participant explained to be coming because she did not want to be seen as a defaulter, which was confirmed by a service provider who said that for some patients it is mandatory to come.
Service providers explained to put the most vulnerable on the palliative care program which is funded by the GZB. These patients in effect get their medication for free.
They also explained that a Dutch doctor sometimes sends medication for free specifically for the CCC.
A service provider suggested that, in relation to this occasional free medication, some patients may come without pocket money hoping to get free medication that day. Participants themselves did not disclose this information.

Regarding the many patients who fail to follow up, service providers try to reach them via phone calls or go for home based care outreaches. They explained to have seen patients in severe conditions because of their inability to pay.

> *"We may contact the patient and say 'hello, why are you not coming to the clinic?' The patient tells us: "Mmm, my nurse, I will not manage to pay. It's better to die here"*
> (Service Provider)

In the discussions, one participant also mentioned that some fail to take medication because they have **no food** to take before it.
For others it was the **distance** to the health facility that made them stop going for treatment, saying *'it is too far we are tired of going there'*.

Occasionally participants said that patients stop medication deliberately, because they **want to die**: regarding all the stress that caused the hypertension.

> *P: "Another died because she refused to take medication"*
> *T: " Why did they refuse?"*
> *P: "This one died because she was bitter she had much stress. Her life was complicated"*
> (Community A/Female)

3.3 Experiences, Needs and Preferences

Findings on people's experiences with the provided care in hypertension include people's suggestions on how to improve services regarding their needs and preferences.
While transportation and distance are already discusses, the following paragraph elaborates on the experience of the services itself. In this, the experienced acceptability, availability and quality are discussed, followed by people's expressed needs and preferences on how to improve the services.

3.3.1 Experience with the Services

Many found medical services to be the best option for treatment. However, many discomforts and distrust were found within the same services. Critical notes came most often from the women in the community which can be explained, as mentioned earlier, by the fact that it is mostly women going for medical treatment.

Although CCC participants had some critical commentary on the services of the CCC, most were satisfied with the **attitude** of the service providers. The opposite opinion was found in the participants of the community that went to the 'closer' public health centres or public hospital, they said service providers *'are very cruel'.*

Those who went to the public health centres in the villages said that there is hardly any medication and equipment to be found there. Also CCC participants mentioned the **absence of the medication** at EMH a number of times, saying this occurred especially late in the morning. Upon asking what actions they undertake when the medication is finished, some responded: '*I just go home and drink water,*' others opted for referral to the central hospital at Mzuzu. Some CCC participants explained to buy them at the more expensive PFP pharmacies outside the hospital. Regarding the fact that patients buy medication equivalent to their available money, as mentioned earlier, this means that they buy fewer medication.

Community and CCC Participants commented on long waiting times and **queuing** at public health centres and the CCC. CCC Participants explained to go through different queues starting from registration and the consultation fee desk via the vital sign office to the actual CCC: *'Sometimes you come at eight and leave at one PM'.*

In one community all participants complained about the **limited opening hours** with centres closing at lunch time. This and the scarce availability of the health care providers at the local health centre, are seen as a reason to go for traditional healing.

> *"At times we go to the clinic with emergency disease. When we are critically ill the doctor is at home. When they go to his house he will say; 'Don't follow me, go away'"*
> (Community D/Female)

Community participants also mentioned that some clinics send you back home **without assessment.**

> *"When I go there, they will ask me: 'Why do you want to me measure you?' They expect us to come when we are at a hopeless stage"* (Community D /Female*)*

Some others found the hospital was **not effective** because of its inability to cure; as hypertension needs lifelong treatment.

> *"If I have received medication I'm not supposed to come back to the hospital with the same complaints, the next time I come it should be another disease. Or else the hospital has failed*"
> (Community B/Female)

Others said that the hospital failed because they still were hypertensive despite the medication. Conversely, one commented that the hospital initially could not find the right treatment but when she persistently came back with her complaints, she eventually received the right treatment.

Another did not trust the hospital, mentioning that it uses chemicals like the chemicals in the crops that make them sick.

