### **REVIEW ARTICLE**



## Feasibility and Acceptability of the Family Centered Model to Manage and Prevent Non Communicable Diseases in Selected Communities of Lusaka Province

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#### ABSTRACT

**Objective:** Our objective was to test the feasibility and acceptability of Family centered model in managing and preventing NCDs in the Zambian context. We used hypertension as our tracer NCD.

**Results:** Six major themes emerged during intervention design based on community conversation: (1) Willingness, (2) importance of family support; (3) incentives for CHWs (4) trainings health workers (5) basic Equipment (6) medical supplies. Participants found FCM to be acceptable and needed in the community. They emphasized the need for training all people involved (HW, CHW and family members) and providing basic equipment to manage hypertension and other NCDs.

**Pilot feasibility stage:** We approached 9 families using an index patient identified at the clinic. One family declined to take part. So 8 families were screened with a total of 32 family members. Hypertension prevalence was 43.8% (14/32) among all those who were screened. During the pilot, four groups were formed based on the FCM, 3 out of the 4 groups managed to form household FCM. Each group had 4-6 members. CHW provided basic training to family members and followed up over a 3 months period, visiting weekly or when needed.

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Hypertension; Family centered care; Cardiovascular diseases; Health workers

## Abbreviations

ART: Antiretroviral Treatment; AIDS: Acquired Immunodeficiency Syndrome; BMI: Body Mass Index; CIRDZ: Center for Infectious Diseases Research in Zambia; FCM: Family Centered Model; NHRA: National Health Research Authority; HCW: Health Care Workers; HIV: Human Immunodeficiency Virus; NCDs: Non Communicable Diseases; OPD: Out-Patient Department; SSA: Sub Saharan Africa; WHO: World Health Organization; ZDHS: Zambia Demographic and Health Survey.

## Introduction

#### Global status of non-communicable diseases

Globally, Non-Communicable Diseases (NCDs) pose a significant public health and economic threat due to the associated disability, loss of productivity and premature deaths from conditions like Cardiovascular Diseases (CVD), diabetes and chronic respiratory diseases [1]. Progress towards achievement of the NCD related targets and implementation of 'best buy interventions' as recommended by WHO remains poor in most Low- and Middle-Income Countries (LMICs) where the burden is highest, and health systems are often tailored towards fighting infectious diseases and have very limited infrastructure and capacity to fight chronic diseases [2-5]. Among the NCDs, cardiovascular conditions (with Hypertension (HTN) as the major associated risk factor) are the global leading cause of mortality. By 2017, 17 million of the 56 million NCD related deaths were attributed to CVDs and it is estimated that the global cost of CVDs will reach US\$47 trillion in 20 years' time [6].

# Burden of hypertension and its consequences in Sub-Saharan Africa LMICs

Hypertension (HTN) is by far the commonest NCD risk factor in LMICs; complications from poorly controlled HTN accounted for 44% of CVD deaths globally [3]. Current evidence indicates that the prevalence is still increasing [7]. Despite HTN being identified by the African Union as a serious health problem second only to HIV/AIDS, the treatment and control remains suboptimal and highly variable across and within African countries [8]. The urbanization of several LMICs has resulted in increased westernized life styles and associated diseases like obesity and HTN [8,9]. Statistics show that one-third of adults in Africa are hypertensive with a significant number being unaware that they actually suffer from the condition [10]. Data from population based surveys across African countries consistently show HTN population prevalence between 19%-40%, which is higher than that of HIV [9-11]. The economic consequences of HTN from both direct and indirect costs such as disability, treatment cost and premature mortality are substantial at both individual and national levels [12].

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# Burden and capacity to manage hypertension in Zambia

Zambia has recorded an increase in cases of HTN and related complications such as stroke [13,14] According to the Ministry of Health, cases of HTN seen in the Out-Patient Department (OPD) increased by 39% for all age groups in 2017 alone [15]. A recent population based survey estimated that 19.1% of the Zambian population had HTN [16-23]. Despite the rising burden of HTN and other NCDs, prioritization of these conditions in the country's agenda has remained poor.

