

Knowledge Gaps and Barriers to Heart Failure and Hypertension Management among Patients in Rural Tanzania: A Patient's Perspective Qualitative Study

Sarah Andrea Lolo^{1,3,*}, Andrew Katende^{3,4}, Leila Samson^{1,3,4}, Chipegwa Mlula⁴,
Evanace Mahundi^{3,4}, Hassan Matimbwa^{1,3,5}, Liliane Pasape², Irene R. Moshi³, Martin Rohacek^{3,4,6,7}

¹School of Life Sciences and Bio-Engineering, Nelson Mandela African Institution of Science and Technology, Arusha, United Republic of Tanzania

²School of Business Studies and Humanities, Nelson Mandela African Institution of Science and Technology, Arusha, United Republic of Tanzania

³Ifakara Health Institute, Ifakara, Morogoro, United Republic of Tanzania

⁴St. Francis Regional Referral Hospital, Ifakara, Morogoro, United Republic of Tanzania

⁵Mzumbe University, Mbeya, United Republic of Tanzania

⁶Swiss Tropical and Public Health Institute, Allschwil, Switzerland

⁷University of Basel, Basel, Switzerland

*Corresponding author: sarahandrew9090@gmail.com

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Abstract Introduction: Information about heart failure and hypertension, and barriers to treatment adherence of patients with cardiovascular diseases living in rural sub-Saharan Africa is scarce. **Objective:** To explore knowledge about heart failure and hypertension, as well as barriers to treatment adherence and follow-up visits among patients with heart failure and hypertension. **Methods:** This cross-sectional qualitative study was conducted from July to November 2023 at the Heart and Lung clinic of the St. Francis Regional Referral Hospital Ifakara. Using purposive sampling, 30 in-depth interviews were conducted among patients with heart failure and hypertension. Data were analyzed thematically. **Results:** Most participants showed limited understanding of risk factors, and of the chronicity of hypertension and heart failure. Salt and fat were commonly reported as the risk factors for hypertension and heart failure. Most participants had a good understanding on how to take their medications daily, and their negative side effects. Challenges were categorized into individual and facility factors. Individual factors included social support, health insurance, financial support, transport costs, distance to healthcare facilities, the chronic condition and severity of illness. Facility factors involved clinic appointments, patient-provider, drug costs, availability, perceived waiting times, and consultation fees. **Conclusion:** This study found a limited understanding on hypertension and heart failure and about risk factors and the chronicity of these conditions. Tailored interventions are essential to address these challenges.

Keywords: Non-communicable disease, knowledge, heart failure, hypertension, cardiovascular disease, medication adherence, follow-up visit, challenge

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1. Introduction

Non-communicable diseases (NCD) cause 41 million death annually and over 86% of these occur in the low to middle income countries [1]. Cardiovascular diseases (CVD) account for the majority of these deaths, and hypertension which affects over 1.2 billion people remains the leading risk factor for heart failure (HF) and stroke [2]. Heart failure is a growing public health concern in low- and middle-income countries [3], causing a higher burden

of disease in African countries than in high-income countries [4,5]. Arterial hypertension is the leading cause of HF and affects one fourth of the population in sub-Saharan Africa [6,7]. Despite its high prevalence, hypertension awareness, treatment, and control remain critically low. Less than half of hypertensive patients are aware of their hypertension, less than half are treated and less than 15% of hypertensive patients, hypertension is well controlled [8].

Also, in Tanzania, hypertension is the leading cause of HF [9] In one study from rural Ifakara, 41% of all heart diseases were due to hypertensive heart disease [9], and

similar numbers were reported in studies done in urban referral centers [10,11]. A study done in an urban referral center reported a 58% one-year mortality of patients with HF [10]. Both hypertension and HF is associated with comorbidities such as chronic obstructive pulmonary disease (COPD), diabetes mellitus, kidney disease and anemia, which poses a huge burden to patients and healthcare systems [11,12].

