

Lived Experience of Adult With Heart Failure at Tibebe Ghion Specialized Teaching Hospital Northwest Ethiopia, Qualitative Phenomenological Study

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Background: Heart failure is major public health problem that affects many people worldwide. It affects all aspects of patients' lives, leading to extreme physical, social, and functional restriction and increasing psychological distress. The purpose of this study was to explore the lived experience of adult patient with heart failure at Tibebe Ghion Specialize Hospital, Ethiopia, 2022.

Method: Qualitative Phenomenological study design was conducted at Tibebe Ghion Specialized Referral Hospital, from November 10 to December 15, 2022. Heterogenous purposive sampling technique was used to select 11 study participants. Data were collected through in-depth interviews guides and observational checklist. The rigor and trustworthiness of the study were maintained by transferability, dependability, credibility, and conformability. Thematic analysis method was used for the development of codes and themes using ATLAS.ti.7 software for analysis.

Result: Five main themes and eleven subthemes were developed that explore the lived experience of adults with heart failure. Impact of heart failure on daily life, psychological and spiritual experiences, financial experiences, experiences related to hospital service, and challenges to getting treatment are major themes. Unavailability of medicine, lab investigations, and the inaccessibility of cardiac centers were the main challenges during their treatment.

Conclusion: This study explored that lived experience of adult HF patients were addressed in in terms of Physical, Psychological and Spiritual, financial, hospital service and challenges to get treatment. Therefore, we recommended providing psychological and economical support for HF patients and in addition to accessing medication and medical care centers.

Keywords: heart failure, lived experience, phenomenological study, Ethiopia

Introduction

Heart failure (HF) is the result of a gradual decline in heart function to pump sufficient blood to meet the body's needs for oxygen that results from several secondary causes. Heart is characterized as an unpredictable, recurrent, chronic, and progressive disorder.¹ HF is a major and growing global health problem associated with significant mortality and morbidity.² It is a serious condition for which there is no cure; characterized by a progressive deterioration of the patient's state of health, it has a significant impact on their well-being.³

According to World Health Organization (WHO) report cardiovascular disease, especially heart failure, will continue to be the leading cause of morbidity and death. Evidence on the global burden of HF shown that the prevalence of this condition is increasing in every country, comprising more than 10% of deaths in high-income countries and 28% of deaths in low- and middle-income countries.⁴ HF places a significant burden on populations in low- and middle-income countries (LMICs).⁵

Heart failure (HF) is the fastest-growing cardiovascular disease worldwide, with approximately 26 million adults affected, including 6.5 million people in the United States and over 14 million people in Europe.⁶ It is the leading cause of hospitalization among adults and the elderly.^{7,8} Heart failure affects approximately 2–5% of adults ages 24 to 65 and >10% of adults ages 80 and older. It is still the leading cause of adult disability and death worldwide.⁹

The Sub-Saharan Africa Survey of HF research discovered an increase in the prevalence of heart failure among people suffering from it, from 23% to 43%. Furthermore, hospital case fatality rates among those with heart failure range from 9% to 12.5%, making heart failure one of the leading causes of cardiovascular deaths in Africa.¹⁰

Moreover, due to the lack of medical services, diagnosing heart failure in Africa can be difficult. Morbidity and mortality from heart failure are increasing in many African countries.¹¹

Heart failure has emerged as one of the leading causes of death in Ethiopia, with numerous cases being diagnosed each year. Evidence of GBD, HF is the fifth leading cause of death, as well as one of the leading causes of hospitalization, and is expected to have a significant impact on future healthcare outcomes in Ethiopia.¹²

HF patients experience number of signs and symptoms including dyspnea, fatigue, poor exercise tolerance, increased heart rate, and peripheral edema that affect their quality of life.¹³ Patients living with HF frequently have a poor quality of life, even treated with modern evidence-based therapies.¹⁴ Adults with HF commonly experience anxiety and depression, as well as significant reductions in their ability to engage in social, recreational activities, and decreased sexual functioning. Furthermore, HF patients are faced not only with devastating functional losses, but also a variety of economic, emotional and occupational concerns that significantly impact their overall quality of life.¹⁵ Patients with HF undergo diverse and meaningful experiences, such as uncertainty caused by unexpected changes in their condition, notable changes in their family, social roles, and spiritual needs.¹⁶

Adult patients with HF experience serious physical limitations, poor mental health, and cognitive impairment, all of which limit their ability to interact socially and result in a reduced quality of life.¹⁷ Heart failure significantly reduces a patient's quality of life due to its poor prognosis, high cost of care, multitude of physical symptoms, frequent hospitalizations, psychological distress, and social and professional limitations.^{18–20} Impaired quality of life not only has a negative impact on life, but also increases the risk of morbidity and mortality.^{21,22}

