

Barriers in the Transition of Care for Heart Failure Patients Attending Clinics in Mwanza City, Tanzania

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Abstract

Introduction: Transition of care strategies have shown to improve quality of lives of heart failure patients, but it has little implemented in clinical settings. **Objective:** To evaluate context-specific perceived barriers and experiences of heart failure patients during their admission and after they were discharged from hospital. **Methods:** A cross-sectional qualitative study was conducted among 13 heart failure patients at two large referral hospitals in northwestern Tanzania. In-depth interviews among heart failure patients, in line with the Consolidated Criteria for Reporting Qualitative research checklist, were used to collect data. Interviews were audio recorded, transcribed, and translated into English. **Results:** Three key barriers were identified, as well as possible solutions that could improve the transition of care for heart failure patients. These include strengthening healthcare provider communications, organizing medication management, and assisting with follow-up appointments. **Conclusion:** The barriers identified are real and challenging in clinical resource-limited settings. Findings suggest they can be overcome when realistic and tailor-made interventions are in place.

Keywords

Heart Failure in Tanzania, Barrier, Transition of Care

1. Introduction

Heart failure affects 26 million people globally and is among major contributor of health expenditure [1]. In sub-Saharan Africa, heart failure ranks among the top five causes of hospital admissions, in-patient deaths, and number of admission days [2] [3] [4]. Unfortunately, heart failure also has very poor prognosis across much of the African continent [2] [3] [5] [6]. For example, twelve months after presentation, studies have reported mortality rates between 28%~58% in Tanzania [2] [5]. The factors that contribute to high mortality and admission rates in sub-Saharan Africa are complex and are often related to healthcare systems, healthcare providers, and patient-related factors [7].

For example, at the health system level, clear communication, effective discharge planning including provision of information, coordination of services and follow-up plans are critical [8] [9]. At the individual patient level, factors such as insufficient patient education, logistical and transportation barriers, cost of care, mental health challenges, patient medication non-adherence, and social challenges have been found to be associated with poor heart failure outcomes [10] [11] [12] [13]. Healthcare providers' choice for the course of treatment has been found to be influenced by knowledge deficits, diagnostic challenges, pharmacological concerns, communication issues, and individual preferences which may not be consistent with evidence-based guidelines [14]. However, these barriers have been reported mostly in high-income countries with little focus on low-middle income countries such as Tanzania.

In order to develop interventions to reduce poor heart failure outcomes in sub-Saharan Africa, there is a critical need to first assess contextual barriers. Heart failure patients' experiences with their healthcare providers and the healthcare system in the transition of care may provide insights on the most salient barriers that interventions must address to reduce poor heart failure outcomes. The objective of this study was to evaluate context-specific perceived barriers and experiences of heart failure patients during their admission and after they were discharged from the hospital.

2. Methods

2.1. Study Design

We conducted a qualitative descriptive study using semi-structured interviews for patients with a diagnosis of heart failure who were attending two large referral hospitals in Mwanza City, Tanzania.

2.2. Study Settings

Participants were from Bugando Medical Centre (BMC) and Sekou Toure Regional Hospital (STRH). STRH is a 300-bed regional hospital serving the greater Mwanza area. BMC is one of the four zonal referral hospitals in Tanzania with 950 inpatient beds, with a catchment area of 18 million people.

2.3. Sample Size Calculation and Sampling Procedure

Sample size was ascertained using the concept of data saturation commonly used in qualitative research [15]. Patients were recruited from two hospitals as part of a larger cohort study and interviews were conducted until we reached data saturation where no additional data were being found in order to develop new categories. Guest et al. proposed that approximately 12 participants are sufficient to achieve saturation [16] [17].

2.4. Participants' Recruitment

Patients were recruited from Hypertensive and Cardiac Clinics, after being seen by attending physicians, patients were eligible for the study if they had attended one of the two hospitals and were 18 years of age, fluent in Kiswahili and capable of providing written informed consent. Those who met heart failure-based Framingham criteria [18] were referred to the study team led by the author (BMW) and two research assistants who introduced the study to them before an in-depth interview was conducted.

Interviews were audio recorded, transcribed, and translated into English. BMW is a trained internal medicine physician and had received training in qualitative research methods. BMW did not have any relationships with the participants. This work was conducted in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (see Supplemental File 1) [19]. Participants were offered a range of between 5,000 - 10,000 Tanzanian shillings (equivalent to approximately 2.5 - 5 U.S. dollars) to reimburse their travel expenses. This fare range was based on how far they lived from the hospital.

