

**HEART FAILURE KNOWLEDGE AND SELF CARE BEHAVIOUR  
PRACTICES AMONG AMBULATORY HEART FAILURE PATIENTS AT  
KENYATTA NATIONAL HOSPITAL**

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## DECLARATION

I **Dr. Irene Ng'ang'a-Oginga** declare that this dissertation is my original work and that to the best of my knowledge, it has not been presented for the award of a degree in any other university.

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## **LIST OF ABBREVIATIONS**

ACC	American College of Cardiology
ACE-I	Angiotensin Converting Enzyme Inhibitor
AHA	American Heart Association
AHFKT	Atlanta Heart Failure Knowledge Test
ARB	Angiotensin Receptor Blocker
BMI	Body Mass Index
DHFKs	Dutch Heart Failure Questionnaire scale
EHFSCBs	European Heart Failure Self Care Behaviour Scale
ESC	European Society of Cardiology
HF	Heart Failure
HFSC	Heart Failure Self Care Practices
HRQOL	Health Related Quality of Life
KNH	Kenyatta National Hospital
LV	Left Ventricle
NYHA	New York Heart Association
SCB	Self care behaviour
SBP	Systolic blood pressure

## **ABSTRACT**

### **Background**

Heart Failure (HF) is a global public health problem associated with a high consumption of medical resources. It is considered a worldwide epidemic and the incidence and prevalence is increasing in developed countries. HF is associated with a high morbidity and mortality despite advances in pharmacological therapy. Self care has been found to impact significantly on HF outcomes and this is highly dependent on patients' HF knowledge and self care behaviour practices. Regionally in Africa, there have been very few studies on HF knowledge and self care behaviour practices in patients on follow-up for HF. In our local set up at Kenyatta National Hospital (KNH), there has been no study conducted to assess the adequacy of HF knowledge as well as the level of adherence to different aspects of self care behaviour in HF patients on follow-up at the cardiology clinic.

### **Objectives**

The aim of this study was to determine HF self care behaviour practices and HF knowledge among ambulant HF patients at KNH and to explore any associations between HF knowledge scale scores and self care behaviour scale scores with demographic variables, level of formal education and duration of HF follow-up.

### **Study design and site**

This was a cross sectional descriptive study at the Kenyatta National Hospital, cardiology clinic.

### **Study Participants**

Study participants were all adult patients with a chart diagnosis of HF that fulfilled the Framingham HF diagnostic criteria retrospectively applied and on follow-up for at least 3 months.

### **Methods**

The study was a cross-sectional descriptive study and was conducted over a period of four months in order to achieve the desired sample size of 288 HF patients. Patients with HF and on follow up at the KNH cardiology clinic for three months or more were screened for eligibility and recruited upon signing informed consent. Patients' socio-demographic data and clinical information was entered into a study proforma. Two pre-tested and validated self-administered questionnaires; the modified Dutch Heart Failure Knowledge Scale (DHFKS) and the modified European Heart Failure Self Care Behaviour scale (EHFSCBs) were used to determine HF knowledge and HF self care behaviour respectively.

## **Data Management**

Questionnaires were coded and verified for completeness. Cleaning of data was done before data entry and analysis was done using Statistical Package for Social Sciences (SPSS) version 21. Descriptive statistics were used to describe socio demographic variables. Means and medians were used for continuous data while percentages and proportions were used for categorical data. Logistic regression was used to determine factors independently associated with adequate HF knowledge and self care behaviour.

## **Results**

Utilizing the DHFKS, the prevalence of poor HF knowledge scores among ambulatory HF patients at KNH was 89.6%. HF knowledge was particularly poor in thematic areas dealing with HF management, symptom recognition and symptom management. As regards self care behaviour practices and utilizing the EHFSCBs, 50.8% of the study participants had poor SCB practices. We found no trends in associations between HF knowledge and HF SCB practices and demographic variables as well as duration of HF follow up probably because the study was not adequately powered to detect any significant associations.

## **Conclusions**

Majority of ambulatory HF patients in KNH had poor HF knowledge while half the study participants had poor SCB.

## **1.0 INTRODUCTION**

The syndrome of heart failure (HF) is chronic and progressive clinical and arises from any structural or functional impairment of ventricular filling or ejection of blood. Currently more than 26 million people worldwide have HF making it a global pandemic almost rivaling cancer (32 million) and HIV (34 million) and this prevalence is projected to increase by 25% by the year 2030(1). The prevalence of HF varies between different regions of the world with that in the USA reported to be about 2-3% (2). The prevalence of HF in the African American population is estimated to be 3% and several epidemiological studies have shown that HF occurs at an earlier age in African Americans compared to other racial groups. There is paucity of data on HF prevalence in Africa as most studies are hospital based although cardiovascular diseases have been found to be responsible for approximately 7-10% of all medical admissions to African hospitals (3). A study conducted locally in Kenyatta National Hospital (KNH) by Kuria et al found a 6-month prevalence of acute decompensated HF of 5.7% (4).

In developed countries, HF is mainly a disease of the elderly with more than 80% of patients in the USA being over the age of 65 years (5). In Africa, however, the mean age at which HF occurs is much lower probably due to etiological differences in the two populations. Two studies in KNH by Kuria et al and Barasa et al found the mean age of HF patients to be 44 years and 47.6 years respectively (4, 6).

While the predominant cause of HF in the western world is ischemic heart disease, the main causes of HF in Africa remain largely non ischemic with hypertension, cardiomyopathy, rheumatic heart disease and pericardial disease accounting for 90% of HF cases. However, due to lifestyle modifications, change in diet and cultural attitudes and with rapid urbanization, newer data confirms the beginnings of an epidemiologic transition to other causes of HF such as coronary artery disease, obesity and diabetes (7).

Owing to research, better knowledge of the pathophysiological mechanisms involved in HF has led to improvements in pharmacological treatment. Despite adequate pharmacological therapy, HF is associated with high morbidity and mortality rates which in turn impose a major burden on health care systems due to the high health care costs involved. As a result, focus has shifted to utilization of non pharmacological therapies in management of HF of which self care behaviour

(SCB) practices such as daily weighing, salt and fluid restriction, smoking cessation, moderation of alcohol intake and yearly flu vaccination form the main components.

Good SCB practices can impact positively on HF outcomes as they have been shown to significantly reduce HF related hospitalizations, improve quality of life and reduce mortality in HF patients(8). Patients' knowledge on HF is the most important factor that positively influences HF SCB because HF patients who have a better understanding of HF have better SCB compared to patients with poor HF knowledge (9). It is therefore important to evaluate the level of HF knowledge in patients with HF, identify deficiencies in knowledge and act on these deficiencies by developing HF education programs. This study has the objective of establishing knowledge and adequacy of self care behaviour practices among Kenyan HF patients as a basis for improving heart failure self care practices and thus HF outcomes.

## **2.0 LITERATURE REVIEW**

### **2.1 PATHOPHYSIOLOGY OF HEART FAILURE**

The syndrome of HF is progressive and represents the end stage of a number of different cardiac diseases such as hypertensive heart disease, cardiomyopathies and valvular heart diseases. These structural or functional disorders impair left ventricular filling as well as ejection of blood leading to decreased cardiac output. Initially there is a variable asymptomatic phase during which compensatory neuro-hormonal mechanisms are able to modulate LV function within a physiological range so that functional capacity of patients is preserved or minimally depressed (10). Eventually, these compensatory mechanisms become maladaptive as their sustained activation subsequently lead to cardiac decompensation thus marking the symptomatic phase of HF. Transition to this symptomatic phase leads to a series of changes in size, shape and infrastructure of the heart leading to a progressive decline in LV performance, a process referred to as ventricular remodeling. This process is central to the progressive nature of HF pathophysiology and is associated with an increase in morbidity and mortality (11).

As cardiac output gradually declines, there is further activation of compensatory mechanisms in an attempt to restore normal cardiac output. Stimulation of the adrenergic and RAAS systems leads to intrarenal vasoconstriction thereby decreasing renal blood flow. In an attempt to restore

adequate renal perfusion and increase intravascular volume, the kidneys avidly retain salt and water thus leading to edema, one of the cardinal features of HF(12).

Ultimately, these pathological processes lead to progressive pump dysfunction which is associated with hypotension, low cardiac output and eventually multiorgan failure leading to death.

## **2.2 MORBIDITY IN HEART FAILURE**

The two main factors that contribute to morbidity in HF include HF related hospitalizations and HF-related quality of life. These factors are important indicators of HF severity and prognosis making their assessment a crucial aspect of HF management.

### **2.2.1 Heart Failure-related Hospitalizations**

Heart failure commonly results in frequent hospital admissions which contribute significantly to the high cost of the disease. In the developed countries, decompensated HF is the leading cause of hospitalizations in adults over the age of 65 years with more than 1 million patients being hospitalized annually with a primary diagnosis of HF and a further 3 million having unscheduled emergency department visits (13). In the US, a survey conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention analyzed HF related hospitalizations in the US over a period of 25 years (1979-2004) during which the number of hospitalizations due to HF was noted to have tripled to approximately 3.8 million in 2004 from 1.2 million in 1979(14).

According to the OPTIMIZE-HF (Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients With Heart Failure) registry, rehospitalization rates at 60 to 90 days after discharge were 30% with half of these being attributed to HF(15).

In sub Saharan Africa, data on the epidemiology of HF is derived from hospital based studies due to lack of published data from population based studies. In Yaounde, Cameroon, Kingue et al found that HF was the sixth leading cause of hospital admissions with the mean age of the patients being 57 years (16). In Kenya, a prospective study conducted at KNH by Kuria et al in the year 2013 reported a 4-6-month rehospitalization rate of 38% among patients hospitalized with acute decompensated HF with the mean time to hospitalization from diagnosis being 69.8

days (4). Of these, 29.5 % of the population was rehospitalized once while 6.2% and 2.3% were rehospitalized twice and thrice respectively. Mutuga et al in a study in KNH in 2014 analyzed the medium term outcome of a cohort of 167 HF patients previously admitted with HF. The two-year all cause readmission rate for this cohort was 30% with 78% having one and 22% having more than one hospital admission (17).

Poor self care practices by patients and health system-related factors such as inadequate access to follow-up care and medication, poor transition of care and lack of social support are factors that contribute to HF related hospitalizations (18). Readmission rates in the early post discharge period may be reduced by as much as 25% through comprehensive discharge planning, education of the patient and caregiver, compliance to medication and follow-up appointments and education on self-care practices (19).

### **2.2.2 Health related quality of life in HF**

Quality of life is defined as the functional effect of an illness and its consequent therapy upon a patient as assessed from the patients' own perspective. Improvement in HRQOL is thereby recognized as an important endpoint in HF treatment strategies (20). Even with optimal therapy, HRQOL is impaired by physical or psychological symptoms, multiple hospital admissions, adverse effects arising from treatment and social limitations (21). The SOLVD trial (Studies of Left Ventricular Dysfunction) found that quality of life independently predicted mortality and HF related hospitalizations in both symptomatic and asymptomatic HF patients. This is supported by other studies which found that lack of improvement in HRQOL after hospital discharge was a powerful predictor of rehospitalization (22, 23).

The HRQOL in HF patients during discharge from the medical wards at KNH as reported by Kuria et al is generally poor with a good scores being reported in only 17.2% of patients while 28.3%, 40.4% and 14.1% were reported to have a fair, poor and worst score respectively (4).

## **2.3 MORTALITY IN HEART FAILURE**

Survival rates remain poor, worse than those for cancers such as prostate, bowel or breast and nearly 300,000 deaths annually are directly attributable to HF making it the number one cause of death in Europe and North America (24).



Despite improvement in survival rates as a result of advanced pharmacological therapies, the absolute mortality rates for HF remain approximately 50% within 5 years of diagnosis (25). The Rotterdam study conducted in Netherlands followed up a cohort of 5225 individuals over a mean follow-up period of 6 years beginning from the year 1990 to 1996. This study reported decreased survival rates in patients diagnosed with HF, with survival rates of 86% at 30days, 63% at one year, 51% at 2 years and 35% at 5yrs (26). Regionally in Tanzania, a prospective study of consecutive new HF admissions by Hanee et al at Muhimbili National Hospital found a 1-month mortality rate of 5.4% (27).

Kuria et al in his study in KNH reported a 4- 6 month mortality rate of 25-38% among 155 HF discharges while Mutuga et al at KNH in the year 2014 assessed a cohort of ambulatory HF patients and found a 2 year all-cause mortality rate of 25% (4, 17).

## **2.4 ECONOMIC BURDEN OF HEART FAILURE**

HF imposes a major burden on health care systems especially in the developed countries. The economic impact of HF is in the form of both direct costs to the health care system and indirectly through loss of the productive work force. HF is characterized by frequent hospital admissions, high mortality rates and high medical resource consumption (28). In some European countries and in the USA, as much as 1% of the health budget is spent on management of HF related morbidity. There is paucity of local data but it is estimated that the health care costs are also high. In South Africa for example, cardiovascular diseases as a whole account for approximately 25% of health care spending which translates to 2-3% of the gross national income. In addition, indirect costs are estimated to double those of direct costs (29). Furthermore, the presentation of HF in younger age groups in Sub Saharan Africa puts an extra economic burden as a consequence of the amount of active life years lost in this productive segment of the population which in turn undermines national productivity.

## **2.5 TREATMENT OF HEART FAILURE**

The management of HF requires a multidisciplinary approach that involves pharmacological and non- pharmacological management. Long term and frequent follow up is often indicated in HF

patients and adherence to medication and lifestyle practices is an essential part of HF management.

### **2.5.1 Pharmacological management**

Most of the drugs are aimed at attenuating the maladaptive compensatory mechanisms activated in HF. Angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers and beta blockers have been shown to have both mortality and morbidity benefits in HF and are recommended as part of standard HF care (30). Despite having no mortality benefit, drugs such as diuretics and digoxin are important in symptomatic treatment and thus are beneficial in improving the HRQOL in HF patients.

### **2.5.2 Non pharmacological Management**

Non pharmacological management is defined as healthy lifestyle measures adopted by a HF patient for successful treatment of HF. These healthy lifestyle practices are generally referred to as self care behaviours (SCB). Non pharmacological management of HF is multi-faceted requiring adequate patient and care giver education in order to improve HF outcomes (31).