Economically, HF is one of the most expensive healthcare problems, second only to stroke in terms of expense.²³ By 2030, the total cost will be projected to increase to \$53 billion.²⁴ These costs include not only the cost of healthcare services and medications, but also the lost productivity of individuals with HF. Its high prevalence, high medical costs, and poor outcomes, HF is an important public health problem. The numerous symptoms and repeated hospitalizations for HF not only negatively affect the patient's quality of life, but also increase their economic burden.²⁵

Studies in Ethiopia conducted on Heart failure focused on identifying risk factors, determine prevalence and comorbidity of the disease were sought. However, to the best of our knowledge there is no evidence how heart failure patients are living with this serious and multifactorial condition. No evidence how people are understanding the disease condition and their response to live with this condition are not well understood. Therefore, this study aimed to explore the lived experience of patients with heart failure to fill this gap.

Methods

Study Setting and Period

This study was conducted at an outpatient clinic in Tibebe Ghion Specialized Hospital (TGSH) of Bahir Dar University, which is one of the tertiary governmental teaching hospitals located in Bahir Dar, North-West Ethiopia, from November 10 to December 15, 2022. The hospital, established in 2019, serves as a reference hospital for neighboring hospitals and health centers in the catchment area, providing services to around seven million people. The study was conducted at an outpatient clinic under the internal medicine department of the hospital on adult's heart failure patients among cardiovascular patients who have regular cardiac follow-up visits. The hospital has a bed capacity of 500. It has two regular medical outpatient clinics (OPDs) for chronic patients' follow-up visit. Cardiac clinic works once a week. In the cardiac clinic 1200 HF patients had follow up.²⁶

Study Design

A descriptive phenomenological study design was conducted in Tibebe Ghion Specialized Referral Hospital (TGSH). The purpose of this phenomenological study design was to explore patients experience and understand of what it is like to be living with heart failure.²⁷

Study Participants and Sampling Technique

We recruited total of 11 adults with Heart failure who had follow up at TGSH Bahir Dar University November 10 to December 15, 2022, and Data saturation was maintained.

The study participants were all purposively selected adult heart failure patients attending in outpatient clinic at TGSH during the study period and who had follow-up visit for at least one year and age ≥ 18 years old. Participant seriously ill who were unable to communicate and unable to provide detail information during interviews were exclude from the study. The period of one year and above was chosen because considering the patients had enough life experience with heart failure.

A heterogeneous purposive sampling technique based on age, gender, educational status was used to select study participants, which ensured meaningful experiences with the phenomenon under study. Purposive sampling technique aids in the purposeful selection of participants who able to communicate and provide an important explanation about their lived experience with heart failure. The study participants were selected from TGSH and had outpatient cardiac follow-up visits. Participant selection was undertaken in collaboration with cardiac unit nurses looking at their book chart diagnosis and appointment list book. Principal investigator was explained the purpose of study to the participants.

Data Collection Technique

In-depth interview guide and observational checklist was used to collect data for this study. The guide was developed first in English and translated into Amharic (the local language) to collect the data ([Interview guide, Annex 1](#)). The interview was performed with known diagnosed adult heart failure patients from November 10 to December 15, 2022. The interview provided detailed information about each person's experiences, views, and feelings related to heart failure. After explaining the purpose, risks, and benefits of the study, and the length of the interview, the participants were asked to sign the informal consent to participate in this study. After informal consent taken principal investigator was collected data. The interviewer was used open, non-directive questions, which allowed participants to freely describe their experiences in daily life after being diagnosed with HF.

The interview was initiated with a broad and general question followed by a probing question, and then the questions get more focused as the data collection progresses. The interview was conducted until it reaches conceptual saturation (to the point no further new information will be obtained anymore). During data collection, participants were naturally engaged, first asking the participant, and listening attentively until they completed their idea, then probing based on the response of the participant by using how and why questions to get adequate data on points of interest.

An in-depth interview takes place at a time when it is comfortable for participants. All participants interviews took place in the hospital in outpatient nursing coordinator office. During the interviews, two of the participants became emotionally upset whilst talking about their illness. When this happened, the interviews were paused and reschedule the interview for the next appointment. The interview lasted between 45 and 60 minutes. All interviews were recorded by using a digital audio recorder. The interviewer was taken field notes parallel to the interview, regarding body language, verbal, and nonverbal cues. Participants were coded as P1.P2...P11 respectively according to their order of interview. The PI asked the participants if there was anything additional, they wanted to discuss or mention after the interview was completed and the interviewer thanked them after completion of the interview.