The explained inconveniences with the health services often result in a preference for going to the TH whose attitude is perceived as acceptable and available throughout the day, also in case of emergency, and is believed to cure the disease with the advantage of using herbs.

3.3.2 People's Needs and Preferences in the Provision of Hypertension Treatment

Almost all participants pleaded for **education within the community**, opting for door to door campaigns, posters, drama or church songs.

> "*We plea to be educated (--) its life saving*!"
> (Community B/Chief)

Many suggested to involve the village leaders as they are key informants and highly influential. When they are overlooked, it will undermine the message.

> "*Start with the elderly (*traditional leaders TP*). Then they will accept knowledge easily. Once you start with the youth the elderly will say; 'Come what was he teaching? They won't accept"* (Service provider)

Some also suggested to involve the TH, church leaders, prophets, community volunteers and the HSAs in the education.

Many believed that education would have great health impact as well as reduce fear and quarrels related to spiritual beliefs.

> "*We need to be educated that by BP people can die a sudden death. Otherwise they will say he is bewitched ahh… (---). If they belief that, they start quarrelling that one has done this and this. At the end they have BP of that stress".* Community D/Village headman

A number of participants referred to previous awareness and sensitization campaigns on HIV and AIDS and on the effect of the training of traditional birth attendances. To the question whether people would leave the spiritual ways and beliefs behind in favour of the knowledge and care of the hospital, a service provider replied: '*Let me take you back to the antenatal mother. Once they had delivered twins they (TBA) had that spiritual knowledge. They were taking the mother sleeping with those twins for sleeping in the bush. But now… it's no longer there because people gave them the knowledge what will happen with them in the bush. Even that spiritual mind set will go away. Once you give someone knowledge they will say let's do this'.*

Indeed, many participants expressed the need to be educated on the causes of hypertension and supporting lifestyle. Others also requested education on medication adherence.

Some CCC participants suggested broader and repeatedly **clinical education**.
Someone explained to have learned about hypertension via a poster in the corridor, saying that the illiterate get very limited education at the CCC. Service providers explained to give health education via an information sheet which was hard to come by and written in English.
An older woman at the CCC, who was unable to answer questions on hypertension and hypertension treatment ended the conversation by saying: '*I just realize now that I lack information about my disease*'.
One suggested that the CCC should involve guardians on the lifestyle education and medication adherence.

Most participants strongly recommended to implement **community based programming** referring to other clinics that provide maternal, under five and HCT services. They suggested to come with a mobile clinic at least monthly, to provide education on health, do early detection, periodical check-ups and to prescribe and give the medication for free.

> *"Maybe if there could be like community services. Like they do with antenatal and the HIV testing and treatment. (--) If they could do these periodical checking up it will help. Not only the pregnant women. But all of them"* (Community A/Female)

Participants assured that those at risk would flock to these services. Some said that they would stop going to the TH while others would want to combine the two.

A number of participants, especially at the CCC, pleaded to have the **services and medication for free**. Some also recommended to have a **greater variety of drugs** in case the first choices are not effective.

Some CCC participants recommended better **time management** in the organization of the clinic. Suggesting to start at the CCC instead of first queuing at the OPD. It was also suggested to have the clinician available at the start of the clinic to assist them sooner.
One opted for two CCC days in the week in order not to have to wait a full week when help is needed.

Many prompted **stress management** activities, for example, on re-creation, reconciliation between family relations or coaching in stress management. Participants believed that this should be undertaken by the community itself, the government and sometimes the CCC or other departments of the hospital (e.g. family planning).
Some recommended to have more time for the patients at the CCC to listen to them. Others suggested trainings in the communities or to lead the discussions within the families.

The CCC health providers said they had never asked patients how they perceive the services. Two of them were quite confident on the satisfaction of the patients, saying that patients would not come if the services were not perceived well.

Chapter 4. DISCUSSION

Firstly, findings show that health literacy on hypertension is influenced by socio economic factors and access to health education, illustrated by the uninformed ideas about chemicals and stress and local belief in witchcraft. Secondly, the perceived ability to control hypertension is found to be influenced by the accessibility, affordability and the acceptability of the services.

