

**SYMPTOM BURDEN AND HEALTH RELATED QUALITY OF
LIFE OF HEART FAILURE PATIENTS ATTENDING JIMMA
UNIVERSITY SPECIALIZED HOSPITAL CHRONIC ILLNESS
FOLLOW UP CLINIC, SOUTH WEST ETHIOPIA**



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**JIMMA UNIVERSITY
COLLEGE OF PUBLIC HEALTH AND MEDICAL SCIENCES
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Abstract

Background: Heart failure (HF) is a global health issue, with a worldwide incidence of 5.7 million cases annually. Heart failure is an escalating public health problem in the United States and around the world. Living with chronic heart failure (CHF) is distressful & affects daily life. People with heart failure also experience major reductions in their health related quality of life and frequent hospital admissions. Because of lack of cure for CHF, there has been a progressive interest in using health-related quality of life (Hr-QoL) as an outcome measurement of the treatment in patients with Chronic Heart Failure.

Objectives: The main aim of this study was to determine the relationship of symptom burden and health related quality of life in patients with heart failure attending Jimma University Specialized Hospital (JUSH) chronic illness clinic.

Methods: A cross-sectional qualitative and quantitative study in which 223 participants and 9 key informants were involved was conducted from February 10 to April 10, 2011 in JUSH. Symptoms and Hr-QoL were assessed using locally adapted version of the Memorial Symptom Assessment Scale—Heart Failure and the Minnesota Living with Heart Failure Questionnaire. Data was analyzed using SPSS windows version 16.0 and manually, bivariate and multivariable logistic regression analyses were employed and the findings of the study were presented by using statements, tables and figures. The significant findings were declared at $p < 0.05$.

Result: From the 223 study participants about 196 (87.9%) have poor health related quality of life. Majority of the respondents 202(90.6%) said the symptoms they were experiencing are affected their quality of daily living in different ways. Of the 32 possible symptoms, the mean number of symptoms a patient had was 10.79 ± 5.3 . High-prevalence symptoms ($\geq 50\%$ of the sample) include lack of energy (86.5%), shortness of breath (81.2%), palpitation (68.6%), feeling drowsy(57.8%), chest pain (57.8%), orthopnea (57.8%), cough (55.6%), waking breathlessness at night (52.5%), and lack of appetite (52%). Lack of energy and dizziness were the most burdensome symptom.

Conclusion and recommendation: Patients with heart failure experience high level of symptoms and symptom burden. Nurses should target interventions to decrease frequency, severity, distress and overall symptom burden and improve HRQOL.

Keywords: Heart failure; health related quality of life; Memorial Symptom Assessment Scale—Heart Failure, Minnesota living with heart failure questionnaire, symptom burden

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Acronym

ACC/AHA: American College of Cardiology and the American Heart Association

ADL : Activities of Daily Living

BSc.N: Bachelor of Science in Nursing

CCI: Charlson Comorbidity Index

CHD: Coronary Heart Disease

CHF: Chronic Heart Failure

COPD: Chronic Obstructive Pulmonary Disease

GDI: Global Distress Index

GDS: Geriatric Depression Scale

HAD: Hypertensive Heart Disease

HF: Heart Failure

Hr-QoL: Health Related Quality of Life

JUSH: Jimma University Specialized Hospital

KCCQ: Kansas City Cardiomyopathy Questionnaire

MHI: Montreal Heart Institute

MI: Myocardial Infarction

MILQ: Multidimensional Index of Life Quality

MLHF: Minnesota living with heart failure

MLHFQ: Minnesota living with heart failure questionnaire

MOH: Ministry of Health

MSAS: Memorial Symptom Assessment Scale

MSc.N: Masters of Science in Nursing

NYHA: New York Heart Association

OR: Odds Ratio

PLWHF: People Living With Heart Failure

QOL: Quality of Life

SD: Standard Deviation

PI: Principal Investigator

WHO: World Health Organization

Chapter I: introduction

1.1. Background

Cardiovascular disease imposes burdens on patients, their families, and society as a whole. Heart failure (HF) levies a heavy burden on global health, with a worldwide incidence of 5.7 million cases annually. Patients also experience major reductions in their health related quality of life and frequent hospital admissions. Prevalence and incidence of heart failure in western world shows average prevalence of 2-2.5% overall, increasing to >10% in octogenarians. Up to 14 million inhabitants of Europe have heart failure. Average incidence of heart failure is 15 per 1000 inhabitants in people 55 years and above, but increases significantly in the elderly (22). Heart failure is an escalating public health problem in the United States and around the world. Patients with heart failure face significant decreases in functional status, multiple hospital admissions, high mortality, multiple physical and psychological symptoms and a diminished quality of life. Specialized heart failure programs have demonstrated ability to decrease readmissions, healthcare costs, and improve patient satisfaction (1, 2).

Despite these advances, managing patient symptoms remains difficult in many cases. Heart failure patients face a wide variety of symptoms that can adversely impact their quality of life. Physical and psychological symptoms such as dyspnea, fatigue, pain, orthopnea, edema, loss of appetite, anxiety and depression are widely reported. More recently, disruption of sleep has been reported in the literature. Amelioration of symptoms may improve functional ability which can ultimately improve quality of life. The incidence of heart failure increases with age and cardiovascular disease is the third leading cause of death for Taiwanese people. Sleep problems are common in patients with heart failure, and have a negative impact on their quality of life. Patients with heart failure often have difficulties in lying supine to sleep, falling asleep, and maintaining sleep, as well as waking up too early (2).

In addition to dealing with the challenges of an incurable disease, patients with heart failure also need to tolerate many discomforts caused by their compromised cardiovascular function. Zambroski et al (2005) found that the five most common symptoms of heart failure were

dyspnea (85.2%), lack of energy (84.9%), dry mouth (74.1%), daytime sleepiness (67.9%), and difficulty falling asleep (64.2%). The most annoying symptoms were lack of energy, difficulty falling asleep, and being woken by nocturnal dyspnea, while the most intolerable symptoms were reported as difficulty falling asleep and lack of energy. Related to this, Parker and Dunbar (2002) found that sleep deprivation occurred for patients with heart failure and that they often suffered from sleep problems that interfered with their daily lives (2).

1.2. Statement of the problem

Ageing of the population in combination with improved treatment options are fuelling the heart failure (HF) epidemic, imposing a significant burden on society. CHF seriously affects quality of life in terms of physical, social and emotional functioning and reduces life expectancy considerably. As CHF touches nearly every important aspect of daily life, patients are encouraged to take responsibility for their day-to-day disease management. Furthermore, in addition to dealing with the medical aspects of CHF, patients face equal difficulties in dealing with its emotional and social consequences (3).

Living with chronic heart failure (CHF) is distressful and affects daily life. Because of the lack of a cure for CHF, there has been a progressive interest in using health-related quality of life (Hr-QoL) as an outcome measurement of the treatment in patients with CHF. Chronic heart failure (CHF) is still the leading cause of morbidity and mortality in the western world. To suffer from CHF changes the whole life situation and affects daily life negatively. Men with CHF perceived a lack of energy and resignation and women perceived, besides the negative physical effects, a loss of self-confidence, worries and anxiety. The whole situation leads to a burden for the families (4).

Heart failure is a common disabling and deadly disorder, and it has recently reached epidemic proportions. The prevalence and incidence of heart failure increase with age. Symptoms of heart failure and consequences from treatment can have a great impact on the lives of patients with heart failure, and therefore improving health related quality of life (Hr-QoL) is generally recognized as one of the major goals of treatment. Dimensions of Hr-QoL that are considered important for patients with heart failure are functional capabilities, symptoms, feeling of well-being and psychosocial perceptions. In previous studies it was found that patients with heart failure described their Hr-QoL as poor; therefore, interventions to improve Hr-QoL need to be targeted at reducing depression and hostility, increasing daily activity levels, improving knowledge of heart failure, and learning self-care skills (5).

Despite recent improvements in survival related to newer therapies, HF remains a condition with a generally poor prognosis, poorest health perceptions compared with other people and a mortality rate as high as 30%. Persons with HF experience psychological distress, decreased cognitive & social functioning, and recurring troublesome symptoms that lead to diminished quality of life. Similarly, Grady and colleagues found that health perceptions were the second independent predictor of life satisfaction among patients with advanced HF awaiting heart transplantation. The outcomes associated with HF are poor; as one in five people with HF die in the first year they are diagnosed. Importantly, readmission is also very common, with 25% of people affected by HF readmitted within six to nine months following an initial HF admission (6).

Optimal self management of any chronic illness involves the patient engaging in activities that promote their health and control the impact of their illness on their daily life. Additionally, self management involves components which are specific to an individual illness, such as HF, including adhering to treatment regimens, and monitoring and managing illness symptoms. Several non modifiable factors, such as age, gender, education, comorbidity and severity of illness, have been identified as related to HF self management, however, any relationship between HF self management and potentially modifiable factors is not as clear (7).

Among patients with HF fatigue is reported to have an impact on all dimensions of wellbeing. People living with HF have reported that they were getting support from others and had feelings of limitations in social functioning. However, the relationship between fatigue, social support and Hr-QoL among patients with HF is unclear, and research in this area is limited. Elderly patients hospitalized for moderate to severe HF had lower levels of Hr-QoL, compared with a healthy control group. Also middle-aged patients with HF in hospital, and outpatients with HF had worse Hr-QoL than healthy controls and groups of patients with other chronic diseases (8).

Symptoms can be conceptualized as multidimensional in nature with components that include frequency, severity and distress. Effective symptom management requires assessment of the multiple dimensions of symptoms, not merely the presence or absence. Absolute freedom from all symptoms may not be a realistic outcome in patients with heart failure. Recognizing this, nurses must direct their care to minimize the frequency, severity, distress and overall symptom burden to the extent possible. Emerging evidence indicates that the symptom experience of patients with heart failure may be substantially more complex than initially thought (1).

Chapter two: Literature review

Chronic Heart Failure (CHF) is an illness that is increasing among older people, foremost within the industrialized society. The illness increases substantially with age, which correlates with symptomatic CHF manifesting in 10% of patients aged over 80 years. Approximately 80% of those suffering from CHF are older than 75 years. Even so suffering from CHF is likely to have an impact on people's everyday life regardless of their chronological age. Debilitating symptoms of CHF include fatigue and breathlessness as well as thirst. Other commonly described symptoms of CHF include psychological symptoms and difficulties with concentration, feelings of nervousness, sadness and irritability have also been described as common (9).

Patients with heart failure experienced a wide variety of symptoms. High-prevalence symptoms (50% of the sample) included shortness of breath (85.2%), lack of energy (84.9%), dry mouth (74.1%), feeling drowsy (67.9%) and difficulty sleeping (64.2%). Chest pain was reported slightly less frequently than other pain (53.7% and 57.4%, respectively). Psychological symptoms such as difficulty concentrating, worry, feeling sad, feeling nervous and feeling irritable were experienced by 50% or more of the patients. Symptoms thought to be common in patients with heart failure including palpitations, weight gain and swelling of the arms or legs were reported by less than half of the patients. Lack of appetite and constipation were experienced by less than one third of the patients. Problem with urination was reported in about 24% of the patients (10).

Of the high-prevalence symptoms, those occurring most frequently were difficulty sleeping (94.1%), other pain (93.3%), lack of energy (93.3%), difficulty concentrating (92.6%), numbness and tingling in the hands and feet (91.7%), feeling drowsy (91.7%) and shortness of breath (91.1%). Psychological symptoms including worrying, feeling nervous, feeling sad and irritability, occasionally in over 70% of those who experienced the symptom. Of the low-prevalence symptoms, numbness and tingling of the hands and feet, problems with sexual activity, itching and lack of appetite occurred occasionally to almost constantly in almost 76% of the patients (9, 10) .

According to study done by Barbara Riegel Terri E Weaver on Poor sleep and impaired self-care ..., among the high-prevalence symptoms, the most severe were difficulty sleeping (96.8%), other pain (90%), lack of energy (88.6%), shortness of breath (88.6%), numbness and tingling of the hands and feet (87%), feeling drowsy (87%) and difficulty sleeping 55%. Psychological symptoms were at least moderately severe in over 65% of the patients. Less than 60% of the patients experienced difficulty breathing when lying flat; approximately 70% reported those symptoms to be at least moderately severe. Of the low-prevalence symptoms, waking up breathless at night, lack of appetite and problems of sexual activity were at least severe in over 70% of those who experienced the symptom. Symptoms that were most distressing were lack of energy, difficulty sleeping, shortness of breath and waking up breathless at night. Dry mouth was at least quite a bit distressing in only about one third of patients. Chest pain was less distressing than other types of pain. 50% described Problems with sexual interest to be a least “quite a bit” distressing. Swelling of the arms and legs was distressing in only about 30% of patients (10, 11).

According to study conducted in two Swedish hospitals on disturbed sleep; a gender difference was identified; women reported more disturbed sleep. A difficulty falling asleep was reported by 21% of the individuals four months after the MI. Of all patients, 55% reported sleep disturbance sometimes to always, 45% reported almost no sleep disturbance, and 79% did not use any sleep medication (12).

A study conducted by Peter Johansson, et al on Factors and interventions influencing Hr-QoL in patients with heart failure found that those patients suffering from insomnia had a poorer Hr-QoL compared to HF patients without insomnia as well as to those in a normal population. Both depression and/or sleep disturbance may be suspected when patients with HF express themselves as being fatigued. Fatigue is a core symptom of HF as well as a symptom of depression (10, 11).

There were no significant differences in pharmacological management between men and women, in functional status or quality of life according to study done on Poor sleep and impaired self-care. Of the 32 symptoms, only feeling nervous and sweats were more prevalent in women than in men. There was no significant difference in the prevalence of problems with sexual interest between men and women, men experienced greater frequency of the symptom, and had a higher

symptom burden score. Beyond problems with sexual interest, there were no other significant differences in frequency, severity or burden of symptoms between men and women. Only nausea was more prevalent in older patients. Shortness of breath and waking up breathless at night were found to be more distressing and burdensome in younger patients (10).

According to study done in California State University Los Angeles Department of Nursing, Women had significantly higher scores on measures of health perception and constructed meaning, one of the components of psychosocial adjustment to illness. Other measures of psychosocial adjustment to illness were higher in women but not significantly different from those of the men (6).

As to this study the percentage of cardiac patients in each group exceeding the threshold for anxiety was 37% to 44%, compared with only 17% among healthy elders. With regard to depression, 63% of heart-failure patients exceeded the threshold for depression. A total of 62% of post-coronary artery bypass graft patients, compared with 34% of healthy elders, exceeded the hostility threshold. Women expressed significantly greater levels of anxiety and depression than men. Individuals with only high school or less education reported experiencing significantly higher levels of anxiety, depression, and hostility than those who had attended at least some college. There was no interaction or main effect of marital status, ethnicity/race, hypertension, diabetes, or medications used on levels of anxiety, depression, or hostility (13).

Four variables explained 67% of the variance in the final model of HRQOL. These predictors were age, NYHA functional class, TOT burden and finally, TOT Prevalence. In other words, lower age and higher NYHA classification, greater symptom burden and prevalence predicted worse quality of life. Symptom burden and prevalence provided the greatest impact on HRQOL. Poor sleep quality adversely influences well-being by negatively affecting psychosocial, physical and occupational functioning. Overall, poor sleep quality causes mood disturbance, cognitive inefficiency, motor impairment, social discomfort, nonspecific physical ailments, reduced productivity, and poor HRQL (10).

As to study conducted at Helsinki, Finland; to identify predictors of depressive symptoms among coronary heart disease patients, physical exercise was performed by 52% of respondents 2 to 3 times weekly, and by 28% once weekly, whereas 19% performed no physical exercise and 10% of respondents were smokers. Alcohol consumption varied, 26% consumed no alcohol, 21% reported drinking once a month, 31% consumed alcohol 2 to 4 times a month, and 22% reported drinking 2 to 3 times a week. Women were significantly older than men, but no other gender differences were found among demographic, lifestyle, health, symptom, treatment, and social-support variables. Depressive symptoms were seen in almost one fourth (24%) of patients. Gender exhibited a significant connection to depressive symptoms. Almost half (47%) of the women had depressive symptoms, whereas one fourth (27%) of the men had depressive symptoms. Of those with depressive symptoms, 18% were receiving medical treatment and taking antidepressants. Impaired cognition has been documented in 25–50% of persons with HF. The dimensions of cognition impaired in persons with HF and in those experiencing sleep deprivation overlap: attention; working memory; long-term memory; executive functioning; and psychomotor speed. Chronic hypotension and low cardiac output can be understood as potential contributors to impaired cognition because of inadequate brain perfusion (10, 14).

