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Self-care among people with heart failure in Uganda: Challenges and potential solutions

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Abstract

Heart failure (HF) accounts for up to 43% of all hospital admissions among adults globally and has a high one-year mortality of up to 8%. Although no African guidelines currently advise on HF self -care management, the European Society of Cardiology recommends that all HF patients receive education and support to facilitate self-care. Self-care among HF has been reported to improve health outcomes, reduce morbidity and mortality. This paper aims to evaluate the barriers and perceived solutions associated with self-care among HF patients in Uganda. We undertook an exploratory qualitative study that was grounded in the Theory of Planned Behavior (TPB) through which we explored barriers and their solutions to self-care for HF patients. We carried out 10 in-depth interviews consisting of 5 health workers who manage HF and 5 HF patients post hospitalization, and one additional focus group discussion involving 6HF patients. Barriers to self-care were categorized into themes according to TPB. Participants expressed negative attitudes towards HF self-care, which included difficulty in initiating and sustaining self-care, lack of self -discipline, and lack of motivation due to slow resolution of symptoms. As subjective norms, participants described how limited health workers support, inadequate social support and negative peer pressure served as barriers to HF self-care. Lack of understanding of the importance of self-care and lack of finances were the identified barriers as perceived limits to behavioral control. Solutions to HF self-care barriers included education about self-care, availability of affordable and sustainable medicines, and improved social support. Practicing self-care among people with HF is challenging and there it is essential to support the uptake of self-care to ensure better health outcomes.

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Data availability statement: The data collected during the interviews contains potentially identifying and sensitive patient information and according to the Mbarara University Research Ethics Committee this information can be shared publically. The data can be accessed from the Mbarara University Research Ethics Committee on email: irc@must.ac.ug and sec.rec@must.ac.ug.

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Background/Introduction

Heart failure (HF) is a clinical syndrome characterized by the reduced ability of the heart to either pump or fill or with blood or both, secondary to abnormality of cardiac structure or function leading to an insufficient cardiac output or adequate cardiac output due to compensatory neurohormonal activation and increased left ventricular filling pressure [1]. About 60 million people live with HF globally, and it is associated with reduced survival rates of 70–80%, 50–60%, and 30% at 1, 5, and 10 years, respectively [2]. HF is increasing as a major public health concern with high morbidity and mortality. HF is the commonest hospital admission diagnosis for all patients with cardiovascular disease globally. In sub Saharan Africa, in hospital mortality due to HF is up to 8.3% [3].In sub-Saharan Africa(sSA), it poses a particularly heavy burden to patients, their caregivers, and the health system [1]. This burden is much higher for sSA than in developed countries, given that HF affects a younger and would-be productive population. HF accounts for 9–43% of all hospital admissions in sSA [4,5] and one-year mortality ranges from 22-58% [5,6]. An estimated 43% of patients hospitalized with HF in Uganda die within 6 months of discharge [7,8].

HF is associate with recurrent hospitalizations, poor quality of life and reduced productivity [9]. Much of HF mortality and morbidity could be prevented with better lifestyle options, good understanding of symptoms and signs of HF, and seeking prompt and effective medical care [10]. HF requires carefully developed management strategies where the cause, symptoms, and chronic care are considered to avoid re-hospitalization and mortality; these recommendation are more likely to be effective when tailored to suit various environments [11]. HF management hinges on the fundamental principles of patient education, early symptom identification and management, patient lifestyle modifications, and adherence to medical therapies and guidelines for better outcomes for patients with HF [12].

Self-care is an independent predictor of better outcomes, reduced hospitalization, and reduced all-cause mortality among HF patients [13,14].. Self-care is the ability of individuals to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health worker, involving health promotion and preventive practices [15]. Effective self-care evolves around the Theory of Planned Behavior that involves supporting an individual's attitude, addressing subjective norms, and bolstering the individual's perceived behavioral control [7,16–19]. The European Society of Cardiology (ESC) recommends that all HF patients receive education and support to facilitate self-care, thereby reducing re-hospitalization and improving survival [20]. ESC HF management guidelines also recommend a multi-disciplinary approach involving specialists and nurses in both the hospital and in the community. These guidelines highlight the importance of involving patients and their caregivers in discharge plans and self-care management which includes adherence to medication, proper healthy diet, exercise daily weight monitoring, recognizing and identifying symptoms of HF and consultation with a health care provider These practices, however, may not always be possible in view of limited resources and strained work force especially in developing countries.