**Community support systems:** Group and community support systems have been associated with better patient adherence and hypertension outcomes. Group dynamics appear to promote positive behavioral change and promote knowledge sharing and psychological support [24]. Redistribution of tasks to Community Health Workers (CHWs) has been shown to be cost-effective and has been used in the management of HIV/AIDS, antiretroviral therapy and maternal and child health interventions in many settings such as Rwanda, Uganda [25,26]. There is now a push to leverage community and family structures to address NCDs, especially where trained health workers are in short supply. There are also opportunities to adopt the growing Information and Communication Technologies (ICT) and social media opportunities to improve communication and information within the communities in addressing HTN in resource constrained settings [24,27,28].

In this paper, we aimed to test the feasibility and acceptability of family centered model in managing and preventing NCDs in the Zambian context. The findings could help inform intervention design to promote family centered care in addressing the growing threat of NCDs in LMIC.

## **Literature Review**

#### **Methods**

**Study design:** This was a qualitative study exploring stakeholder perspectives and experience with Family Centered Model (FCM), for NCDs control in Zambia. The study had three phases, initial gaps analysis, intervention discussion and short pilot. We present overall lessons about acceptability and feasibility of FCM using intervention development, using CHWs, we aimed to access feasibility of linkage to care for hypertensive patients that were identified using the Family Centered Model (FCM). The data reported in this article are from semi-structured interviews with health providers (n=9) and patients with NCDs (n=9). The findings from this work will be used to refine the intervention, which will subsequently be tested through a randomized trial in Lusaka province.

**Study procedure:** We conducted the pilot study in two rural sites of Zambia (Kafue district). We identified health workers, community health workers and patients with NCDs mostly hypertensive patients. The initial phase included identifying gaps and developing questions that address gaps and also proposing elements of Family centered care based on literature. We then piloted the initial components in the FCM with the view to refining the intervention further for testing under a future effectiveness clinical trial. The components tested were patient consultations, community health coordination and family centered care formation and use of WhatsApp to support patient information and communication.

In the pilot, the number of people per family recruited ranged from 5-8 people per household in the study areas. Nine 9 families were recruited in the 2 pilot sites. Four groups were formed based on the FCM. Each group was allocated one CHW who visited them bi-weekly for 2-3 months. The groups were coordinated by the WhatsApp whose administrator was a CHWs.

**Sampling and participants:** While the intervention development involved all the three districts, initial pilot was conducted only in one district in two sites. We conducted 18 in-depth interviews with

key informants at health facility level and in the communities with patients with NCDs and their families. The study participants were drawn from all levels where the intervention was developed and later piloted in three districts of Lusaka Province namely Kafue, Chongwe and Luangwa. The three districts have similar geographic and economic activities; predominately-farming areas characterized by an influx of female headed households. The Family Centered Model (FCM) recruited patients who were diagnose with hypertension in the last 6 months from health facilities and with their consent, were then followed to their homes were screening of family members aged 18 years and above was done upon getting consent. We recruited a purposive convenience sample of health care providers and patients with NCDs. Trained and experienced research assistant's recruited patients who have been diagnosed with any NCDS to participate in a one-on-one qualitative interview at the health facility or in their communities. Health care providers were also recruited to participate upon given consent.

### Data collection and analysis

Two experienced local Zambian interviewers (one male, one female) lead the interviews in the local language (Nyanja, Bemba, or English) using semi-structured interview guides. Topics focused on content acceptability of the family centered model, including family health topics and considerations for conducting NCDs screening within communities. The interviews were conducted in a separate private room at the health facility or in another private location (e.g., participant's home). Interviews lasted between 20-60 minutes. The research team met weekly to discuss observations and experiences from the interviews and identify additional probes or follow-up questions to be included in the next round of interviews. These reviews also helped to determine when theoretical saturation had been reached.

Interviews were audio-recorded using digital recorders, translated, and transcribed by local Zambian research assistants. Transcripts and audio-files were uploaded onto a secure server and imported into NVivo (computer software) version 11 for analysis. Two authors (Perfect Shankalala and Oliver Mweemba) independently coded the transcripts using a content analysis approach under the supervision of the primary investigator (Wilbroad Mutale). Our thematic content analysis approach consisted of writing memos, coding and identifying major and sub-themes in an iterative manner using both deductive (a priori codes) and inductive (emergent codes) methods.