Comorbid illnesses contribute to sleep loss and fragmentation in persons with HF. Several illnesses that are common comorbid diagnoses in those with HF are associated with poor sleep including diabetes, chronic obstructive pulmonary disease, nasal problem, thyroid disease, stroke, and arthritis. Most HF patients are elderly, and insomnia is common in older people. In a survey of elders, pains at night at least three times per week and wheezing or whistling from chest at night were associated with excessive daytime sleepiness. One common but frequently overlooked contributor to poor sleep is the medication regimen including drugs commonly prescribed for HF. Beta-blockers, for example, are associated with impaired sleep, perhaps by causing a decrease in nocturnal production of melatonin. Polypharmacy, common in HF, increases the likelihood of taking drugs that cause excessive daytime sleepiness as a side-effect (10).

HF is notable for its strikingly negative effect on patients' HRQoL. Heart failure has more influence on HRQL than arthritis, chronic lung disease and other cardiac illnesses. Poor HRQL

can be traced to symptom burden and functional limitations. In one study, an average of 7.2 symptoms was identified on HF hospital admission; 6 weeks after discharge these same patients still had 4.2 symptoms, on average. Initially, shortness of breath was most prevalent, but by 6 weeks after discharge, fatigue became the primary symptom. In another sample of HF patients, higher dyspnea scores were associated with poorer HRQL. These symptoms cause significant physical limitations that decrease mobility and usual activities. Persons with HF report levels of vigor lower than other patient populations and similar to those with cancer. Worse HRQL is associated with hospitalization and death in persons with HF (10).

Study by Peter Carson, MD, et al to identify the Relationship of Quality of Life Scores With Baseline Characteristics and Outcomes in the African-American Heart Failure Trial showed that women with HF report worse Hr-QoL than different normative groups as well as when compared to patients with chronic conditions such as diabetes, Parkinson's disease, COPD and females with myocardial infarction. In some of the reviewed studies, women with HF also rated a poorer Hr-QoL than men with HF. Compared to male HF patients; females had more problems in Hr-QoL areas such as sleep, symptoms, energy, physical functioning, emotional and global health. One year after hospital discharge, Hr-QoL had improved in both genders, but the improvements were greater among the male patients. The strongest influencing factors on Hr-QoL in women with HF are physical symptoms such as dyspnoea, physical health and functional status (i.e., NYHA class). Influencing factors may be the same for both genders, but how these factors affect Hr- QoL for men and women may be different. Worse (higher) MLHFQ scores were associated with younger age (<65 years), female sex, high body weight and body mass index, high NYHA class, nonischemic etiology, low systolic blood pressure, high heart rate, and chronic obstructive pulmonary disease (11, 15) .

In research done by Barbara Riegel, et al on Gender-specific barriers and facilitators to heart failure self-care, men described confidence in their abilities to interpret their symptoms as related to HF (“I know if something changed . . . I feel fairly confident . . .”), in spite of the fact that they had more comorbid illnesses than the women. In contrast, women described uncertainty in their assessments of HF symptoms. For men, robust social support from spouses, children and parents facilitated execution of day-to-day self-care practices. Women reported better emotional

support from family and friends than the men. Men, on the other hand, described feeling anxious or fearful rather than feeling depressed. Another mood revealed only by young men in the sample was anger (16).

In Symptom Burden, Depression, and Spiritual Well-Being study by David B. Bekelman, MD, et al in Baltimore, Maryland after adjustment for demographic characteristics, patients with heart failure had similar levels of symptom burden, depression symptoms, and spiritual well-being compared to patients with advanced cancer. More than half of heart failure patients reported shortness of breath, lack of energy, pain, feeling drowsy, or dry mouth. 30% of heart failure patients had probable depressive disorder using the cutoff score of five on the GDS. Patients with worse heart failure-specific health status (KCCQ score < 50) had a greater overall symptom burden, more depression symptoms, and worse spiritual well-being compared to patients with better heart failure-specific health status after adjustment for socio-demography & had a mean of 13.2 physical symptoms in the prior week compared to 7.6 symptoms in the better heart failure-specific health status group (17).

As to study conducted at Beth Israel Medical Center in New York, on Symptom Distress and Quality of Life, patients reported a high prevalence of many symptoms, as well as relatively high levels of symptom intensity, frequency and distress. The median number of symptoms per patient was nine (range 0–26). Symptoms with the highest prevalence were lack of energy (66%), dry mouth (62%), shortness of breath (56%), and feeling drowsy (52%). Other prevalent symptoms included numbness or tingling in hands and feet (48.5%), difficulty sleeping (44.1%), cough (40.8%), anorexia (31.1%) and a cluster of psychological symptoms: worrying (43.7%), feeling sad (42.7%), feeling nervous (35.9%), difficulty concentrating (33%), feeling irritable (33%) & Pain (“chest pain or pressure” 29% and “other pain” 37% of patients. Symptom distress was reported by a substantial proportion of those patients with the most prevalent symptoms: lack of energy 44.8%, dry mouth 14.1%, shortness of breath 43.1%, and feeling drowsy 24.1%. High symptom-associated distress was similarly reported by 26.7% of patients with chest pain, 54.1% of those with other types of pain, and 33.3% and 34.1% of those who endorsed the symptoms of worrying and feeling sad, respectively (18).

In this study done in Beth Israel Medical Center in New York, although most patients reported relatively high levels of psychological well-being, 24% were at or below the cut-off for depression. Overall, patients noted a relatively mild degree of functional impairment, and a moderate compromise in global quality of life.

Quality of life, as measured by the MILQ composite score, demonstrated a strong negative association with all indices of symptom distress; the score on the MSAS GDI had the greatest absolute value, suggesting the strongest association between global symptom distress and impaired quality of life. Impairment in quality of life also was associated with the number of co morbidities, female sex, and functional impairment, as depicted on the SIP. Overall psychological dysfunction appeared to show a greater association than physical dysfunction. Psychological well being, as measured on the MHI-5, was positively related to the MILQ (18).

The result of study done on Pain and Quality of Life in Hospitalized Patients in two acute care hospitals in Norway showed that as many as 80% of the patients reported having one or more chronic conditions in addition to HF. The most common co morbidities were lung disease (31.2%), diabetes (30.1%), musculoskeletal disease (21.5%), cancer (16.1%), skin disease (15.1%), gastrointestinal disease (14.0%), and psychiatric disorders (4.3%). In addition to HF, one condition was reported by 47.3% of the patients, two by 16.1%, three by 12.9%, and four or five by 3.3% of the patients. Data on medications were collected for 78 (83.9%) of the patients. While in the hospital, patients were taking an average of seven medications for HF, other medical conditions, and pain (20). The mean QOL score was 54.7. QOL scores ranged from a low of 6.0 to a high of 95.1. With respect to demographic characteristics, no differences in mean QOL scores were found based on age, gender, marital status, cohabitation, or educational level. With respect to disease-specific characteristics, a significant negative correlation was found between the patients' EF values and total QOL scores. In addition, significant differences in total QOL scores were found among the four NYHA classes (19).

A study undergone in Ontario, Canada on Symptom of Pain in Individuals Hospitalized for Heart Failure showed that at the time of discharge from hospital, 68% of the participants reported experiencing pain (the reported pain group). The severity of pain also varied throughout the 6-

week period. At discharge, 69% of these individuals rated their pain as moderate or severe, and by week 6, just over half, 59%, continued to experience pain at this intensity. Fifty-four individuals (31%) did not report pain at discharge (the no pain group) (20).

At discharge, the difference in the total MLHFQ scores between the reported pain and no pain groups reflected a clinically important difference of 13.29 (minimally clinical importance difference being 5 points), which was statistically significant with the no pain group reflecting less deficit from HF. Significant differences between the groups were also identified at discharge for emotional aspects such as depression, worry, feeling a loss of control over one's life, and feeling as if one was a burden to one's family. Those who reported pain also reported more difficulties sleeping. For the no pain group at discharge, there was a statistically significant decrease in the total MLHFQ scores from time of discharge (35.24) to week 2 (27.61) (20)

According to study done by Craig D. Blinderman, Peter Homel, J. Andrew Billings et al. on 'Symptom Distress and Quality of Life' in America and England, the most prevalent symptoms were lack of energy (66%), dry mouth (62%), shortness of breath (56%), and drowsiness (52%). Pain was reported by about one-third of patients. Quality of life was moderately compromised (MILQ composite, median = 56, possible range 12–84). Impairment in quality of life was strongly associated with global symptom distress; burden of comorbid conditions, female sex, functional impairment, particularly psychological impairment, and poorer psychological well-being. Distressful symptoms related to impaired quality of life included lack of energy, irritability and drowsiness. Community dwelling patients with advanced CHF experience numerous symptoms, significant symptom distress, and a compromised quality of life. Overall quality of life was strongly associated with symptom distress, psychological well-being and functional status (18).

Significance of the study

Heart failure is an escalating public health problem around the world. Cardiovascular disease imposes burdens on patients, their families, and society as a whole. Living with chronic heart failure (CHF) is distressful and affects daily life. Optimal self management of any chronic illness involves the patient engaging in activities that promote their health and control the impact of their illness on their daily life. Despite this most heart failure patients have substandard quality of life and impaired activity performance to take care of themselves.

So far there are no studies that documented the effect of symptoms of heart failure on the quality of life of cardiac patients in the study area. The majority of the heart failure symptoms researches in patients with cardiovascular diseases have been performed by physicians within cardiovascular medicine, pulmonary medicine and cardiology; and only a few studies are performed by cardiovascular nurses. Hence, many questions associated to heart failure symptoms still remain to be examined from a cardiovascular nursing perspective. Development of tools to recognize heart failure symptoms related sleep and breathing disorders in clinical practice is of great importance.

So this study is aimed to assess the relationship between different symptoms of heart failure and patients' quality of life and to identify priority nursing intervention areas for patients suffering from chronic heart failure. In addition related studies to this topic are not yet conducted in Ethiopia and the findings of this study will be used as a baseline data for future studies.

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Conceptual framework

The following diagram is formulated after referring different literatures to represents the relationships among variables under study on how they affect each other. Patient socio-demographic characteristics as well as disease and treatment related factors influence health related quality of life in patients with heart failure

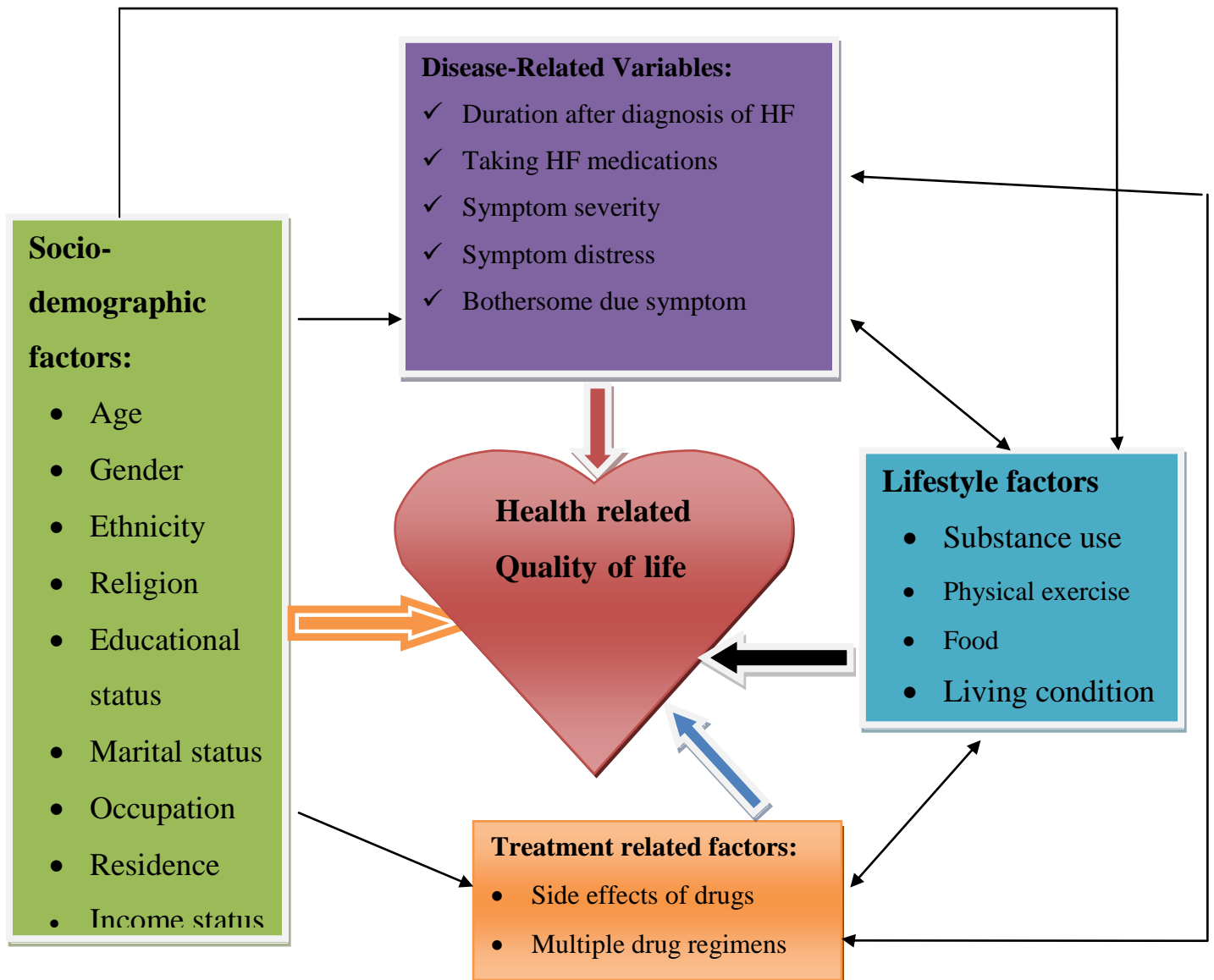


Figure 1: Conceptual framework

Chapter three: objectives

3.1. General objective

The main aim of this study is to determine the relationship of symptom burden and health related quality of life in patients with heart failure attending JUSH chronic illness clinic.

3.2. Specific objectives

- 1) To identify the symptom burden in terms of prevalence, severity & distress in patients with heart failure attending JUSH chronic illness follow up clinic.
- 2) To identify predictors of health related quality of life (HRQoL) in patients with heart failure attending JUSH chronic illness follows up clinic.
- 3) To determine the relationship of symptom burden and health related quality of life (HRQoL) in patients with heart failure attending JUSH chronic illness follow up clinic.

Chapter four: Methods and materials

4.1. Study area and period

This study was conducted from February 10 to April 10, 2011 in Jimma university specialized hospital (JUSH) found in Jimma Town. The town is located 357Kms South West of Addis Ababa. The town is divided in to 3 Woreda/ Keftegnas which are further divided in to 13 kebele. Population of Jimma town is estimated to be 120,600 of which 60,590 are males and 60,010 are females (2007 census). Jimma University specialized hospital (JUSH) is one of the oldest public hospitals in the country. It was established in 1937(1930 E.C) by Italian conquerors for the service of their soldiers. At first, it was called “Ras Desta Damtew hospital” after the name of an Ethiopian patriot during Italian career. It provides specialized health services through its 9 medical and other clinical and diagnostic departments for approximately 9,000 inpatients and 80,000 outpatients each year with bed capacity of 440 and a total staff of more than 557. Currently, the hospital has more than 340 health professionals of different categories ranging from health assistant to senior specialists, and 258 support staffs. Out of these health professionals, 213 are different category of nursing staff as MSc.N, BSc Nurse, BSc midwifery, psychiatric nurse, diploma midwifery nurses, anesthetic nurse, ophthalmic nurse, dental nurse, and other staffs including 65 physicians, 20 pharmacist and pharmacy technicians, 21 medical laboratory and laboratory technicians, 10 radiographers & radiologists and 15 patient registration clerks and others like anesthetists, physical therapists. Chronic illness clinic is one of the units of JUSH. Currently the number of PLWHF coming to the chronic illness clinic of JUSH is about 502. The clinic is currently running with 5 nurses and others including senior residents and interns who are changing from time to time.

4.2. Study design

A cross-sectional study design using both quantitative and qualitative data capture methods was conducted to assess symptom burden and health related quality of life (Hr-QoL) in patients with heart failure

4.3. Population

4.3.1. Source population

All **adult** heart failure patients attending JUSH chronic illness follow up clinic during the study period.

4.3.2. Study population

All adult heart failure patients attending JUSH chronic illness follow up clinic during the study period who were selected to participate in the study.

Inclusion criteria

- ✓ All adult PLWHF.

Exclusion criteria

- ✓ PLWHF attending JUSH chronic illness follow up clinic who can't respond to the questionnaires because of hearing or mental impairments secondary to severity of symptoms or other problems.