This chapter discusses these findings in relation to findings in literature, leading to suggestions on how to address said observation. These suggestions are from the perspective of PCHS in the provision of hypertension treatment in the services of the CCC including their communities.

4.1 Health Literacy and Beliefs

4.1.1 Educational Level, Distance and Informing Communities

The further from the hospital we went, the less people knew about the concept of hypertension, its signs and symptoms, causes, consequences and the treatment options of hypertension. Rural communities in Malawi, as outlined in the introduction, are **less educated**. This relates to findings in different studies on low income and vulnerable populations showing that hypertensive patients with low literacy have more trouble comprehending health information(42)(43). While health literacy is key in adherence to hypertension treatment, national surveys in Malawi show that the health indicators for hypertension are worse among people with no or little education compared to those who receive(d) secondary education(3)(19).

Participants explained that health information has to come from the hospital. This means that rural communities have **less access to health literacy** then those living closer to a hospital. Additionally, hypertension and the education on hypertension has not been prioritized in community health in Malawi, because the focus was on reducing child mortality, maternal mortality and combatting HIV and AIDS. NCDs and health education on NCDs have therefore been overlooked(19). This explains that even the HSAs in this research had limited knowledge on hypertension even though they are seen as key health informants in the communities.

Participants pleaded that the CCC **inform the communities** on hypertension. They were convinced that the community would listen and adopt the advice. They said that communication should be provided by health personnel, first targeting community leaders and church leaders as approaching other target groups without consulting the leaders would have an adverse effect.

Participants referred to awareness campaigns on HIV and antenatal care, illustrating that the information has to be given repeatedly and in different ways; via drama, posters, teachings and songs. They were convinced that these teachings stopped harmful cultural practise and improved health behaviour.

Lessons learned on HIV are well documented and can indeed be implemented in the campaign on hypertension(44). What can be learned from health education in antenatal care is the importance of incorporating traditional roles in the provision of the care. For example, the training and involving of traditional birth attendances in antenatal care(45)(46).

Participants also agreed that knowledge on prevention and control of hypertension should be incorporated in the training of HSAs and community volunteers. Elsewhere in Malawi it is also suggested to educate and involve them in public campaigns on hypertension(47).

4.1.2 Knowledge and Local Beliefs on Causes of Hypertension

According to the WHO, raised blood pressure is often a result of inadequate lifestyles that entail tobacco use, physical inactivity, unhealthy diet and harmful use of alcohol(48).
However, participants in this study named stress, excessive intake of salt and oil as risk factors to hypertension, but very few mentioned physical inactivity and none of them related smoking or alcohol to hypertension. Whereas alcohol could be a risk factor in Ngoni men, since beer is part of their culture(15), other studies on NCD in Malawi found that other "traditional" risk factors of hypertension are relatively uncommon in the Malawian adult population. Obesity, raised cholesterol and smoking are relatively uncommon in Malawi in comparison to data from high-income countries that show most patients with hypertension to be obese and/or smoking(49)(50)(60). This is confirmed by the participants who mention that 'in earlier days hypertension was in the obese but nowadays also in the thin'.

The findings on **salt and oil** as causes of hypertension are in line with previous studies. A study in Malawi in 2018 found that salt intake is high in all areas(50). Moreover, it is found that for Africans salt poses a greater risk than for Western people. With the by-effect that lowering the dose of salt has great influence in the prevention of hypertension in African countries(51).
The suggested concerns on the cooking oil are backed up by found evidence that it causes arterial sclerosis and as such hypertension(52). Studies also showed the impact of education on the reduction of salt and oils, in the prevalence of hypertension in Africa (44)(52)(53)(49)(54). As such, an openness of the community to health education (see par 4.1.2) and life style advice has the potential to effectively prevent and control hypertension in Malawi.

Another, often overlooked, cause for hypertension in Africa is the relationship between **birth weight** and hypertension in later life. Although there is relatively small research done on this area in Africa, the relationship between birth weight and hypertension in later life is observed in Western settings(55). With Malawi having a prevalence of twelve percent of infants with a birth weight of less than 2,5 kg in 2015, this may be considered as a risk factor(11).