The chronicity of these diseases needs lifelong care and follow-up, which is important not only to address blood pressure control, but also to control commodities, risk factors, and to modify lifestyle. Retention in care can be affected by an interaction of patient, health facility and system related factors [13], which might differ between urban and rural settings. Studies from urban tertiary hospitals report high rates of poor medication adherence of up to 75%, leading to high re-hospitalization- and mortality rates [14]. Regular visits in clinics have been shown to influence medication adherence and also provide an opportunity for patients to receive health care services and support [15]. Several factors were detected to influence adherence, such as patient-provider relationships, transport costs, health insurance, social support, and drug burden [17,18]. Additionally, limited patient knowledge about causes, symptoms, and treatment has been linked to poor adherence and delayed care-seeking [19]. However, these studies were mainly quantitative studies which were conducted in urban settings. Information about knowledge of HF and arterial hypertension, and about barriers to treatment adherence of patients living in rural sub-Saharan Africa is scarce. In response to the rising burden of NCDs, Tanzania launched a national NCD program in 2019, within a health care system that was initially not designed to have an NCD care model [20]. There is a need to explore patients' perspectives on NCDs to adapt and develop patient centered interventions that favor chronic care for patients living in rural settings. In this qualitative study, we explored i) the knowledge about HF and hypertension, and ii) barriers to HF and hypertension treatment adherence and to follow-up visits among patients with HF and hypertension attending a rural Heart and Lung clinic in Tanzania.

2. Methods

2.1. Setting

This study was conducted at the Heart and Lung clinic of St. Francis Regional Referral Hospital Ifakara from July to November 2023. This hospital serves a population of about 1 million people living in the Kilombero, Ulanga, and Malinyi districts in the Morogoro region.

2.2. Study Design

This was a cross-sectional qualitative study involving patients with HF and hypertension who attended the clinic.

2.3. Study Population

Eligible were adult patients aged above 18 years living with HF or hypertension receiving care at the Heart and

Lung clinic. Patients with severe conditions unable to do an interview, and those who did not sign an informed consent form were not eligible.

2.4. Sample Size and Sampling Method

Participants were purposively selected by the study team at the clinic. The criteria for purposive sampling included age, sex, and correct diagnosis. The diagnosis of patients was determined during the routine care visit at the clinic, which included clinical history, physical examination, and a comprehensive echocardiography. A total of 15 participants with HF and 15 with hypertension were enrolled, and this was sufficient to achieve saturation [20].

2.5. Study Procedures and Data Collection.

During routine care visits at the clinic, study team clinicians (AK, CM, and EM) screened patients for diagnosis eligibility criteria. Those meeting the diagnosis of HF or hypertension were welcomed to participate in the study. After informed consent, participants who agreed to participate in the study were interviewed. In-depth interviews (IDI) were conducted in a quiet room, with privacy face to face by interviewer (SAL) and a counselor and public health research expert (LS) who had prior experience with qualitative research and had no affiliation with providing clinical care at the clinic. The IDI guide used was developed and results presented based on the Andersen's Behavioral model of health service utilization (ABMHSU) [21]. Andersen's behavioral model suggested that environmental factors, a person's characteristics, and health behavior may influence health outcomes [21]. In this study, the main domains include individual characteristics and environmental (i.e health care system). The topics described the knowledge, medication adherence, and follow-up visits among the patients with heart failure and hypertension. The English version of the interview guide was translated into the Swahili language and piloted. Interviews took approximately 30 to 50 minutes and were audio recorded, and notes were taken. A code was given to each participant to keep the interview anonymous.

2.6. Data Analysis

Audio recordings were transcribed verbatim by two research team members (SAL and HM). Two research team members (SAL and LS) independently reviewed the transcripts and developed a codebook. These transcripts were uploaded into Nvivo 12 for organization based on the final codebook. Two team members (SAL and LS) identified initial ideas, codes, and patterns by reading and re-reading the transcripts independently. Similar codes were grouped into sub-themes and themes. The common themes matched pre-identified ones used to guide the interviews, while new emerging themes were also included. This analysis used both deductive and inductive approaches. The inter-coder agreement was used to finalize themes and ensure validity. Vague or irrelevant codes were discussed and either resolved or discarded after revising the data.