4.4. Sample size determination and sampling techniques

4.4.1. Sample size determination for quantitative study

The sample size was calculated using a formula for estimation of single population proportion based on the following assumptions. Since the proportion of poor health related quality of life of PLWHF was unknown in Ethiopia, 50% of population proportion was used to determine sample size. In addition, a desired precision of 5%, 95% confidence level and 5% none -response rate was considered.

$$n = \frac{(Z\alpha/2)^2 p(1-p)}{d^2} = 384$$

Where: Z= is standard normal variable at 95% confidence level (1.96)

p= the proportion of poor health related quality of life of PLWHF (50%)

d= the desired marginal error (5%)

n= the total sample size

With which sample size (n) become 384. Since the number of source population is less than ten thousands, the population correction formula was employed.

$$n_f = \frac{n}{1+n/N}$$

Where:

N= total number of PLWHF attending chronic illness follow up clinic of JUSH (502)

$$n_f = \frac{384}{1+384/502}$$

$$n_f = 218$$

After which n_f become 218 and considering 5% non-response rate of this, lastly the final sample size was 229.

4.4.2. Sample size determination for qualitative study

The sample size was determined by saturation of required data based on the interview guide questions related to commonly experienced symptoms. Accordingly 9 key informants were involved in qualitative study.

4.4.3. Sampling technique for quantitative study

To select the sampling units, simple random sampling method was used. To do this, first sampling frame of those PLWHF 15 years or above was prepared according to the JUSH card room registration number. Cards of the sample units were selected randomly from 502 heart failure patients attending their follow up at JUSH chronic illness clinic and the clients were interviewed on the day of their appointment.

4.4.4. Sampling technique for qualitative study

After thorough discussion with nurses working in chronic illness clinic of JUSH, key informants (those heart failure patients) who are willing, not participated in the quantitative study and able to respond properly to the study questions were selected and interviewed purposively from those PLWHF attending the clinic.

4.5. Method and tools of data collection

4.5.1. For quantitative study

The assessment tool was composed of questions to assess socio-demographic characteristics, prevalence of HF symptoms and effect of symptom prevalence and symptom burden on health related quality of life. For symptom prevalence and burden the modified revised version of the memorial symptom assessment scale (MSAS) and Minnesota living with heart failure questionnaire (MLHFQ) were used after local adaptation. Four Nurses working in the chronic illness follow up clinic and other units of JUSH were trained a week ahead of the actual data collection period, and were recruited as data collectors. Data were collected by using structured interviewer administered questionnaire. The data collection method employed was an interview. Additionally, as supervisor, one nurse with more experience and who can speak English, Afan Oromo and Amharic languages was trained and recruited.

4.5.2. For qualitative study

For exploration of symptom prevalence and their effect on daily life activities, an in depth interview was conducted with key informants by using semi structured interview guide till data saturation reached. All interviews were tape recorded and a field note was taken and transcribed to statements immediately after recording in order not to miss information.

4.6. Study variables

4.6.1. Independent variables

Socio-demographic variables

- Age
- Gender
- Ethnicity
- Religion
- Educational Status
- Marital Status
- Occupational status
- Residence
- Income status

Disease-Related Variables

- ✓ Duration after diagnosis of HF
- ✓ Taking heart failure medications
- ✓ Symptom severity
- ✓ Symptom distress
- ✓ symptom burden

Treatment related factors

- side effects of medications
- multiple drug regimens
- physical exercise

Lifestyle factors

- Living condition
- Substance abuse
- Physical exercise
- Food restriction

4.6.2. Dependent variable

- Health related Quality of life

4.7. Operational definitions

Hr-QoL (Health related Quality of life): is defined as the perception of the effect of an heart failure and its treatment on physical, emotional, social, and economic aspects of daily life

Good health related quality of life: if the patient's score for quality of life measurement scale is greater than or equal to mean plus standard deviation he/she is considered to have good health related quality of life and if less than mean plus standard deviation he/she was considered as having poor health related quality of life.

Symptom severity

- ✓ ***Mild Symptom***: if the clients' perception for rating of symptom severity is 1 it is considered as mild symptom
- ✓ ***Moderate symptom***: if the clients' perception for rating of symptom severity is 2 it is considered as moderate symptom
- ✓ ***Severe symptom***: if the clients' perception for rating of symptom severity is 3 it is considered as severe symptom

Symptom prevalence: The presence of a symptom. It may be further described in terms of *frequency, onset and duration*.

Symptom distress: "the degree of physical or mental upset, anguish, or suffering experienced from a specific symptom". Classified as follows:

- ✓ ***Mild distress/bothersome due to symptom***: if the clients' perception for rating of symptom distress/bothersome is 1 to 2 it is considered as mild distress/bothersome symptom
- ✓ ***Moderate distress/bothersome due to symptom***: if the clients' perception for rating of symptom distress is 3 it is considered as moderate distress/bothersome symptom

- ✓ **Severe distress/bothersome due to symptom:** if the clients' perception for rating of symptom distress/bother is 4 to 5 it is considered as severe distress/bothersome symptom

Definitions of terms

Heart failure: HF is the inability of the heart to pump sufficient blood to meet the needs of the tissues for oxygen and nutrients.

Quality of life: The degree to which a person enjoys the important possibilities of his or her life. Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors.

Chest pain: Chest pain may be a symptom of a number of serious conditions and is generally considered a medical emergency. Even though it may be determined that the pain is **non-cardiac** in origin, this is often a diagnosis of exclusion made after ruling out more serious causes of the pain.

Constipation: A condition in which one is not passing stools, which are hard and small and painful, for a week and/or experiencing a feeling of fullness in the stomach.

Cough: A form of violent exhalation which may be accompanied by persistent and dry or productive yellowish, greenish, or whitish sputum.

Depression: When one may feel "blue/causing a feeling of despair and hopelessness," "low," "depressed," or "sad." These feelings may also be associated with insomnia (trouble sleeping), weight loss or gain, a change in one's appetite. The client may notice that he/she does not have any interest in things that once gave him/her pleasure.

Diarrhea: A condition in which one may experience three or more loose or watery stools (bowel movements) per day.

Dizziness: A state in which one may experience black outs (to lose consciousness, sight, or memory temporarily) when trying to stand

Fatigue: States in which one may feel tired or weary, exhausted, or experience a loss of concentration. Some fatigue in life is to be expected.

Feeling "Bloated": These gas-related symptoms are not just uncomfortable; they can be embarrassing and even painful.

Feeling sad: Feeling sad or unhappy is normal when something goes wrong or you lose someone. These feelings often go away with time and you feel better. If these feelings are severe or affect everyday life for more than 2 weeks, a person should see his/her doctor

Insomnia (loss of sleep): When one may be unable to sleep, sleep prematurely, have sleep that is interrupted by periods of wakefulness.

MLHFQ: The minnesota living with heart failure questionnaire is composed of 21 questions. The patient is expected to grade each question from 0 to 5. His/her judgement must be based on how much his/her heart condition influenced the specific activity over the last two weeks. The best score is 0 and the worst score is 105.

Nausea: A condition in which one may experience nausea, upset stomach, retching, heaving, sickness of the stomach. At time, nausea is accompanied by vomiting. He/she may also experience headaches and loss of appetite (no desire for food), which may result in loss of weight.

Numbness and tingling: these are abnormal sensations that can occur anywhere in your body, but are often felt in your fingers, hands, feet, arms, or legs

Palpitation: forcible and/or irregular beating of the heart such that the person becomes conscious of its action

Shortness of Breath: A condition in which one may feel an unpleasant sensation of difficulty breathing, inability to take a deep breath, being “winded,” or a “smothering” feeling.

Symptom: “Any morbid phenomenon or departure from the normal in structure, function, or sensation, experienced by the patient and indicative of disease. It is a change in the way the body works or a change in the body’s appearance, which shows that a disease or disorder is present and which the person is aware of.

Symptom burden: the distress or bother resulting from one or more symptoms, in isolation or with a cumulative effect, as perceived by the patient and reported by the patient or significant others, thereby attaching their own meaning and related burden. The major antecedent was multiple symptoms related to worsening disease status. Consequences of symptom burden included decreased survival, poor prognosis, delay or termination of treatment, increased hospitalizations and medical costs, decreased functional status, and lowered self-reported quality of life. Symptom burden is defined as the subjective, quantifiable prevalence, frequency, and

severity of symptoms placing a physiologic burden on patients and producing multiple negative, physical, and emotional patient responses.

Vomiting: - is the expulsion of stomach contents through the mouth. When the effort of vomiting is made, but nothing is brought up the process is known as retching.

Weight Loss (Unplanned): When one may experience a loss of 10% or more of his/her usual body weight, when he/she did not intend to lose weight

Worry: Worry is thoughts and images of a negative nature in which mental attempts are made to avoid anticipated potential threats. As an emotion it is experienced as anxiety or concern about a real or imagined issue, usually personal issues such as health or finances or broader ones such as environmental pollution and social or technological change (21, 22).

4.8. Data processing and analysis procedures

4.8.1. For quantitative study

Data were coded and entered into SPSS windows version 16.0 soft ware package for analysis. Binary and multivariable logistic regression analysis were used to examine the likelihood of effect of the symptom prevalence and burden on health related quality of life that was summarized and categorized from the questionnaires as reported by the study respondents. Common descriptive statistics were considered as per variables of interest. Significant values were declared at p value of less than 0.05.

4.8.1. For qualitative study

Qualitative data were first transcribed from Amharic and/or Afan Oromo to English in verbatim and color-coded and grouped based on thematic frameworks. The themes were symptom prevalence, symptom frequency, symptom severity and symptom distress. Concepts extracted from themes were presented in narratives and triangulated with the quantitative results using the verbatim of subjects as illustrations.

4.9. Data quality management

The questionnaire was prepared in English and then translated into Amharic and Afan Oromo and back to English to check for consistency by three language experts separately and then combined together. The Amharic and/or Afan Oromo version of the questionnaire was pre-tested

on 5% (11) of the sample size a week before the beginning of actual data collection period at Limmu Genet Hospital chronic illness follow up clinic and some amendments were made. After the pre test one question was totally eliminated from the tool because it was not well understood by the study participants and not applicable for them and arrangement of the questions were made because there were sexuality sensitive questions and they were brought to be asked at last not to frustrate the participants. Moreover, during the data collection, data collectors were strictly supervised. At the end of each data collection day the principal investigator was checked out the completeness of filled questionnaires and whether recorded information made sense to ensure the quality of collected data. Any error, ambiguity, incompleteness, or other encountered problems were addressed on the following day before starting next day's activities.

4.10. Ethical considerations

Ethical clearance letter was obtained from Jimma University College of Public Health and Medical Sciences Ethical Committee. Then written consent was secured from JUSH matron office, which was provided to the respective bodies of chronic illness follow up clinic of JUSH. Further, study participants were briefed about the study by data collectors stating the main objective of the study and clarifying any unclear points related to the study after which the interviews were started. In addition participants were informed that they have full right to refuse participating in the study and can interrupt the interview if not comfortable with the interview, but they were informed that their participation in the study will have invaluable importance. Confidentiality of the information was assured and privacy of the study population was respected and kept as well. To ensure this confidentiality the name of the respondents were not written on the questionnaire sheet. Moreover, to keep confidentiality and privacy, the data collection was made by those nurses working in the chronic illness follow up clinic in collaboration with other nurses from other units.

4.12. Dissemination of results

The result of the study will be presented for jimma university scientific community, disseminated to Jimma University College of Public Health and Medical Sciences Graduate School, Jimma University Department of Nursing and JUSH. Further, the result will also be accessed for

utilization for all recognized bodies working on alleviating related concerns of PLWHF. It will also be published on peer reviewed journals.

Chapter Five: Results

A total of 223 heart failure patients attending their follow up at JUSH chronic illness clinic were involved in the study giving a response rate of 97.38%. In addition 9 qualitative informants were interviewed.

5.1. Socio-demography

From the 223 patients involved in the study 118(52.9%) were males and 46(20.6%) were within the age group greater than 65years and the least 22(9.9%) were in the age group 15-24 with over all mean age of 47.12 ± 17.65 years. Concerning ethnicity majority 173(77.6%) were Oromo and 2(0.9%) Tigre. With regard to religion 160(71.7%) were muslim. concerning occupation majority 104(46.6%) of the respondents were farmers. About 141(63.5%) were from rural areas. The majority 218(97.8%) were living with their families whereas only 3(1.3%) and 2(0.9%) were living alone and with their relatives respectively (Table 1).

Table 1: Socio-demographic characteristics of PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

	Variables	Frequency	Percent
Age group	15-24	22	9.9
	25-34	38	17.0
	35-44	45	20.2
	45-54	32	14.7
	55-64	40	17.9
	65+	46	20.6
Sex	Male	118	52.9
	Female	105	47.1
Ethnicity	Oromo	173	77.6
	Amhara	16	7.2
	Tigre	2	0.9
	Dawro	15	6.7
	*Others	17	7.6
	Religion	Muslim	160
	Orthodox	39	17.5
	Protestant	24	10.8
Occupation	Student	16	7.2
	Farmer	104	46.6
	Government employee	17	7.6
	Daily laborer	8	3.6
	Housewife	63	28.3
	Merchant	6	2.7
	**Others	9	4.0

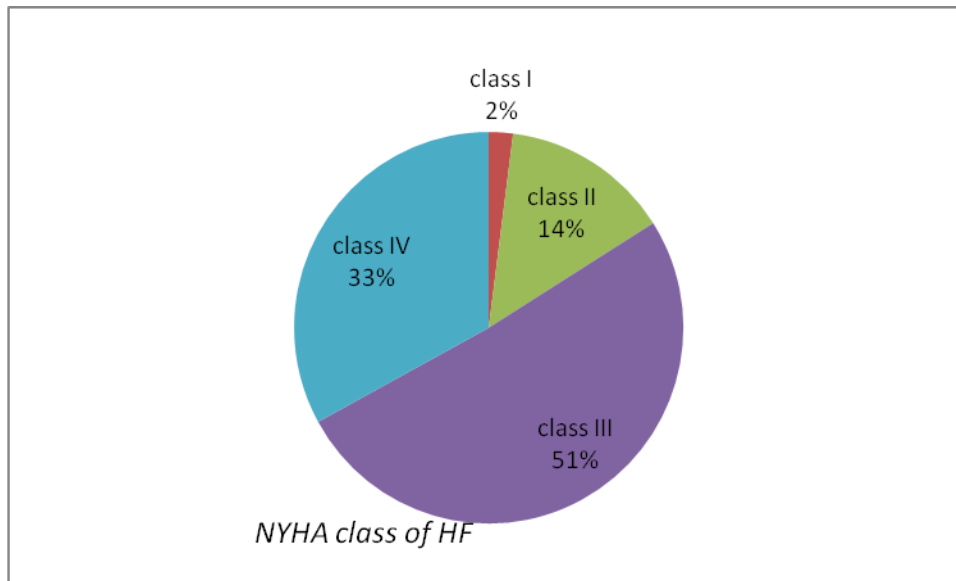
Sociodemographic data cont'd ...			
Variables		Frequency (n=223)	Percent
Educational status	Illiterate	135	60.5
	Read and write only	7	3.2
	1-6 grade	33	14.8
	7-8 grade	13	5.8
	9-10 grade	15	6.7
	11-12 grade	7	3.2
	College or above	13	5.8
Living Condition	With family	218	97.8
	Alone	3	1.3
	With relatives	2	0.9
Place of Residence	Urban	82	36.8
	Rural	141	63.2
Monthly income	<150	55	24.7
	150-300	49	22.0
	301-450	33	14.8
	451-600	32	14.3
	601+	54	24.2
Marital status	Single	36	16.1
	Married	160	71.7
	Divorced	6	2.7
	Widowed	21	9.4
Family size	<4	55	24.7
	4-8	136	61.0
	9- 12	31	13.9
	>12	1	0.4
Duration after diagnosis	<=3years	131	58.7
	Greater than 3 years	92	41.3

*yem, kefa, guraghe, sidama

** cherchari, cleaner, secretary, runner

5.2. NYHA class of patient's HF

About 114(51%) of the respondents were on heart failure NYHA class III and only 4(1.8%) of them were on class I.