2.5. Data Collection

Data were collected using semi-structured interviews between March and June 2018. The benefits of carrying out semi-structured interviews are that they guarantee a predetermined set of the interview questions will be covered, yet remain open for relevant follow-up questions [20] [21]. By using semi structured interviews, we can inquire further in accordance with the participants' preliminary answers through follow-up questions, encouraging them to provide additional explanation and clarification, thus gaining potentially a newer or more profound understanding with regard to their feelings and perceptions [22]. The interview guide was developed through a team-based process informed by the American Heart Association's Transition of Care in Heart Failure (TCHF) frame-

work that seeks to identify and address prominent factors impeding transitions of care among patients with heart failure to identify the main barriers to care that patients face through the transition of care process [10]. A preliminary guide was administered to three participants in the pilot phase. We used data from the pilot phase to refine the interview guide and these data were not included in the final analysis.

The final interview guide contained questions examining perceptions of access and quality of care, including hospital healthcare providers' ability and willingness to address participant concerns, the clarity of the treatment plan, medication management including availability, and plans for follow up appointments.

2.6. Data Analysis

For descriptive statistics, categorical variables were presented as frequencies and percentage, while continuous variables were presented as mean and standard deviation. For qualitative data, transcripts were analyzed using content analysis guided by principles drawn from grounded theory (*i.e.*, open coding and constant comparison) to identify participants' experiences and challenges during transition of care [23] [24] [25]. Using NVivo software Ver.12, two authors (AJ, CYK) independently coded three transcripts to identify categories and codes present in the data to develop a preliminary codebook using apriori codes from the TCHF framework [10]. AJ and CYK then compared the codes; re-read transcripts to evaluate selected codes, and identified higher order themes by integrating conceptually related codes and other emerging themes. The coders then independently coded the remaining transcripts and continually checked for consistency in applying the codebook through discussion and reconciliation. Throughout this process, a third reviewer (CM) reviewed the coding for consistency and assisted the coders in resolving disagreements and arriving at consensus.

3. Results

Data from thirteen participants were included in the final analysis and participants ranged in age from 26 to 74 years (mean age = 55; SD = 12 years). Interviews lasted between 25 and 35 minutes. A majority of participants were peasant farmers (n = 8), were from Mwanza city (n = 10), and were female (n = 9) (Table 1).

We identified four major themes that covered both in-hospital and post-discharge barriers. See Table 2.

We identified three barriers and their possible solutions in improving transition of care for heart failure patients as followed:

3.1. Healthcare Providers Communication

In describing their experiences, a majority of patients described a lack of or an inconsistent way in which their providers communicated. Participants described

Table 1. Social-demographic characteristics of Participants.

Variable	n (%)
Sex	
Male	4 (30.8)
Female	9 (69.2)
Age, mean (SD)	54.8 (12.2)
Residence	
Mwanza	10 (76.9)
Outside Mwanza	3 (23.1)
Occupation	
Peasant	8 (61.5)
Petty trader	2 (15.4)
Other (Teacher, Driver, Retired)	3 (23.1)
Health insurance status	
Yes	2 (15.4)
No	11 (84.6)
Diagnosis	
Peripartum Cardiomyopathy	2 (15.4)
Hypertension TN	11 (84.6)

Table 2. Barriers Faced by Patients hospitalized for Heart Failure condition.

S No	Participants (n = 13)	Description	Illustrative Quotes
1.	8	Identifying patient needs prior to discharge, implementing interventions prior to discharge	“A doctor came and he was holding a paper he said to me that I have been discharged, I told them, ‘You are discharging me now but the people who brought me to the hospital are not here, how can I go because I cannot walk on my own, I need someone to help me.’”
2.	9	Identifying patient needs prior to discharge, taking into account the patient and caregiver’s access needs, such as transportation, cost, or medications	“They were quick in treating me but the only thing that was giving me trouble was financial challenges, I didn’t have money to buy the medicines. I came here, they prescribed the medicines for me but I didn’t have money to buy the medicines. I have the prescriptions until today.”
3.	3	Focuses on the content of the information delivered from pre-discharge to post-discharge	“I usually go back to the doctor and tell him that when I take these medicines, I get such and such a problem. After telling him that, he prescribes other medicines.”
4.	7	Education to patients and caregivers, using principles of health literacy, teach-back, and encouraging self-advocacy	“You know the condition changes all the time with this disease; sometimes I wake up feeling good, other times I wake up feeling sick, sometimes I feel like my heart is tightened and I can’t breathe properly. That’s why I wanted to ask one question; What is the cause of my coughing?”
5.	7	Medication reconciliation across the continuum of care	“Some medicines are not available; I just take the medicines I have... But many days have passed; I haven’t taken any medicines. They prescribe the medicines but I do not have money to buy them.”

a lack of discharge planning with patients or caregivers unaware of when discharge would occur or why it was occurring. Some participants said that the discharge was often sudden with no prior notice. They said that a doctor or nurse provided a discharge slip, medication prescription, and a follow-up clinic appointment date without clear follow up plans.