Only few participants mentioned medical family planning as a risk behind hypertension. Evidence is found in studies that, indeed, with the use of **hormonal family planning** the chance of hypertension is two to three times higher than for those who don't(56). Over 30% of the women in reproductive ages in Malawi use hormonal contraceptives(11). This may be one of the reasons why the CCC sees more female patients than male. The fact that only a few participants mentioned family planning suggests that women lack information from the family planning clinic about the side effects.

Only occasionally did participants relate **HIV** to hypertension while people on antiretroviral therapy (ART) are, indeed, at greater risk of hypertension(29). Whether this can be seen as a major risk factor in the area of Ekwendeni is debateable because based upon verbal report, given by the director of the community department of EMH, the area has an HIV prevalence of only three percent.

The finding that many participants believe that sicknesses and deaths are caused by **witchcraft** is very common all over Africa(57)(58)(59). As mentioned earlier, the further the distance from the hospital the less health literacy on hypertension was found and the more they would relate the disease to witchcraft. The same is observed elsewhere in Malawi: in the absence of knowledge people relate physical discomforts like headache, dizziness or convulsion to witchcraft(34).

Studies revealed that accusations of witchcraft are more frequent in unstable communities with problematic social relations and/or that are economically deprived(31)(61). Instead of blaming the complex economic systems, communities turn against members of their own society.
This can be interlinked with the finding that the communities in this research experience poverty and erosion of traditions. It appears to be a vicious cycle: loosening traditions and poverty come with blaming, shaming and jealousy and result in more distrust and sociological problems.
These traditional beliefs in Malawi and elsewhere in Africa, are described as health care delays and remain often unaddressed(45)(46). Adequate health education, as suggested earlier, may correct misplaced beliefs like blaming others for your disease and pointing to persons who are believed to be witches(50).

The finding that many participants related **sudden deaths** with hypertension is in line with statistics on CVD being the most common cause of sudden death in adults worldwide(62). Based on this statistic, we may assume that many sudden deaths in Malawi are indeed related to hypertension or heart attacks. However, proper statistics on the causes of deaths within Malawi are not available since most people die without medical assistance, and so the cause of their death is not confirmed by a medical person(19). These deaths are not registered and not taken up in national statistics.

The relation between chronic psychosocial **stress** and hypertension has found evidence in other studies, however acute stress was not considered a risk factor for hypertension(63)(64). Which undermines beliefs that hypertension is suggested in all cases of '*fast heartbeats*'[3].
The position of women, the dependency on fertilizer and poverty, loosening traditions, respect for elders and individualisation are elsewhere documented as chronic stress factors in Malawi(65)(66).

Nevertheless, stress has often been overlooked in studies and approaches on hypertension in Africa and elsewhere in the world(64). The many protocols in the treatment focus on lifestyle changes like diet, exercise, alcohol and smoking, only on very few occasions is stress management integrated in the care plan for hypertensive patients(64).
Interestingly, participants requested the CCC to include stress relief in their activities. Suggestions varied from providing a listening ear, offering counselling for couples and organise educative and recreational stress relief actions within the community. It requires more research to define which interventions, in addressing stress, are effective and possible to implement in the provision of hypertension treatment.

People's conceptions of **chemicals and fertilizer** as a major cause of hypertension is comparative with findings in a study on hypertension in Ghana where people believed the same(67). However, an extensive search in the different online databases resulted only in literature with evidence on the correlation of the excessive use of pesticides and CVD in farm workers. In those cases, CVD and cancer were caused by the toxicity of the pesticides(68)(69). It is also known that excessive use of fertilizer may pollute the ground water with nitrate. Eventually, this may lead to an escalation of birth defects or chronic kidney diseases(69)(36). Overall, there was no clear evidence to be found on the use of chemicals or fertilizer and the prevalence of hypertension. Meaning that the belief in chemicals, especially fertilizer, being a common cause of hypertension lacks evidence and as such needs more research.

[3] Referring to paragraph 3.1.3 *kuchimbira kwa ndopa' or 'when the blood runs too fast'.*

4.2. Hypertension Treatment and Services

This paragraph, in line with the PCHC approach, discusses the concerns of the participants on the treatment of hypertension and their preferences in the delivery of hypertension treatment.