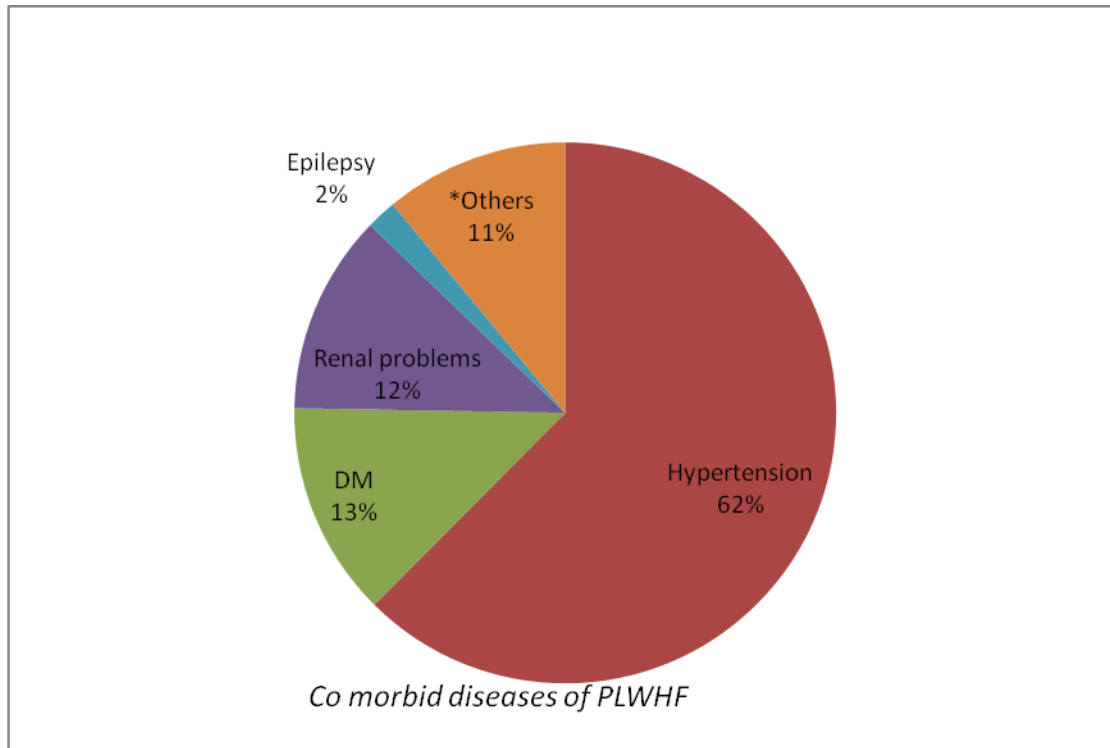


NYHA: New York heart association class of severity of the disease

Figure 2: NYHA classification of the heart failure status of PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

5.3. Co morbidity

From all the study participants 109(48.9%) have co-morbidity of other chronic illnesses among which hypertension 68(62.4%), DM 14(12.8%), epilepsy 2(1.8), and others 25(22.9) etc were reported. This is supported by majority of qualitative key informants in which most of them reported presence of hypertension, renal failure, diabetes mellitus and epilepsy in addition to heart failure. For instance, one 56 years old man said “...hypertension is more distressing/bothering me than heart failure...”



*others: MI, gastritis

Figure 3: Co morbid diseases of PLWHF attending chronic illness follow up clinic of JUSH, April 2011

5.4. Effects of symptom burden on activities of daily living

From the total respondents, majority 208(93.3%) reported impairment of activity of daily life among which about 193(92.3%), 173(83.2%), 125(60.1%), 15(7.2%) and 16(7.7%) reported impairment in doing yard work, walking, shopping and keeping their grooming and going to toilet independently respectively. Similar with this finding, all qualitative study participants reported that they are unable to perform their activities of daily living as when they were healthy so that they are dependent on their families and relatives. Two of the key informants reported that *it is very tiresome even to keep their personal hygiene, to feed and cook their own food*. One 36 years old man said “...I was completely ceased from farming activities after I caused this heart failure...”

Table 2: Impairment in activities of daily life among PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

Impairment in:	Frequency	Percent
Self feeding	19	9.1
Self grooming	15	7.2
Self dressing	25	12.0
Walking	173	83.2
Shopping	125	60.1
Yard working	193	92.8
Toileting	16	7.7
Cooking	71	34.1
Bathing	24	11.5

Majority of the respondents 202(90.6%) said that those symptoms they were experiencing are affecting their quality of daily living in different ways. Of the total 223 study participants about 194(87.0%) have complained the presence of respiratory problems at different times during a day. About 131(59.0%), 78(35.1%), 11(5.0%) and 3(1.4%) of the respondents reported that they were using 1, 2, 3 and 4 pillows respectively during their sleep times. This finding is supported by qualitative study in which *majority of the key informants said that they are suffering from respiratory difficulties during activities and even at rest after this illness as they all using more than 2 pillows during their sleep or lying down.*

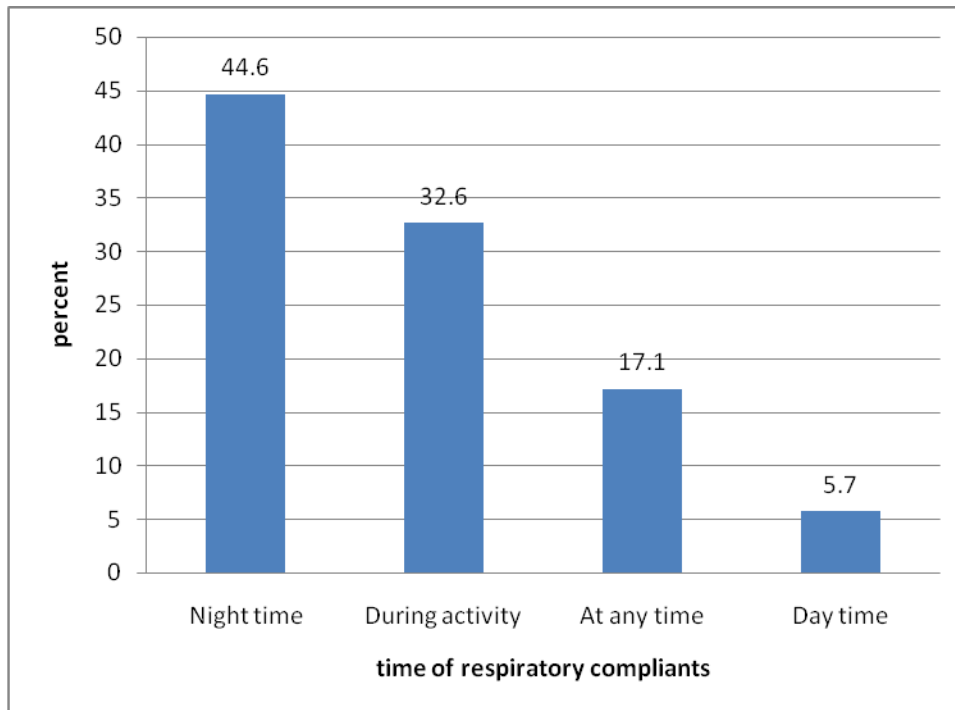


Figure 4: Time/period of respiratory complaints reported by PLWHF attending chronic illness follow up clinic of JUSH, April 2011

5.5. Medication being used by the study participants

Concerning medications being used by the study respondents (patients) 196(87.9%) were taking different types of diuretic medications especially lasix and spiranolactone. Similarly some of qualitative key informants reported that they were using combined or single diuretics, ACEIs, digitalis β -blocker and ASA in addition to other medications. However, two key informants did not know exactly the name and types of medication they were taking: simply they said “...*the white, the red, the small tablets...*” to describe the type of medicating being used.

Table 3: Types of medications PLWHF attending chronic illness follow up clinic of JUSH were using, April 2011((n=221)

Medication being used by the patients	Frequency	Percent
ACEI	156	70.0
Diuretics	196	87.9
Digitalis	105	47.1
β - blockers	89	39.9
Anticoagulants (ASA)	134	60.1

**the total percent is >100% because a single patient can take two or mere medications at a time.*

As to the number of medications being used by a single patient; 2(0.9%) individuals were not using any type of medication, 50(22.4%) and 71(31.8%) individuals were using 3 and 4 medications, respectively while only one patient used 6 medications together. The average number of medications being used by the study participants was 3.1 ± 1.3 (ranging from 0 to 6). There is no statistical association between multiple drug use and health related quality of life. (Table 4)

Table 4: The number of medication a single patient was using during the study period among PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

Number of medication	Frequency	Percent	Mean	Std. Deviation
0	2	0.9		
1	25	11.2		
2	47	21.1		
3	50	22.4	3.1121	1.25597
4	71	31.8		
5	27	12.1		
6	1	0.4		

5.6. Perceived medication side effects

Even though almost all of the study subjects were using one or more medications only 34(15.4%) reported the presence of perceived medication side effects while the rest 187(86.4) had no side effect of medications. Of these about 16(47.1%) reported that the side effects were due to lasix and about 14(41.2%) said that they did not know which medication is causing the side effects. (Table 5) Medication side effect has no significant relation with health related quality of life ($p > 0.05$).

Table 5: Perceived medication side effects by the study participants and measure they have taken to halt those side effects among heart failure patients attending chronic illness follow up clinic of JUSH, April 2011 (n=34)

Medication	Frequency (%)	Perceived side effects	Measure taken
Lasix	16(47.1)	Polyurea, gastritis	Antiacids, consulting their doctors, no measure taken
Enalapril	1(2.9)	Gastritis, cough	Antiacid
Predinsolone	1(2.9)	Gastric pain	No measure taken
Unknown	14(41.2)	Cough, weakness, blurred vision, hearing problems, polyurea, loss of appetite, gastric pain, loss of sleep, abdominal discomfort	Consulting their doctors, taking antiacids, deciding to stop taking medication, eating 'berbere', decreasing the dose of medications, 'drinking telba', taking no measure
The white medication	2(5.9)	Polyurea	No measure taken

5.7. Substance use

Of the total 223 only 55(24.7%) chew khat and/or drink alcohol of which 48(87.2%) chew khat and 7(12.8%) drink alcohol (Fig 5). About 42(85.7%) of them use these substances rarely and 7(14.3%) uses frequently. *This is not supported by qualitative findings.* There is no statistical significance in health related quality of life and substance use ($p>0.05$).

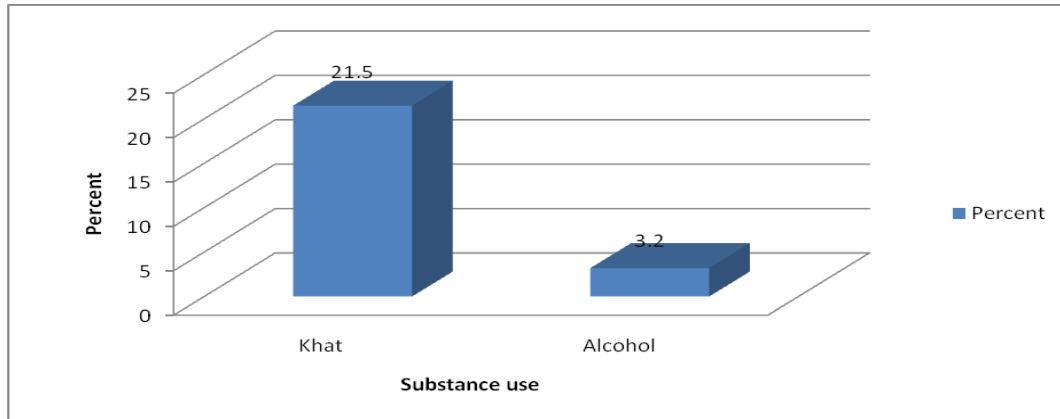
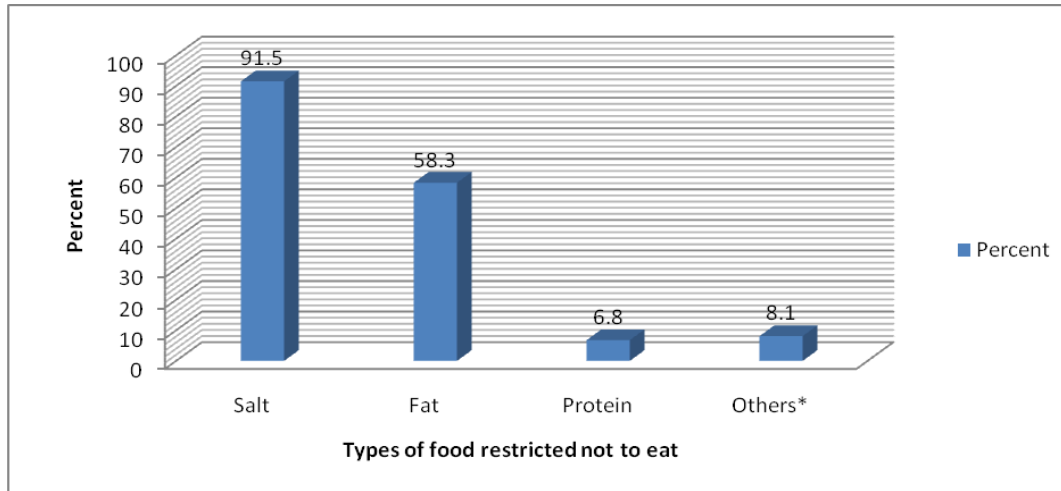


Figure 5: Percentage of patients using khat and alcohol among PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

5.8. Diet/food restriction and exercise

Regarding their diet from the total 223 respondents 209(93.7%) had at least one food restriction. This is strengthened by qualitative informants in which *all had at least one food restriction. For example, almost half of participants reported that they were restricted salt and fat, one-third restricted only salt diet and about one-fourth restricted others such as protein, coffee, tea.*



* bread, tea, berbere

Figure 6: Percent of different types of food patients were restricted not to eat, April 2011

Only 33(14.9%) of respondents get social support from kebeles and local edirs. Of the total 223 study respondents only 10(4.5%) do physical exercises while the rest 95.5% did not do any type of physical exercise. The types of physical exercises they were doing were lifting weight, playing foot ball for short period, playing basket ball, walking, moving legs while lying flat and doing other minor activities. *Only one participant of the qualitative study does physical exercise while the rest did not.* There is no statistically significant association between health related quality of life and doing physical exercise ($p>0.05$).

5.9. Symptom burden

Regarding the number of symptoms patients had in two weeks prior to the study period 2(0.9%) had no symptom, 10(4.5%) had only 2 symptoms, 9(4%) had 4 symptoms while 24(10.8%), 23(10.3%), 17(7.6%), and 15(6.7%) respondents had 7, 11, 9, and 8 symptoms respectively. Only 1(0.4%) patient had 27 and another 1(0.4%) patient had 26 symptoms (Table 6). As reported by the study participants in the qualitative study *all the nine informants had greater than or equal to 8 symptoms with mean being 13 symptoms in two weeks prior to the study with two of them having 18 symptoms, four having 12 symptoms and the rest having 8, 11 and 14 symptoms.*

Table 6: Number of symptoms among PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

Number of symptoms	Frequency	Percent
0	2	0.9
2	10	4.5
3	4	1.8
4	9	4.0
5	7	3.1
6	11	4.9
7	24	10.8
8	15	6.7
9	17	7.6
10	13	5.8
11	23	10.3
12	14	6.3
13	13	5.8
14	13	5.8
15	4	1.8
16	10	4.4
17	6	2.7
18	6	2.7
19	7	3.1
20	5	2.2
21	5	2.2
23	1	0.4
25	2	0.9
26	1	0.4
27	1	0.4

5.10. Symptom prevalence

Patients with heart failure experienced a wide variety of symptoms. On average the respondents had 10.79 ± 5.3 symptoms. High-prevalence symptoms ($\geq 50\%$ of the sample) included lack of energy (86.5%), shortness of breath (81.2%), palpitation (68.6%), feeling drowsy (57.8%), chest pain (57.8%), orthopnea (57.8%), cough (55.6%), waking up breathlessness at night (52.5%), lack of appetite (52%) and dizziness(45.7%). Qualitative finding support this result. For instance, one 56 years old interviewee said that he *commonly experienced lack of energy, SOB, palpitation, chest pain and lack of appetite*. In addition one 42 years old women said “...*in the past two weeks I felt very tired, I had no interest to eat as usual, I felt drowsy at day time, I suffered a lot from shortness of breath and there was stab like pain ‘wugat’ in my chest...*”

Symptoms thought to be common in patients with heart failure including worrying, difficulty sleep and swelling of the arms or legs were reported by less than half of the patients in this sample. Diarrhea, problem urination, weight loss, weight gain, other pain, and vomiting were experienced by less than 15% of the patients (Table 7). *Only one 59 years old man in qualitative study reported having swelling of legs in the past two weeks before the study.*

5.11. Symptom frequency

Of the high-prevalence symptoms, those occurring most frequently were lack of energy (52.8%), chest pain (44.9%), Shortness of breath (34.2%), palpitation (28.8%), cough (28.2) and orthopnea (24.8%). Psychological symptoms including feeling sad, feeling nervous, feeling irritable and worrying occurred at least frequently to almost constantly in about 10-25% of those who experienced the symptom. Of the low-prevalence symptoms, diarrhea, problems with urination, itching, other pain and vomiting occurred at least frequently to almost constantly in less than 38% of those who experienced the symptom(Table 7). One 36 years old man said “...*I repeatedly suffered from weakness, orthopnea (breathlessness at lying position), and palpitation, problem during urination like burning sensation, polyurea and shortness of breathing...*” Another 24 years old lady said “...*my main problem in relation to this illness is that I always feel tired especially when walking and doing any type of activity so that I withdrawn from my school...*” In addition to this tiredness she said “...*I have experienced SOB, chest pain, cough, feeling drowsy and sadness frequently in the past two weeks...*”

5.12. Symptom severity

Among the high-prevalence symptoms, the most severe (ranging from moderately severe to severe) were lack of energy (91.2%), shortness of breath (81.2%), orthopnea (77.5), cough (66.9%) and feeling drowsy (53.6%). Difficulty sleeping was rated to be a moderately severe to severe in 76% of those reporting the symptom. Psychological symptoms including difficulty concentrating, worrying, feeling nervous, feeling sad and feeling irritable were at least moderately severe to severe in over 61% of those patients who have experienced the symptoms. Of the low-prevalence symptoms sweating, difficulty concentration, problem with sexual activity or interest, constipation, and problems of urination were at least moderately severe to severe in over 60% of those who experienced the symptoms (Table 7). This is almost similar with qualitative findings. For instance one 40 years old man reported the most severe symptoms he was suffered from were *weakness/ lack of energy and shortness of breathing*. Another 47 years old woman said “...*the most severe symptoms I was suffering from in the past two weeks were chest pain, cough, lack of energy, shortness of breath and difficulty sleeping*”.