2.7. Ethical Approval and Consent to Participate

The study received ethics approval from Ifakara Health Institute - Institutional review board (IHI-IRB) with ethical number IHI/IRB/No: 44-2023, and the National Institute for Medical Research with reference number NIMR/HQ/R.8c/Vol.1/2076. We obtained informed consent from all participants before data collection; thus, they were aware of all information about the study.

3. Results

3.1. Characteristics of the Participants

Thirty in-depth interviews were conducted among 30 participants, 15 of them with HF and 15 who had hypertension without HF. A total of 17 (56.7%) were female and 13 (43.3%) were male. The median age was 55 (IQR 42-66) years. All participants were prescribed medication, and of those with hypertension, 11 (73%) participants had controlled blood pressure (i.e. <140/80mmHg) on the day of the interview. The details of the participants are shown in [Table 1](#).

Table 1. Socio-demographic and clinical characteristics of the study participants

Participants' characteristics	Participants with heart failure (N=15)	Participants with hypertension (N=15)
Sex		
Female	10 (67%)	7 (47%)
Male	5 (33%)	8 (53%)
Age (years), median (IQR)	52 (36-68)	56 (53-67)
Level of Education		
Primary	12 (80%)	12 (80%)
Secondary	2 (13%)	2 (13%)
None	1 (7%)	1 (7%)
Occupation		
Employed	0	2 (13%)
Self employed	13 (87%)	10 (67%)
No occupation	2 (13%)	3 (20%)
NYHA functional class		
I	1 (7%)	0
II	8 (53%)	0
III	6 (40%)	0
IV	0	0
Health Insurance		
Insured	7 (47%)	6 (40%)
Not insured	8 (53%)	9 (60%)
BP mmHg, Median (IQR)	114 (100-119)/75 (65-78) mmHg	131(123-149)/85(83-88)

IQR, interquartile range. BP, blood pressure.

*New York heart Association (NYHA) classification

I. Diseases but no symptoms and no limitation in ordinary physical activity

II. Mild symptoms and slight limitations during ordinary activity

III. Significant limitation in activity due to symptoms, comfortable only at rest

IV. Severe limitation at rest

3.2. Knowledge About Cause or Risk Factors of Heart Failure and Hypertension

In this study, all participants reported beginning to learn about their conditions after diagnosis, with additional information provided by doctors during clinic visits.

However, 11/30 (37%) of the participants were unclear on whether hypertension and HF could be contagious or inherited, though some thought they were not inherited due to the absence of family history. When asked about the cause and risk factors of hypertension and HF, unhealthy diets high in salt and fat were commonly reported. Few participants (5/30, 17%) reported physical inactivity, alcohol intake and smoking as high-risk behaviors for hypertension and HF. However, a total of (10/30, 33%) who did not use alcohol or cigarettes found it challenging to understand if these substances could contribute to the diseases:

"In the beginning, I didn't know very well, until I started going to the clinic that I learned about high blood pressure" (IDI Participant number 25, hypertension patient).

"I have never used alcohol, so I am not sure if it can lead to heart failure" (IDI participant number 26, heart failure patient).

"In my opinion, the disease I have is not inherited since neither of my parents had this particular condition" (IDI Participant number 10, hypertension patient).

Additionally, some participants (7/30, 23%) stated that certain life events, such as stress, life struggles, or marital conflict, were the cause of their hypertension or HF. As a result, it became challenging to identify other potential causes of their condition:

"This disease is due to stress" (IDI participant number 23 hypertension patient).

3.3. Knowledge Regarding Hypertension and Heart Failure Symptoms

All participants (30/30, 100%) reported symptoms experienced prior to diagnosis, such as headache, exhaustion, palpitations, coughing, sweat at night, dizziness, and chest pain. However, most were not aware of the disease at the time when symptoms were not present. Only a few (2/30, 7%) hypertensive patients were aware that hypertension is asymptomatic until headache or end-organ damage occurs. Detailed explanations were given for recurring symptoms, with coping strategies like resting and drinking plenty of water. Few (11/30, 37%) sought medical advice for unmanageable symptoms. Participants identified high fat- and salt intake, medication non-adherence, alcohol consumption, and physical inactivity as factors that worsened their symptoms: *"I was coughing a lot and had trouble breathing"* (IDI Participant number 27 heart failure patient).