### **Ethical considerations**

The University of Zambia Biomedical Research Committee (UNZ-BREC) approved the proposal. All participant were informed about the study and provided written consent to take part in the study. Confidentiality was maintained throughout data collection process.

#### **Intervention design**

The following 6 themes emerged during intervention design based on community conversation: (1) Willingness, (2) importance of family support; (3) incentives for CHWs (4) trainings health workers (5) basic equipment (6) medical supplies.

**Willingness to have FCM implemented:** During the process of intervention development, we received positive feedback about the FCM in relation to willingness for stakeholders to have the FCM implemented to support service delivery in the Zambian context. The following quotations reflect the feeling of those who participate in the development of the intervention.

"Yes it will be nice to have people coming to our homes to test us at least once a month for checking our BP's, and sugar levels...... sometimes this side you find old people sometimes they can't even manage to come to the clinic because of distance and so coming to our homes will be a good thing", As per the quotation given by NCD\_indexpatient004.

"We are yet to implement screening of NCDs in the communities ....

We are in the process like right now....ummm we've identified those people with such problems (NCDs) and all we need is to provide services right in the communities. If we form groups and identified people that have those conditions and also if we have like door to door visitations we can be able to identify people with NCD's and link them to care?.", As per the quotation given by Healthworker\_001.

**Importance of family support:** It was acknowledged that chronic care was a big problem in the community and that families played a central role in providing care for sick family members. However, as was noted in study, family members providing care need to be supported to provide quality care and ensure synergy with the formal health system. Therefore, training of family members was seen as a crucial ingredient of FCM.

"If only they...(family member) can receive sensitization of these NCDs and how we can prevent them, it can be good for our family because they are the ones who cook and put salt and cooking oil to our food and so they need to be educated also.", As per the quotation given by NCD\_indexpatient009.

"My family stands with me especially on emotions, they know i avoid getting very excited and i used to be very short tempered but now am able to control and avoid arguments.", As per the quotation given by NCD\_indexpatient002.

It was confirmed during our study that several community and families suffer from NCDs especially hypertension. Complications such as stroke and deaths were commonly mentioned as related to difficult accessing care in time. Therefore, family empowerment was seen as an effective way to address shortages in human resources and supporting health system. Talking about this issue, one of the hypertensive patient said:

"They are a lot of people suffering from hypertension, it even leads to stroke but they have no one to come and talk to them, even at church or within the communities...I think what you are proposing will work better than at the hospital because some of these old people fear going to the hospital but home they will be that confidentiality." As per the quotation given by NCD\_indexpatient006.

"The components of the model will work very well in our setting because we have had people dying of NCDs in our communities due to long distances to access our facilities and therefore reaching out to families in their respective communities and screen for NCDs will help prevent premature deaths and link NCD patients to care. CHW needed more supervision from health care providers and also equipping them with communication tools such as phones for easy troubleshooting through whatsApp in real time", As per the quotation given by Healthworker\_003.

**Incentives for CHWs:** Incentives for the CHWs was seen as a crucial part of FCM. This was closely linked to the need to provide training of CHWs as a form of incentive.

"Indeed the use of mobile phones made our work even easier because we were able to contact family members and coordinate the screening process and delivery of essential drugs for hypertensive patients....we had challenges with health facilities in terms of drug stock out, but if this can be addressed, we can reach a lot of people", As per the quotation given by Healthworker\_005.

**Re-training of health workers:** The importance of having trained health worker in NCDs was emphasized, noting that most of them needed refresher training as NCDs were not seen as a priority from donors. It was also reported that most in-service training provided by government or partners was tailored towards HIV.

"Training in new methods of managing NCDs at facility level and refresher courses for facility staff would be good for us. Currently we have no training opportunities for NCDs, we usually participates in infectious diseases training like HIV, TB and in some cases cervical cancer screening but we equally need refresher training for NCDs", As per the quotation given by Healthworker\_007. "Currently we have no training opportunities for NCDs, we usually participates in infectious diseases training like HIV, TB and in some cases cervical cancer screening. Training for NCDs hasn't been priotised at our facility despite I high number of NCD cases we attend to on a diary basis.", As per the quotation given by Healthworker\_007.