5.13. Symptom distress

Symptoms that were most distressing were lack of energy (49.7%), orthopnea (34.1%), feeling bloated (25%), problem with sexual activity or interest (29.6%), constipation (28.9%) and problem of urination (34.4%) in those experiencing the symptoms. Symptoms that were least distressing were feeling drowsy (8.6%), feeling sadness (9.2%) and change in the way food taste (5.6%) among those patients experiencing the symptoms. Shortness of breath and lack of appetite which were present in over 52% of the respondents were quite a bit to very much distressing in only about 32% and 18.9% of those patients having the symptoms respectively. Chest pain, cough and dizziness while present in 57.8%, 55.6% and 45.7% of the patients, were less distressing (only in about 27.1%, 19.3% and 13.7% respectively). One symptom swelling of the arms and legs, present in 27.4%, frequent to constant in 37.7% and even when moderately to severe in severity in 67.3%, was distressing in only about 18.1% of patients who experienced it (Table 7). One 34 years old man qualitative study informant said “...*from the symptoms those which made me worry were lack of energy and shortness of breath during activities because they made me unable to perform my usual farming activities and I and my families suffered*

poverty...” Another 24 years old lady said “...the most distressing/ bothersome symptom I had was weakness/lack of energy which made me cease from school...”

Table 7: Memorial symptom measurement scale of the 32 symptoms of heart failure patients among PLWHF attending chronic illness follow up clinic of JUSH, April 2011(223)

Symptoms	Prevalence		Frequency at least frequently to Constantly		Severity at least moderate to severe		Distress quite a bit to very much	
	Frequency	%	Frequency	%	Frequency	%	Frequency	%
Shortness of breath	181	81.2	62	34.3	147	81.2	58	32
Lack of energy	193	86.5	102	52.8	176	91.2	96	49.7
Dry mouth	83	37.2	26	31.3	52	62.7	16	19.3
Feeling drowsy	129	57.8	11	15.9	37	53.6	6	8.6
Difficulty sleeping	100	44.8	42	42	76	76	33	33
Worrying	78	35	19	24.3	48	61.5	14	17.9
Orthopnea	129	57.8	32	24.8	100	77.5	44	34.1
Vomiting	11	4.9	1	9.1	4	36.4	2	18.2
Nausea	36	16.1	5	13.9	24	56.7	7	19.4
Cough	124	55.6	35	28.2	83	66.9	24	19.3
Feeling sad	76	34.1	8	10.5	52	68.4	7	9.2
Feeling nervous	87	39	13	14.9	61	70.1	10	14.4
Sweating	86	38.6	27	31.4	53	61.6	16	18.7
Feeling irritable	53	23.8	11	20.8	33	61.1	10	18.9
Chest pain	129	57.8	45	44.9	92	71.4	35	27.1
Other pain	20	9	3	15	10	50	4	20
Feeling bloated	36	16.1	11	30.5	16	44.4	9	25
Dizziness	102	45.7	10	9.8	59	57.8	14	13.7
Difficulty concentrating	43	19.3	13	30.3	28	65.1	10	23.3
Waking up breathless at night	117	52.5	37	31.7	76	65	28	23.9
Palpitations	153	68.6	44	28.8	113	83.9	35	23
Swelling of arms or legs	61	27.4	23	37.7	41	67.3	11	18.1
Problems with sexual activity	54	24.2	16	29.7	34	62.9	16	29.6
Numbness/tingling in hands/feet	70	31.4	15	21.5	45	64.2	10	14.3
Itching	17	7.6	4	23.6	10	58.8	3	17.7
Weight gain	21	9.4	*	*	*	*	*	*
Weight loss	31	13.9	*	*	*	*	*	*
Lack of appetite	116	52	27	23.1	74	63.8	22	18.9
Constipation	45	20.2	5	11.1	33	73.3	13	28.9
Diarrhea	15	6.7	*	*	4	26.7	*	*
Problem with urination	32	14.3	12	37.5	20	62.5	11	34.4
Change in the way food tastes	38	17	7	18.4	20	52.6	2	5.6

* The value not recorded #frequently to constantly: sum of those who said 3 and 4 for symptom frequency \$moderate to severe: sum of those reported 2 & 3 for severity. Distress quite abit to very much: sum of 4 & 5

5.14. Health related quality of life

From the 223 study respondents about 196 (88%) had health related quality of life below mean plus standard deviation (poor health related quality of life) while the rest 12% had health related quality of life above the mean plus standard deviation (good health related quality of life).

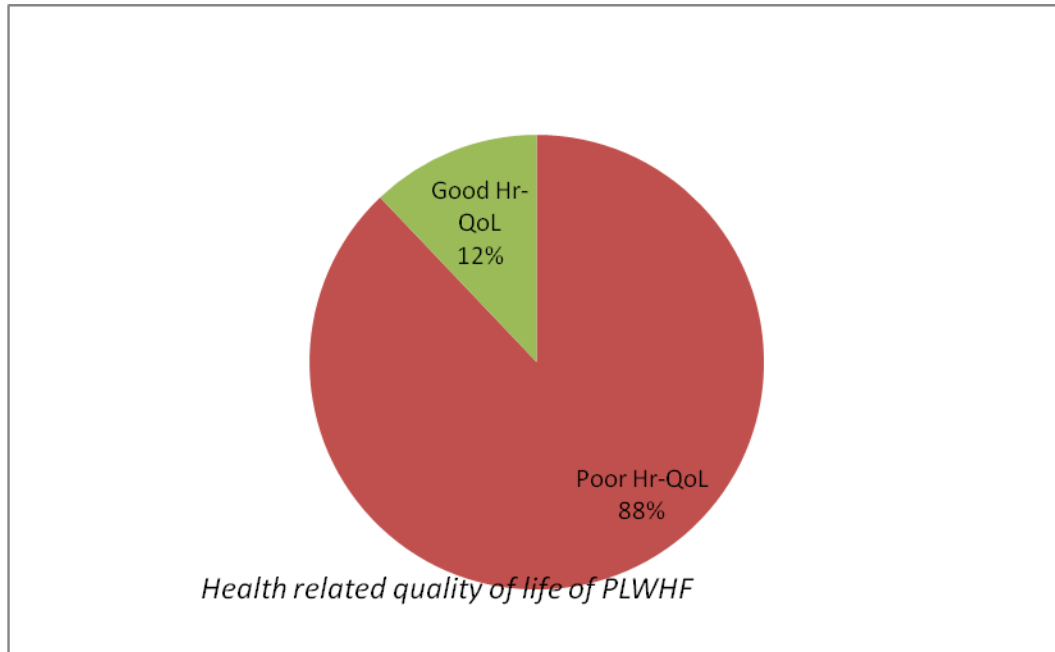


Figure 7: Health related quality of life of PLWHF attending chronic illness follow up clinic of JUSH, April 2011 (n=223)

5.15. Predictors of health related quality of life of heart failure patients

Multivariable logistic regression analysis showed that there is statistically significant relationship between educational status of the respondents, occupation and NYHA classification of heart failure and health related quality of life. Thus those who can read and write are 97.5 times less likely to have poor health related quality of life than those illiterate ($p = 0.007$) and those who completed grade 1-6 are 92.7 times less likely to have poor health related quality of life than the illiterate ($p=0.005$). Regarding occupation government employees are 96.6 times less likely to have poor health related quality of life than students ($p = 0.04$). Concerning NYHA class, those patients with class III & IV are 5.17 times more likely to have poor health related quality of life than those with class I & II ($p = 0.04$) provided that occupation, education, age, income, duration after diagnosis and NYHA class were in the model (Table 9).

Table 8: Crude and adjusted odds ratio for variables having statistical association with health related quality of life (n=223)

	Variables	Crude OR(95.0% CI)	Adjusted OR(95.0% CI)
Occupation	Student	1	1
	farmers(1)	3.769(0.840, 16.923)	3.203(.112, 91.389)
	Gov't employee(2)	0.162(0.033, 0.787)*	0.034(.001, 0.875)
	Nongov't employee(3)	3.728(.000, 21.001)	1.203(.000,33.987)
	Daily laborer(4)	2.192(0.484, 9.936)	2.028(0.059, 70.140)
	House wife(5)	1.154(0.096, 13.877)	0.212(0.004, 12.419)
	Others (6)	1.846(0.163, 20.939)	1.389(0.043, 44.533)
Educational status	Illiterate	1	1
	Read and write (1)	0.038(0.004, 0.324)**	0.025(0.002, 0.364)**
	Grade 1-6(2)	0.047(0.009, 0.234)**	0.073(0.012, 0.457)**
	Grade 6-8(3)	0.050(0.007, 0.336)**	0.127(0.010, 1.697)
	Grade 9-10(4)	0.060(0.009, 0.396)**	0.538(0.027, 10.687)
	Grade 11-12 (5)	2.429(.000,3.987)	1.052(.000, 34.990.)
	College and above (6)	0.007(0.001, 0.042)**	0.421(0.015, 12.091)
hNYHA[§]	I &II	1	1
	III & IV (1)	2.635(0.1.050, 6.617)*	5.168(1.027, 26.009)

[§]NYHA: New York heart association class of heart failure status

*statistically significant at $p < 0.05$

**statistically significant at $p < 0.01$

Age, income, duration after diagnosis and MLHFQ score all had significant relationship with health related quality of life when analyzed individually in binary logistic regression analysis but were not significant when entered into multivariable logistic regression. From sociodemographic characteristics: sex, marital status, religion, ethnicity and place of residence all did not had significant statistical relationship with health related quality of life of the patients even in binary logistic regression analysis.

From the top ten prevalent symptoms frequency of lack of energy and dizziness have significant relationship with health related quality of life of heart failure patients in binary logistic regression analysis but not in multivariable analysis. Thus those reporting frequency of lack of energy to be occasional, frequent and constant are 4.4, 6.3 and 16.5 times more likely to have poor health related quality of life than those reporting it to be rarely occurring (p value 0.038, 0.017 and 0.018) respectively. Participants reporting frequency of dizziness as occasional are 6.9 times more likely to have poor health related quality of life than those reporting dizziness to occur rarely (p value 0.016).

Table 9: Logistic regression showing adjusted odds ratio for frequency of lack of energy and dizziness and their relation with health related quality of life

Symptom frequency	P	AOR[95.0% CI]
Lack of energy rarely	0.044	1
Lack of energy occasionally (1)	0.038	4.438(1.089, 18.090)*
Lack of enenergy frequently (2)	0.017	6.300(1.396, 28.421)*
Lack of energy constantly (3)	0.018	16.500(1.616, 168.479)*
Dizziness rarely	0.120	1
Dizziness occasionally (1)	0.016	6.914(1.438, 33.257)*
Dizziness frequently (2)	0.845	1.257(0.127, 12.460)
Dizziness constantly (3)	0.999	5.077(0.000, 11.765)

*statistically significant at $p < 0.05$

Chapter VI Discussion

Patients with heart failure face high number of symptoms and significant symptom burden. Symptom prevalence and symptom burden were the greatest predictors of diminished Hr-QoL (9, 10). In this study on average the respondents had 10.79 ± 5.3 symptoms which is lower than the report of a study conducted in three Universities in united states in which the mean number of symptoms was 15.1 ± 8.0 (1). This variation might be due to difference in socio-economic characteristics, study subjects in united state might have relatively better knowledge regarding reporting of any symptoms, better health care service, adequate health care facilities and good living condition in USA than the current population, which are important in detection and reporting of symptoms.

In this study the most frequently reported symptoms were lack of energy (52.8%), chest pain (44.9%), Shortness of breath (34.2%), palpitation (28.8%), cough (28.2) and orthopnea (24.8%). This is slightly different from the study conducted by Barbara et al in University of Pennsylvania School of Nursing, United States (10) in which the most frequently reported symptoms were difficulty sleeping (94.1%), other pain (93.3%), lack of energy (93.3%), difficulty concentrating (92.6%), numbness and tingling in the hands and feet (91.7), feeling drowsy (91.7%) and shortness of breath (91.1%). This difference might be due to small sample in study conducted by Barbara et al or it might also be because of the lower knowledge and awareness of the current respondents in detecting and differentiating the symptoms.

In the recent study, the low-prevalent symptoms were diarrhea, problems with urination, itching, other pain and vomiting occurred at least frequently to almost constantly in about 38% of those who experienced the symptom. Whereas according to study by Solvig F, Anna-Karin W, Evy L. Numbness and tingling of the hands and feet, problems with sexual activity, itching and lack of appetite occurred occasionally to almost constantly in almost 76% of the patients (10, 11). This slight difference in symptoms might be due to relatively larger sample size in this study and/or in addition this might be due to differences in socioeconomic status of the study participants which make their concerns differ.

The findings of this study showed that among the high-prevalence symptoms, the most severe (ranging from moderately severe to severe) were lack of energy (91.2%), shortness of breath (81.2%), orthopnea (77.5), cough (66.9%) and feeling drowsy (53.6%). Difficulty sleeping was rated to be a moderately severe to severe in 76% of those reporting the symptom. This finding is almost consistent with study done by Barbara Riegel Terri E Weaver (10, 14) in which among the high-prevalence symptoms, the most severe were difficulty sleeping (96.8%), other pain (90%), lack of energy (88.6%), shortness of breath (88.6%), numbness and tingling of the hands and feet (87%), feeling drowsy (87%) and difficulty sleeping 55%. Less than 60% of the patients experienced difficulty breathing when lying flat; approximately 70% reported those symptoms to be at least moderately severe.

The result of this study indicated that significant numbers of those suffering from heart failure were older than 65 years. Even so suffering from CHF is likely to have an impact on people's everyday life regardless of their chronological age. This is consistent with Study by Solvig F, Anna-Karin W, Evy L. which found that the illness increases substantially with age, which correlates with symptomatic CHF manifesting in 10% of patients aged over 80 years. Approximately 80% of those suffering from CHF are older than 75 years (11).

In this study older individuals had worse health related quality of life when compared to younger adults that means as the age of the patient increases the Hr-QoL score decreases. This result is contradicting with the finding of the study conducted in United States in which younger age predicted a lower quality of life in patients with heart failure despite no significant differences in symptom prevalence between younger and older patients. This variation might be because majority of the older patients in this study were farmers and from rural areas where there is no adequate facilities to take care of themselves and they relate their quality of life with their inability to perform activities of daily living (1).

Lack of energy, difficulty sleeping and respiratory symptoms was most distressing to patients in this sample. This result is similar to previous findings in patients awaiting heart transplant. Grady

et al. found the most frequent and distressing symptoms were tiredness, difficulty breathing with activity and difficulty sleeping. In this study, symptom prevalence and symptom burden were predictive of lower quality of life which is similar with the studies by Grady et al in which those with high symptom prevalence and symptom burden had a worse health related quality of life.

In this study health related quality of life is highly associated with educational status, occupation, NYHA class of heart failure and specific symptom frequency, severity and distress. Symptoms affecting health related quality of life include lack of energy and dizziness ($p < 0.05$). This is different from study conducted by Craig D. et al in England and America in which impairment in health related quality of life was strongly associated with global symptom distress; burden of comorbid conditions, female sex, functional impairment, particularly psychological impairment, and poorer psychological well-being. Distressful symptoms related to impaired quality of life include lack of energy, irritability and drowsiness (19). This variation might be because majority of the respondents of this study were illiterate and had no adequate knowledge and economy to lead improved quality of life, their rating of symptom frequency, severity and distress might be subjective, and majority of the study participants were farmers in occupation and their ADL might affected their health related quality of life.

In this study from the 32 symptoms lack of energy is the top predictor of health related quality of life. Regarding the frequency of lack of energy those reported lack of energy to occur occasionally, frequently and constantly are about 4.44, 6.30 and 16.50 times more likely to have poor health related quality of life respectively than those who reported lack of energy to occur rarely (all $p < 0.05$). Concerning the severity of lack of energy those with moderately severe and severe lack of energy are 5.5 and 11.5 times more likely to have poor health related quality of life respectively than those with mild severity of lack of energy. With regard to its distress or bothersomeness those with medium, quit a bit and very much distress of lack of energy are about 6.00, 27.11 and 7.11 times more likely to have poor health related quality of life respectively than those reported little bit distress of lack of energy ($p < 0.05$). Another symptom predictor of Hr-QoL in this study was dizziness in which those with high frequency of dizziness are at high risk of having poor health related quality of life. Thus patients who reported to have dizziness occasionally are 6.91 times more likely to have poor health related quality of life than those

having it rarely ($p=0.016$). This finding is different from the finding of study conducted by Cheryl et al in Universities of United States in which the top predictors of health related quality of life were difficulty sleeping and shortness of breathing ($p < 0.05$) (1). This difference might be because lack of energy is directly related to the daily activities of the study participants of this study so that they related their health related quality of life with their ability to perform their daily activities such as farming, shopping, walking etc which all need energy and in addition to this they may have no awareness and concern about their sleep quality and pattern as those westerners.