Also, some participants described being in poor health at the time of discharge, and therefore did not understand why they were being discharged. One participant said,

“When I came to the hospital, I was so sick, so when some of the doctors said I have to be discharged I said, ‘I will not leave because I am not feeling well.’ I told them can’t they see that I am on this bed struggling to breathe? My condition was not good at all, but they just left me there. You should treat me, I swear, you have to be fair! How can you discharge me before telling me what I am suffering from?”

Another participant said,

“You know my relatives were the ones following all of the procedures. I couldn’t do it because I didn’t have the strength, but I remember they got the clinic appointment when they went to the pharmacy to take the medicines.”

Most participants reported that details about their treatment plans were not well communicated by their healthcare providers. They said that their communication on important discharge information like date of the next appointment after discharge and the frequency of follow-up appointments were not clear. For example, one participant said:

“They asked me to go to the clinic every day, but I told them that I live far away and they gave me the medicines to take for 30 days and they told me once the medicines are over, I should go back to the hospital for check-up.”

Another participant said:

“I think if they make a clinic appointment and prescribe the medicines, they should give me the medicines to take up to the next clinic appointment because sometimes I don’t get the medicines enough to take up to the next clinic appointment.”

Participants reported that they had limited knowledge about heart failure and the plan for follow-up care. Very few participants described receiving education or guidance related to self-care such as dietary changes or physical activity. For example, the following description was common:

“They gave me the medicines to take for 30 days and they told me that once the medicines are over, I should go back to the hospital for a check-up.”

One participant mentioned being counseled on diet during a follow-up ap-

pointment.

“They thought I was doing well because I was able to walk on my own to the bathroom without any help, even myself I thought I was getting well. But after going home and stay for some weeks, the problems started again especially if I eat the food with salt or oil, if I take a cold shower or drink cold water, I get problems. They told me [at clinic], they said I have to put very little salt in my food, they also told me not to put oil in my food because my heart has become big.”

3.2. Medication Management

Participants described challenges with medication management while admitted in the hospital. Some participants reported not being able to access the medicines they needed as inpatients because the hospital did not have them in stock. As one participant said,

“Why is that when we go to the hospital, we do not get the medicines and we are asked to go and buy them in pharmacies outside the hospital?”

When inpatients purchased medicines outside the hospital, some participants reported being confused about how and when to take them. A participant describes his experience as follows,

“I went to buy the medicines and when I came back, I was waiting for them to come and tell me how to take the medicines, while waiting I wanted to take the medicine but I was afraid that I might make a mistake. Then I decided to tell them that I have got the medicines already, should I take them? They told me no, I shouldn't, I have to give to them. Even after giving the medicines to them still, they stayed with the medicines for one hour, then they came to treat me.”

Cost of medications was also a significant barrier to the participant and this affected their ability to adhere to their medications. For example, one participant said,

Yes, I have financial problems, it reaches a point when I don't get money to buy the medicines and I just take some type of medicines not all prescribed medicines.

A less common, but still important, cause of non-adherence was medication side effects. The most common side effects described included dizziness and upset stomach. As participant described;

“I had some challenges for example when I was taking the medicines. I was getting headaches to the point of vomiting. After feeling this, I sent my daughter to the doctor where we bought the medicines and the doctor told her that, those were the side effects of the medicines. I thought maybe the medicines that I was given had expired, but slowly as days went by I became

used to the medicines.”

Another participant described having to find the balance between the inconvenience of the side effects with the benefit for their heart health:

“I was required to eat a lot of food and take porridge when I took the medicines, and when I took them, I couldn’t wake up the following day. I was feeling very exhausted, but I continued taking them maybe they were the ones which made me to feel better.”

Another one said,

“I didn’t see anything good in the services I got because my legs are still swelling, of course I was given the medicines which makes me urinate a lot and when I do this I feel well at least.”

3.3. Follow-Up Appointment

Participants observed a lack of content of patient care information such as discharge summaries, diagnosis, treatment and response plans, and medication information for transferring within hospital to post-discharge care. This led to other challenges after the participants were discharged. Unavailable and cost of prescribed medications were reported as significant barrier to the effectiveness of follow-up care.

For example, a significant number of participants reported being discharged without the medications they needed.

“The biggest problem I see is the fact that medicines are not easily available. I have to go to several pharmacies to look for them, and sometimes I don’t have money to buy them. I go to the hospital and come back home without any medicines. I have to look for money to buy the prescribed medicines. (Accessing) medicine is the biggest challenge for heart patients.”

Other participants described having their prescriptions changed, without regard to their ability to afford the new medications. For example, a participant said,

“Yes, I get some medicines but some of them are not available. I just take what I have, and when the medicines are finished, I go back to the hospital and they prescribe other medicines. ... Even now, many days have passed (since I took my medicine). I went to the hospital two months ago and they prescribed medicines, but I didn’t have money to buy them.”