## **2.6 SELF CARE BEHAVIOUR IN HEART FAILURE**

Self care is an important aspect of non-pharmacological management of HF as it comprises key behaviours that have been shown to improve clinical outcomes for HF patients. Self care has been described as an individual's ability to manage symptoms, treatment, physical, psychological and psychosocial consequences and lifestyle changes inherent with living with a chronic condition (32). There are three principals involved in self care and these include self-care maintenance, self-care management and self-care confidence. Self-care maintenance is the ability of the patient to adhere to prescribed pharmacological and non pharmacological treatment in order to maintain clinical stability. Self-care management involves recognizing a change in symptoms and responding to this change by implementing a treatment strategy such as taking an extra diuretic, limiting fluid intake or contacting a health care provider. Self care confidence is the belief in one's ability to perform SCBs effectively (33).

Important HF SCB practices as recommended in clinical practice guidelines include medication adherence, recognition of HF symptoms, salt and water restriction, smoking

cessation, moderation of alcohol intake, healthy nutritional choices, weight monitoring and physical exercise(34). Results from several randomized control trials report that SCB practices significantly reduce all-cause readmissions in HF patients by 32-40%, HF-related readmissions by 40-56% and the combined end-point of hospital readmissions and mortality by 35% (8). HF SCB practices are also beneficial in improving quality of life for patients and their families and reducing health care costs (31).

Evidence-based practice guidelines from the American College of Cardiology/American Heart Association (ACC/AHA), and the European Society of Cardiology (ESC) stress the importance of individualized patient education with the aim of enabling HF patients acquire knowledge and skills necessary for self-care capabilities (31, 34). A systematic review of 35 educational intervention studies in patients with HF demonstrated benefits associated with HF education. Education was shown to improve HF knowledge, self-monitoring, adherence to medication, decrease hospitalization rates and reduce length of hospital stay (35).

## **2.7 COMPONENTS OF SELF CARE BEHAVIOUR IN HEART FAILURE**

The American College of Cardiology/American Heart Association (ACC/AHA), the Heart Failure Society of America (HFSA) and the European Society of Cardiology (ESC) have outlined several components of HF education that enable patients engage in adequate SCB. These include symptom recognition, fluid restriction, weight monitoring, smoking cessation, moderation of alcohol intake, sodium restriction, physical activity and yearly flu vaccination (31, 36).

### **2.7.1 Symptom recognition**

The main signs of decompensated HF are dyspnea, orthopnea, easy fatigability and leg swelling. Several studies have shown that HF subjects delay for days before seeking care for HF symptoms and this may be due to lack of symptom monitoring or an inability to recognize and interpret symptoms of HF decompensation when they occur(37). ESC guidelines for HF treatment recommend that patients and/or caregivers know that symptoms of HF decompensation vary considerably. HF patients should learn to recognize these warning symptoms so as to enable them take appropriate and timely action (38).

### **2.7.2 Fluid restriction and weight monitoring**

Maintenance of euvolemia is a key feature of HF management as fluid overload usually leads to worsening of HF symptoms and increased rate of hospitalizations. According to the ESC guidelines, routine fluid restriction in patients with mild to moderate symptoms does not confer clinical benefit but in those with severe HF, fluid restriction to 1.5-2 litres per day may be considered (39). Patients should therefore be advised to monitor their weight as sudden unexpected weight gain of more than 2kg in three days may indicate fluid overload due to worsening heart failure (38). The EuroHeart Failure survey reported that only 50% of patients with a clinical diagnosis of HF recalled receiving advice on regular weight monitoring and of these, only about 70% followed the advice completely (36). Barasa et al in a study of HF patients in KNH in 2009 reported that only 3% of these patients received information on weight monitoring prior to discharge (6). Kuria et al in KNH as well reported that 93.8 % of HF patients did not check their weight regularly and of these, 98% did not do anything in case of sudden weight gain. As regards fluid intake, only 59% of HF patients limited their fluid intake (4).

### **2.7.3 Weight Management**

Assessment of nutritional status is recommended in all HF patients. The Framingham Heart study followed up a cohort of 5881 participants over a 14-year period and showed that the risk of HF increased by 5% in men and 7% in women for every 1kg/m<sup>2</sup> increase in BMI with graded increase in the risk of developing HF noted across all BMI categories (40).

Despite the adverse effects of obesity on both systolic and especially diastolic function, numerous studies have suggested that obese HF patients have a better prognosis than leaner HF patients in a phenomenon known as the *Obesity Paradox* (41). Cardiac cachexia, defined as weight loss of >6% of previous stable weight without evidence of fluid retention during the past 6 months is seen in approximately 10% of patients with advanced HF and is associated with a poor prognosis as it is an indicator of significant neuroendocrine and immune activation (42). A consensus statement from AHA recommends that weight loss should be encouraged in HF individuals with a BMI of more than 40kg/m<sup>2</sup> but if BMI is less than 30kg/m<sup>2</sup>, weight loss should not be encouraged. Although evidence for this AHA recommendation on BMI is

inconclusive, the rationale stems from the fact that weight loss is a powerful independent variable that predicts mortality in patients with CHF (31).

#### **2.7.4 Smoking cessation**

Patients with HF should be advised to stop smoking as it is the most preventable risk factor for cardiovascular disease. Smokers are at an increased risk of pulmonary disease and lung cancer which can worsen HF symptoms such as dyspnea and fatigue as it is postulated that nicotine has vasoconstrictor and proinflammatory activity(43). Studies have shown that smoking cessation reduces morbidity and mortality in HF with one study showing a 30% reduction in mortality in those who stopped smoking compared to current smokers. This mortality benefit was comparable to that of treatment with ACE-Inhibitors, beta blockers and aldosterone inhibitors (44).

Despite the clinical benefits of smoking cessation in HF patients, most physicians do not advise HF patients to stop smoking. Results from the EuroHeart Failure study showed that less than 50% of patients recalled receiving any advice to stop smoking and of these, only three quarters actually adhered to that advice. This was comparable to population based studies in the US which reported that only 46% of HF patients attended to by physicians actually received advice on smoking cessation. Kuria et al in KNH established that only 14% of smokers received advice to quit smoking (4).

#### **2.7.5 Moderation of Alcohol Intake**

Patients should limit their alcohol intake to no more than two standard drinks of ethanol in men and one standard drink of ethanol in women per day and alcohol should be completely avoided in HF due to alcoholic-induced cardiomyopathy. Higher alcohol intake than what is recommended is associated with increased risk of arrhythmias, hypertension and additional fluid burden and has been noted to have a negative inotropic effect on the heart. Reports from the EuroHeart failure survey indicate that only 30% of HF patients received any information on alcohol consumption though almost all patients who received this advice adhered to it. Data from a KNH study reported that only 10% of HF patients who admitted to taking alcohol actually received advice to stop alcohol intake.

### **2.7.6 Sodium Restriction**

Sodium restriction in patients with HF is commonly recommended for the purposes of preventing fluid retention, symptoms exacerbation and decompensation of HF with only less than half of the patients complying with this recommendation (45, 46). Several trials have however reported inconsistent findings regarding recommended sodium intake in HF. Data from observational studies have linked high sodium intake with fluid retention and increased risk for HF hospitalization (47, 48). Other studies report worsening neurohormonal profile in HF patients who restrict their sodium intake (49, 50). Sodium intake in the general population in the US is typically high and can average more than 4 grams per day. In one randomized clinical trial of HF patients with NYH class II HF, low sodium intake (80mmol) was compared with normal sodium intake (120 mmol) , a higher rate of readmission over a 6-month period was documented in the sodium restricted group (49). It is postulated that a low sodium diet in patients with HF could enhance activity of the RAAS and SNS system. However, these studies have been carried out predominantly in whites yet black patients have a different cardiovascular and renal physiology. Secondly, the studies were carried out in the subset of patients with HF with reduced ejection fraction and again, most patients were not optimally treated for HF.

ACC/AHA guidelines recommend a sodium intake of no more than 1.5g/d in patients with stage B HF while for patients with stage C or D HF, the recommended sodium intake is no more than 3g/d (51).

### **2.7.7 Physical Activity**

CHF is characterized by exercise intolerance with HF patients often experiencing fatigue and shortness of breath. Anaerobic metabolism leading to rapid lactate accumulation is a common physiological change in CHF and thus contributes to symptoms such as fatigue (52). These symptoms often affect the ability of HF patients to perform activities of daily living and therefore contribute significantly to reduced participation and quality of life of these patients. Regular moderate daily activity has been demonstrated to be beneficial in patients with chronic HF unless they have limiting symptoms or have advanced HF (NYHA IV) (53, 54). Physical activity increases exercise capacity, reduces HF symptoms during exercise and is associated with improved quality of life. Exercise also improves indices associated with adverse HF outcomes

such as heart rate and heart rate variability and neuro-hormonal activation and therefore improves survival (54). In addition, exercise improves aerobic metabolism, peripheral perfusion, ventilatory control, decreases systemic inflammation and leads to significant improvement in cardio respiratory fitness.

The HF ACTION was a multicenter randomized control trial of 2331 medically stable patients with HF with reduced ejection fraction. This trial was carried out from April 2003 to February 2007 at 82 centers within USA, Canada and France. HF patients were randomized into groups of supervised training and usual care with a recommendation to maintain physical activity in the latter group. Exercise was associated with a significant reduction of approximately 28% in all-cause hospitalization and improvement in HRQOL scores in at least 37% of patients after adjustments had been made for highly prognostic predictors of end point (55). A recent Cochrane review in 2010 reported an overall 28% reduction in HF specific hospital admissions and a significant improvement in QOL scores among HF patients who adhered to exercise recommendations (56).

In spite of the obvious benefits of exercise, few persons with HF engage in exercise. One study found that 53.2% of patients did not engage in any physical activity and in another study, 35% admitted to being active two times or less per month (57) (9). In KNH, 75.3% of HF patients admitted to never engaging in any form of exercise at all (4).

### **2.7.8 Vaccination**

Several guidelines recommend yearly vaccination for influenza and vaccination against pneumococcal disease in patients with symptomatic HF. HF is commonly associated with pulmonary congestion and this predisposes most patients to pulmonary infections such as those caused by the influenza virus as this virus has a high prevalence within communities. Patients with cardiovascular disease and particularly those over the age of 65 years are prone to complications arising from either influenza or a pneumococcal infection. Several non-randomized studies have shown reduced rates of hospitalizations in this age group following vaccination for influenza and pneumococcal organisms (58).

## **2.8 FACTORS THAT INFLUENCE SELF CARE BEHAVIOUR**

Despite the obvious benefits of self-care, many patients with HF do not adhere to the recommended lifestyle practices. There are several factors that have been found to influence adherence to self-care regimens in HF patients and these factors are broadly classified into patient-related factors and health system related factors. Examples of patient-related factors that influence HF SCB include: patients' heart failure knowledge, adherence to therapy, gender, presence/absence of social support, depression and cognitive dysfunction. Health care system related factors that influence SCB mainly involve deficiencies of care by health care providers.

### **2.8.1 Heart Failure Knowledge**

Knowledge is a major determinant of SCB in HF including compliance to pharmacological treatment. HF guidelines recommend that HF patients need knowledge on HF in general, modes of pharmacological and non pharmacological therapy, symptom recognition and action to be taken in the event of acute HF decompensation.

Generally, initial education about HF first occurs during hospitalization at a time when a patient may be too ill and this may therefore interfere with retention of information (59). HF patients are usually followed up at outpatient clinics where further pharmacological and non-pharmacological management continues to take place. Health care providers are expected to continually reinforce HF knowledge during clinic appointments, ensure adherence to medication and to SCB. This is because lack of HF knowledge on the part of the patient is associated with poor quality of life, poor adherence to both pharmacological treatment and non pharmacological treatment, social isolation and increased risk of co morbid conditions (60).

A study by Hanyu Ni et al of 113 new HF patients attending a cardiology clinic in the USA assessed their HF knowledge and found that 37% reported knowing 'a little or nothing' about HF, 49% had 'some' knowledge and only 14% reported knowing 'a lot' concerning their illness. Poor knowledge was noted in those with poor adherence to SCB and those who were unmarried while a higher knowledge score was associated with being married (9). Regionally in Africa, Owusu et al found that 73% of patients admitted to a University teaching hospital in Ghana never received any form of non pharmacological therapy (61). Locally, Kuria et al in KNH found that no proper focused information was given to HF patients prior to discharge from the hospital.



Approximately, 25% of HF patients were reported to be smokers and alcohol consumers yet only 14% and 10% of them respectively ever received information on the need to stop smoking and alcohol use. As regards exercise and weight monitoring, only 7% and 3% of HF patients respectively received information on role of exercise or importance of weight monitoring prior to discharge despite these being important aspects of non pharmacological management of HF (6).

Health literacy is a term closely related to health care knowledge and has been described as the ability to read and understand prescription medication instructions, appointment cards and health care materials. It affects the ability of patients to process and understand basic health information and services in order to make effective health decisions. However, many HF patients especially the older adults, have low health literacy (62). This leads to poor health outcomes and is a predictor of increased emergency department visits for HF-related problems.

### **2.8.2 Other Factors That Influence Self Care Behaviour**

Adherence to both pharmacological and non pharmacological therapy is another factor that influences HF self care. Adherence has been defined as the ‘active, voluntary and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result’ (63). Poor adherence to treatment among patients with chronic diseases is recognized as a global health issue as it leads to negative health outcomes and increased health resources utilization (64). It is estimated that half of the HF readmissions are preventable with poor adherence to recommended SCB practices being identified as a contributing factor in many cases (65).

As has been demonstrated in studies, HF patients show selective adherence to different aspects of SCB. Most patients have less difficulty adhering to medications while majority have difficulty adhering to exercise. A study by the Atlanta Cardiomyopathy Consortium found that the highest adherence by HF patients was with regards to taking medication followed by symptom monitoring, and the lowest adherence was in relation to exercise. Regionally, a study in South Africa found the rate of adherence to clinic appointments to be as high as 95% while only 2.5% of HF patients adhered to daily weight monitoring (66).

Gender is another factor that has been shown to influence HF self care. Women with HF tend to have poorer SCB when compared to men. This is because, women have a greater need for social

support and are also more likely to have psychosocial distress, two factors that are associated with poor self-care (67).