"I don't know its symptoms because I often see many people who may feel unwell, get tested, and be told they have high blood pressure (BP), but previously, the person was unaware if they had BP." (IDI participant number 11, heart failure patient).

"If the situation has changed, I seek out time to rest or visit the health facility, and then I take medicine" (IDI participant number 22, hypertension patient).

3.4. Knowledge About Hypertension or Heart Failure Treatment

Almost all participants (26/30, 87%) showed good understanding of their medication intake and emphasized

the importance of adherence to avoid negative consequences such as stroke, death, or worsening symptoms. Additionally, many patients (28/30, 93%) expressed concerns about negative side effects like headache, palpitations, swelling, frequent urination, and dizziness from their prescribed medication. Medication adjustments were reported as the primary response to address these issues. However, more than half of the participants (19/30, 63%) demonstrated minimal understanding of the duration of treatment needed; many did not perceive a lifelong need for medication.

"I follow the doctor's instructions, so if he tells me to take this medication once, I do as he says. But I usually prefer to drink it in the morning" (IDI participant number 22, hypertension patient).

"When I first started taking the drug, my legs started to swell; sometimes I got headaches, so I had to visit the doctor again, who adjusted my dosage" (IDI participant number 24, hypertension Patient).

"I have no idea how long I'll take these drugs, maybe they'll tell me to stop at some point, or maybe I'll take them until the day I die" (IDI participant number 14, hypertension patient).

3.5. Challenges in Medication Adherence and Clinic Follow-up Visits

3.5.1. Enabling Factors

The majority (25/30, 83%) of participants reported receiving support from family members, especially children and close relatives who reminded them to take medication, accompany them to clinics, and ensure food availability. However, some participants (6/30, 20%) noted a lack of social support, particularly females who reported not receiving support from their husbands, impacting their clinic visits due to a lack of trust and harassment. Additionally, inadequate assistance from family members due to minimal understanding of the diseases was reported, as they perceived patients to have recovered due to the absence of symptoms:

"My daughter, who is very strong, cannot sit still without making sure if her mother has taken medication or if she has eaten" (IDI participant number 21, hypertension patient).

"Because they do not understand this problem, if they see someone talking or walking, they think that he has already recovered. They can only support me when I become seriously ill" (IDI participant number 26, heart failure patient).

A total of 4/30 (13%) participants reported experiencing stigma and discrimination from friends and relatives due to their symptoms. Excessive weight loss, coughing, and frequent fever led to mockery and suggestions to get tested for human immunodeficiency virus (HIV). Additionally, the medication they took was often linked to HIV treatment.

"Some, who are aware that I take medication daily, tell me: 'you are suffering from HIV.'" (IDI participant number 26, heart failure patient).

Few patients (13/30, 43%) reported possessing health insurance, which enables them to access medical care whenever necessary. However, most participants (9/13,

69%) noted that their insurance did not cover all medical costs, requiring them to purchase drugs out of pocket. Additionally, some patients found it difficult to receive care at nearby health facilities that did not accept health insurance, leading to missed clinic appointments due to transport expense and distance.

"When you visit the hospital, you can be informed that there is no medication available or that it is not covered by insurance; in this case, it becomes problematic because you need to take medication daily. What happens if you don't have money?" (IDI participant number 11, heart failure patient).

Patients living far from health facilities reported travel difficulties, primarily due to a lack of money to cover transport fees. As a result, some seek treatment at nearer facilities, where they complain about receiving poor care due to the absence of specialized clinics and personnel.

"Frequently, I fail to show up on the day I was scheduled to return. Although my insurance covers the cost of the medication, I am still missing the transport fare." (IDI participant number 25, hypertension patient).

Most patients (28/30, 93%) reported receiving insufficient financial support due to their families' financial difficulties. Supporters' responsibilities, like caring for their own families, limit their ability to provide adequate support.