4.2.1 Reasons and Suggestions for Community Based Programming by the CCC

Most participants experienced difficulties reaching health facilities due to distance and obstacles in accessibility. Additionally, they were dissatisfied with the public health services. Complaints include overcrowding, unfriendly service, poorly staffed and stocked and poor quality of care. The same opinions are found elsewhere in Malawi(70).

People in need of medical help would rather visit a TH or prophet due to their relatively cheap cost, possibility of paying in kind. Whereby community beliefs on the effectiveness of TH contributes. This observation has been found in other studies in Malawi and elsewhere in Africa(71)(72)(73).

Additionally, participants described their demanding life, meaning that early signs and symptoms of diseases are less prioritized. Previous studies in Malawi found that household chores and responsibilities indeed influence the decision to timely seek health care(57). This is remarkable in view of the finding that it is mostly women who go for medical help, yet male and female agree that women carry the heaviest burden. Another study found that Malawian women indeed prioritize health care seeking in contrast to men(74).

In regard of these multiple problems and being dissatisfied with the public health services, participants preferred EMH as a private hospital for medical care, although distance and costs still remain barriers to go there(57).

Respondents consistently emphasized the need for **community-based programming** by the CCC of EMH. Their suggestion corresponds with others requesting essential health care, including hypertension treatment, via mobile clinics within communities in Malawi(34)(75). Participants and health care providers were convinced that it would be effective to have a hypertension clinic at least monthly, similar to the under-five clinics and antenatal clinics. Regarding the limited resources in Malawi, it has been widely suggested to integrate hypertension services in other services like HIV services(34)(76)(77). Studies have shown positive outcomes on the integration of HIV and NCD (e.g. hypertension) approach. It should be noted that HIV efforts have already created widespread community structures and a platform for communicating health messages which could be used to scale-up integrated HIV/NCD approaches(44)(76). Integrating HIV and hypertension approaches is also recommended considering the fact that people with HIV are more vulnerable to hypertension(78). However,it is suggested not to fully integrate hypertension services in HIV services, but rather to employ parallel chronic care services (e.g. hypertension) services regarding stigmatization(78). The same recommendation applies to other services like family planning clinics(79). Because participants revealed the lack of education, screening and control of hypertension at family planning clinics, improvement in awareness, screening and control of hypertension can be expected.

Apart from **screening** and **treatment,** participants suggested to include continued **education**. Reasons for education in the provision of the treatment are found in the fact that many community participants stopped the medication, due to the explained barriers as well as due to poor understanding of the condition of the disease and the effect of lifestyle adherence. Importantly, participants and health providers at the CCC agreed that hypertension treatment is only effective in the combination of medication and life style adherence. This is confirmed by studies in Ethiopia and Kenya, showing that patients engaged in healthy lifestyle and adherence to the prescribed medications had a lower mean blood pressure than those on medication only(80)(81). It is requested, regarding illiteracy (see par 4.1.2), to spend extra time, communication skills and techniques on health education(3).

While participants had mixed opinions on the function of the TH it is debateable, whether they should be incorporated in or be complementary to the provision of hypertension treatment. WHO argues that traditional healers are widespread and as such are accessible to everyone and also that traditional medicine can be effective in the treatment (of e.g. hypertension)(4). However, while participants said to visit the TH, many of them also found it very controversial, arguing that THs are after money, using magic and bringing quarrels by blaming others to have caused the disease. Few participants argued that traditional medicine like herbs can be effective, but that they prepare it themselves without seeing the TH. Moreover, THs are officially banned in Malawi because they are accused of harmful practices amongst people with albinism(89). The same happened to the Malawian traditional birth attendances (TBA) in earlier days, but evidence showed that the banning of TBA did not bring down maternal mortality rates (MMR)(82). When Malawi, in later years, officially recognized them and trained the TBAs, the number of MMR eventually declined. Evidence shows that training, constant supervising and effective referral systems made the TBA program effective(83). Consequently, the opportunities to include traditional healers in the management of hypertension could be identified and considered in Malawi's health policy.