Studies have shown that social support in HF patients is associated with fewer hospital readmissions and lower mortality rates as it positively influences some aspects of HF self care such as adherence to medication and SCB (68). Wu et al found that the level of perceived social support was particularly significantly related to SCBs such as fluid restriction, health-seeking behavior following weight gain, adherence to medication, regular exercise as well as flu vaccination. The importance of social support in HF is further emphasized by the fact that poor SCB and depression have been associated with social isolation and living alone (69).

Co morbidities are very common in HF and are associated with a negative impact on self care. In a large multicenter study in the US, 73% of patients admitted in acute decompensated HF had coexisting hypertension, 55% had coronary artery disease, 44% had diabetes mellitus while 30% had underlying renal disease (70). Co morbidities affect self care abilities in areas such as medication and dietary adherence, symptom monitoring and ability to make sound decisions in the face of multiple health conditions (71).

Depression is the most common mood disturbance in HF and depressive symptoms are independently associated with hospitalization and mortality in HF patients (72). CHF patients have been noted to have higher rates of depression when compared to the general population with prevalence rates ranging between 13-77% (73). The presence of depression is linked to worse health status and symptom burden, poor physical and social functioning and poor QOL (74). Social isolation arising from depression leads to poor social support which is important in self care skill development. Depression also contributes to poor SCB as it leads to poor cognition particularly among the elderly, impaired ability to learn, perceive, judge severity and make decisions about symptoms. HF self care interventions should therefore also focus on the screening and treatment of depression (75).

Cognitive dysfunction affects 25% to 50% of HF patients (76) and these patients not only have less knowledge about HF compared to those with intact cognitive function but also have poor SCB (77). The most likely cause for impaired cognition not associated with dementia in HF is inadequate cerebral perfusion and cerebral hypoxia as a result of low cardiac output (78). Co

morbidities, drug interactions, medication adverse effects and sleep disturbances may also contribute to impaired cognition in HF patients. In a study by Lichtman et al, patients with poor SCB were noted to be those with more daytime sleepiness while patients with good SCB had less daytime sleepiness (77). Factors contributing to poor sleep in HF include sleep disordered breathing which is very common in HF, sleep fragmentation due to nocturia arising from use of diuretics and poor sleep associated with co morbid conditions such as depression, diabetes mellitus, COPD, stroke, thyroid disease, nasal problems and arthritis (79). Screening for cognitive dysfunction and sleep disturbances is therefore very important as it helps identify HF patients at risk of poor SCB and hence enable designing of appropriate health care interventions.

The health care system has a role to play in influencing SCB but virtually every component of the health care system fails in promoting self care for HF patients. Amongst physicians, there are significant deficits in adhering to guidelines and performance measures for acute and CHF (80). Inadequate instructions regarding HF self care can be as a result of inadequate knowledge regarding SCB by the healthcare provider, time and resource constraints and poor hospital discharge instructions. Currently, no guidelines or quality measures exist for HF patients with multiple co morbidities making incorporation of SCB into HF treatment of patients with preexisting co morbidities a big challenge for health care providers.

## **2.9 ASSESSMENT OF HEART FAILURE KNOWLEDGE**

Assessment of HF knowledge is also very essential to the health care provider because a clinicians' understanding of patients' HF knowledge enables analysis of quality of follow up care and also facilitates further improvement of the patients' HF knowledge (81). Furthermore, identifying patients' knowledge about their disease is usually the initial step before setting up educational interventions.

Several HF knowledge tools have been developed. One such example is 'The Questionnaire about HF patients' knowledge of their disease' which was developed by Bonin et al (82). The tool was developed based on the Coronary Artery Disease Education Questionnaire and consists of 19 multiple choice questions covering HF concepts, pathophysiology, pharmacology and non-pharmacological treatment. However it is designed for use by patients participating in cardiac rehabilitation programs which are not available in KNH.

The Atlanta Heart Failure Knowledge Test (AHKFT) was developed by Reilly et al and is a 30-item multiple choice questionnaire that was designed to measure change in knowledge scores after exposure to a specific education and self-management intervention for HF patients and their family members (81). It measures various domains of patient education on HF such as the disease process, diet, fluid and sodium restriction, medication adherence and symptom monitoring.

The main disadvantage with the AHKFT is that it is long (27 multiple choice questions) and therefore time consuming. The questionnaire also has certain questions that may not be relevant to our setup here in Kenya. Questions requiring patients to identify either high or low sodium foods from several provided options are particularly irrelevant as most of the foods mentioned such as cheeseburger, taco salad or hot fudge sundaes are only known to a very small minority of the Kenyan population. There are also questions regarding interpretation of food labels and again, this may pose a big challenge to our predominantly low-income population.

The Dutch Heart Failure Knowledge Scale (DHFKS) has been widely used in clinical settings in Europe, USA and Africa to evaluate patients' HF knowledge (83). During questionnaire development, face, content and construct validity was tested in HF patients in 19 hospitals in the Netherlands and the instrument was found to be a valid and reliable scale that can be used in research. The DHFKS has been used widely in the US and Europe well as in Ethiopia and Vietnam. It is a self-administered questionnaire consisting of 15 multiple-choice questions concerning HF in general (4 items on function of the heart, meaning of HF, etiology of HF and causes of HF decompensation), HF treatment (6 items on diet, fluid restriction, alcohol intake and physical activity) and symptom recognition (5 items on cough, leg swelling, shortness of breath, weight gain and weight monitoring). For each of the 15 items in the scale, patients choose from three options, with one of the options being the correct answer. The minimum score is 0 (no knowledge) and the maximum score is 15 (optimal knowledge). A cut-off point of 10 or more has been used in some studies to indicate adequate knowledge.

The main advantage of the DHFKS is that it is shorter compared to the AHKFT and has questions that can easily be understood by Kenyan HF patients.

## **2.10 ASSESSMENT TOOLS FOR SELF CARE BEHAVIOUR IN HF**

One of the biggest challenges faced by health care providers is identifying and supporting patients who are at the highest risk for poor SCB (84). It is therefore important to understand which patients engage in good or poor self-care and why this is the case.

Various instruments have been used to conduct assessment of HF-related self-care behaviours. These instruments fall largely into two groups- generic instruments and disease- specific instruments. Generic instruments are not designed for any particular health condition and as such can be used for a variety of illnesses. Examples include instruments such as the Self care Behavior questionnaire and the Self care in Chronic Illness questionnaire. Disease-specific instruments are specifically designed for particular illnesses or disease conditions. The most widely used disease-specific tools for measuring SCB in HF are the European Heart Failure Self Care Behaviour Scale (EHFSCBs)(85) and the Self-Care of Heart Failure Index (SCHFI)(86).

### **2.10.1 The European Heart Failure Self-Care Behaviour Scale (EHFSCBs)**

The European Heart Failure Self care behavior scale was first developed in 2002 by Jaarsma et al and is available in 14 languages (85). It has been validated in different countries in Europe, Asia and the USA and locally, this tool has been used in Ethiopia, Vietnam and Iran. The EHFSCBs is a self-administered questionnaire that covers items concerning HF SCB such as daily weighing, fluid restriction, rest, exercise, vaccination and contacting a health care provider. It comprises 12 items rated on a 5-point Likert scale between 1 (I completely agree) and 5 (I completely disagree). The total score ranges from 12-60 with higher scores indicating worse self care. The EHFSCBs is used in medical practice to evaluate deficiencies in self-care in an individual patient and to also identify specific education and counseling needs. The EHFSCBs is also useful in monitoring progress as regards adherence to SCB of individual HF patients during subsequent visits to the health care provider.

### **2.10.2 The Self Care of Heart Failure Index (SCHFI)**

The Self-Care of Heart Failure Index (SCHFI) is another tool that is used to measure SCB. It was developed by Barbara Riegel and first published for use in 2004 (86) . The SCHFI is a 22-item questionnaire that assesses three major areas of self care- self care maintenance, self care

management and self care confidence therefore providing precise information about areas of deficiency in self care. The advantage of the EHFSCBs over the SCHFI is that it is a brief and practical measure that focuses on assessment of SCB. It also has the advantage of being easy to use when compared to the SCHFI which is lengthy making the EHFSCBs preferable for use in the local Kenyan population. One other disadvantage of the SCHFI however, is that only two symptoms- trouble breathing and ankle swelling- are used to assess self care management.

## 2.11 STUDIES ASSESSING HEART FAILURE SELF CARE KNOWLEDGE AND SELF CARE BEHAVIOUR PRACTICES

### Summary of studies on HF self care Knowledge and SCB practices

Study (n)	Location	Variable Assessed	Tool	Results (%)
Beker et al 2014 (n=264)	Ethiopia	HF Knowledge  HF SCB practices	In-depth Interviews  EHFSCBs	75.3 Poor knowledge  59.2 Poor SCB
Negese et al 2015 (n=328)	Ethiopia	HF Knowledge  HF SCB practices	DHFKS  Structured questionnaires	89.3% Poor Knowledge  17.4% Poor SCB
Sliwa et al 2007 (n=200)	South Africa	HF knowledge  HF SCB practices medication and adherence survey	Medication adherence & Knowledge on HF survey	Knowledge score 69%  Adequate SCB 2.5-98%
Manwere et al 2009 (n=65)	Zimbabwe	SCB and its relationship with admissions in CHF	Chronic HFSC practices interview & In-depth interviews	53.8 Poor SCB
Nguyen et al 2011 (n=126)	Vietnam	SCB & related factors	DHFKS  EHFSCBs	76.2 Low HF knowledge  50.9% Poor SCB
Min-Hui Liu et al 2008 (n=141)	Taiwan	HF knowledge  HF SCB QOL after HF education for 1 yr	DHFKS  EHFSCBs MLWHF	HF knowledge 24.8→35 HF SCB 37.4→29.2
Ahmad Ali-et al 2014 (n=184)	Iran	SCB in elderly patients with HF	EHFSCBs	38% good SCB 56.5% moderate, 5.5% poor SCB
Van der Wal 2005 (n=501)	Netherlands	HF Knowledge  Compliance to SCB	DHFKS  Revised HF compliance questionnaire	Mean HF knowledge 11.0±2.4  72% good compliance to SCB
Lupon et al 2007 (n=151)	Spain	SCB improvement after educational program	EHFSCBs	EHFSCBs scores (24.2→20); significant

With optimization of self care as a focus of health care, a number of studies have been done worldwide assessing HF self care knowledge and HF SCB practices. Substantial differences in health care systems has made it necessary to have a description of SCB practices in different countries as this enables each country target and individualize specific needs of HF patients in each country.

Beker et al in Ethiopia sampled 264 HF patients on follow up at a specialized cardiac unit and assessed for knowledge on HF using in depth interviews and for adequacy of SCB practices using the EHFSCBs. The cut-off for adequate knowledge was based on the mean knowledge score while the cut-off for adequate SCB was based on the median score. 24.7% of patients were reported to have low levels of HF knowledge while 59.2% of patients had poor SCB practices. Low knowledge level, depression, cognitive dysfunction, shorter duration of HF and presence of co morbidities were found to be significant predictors of poor SCB (87). A similar study by Negese et al in Ethiopia on 328 ambulatory HF patients assessed HF knowledge using the DHFKS while SCB practices were assessed using structured questionnaires based on the various components of HF SCB. A score of  $\geq 10.5$  was used as a cut-off for adequate knowledge with 89.3% of the study participants being reported to have poor HF knowledge. In regards to SCB, patients were categorized as having good adherence if they had a score of  $\geq 75\%$ . Most (82.6%) of patients were reported to have poor adherence to HF SCB practices (88).

A study in South Africa by Ruf et al assessed the level of HF knowledge and adherence to individual SCB practices of 200 HF patients and found an average knowledge score of 69% to ten HF questions with scores ranging from 29% to 89% for each of ten different questions. Adherence to different SCB practices ranged from 2.5-98% with patients demonstrating a high level of adherence to moderation of alcohol intake (98%) and adherence to clinic appointments (96.5). Daily weight monitoring was the least practiced SCB with only 2.5% of patients adhering to this recommendation (66).

In Zimbabwe, Manwere et al utilized a structured questionnaire to assess the frequency of various SCB among 65 ambulatory HF patients. Using the mean score as a cut-off for dichotomizing SCB as good or poor, he established that 53.8% of the study participants had poor SCB practices. All study participants were reported to be abstaining from alcohol and smoking,



however, most patients did not demonstrate good adherence to pharmacological treatment and daily weight monitoring (89).

A study of 126 HF patients in Vietnam by Nguyen et al reported that 76.2% of study subjects had low levels of HF knowledge while 50.9% of patients analyzed had poor SCB practices. These study participants were analyzed using the DHFKS and the EHFSCBs respectively and the mean scores for each of the two scales was used to define the score cut offs for both adequate HF knowledge and HF SCB. HF knowledge and presence of social support significantly correlated with good SCB practices in this cohort of patients (90).

In Taiwan, the effects of a HF education program on SCB practices, HF knowledge and HRQOL scores after a period of one year was tested in 141 HF patients by Min-Hui et al using the EHFSCBs, the DHFKS and the MLWHF questionnaires respectively. Analysis of these three parameters was based on the change in the SCB, HF knowledge and HRQOL scores after one year following intervention by way of HF education. There were no pre-determined score cut-offs, however, HF education was found to significantly improve HF knowledge scores, SCB scores and HRQoL scores in these patients (91).

In Iran, 180 elderly patients (age >60) sampled from four teaching hospitals by Ahmad Ali et al had their HF SCB practices determined using the EHFSCBs. SCB scores for each study participant was categorized as good (scores of 12-28), moderate (scores of 29-44) or poor (scores of 45-60). Majority of the patients (56.5%) had moderate SCB, 38% had good SCB while 5.5 % had poor SCB. Exercise, taking a flu shot and weight monitoring were the least performed SCB practices while the most performed SCB practices were related to taking the prescribed HF medication, of adherence to a low salt diet and contacting a doctor in case of increased shortness of breath (92).

In the COACH study in Netherlands, HF knowledge and SCB was analyzed in a cohort of 501 HF patients using the DHFKS and the Revised HF compliance questionnaire respectively. The mean HF knowledge was  $11.0 \pm 2.4$  with 73% of the study participants scoring 10 and above. Study participants were considered compliant if they adhered to HF SCB 'always' or 'most of the time' with 72% reported to be compliant to HF SCB practices. (93).