With a rising burden of HF in Uganda, culturally driven, locally tailored understanding of the barriers and facilitators to self-care among HF patient has a crucial role to play in the development of interventions to improve survival and quality of life. Understanding the facilitators and barriers will foster effective education and ongoing support to patients with HF and their families so as to empower them to take charge of their illness. In this study, we set out to explore with the goal of getting a conceptual insight into understanding the challenges and perceived solution to self-care among HF patients who had been previously hospitalized for heart failure in southwestern Uganda using the Theory of Planned Behavior.

Methods

Ethics Statement. This study was approved by the Mbarara University of Science and Technology Research and Ethics Committee (MUST REC), Mbarara Uganda (MUST-2024–1651) and the Uganda National Council for Science and Technology (UNCST), Kampala, Uganda (HS5307ES) and administrative clearance was granted by Mbarara Regional Referral Hospital, Mbarara, Uganda. All participants provided a written informed consent prior to participation in the study

Study setting. This study took place at the Mbarara Regional Referral Hospital (MRRH) in Mbarara City, Uganda, which is located in the southwestern part of Uganda with a mixture of both urban and rural populations. The hospital is located 250km from the capital city – Kampala and serves about 5 million people from its catchment area of 13 districts and the neighboring countries of the Democratic Republic of Congo, Rwanda, and Tanzania. MRRH is a teaching hospital for Mbarara University of Science and Technology. As the biggest hospital in the region, it offers a variety of diagnostic, curative, and sub speciality care including cardiology services. The study took place at the HF outpatient follow-up clinic, which runs one day a week. The services offered by the clinic include clinical reviews for response to medical therapy, medication refills, and labs and diagnostic testing as deemed fit by the attending health worker. The clinic is run by one nurse, physicians including a cardiologist and a number of postgraduate students who rotate in the clinic

Study design. We undertook an exploratory qualitative study from January to March 2025. The study used the Theory of Planned Behavior (Fig 1) as a sensitizing theory, adapting it the local concept and giving direction through which we explored facilitators and barriers to self-care for HF patients. Specifically, we evaluated participants' attitude and subjective norms towards HF, their perceived behavior control, and situational barriers to self-care, including cost and time, which are highly relevant for patients with HF. This information can then be used to enhance uptake of self-care for HF by both the health workers and the HF patients in HF management.

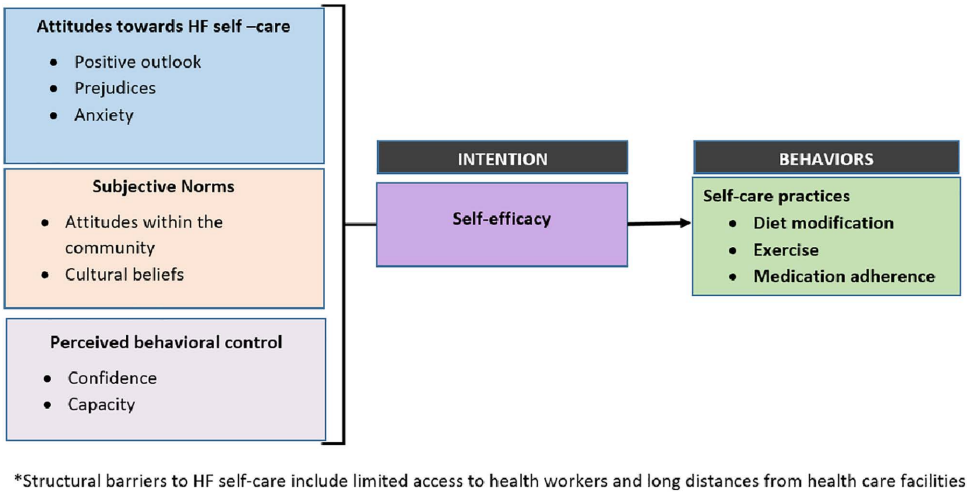


Fig 1. Theory of Planned Behaviour conceptual frame work and chronic disease management principles, adapted to HF self-care.

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Study participants. We recruited two types of participants: adults with HF post hospitalization and healthcare providers who take care of people with HF. First, we used convenience sampling to select people with HF who were attending the outpatient follow-up clinic, having been discharged from MRRH for acute HF within the past four weeks and who had the ability to speak the local language (Runyankole). We purposively sampled men and women and ages <60 and ≥60 years. Second, we interviewed all the physicians who were working in the outpatient MRRH HF clinic during the study period.