Most participants attended clinic once per month and participants were nearly equally split in describing the ease of obtaining prescribed medication. In several cases, participants chose to take half doses of their medication because they could not afford to take the prescribed dose each day:

“It really troubles me. Sometimes we borrow money and we get enough to buy the dose in halves and when the pills are gone, we borrow money

again.”

Another one said,

“When I go they just do the check-up, I lastly told them that I don’t have money to buy the prescribed medicines, I will stop going because when I go to the clinic they will do check-up they will prescribe medicines but I don’t have money to buy those medicines. I have been going to the hospital several times, they prescribe the medicines but I do not have money to buy them.”

4. Discussion

Transition of care is a relative new concept in Sub Saharan Africa. To the best of our knowledge, this work is the first to be done in the region to assess barriers on transition of care for heart failure patients on patients own perspectives.

Few studies done in sub-Saharan Africa, were look at sustainability of health interventions, whereby health care worker shortage and weak health systems were among the challenges identified [8]. This was a systematic review looking for challenges towards sustainable health services. The challenges identified are important, but very broad, which need a depth analysis so as to come up with issues which when acted upon can improve health services and eventually quality of care to patients.

Through in-depth interviews with patients with heart failure in northern Tanzania, we identified several challenges in the transition of care faced by heart failure patients. Our study highlighted some important gaps in provision of care, based on patients’ experiences at referral hospitals that may contribute to poor heart failure outcomes.

From patients’ experiences, there were challenges in the transition of care from inpatient to outpatient settings. Health care provider communications about discharge procedures, medication management and also follow-up appointments were highlighted as key challenges. Discharge planning is recommended at the start of admission to reduce the likelihood of rehospitalization and other poor outcomes for heart failure patients [8]. Current heart failure guidelines recommend that healthcare provider teams develop early discharge planning in order to reduce readmissions and other negative heart failure outcomes [26]. The Ideal Transition in Care Framework is a framework that outlines 10 domains to advance multiple transitional care interventions that have demonstrated effectiveness [27]. Eight of the 10 domains occur at pre-discharge or at the time of discharge, including early discharge planning; complete communication of information, availability; timeliness, clarity, and organization of information; medication safety; patient education and self-management promotion; advance care planning; and care coordination.

This study found challenges in several domains. For example, there were challenges reported in the discharge planning domain which were exacerbated

by a lack of complete communication of information. Discharge planning involves planning ahead for hospital discharge while the patient is receiving treatment in the hospital and complete communication of information refers to the content that should be included in discharge summaries and other means of information transfer from hospital to post-discharge care in order to increase the likelihood of optimal outpatient follow-up [28] [29]. Taking into account contextual factors such as maldistribution of healthcare workers and high patient-physician ratio [30], future research should focus on implementation strategies that can support these two critical domains. There is also a need to take into account other environmental factors such as transportation to and from the outpatient settings during the discharge planning. Future research should also focus on provider experiences in transition of care and employ strategies such as training in areas found to have deficits.

We also found several challenges in medication management and safety. Participants description of the drivers of non-adherence ranged from availability, cost, and information about the need for adherence. Participants reported that they could not afford to pay for their medications and also if they had the funds, the medications were not available in the hospitals and also in pharmacies. Medications are key in management of heart failure conditions, and are supposed to be given regularly and for life [31]. Given these healthcare systems and financial challenges, future interventions should focus on ensuring that there is an adequate supply of affordable medications for heart failure patients in Tanzania. This may include improvements in the supply chain and health insurance coverage which is needed to cover almost 70% of the population [32].

5. Conclusion

The findings from our study have identified the real challenges patients are facing when using health facilities that can impair quality of services and health outcome.

Recommendation

The tailored made interventions strategies are needed to improve these barriers. Because the challenges raised are more practical, which need little cost in changing policy and updating standard operating procedures.

Ethical Considerations

Ethical approval for the conduct of the study was obtained from the institutional review board at the Catholic University of Allied Health Sciences [33]. Written Informed consent was obtained from all participants included in this study.

Conflicts of Interest

The authors declare that they have no competing interest.

Consent for Publication

Permission to publish was obtained from ethical clearance committee, Catholic University of Health and Allied Sciences, certificate number CREC/122/2016.

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Author Contributions

BMKW, principal investigator, study design, data collection, analysis and manuscript preparation; CM, RNP, JB, NM and AJ contributed to the study design and manuscript preparation. CYK, EBM, DM, AZM and BAK contributed to data analysis and interpretation. All authors contributed to the study design, interpretation and drafting of the article. All authors read and approve the final version of the paper.

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