In Spain, in a prospective study by Lupon et al, 151 HF patients had their SCB scores assessed at baseline and after a 1 year educational intervention program using the EHFSCBs. SCB scores were analyzed at baseline and again at one year. The study reported a significant improvement in SCB scores in almost all aspects of HF SCB (94).

### **3.0 STUDY JUSTIFICATION**

The prevalence of HF is increasing even in developed countries where it remains a significant public health problem. Despite advances in pharmacological therapy, HF morbidity and mortality remain high and more emphasis should be placed on non pharmacological management of HF whose main aspect is self care management. The level of HF knowledge which is commonly low among patients with HF has been shown to significantly influence self care abilities. There are no local studies on HF knowledge and the influence it has on self-care abilities among our HF population. Since heart failure educational programs have been found to improve HF outcomes, it is important to have a good understanding of self care behavior among HF patients as well as understand which patients do not engage in self care and why this is the case. Equally important is to characterize which patients engage in good self care behaviour and why they do so. Moreover, development of self care skills requires identifying SCBs that are most problematic for HF patients and emphasizing on them. Information obtained from the results of this study will be useful for the purpose of developing effective educational programs and pointing out action areas for improvement which will ultimately help improve health care delivery and outcomes for HF patients.

### **4.0 RESEARCH QUESTION**

What is the level of heart failure knowledge and the self care behaviour practices among subjects with chronic heart failure in Kenya and what opportunities are there for improvement?

### **5.0 OBJECTIVES**

#### **5.1 BROAD OBJECTIVE**

The objective of the study was to assess heart failure self care knowledge and heart failure self-care behaviour practices among ambulatory heart failure patients at Kenyatta National Hospital.

## **5.2 SPECIFIC OBJECTIVES**

### **Primary Objectives**

1. To determine the proportion of ambulatory heart failure patients with adequate heart failure self care knowledge using the modified Dutch Heart Failure Knowledge scale.
2. To determine the proportion of ambulatory heart failure patients with adequate heart failure self care behaviour practices using the modified European Heart Failure Self Care Behaviour scale.

### **Secondary Objectives**

1. To correlate heart failure knowledge scale scores to demographic variables, level of formal education and duration of heart failure follow-up.
2. To correlate heart failure self care behaviour practices scale scores to demographic variables, level of formal education and duration of heart failure follow up.
3. To correlate heart failure self care knowledge scales scores to heart failure self care behaviour practices scale scores.

## **6.0 METHODOLOGY**

### **6.1 STUDY SITE**

The study was carried out at Kenyatta National Hospital which is the largest teaching and referral hospital in East and Central Africa. In Kenya, it is one of two referral hospitals with the other hospital being Moi Teaching and referral hospital in Eldoret. It is located in Nairobi with the catchment population being mainly from Nairobi, Central and Eastern regions of the country. KNH has several clinics which run on weekdays including specialized clinics such as the cardiology clinic. The study site was the cardiology clinic which runs on Tuesdays between 8am to 1pm. On average, 80-90 patients attended this clinic with approximately half being on follow-up for heart failure.

### **6.2 STUDY DESIGN**

This study was a descriptive cross sectional study

### **6.3 STUDY POPULATION**

The study target population was patients with a chart diagnosis of heart failure and on follow up at the cardiology clinic.

### **6.4 CASE DEFINITION**

Cases were defined as all adult patients with a chart diagnosis fulfilling the Framingham criteria retrospectively applied and on follow up at the specialized cardiac clinic for at least three months.

### **6.5 SAMPLING TECHNIQUE**

Consecutive sampling method of the first 20 cases of heart failure was done per clinic session during the study period to obtain the desired sample size.

## 6.6 SAMPLE SIZE

The sample size was estimated using the formula for cross-sectional studies (Daniel, 1999). This was appropriate since the study was designed to estimate the proportion of the HF population with adequate heart failure knowledge. The size of the sample was calculated as follows:

$$n = \frac{Z^2 \times P(1-P)}{d^2}$$

**n** – Was the sample size required to estimate the proportion of patients with adequate HF knowledge.

**Z** – Was the 95% confidence interval (standard value of 1.96)

**P** – Was the estimated proportion of patients with adequate heart failure self care knowledge = 25% (Beker et al in Ethiopia, 2014)(87)

**d** – Was the margin of error (precision error) =  $\pm 5\%$

Substituting into the formula, **n** was 288.

A minimum of 288 heart failure patients needed to be sampled to estimate HF self care knowledge within a 5% margin of error.

## 6.7 SCREENING AND RECRUITMENT

Every clinic day, the PI and three trained study assistants (registered clinical officers) reviewed medical records of all patients on follow up at the cardiac clinic to identify patients who met a file diagnosis of HF. The PI confirmed the diagnosis of HF from the patient's medical records by applying the Framingham criteria retrospectively and echocardiographic data where available. Documented evidence of either two major criteria or one major and two minor criteria not attributable to another medical condition were required to confirm the diagnosis of HF.

Patients who met the inclusion criteria were approached and informed of the study and those who gave informed consent were recruited into the study.

### **6.7.1 Inclusion criteria**

1. Patients who had a diagnosis of heart failure gave informed consent.
2. Patients aged 18 years of age and above.

### **6.7.2 Exclusion criteria**

1. Patients who were unable to communicate.
2. Patients who were not literate in English and Kiswahili.

## **7.0 DATA COLLECTION**

Patients had a brief targeted history taken by either the PI or a trained research assistant who was supervised by the PI. Information on demographic variables such as age, gender, marital status, residence, level of education and current NYHA classification was obtained from history taking. This information was entered into a structured data collection tool (appendix 3). Patients' files were also scrutinized for information on the duration of HF diagnosis, length of follow-up period, cause of heart failure, and pre-existing co morbidities. This information was documented in the study proforma. A separate log linking the patients' names and their respective unique study number was kept by the PI in a password protected database and was used solely for the purpose of giving feed back to the respective patients.

Two validated self-administered questionnaires were utilized in this study. The modified Dutch Heart Failure Knowledge scale (see appendix IV) was used to assess HF knowledge while HF related self care behaviour practices were assessed using the modified European Heart Failure Self Care Behaviour scale.(see appendix V). For patients who did not understand English, a Swahili version of each questionnaire was used.

### **7.1 TOOL 1: Modified Dutch Heart Failure Knowledge Scale (DHFKS)**

The Dutch Heart Failure Knowledge Scale (DHFKS) is a self-administered questionnaire consisting of 15 multiple-choice questions concerning HF in general (4 items), HF treatment (6 items on diet, fluid restriction and activity) and symptom recognition (5 items). For each item, patients chose from one of three options, with one of the options being the correct answer. The minimum score is 0 (no knowledge) and the maximum score is 15 (optimal knowledge). The DHFKS underwent face, content and construct validity in our set up by two local experts in the field of cardiology. During validation, two questions were slightly modified in order to be more applicable to our setup. One question in the original questionnaire asking about the most common cause of HF had the correct option as myocardial infarction and high blood pressure which is not the case in the developing world. The correct response was altered to give rheumatic heart disease and cardiomyopathies (heart muscle disease) as the appropriate response. A second question asking HF patients on the correct thing to do in case of thirst had sucking ice cubes as the correct answer. The experts felt that this question should be replaced by a question regarding

the need to avoid alcohol in HF patients. This is because alcohol is an important factor as regards HF in our setup and the questionnaire had no other question addressing alcohol use. Secondly, there was already a question assessing fluid intake in patients with HF. While the DHFKS is designed to assess improvement in HF knowledge scores after intervention by way of HF education, other studies have adopted their own method of analysis. Nguyen et al in Vietnam utilized means as a cut off to define adequate HF knowledge(90). However, Negese et al in Ethiopia and Aurelia et al in the USA utilized a cut-off score of 10 and above to determine adequate HF knowledge. (88) (95). For this study, we adopted a cut-off point of 10 to define adequate HF knowledge similar to the Ethiopian study as Ethiopia is much closer regionally and comparisons can be made.

## **7.2 TOOL 2: Modified European Heart Failure Self-care Behavior Scale (EHFScBS)**

Self care behaviour was assessed using the modified European Heart Failure Self-care Behavior Scale (EHFScBS). This is a 12-item questionnaire that assesses three theoretical aspects of SCB in HF patients: complying with the regimen (daily weighing, fluid restriction, medication adherence, low sodium diet, flu vaccinations), adapting activities (rest, physical activity) and contacting health care providers in case of symptoms of HF decompensation (shortness of breath, increased fatigue, lower limb swelling, considerable weight gain over a period of time). For each of the 12 items, patients rated their self care behavior on a 5-point Likert scale ranging from 5 (“I completely agree”) to 1 (“I do not agree at all”). The higher the score, the poorer the self-care behavior. The level of adherence to self care for each of the individual statements was determined with scores of 1-2 corresponding to high level of adherence to SCB practices and scores of 3-5 corresponding to low levels of adherence to SCB practices. The primary analysis was based on the overall SCB scores. The total SCB score for each patient was also calculated and categorized as good SCB (scores 12-28), average SCB (scores 29-44) or poor SCB (scores 45-60). Alternatively, overall SCB was dichotomized into good and poor SCB using the median as a cut-off.

The EHFSCBs has been translated and validated in many countries and has also been used in Ethiopia, Iran and Vietnam. Locally, in KNH, the questionnaire underwent a face, construct and content validity resulting in one minor modification regarding the question on taking a flu shot



every year. This was changed to ‘I get vaccinated against influenza every year’ as it was agreed that most patients would not understand what a ‘flu shot’ meant.

## **SENSITIVITY ANALYSIS**

It was hypothesized that administration of the DHFKS questionnaire administered first followed by the EHFSCBs as per the study protocol, would significantly influence patient responses as regards their self care behaviour. We therefore assessed SCB prior to assessing HF knowledge in a stratum (30%) of the study population and compared the results.

## **8.0 QUALITY ASSURANCE**

The DHFKS has been validated and used in the USA and in Europe while the EHFSCBs has been validated in many countries in Europe, North and South America and Asia. Both questionnaires have not been validated in Sub Saharan Africa though both have been used in Ethiopia and also in Vietnam and Iran. The DHFKS and the EHFSCBs underwent face, content and construct validity by local experts. This validation process resulted in a few modifications in the original questionnaires and these changes were also communicated to the original authors of both questionnaires. The questionnaires were also tested for suitability and practicability through a pilot study of twenty patients at the cardiology clinic. For patients who did not understand English, the Kiswahili version of both questionnaires was used. The questionnaires were translated into Kiswahili by two individuals fluent in Kiswahili and then back translated into English by a non medical individual prior to their use with the aim of ensuring validity of the Kiswahili version.

## **9.0 DATA VARIABLES**

Independent variables included age, gender, level of education and duration of HF follow up. Dependent variables included HF knowledge and HF self care behaviour practices scale scores.

## **10.0 DATA MANAGEMENT**

Questionnaires used for data collection were given a unique individual identification number in order to maintain patient confidentiality and kept in a lockable safe only accessible by the

principal investigator. Data was cleaned and verified for completeness before analysis. Data entry was done electronically using Statistical Sciences for Social Packages (SPSS) version 21.0.

Upon completion of the study, all data in both hard and soft copy format was stored in a repository room in the department of clinical medicine and therapeutics under lock and key.

## **11.0 DATA ANALYSIS**

Descriptive analysis of the study population was done using socio-demographic variables. Continuous data such as age and duration of follow up was summarized as means (standard deviation) and medians (interquartile ranges). Categorical variables such as gender, marital status, and number of prior hospitalizations were presented as proportions or percentages.

A score of  $\leq 10$  was used as a cut off point for adequate HF knowledge as assessed by the DHFKS. Results were represented as percentage of patients with adequate or poor knowledge. The mean value for the HF knowledge scores of the study participants was also computed.

SCB for each of the twelve items in the EHFSCBs was analyzed with a score of 1 or 2 corresponding to a high level of adherence to SCB while a score of 3 and above corresponded to a low level of adherence to SCB. The percentage of patients with either a high or low level of adherence to SCB for each of the twelve individual items of the EHFSCBs was then computed. Each of the 12 items of the EHFSCBs was then categorized into three domains which represent the three theoretical aspects of self care. The median score for each domain was calculated and used to dichotomize SCB as high or low for that particular domain. Overall SCB was analyzed in two different methods. The total (aggregate) SCB score for each patient was calculated and categorized into proportion (percentage) of patients with good SCB (scores 12-28), average SCB (scores 29-44) and poor SCB (scores 45-60). Overall SCB was also dichotomized into either good SCB or poor SCB based on the median score.

Adequate knowledge and SCB were correlated with age, gender, level of formal education and duration of HF follow up using chi square/ Fisher's exact test for categorical variables and Student's t/Mann Whitney U test for comparison of means/medians. Factors independently associated with adequate knowledge and adequate SCB were determined using a logistic regression model. All statistical tests were considered significant at a p value of  $\leq 0.05$ .