Study procedures. We conducted 10 in depth interviews (IDs) with involving 5 post hospitalization HF patients and 5 HF health workers who were treated for HF using a pretested interview guide (see Appendix). IDI questions included questions about HF knowledge, self-care knowledge like diet, daily weighing, adherence to medication, consultation with a health worker, challenges of self-care and proposed solutions to the challenges, additionally we conducted a one focus group discussion (FGD) involving six people with HF to collect views and insights on the subject arising from interactive participation and allowed for exchange of ideas amongst the HF participants. Each IDI interview lasted on average one hour; the FGD lasted one and a half hours. HF participants were selected based on having been recently hospitalized with HF. The interviews were conducted until saturation which was determined when no new ideas were being generated from the participants. Interviews followed an interview guide that had been previously developed, discussed among the research team and piloted before it was administered to the participant. Open-ended questions and probing questions were used to collect more in-depth data about participants' experiences. Qualitative data was collected, coded and interpreted following then ISSM COREQ Checklist for qualitative research [21]

All interviews were held in a quiet and private room in the study setting to allow for uninterrupted exploration of the participant's views. The interviews were audio-recorded in real time with notes taken. Interviews were conducted in the local language for the HF patients and later transcribed and translated into English. Interviews were conducted and transcribed in English for the health workers.

Analysis. Qualitative data was analyzed using Nvivo 14 software. FGD and IDIs transcripts were assessed using thematic content analysis [22]. Specifically, we identified recurrent themes and ideas within the transcribed data. All transcribed data was read by the principal investigator (author DN) thoroughly, and meanings were formulated to generate codes that were aggregated into themes. The coding was done by two coders (authors DN, EK) to minimize possible bias.

Ethics. This study was approved by the Mbarara University of Science and Technology Research and Ethics Committee (MUST REC), Mbarara Uganda (MUST-2024–1651) and the Uganda National Council for Science and Technology (UNCST), Kampala, Uganda (HS5307ES) and administrative clearance was granted by Mbarara Regional Referral Hospital, Mbarara, Uganda. All participants provided a written informed consent prior to participation in the study

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Inclusivity in global research. Additional information regarding the ethical, cultural, and scientific considerations specific to inclusivity in global research is included in the Supporting Information (S1 Checklist)

Results

Participant characteristics

A total of 16 people participated in the study, seven males and nine females. Out of the 16 participants, 11 participants were people with HF while 5 were health workers. Three people with HF had New York Heart Association (NYHA) classification II, while the rest were NYHA classification III and IV. The mean age was 63 years (range 46–78 years). Five health

Table 1. Patient characteristics.

IDI-PT- STUDY -ID	SEX	AGE	NYHA HF CLASSIFICATION	DURATION OF HF DIAGNOSIS
PT-01-	**M**	**64**	**III**	**5 YRS**
PT-02	M	76	III	2YRS
PT-03	F	46	III	3YRS
PT-04	F	60	IV	4YRS
PT-05	F	58	II	3YRS
FGD-PATIENT. STUDY-ID				
FGD-PT	M	68	IV	7YRS
FGD-PT	M	62	III	1 YR
FGD-PT	M	64	II	5 YRS
FGD-PT	F	53	III	3 YRS
FGD-PT	F	78	IV	6 YRS
FGD-PT	F	67	II	12 YRS
				HW Experience with HF care
HW-01	M		N/A	3 YRS
HW-02	F		N/A	2 YRS
HW-03	M		N/A	1YR 6 months
HW-04	F		N/A	1YR 6 months
HW-05	F		N/A	11 YRS

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worker participants (one cardiologist and four general physicians working with people with HF) with an average experience with HF care of 3.8 years (range 1.5-11.0 years); 2 were males and 3 females (Table 1).

Qualitative results overview

We categorized the barriers to self-care among HF patients into attitudes towards HF self-care, their subjective norms and perceived behavioral control (Table 2). The suggested solutions reflected themes of education about self-care, availability of affordable and sustainable medicines, and improved social support.