4.2.2 Organization and Provision of Care at the CCC

CCC Participants suggested to organize the clinic differently. While currently queueing at the Out Patient Department (OPD) for registration and the consultation fee, followed by queuing for vital signs before going to the CCC, they suggest going directly to the CCC doing it all there. Secondly, they preferred to have the clinician and the nurse available at 7:30 AM when the CCC opens. Although participants did not clearly say that waiting times prevent them from coming, it was definitely a concern to them. A study in the neighbouring country, Mozambique, showed an increase in clinical uptakes after improving time management(84). Upon the findings at the CCC, it is suggested to use the already existing equipment like the computer for registration and the blood pressure machine, and it would be good to have protocols around patient flow management as well as the dedication of the nurse and the clinician to help the patients timely. It will also reduce the workload of the nurse when she uses the computer instead of having to write in three different record systems.

Participants consistently stated the unaffordability of paying the full amount service fees; transport, if necessary; and medication. The latter especially because, as hypertension needs lifelong treatment, medication remains a continuous financial burden. Several studies show that these costs can be catastrophic to the poorest because it may force them to borrow money or sell their belongings in order to pay the medical costs(60)(85).

Some participants at the CCC explained that in the absence of medication at the hospital they buy medication at commercial pharmacies outside the hospital where it is more expensive. Meaning that they, with the little money they have, buy less of the prescribed amount. The same happens elsewhere in the country(70).

For this reason, CCC participants requested the hospital to have the prescribed medication in stock. The suggestion to have multiple types of medication available is conform guidelines and studies. Studies on the availability and affordability of essential medication in Malawi revealed that one specific hypertensive medication called hydrochlorothiazide is widely available and relative cheap, but other medications recommended by the WHO like captopril, methyldopa and bisoprolol have limited availability and are often too expensive for one to buy(49)(86). Evidence is found that combination therapy even in low doses is five times more effective then escalating hydrochlorothiazide (54). This is encountered by the professionals in health planning and although they are aware of the epidemiological transition in which the prevalence of NCD is rising, resource constraints, as explained in the introduction, prevent from expanding medication and interventions targeting NCDs as hypertension(19)(34).

Participants suggested to look for funding strategies outside the hospital by approaching mission organizations or INGOs to provide medication for free. Strengthening partnerships, networking and creative funding strategies in the management of NCD in Malawi is in other studies suggested(60). While some patients could be better assisted with a combination therapy, most patients were satisfied with the effectiveness of the treatment.

Although health providers noticed many patients failing to come to follow-ups, most of them were not aware of patients' inconveniences in coming to the clinic. Initial resistance amongst health workers was reported by WHO as a common thread in the implementation of (87). Regarding the readiness of the health care providers to learn from the community on mattering issues in hypertension treatment; introducing PCHS, as outlined in the introduction, could be an effective design of the clinic. In addition, using the ICHOM on hypertension in LMIC, as outlined in the introduction and used to guide this research, could be a helpful tool. ICHOM focusses on what matters most to patients in the care of hypertension: it creates services around the patients' needs and preferences, in effect creating more responsiveness and participation with the patient regarding their own health care process(87)(88). ICHOM's instruments are quite elaborated so they may need to be adjusted to meet the needs at the CCC in a way that it helps to create better and more convenient services rather than increasing workload. It goes beyond the scope of this research to give adequate suggestions on how to implement ICHOM at the CCC, but it is an opportunity for more study.

4.3 Limitations of the Study

Since this study was an exploration of people's knowledge and ideas about hypertension and hypertension treatment, there is no actual data collected on the number of diagnosed hypertension patients in the community and how many of them receive treatment. It may be meaningful to collect this data before implementing strategies on the prevention and control of hypertension in order to measure the effectiveness and outcomes of the strategies.

Additionally, related to the intention of the study, research on the actual causes of hypertension was not included. As such, it remains unclear to what extend low birth weight, alcohol, family planning and other factors are related to the prevalence of hypertension in this area.

Since this research did not focus on the service providers perceptions on PCHS, their understanding and readiness to work with a people-centred approach is not known. Although some readiness is to be expected, more investigations may be useful.