## **12.0 ETHICAL CONSIDERATIONS**

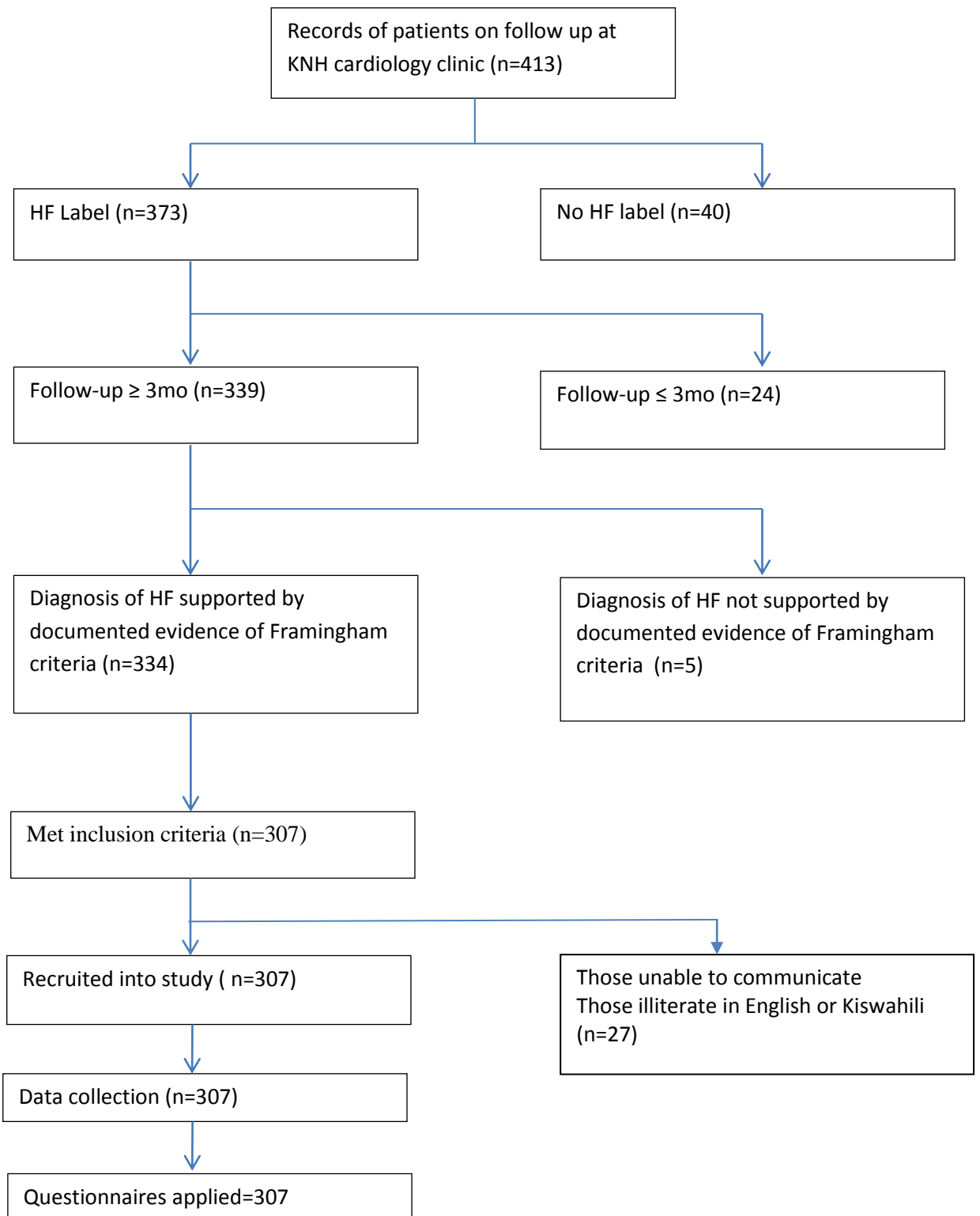
The study was conducted after approval by the Department of Clinical Medicine and Therapeutics, University of Nairobi and the Kenyatta National Hospital Scientific and Ethical Review Committee.

The study objectives were explained to eligible participants in English or Kiswahili prior to inclusion in the study. Only patients who gave written informed consent were enrolled into the study. Those who declined to give consent or withdrew from the study for any reason were not victimized and still underwent the routine clinic evaluation and management. Information gathered from the study participants was kept confidential. All patients were counseled on adherence to prescribed lifestyle practices and were also educated on heart failure self care behaviour practices. The study results were disseminated to health care providers to aid in patient care.

## **13.0 RESULTS**

This study was carried out between 28<sup>th</sup> July and 27<sup>th</sup> October 2015 at the Kenyatta National Hospital cardiac clinic and study participants were recruited by consecutive sampling. During this period, a total of 413 patients were seen in the cardiology clinic. Of these, 339 consecutive patients had a file diagnostic label of heart failure and had been on follow-up for a period of three months or more. The diagnosis was reaffirmed retrospectively by applying the Framingham criteria retrospectively thus identifying 334 study determined heart failure cases. Four patients were excluded on the basis of being less than 18 years of age, while 7 patients declined to give consent and sixteen patients on the basis of being illiterate in English and Kiswahili. Three hundred and seven patients were thus recruited into the study after meeting the inclusion criteria.

## FLOW CHART



## **SOCIODEMOGRAPHIC CHARACTERISTICS**

Age ranged between 18 and 89 years with a median of 48.0 (IQR 35.0-59.0) years. 58.6% were females and 71.7% of the study participants were married. The study design required that all the participants have some level of formal education with majority (63%) having attained post primary education. 62% of the patients were engaged in some form of employment (Table 1).

## **HEART FAILURE CHARACTERISTICS**

The median age at diagnosis of HF was 40 years (IQR 30.0-52.0). At study evaluation, 70% of the patients were in cardiac functional class I & II and 24 % and 5% were in class III & IV HF respectively. 1.7 % of the study participants were not on HF medication. A third of the population had never been hospitalized for HF. 73.3% had prior history of HF hospitalization; 47.6%, 30.6%, 12.9% and 3.6% having been hospitalized once, twice, thrice and four times respectively. Approximately a third (31.5%) of the study participants had been on follow up for HF for a period of one year or less while 40.7% had been on follow up for a period ranging between one to five years and 27.7% had been on follow up for more than 5 years (Table 5).

**Table 1: Socio-demographic characteristics of the study subjects**

<b>Variable n=307</b>	
Age (yrs) n=307 Mean (SD) Median (IQR) Min-Max	46.9 (15.6) 48.0 (35.0-59.0) 18.0-89.0
<b>Variable</b>	<b>Frequency (%)</b>
Gender Male Female	127 (41.4) 180 (58.6)
Marital Status Never married Married Separated Divorced Widowed	41 (13.4) 220 (71.7) 18 (5.9) 5 (1.6) 23 (7.5)
Occupation/Employment Unemployed Formally employed Informal sector employed Self employed Student	116 (37.8) 52 (16.9) 60 (19.5) 64 (20.8) 15 (4.9)
Highest level of education attained Primary Secondary College/University	115 (37.5) 122 (39.7) 70 (22.8)

**Table 2: Clinical characteristics of the study subjects**

<b>Variable</b>	
Age at diagnosis of HF (n=307) Mean (SD) Median (IQR) Min-Max	41.8 (14.7) 40.0 (30.0- 52.0) 9.0-88.0
<b>Variable</b>	<b>Frequency (%)</b>
Duration of HF follow-up in KNH (n= 307) <1yr 1-5 yrs >5 yrs	97 (31.5) 125 (40.7) 85 (27.7)
NYHA class at time of evaluation (n=300) Class I Class II Class III Class IV	94 (31.3) 117 (39.0) 74 (24.6) 15 (5.0)
On HF medication (n= 299) Yes No	294 (98.3) 5 (1.7)
Hospitalizations for HF  <b>Number of HF admissions (n=225)</b> 1 2 3 ≥4	225 (73.3)  107 (47.6) 81 (36.0) 29 (12.8) 8 ( 3.6)



## LEVEL OF KNOWLEDGE ON HEART FAILURE (HF)

As illustrated in Table 3, utilizing the modified Dutch Heart Failure Knowledge scale (DHFKS), 89.6% of the ambulatory HF patients had poor HF knowledge with a mean score (SD) of 6.9 (2.1) out of a highest possible score of 15.

HF knowledge was further analyzed on the basis of the three thematic areas of the modified DHFKS. These themes include, knowledge of HF in general (4 questions), knowledge on HF treatment (6 questions on diet, fluid restriction and activity) and knowledge on HF symptoms and symptom recognition (5 questions). Patients scored poorly in all thematic areas with most patients having poor scores as regards knowledge of HF management (94.1%) and knowledge of HF symptoms and symptom recognition (89.3%). In the theme focusing on knowledge of HF in general, relatively less study participants (65.5%) had inadequate HF knowledge scores (Table 4).

**Table 3: Modified Dutch Heart Failure Knowledge Scale scores**

<b>Variable</b>	<b>n=307</b>
	<b>n (%)</b>
<b>HF Knowledge</b>	
Adequate	32 (10.4)
Poor	275 (89.6)

**Table 4: Modified Dutch Heart Knowledge Scale themes**

<b>Variable (n=307)</b>	<b>Frequency (%)</b>
<b>HF knowledge in general (Theme 1)</b>	
Adequate	106 (34.5)
Poor	201 (65.5)
<b>Knowledge of HF management (Theme 2)</b>	
Adequate	18 (5.9)
Poor	289 (94.1)
<b>HF symptoms &amp; symptom recognition (Theme 3)</b>	
Adequate	33 (10.7)
Poor	274 (89.3)

## HEART FAILURE SELF CARE BEHAVIOUR PRACTICES

Utilizing the modified European Heart Failure Self Care Behaviour Scale (EHFSCBs), the overall self care behaviour (SCB) score for each patient was calculated and stratified into proportion of patients with good SCB (scores 12-28), average SCB (scores 29-44) or poor SCB (scores 45-60). Good and adequate SCB was equally distributed (49.2%) among the study participants while a minority 1.6% had poor self care behaviour (Table 5).

SCB was further dichotomized as either good or poor on the basis of median score of 29 (IQR 24-33) as a cut-off. Utilizing this approach, 50.8% (95% CI 45.3-56.4) of the study subjects had poor SCB while 49.2% (95% CI 43.6-54.7).

**Table 5: Modified European Heart Failure Self Care Behaviour based on categories**

<b>Variable</b>	<b>n=307</b>
	<b>n(%)</b>
<b>Self-care behavior score categories</b>	
Good (12-28)	151(49.2)
Average (29-44)	151(49.2)
Poor (45-60)	5 (0.6)

### Self care behaviour domain analysis

Posthoc exploratory analysis of SCB based on the three domains of the Modified European Heart Failure Self Care Behaviour scale (EHFSCBs) was also performed. Domain 1 consists of questions concerning compliance with the heart failure self care regimen, (daily weight monitoring, fluid restriction, consuming a low salt diet, compliance to drugs and yearly flu vaccination), domain 2 involves adapting activities (rest and physical activity) and domain 3 assesses contacting health care providers in case of symptoms of HF decompensation such as increased shortness of breath, leg swelling, fatigue and weight gain.

In domain 1 (complying with the HF regimen), 58.6% (95% CI 52.8-64.5) of the study participants had low levels of adherence. In domain 2(adapting activities) and 3(contacting

health care providers), low adherence was reported in 37.5% (95% CI 32.6-43.0) and 38.4% (95% CI 32.9-44.3%) of study participants respectively.

### **Individual Self Care Behaviour practices**

There were varying rates of adherence to each of the individual components of the modified EHFSCBs. The SCBs that were associated with low levels of adherence (score >2) were yearly flu vaccines which had the least level of adherence (8.4%) followed by daily weight monitoring (22.8%) and fluid restriction (54.6%). Approximately 50.9% of study participants were reported to have low levels of adherence to regular exercise. Overall, 59.6% of the study participants had high levels of adherence (score 1 and 2) to SCBs that involved taking a rest during the day or taking a rest in the event that one experiences shortness of breath (64.5%), taking a low salt diet (65.4%) and adherence to prescribed medication (90.6%). Relatively more study participants contacted a doctor or nurse if they became increasingly short of breath (83.9%) or developed leg swelling (82.4%) than those who experienced fatigue (54.7%) or weight gain (49.8%).

## **ASSOCIATION OF VARIABLES**

### **Association between the level of Heart failure Knowledge scores and socio-demographic variables**

Bivariate analysis was used to explore the association between the level of HF knowledge and specific socio-demographic variables. There were no trends in association between HF knowledge and age, gender, level of education and duration of HF follow-up (Table 6).

**Table 6: Factors associated with Heart Failure knowledge**

Variable	Level of knowledge		P value
	Adequate	Poor	
Age, mean (SD)	44.5 (16.1)	47.2 (15.6)	0.346□
<b>Gender</b>			
Male	10 (7.9%)	117 (92.1%)	0.219†
Female	22 (12.2%)	158 (87.8%)	
<b>Education level</b>			
Primary	10 (8.7%)	105 (91.3%)	0.657†
Secondary	15 (12.3%)	107 (87.7%)	
Tertiary	7 (10.0%)	63 (90.0%)	
<b>Duration of follow up</b>			
<1	8 (8.2%)	89 (91.8%)	0.402†
1-5	12 (9.6%)	113 (90.4%)	
>5	12 (14.1%)	73 (85.9%)	

□ Statistical test used is the T test †Statistical test used is the chi square test

### **Association between the level of Heart Failure Self Care Behaviour and socio-demographic variables**

There were no trends in association between HF SCB and age, gender, level of education and duration of HF follow-up (Table 7).

**Table 7: Factors associated with self-care behaviour scores**

Variable	Self-care behaviour Adherence		P value
	Good	Poor	
Age	47.3 (15.5)	46.4 (15.8)	0.657 □
<b>Gender</b>			
Male	58 (45.7%)	69 (54.3%)	0.301 †
Female	93 (51.7%)	87 (48.3%)	
<b>Education level</b>			
Primary	58 (50.4%)	57 (49.6%)	0.320 †
Secondary	64 (52.5%)	58 (47.5%)	
Tertiary	29 (41.4%)	41 (58.6%)	
<b>Duration of follow up</b>			
<1	53 (54.6%)	44 (45.4%)	0.205 †
1-5	54 (44.3%)	71(55.7%)	
>5	44 (53.0%)	41 (47.0%)	

□ Statistical test used is the T test †Statistical test used is the chi square test

**Association between Heart failure knowledge scale scores and heart failure self care behaviour scores**

There was no significant association between HF knowledge scores and HF SCB scores (Table 8).