Barriers to self-care

Attitudes towards self-care

Self-care is difficult to initiate and sustain. Both health workers and people with HF reported an inertia to initiate self-care mainly due to a gap in information about self-care. Some participants said that they initiated a self-care regimen, including regular exercise, diet, and/or prescribed medicine, but they were unable to sustain the program due challenges in changing lifestyle habits like exercise and adherence.

> "Some of these lifestyle things are very hard to initiate or even sustain by these patients." (Physician with 3 years' experience in HF management)

> *"I think there is a gap in having this information being practiced. That is understandable because these things involve you changing things you've been doing for a very long time, the bad habits*." (Physician with 2 years' experience with HF management)

> *"We don't receive health education. Who is here to educate us?"* (68 year old male with HF for 7 years)

Table 2. Barriers to self-care among HF patients according to the Theory of Planned Behavior.

Category	Subcategory
Attitudes towards self-care	Self-care is difficult to initiate and sustain
	Lack of self-discipline limits self-care
	Slow resolution of symptoms is demotivating
Subjective norms	Health workers have limited time to provide support
	Follow-up with health workers to guide self-care is lacking
	Social support for self-care at home is inadequate
	Misinformation with negative peer pressure
Perceived behavioral control	Patients lack of understanding about the importance of self-care
	Patients forget prescribed self-care practices
	Lack of finances takes away control of self-care (e.g., purchasing medication, engaging in lifestyle changes, getting to clinic)

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Lack of self-discipline limits self-care

Participants noted that they did not practice self-care because of a lack of self-discipline. Alcohol consumption commonly accompanied such feelings. They stated that they had no specific reason to stop alcohol consumption; they just did not have enough self-discipline to comply with the health workers' advice.

> *"This thing of alcohol consumption, it's a tug of war. It's difficult to stop taking alcohol when it's always in your vicinity."* (46-year-old female with HF for 3years)

> *"……. our innate lack of self-discipline. Majority of the humans are not disciplined. You tell them about that but they might not be able to change. They might keep working to keep the carbohydrates and junk food they've been eating. There is that innate inertia in the patients or in us humans to really change*." Physician with 3 years' experience in HF management

Slow resolution of symptoms is demotivating

Patients reported being adherent to provider recommendations, such as exercising, with the expectation of a quick resolution of symptoms. When the symptoms persist, the initial positive attitude shifts to a negative attitude resulting in abandonment of self-care.

> *"But for most patients I think when they try a bit and don't see drastic improvement immediately, they are bound to keep doing the same things they've always done before."* Physician with 3 years' experience in HF management

> *"You see you give us medicines but we don't heal, so I would like to know; do you cure the disease or you're just controlling it? That is what I want to know, you don't tell us by the way."* 60-year-old male with HF for 4 years

> *"Some patients think that it is an acute problem that will end within two months. They can't understand why they have had a disease for 6 months or 3 years"* Physician with 2 years' experience with HF management

Subjective norms

Health workers have limited time to provide support. Health worker participants noted that they have limited time to support self-care for people with HF and give it the attention it deserves. They also remarked that the patients are many and the physicians are few, yet all have to be seen. As a result, they do not take time to explain to them the details of

health care and how to fit it in their day-to-day lives. They emphasized a few aspects like medication adherence, but not much more. The only alternative for HF patient participants is to resort to peers who have inaccurate information, which may be contrary to self-care goals.

> *"The trouble with the outpatient clinic is that we are constrained by time and numbers and human resources"* (Physician with 2 years' experience in HF management)
>
> *" ….telling these patients the things they should do but maybe we don't stress it that enough, yet it contributes significantly. As health workers we feel like the medicine we have written for them are going to be the magic bullet to healing this person."* (Physician with 3 years' experience in HF management)
>
> *"……. healthcare workers here give information but not for the most part, you come here and tell them your problems and they only prescribe for us drugs. But as a heart failure patient, you keep searching for your own information from the old heart failure patients or from the newspapers"* 64-year-old Male, FGD HF patient.

Lack of follow-up with health workers to guide self-care

Among other barriers, HF patient participants noted the inability to contact health workers once they were out of the clinic or hospital. They noted lack of telephone contact with any health worker in case they had an inquiry or needed a clarification about their medicine or anything else relevant to their illness. They also noted that in most cases when they came to hospital, they would find different health workers who prescribed new medications without giving them any explanation. They lamented the inability to contact the previous health worker for clarification. This situation caused confusion that resulted in abandonment of care.