"My son gives me five thousand shillings (about 2 USD) to come here, and he has to struggle for me to be able to buy medicine; also, he has children who are studying" (IDI participant number 20, heart failure patient).

3.5.2. Need Factors

(20/30, 67%) of patients reported that they had temporarily stopped taking their prescriptions, and some of them had turned to natural remedies because they were tired and frustrated with taking medications daily.

"After realizing the difficulties of taking medication every day, I gave up and began looking for alternative medicines that can be taken for a short time" (IDI participant number 26, heart failure patient).

Due to a lack of symptoms, more than half of the participants (19/30, 63%) reported stopping their medications and clinic visits. When they take medication and see improvement, they think that they have already healed. However, participants reported resuming their medication and started to visit the clinic when their symptoms became worse.

"Whenever I stop taking medications, I see changes such as sweating and difficulty in breathing. But if I take the medication, my symptoms improve. Therefore, I have realized that the disease still exists if the medication is stopped" (IDI participant number 03, hypertension patient).

3.5.3. Facility Level Factors

Participants highlighted medication adherence challenges due to high costs, especially for those without insurance. Concerns about drug expenses made it difficult for them to adhere to prescriptions. Some coped by purchasing smaller amounts or half dosages to maintain their medication regimen. Moreover, participants unable to afford medications were less likely to visit clinics.

"I was supposed to come back on the 20th of May 2023,

but I haven't come back, although it wasn't far because I was worried that I don't have money for buying medicines" (IDI participant number 01, heart failure patient).

The majority of patients (25/30, 83%) expressed satisfaction with the services provided during clinic visits. They described healthcare providers as loving, caring, and kind, offering good care and addressing difficulties encountered in managing their diseases at home, particularly concerning medication issues and necessary meals.

"Clinicians tell me to pay attention to their instructions, for example, the use of salt, taking medication on time, and stop saying that I'm okay and I'll take the medication tomorrow. They emphasize." (IDI participant number 30, heart failure patient).

Most participants (23/30, 77%) reported spending a lot of time at the clinic waiting for the services. Large queues resulted in extended waiting periods and additional expenses, particularly for food and lodging, especially when patients had not completed their treatment.

"Even if you came early, you stay for a very long time, so for me it is an extremely difficult challenge" (IDI participant number 28, heart failure patient).

Some (13/30, 43%) participants reported that their scheduled clinic dates do not align with the quantity of medication prescribed. Consequently, their medication occasionally runs out before their next scheduled clinic date. This acts as a significant barrier to medication adherence because when they are waiting for the date of their clinic appointment, they miss taking their medication.

"Today I have not taken medication because, as I told you, you may be told to use these medicines for a month. But medications run out three days before the clinic date" (IDI participant number 22, hypertension patient).

Investigation and consultation costs pose a significant barrier to clinic attendance for some participants, particularly those without insurance subscriptions. Patients who lack adequate financial support, the elderly, and the unemployed, are also affected by these expenses.

"I don't have any job; what will I do? I miss the clinic appointment because if I go to the clinic, where will I get five thousand? If I get five thousand for an investigation, where will I get medicine? That's why sometimes I miss clinic appointment." (IDI participant number 20, heart failure patient).

4. Discussion

In this study, most participants began learning about their conditions after diagnosis, with additional information provided by doctors during visits. While many associate these conditions with high fat- and high salt diets [22], few recognized other risk factors such as physical inactivity, alcohol, and smoking. Some participants who never used alcohol or cigarettes didn't believe these could be risk factors. Our findings contrast with other studies that showed that most participants were aware that alcohol and cigarettes can cause heart disease [23,24]. Most participants could list the initial symptoms experienced before diagnosis and the recurring symptoms during their illness [25]. Common self-monitoring strategies, including drinking water and resting, were used to manage recurring symptoms. Few participants noted to

seek medical attention for intolerable symptoms [26]. Frequently mentioned recurring symptoms were palpitations, shortness of breath, chest pain, and headaches. While hypertension is asymptomatic until headache or end-organ damage occurs, only a few hypertensive patients were aware of this in this study.