**Table 8: Association between Heart Failure Knowledge scores and Heart Failure Self Care Behaviour scores**

Variable	Level of knowledge		P value
	Adequate Frequency (%)	Poor Frequency (%)	
<b>Self-care behaviour</b>			
Good	16 (50.0%)	135 (49.1%)	0.936
Poor	16 (50.0%)	140 (50.9%)	

## SENSITIVITY ANALYSES

### Heart Failure Knowledge

A strata of the population (Strata B, n= 96) had the EHFSCBs questionnaire administered first followed by the DHFKS questionnaire for the purposes of exploring whether testing HF knowledge first, as per the study protocol, followed by assessment of SCB had any significant influence on patient responses as regards their SCB. We also explored if assessing SCB prior to testing HF knowledge had any significant influence on HF knowledge scores. There was no significant difference in the SCB scores or the HF knowledge scores in either of the population strata. Questionnaire sequencing therefore, had no significant influence on the response by study participants to either of the two study questionnaires (Tables 9 & 10)

**Table 9: Modified European Heart Failure Self-Care Behavior scores by strata**

	<b>Overall population (n=307)</b>	<b>Strata A (n=211)</b>	<b>Strata B (n=96)</b>
	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>Self-care behaviour score</b>			
Good	151 (49.2)	95 (45.0)	40 (41.7)
Poor	156 (50.8)	111 (52.6)	56 (58.3)

\*Strata A- Patients who had the DHFKS administered prior to the EHFSCBs

†Strata B- Patients who had the EHFSCBs administered followed by the DHFKS

**Table 10: Modified Dutch Heart Failure Knowledge scale scores by strata**

<b>Variable</b>	<b>Overall study population n=307</b>	<b>Strata A n=211</b>	<b>Strata B n=96</b>
	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>HF Knowledge</b>			
Adequate	32 (10.4)	22 (10.4)	10 (10.4)
Poor	275 (89.6)	189 (89.6)	86 (89.6)

\*Strata A- Patients who had the DHFKS administered prior to the EHFSCBs

†Strata B- Patients who had the EHFSCBs administered followed by the DHFKS

## 14.0 DISCUSSION

This is the first study conducted in Kenya to determine heart failure (HF) knowledge and self care behaviour (SCB) practices in patients with chronic ambulatory heart failure. The study site was the outpatient cardiac clinic at Kenyatta National Hospital.

We established that 90% of ambulatory HF patients attending the KNH cardiology clinic demonstrated poor HF knowledge. Most study participants had inadequate HF knowledge in all the three themes of the Dutch HF knowledge scale (DHFKS) and especially in the themes concerning knowledge of HF management and knowledge on HF symptoms and symptom recognition (94.1% and 89.3% respectively). However, relatively less study participants had inadequate knowledge on the theme assessing knowledge on general aspects of HF (65.5%). The overall SCB as analyzed by the European Heart Failure Self Care Behaviour Scale (EHFSCBs) was poor in half of the study participants. When analyzed on the basis of the three categories of overall SCB scores, (i.e. good, average or poor SCB scores), good and average SCB was equally distributed among the study participants (49.2%) while 1.6% had poor SCB. In our analysis of the three major domains of the European Heart Failure Self care Behaviour Scale (EHFSCBs), majority (58.6%) of the subjects had low levels of adherence in the domain relating to adherence to self-care regimens while 37.5% had low levels of adherence in the domain relating to adapting activities while 38.4% had low levels of adherence in the domain relating to contacting health care providers.

The contributors to low levels of HF knowledge and poor SCB among heart failure (HF) patients mainly involve health system related factors and patient related factors. Although the factors associated with poor knowledge and SCB were not studied, results from other regional studies may provide insight into this. Findings from other studies have shown that physicians often fail to provide focused HF education to patients prior to hospital discharge (4, 66). Barasa et al in 2009, conducted a study on patients admitted with a diagnosis of acute decompensated HF in KNH and found that there was no formal HF education given to patients prior to discharge from the wards with most of the patients only receiving advice on the need for clinic follow up (6). Additionally, there are no HF education programs in place at the KNH cardiac clinic despite the findings in Barasa's study which showed poor knowledge on SCB of HF patients. The high patient to doctor ratio accompanied by the long intervals between clinic appointments limits

contact time between patients and health care providers. This, therefore, makes it difficult to deliver, assess and reinforce relevant HF knowledge and good SCB practices. The KNH diabetic clinic on the other hand has regular mini clinics run by registered clinical officers and nurses thus increasing contact time between patients and health care providers.

In addition to our study findings of poor HF knowledge in majority of the study participants, we also found that half had low levels of adherence to HF SCB practices. Likely explanation for this trend in results may be explained by findings from similar studies done in Sub-Saharan Africa. Patient related factors that have been found to contribute to poor HF knowledge and HF SCB practices include the high prevalence of co morbidities commonly found in patients with HF. Anane et al in a University teaching hospital in Ghana found that out of 583 patients with chronic HF, 47.5% had associated co morbidities such as diabetes, chronic kidney disease, atrial fibrillation, hypertension and anemia (96). Thus, many HF patients have to deal with multiple health conditions which can negatively interfere with symptom monitoring and decision making (71). For example, patients with obstructive lung disease may be unable to distinguish between worsening HF versus their lung disease as a cause of dyspnea. Additionally, patients with HF commonly have cognitive impairment and depression which have been found to hinder patients' ability to acquire adequate knowledge. Ademola et al in a study conducted in a university teaching hospital in Ghana found that two thirds of patients hospitalized with HF and one third of stable outpatients had depression. (97). Depression and cognitive impairment further contribute to low motivation towards learning and adherence to SCB and impairs a patients' ability to judge severity and make decisions about HF symptoms (77) (76). Furthermore, many HF patients especially the elderly have poor health literacy which affects their ability to process and understand basic health information and services in order to make effective health decisions (95). Thus, observations from these studies may explain our study results as regards the high proportion of study subjects with poor HF knowledge.

Our study findings as regards the high proportion of HF patients with poor HF knowledge compares well with regional data from other developing countries. In Ethiopia a study conducted by Beker et al in 2012 on 255 ambulatory HF patients attending the cardiology clinic of a university hospital utilized the Dutch Heart Failure Knowledge scale (DHFKS) and reported that 75.3% of the study participants had poor HF knowledge. A second study in 2013 in Ethiopia by



Negese et al of 328 ambulatory HF patients attending the cardiology clinic of a tertiary institution and utilizing the DHFKS as well reported poor HF knowledge in 89.3% of the study participants (88). In Vietnam, a study by Nguyen et al in 2011 of 126 stable HF patients attending a cardiology clinic also utilized the DHFKS and established that 76% of the study participants had poor HF knowledge (90). However, compared to developing countries, most studies on HF knowledge in developed countries have found relatively higher knowledge scores. The COACH study, a multicentre study in the Netherlands by Van der Waal et al analyzed HF knowledge using the DHFKS in 501 consecutive patients hospitalized for HF and found that most (73%) of study participants had adequate HF knowledge scores (93). The mean HF knowledge score for the COACH study was  $11.0 \pm 2.4$  which was significantly higher than the mean knowledge score of  $6.9 \pm 2.1$  that we found in our study. In USA, Dennison et al (2010) studied HF knowledge in 172 HF patients hospitalized in a teaching hospital and found a mean knowledge score of  $11.43 \pm 2.26$  which was higher than our mean score of  $6.9 \pm 2.1$ . The existence of structured health education programs in developed countries accompanied by frequent patient follow-ups either by way of home visits, regular phone calls or electronic mail can explain the disparities observed in the level of HF knowledge between developing and developed countries.

As regards SCB in other regions, Beker et al in Ethiopia and Nguyen et al in Vietnam found that 59.2% and 50.9% of ambulatory HF patients respectively had poor adherence to SCB which is similar to our study findings of 50.8% (87, 90). When we analyzed SCB on the basis of pre-specified categories, our study findings were comparable to that of a study conducted on ambulatory HF patients by Ahmad-Ali et al in Iran. In the Iranian study, the proportion of patients with good SCB was 56.5% (vs. 49.2% in our study), average SCB was reported in 38.0% (vs. 49.2%) while 5.5% of the study participants were reported to have poor SCB (vs. 1.6% in our study). A study done in KNH in 2013 by Omari et al on ambulatory diabetic patients reported suboptimal SCB in that cohort of patients hence reflecting the general level of adherence to SCB across different chronic disease states (98). This similarity in study findings between our study and that of other studies can be explained by existence of similar healthcare system challenges such as lack of structured patient educational programs accompanied by a high patient burden which puts considerable strain on available medical resources. Findings from the COACH study in Netherlands reported a much higher proportion (72%) of HF patients with

good compliance to SCB probably highlighting differences in health care systems in different regions of the world.

The domain relating to adherence to the HF self care regimen had the majority of participants demonstrating low levels of adherence to SCB practices. Deficiencies in this domain were specifically noted with regards to adherence to yearly flu vaccination, daily weight monitoring and fluid restriction. The least performed SCB by the study participants was getting a yearly flu vaccination with only 9.5% of the study participants reporting high levels of adherence to this SCB. Studies have shown that lack of patient knowledge on the relationship between influenza and HF deterioration and failure by health care providers to routinely remind patients with HF to get a flu vaccine contributes to low adherence (99).

Daily weight monitoring was the second least performed SCB in our study with less than a third (22.8%) of the participants reporting good adherence to this. A likely explanation is that very few patients know that weight gain is one of the signs of worsening HF and thus may consider it unrelated to heart failure altogether (9). However, our figures are much higher compared to those found in a previous study on heart failure patients in KNH where only 2% of the patients were adherent to daily weight monitoring. The main reason cited for failure to adhere to this recommendation was lack of a weighing scale at home and again, only 3% of the study participants actually received advice on the importance of daily weight monitoring (6). Our study did not explore what proportion of our study patients actually had weighing scales at home or even the proportion of patients who had been counseled on daily weight monitoring as this could actually explain the differences between the results of the two studies.

Fluid restriction was adhered to by less than half (45.8 %) of our study population and this is likely because most HF patients believe drinking water is beneficial. This misconception on fluid intake by HF patients is supported by findings of the Oregon Heart failure in which 38.1% of the patients believed that they should drink lots of fluids as part of HF self care management (100). There were no significant associations between HF knowledge and HF SCB and age, gender, level of education and duration of HF follow up. Neither was there any association between HF knowledge and HF SCB practices. Negese et al in Ethiopia on HF patients also showed no association between HF SCB and age, gender and level of education (88).

## **15.0 CONCLUSION**

This study demonstrated that majority of heart failure patients have poor HF knowledge and poor adherence to SCB practices. Knowledge deficiencies were especially related to HF management, symptom recognition and symptom monitoring. Adherence to SCB was low in the domain relating to compliance to the HF regimen. The least performed SCBs were daily weighing, yearly flu vaccination and fluid restriction.

Poor HF knowledge and SCB as reported in our study may be impacting negatively on our HF outcomes. This highlights the urgent need to establish standardized HF education programs for both in and outpatients. Focus should also be aimed at identifying and reinforcing any observed deficits as regards HF knowledge and SCB.

## **16.0 RECOMMENDATIONS**

There is need to establish a well structured health education program for patients and their caregivers for the purpose of providing education on HF and self management of HF. This education should be initiated in the hospital setting prior to discharge and reinforced at every clinic visit. Establishment of regular HF mini clinics similar to the model used in the diabetic clinics might also prove beneficial. Establishment of support groups might also prove beneficial in establishment of HF programs. Finally, assessment of HF knowledge and self care should be a continuous process whereby deficits are identified and addressed.

## **17.0 STRENGTHS**

Our study had similar demographics as other local studies hence representative of the ambulatory KNH HF population. The tools used are validated and in wide usage thus allowing comparisons between various studies. Sensitivity analysis was also done whereby alteration in the sequence of administration of study questionnaires showed that there was no significant influence on either SCB scores or HF knowledge scores.

## **18.0 LIMITATIONS**

This being a single centre study, the results may not be generalisable to heart failure patients in Kenya. The SCB questionnaire relied on individual self report and patients may have underestimated or overestimated their level of adherence to SCB due to the need by patients to maintain social desirability. The study also excluded hospitalized patients and illiterate patients hence introducing a selection bias. Hospitalized and illiterate patients are usually at risk of poor HF knowledge and SCB and we may have underestimated the true level of HF knowledge and SCB.

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## **20.0 APPENDICES**

### **APPENDIX 1- PATIENT CONSENT EXPLANATION FORM**

#### **Introduction**

I am Dr. Irene Ng'ang'a-Oginga, from the University of Nairobi. I am currently undertaking my postgraduate studies in Internal Medicine. As part of my postgraduate studies, I am undertaking a study on heart failure knowledge and heart failure related self care behaviour in heart failure patients at the Kenyatta National Hospital.

#### Procedures involved

This process will take approximately 45 minutes and will involve indicating certain basic information in a study proforma. For the purposes of this study, you will be given two questionnaires to fill in. One questionnaire will be for the purposes of assessing your knowledge on heart failure and will have 15 multiple choice questions. You will be required to tick the correct response out of three options given. The second questionnaire will be for the purposes of assessing the things you do as a result of your heart condition and will have 12 questions with the answers ranging from 'I completely agree' to 'I don't agree at all'. Kindly respond to all the questions to the best of your ability. Do not seek assistance from anybody in deciding on your answers.

#### **Your rights as a participant in this study**

Your participation in this study is voluntary.

Whether you choose to participate or not will not affect your medical care.

You are free to terminate the interview and withdraw from the study at any time.

You are free to ask questions before signing the consent form and during the study.

None of the information collected will be attributable to you or be traced to you nor shared with any other party. Information gathered will only be used for the purposes of this study.

### **Risks of participation**

There are no risks that you will experience.

There will be no costs incurred by you as the patient should you choose to participate in this study.

### **Benefits of participation**

At the end of the study, I will hand over the findings to the Internal Medicine department of UoN. All useful information that will improve the quality of care will be shared your doctor.

### **Confidentiality**

All information gathered during the study will be kept confidential. Only researchers have access to personal information. Information gathered will be documented and analyzed anonymously.

If you have any question during the course of the study, you may contact the following:

1. DR. IRENE NG'ANG'A-OGINGA, UNIVERSITY OF NAIROBI,  
DEPARTMENT OF CLINICAL MEDICINE AND THERAPUTICS, UON  
Mobile: 0721-583757. **OR**
2. PROF. M. D. JOSHI  
ASSOCIATE PROFESSOR & CONSULTANT CARDIOOGIST,  
DEPARTMENT OF CLINICAL MEDICINE AND THERAPEUTICS,  
UNIVERSITY OF NAIROBI,  
P.O BOX 19676,NAIROBI  
TEL: 0722516904. **OR**
3. CHAIRPERSON, KNH/UON ETHICAL REVIEW COMMITTEE,  
TEL: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723, Nairobi.

Before I involve you in my study, I request you to sign the consent form below.

## **KIAMBATISHO 1- FOMU INAYOELEZA IDHINI**

### **UTANGULIZI**

Mimi ni Dkt. Irene Ng'ang'a-Oginga, kutoka Chuo Kikuu cha Nairobi. Kwa sasa nasomea uzamili katika Tiba ya Ndani. Kama sehemu ya masomo yangu ya uzamifu, ninafanya uchunguzi ambao utathmini Utoshelevu wa Umaarifa na Utoshelevu wa Huduma Binafsi baina ya wagonjwa wanaougua Ugonjwa wa Moyo kupungua nguvu katika Hospitali Kuu ya Kenyatta.