> "*Another thing I have seen at this referral hospital; I get a new doctor on every review. So you find you don't have a doctor to call your own because they change over and over again*." 64-year-old male HF patient for 5 years
>
> "*I don't have my own doctor to call in case I get a problem. I have to first come back and meet whoever I meet and if you want one, how do you get him? Do you pay? (for a personal doctor) I also don't know how to handle that*" 60-year-old female HF patient for 4 years
>
> "I *will start taking these medicines; I don't even have doctor's phone number. What if something wrong happens, where can I run to*?" 76-year-old male patient for 2 years

Support for self-care at home is inadequate

Participants reported the lack of social support at home to help them with self-care for HF. No one could reliably help with preparing healthy meals, reminding them to take medicines, or supporting them with exercise. With lack of social support from home there is no one to be accountable to and the people with HF may not be compelled to practice self-care. For some, due to their age, self-care was hard without any support.

> *"You see this self-care (at home); it doesn't involve a doctor. The doctor just gives them the advice but it involves them and their family members. So, if I give all this advice but there is nobody to help get that implemented, then it means equally not done"* - HF physician with 11year experience
>
> *"I can be in need of drugs but still have no one to send. It is also a problem. I have a husband but he doesn't give me any support. So, when I think of such, it also becomes a challenge to me"* - 58-year-old female HF patient – 3 years with HF

Misinformation with negative peer pressure

Some participants were influenced by their peers and other members to stray off the prescribed self-care regimen. For example, some participants with HF believed that taking certain brands of alcohol reduces the fat content in their blood vessels and therefore encouraged to take alcohol more frequently.

> *"People say it, that you can always take some alcohol to reduce your body size. Now these healthcare providers are telling us not to take alcohol, yet it is of various types."* ……..n*ow like Tusker light [a type of beer], they say that heart failure patients can take it since it doesn't contain sugar. They say it is not bad, but the rest can cause abdominal swelling or swelling of other parts of the body*." - 46 year old female patient with 3 years of HF

Perceived behavioral control

Patients lack of understanding about the importance of self-care. Lack of understanding of the importance of self-care was a significant barrier to self-care. This may underscore the need to invest in resources like money and time or make selfcare a priority, thus compromising some components of self-care, like medication adherence, daily weighing and regular targeted exercise. Health workers thought that people with HF perceived medicine as the only important factor in improving the outcome of their disease process, making it difficult for them to practice other self-care advice. HF patients also had challenges in understanding the importance of taking all the medicines as prescribed by the health workers.

> *"When you tell me to take care of myself, how? How can I take care of myself? Tell me do this and that. Self-care should include this and this, even if it is not big, at least give me something really. When you tell me to take care of myself, you're leaving me in suspense. I can't know how to take care of myself."* 60year old female HF patient for 4years

> "*But for most patients who are illiterate, I think they might feel that the drugs (medicines) they've been given are the ones that are going to be the magic and maybe the other things we were telling them to do might not do so much in helping to improve the symptoms*"- Physician with 3 years' experience in HF management

> *"…….. they don't realize how important these things are to improving their outcomes of management of those patients. So, I can say there is a knowledge gap*" - HF physician with 1.5 years' experience

> "*But also, sometimes the patients don't understand why they should take the treatment the way they are taking it. Sometimes they might not get the adequate health information or education they need*." HF physician with 2 years' experience

The HF patient participants reported that little emphasis was put on teaching them about self-care, and the health workers were often overwhelmed with little time to explain to them. They reported that health and self-care talks were not done regularly, and there were no reminders or visual aids about self-care within the clinic.

> "*Another thing, we have never gotten heart failure education sessions to teach us about our disease*."- 60year old male FDG HF patient for 7 years

Given the lack of consistent and reliable health education about selfcare, HF patient participants received a lot of unverified information from their peers and other people with no specific medical training; that information was inaccurate most of the time as noted by the health workers.

> "*There is a lot of information out there. I have had patients oftentimes tell me how the doctor told them they have cholesterol. Their peers or the "Basawo" [traditional healers] down there tell them they have to drink a bit of alcohol, the other "Waragi" that it will also help them bring down fats*." - Physician with 3 years' experience in HF management

"*Now for us who are fat, they tell us to drink "waragi" [an alcoholic spirit] to reduce on the body size*." 46-year-old female patient with 3 years of HF

Patients forget prescribed self-care practices

Participants said that forgetfulness was one of the barriers to self-care. They stated that advanced age made it hard for them to recall some instructions without having constant reminders. Those who had jobs reported missing some of the doses of medicine while at work due to busy schedules. Some of the medications had inconvenient prescribed times for them to adhere to, so they would postpone the medicine and end up missing completely. Forgetfulness was also related to illiteracy and not being able to remember their review dates that were written on their medical documents.