Strength of the study

- ❖ The study used both quantitative and qualitative data collection techniques and record review.

Limitations of the study

- ❖ Recall bias might have occurred because patients might forget symptoms they were experiencing in the past two weeks prior to the actual study period.
- ❖ Social desirability bias might have occurred because there are some sex sensitive questions in the tool.

Chapter VII Conclusion and Recommendation

7.1. Conclusions

Patients with heart failure experienced a wide variety of symptoms with the mean number of symptoms HF patients attending JUSH experiencing being 10.79 ± 5.3 . The top ten prevalent symptoms experienced by HF patients attending JUSH are lack of energy, shortness of breath, palpitation, feeling drowsy, chest pain, orthopnea, cough, waking breathlessness at night, dizziness and lack of appetite. Significant numbers (more than 20%) of study participant were in the age group greater than 65 years which may indicate that the risk of developing heart failure is increasing with age.

The risk of developing heart failure is increasing with age. About 196(88%) of HF patients attending JUSH have poor health related quality of life. This seeks greater attention to improve the health related quality of life of the heart failure patients because greater than two-third of the study participant were illiterate and have no adequate knowledge and awareness to halt their symptoms. Generally, in both qualitative and quantitative part of the study the findings were almost similar in which the participants complain similar symptoms.

Generally, the study revealed that people living with heart failure are suffering from multiple and complex physical, psychological, social and emotional symptoms which affected their health related quality of life. The finding of this study shows that health related quality of life of HF patients is highly associated with educational status, occupation, NYHA class of heart failure and specific symptom frequency, severity and distress.

Symptoms mostly affecting health related quality of life HF patients are lack of energy and dizziness.

7.2. Recommendations

Based on the results of this study the following recommendations were forwarded:

- 1.** The involvement of PLWHF in self-care is an integral component in the successful improvement of their health related quality of life.
- 2.** Because PLWHF are suffering from multiple and complex symptoms which might affect their health related quality of life. Governmental and non-governmental organizations working on cardiac care and support or related issues should work on assessment and reduction of prevalence of symptoms.
- 3.** More over those nurses and other professionals working in the chronic illness follow up clinic should get more sensitization and refreshment training on those symptoms experienced by PLWHF and their potential self-care.
- 4.** The integration of symptom assessment and education regarding self-care in the routine care and support for PLWHF should be considered by all responsible bodies.
- 5.** Every single adult person living with the HF coming to the chronic illness follow up clinic of JUSH should be aware on the relationship between HF symptom burden and health related quality of life.
- 6.** Health care professionals working at JUSH chronic follow up clinic should target interventions that decrease frequency, severity, distress and overall symptom burden and improve Hr-QoL
- 7.** Nurses should focus on ameliorating prevalent physical symptoms and psychological distress, along with supportive measures that promote functional mobility to lead to an improvement in the health related quality of life of HF patients.

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Annex II: Questionnaires

Jimma University College of Public Health and Medical Sciences Department of Nursing

Consent Form

This questionnaire is prepared to assess effect of symptom burden on quality of life in patients with heart failure attending JUSH chronic illness follow up clinic.

Introduction:

My name is _____. I am working with Mr. Abebe Abera who is doing a research as partial fulfillment for the requirement of Masters in Adult Health Nursing at Jimma University Department of Nursing. We are interviewing PLWHF to determine effect of symptom burden on their quality of life. I am going to ask you some questions that could be important for achieving the objective of the study. Your name will not be written in this form and the information you give will be kept confidential. If you are not interested to answer all or some of the questions, you do have full right to interrupt. However your willingness to answer all of the questions would have an invaluable input for this study.

Are you willing to participate in responding to the questions in this questionnaire?

Yes

No

Respondent's Signature _____

Interview code no _____

General instructions:

For each of the responses of a question tick the box in front of the chosen answer. For the scaling of Symptom Severity, Symptom affecting daily life and Symptom Bothersomeness, tick the box rating of the client for which the scale is provided.

1. Socio-demographic characteristics

1.1. Card no _____

1.2. Sex:

Male

Female

1.3. Age (in years): _____

1.4. Ethnicity:

Oromo

Dawro

Amhara

Kefa

Tigre

Other (Specify)_____

1.5. Religion

Muslim

Catholic

Orthodox

Other(specify)_____

Protestant

1.6. Marital status

Single

Divorced

Married

Widowed

1.7. Occupation

Student

Daily laborer

Farmer

House wife

Government employee

Merchant

Non government employee

Other(specify)_____

1.8. Educational status

Illiterate

Grade 9-10

Grade 1-6

Grade 11-12

Grade 6-8

College/above complete

1.9. Residence

Urban

Rural

1.10. Income per month _____ (in birr).

1.11. Family size _____

1.12. With whom do you live? _____

2. Questions related to symptom prevalence:

2.1. How long have you stayed since diagnosis of heart failure? _____

2.2. NYHA classification of his/her heart failure (refer patient card)

A. I

B. II

C. III or IV

2.3. Do you have Co-morbidity of other chronic illnesses (see pt card)

A. Yes

B. No

2.4. If “yes” to Q_{2.3} which of the following?

A. Hypertension

D. MI

B. Diabetes mellitus

E. Others (specify) _____

C. Epilepsy

2.5. Have you identified symptoms of heart failure?

Yes

No

2.6. If ‘yes’ for Q_{2.5}, please check which of the following symptoms do you had during the past two weeks? Possible to choose more than one.

Shortness of breath/dyspnea

Feeling bloated

Lack of energy

Dizziness

Dry mouth

Difficulty concentrating

Feeling drowsy

Waking up breathless at night

Difficulty sleeping

Palpitations

Worrying

Swelling of arms or legs

Orthopnea

Problems with sexual activity

Vomiting

Numbness/tingling in hands/feet

nausea

Itching

Cough

Weight gain

Feeling sad

Weight loss

Feeling nervous

Lack of appetite

Sweating

Constipation

Feeling irritable

Diarrhea

Chest pain

Problem with urination

Other pain

Change of food tastes

Others (specify)_____

2.7. Please fill the following chart for the prevalent symptoms

Memorial symptom assessment scale

Instruction: In the following table there are a list of 32 symptoms to assess how often they occur, how severe they were and how much they distressed or bothered the patient during the past two weeks. If the patient did not have the symptom please make “X” in the box under ‘no’ and if the patient have the symptom put (✓) in the boxes under the three variables respectively based on the patients’ rating for each symptom one by one.

Sno	Since the past 2weeks did you experienced any of the following symptoms? If 'yes' fill the front boxes!	No	If 'yes'											
			Frequency				Severity			Distress				
			Rarely	Occasionally	Frequently	Constantly	Mild	Moderate	Severe	Little bit	Somewhat	Medium	Quite bit	Very much
0	1	2	3	4	1	2	3	1	2	3	4	5		
1	Shortness of breath/dyspnea													
2	Lack of energy													
3	Dry mouth													
4	Feeling drowsy													
5	Difficulty sleeping													
6	Worrying													
7	Difficulty breathing when lying flat (orthopnea)													
8	Vomiting													
9	Nausea													
10	Cough													
11	Feeling sad													
12	Feeling nervous													
13	Sweating													

14	Feeling irritable													
15	Chest pain													
16	Other pain													
17	Feeling bloated													
18	Dizziness													
19	Difficulty concentrating													
20	Waking up breathless at night													
21	Palpitations													
22	Swelling of arms or legs													
23	Problems with sexual activity													
24	Numbness/tingling in hands/feet													
25	Itching													
26	Weight gain													
27	Weight loss													
28	Lack of appetite													
29	Constipation													
30	Diarrhea													
31	Problem with urination													
32	Change in the way food tastes													
If you had any other symptom during the last month please list them and indicate your rating for each as for the above														

3. Questions related to impact of symptom prevalence & burden on Hr-QoL:

3.1. Do these symptoms have effect on your daily life?

- Yes no

3.2. If 'yes' to Q_{3.1}, how?

3.3. Do you have respiratory problems?

- Yes no

3.4. If 'yes' to Q_{3.3}, when?

- Day time Night During activities

3.5. How many pillows do you use? _____

3.6. Do you have impairments of activities of daily life related to this illness?

- Yes no

3.7. If 'yes' to Q_{3.6}, to which of the following activities of daily living you feel difficulties?

- | | |
|--|---|
| <input type="checkbox"/> Feeding | <input type="checkbox"/> Yard working |
| <input type="checkbox"/> Grooming | <input type="checkbox"/> Toileting |
| <input type="checkbox"/> Dressing/clothing | <input type="checkbox"/> Cooking |
| <input type="checkbox"/> Walking | <input type="checkbox"/> Bathing |
| <input type="checkbox"/> Shopping | <input type="checkbox"/> Others(specify)_____ |

4. Minnesota living with heart failure questionnaire

The following questions ask how much the heart failure (heart condition) affected patients' life during the past 2 weeks. After each question, put (√) under 1, 2, 3, 4 or 5 to show how much patients' life was affected. If a question does not apply to the patient, put (√) under 0 in front of that question.

Sno	Problems	If 'yes'				
		No	Scores			
			Very little	Little bit	Somewhat	Quite bit
0	1	2	3	4	5	
	<i>Did your heart failure prevented you from living as you need during the past two weeks by:</i>					
1	Causing swelling in your ankle or legs					
2	Making you sit or rest down during the day					
3	Making your walking or climbing about stairs difficult					
4	Making your working around the house or yard difficult					
5	Making your going places away your home difficult					
6	Making your sleeping well at night difficult					
7	Making your relating or doing things with your friends or families difficult					
8	Making your working to earn life difficult					
9	Making your recreational pastimes, sports and hobbies difficult					
10	Making your sexual activity difficult					
11	Making you eat less of the food you like					
12	Making you short of breath					
13	Making you tired, fatigued or low of energy					
14	Making you stay in hospital					
15	Costing you money for medical care					
16	Giving you side effects from treatments					
17	Making you feel you are a burden on your family or friends					
18	Making you feel a loss of self control in your life					
19	Making you worry					
20	Making it difficult to you to concentrate or remember things					
21	Making you feel depressed					

5. QUALITY OF LIFE SCALE

Instructions for scoring the quality of life scale

This form of the Quality of Life Scale (QOLS) has 16 items. The instrument is scored by summing the items to make a total score. Subjects should be encouraged to fill out every item even if they are not currently engaged in it. Missing data can be treated by entering the mean score for the item. Please read each item and put (√) under the number that best describes how satisfied/dissatisfied the patient is. Please answer each item even if the patient does not currently participate in an activity or have a relationship. The patient can be satisfied or dissatisfied with not doing the activity or having the relationship. SF-36 scores will be converted to a scale of 16 to 100, a higher score indicating a better quality of life.

Sno	Activities	Scores				
		Completely dissatisfied	Mostly dissatisfied	Mixed	Mostly satisfied	Completely satisfied
		1	2	3	4	5
1	Material comforts at home, food, conveniences, financial security(such as bed, pillow, chair, tables, etc)					
2	Health - being physically fit and vigorous					
3	Relationships with parents, siblings & other relatives-communicating, visiting, helping					
4	Having and rearing children					
5	Close relationships with spouse or significant others					
6	Close relationships with friends					
7	Helping, encouraging, volunteering, & giving advice for others					
8	Participating in organizations and public affairs					
9	Learning- attending school, improving understanding, getting additional knowledge					

10	Understanding yourself - knowing your assets and limitations - knowing what life is about					
11	Work/ job in or outside your home					
12	Expressing yourself creatively					
13	Socializing - meeting other people, doing things, parties, etc					
14	Reading, listening to music, or observing entertainment					
15	Participating in active recreation					
16	Independence, doing for yourself					

6. Questions related to treatment

6.1. What is/are the specific medication/s the patient is using currently? (refer patient card)

6.2. Category/type of medication/s the patient is using (may be filled by Principal Investigator)

- | | |
|-------------------------|--------------------------|
| A. ACE inhibitors | D. β -blockers |
| B. Diuretics | E. Anticoagulants |
| C. Digitalis glycosides | F. Others (specify)_____ |

6.3. Did you have perceived medication side effects?

- | | |
|--------|-------|
| A. Yes | B. No |
|--------|-------|

6.4. If 'yes' to Q_{6.3} what were the perceived side effects? _____

6.5. If 'yes' to Q_{6.3} which medication has perceived side effect? _____

6.6. What measures have you used to minimize these side effects? _____

7. Questions related to lifestyle

7.1. Do you use substances?

- A. Yes B. No

7.2. If 'yes' to Q_{7.1} what types of substances do you use?

- A. Chat D. Drugs
B. Alcohol E. Others (specify) _____
C. Cigarette

7.3. How frequent do you use the substance you were using?

- A. Rarely B. Frequently C. Constantly

7.4. Do you do physical exercise?

- A. Yes B. No

7.5. If 'yes' to Q_{7.4} what type of physical exercise do you do?

7.6. Do you have food restriction?

- A. Yes B. No

7.7. If 'yes' to Q_{7.6} which type of food?

- A. Salt D. Carbohydrate
B. Fat E. Others (specify) _____
C. Protein

7.8. Do you get social support?

- A. Yes B. No

7.9. If 'yes' to Q_{7.8} from whom do get social support?

Thank you for your time

Data collectors

Name _____

Signature _____

Date ____/____/____

ANNEX II: INTERVIEW GUIDE QUESTIONS FOR QUALITATIVE STUDY

Consent Form

Jimma University College of Public Health and Medical Sciences Department of Nursing

This questionnaire is prepared to assess effect of symptom burden on health related quality of life of PLWHF attending JUSH chronic illness follow up clinic.

Consent Form, Introduction:

My name is _____. I am working with Mr. Abebe Abera who is doing a research as partial fulfillment for the requirement of Masters in Adult Health Nursing at Jimma University Department of Nursing. We are interviewing PLWHF to determine effect of symptom burden on health related quality of life of HF patients. I am going to ask you some questions that could be important for PLWHF and organizations working on HF. Your name will not be written in this form and the information you give will be kept confidential. If you don't want to answer all of or some of the questions, you do have the right to do so. However your willingness to answer all of the questions would be appreciated.

Would you participate in responding to the questions in this questionnaire?

Yes

No

Thank you for agreeing to be part of this study.

Age of the key informant _____

Sex of the key informant _____

Time interview started _____

Time interview completed _____

In depth interview questions

S.N^o	Guiding Questions	PROBS
1	Have you been experiencing any symptom since the last two week?	How frequently?
2	If “yes” would you describe those symptoms?	What else?
3	Would you explain the severity of those symptoms?	Anything else?
4	Would you describe how much those symptoms bother you?	What else?
5	Would you describe how those symptoms affect your daily life?	How often? Can you give me examples?
6	How much are you satisfied with your health related quality of life?	Can you give example?
7	What were the most commonly experienced symptoms?	How severe, distressing they were?
8	Do you have perceived medication side effect during the past two weeks	What are they? To which medication?
9		

Thank you for your participation

Date: _____

Signature of the interviewer: _____

በአሜሪካ የተዘጋጀ ማጠቃለያ

ጅም ዩኒቨርሲቲ የህብረተሰብ ጤና ሕክምና ሳይንሶች ኮሌጅ ነርሲንግ ትምህርት ክፍል

የሰምሳት ቅጽ

ይህ ጥናት የልብ ድካም ህመምን የህመም ምልክቶች በአኗኗራቸው ላይ የሚያመጣውን ተጽዕኖ ለማወቅ ያለመ ነው፡፡

መገቢያ :

ስሜ _____ ይባላል፡፡ እኔ ከአቶ አበበ አበራ ሀላፊ ሲሆን ዲግሪውን ለማግኘት የሚያስችለውን ምርምር እየሠራ ካለው ጋር እየሠራሁ ነው፡፡ የዚህ ጥናት ዋና ዓላማ የልብ ድካም ያለባቸውን ታምሟቸው በማጠቃለያ የበሽታው አስከፊነት ለማወቅ ነው፡፡ እናም አሁን ለዚህ ዓላማ ስኬት የሚጠቅሙ አንዳንድ ጥያቄዎችን ልጠይቅህ/ሽ ነው፡፡ ስምህን/ሽን ማጻፍ አያስፈልግም እንደሁም የሚታዘብ/ጩራ ሚዲያ ምስጢራዊነቱ የሚጠበቅ መሆኑን ካሁኑ ላረጋግጥ እወዳለሁ፡፡ ጥያቄዎቹን በመላም ሆነ በከፊሉ ለመመለስ ፈቃደኛ ካልሆንክ/ሽ የሚቋረጥ መሆኑን አለህ/ሽ፤ ሆኖም ግን ያንተ/ቺ ፈቃደኝነትና አስተዋጽኦ የሚይናቅ ጠቅሜታ አለው፡፡

ለመሳተፍ ፍቃደኛ ነህ/ሽ?