### **Taratibu zitakazohusishwa**

Upimio huu utachukua takribani dakika 45 na utahusisha kuangalia rekodi zako za hospitali na kujibu maswali kadhaa katika fomu. Kwa madhumuni ya utafiti huu, utapewa madodoso mawili. Dodoso moja itakuwa kwa madhumuni ya kutathmini ujuzi wako kuhusu ugonjwa wa moyo kupungua nguvu na itakuwa na maswali kumi na matano. Kwa kila swali, utachagua jibu sahihi kati ya majibu tatu ambayo umepewa. Dodoso ya pili itahusu kutathmini utoshelevu wa mazoea ya huduma binafsi miongoni mwa wale wanaougua ugonjwa wa moyo kupungua nguvu. Itakuwa na maswali kumi na mawili yenye majibu katika hatua tano kuanzia ' Mimi kabisa nakubaliana' mpaka ' Mimi kabisa sikubaliani'. Utachagua hatua ambayo utakubaliana nayo. Tafadhali jibu maswali yote kadri ya uwezo wako.

### **Haki yako kama mshiriki katika utafiti huu**

Ushiriki wako katika utafiti huu ni wa kujitolea. Hata ukichagua kushiriki au ukatae kushiriki haitaathiri matibabu yako. Una uhuru wa kujiondoa katika mahojiano na katika utafiti huu wakati wowote. Una uhuru wa kuuliza maswali kabla ya kutia sahihi katika fomu ya idhini na wakati wa utafiti. Maswala yote yatahifadhiwa kwa siri wakati wote.

Habari zitakazokusanywa zitawekwa siri na hazitajulikana zimetokana na wewe wala kuwa chanzo chake ni wewe wala hazitapewa mtu mwingine. Habari zitakazokusanywa zitatumika tu kwa madhumuni ya utafiti huu.

## **Hasara za ushiriki**

Hakuna hasara yoyote utakayopitia au kupata.

Hakutakuwa na gharama zitakazotumika na wewe kama magonjwa iwapo utaamua kujiunga na utafiti huu.

## **Manufaa ya kushiriki**

Mwishoni mwa utafiti huu, nitawasilisha matokeo ya utafiti katika idara ya Tiba ya Ndani katika Chuo Kikuu cha Nairobi. Habari zozote muhimu zitakazotokana na utafiti na ambazo zitafanya malezi kuwa bora, walezi watafahamishwa ili hatua mwafaka ichukuliwe.

## **Siri**

Habari zote zitakazokusanywa wakati wa utafiti zitahifadhiwa kwa siri. Ni watafiti pekee ndio wanaoweza kufikia habari za kibinafsi. Habari zitakazokusanywa zitaandikwa na kuainishwa bila kutaja washiriki.

Ikiwa una swali lolote wakati wa utafiti, unaweza kuwasiliana na wafuatao:

1. DKT.IRENE NG'ANG'A-OGINGA, CHUO KIKUU CHA NAIROBI,

IDARA YA MAFUNDISHO YA UDAKTARI NA MATIBABU YA MAGONJWA,  
Simu ya mkono: 0721-583757. **AU**

2. PROF. M. D. JOSHI

IDARA YA MAFUNDISHO YA UDAKTARI NA MATIBABU YA MAGONJWA,  
PROFESA NA MSHAURI WA MAGONJWA YA MOYO,  
CHUO KIKUU CHA NAIROBI,  
P.O BOX 19676, NAIROBI  
Simu ya mkono: 0722516904. **OR**

3. MWENYEKITI, KNH/UON KAMATI INAYOSHUGHULIKIA MAADILI,

Nambari ya simu: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723,  
Nairobi.



**APPENDIX 2: CONSENT/ASSENT FORM-PATIENTS**

STUDY NO.....DATE.....TIME

I hereby give my written and informed consent as ..... to participate in this study on heart failure knowledge and heart failure related self care behaviour in chronic heart failure patients at the Kenyatta National Hospital. I have been adequately explained to about the study by Dr. Irene Ng’ang’a-Oginga/her assistant. I do this with the full understanding of the purpose of the study procedures involved which include review of my file records and answering to a study proforma and two questionnaires which have been explained to me. I understand that my rights will be respected, and confidentiality maintained at all times.

I also understand that the consent is voluntary, and I am at liberty to withdraw from the study without my care being affected.

Patient’s signature.....

Patient’s Name.....

**INVESTIGATOR’S STATEMENT:**

I, the Principal Investigator, have fully educated the research participant on the purpose and implication of this study.

Signed..... Date.....

For any further clarification, you may contact

Dr. Irene Ng’ang’a-Oginga, at Tel No: 0721-583757.

Or: Professor M.D Joshi, at Tel No. 0722-516904

Or: KNH/ERC (Kenyatta National Hospital/Ethics & Review Committee) TEL: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723, Nairobi

## **KIAMBATISHO 2: FOMU YA IDHINI /KUBALI- WAGONJWA**

NAMBARI YA UCHUNGUZI.....TAREHE.....WAKATI.....

Natoa idhini andishi na ninayoifahamu ili kuniruhusu mimi.....kushiriki katika utafiti huu amabao utatathmini Utochelevu wa Umaarifa na Utochelevu wa Huduma Binafsi baina ya wagonjwa wanaouguu ugonjwa wa moyo kupungua nguvu katika Hospitali Kuu ya Kenyatta.

Nimepewa maelezo yanayofaa kuhusu utafiti wa Dkt. Irene Ng'ang'a-Oginga/msaidizi wake. Ninafanya hivi kwa vile naelewa lengo kuu la utafiti huu na taratibu zitakazohusishwa kama vile kuangaliwa kwa maagizo ya daktari na kujibu maswali katika fomu ambayo nimepewa maelezo yake.

Ninaelewa kuwa haki zangu zitaheshimiwa, na suala la kuhifadhi utambuzi wangu utadumishwa wakati wote.

Pia ninaelewa kuwa idhini ya kushiriki ni ya kujitolea, na nina uhuru wa kujiondoa katika utafiti huu bila malezi yangu kuathiriwa.

Sahihi ya Mgonjwa.....

Jina la Mgonjwa.....

### **KAULI YA MCHUNGUZI:**

Mimi, Mchunguzi Mkuu, nimemuelimisha mshiriki wa utafiti kuhusu lengo kuu la utafiti na kinachodokezwa na utafiti huu.

Sahihi..... Tarehe.....

Kwa maelezo zaidi, unaweza kuwasiliana na

Dkt.Irene Ng'ang'a-Oginga, katika nambari ya simu: 0721-583757.

Au: Profesa M.D Joshi, katika nambari ya simu: 0722516904

Au: MWENYEKITI, KNH/UON KAMATI INAYOSHUGHULIKIA MAADILI

Nambari ya simu: 020-2726300/0722829500/0733606400/EXT 4

# APPENDIX 3: STUDY PROFORMA

**STUDY INVESTIGATOR:** .....

**DATE OF ASSESSMENT:** .....

**IP NO:** .....

**UNIQUE STUDY NUMBER:**

## Demographics/PATIENT DETAILS

1. Date of birth  /  /  (dd/mm/yyyy)

2. Age  yrs

3. Gender  Female  Male

4. District of Birth \_\_\_\_\_

5. District of Residence in last 5 yrs \_\_\_\_\_

6. Educational level  None  Standard 1-5  Standard 6-8  Secondary  
 College/University

7. Occupation/employment

- (i) Unemployed
- (ii) Formally employed
- (iii) Informal sector
- (iv) Self-employed
- (v) Student

8. Marital status

(i) Never Married  (ii) Married  (iii) Separated

(iv) Divorced  (v) Widowed

9. Living Arrangement Alone  With Others

10. Age at diagnosis of heart failure \_\_\_\_\_

11. Duration of HF follow up

≤ 6 months  10 yrs

- ≥6 months
- 1-5 years
- 5-10 years
- 

12. Have you ever smoked?  Yes  No

**If no, skip to the next section**

Do you still smoke? Yes  No

If No, when did you stop? .....(Year, Month)

Why did you stop?  No reason  Advised because of HF  Self Volition because of HF

On average, how many cigarettes do you smoke during on a single day?.....

For how many years have you been smoking to this extent?.....

**Alcohol**

13. Have you ever consumed a drink that contains alcohol? Yes  No

**If no, skip to the next section**

Do you still take alcohol?  Yes  No

If No, when did you stop? .....(Year, Month)

Why did you stop?  No reason  Advised because of HF  Self Volition because of HF

Of the following which is the type of alcohol most frequently consumed?  Chang'aa  busaa

other local brews  commercial beer  wine  spirits  muratina  kumi-kumi

On average, how many drinks do you take during on a single day?.....

For how many years have you been drinking to this extent?.....

**Current cardiac functional state (NYHA)**

Class I  Class II  Class III  Class IV

14. Are you on HF medication?

- Yes
- No

15. Prior hospital admissions for HF

Yes  No

If yes,

No. of prior admissions

1  2  3  ≥4

Conclusion	
<b>TYPE OF HF</b>	
Diastolic dysfunction	<input type="checkbox"/> Yes <input type="checkbox"/> No
Systolic dysfunction	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>Possible Diagnosis</b>	
Rheumatic Heart Disease	<input type="checkbox"/> Yes <input type="checkbox"/> No
Dilated – Idiopathic CM	<input type="checkbox"/> Yes <input type="checkbox"/> No
HTN CM	<input type="checkbox"/> Yes <input type="checkbox"/> No
Alcoholic DCM	<input type="checkbox"/> Yes <input type="checkbox"/> No
Ischemic Heart Disease	<input type="checkbox"/> Yes <input type="checkbox"/> No
Peripartum CM	<input type="checkbox"/> Yes <input type="checkbox"/> No
HIV CM	<input type="checkbox"/> Yes <input type="checkbox"/> No
Pericardial effusion	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other (Specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No

## **APPENDIX 4: MODIFIED DUTCH HEART FAILURE KNOWLEDGE SCALE**

M.H.L van der Wal, T. Jaarsma

This list contains a number of questions and statements about heart failure. Please tick off what you think is the right answer (only tick I box per question).

**1. How often should patients with severe heart failure weigh themselves?**

- Every week
- Now and then
- Everyday

**2. Why is it important that patients with heart failure should weigh themselves regularly?**

- Because many patient with heart failure have poor appetite
- To check whether the body is retaining fluid
- To assess the right dose of medicines

**3. How much fluid are you allowed to take at home each day?**

- 1.5 to 2.5 litres at the most
- As little fluid as possible
- As much fluid as possible

**4. Which of these statements is true?**

- When I cough a lot, it is better not to take my heart failure medication
- When I am feeling better, I can stop my medication for heart failure
- It is important that I take my heart failure medication regularly

**5. What is the best thing to do in case of increased shortness of breath or swollen legs?**

- Contact the doctor or nurse
- Wait until the next check-up
- Take less medication

**6. What can cause a rapid worsening of heart failure symptoms?**

- A high-fat diet
- A cold or the flu
- Lack of exercise

**7. What does heart failure mean?**

- That the heart is unable to pump enough blood around the body
- That someone is not getting enough exercise and is in poor condition
- That there is a blood clot in the blood vessels of the heart

**8. Why can the legs swell up when you have heart failure?**

- Because the valves in the blood vessels in the legs do not function properly
- Because the muscles in the legs are not getting enough oxygen
- Because of accumulation of fluid in the legs

**9. What is the function of the heart?**

- To absorb nutrients from the blood
- To pump blood around the body
- To provide the blood with oxygen

**10. Why would someone with heart failure follow a low salt diet?**

- Salt promotes fluid retention
- Salt causes constriction of the blood vessels
- Salt increases the heart rate

**11. What are the main causes of heart failure?**

- Disease of the valves and heart muscle
- Lung problems and allergy
- Obesity and diabetes

**12. Which statement about exercise for people with heart failure is true?**

- It is important to exercise as little as possible at home in order to relieve the heart
- It is important to exercise at home and to rest regularly in between
- It is important to exercise as much as possible at home

**13. Why are water pills (eg. Lasix) prescribed to someone with heart failure?**

- To lower the blood pressure
- To prevent fluid retention in the body
- Because they can drink more

**14. Which statement about weight increase and heart failure is true?**

- An increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
- In case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse



- In case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

**15. Why should alcohol be avoided in HF?**

- Because alcohol leads to weight gain
- Because alcohol worsens HF symptoms
- Because alcohol leads to poor appetite

## **KIAMBATISHO 4: DODOSA LA UHOLANZI LA MAARIFA KUHUSU MARADHI YA MOYO KUPUNGUA NGUVU (YENYE MAREKEBISHO)**

Tunaomba ujibu maswali haya kuhusu ugonjwa wako wa moyo. Tafadhali chagua jibu moja lililo sahihi kati ya yote matatu.

**1. Wagonjwa wanaougua maradhi ya moyo kupungua nguvu wanapaswa kupima uzani wao kila baada ya muda upi?**

- Kila wiki
- Mara kwa mara
- Kila siku

**2. Je, ni kwa nini ni muhimu kwa wagonjwa wenye shida ya moyo kupungua nguvu kujipima ratili mara kwa mara?**

- kwa sababu wengi wa wagonjwa wenye maradhi ya moyo kupungua nguvu wanakosa hamu ya chakula
- Ni njia ya kuangalia kama mwili unahifadhi maji
- Inasaidia kujua dozi inayofaa ya dawa

**3. Je, ni kiwango kipi cha maji unaruhusiwa kunywa nyumbani kila siku?**

- Lita 1 hadi 2.5 ikizidi
- Kiwango kidogo kiwezekanavyo
- Kiwango kikubwa kiwezekanavyo

**4. Je, ni hoja gani kati ya haya matatu iliyo ya kweli,**

- Nikikohoa zaidi, ni vyema kuacha dawa au madawa niliyopewa ya shida yangu ya moyo kupungua nguvu
- Nikipata nafuu, ninaweza kuacha madawa ya ugonjwa wa moyo kupungua nguvu
- Ni muhimu kutumia dawa/madawa ya ugonjwa wa moyo kupungua nguvu mara kwa mara

**5. Ni jambo lipi bora kufanya ikiwa nitahisi upungufu wa kupumua au miguu ikipata kufura**

- Nawasiliana na daktari au muuguzi (nurse)
- Kungoja siku uliopewa kurudi kumwona daktari au muuguzi
- Kujipunguzia kiwango cha dawa zako

**6. Je, ni nini kinaweza sababisha kukithiri (kuongezeka haraka) kwa dalili za ugonjwa wa moyo kupungua nguvu?**

- kula chakula chenye kiwango kikubwa cha mafuta
- kupata homa ama mafua kali
- kutofanya mazoezi

**7. Maana ya moyo kupungua nguvu ni nini?**

- Moyo umeshindwa kupampu damu mwilini
- Mtu huyo hafanyi mazoezi ya kutosha ,hivyo basi yuko hali mbaya
- Kwamba kuna damu imeganda kwenye mishipa ya moyo

**8. Ni kwa nini miguu inaweza pata kufura wakati una ugonjwa wa moyo kupungua nguvu?**

- Kwa sababu mishipa ya miguu haipeleki damu inavyostahili
- Kwa sababu misuli ya miguu haipati oksijeni ya kutosha
- Kwa sababu ya mkusanyiko wa maji katika miguu.