"And other things we are forgetting most of the time, most of the patients are older, above 60 years. Most of these patients need to come to the clinic with caretaker. Most of these patients are coming alone. Once you give the information, they can forget." HF physician with 1.5 years' experience

"It is okay because they're telling us to take your medicines on time, but sometimes we forget because we get so much occupied by activities." HF physician with 1.5 years' experience

Lack of finances takes away control over self-care (e.g., buying medicines medication, engaging in lifestyle changes, getting to clinic)

HF participants stated that a lack of finances takes away their ability to control their behavior. Almost all participants mentioned that self-care placed a big financial strain especially when it came to the purchase of medicine, eating healthy foods, getting the necessary monitoring of disease and even hospital visits.

Cost of medicine

The majority of participants said that the cost of HF medicine was very high. Most of the participants reported taking more than three drugs for heart failure, and those who had other comorbidities had even more medicines. The cost of these medicines was high and most of the medicine was not available freely in the hospital. As a result, participants reported adhering to medication as long as there was money to buy the drugs.

"*The healthcare providers we meet, it's true they try to treat us and prescribe the medicine but there is no medicine in the hospital. Also, those medicines are expensive.*" - 60year old male FDG HF patient for 7 years

"*They [the health workers] only prescribe for you to go and buy, yet the problem is that we don't have money. The heart failure gets better when you have money but lack of money leads to poor drug adherence*." 53year old female FDG HF patient for 3 years

Due to lack of funds people with HF resorted to taking medicine only when they had money to buy it and if the money was not available, they would not take the medicines.

"*There are challenges that we can't solve. We can't solve everyone's problem. We can't solve their finances, especially regarding medication. If they don't have money, they don't have it*". HF physician with 11 years' experience

HF patients stop taking medicine or buy medicine daily, which results in missing of treatment on most days when the money is insufficient. Some participants reported buying medicine selectively based on their perceived needs or

affordability. They would choose to buy the least expensive drug and take only that instead of all the medicines that were prescribed.

> "These *medicines you're seeing, they are expensive, sometimes they can write for you medicines that cost like 250,000 [Uganda shillings (60 euros)] then I go and buy for like that of 40,000 (9 euros).*" 46-year-old Female- 3 years with HF

Lifestyle changes are expensive

Most participants thought lifestyle changes were also expensive and not affordable. They associated lifestyle modification with affluency. For example, they reported that getting health foods like fruits, vegetables, and animal protein was quite expensive. Some had to rely on the available food even if it was not healthy

> "*The other is about finances, social economic issues. If you're telling someone to eat a good diet, that would mean a lot of vegetables and fruits. …… These things cost money and the only way is to buy them.*" - HF physician with 3 years' experience

> "*You may want to take care of yourself, but you find yourself without food, or what you're supposed to eat because they say that if you have heart failure, try to have a good diet. Don't eat bad food. But sometimes you lack what to eat.*" - 58 year old Female- 3 years with HF

Furthermore, all HF patient participants reported that daily weighing was a foreign concept. The cost of owning a weighing scale was prohibitive, and the transport costs to the nearest health center for daily weighing were discouraging.

> "*……. but sincerely, can we afford measuring our weights daily, in our villages? You see this issue of heart failure; it is an expensive disease. I don't have money to buy a weighing scale. What other alternatives can you put for me to measure my weight?"-* 60year old Female- 4 years with HF

Transport costs to doctor's appointments

Participants noted availability of money was very significant in determining whether they came back to hospital for review. Coming to the hospital was associated with transport costs, doing expensive tests and getting new prescriptions for medicines that all require money. When the money was not enough, participant would do self-drug refills using the previous prescription to buy medicines from the pharmacy and only came to hospital when symptoms worsen.

> "*So I don't get to know that (If I am getting better) because I don't get money for doing investigations. I would like to know that too, but I lack money to take me back to the hospital.*" 58 year old Female- 3 years with HF

Participant proposed solutions to the challenges

In addition to noting barriers to self-care, participants suggested solutions that would make self-care easier which included self-care education and follow-up for people with HF, empowering health workers, winning the trust of patients, and availability of affordable medicines.