አዎ

አይደለሁም

የተጠየቁት ፊርማ _____

የእንተርቪው ማለያ ቁጥር _____

ዋና መሠሪያ (ለሚጻጹ ሰብሳቢ) :

ለያንዳንዱ መልሶች ከጥያቄው ፊትለፊት የሚገኙ ሳጥኖች ወስጥ የእርምጃ ምልክት (✓)ን እንደ ተጠየቁት አስተያየት አስቀምጥ/ጩ፡

ጥያቄው የተጀመረበት ሰዓት _____

ያለቀበት ሰዓት _____

1. የታማሚው አጠቃላይ መረጃ

1.1. የካርድ ቁጥር _____

1.2. ፆታ:

- ወንድ ሴት

1.3. ዕድሜ: _____

1.4. ብከር :

- አሮሞ ዳወደ
 አሜራ ከፋ
 ትግሬ ሌሎች (ዘርዘር) _____

1.5. ሃይማኖት

- መስጊድ ካቶሊክ
 ኦርቶዶክስ ሌሎች (ዘርዘር) _____

1.6. የትዳር ሁኔታ

- ያላገባ/ች የተለያዩ
 ያገባ/ች የሞተችበት/ባት

1.7. ሥራ

- ተሜ የቀን ሠራተኛ
 አርሶአደር/ አርብዳኤር የቤት እመቤት
 የመንግስት ሰራተኛ ነጋዴ
 መንግሥታዊ ያልሆነ ድርጅት ሠራተኛ ሌሎች (ዘርዘር) _____

1.8. የትምህርት ደረጃ

- ያልተሟላ/ች ከ9-10 ክፍል
 ማኅበራዊ መጻፍ ብቻ ከ11-12 ክፍል
 ከ1-6 ክፍል ኮሌጅ/ከዛ በላይ
 ከ6-8 ክፍል

1.9. የመኖሪያ ቦታ

- ከተማ ገብር

1.10. የወር ገቢ _____ (በብር)

1.11. የቤተሰብ ብዛት _____

1.12. ከማን ጋር ትኖራለህ/ሽ? _____

2.7. ታምሞ/ዋ ላለው/ላት ምልክት/ቶች የሚከተለውን ሠንጠረዥ መላ/መይ::

ሚህሪያል ስምጥተም መዘር መንገድ ስኬል

ትህዛዝ: የሚከተለው ስንጠረዥ 32 የሚሆኑ የልብ ደካም ምልክቶችን ይዟል:: ሠንጠረዥ ባለፉት ሁለት ሳምንታት ውስጥ የምልክቶቹ ደግግሞሽ፣ ክብደት እና ምን ያህል ሰውዬውን እንደሚያስቸግሩ የሚጻጻይ ነው:: ታምሞ/ዋ ምልክቱን ከለለው የ“X” ምልክት ከየለም ሥር ፣ ካለሁ ደግሞ (✓) ከሶስቱ ሪዕሶች ስር የተዘረዘሩ ቁጥሮች ስር ሳጥን ውስጥ እንደታምሞው አስተያየት በደረጃ አስቀምጥ/ጩ::

ተቋ	ባለፉት ሁለት ሳምንታት የሚከተሉትን ምልክቶች በሪሲስ/ሽ ላይ አይተ/ሽ ነበረ?	መልሱ "አዎ" ከሆነ												
		ደግግሞሽ					አስቸጋሪነቱ/ ክብደቱ			አሳሳቢነቱ				
		0	1	2	3	4	1	2	3	1	2	3	4	5
1	የትንፋሽ መቆራረጥ													
2	አቅም ማጣት													
3	የአፍ መድረቅ													
4	እንቅልፍ እንቅልፍ ማለት													
5	እንቅልፍ ማጣት													
6	መጨናነቅ													
7	ተኝቶ መተንፈስ አለመቻል (orthonea)													
8	ማክመለስ													
9	ማቅለሽለሽ													
10	ሳል													
11	መከፋት													
12	መናደድ													
13	ማለብ													
14	የመካ ጫ ጭ ስሜት													
15	የደረት እመም													
16	ለሌሎች እመሞች													
17	የሆድ መካፋት ስሜት													

18	የራስ ማንን መሃት (ማዘር)																			
19	የማህብ ችሎታ መቅነስ																			
20	በትንፋሽ መቆራረጥ ምክንያት ለሊት ለሊት ከእንቅልፍ መቃቃት																			
21	ያልተለመደና ፈጣን የልብ ምት																			
22	የእጅና እግር ማጠጥ																			
23	የወሲብ ችግር																			
24	የጣዦች መደንዘዝ/መጠበብ																			
25	ማህከከ																			
26	ክብደት መጨመር																			
27	ክብደት መቅነስ																			
28	የምግብ ፍላጎት መቅነስ / ማጣት																			
29	የሆድ ድርቀት																			
30	ተቅማጥ																			
11	የሽንት ችግር																			
32	የምግብ ጣይም መቀየር																			
ባለፉት ሀላት ሃምንታት ከነዚህ ወይን ሌሎች ምልክቶች በራስህ/ሽ ላይ አይተህ/ አይተሽ ከሆነ ዘርዘር/ሪ																				

3. ከምልክቶቹ መኖርና በህመማቸው/ዋ ህይወት/አኗኗር ላይ የሚያሳዩት ተጽዕኖ ጋር የተያያዙ ጥያቄዎች:

3.1. እነዚህ የልብ ድካም ምልክቶች ያንተ/ቺ ህይወት ላይ ተጽዕኖ አሳድረዋል?

- አዎ የለም

3.2. ለጥያቄ ቁ_{3.1} መልሱ "አዎ" ከሆነ እንዴት?

3.3. የአተነፋፈስ ችግር አለብህ/ሽ?

- አዎ የለም

3.4. ለጥያቄ ቁ_{3.3} መልሱ "አዎ" ከሆነ መቼ መቼ?

- ቀን ቀን ለሊት ለሊት ሥራ ስራ

3.5. ስንት ትራስ ትጠቀማለህ/ሽ? _____

3.6. ይህ በሽታ የተለመደው ሥራ በትክክል እንዳትሰራ/ሪ አዳግቶል/ሻል?

- አዎ የለም

3.7. ለጥያቄ ቁ_{3.6} መልሱ "አዎ" ከሆነ የትኛው/ኛቹን ሥራ/ዎች ስትሰራ/ሪ ይደክምል/ሻል?

- መግብ የጓሮ ሥራ መስራት
- መውጣት መጻዳዳት
- ልብስ መልበስ ምግብ ማበሰል
- መራመድ መታጠብ
- መገናኛ ቦታ
- ሌሎች (ግለጽ/ጩ) _____

4. ማዕረግ ከልብ ደካም ጋር የሚያደርጉ ጥያቄዎች

የሚከተሉት ጥያቄዎች የልብ ችግሩ (ሁኔታ) ምን ያህል የታመሙ ሕይወት ባለፉት ሁለት ሳምንታት እንደጎዳ የሚጠይቁ ናቸው፡፡ ከእያንዳንዱ ጥያቄ በኋላ ከ 1, 2, 3, 4 ወይም 5 ሥር ባለት ሳጥኖች ወስጥ እንደታመሙ አስተያየት (✓) አስቀምጥ/ጨፈ፡፡ ጥያቄው ታመሞ የሚመለከት ከሆነ ከ0 ሥር (✓)ን አስቀምጥ/ጨፈ፡፡

ተቁ	ችግሮች	ነጥብ					
		የላም	ኋተቅዚ ላም	ዝቅዚ	ሚካከላኛ	ኋተቅዚ ላም	
	ያንተ/ቺ የልብ ሁኔታ እንደፍላጎትህ/ሽ እንዳትኖር/ሪ የሚደርግ/ሽ ከሆነ ከሚከተሉት ችግሮች የትኛውን በሚከተል ነውላለት ችግሮች የችግሩን ደረጃ እንደታመሙ አስተያየት አስቀምጥ/ጨፈ	0	1	2	3	4	5
1	እግሮቼ እንዲአብጡ በሚደረግ						
2	ቀንቀን ስለሚደክመኝ						
3	ሚመድ ወይም ዳገት መወጣት ስለሚደግግኝ						
4	ቤት አካባቢ ወይም የጓሮ ሥራ መስራት ስለሚቅጥኝ						
5	ሩቅ ቦታ ማድረግ ስለሚብደኝ						
6	ሌሊት ሌሊት መተኛት ስለሚብደኝ						
7	ከጓደኞቼ ወይም ከቤተሰቦቼ ጋር መጫወት ወይም መሥራት ስለሚብደኝ						
8	ኑሮን ለማሸነፍ የሚሠራቸውን ሥራዎች ስለሚሠራኝ						
9	መዝናኛትን፣ ስፖርትንና የፍላጎቴን ሥራ አድካሚ ስለሚደርግብኝ						
10	በግብረሥጋ ግኑኝነት ጊዜ ችግር ስለሚጋጥመኝ						
11	የምደደውን ምግብ እንዳልበላ ስለሚደርገኝ						
12	ትንፋሼን ስለሚቆራረጠኝ						
13	ስለሚደክመኝ እና አቅም ስለሚሳጣኝ						
14	ሆስፒታል ወስጥ ረዥም ጊዜ እንድቆይ ስለሚስገድደኝ						
15	ለህክምና ብዙ ወጪ ስለሚጠይቀኝ						
16	መድሃኒቶቼ የጎንጎሽ ጠንቆች ስለሚሳደሩብኝ						
17	ለቤተሰቦቼና ጓደኞቼ ሸክም እንደሆንኩ ስለሚሰጠኝ						
18	የራሴን ሕይወት በትክክል በራሴ እንዳልሚራ ስለሚደርገኝ						
19	ስለሚሰጠኝ						
20	የሚገታወስ ወይም ማላላላት ችለታዬን ስለሚቆይኝ						
21	የድብርት ስሜት ስለሚጠይቀኝ						

5. የልብ ደካም ታመሞች የአኗኗር ሁኔታ ማሳኪያ ስኬል

መሠረት: የሚከተለው ሠንጠረዥ 15 ነጥቦችን የያዘ ነው። ሁሉንም ነጥቦች በደንብ ካነበብ/ሽ በኋላ እንደ ታምሞው መልስ ከቁጥሮቹ ሥር (✓) አስቀምጥ/ጩ። ባሁኑ ሰዓት ታምሞ/ዎ ከችግሩ ነጻ በሆነም ሠንጠረዥ መሣላት አለበት።

ተ ቁ	የሚጠየቁ ነጥቦች ከዚህ በታች በተዘረዘሩት ነጥቦች ዙሪያ ታምሞ/ዎ ምን ያህል ደስተኛ እንደሆነ /ች እንደታምሞው አገላለጽ ከቁጥሮቹ ሥር (✓) አስቀምጥ/ጩ	ነጥብ				
		መጠኑ በመጠኑ ደስተኛ አይደለም	በአብዛኛው ደስተኛ አይደለም	መካከለኛ	በአብዛኛው ደስተኛ ነኝ	መጠኑ በመጠኑ ደስተኛ ነኝ
		1	2	3	4	5
1	የቤት ዕቃዎች (ወንበር፣ አልጋ፣ ትርሃስ እና የመሳሰሉት)፣ ምግብ፣ ገንዘብ ምኞት					
2	የሰውነት ጠቅና ተገዳሪ ጥንካሬ					
3	ከቤተሰብ እና ዘመዶች ጋር መቀራረብ፣ መነጋገር፣ መረዳዳትና መጠየቅ					
4	ልጅ መሰለጠን ማዘጋጀት					
5	ከትዳር ጓደኛ ወይም ሌላ ከሚያስፈልግህ/ሽ ሰው ጋር የቅርብ ግንኙነት መፍጠር					
6	ከቅርብ ጓደኛ ጋር ጥሩ ግንኙነት መፍጠር					
7	ሌሎችን መርዳት፣ ማበረታታትና መከታተል					
8	የድርጅት ወይም የህዝብ ጉዳዮች ላይ መሳተፍ					
9	መሥሪያ ቤት/ቤት መከታተል፣ የሚከተሉት ችሎታን ማዳበር፣ ተጨማሪ ዕውቀት መግኘት					
10	የቤት እና የጓደኛ ሥራዎችን መስራት					
11	ራስን በትክክል መገለጽ					
12	ከሌሎች ሰዎች ጋር መስማማት፣ መገናኘት፣ ነገሮችን በትክክል መገኘት፣ ጋር ተወዳጅ ላይ መሳተፍ እና የመሳሰሉት					
13	ማንበብ፣ መዘቃ መስማት ወይም የ መዘናኛ ፕሮግራሞች መከታተል					
14	እንደፍላጎትህ/ሽ መዘናኛ					
15	ነጻነት፣ ለራስ መስራት					

6. ከሕክምናው ጋር የተያያዙ

6.1. የአካል እንቅስቃሴ ታደርጋለህ/ሽ?

A. አዎ

B. የለም

6.2. ለጥያቄ ቁ_{6.1} መልሱ አዎ ከሆነ ፣ ምን አይነት?

6.3. በአሁኑ ሰዓት ምን አይነት መደሃኒት ትጠቀማለህ/ሽ? (ከካርድ የሚወሰድ)

6.4. የመደሃኒት/ቶች የጎንዮሽ ጠንቅ/ቆች አጋጠሙ/ሽ ያወቃል/ሉ?

A አዎ

B የለም

6.5. ለጥያቄ ቁ_{6.4} መልሱ "አዎ" ከሆነ ለየትኛው መደሃኒት ነው?

6.6. የጎንዮሽ ጠንቅ/ቆች ምንድን ነው/ናቸው?

6.7. የጎንዮሽ ጠንቅ/ቆችን ለመቀነስ ምን ዓይነት እርምጃ ትወስዳለህ/ጃለሽ?

7. ከታማሞ/ዋ የአኗኗር ሁኔታ ጋር የተያያዙ ጥያቄዎች

7.1. አደንዛኝነት ነገሮችን ትጠቀማለህ/ሽ?

A. አዎ

B. የለም

7.2. ለጥያቄ ቁ_{7.1} መልሱ/ሽ "አዎ" ከሆነ ምን አይነት አደንዛኝነት ነገር ትጠቀማለህ/ሽ?

A. ጭንቀት

D. መደሃኒት

B. አልኮሎል

E. ሌሎች (ዘርዘር)

C. ሥጋራ

7.3. መቼ መቼ ትጠቀማለህ/ሽ?

A. በጣም አልፎአልፎ

B. ብዙ ጊዜ

C. ሁል ጊዜ

7.4. የአካል እንቅስቃሴ ታደርጋለህ/ሽ?

A. አዎ

B. አላደርግም

7.5. ለጥያቄ ቁ_{7.4} መልሱ "አዎ" ከሆነ ምን አይነት እንቅስቃሴ?

7.6. እንዳትበላ የተከለከለከው/ሽው የምግብ አይነት አሉ?

A. አዎ

B. የለም

7.7. ለጥያቄ ቁ_{7.6} መልሱ "አዎ" ከሆነ የትኛውን ምግብ?

A. ጨው

D. ካርቦሃይድሬት

B. ጫማ/ቅባት ነገሮች

E. ሌሎች (ዘርዘር)

C. ፕሮቲን

7.8. ከሕብረተሰቡ ድጋፍ ታገኛለህ/ሽ?

A. አዎ

B. የለም

7.9. ለጥያቄ ቁጥ. 7.8 መልሱ "አዎ" ከሆነ ድጋፉን ከማን ታገኛለህ/ሽ?

የሚገኝ ሰብሳቢዉ

ስም _____

ፊርማ _____

ቀን _____ / _____ / _____

ለትብብርዎ ከልብ እናመሰግናለን!!

Gaaffilee Afaan Oromootiin Qophaa'an

Yuunivesiitii Jimmaatti Kolleejjii Saayinsii Fayyaa fi Hawwaasummaa Gola Barnootaa Neersummaa

Guca walii galtee

Gaaffileen kun rakkina baay'inni mallattoolee dhibee dadhabbi onnee haala jireenya gaarii nama dhibee sana waliin jiraatuu irratti fidan qorachuuf kan qophaa'anii dha. Qorannoon kun kan geggeeffamu dhukkubsattoota dhibee dadhabbi onnee qaban Hospitaala Ispeeshaalayizdii Yuunivesiitii Jimmaatti deddeebi'anii yaalaman irratti ta'a.