**Need for basic equipment:** The majority of participants indicated that most health facilities had limited basic equipment to manage NCDs at health facility level. Most of the equipment's were either not available or mal-functional.

"...like diabetes, we don't have any equipment for that and hypertension we only have the high blood pressure machines...equipment's are inadequate and in cases where a diabetes patient comes, we just examine them clinically in the lab and send them to Chongwe to have their blood sample checked.", As per the quotation given by Healthworker\_001.

**Medical supplies:** From both providers and patients, medical supplies were seen as a bridge between the community and health facilities. The lack of medical supplies especially drugs undermined trust in the health system. Some participants indicated that they experience drug stock outs for hypertension and complained about the long distances between the health facility and the district pharmacy. One participant had this to say.

"We usually experience drug stock out especially essential drugs to manage NCDs has been a challenge for our facility, most often we write prescriptions for the patients to buy on their own. Our facility is about 40 plus kilometers from the district pharmacy so if we have a shortage we have to go that far.", As per the quotation given by Healthwork-er\_006.

#### Intervention feasibility

**Recruitment and group formation:** We recruited the patients from the facilities and others were identified by CHW from the community. Recruitment of patients was easy and several were happy to act as point of contact persons for others to test for blood pressure in the community. The number of people ranged from 5-8 people per household in the study areas.

We approached 9 families. One family declined to take part. So 8 families were screened with a total of 32 family members. Hypertension prevalence was 43.8% (14/32) among all those who were screened.

During the pilot, four groups were formed based on the FCM, 3 out of the 4 groups managed to form household FCM, with about 4-6 people with hypertension within each household identified. One group had insufficient number of people to make a family based groups and therefore other community members with hypertension were allowed to join. Each group was allocated one CHW who visited them bi-weekly for three months.

**Communication by whatsapp in the groups:** The groups were coordinated by the WhatsApp whose administrator was a CHWs. The major issues raised related to information about hypertension and new people wanting to join the group from the community. Mobile network coverage was good with internet connectivity working as long as bundles were bought for the groups. There were very affordable WhatsApp bundles from local mobile service providers about \$1-\$2 for one month's subscription.

**Use of automated blood pressure machines at community level:** The use of automated BP measurements was acceptable, with few encounters of finished batteries and technical problems with cuff placement. With support from CHW, these errors were not reported by the third month in all the four groups.

**Refresher training of health workers:** From the health system side, we conducted a short refresher course for the Health workers at each health center using national guidelines for hypertension management in Zambia. Most clinicians were aware about the management and just needed few reminders especially consistence in management of pa-

tients. Dietary and life style information was also provided to share with patients. Basic drugs for hypertension were available and there was no stock out during the pilot period.

Refresher training of HW was a vital starting point to change altitudes for health workers. It was important that the team leader of the group or a member can read and write and be technologically able to use WhatsApp or have this help within the group.

"Refresher training in hypertension was very refreshing...currently we have no training opportunities for NCDs, we usually participate in infectious diseases training like HIV, TB and in some cases cervical cancer screening but we equally need refresher training for NCDs."

## Discussion

Our study has demonstrated that it is feasible to use family support and structures to address NCDs in low-income settings. We have also shown how feasible it is for an index hypertensive patient to can act as a link between health system and the family, when given appropriate community and technological support. This approach has potential to increase detection and management of hypertension in the community, thus, opening opportunities and possibilities for utilizing local and family resources to tackle the growing burden of NCDs in Africa where the health system remains overwhelmed and stretched [29-43].

Zambia has recorded high prevalence of hypertension and related complications such as heart failure and stroke [15,16]. The major reasons for these complications are lack of knowledge, late presentation and poor adherence to treatment [16].

The FCM seem to address these route causes, through providing opportunities for hypertension screening in high risk families and linking them to care. In addition, the family appears to support adherence within the trusted family settings [43].