Education about self-care

Educating both the health workers and people with HF about the importance of selfcare was suggested by both types of participants as a feasible solution for improving self-care. Patient participants acknowledged that if the health workers

gave them sessions in self-care at every visit, they would be able to learn and practice self-care. This would help create trust and reduce relying on unclear sources of information about self-care for people with HF.

> *"Still repeat the same things once again because health education is continuous. You don't teach once and stop. You have to keep reminding."* HF physician with 11 years' experience
>
> *"I think largely it's patient education. I think it's being able to win the trust of the patient so that they believe what you're telling"* HF physician with 1.5 years' experience
>
> *"…….I request that you try and organize some workshops and health education sessions for us*" 62year old female FDG HF patient for 1 year

Improving social support and self-care at home

Getting self-care messages through digital health platforms to HF patients could improve selfcare and social support. Participants believed that if they were advised about what to do in their home environment, they were likely to adhere to self-care.

> *"…….also through tele-health where you send patients reminders. When patients receive reminders to take their drugs, it can be on phone. Let's say social media or you have SMS that go out frequently to remind them to take their treatment…."* HF physician with 2 years' experience

Empowering health workers at lower health facilities

Participants suggested that if health workers at the lower health facilities in the community were empowered with the right tools to deliver self-care packages, it would reduce on their transport cost and would also allow them to consult nearer to their homes. Health workers noted that people with HF would trust the health providers closer to them as they are more accessible

> "*…empowering those frontline health workers to be able to deliver this information because it is really easy since any nurse or midwife can be able to provide it. You find they have a lot of trust in those people much more than us who have only seen them for one or two days. So that is one important thing.*" HF physician with 2 years' experience
>
> *"….training those frontline health workers would go a long way in improving these outcomes so that when these patients are discharged from tertiary hospitals, they are going to the health center nearby where they will be able to give them this information*" HF physician with 3 years' experience

Getting consistent and affordable medicines

Participants suggested that self-care would be easier if health workers were consistent with medicine prescriptions. They noted that their drugs were changed almost at every visit making at times to more expensive drugs. They proposed that health workers should prescribe medicines that were affordable other than insisting on expensive brands that they would not afford making it difficult to be consistent with the medicines. They further suggested streamlining HF self-care to function like HIV care with availability of free medicines for all.

> "*If they can't afford the medication, we can put them on a cheaper medication that might do a good job, not as good as the other one, but they can do good work*." HF physician with 3 years' experience

"…*Another thing, let the healthcare workers try to give us some medicines. We used to find here some drugs but we no longer find them now days. Out of 5 drugs, they should give us like 3 and we look for the 2* "46 year old female HF patient for 3 years

" *Another thing, like in HIV patients, they have access to free drugs, you can also do the same for heart failure patients because we are also many nowadays*." 67 year old female HF patient for 12 years

Discussion

This study had a duo population of HF patients and their health workers and it explored barriers to self-care among HF patients and their proposed solutions using the Theory of Planned Behavior, looking at the perspective of both health workers and people with HF. They identified key areas for improvement in self-care, including the need to address personal barriers through education by health workers and multi-layered support at home and in the community. Cost was a dominant issue that may overwhelm the best of intentions for self-care among people with HF.

Individual attitude towards self-care has been found to affect adherence to self-care among HF patients. However, attitude is driven by access to self-care education and understanding its importance allows adherence to self-care. In a randomized controlled trial involving eighty-two patients with HF where the half the group (intervention group) received self-regulation education and follow up telephone calls while the other half received routine care in an outpatient department in Northern Taiwan, the intervention group showed improved self- care management following compared to the control group while at home [23].

Subjective norms played an important role in self-care among the people with HF, including norms within the healthcare system and in the community. Health workers are crucial in determining whether people with HF practice self-care. Health workers often do not give enough emphasis on self-care and do not frequently educate patients about it and also do not follow up on patients to offer guidance about self-care [24,25]. This shortcoming in the healthcare system could be related to inadequate health worker training or their own lack of knowledge in self-care; it also undermines the patients' perception of the importance of self-care.