Seensa:

Maqaan koo _____ jedhama. Ani obbo Abbabee Abarraa kan qorannoo digirii lammaffaa argachuuf isaan barbaachisu Yuunivesiitii Jimmaa gola barnootaa Neersummaatti hojjechaa jiran waliin hojjedha. Nuti rakkina baay'inni mallattoolee dhibee dadhabbi onnee haala jireenya gaarii namoota dhibee dadhabbi onnee waliin jiraatan irratti fidan qorachuuf gaaffilee armaan gadii gaafachaa jirra. Kanaafuu amma gaaffilee qorannoo kanaaf barbaachisan tokko tokko si gaafachuufan deema. Maqaa kee barreessuun hin barbaachisu akkasumas odeeffannoon ati naaf laattu icciitiidhaan qabama. Gaaffilee gafatantu deebisuun yoo sitti hin tolle ta'e yeroo barbaaddetti addaan kutuuf mirga guutuu qabda; haa ta'u malee qorannoo kana keessaatti qooda fudhachuun kee bu'aa hedduu qaba.

Qorannoo kana keessatti hirmaachuuf fedhii qabdaa?

Eeyyee

lakki

Mallattoo _____

Koodii lakkoofsa gaaffii qomee _____

Qajeelfama walii galaa (nama odeeffannoo guuruuf):

Gaaffilee hundaaf saanduqa gaaffii sana fuuldura jiran keessa mallattoolee "X" ykn (✓) akka odeeffannoo dhukkubsataa irraa argatteetti katabi.

Odeeffannoo walii galaa

1.1. Lakkoofsa kaardii _____

1.2. Saala:

dhiira

dhalaa

1.3. umurii: _____(waggaadhaan)

1.4. Sublammii:

Oromoo

Daawuroo

Amaara

Kafaa

Tigiree

Kan biroo (ibsi) _____

1.5. Amantii

Musiliima

Caatolikii

Ortodooksii

Kan biroo (ibsi) _____

Pirotestantii

1.6. Haala gaa'elaa

Kan hin fuune/hin heerumne

Kan wal hiikan

Kan fuudhe/heerumte

Kan warri duraa du'e/duute

1.7. Hojii/hojjaa

Barataa/ttuu

Haadha warraa

Qonnaan bulaa

daldalaa

Hojjetaa mootummaa

Kan biroo (ibsi) _____

Hojjetaa mit-mootummaa

1.8. Sadarkaa barumsaa

Kan hin baratne

kutaa 9-10

Barreessuu fi dubbisuu qofa

kutaa 11-12

kutaa 1-6

kolleejjii ykn sanaa ol kan xumure/te

kutaa 6-8

1.9. Bakka jireenyaa

Magaalaa

Baadiyaa

1.10. Galiin kee giddu-galeessaan ji'atti qarshii meeqaa? _____ EB.

1.11. Baay'ina maatii _____

1.12. Eenyuu wajjiin jiraatta? _____

- dafqisiisuu/hunnasiisuu
- jeeqamuu
- dhukkubbii laphee/qomaa
- dhukkubbii kan biroo
- garaa bokoksuu
- joojessuu/ lafti ittiin maruu
- qalbeefachuu dadhabuu
- halkan halkan rakkoo hafuura kutaan hirriba keessaa dammaquu
- onneen amma yeroo kaaniin ol rukutuu
- dhidhitina harkaa fi miillaa
- rakkoo yeroo wal quunnamtii saalaa
- hadooddi/gubaa harkaa ykn miillaa
- qaama hooqsisuu
- ulfaatina qaamaa dabaluu
- ulfaatina qaamaa hir'isuu
- fedhii nyaataa dhabuu/hir'isuu
- garaa gogsaa
- garaa kaasaa/teessisaa
- rakko boolii bishaanii/fincaanii waliin walqabate
- jijjiirama dhandhama nyaataa
- kan biro addeessi _____

2.7. Mallattoolee armaan olii keessaa kan adda baaste irratti hundaa’uun unka armaan gadii guuti.

“Memorial symptom assessment scale”

Qajeelfama: Gabatee armaan gadii keessa mallattooleen 32n tarreeffaman torban lamaan darban keessatti hagam akka dhibamaa/tuu irratti akka argaman, hammaataa ta’anii fi yaaddessan/dhiphisana sakkata’uuf gargara. Yoo dhukkubsataan sun mallattoo sana kan hin qabne ta’e mallattoo “X” sirrii ‘lakkii’tiin jiru keessa kaa’i; yoo kan qabu ta’e ammoo mallattoo (√) saanduqoota mata duree sadan jala jiran keessa akka yaada dhukkubsataa sanaatti kaa’i.

Lakk.	<i>Turban lamaan darban keessa mallattoolee asii gadii ofirratti argitee ni beektaa? yoo kan jiru ta’e sadarkaa isaanii ibsi</i>	Lakki	Yoo argite ta’e										
			yeroo meeqa				hagam si rakkise			hagam si yaaddesse			
			Baay’ee turee turee	Yeroo tokko tokko	Yeroo baay’ee	Yeroo hunda	salphaa	Giddu-galeessa	hamaa	Xiqqoo	Hamma tokko	Giddu galeessa	Baay’ee
1	2	3	4	1	2	3	1	2	3	4			
1	hafuura kutaa												
2	Humna dhabuu												
3	Afaan goggogsuu												
4	Muusessaa												
5	hirriba dhabuu												
6	yaaddoo												
7	yeroo ciisichaa hafuura baafachuu dadhabuu												
8	hoqqaasiisuu/olguuraa												
9	ol-xuquu (nausea)												
10	qufaasisaa												
11	gadduu												

12	dhiphachuu/ aarii																		
13	dafqisiisuu/hunnasiisuu																		
14	jeeqamuu																		
15	dhukkubbii laphee/qomaa																		
16	Dhukkubbii kan biro																		
17	garaa bokoksuu																		
18	joonjessuu/ lafti ittiin maruu																		
19	qalbeefachuu dadhabuu																		
20	halkan halkan rakkoo hafuura kutaan hirriba keessaa dammaquu																		
21	onneen amma yeroo kaaniin ol rukutuu																		
22	dhidhitina harkaa fi miillaa																		
23	rakkoo yeroo wal quunnamtii saalaa humna dhabuu																		
24	hadooddi harkaa ykn miillaa																		
25	qaama hooqsisuu																		
26	ulfaatina qaamaa dabaluu																		
27	ulfaatina qaamaa hir'isuu																		
28	fedhii nyaataa dhabuu/hir'isuu																		
29	garaa gogsaa																		
30	garaa kaasaa/ teessisaa																		
31	rakkoo boolii bishaanii/fincaanii waliin walqabate																		
32	jijjiirama dhandhama nyaataa																		
Kanneen ibsamaniin alatti mallattoolee kan biroo turban lamaan darban keessa kan argite yoo ta'e bakka duwwaa armaan gadii keessatti guuti, haala isaaniis akka armaan oliitti ibsi.																			

3. Gaaffilee dhiibbaa jiraachuunii fi baayyinni mallattoolee kanaa jireenya nama sanaa irratti fidan/qaban qorachuuf qophaa'an:

3.1. Mallattooleen kun jireenya kee guyyaa-guyyaa irratti dhiibbaa ni fiduu?

Eeyyee

Lakki

3.2. Deebiin gaaffii lakk. 3.1^{ffaa} "eeyyee" yoo ta'e, akkamitti?

3.3. Rakkoo sirna hargansuu qabdaa?

Eeyyee

Lakki

3.4. Deebiin gaaffii lakk. 3.3^{ffaa} "eeyyee" yoo ta'e, yoom yoom?

Guyyaa-guyyaa

Yeroon

hojii

Halkan-halkan

hojjedhu

3.5. Boraatii meeqa fayyadamta? _____

3.6. Dhukkubni kun hojii kee kanaan dura guyyaa-guyyaan hojjettu akka sirriitti hin hojjenne si taasiseeraa?

Eeyyee

Lakki

3.7. Deebiin gaaffii lakk. 3.6^{ffaa} "eeyyee" yoo ta'e kanneen armaan gadii keessaa isaan kamiin akka hin raawwanne si taasise?

Nyaata nyaachuu

Of babbareechuu

Uffata uffachuu

Adeemsa adeemuu

Daldaluu/bittaa meeshaalee

fuduraa fi muduraa adda addaa
oomishuu

mana fincaanii fayyadamuu

nyaata bilcheeffachuu

qaama dhiqachuu

kan biroo (ibsi) _____

4. Bargaaffii onnee dadhabdee waliin jiraachuu minisootaa

Gaaffileen armaan gadii hangam dadhabiin onnee torban lamaan darban keessatti jireenya dukkubsatootaa irratti dhiibbaa geessise ilaallata/gaafata. Hagam jireenya dhukubsatootaa irra dhiibaan akka ga'e beekuuf tokkoo tokkoon gaaffilee booda axaaroo ($\sqrt{\quad}$) 0, 1, 2, 3, 4 ykn 5 jalattii kaa'i.

Lakk.	Dhiibba/miidhaa <i>Torban lameen darban keessatti dhibeen onnee ati qabdu akka feetetti akka hin jiraanne si-ittiseeraa? "Eeyyee" yoo jette akkamiin?</i>	'Eeyyee' yoo ta'e hagam					
		lakki	Baay'ee xiqqoo	xiqqoo	Giddu galeessa	Baay'ee	Baay'isee baay'ee
			0	1	2	3	4
1	Miilli ykn gulubiin kee akka dhiita'u gochuudhaan						
2	Hojii dadhabdee akka teessu ykn boqottu gochuun						
3	Adeemsa tabba/gaara ba'uu dadhabsiisaa gochuun						
4	Dalagaa qee'ee/oohiruu keessaa irratti sidadhabsiisuun						
5	Manarraa fagaattee deemuu irratti si dadhabsiisuun						
6	Hirriba halkanii irratti rakkoo sitti fiduun						
7	Maatii ykn miiltoo kee waliin hojjechuu ykn walitti dhufeenya kee waan addaan kutuuf						
8	Jireenya kee mo'achuuf hojii ati hojjettu ulfaataa waan sitti taasisuuf						
9	Hojii yeroo boqonnaa keetii, ispoortii garagaraa akkasumas waan hawwii keetii akka hin hojjenne waan si taasisuuf						
10	Wal-quunnamtii saalaa yeroo gootu akka sitti ulfaatu waan taasisuuf						
11	Nyaata kanaan dura jaallattu akka jibbitu waan si taasisuuf						
12	Hafuurri kee akka ciccitu waan taasisuuf						
13	Akka dadhabdu ykn human dhabdu waan si taasisuuf						
14	Mana yaalaa keessa ciistee akka turtu waan si taasisuuf						
15	Qarshii baaay'ee mana yaalaatti akka baastu waan si gaafatuuf						

16	Dawwaan/qorichi ati fudhattu miidhaa dabalataa waan sirraan ga'uuf						
17	Maatii ykn hiriyoota kee irratti ba'aa akka taatetti waan si yaadchisuuf						
18	Akka nama waa'ee isaa murteessuu hin dandeenyeetti waan of ilaaltuuf						
19	Baay'ee waan si yaadchisuuf/dhiphisuuf						
20	Waan darbe tokko yaadachuun ykn hubachuun waan sitti ulfaatuuf						
21	Waan si muusessuuf						

5. MADAALLII HAALA JIREENYAA GAARII “QUALITY OF LIFE SCALE”

Qajeelfama haala qaphxeessuu madaalli qulqullina jireenyaa

Unki qaphxeessuu madaallii qulqullina jireenyaa gaaffii 15 qaba. Yoo yeroo ammaa kana dhukkubsataa sanairratti kan hin hirmaanne ta’ee illee qooda fudhattoonni akka tokkoo tokkoo gaaffilee guutaniif jajjabeeffamuu qabu. Odeeffannoon hir’aanfamee qaphxii giddu-galeessa kaa’uun bakka bu’a. Maaloo tokkoo tokkoo gaaffilee dubbisuun lakkofsa isa dhukkubsataan yeroo ammaa haala gammachuu isaanii ibsan axaaressi. Yoo yeroo ammaa dhukkubsattootni qooda kan hin fudhanne ta’e illee ykn walitti-dhufeenya hin qabaanne illee tokkoo tokko gaaffileef deebii kenni. Dhukkubsataan utuu hin dalagiin ykn walitti-dhufeenya hin qabaatin gammaduus gammaduu dhiisuus ni danda’a.

Sno	Gaaffiilee	Qaphxii				
		Guutummaatti natti hin tolu	Gara caalu natti hin tolu	Giddu galeessa	Gara caalu natti tola	Guutummaatti natti tola
		1	2	3	4	5
1	Meeshaalee mana keessaa(siree, boraatii, teessuma, kkf), nyaata akkasumas qarshiidhaan of danda’uu					
2	Fayyaa – jabinaafi fayyummaa qaamaa cimaa ta’e qabaachuu					
3	Maatii, ijoollee fi firoota ofii waliin walitti dhufeenya, haasawaa fi wal gargaarsa gaarii ta’e qabaachuu					
4	Ijoollee godhachuu fi guddisuu ykn sooruu danda’uu					
5	Haadha warraa ykn abbaa warraa ofii fi namoota kan biroo waliin walitti dhufeenya gaarii ta’e qabaachuu					
6	Hiriyaa dhiyoo/cimaa ta’e horachuu					
7	Namoota rakkoo qaban kan biroo fedhii ofiitiin gargaaruu, jajjabeessuu akkasumas gorsuu danda’uu					
8	Dhimma gumii/dhaabbata hawaasummaa adda addaa keessatti hirmaachuu					

9	Barachuu- daree seenanii hordofuu, hubannaa ofiii guddifachuu fi beekumsa dabalataa horachuu					
11	Hojii mana keesaa fi kan alaa sirriitti hojjechuu danda'uu					
12	Sirriitti of ibsuu danda'uu					
13	Waliin jireenya- nama kan biraan wal quunnamuu, wantoota garaagaraa hojjechuu fi paartiilee bashannanaa adda addaa irratti hirmaachuu danda'uu					
14	Wantoota garaa garaa dubbisuu, muuziqaa dhaggeeffacuu, ykn bakka bashannana adda addaa do'achuu danda'uu					
15	Bashannana adda addaa keessatti akka gaariitti hirmaachuu danda'uu					
16	walabummaa – ofiif hojjechuu danda'uu					

6. Bargaaffilee wal'aansa yaalaatiin wal qabatan

6.1. Sochii qaamaa garaagaraa ni raawwattaa?

- A. Eeyyee B. lakki

6.2. Yoo deeniin kee gaaffii lakk. 6.1^{ffaa} kan raawwattu ta'e maal fa'a?

6.3. Sadarkaan dhibee onnee dhukkufsataa sanaa meeqa? (Kaardii ilaali) _____

- A. I B. II C. III ykn IV

6.4. Qorichi/dawwaan yeroo ammaan tana fudhachaa jirtu maal jedhama? (kaardii irraa kan fudhatamu) _____

6.5. Rakkoo addaa qarichi ni fida jedhamee yaadamu ni qabdaa?

6.6. Deebiin kee 'eeyyee' yoo ta'e qaricha isa kamtu rakkoo sitti fide? _____

6.7. Rakkoon qarichi sitti fide sun maalinni? _____

6.8. Rakkoo kana hir'isuuf fala maalii barbaadde? _____

7. Gaaffillee haala jireenya nama sanaa waliin walqabatan

7.1. Wantootaa araada nama qabsiisan ni fayyadamtaa?

- A. eeyyee B. lakki

7.2. Yoo deebiin kee gaaffii lakk. 7.1^{ffaa} 'eeyyee' ta'e wantoota akkamii fayyadamta?

- A. jimaa D. dawwaa
B. alkoolii garaagaraa E. kan biroo (addeessi) _____
C. tamboo

7.3. Hagam daddaftee fayyadamta?

- A. yaraa B. yeroo baay'ee C. yeroo hunda

7.4. Jabeenya qaamaa ni dalagdaa?

- A. eeyyee B. lakki

7.5. Yoo deebiin kee gaaffii lakk. 7.4^{ffaa} 'eeyyee' ta'e gosa akkamii?

7.6. Gosa nyaataa akka hin sooratne dhorkamte qabdaa?

- A. eeyyee B. lakki

7.7. Yoo deebiin kee gaaffii lakk. 7.6^{ffaa} ‘eeyyee’ ta’ nyaata akkamii?

A. Ashaboo ykn soogidda

D. kaarboohaaydireetii

B. Coomaa ykn dibata

E. kan biroo (addeessi) _____

C. pirootiina

7.8. Gargaarsa hawaasummaa garagaraa ni argattaa?

A. eeyyee

B. lakki

7.9. Yoo deebiin kee gaaffii lakk. 7.8^{ffaa} ‘eeyyee’ ta’e qaama kamirraa/eenyurraa argatta?

Hirmaannaa keessaniif galatoomaa!!!!

Waa’ee nama odeeffannoo guuruu

Maqaa _____

Mallattoo _____

Guyyaa ____/____/____