**9. Kazi ya moyo ni nini?**

- kutumia chembechembe ya chakula tunachokula
- kupampu damu sehemu zote za mwili
- kuweka oksijeni katika damu

**10. Je, ni kwa nini mtu wenye ugonjwa ya moyo yuafaa ale kiwango kidogo cha chumvi kwenye mlo?**

- Chumvi hufanya mwili uhifadhi maji
- Chumvi hufanya mishipa ya damu kuwa nyembamba
- Chumvi huongeza kupiga kwa moyo

**11. Ni magonjwa yepi ama shida zipi za mwili zinazofanya moyo kuanza kuishiwa na nguvu?**

- Presha (shinikizo la damu) na magonjwa ya misuli ya moyo
- Magonjwa ya mapafu na hali ya mwili kukataa vitu vya kawaida kwenye mazingira (allergy)
- kunona kupindukia (fetma) na ugonjwa wa kisukari

**12. Je, ni wazo gani kati ya haya matatu ni la ukweli kuhusu kufanya mazoezi kwa wenye shida ya moyo kupungua nguvu?**

- Ni muhimu kufanya mazoezi kidogo iwezekanavyo ukiwa nyumbani ili kupumzisha moyo
- Ni muhimu kufanya mazoezi nyumbani na kupumzika mara kwa mara baina ya mazoezi
- Ni muhimu kufanya mazoezi kabisa iwezekanavyo ukiwa nyumbani

**13. Je, ni kwa nini mtu mwenye shida ya moyo hupewa dawa za kutoa maji mwilini?**

- Kuteremsha presha (shinikizo la damu)
- Kuzuia kuhifadhi kwa maji mwilini
- Kwa sababu wanaweza kunywa vinywaji zaidi

**14. Je, ni wazo lipi kati ya haya matatu kuhusu kuongeza ratili (kilo/uzani) na ugonjwa wa moyo kupungua nguvu lililo la ukweli?**

- Kuongezeka kwa kilo zaidi ya mbili katika muda wa siku mbili hadi tatu inapaswa kuripotiwa kwa daktari siku ya kuangaliwa ikifika.
- Ikiwa kutakuwa na ongezeko la kilo zaidi ya mbili katika siku mbili au tatu, unapaswa kuwasiliana na daktari au muuguzi (nurse)
- Ikiwa kutakuwa na ongezeko la kilo zaidi ya mbili katika siku mbili au tatu, unapaswa kula chakula kiasi kidogo zaidi

**15. Je ni kwa nini wale wenye ugonjwa wa moyo kupungua nguvu wanafaa wajiepushe na pombe?**

- Pombe huongeza dalili za moyo kupungua nguvu
- Pombe hufanya magonjwa kuongeza uzani
- Pombe hupunguza hamu ya chakula

## **APPENDIX 5: (ORIGINAL) DUTCH HEART FAILURE KNOWLEDGE SCALE**

M.H.L van der Wal, T. Jaarsma

This list contains a number of questions and statements about heart failure. Please tick off what you think is the right answer (only tick I box per question).

- 1. How often should patients with severe heart failure weigh themselves?**
  - Every week
  - Now and then
  - Everyday
  
- 2. Why is it important that patients with heart failure should weigh themselves regularly?**
  - Because many patient with heart failure have poor appetite
  - To check whether the body is retaining fluid
  - To assess the right dose of medicines
  
- 3. How much fluid are you allowed to take at home each day?**
  - 1.5 to 2.5 litres at the most
  - As little fluid as possible
  - As much fluid as possible
  
- 4. Which of these statements is true?**
  - When I cough a lot, it is better not to take my heart failure medication
  - When I am feeling better, I can stop my medication for heart failure
  - It is important that I take my heart failure medication regularly
  
- 5. What is the best thing to do in case of increased shortness of breath or swollen legs?**
  - Contact the doctor or nurse
  - Wait until the next check-up
  - Take less medication
  
- 6. What can cause a rapid worsening of heart failure symptoms?**
  - A high-fat diet
  - A cold or the flu
  - Lack of exercise
  
- 7. What does heart failure mean?**
  - That the heart is unable to pump enough blood around the body

- That someone is not getting enough exercise and is in poor condition
- That there is a blood clot in the blood vessels of the heart

**8. Why can the legs swell up when you have heart failure?**

- Because the valves in the blood vessels in the legs do not function properly
- Because the muscles in the legs are not getting enough oxygen
- Because of accumulation of fluid in the legs

**9. What is the function of the heart?**

- To absorb nutrients from the blood
- To pump blood around the body
- To provide the blood with oxygen

**10. Why would someone with heart failure follow a low salt diet?**

- Salt promotes fluid retention
- Salt causes constriction of the blood vessels
- Salt increases the heart rate

**11. What are the main causes of heart failure?**

- A myocardial infarction (heart attack) and high blood pressure
- Lung problems and allergy
- Obesity and diabetes

**12. Which statement about exercise for people with heart failure is true?**

- It is important to exercise as little as possible at home in order to relieve the heart
- It is important to exercise at home and to rest regularly in between
- It is important to exercise as much as possible at home

**13. Why are water pills (eg. Lasix) prescribed to someone with heart failure?**

- To lower the blood pressure
- To prevent fluid retention in the body
- Because they can drink more

**14. Which statement about weight increase and heart failure is true?**

- An increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
- In case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse
- In case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

**15. What is the best thing to do when you are thirsty?**

- Suck an ice cube
- Suck a lozenge
- Drink a lot

**APPENDIX 6: MODIFIED EUROPEAN HEART FAILURE SELF CARE BEHAVIOUR SCALE**

		<b>I completely agree</b>			<b>I don't agree at all</b>	
1.	I weigh myself everyday	1	2	3	4	5
2.	If I get shortness of breath, I take it easy	1	2	3	4	5
3.	If shortness of breath increases, I contact my doctor or nurse	1	2	3	4	5
4.	If leg/feet are more swollen, I contact a doctor or nurse	1	2	3	4	5
5.	If I gain weight, I contact a doctor or nurse	1	2	3	4	5
6.	I limit the amount of fluids I take	1	2	3	4	5
7.	I take a rest during the day					
8.	If I experience fatigue, I contact a doctor or nurse	1	2	3	4	5
9.	I eat a low salt diet	1	2	3	4	5
10.	I take my medication as prescribed	1	2	3	4	5
11.	I get vaccinated against severe cold (flu) every year	1	2	3	4	5
12.	I exercise regularly	1	2	3	4	5



## KIAMBATISHO 6: DODOSO LA ULAYA LA MAZOEJA YA HUDUMA BINAFSI KWA WANAUGUA UGONJWA WA MOYO KUPUNGUKA NGUVU

**Maelekezo kwa wagonjwa:** Dodoso lifuatalo lina kauli tofauti kuhusu ugonjwa wa moyo kupungua nguvu. Jibu kila kauli kwa kuweka mviringo kwenye namba unayofikiri ni bora na wewe. Kumbuka kwamba, kila kauli lina jibu tofauti mbadala kuanzia ‘Nakubali kabisa’ (1) hadi ‘Sikubali kabisa’ (5). Hata iwe hauna uhakika kuhusu jibu fulani, jibu kila kauli kwa kuweka duara kwenye jibu ambalo unahisi li bora na wewe.

		Kabisa				
		nakubaliana			Kabisa sikubaliani	
1.	Najipima uzito wa mwili kila siku	1	2	3	4	5
2.	Nikipata shida ya kupumua (kuhema), huwa napumzika	1	2	3	4	5
3.	Shida ya kupumua (kuhema ) ikiongezeka, natafuta ushauri wa daktari au muuguzi	1	2	3	4	5
4.	Miguu ikifura (ikivimba), natafuta ushauri wa daktari au muuguzi	1	2	3	4	5
5.	Uzito wa mwili ukiongezeka, natafuta ushauri wa daktari au muuguzi	1	2	3	4	5
6.	Najizuia kiasi cha maji ninachokunywa	1	2	3	4	5
7.	Napumzika wakati wa mchana	1	2	3	4	5
8.	Nikihisi uchovu, natafuta ushauri wa daktari au muuguzi	1	2	3	4	5
9.	Natumia chumvi kidogo katika chakula	1	2	3	4	5
10.	Natumia dawa kama ipasavyo	1	2	3	4	5
11.	Napata chanjo ya homa(mafua) kila mwaka	1	2	3	4	5
12.	Nafanya mazoezi mara kwa mara	1	2	3	4	5

## APPENDIX 7: (ORIGINAL) EUROPEAN HEART FAILURE SELF CARE BEHAVIOUR SCALE

**Instructions to patients:** The scale contains statements about heart failure. Respond to each statement by circling the number you think best applies to you. Note that the different answer alternatives constitute a scale ranging between the extremes of ‘I completely agree’ (1) to ‘I don’t agree at all’ (5). Even if you feel uncertain about a particular statement, circle the number you feel is most true for you.

		<b>I completely agree</b>				<b>I don’t agree at all</b>
1.	I weigh myself everyday	1	2	3	4	5
2.	If I get shortness of breath, I take it easy	1	2	3	4	5
3.	If shortness of breath increases, I contact my doctor or nurse	1	2	3	4	5
4.	If leg/feet are more swollen, I contact a doctor or nurse	1	2	3	4	5
5.	If I gain weight, I contact a doctor or nurse	1	2	3	4	5
6.	I limit the amount of fluids I take	1	2	3	4	5
7.	I take a rest during the day					
8.	If I experience fatigue, I contact a doctor or nurse	1	2	3	4	5
9.	I eat a low salt diet	1	2	3	4	5
10.	I take my medication as prescribed	1	2	3	4	5
11.	I get a flu shot every year	1	2	3	4	5
12.	I exercise regularly	1	2	3	4	5

## APPENDIX 8- ETHICAL APPROVAL LETTER



UNIVERSITY OF NAIROBI  
COLLEGE OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
(254-020) 2726300 Ext 44355



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Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)  
Website: <http://erc.uonbi.ac.ke>  
Facebook: <https://www.facebook.com/uonknh.erc>  
Twitter: @UONKNH\_ERC [https://twitter.com/UONKNH\\_ERC](https://twitter.com/UONKNH_ERC)



KENYATTA NATIONAL HOSPITAL  
P O BOX 20723 Code 00202  
Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/327

24<sup>th</sup> July 2015

Dr. Irene H. Ng'ang'a-Oginga  
H58/69640/2011  
Dept. of Clinical Medicine and Therapeutics  
School of Medicine  
University of Nairobi

Dear Dr. Ng'ang'a

**RESEARCH PROPOSAL – HEART FAILURE SELF CARE KNOWLEDGE AND SELF CARE BEHAVIOUR PRACTICES AMONG AMBULATORY PATIENTS AT KENYATTA NATIONAL HOSPITAL (P393/06/2015)**

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 24<sup>th</sup> July 2015 – 23<sup>rd</sup> July 2016.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- g) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website [www.erc.uonbi.ac.ke](http://www.erc.uonbi.ac.ke)

Protect to discover



Yours sincerely,

**PROF. M. L. CHINDIA**  
**SECRETARY, KNH/UON-ERC**

- c.c. The Principal, College of Health Sciences, UoN
- The Deputy Director CS, KNH
- The Chair, KNH/UoN-ERC
- The Assistant Director, Health Information, KNH
- The Dean, School of Medicine, UoN
- the Chairman, Dept. of Clinical Med. & Therapeutics, UoN
- Supervisors: Prof. Mark D. Joshi, Dr. Anne Mugeru, Dr. Edna Kamau

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## APPENDIX 9: KNH APPROVAL LETTER TO CONDUCT STUDY



KENYATTA NATIONAL HOSPITAL  
P. O. Box 20723, 00202 Nairobi

Tel: 2726300/2726450/2726550  
Fax: 2725272  
Email: [knhadmin@knh.or.ke](mailto:knhadmin@knh.or.ke)

Ref: KNH/SAD-MED/42B/VOL.I/318

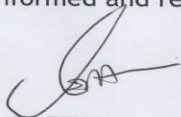
Date: 13<sup>th</sup> October 2016

Dr. Irene Hannah Njeri Ng'ang'a - Oginga  
Department of Clinical Medicine & Therapeutics  
School of Medicine  
College of Health Sciences  
University of Nairobi

### RE:APPROVAL TO CONDUCT A STUDY IN MEDICINE DEPARTMENT

Following approval of your study by the KNH/UoN ERC and completion of the KNH study registration form, permission is hereby granted for you to collect data in Medicine Department, Medical Outpatient Clinic (MOPC) to enable you complete your study on "*Heart failure self care knowledge and self care behavior practices among ambulatory patients*" at Kenyatta National Hospital, Nairobi County, Kenya.

Kindly liaise with the Assistant Chief Nurse Incharge MOPC Clinic for facilitation. By a copy of this letter, the Assistant Chief Nurse Incharge - MOPC is informed and requested to facilitate.

  
**DR. P. ETAU**  
**AG.HOD - MEDICINE**

Copy to: Assistant Chief Nurse Incharge - MOPC

*Vision: A world class patient-centered specialized care hospital*



ISO 9001: 2008 CERTIFIED