Social support in the community is one of the strongest pillars of chronic care including self-care in HF. Studies have shown that strong social support improves adherence to medication and self-care and is associated with excellent outcomes [26,27]. Examples of good health outcomes have been studied in HIV care where patients with treatment support fared better than those without support [28]. It is also well known the role of social support in improving adherence and retention in care in chronic illnesses especially HIV. A study done in South Africa found out that social support enhanced uptake of care, access to medication and improved adherence [29]. This was done in a population similar to the population that is most commonly affected by HF where there is chronicity of the disease, limited resources and constrained health care. Furthermore, in Ethiopia, insufficient social support was associated with poorer quality of life among people living with HIV. Similarly, in a study involving 708 people in 4 HIV care clinics in the U.S found that low social support was associated with reduced antiretroviral adherence, illicit drug use and lower engagement in care and lower health related quality of life [30,31]..

For people with HF to be successful in practicing self-care, they have to feel in control and empowered. Failure to understand the importance of self-care management hinders HF patients from practicing it. This could be attributed to the fact that patients lack knowledge and education about the importance of self-care. In a study done in Ethiopia among 308 adults with HF, improved understanding of HF knowledge among patients was associated with improved adherence to self-care. Likewise, in a clustered randomized controlled trial in Ethiopia, an intensive training intervention with follow-up and illustrated educational leaflets had a four-fold increase in adherence to self-care compared to the control group [32,33]. HF patients' perception of self-care plays an important role in its uptake. However, this perception is fostered by complete understanding by the patient [34].

Limited finances and access to care were noted as significant barrier to self-care by many participants. This finding has been reported in various studies where the cost determines of purchase of medicine, finances influence adapting to healthy lifestyles, and access to quality health care. A systemic review done in the US attributed high cost to the management of HF and this was worsened by type of HF, associated comorbidities and hospitalization related to HF [13,35–38]. Furthermore, the presence of other comorbidities increases the number of medicine and health needs thus the cost of care [38–41].. In low- and middle- income settings, the majority of patients are under-privileged without access to universal health insurance or aid to cater for these expenses [42,43]. Scarcity of reliable HF clinics near most HF patients makes them powerless to effectively keep doctor's appointments. Easy access to reliable HF clinics in health centers reduces barriers to HF care [44]. Another study has highlighted the importance of access to HF care as a vital step in improving outcomes among HF patients [45].

Suggested solutions to promote self-care included self-care education through repeated health talks on clinic days, self-care posters around the clinic, and follow up education thus improving knowledge and increasing access to self-care information. In a study in Ethiopia, educational intervention was found to improve self -care among patients with chronic heart failure [33].

In addition, use mobile health (mHealth) modalities, like telephone calls and texting, can improves uptake of self-care among patients. A study in Taiwan where patients with heart failure were followed up with educational phone calls found increased adherence to self-care. This approach can foster adherence to self-care, thus improving outcomes [23].

Affordability of self-care services through subsidized options in medicine and government aid is crucial in maintaining standard of care for HF patients. Government involvement in providing medicines and decentralizing care has been a cornerstone model in the management of HIV [46]. Adopting similar models for HF could help in improving uptake of self-care where medicines for HF are available in most health care facilities.

A major strength of our study is the first study in Uganda to looking at post hospitalization HF patients and their health workers, using the Theory of Planned Behavior as a guiding theory to deeply understand the HF self-care barriers and potential solutions generated by the people with HF and their health workers. Our study also had some limitations. First, we can only comment on the experiences of HF patients and healthcare workers in one site. Future studies should involve other populations. We also did not include hospital administrators and policy makers who could add valuable perspectives on potential solutions to improving self-care practices among people with HF. Given the limited pre-existing frameworks on self-care in HF, this open approach we employed in this study was appropriated given the novelty of the study.

Conclusions

People with HF face challenges in practicing self-care that can be understood through their attitudes, subjective norms in the healthcare setting and community, and their perceived control of their own health. Lack of self-care awareness and education, cost of self-care, and limited health worker involvement are key challenges for self-care management among people with HF. We suggest borrowing concepts from HIV programs to provide free access HF treatment, community involvement, increase education and sensitization about HF, engaging with Ministry of Health to empower and support patients through programs dedicated to the creating awareness and encouraging uptake self-care for better outcomes among people with HF.

Supporting information

S1 Checklist. Inclusivity-in-global-research-questionnaire.
(DOCX)

Author contributions

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