Most participants in our study accurately stated the number of drugs they took daily. This contrasts with a previous study where most participants couldn't correctly mention their drug number and dosage [28]. However, participants with lower education levels and the elderly had difficulty recalling drug names [27]. In our study, most participants could identify common drug side effects like headache, constipation, and frequent urination, consistent with other studies [29,30]. To differentiate drug side effects from disease symptoms, patients stopped medication and consulted physicians for possible adjustments or changes. This contradicts other studies [27]. Most participants misunderstood medication duration as they expected temporary use of their medication. These findings are inconsistent with previous studies [29,31].

Our study highlighted challenges to medication adherence and follow-up visits, with enabling factors often identified as barriers. While many patients received significant family support, such as being escorted to clinics and reminded to take medication [27], others lacked such support due to limited disease understanding and financial constraints, which aligns with another study [32]. Some women also reported a lack of trust and moral support from partners as a barrier. Additionally, stigma played a role, with some participants stopping medication after friends and relatives associated their treatment with antiretroviral treatment taken by people living with HIV, which is in line with other studies [17,27].

Additionally, most participants reported transportation expenses and distance as major obstacles to clinic attendance, consistent with other studies [17,33]. Some opted for nearby facilities but expressed dissatisfaction due to limited specialist services. Despite being insured, participants mentioned uncovered medications and frequent refill appointments as barriers adherence. Participants without health insurance mentioned high treatment costs as a significant burden [17], and some skipped medications or appointments due to financial hardship [34]. Most participants were satisfied with healthcare services during clinic visits, despite long waiting times sometimes leading to extra expenses for food and lodging [35]. However, our study contradicts previous studies which showed poor provider-patient relationship [17,33].

Consistent with other studies [14,17,27], consultation, investigation, and drug costs hindered adherence and follow-up. In the present study, some participants purchased small amount or half dosage to maintain their prescriptions. Some missed clinic appointments despite having transportation and consultation fees due to medication costs. Clinic appointments posed significant barriers to medication adherence, with patients sometimes running out of medication before their scheduled visit.

Severity and chronicity of illness significantly influence medication adherence and follow-up visits. In our study participants often neglected medication intake and appointments when symptoms were absent, which is in

line with other studies. [17,34]. Also, many felt burdened by daily medications, opting for traditional medicines due to affordability and shorter duration of use [34].

This study offered significant insights on knowledge about HF and hypertension of patients, as well as challenges with medication adherence and follow-up visits. In-depth interviews provided a thorough understanding of participants' experiences with these diseases. Exploring the daily challenges faced by participants in disease management can inform the development of necessary patient-centered interventions. However, there are limitations. First, the study involved only patients from a rural area who received care at a specialized Heart and Lung clinic, and results cannot be generalized to urban settings and to patients who have not received specialized care. Second, the study lacks perspectives from stakeholders, such as healthcare workers and caregivers, who may directly impact the patient's disease management. Future studies should involve healthcare providers and caregivers to gain comprehensive perspectives on heart failure and hypertension management.

5. Conclusion

This qualitative study found a limited understanding of patients about risk factors and the chronicity of HF and hypertension, and about the need of long-term medication intake to treat these diseases. This highlights the need for patient-centered interventions to improve understanding of hypertension and HF. Challenges related to medication adherence and clinic follow-ups were mainly due to high treatment costs, including consultation, investigation, drug, and transport fees. Addressing these financial barriers is crucial for enhancing adherence to medications and clinic appointments.

On the policy level, implementing non-communicable disease education programs will enhance public awareness and promote early detection. Expanding health insurance coverage and financial protection for rural populations would reduce the economic burden of care.

On the practitioner level, interventions should focus on delivering tailored counseling and health education during clinic visits, as well as strengthening patient-provider communication to foster trust and long-term engagement in care.

Future studies should adopt longitudinal designs to evaluate how patient knowledge and treatment adherence evolve over time. Additionally, including urban populations in future research will allow for rural-urban comparisons and help to identify context-specific barriers to care.

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