While the study was guided by ICHOM, ICHOM did not provide guiding questions on differences in men and women regarding hypertension and hypertension treatment and control. Little has been found on gender notions. The various underlying causes for the differences in health care seeking between males and females suggests the need for this information in the implication of health education and hypertension programming.

This study chose village headmen, HSAs and health care providers as key informants, leaving out the TH for the reason that they are officially banned and not openly practising. Considering the role they still play in health seeking amongst people in the community it should be considered in further studies to have them involved.

Since this study was focused on the area of EMH, and especially in communities with a relatively higher prevalence of hypertension, findings are not applicable to other areas. Still some lessons can be learned from it for other areas, taking into account differences such as cultural backgrounds, educational levels, health seeking behaviours and others.

CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

- **People in the communities have limited chance of accessing and obtaining health knowledge, therefore their understanding of hypertension is limited and shaped by cultural misbeliefs.** Reasons for this are found in low literacy levels and the physical distance between them and those who are knowledgeable about hypertension.
- **People's understanding of the causes of hypertension differ from the "traditional" risk factors as mentioned by institutions like WHO.** Where WHO sees inadequate lifestyles including use of tobacco, physical inactivity, unhealthy diet and harmful use of alcohol as underlying causes of hypertension, the people in this research regarded stress, chemicals and unhealthy diet as causes. Other causes such as low birth weight, family planning, alcohol and HIV are often overlooked but important to take into account. It is also unclear to what extend these factors contribute to the prevalence of hypertension around EMH, which may also differ between males and females. Without this information, people may be misinformed or uninformed on the recommended lifestyle interventions.
- **People in the communities experience many barriers to health care seeking regarding hypertension treatment such as accessibility, acceptability, affordability, and availability of the services.** Most participants lived over 8 kilometres away from health services, and it should be noted that in rural primary health care clinics comprehensive hypertension treatment is not included in the package. In addition, their services are perceived as unacceptable. Reasons for consulting a TH are connected to those obstacles. In addition, it is suggested that male and females may experience different obstacles in accessing health care.
- **People's experienced obstacles in the uptake of the services at the CCC lies within the costs and the organization of the clinic.** The main cause of low uptake at the CCC and adherence to their treatment is because of costs. Secondly, the time management of the clinic is a contributing factor. Additionally participants at the CCC also lacked information especially on life style modification and duration of the disease.
- **Little is known on effective stress management in hypertension.** Although acute stress is not found to be directly related to hypertension, the evidence in studies does show that stress can be a risk factor in hypertension. Nevertheless, interventions on stress are rarely included in the management of hypertension. This can be seen as a missing component in the management of hypertension from an PCHS approach, especially when regarding people's expressed needs in addressing their feelings of stress.,.
- **People-centred health services, using ICHOM, have shown to be an effective tool to investigate people's needs and preferences in hypertensive services.** Via PCHS and ICHOM, this research was able to collect new and relevant information useful for the CCC in their provision of hypertension treatment. Some further study and guidance in the implementation of this approach may be needed.

5.2. Recommendations

5.2.1 Recommendations for the CCC

This section is addressed to the management and service providers of the CCC and the programme managers or planners at the Gereformeerde Zendingsbond (GZB).

5.2.1.1 Education and Awareness

This study suggest that the greatest gain in controlling hypertension can be found in community-based primary prevention by providing repeated education using various educational media, and incorporating local cultural and health representatives. This suggestion is backed up especially by the fact of the improved health outcomes after reducing salt and oil.

5.2.1.2 Community-based Programming

Attempts should be made for secondary prevention in the community by early detection of hypertensive patients and providing them with the best possible and affordable non-pharmacological and pharmacological treatment via community-based programming. Meaning that it is suggested to the CCC to plan proposal writing and fundraising in their activities in order to find recourses accordingly, since hypertension treatment is not expected to be in the PHC package shortly. Also regarding the lack of recourses it is suggested to integrate hypertension treatment in the already existing programs and structures like HIV and family planning services. It needs extensive discussion and more research assigning roles to the THs in this.

5.2.1.3 Stress Management

Define and include strategies on stress management in the provision of hypertension treatment. Attempts should be made to find the best practises on stress management for patients with hypertension and implementation.