In our study, family members of index patient were happy to screen for hypertension and learned how to measure blood pressure. Training of family members and patient required dedicated community health workers, who were available for trouble shooting within their local communities after initial training. Therefore, adoption of similar models requires particular attention to on-going training and support for family members and patients to ensure quality and consistence in services offered outside clinic or hospital settings. Similar studies conducted in Sub-Saharan Africa have reported the importance of training for patient centered care to improve confidence in self-management and overall care for patients with chronic conditions [44].

Apart from patients and family members, the FCM was appreciated by health workers. There were concerns during the formative phase that families might fail to support patients adequately and might delay patients from seeking care. However, after the, period of pilot health workers who supervised community health workers and patient groups, were appreciative of the continuum of care and patient empowerment which came with FCM. Family centered models have shown similar acceptability in other settings [42].

Another innovation we added to our feasibility study, was social media platform which was led by community health workers for communication and sharing information. Despite initial concerns about practicality of using WhatsApp for this purpose, our study revealed that this is acceptable and feasible. There still remain concerns about privacy, but for this study we mainly used it for sharing general not personal information. Social media platforms are being evaluated for use in other African settings [45,46]. However, we recommend that future studies focus on developing innovations that not only easy to use but also have capability to protect personal information, thus being ethically acceptable to collect patient level data.

In this study, we found that, the major motivation for community health workers was not the stipend but the training, support and equipment to carry out their work. We noted that providing basic training in hypertension management, preventive strategies and use of mobile phone was valued more than the stipends. Similar studies conducted in resource limited communities also indicated the importance of none financial incentives [46].

The study has several limitations, firstly being a qualitative study with short term follow-up time, we cannot generalize our findings outside our settings and we are were unable to determine whether the FCM can actually lead to controlled hypertension in our study participants. A more robust study design is required to determine the long impact of such an intervention.

Second, the participants interviewed were also part of the those who helped design and implement the intervention especially health workers and community health workers. This could have caused them to be attached to the intervention and therefore could have given a more favorable outlook for the DCM. However, the fact that patients and family members independently reported satisfaction with FCM, is more assuring.

#### Summary of the pilot for feasibility

The FCM was found to be feasible in the Zambian rural health care settings, with most of our concerns about technology and linkage to care being unfounded.

Health workers found it acceptable and complementary to their work while the community felt empowered and used the model to share information about hypertension in the community. Where the FCM was not able to find enough household members, neighboring community members were added to the group.

Future studies should focus on the effectiveness of FCM and long-term implementation challenges as this pilot was limited to few sites and for a short period of time.

## Conclusion

In this study, we applied a qualitative study exploring stakeholder perspectives and experience with family FCM for NCDs control in Zambia. Generally, the FCM was found to be feasible in the Zambian rural health care settings, with most of our concerns about technology and linkage to care being unfounded. Health workers found it acceptable and complementary to their work while the community felt empowered and used the model to share information about hypertension in the community. Future studies should focus on the effectiveness of FCM and long-term implementation challenges as this pilot was limited to few sites and for a short period of time.

### Limitation

The study was unable to determine how Family Centered Model would be generalized to the entire rural population of Zambia because quan-

titative data was not collected to validate the qualitative outcomes.

## Declarations

### Ethics approval and consent to participant

The University of Zambia Biomedical Research Ethics Committee approved the protocol (I.R.B No. 00005948). Permission to conduct the study was granted by, Ministry of Health (MoH) through the National Health Research Authority (NHRA) and the district authorities in Lusa-ka province. All respondents in the survey provided individual written informed consent and the study was undertaken in compliance with declaration of Helsinki and key tenets of good clinical practices. There is no risk of confidentiality, as the data cannot be linked to the participating patients.

### Availability of Data

Data for this study can be made available upon request to the cor-

responding author. The request should state the title and aim of the research for which the data is being requested.

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# **Consent for Publication**

Not applicable.

## **Competing Interests**

The authors declare that they have no competing interests.

# **Author's Contributions**

PS, WM, RC SB conceived and designed the study. PS, WM performed the statistical analysis. PS, SB, RC, DH, WM interpreted the results. PS, WM drafted the manuscript. All authors revised the manuscript critically for important intellectual content. All authors read and approved the final version of the manuscript.

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