5.2.1.4 Organization of the Clinic

Chances of improved uptake at the clinic lie within a good flow from entrance to exit. Organizing the registration, measuring the vitals and the availability of the health care providers starting from the opening hours may bring great improvement. It is recommended to spend a little more time on each patient (and their guardians) to explain more about the treatment and control of hypertension. Some more guidance by knowledgeable facilitators may be suggested in the implementation of PCHS and ICHOM.

5.2.1.5 Removed Service and Medication Fees

It is recommended, in line with paragraph 5.2.1.2, to undertake initiatives in detecting and allocating resources to unburden the patients with the requested fees.

5.2.2 Policy Recommendations

This section is addressed to DHO at Mzimba and MOH of Malawi.

5.2.2.1 Nationwide Awareness Programming

Lessons learned from the findings of this research may be useful for nationwide programming on hypertension. Regarding the limited recourses, interventions on primary prevention, such as health education on the diet, are highly recommended.

5.2.2.2 Nationwide Community-based Programming

It is recommended to look for collaboration with WHO, INGOs and others for additional recourses to include hypertension treatment in the EHP. It is suggested to integrate it in other services like HIV and family planning programming and to expand the recommended effective treatment regime.

5.2.3 Recommendations for Further Study to CCC, MOH and Universities

5.2.3.1 Data Collection
It is suggested to gain information on the actual figures of detection, uptake and control of hypertension and hypertension treatment by collecting quantitative data in these issues.

5.2.3.2 Causes of Hypertension
More research is needed on the actual causes of hypertension, especially regarding the suggested impact of chemicals including fertilizers, alcohol and family planning.

5.2.3.3 Stress Management
The CCC and other service providers in hypertension treatment may be greatly assisted by evidence-based practises on how to implement stress release in their services.

5.2.3.4 Gender Notions
It is recommended to identify the actual determinants in hypertension differentiated by males and females in order to address them accordingly in the approaches on hypertension prevention and treatment.

5.2.3.5 Traditional Healers
It needs more research to what extend the TH should be included in the provision of hypertension treatment. It is especially suggested to find out the effectiveness of their herbal medicine and the perspectives of the community in this.

5.2.3.6 PCHS and ICHOM
PCHS and ICHOM being new in hypertension treatment at the CCC, more study is recommended on the opportunities and threats, and how to address these in the implementation of recommended approaches in the daily activities of the CCC.

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All Communications should be addressed to:

The Secretary for Health and Population

In reply please quote No.

MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

10th April, 2019

Thea Ploeg
Tropical Institute Amsterdam (KIT)

Dear Sir/Madam,

Re: Protocol # 19/01/2241: People's Knowledge, Behaviour, Experiences and Perspectives on Hypertension and Hypertension Treatment in Ekwendeni Area, Malawi

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER** : **2241**
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE** : **10/04/2019**
- **EXPIRATION DATE**
  This approval expires on **09/04/2020**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on phone number *+265 994 063 425* or by email on mwhdoccentre@gmail.com.
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

SECRETARY FOR HEALTH
2019 -04- 10
P.O BOX 30377, CAPITAL CITY, LILONGWE 3

For: CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

Promoting Ethical Conduct of Research

KIT Royal Tropical Institute

Contact
Meta Willems
Telephone +31 (0)20 568 8514
m.willems@kit.nl

KIT Health
P.O. Box 95001, 1090 HA Amsterdam,
The Netherlands

BY E-MAIL:
tcploeg@hotmail.com

Our reference KIT Health Amsterdam, 8 February 2019

Subject Decision Research Ethics Committee on Proposal S96

Dear Thea,

The Research Ethics Committee of the Royal Tropical Institute (REC) has reviewed your application for ethical clearance for the proposal "Peoples knowledge, behavior, experiences and perspectives on hypertension and hypertension treatment in Ekwendeni area, Malawi".
The REC is pleased to see that you have made the improvements and clarifications to our full satisfaction.

Kind regards,

Prisca Zwanikken
Research Ethics Committee, KIT

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Royal Tropical Institute