Rigor and Trustworthiness of Study

Rigor and Trustworthiness was maintained by the dimensions of credibility, transferability, dependability, and conformability.²⁸

Credibility: was maintained by allocating adequate time to data collection and analysis, good relationships with participants in cardiology clinic (prolonged engagement in the field), and constantly comparing the data with each other through triangulating interview data with field notes obtained from the participant through observation while interviewing them. All interviews were audio recorded and the interview guide and observation checklist were reviewed by peers who had qualitative research experience and consultants prior to data collection. Peer debriefing and feedback from colleagues and advisors were used in managing the data.

Dependability: The stability of the data was maintained using a standard guide for the interviews holding and transcribing all interviews by the PI. Dependability was ensured through accurate documentation by minimizing spelling errors through spot audits, frequently observing data, including all documents in the final report, such as notes taken during the interview, and ensuring that the processes of data collection, data analysis were detailed. The data collection, analysis, interpretations, and conclusions were regularly evaluated.

Conformability: was ensured by providing rich quotes from the participants and no bias or established audit trail in the process of choosing methods, recording of each activity of the participant at the time of the interview, and every procedure of the study such as analysis of data, and interprets of result.

Transferability: was ensured by purposefully selecting study participants who met the inclusion criteria, and transferability of this study was ensured by clearly and in detail describing the research context, setting, sample, and data collection procedure and assumptions that were central to the research to enable the reader to assess the findings' capability of being transferable. The interview was conducted with the aid of digital audio records and field notes for observational data.

Data Analysis

Thematic analysis was used to analyze the data obtained from the participants' interview. The data were analyzed by using software (Atlas.ti7). Data were analyzed following the principles of thematic analysis. The analysis was started early at the time of data collection and all data was interpreted. All interviews and field notes were transcribed in the Amharic language and translated to English conceptually by the principal investigator. Data was transcribed by PI, read several times, critically evaluate to get the concept and group into themes based on the concept it contains. Every day after completing each interview, the field notetaking from observation was written focusing on the nonverbal communication of the participant. After familiarization with the data, we were assigned code based on the context of the sentence line by line ([Code book: Supplementary Table 1](#)). After assigning code for each data with similar meaning collected to the same to categorize and it forms sub-themes and then major themes was developed. Quotes were used to highlight each category and show association with each theme. The initial list of themes was reviewed and then refined based on advisor comment. Then statements were developed to complete a description of the lived experience of adult heart failure patients' experience.

Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) Bahir Dar University, College of Medicine, and Health Science School of public health (protocol No: 548×2022). Informed written consent was taken from each participant after clarifying the study objective. To keep the confidentiality of participant name was not included in the in-depth interviews instead we were used coding method and keeping it with the principal investigator only. They were also informed of they had the right to withdraw from the study at any time. The participants informed consent included publication of anonymized response and the ethical clearance was based on Declaration of Helsinki.

Result

Socio-Demographic Characteristics of Participants

We recruited eleven participants for this study. Four of the participants were females, and seven were male. The age of participants ranges from 21 to 63 years. All the participants had been diagnosed with HF for a range of approximately 1 to 7 years (Table 1).

Thematic Findings

The findings that emerged from the analysis of interview were presented and arranged as themes, and sub-themes. Data analysis has revealed five themes and eleven sub-themes that express the lived experience of adults with heart failure (Table 2). The relationship between one theme with others are showed in Figure 1.

Theme One: Impact of HF on Patients Daily Life

The impact of HF on daily life was the common theme. This theme derives from the following two sub-themes: namely reduced physical function and social life limitation. Participants often reflected on the impact of heart failure on their social life, physical ability restriction to do their work, and hobbies restriction. Most participants reported that heart failure had an impact on their daily lives in many aspects, including reduced physical function, reduced social life, and social roles in the community and family.

Table 1 Socio-Demographic Information of Participants at an Outpatient Cardiac Clinic in Tibebe Ghion Hospital, Bahir Dar, Northwest Ethiopia, 2023

Characteristics	Category	Frequency	Percentage (%)
Sex	Male	6	54.5
	Female	5	45.5
Age	18–27	1	9.1
	28–37	5	45.4
	38–47	1	9.1
	48–57	1	9.1
	>=58	3	27.3
Marital status	Single	1	9.1
	Married	8	72.7
	Divorced	2	18.2
Educational status	Cannot read and write	2	18.2
	High school	1	9.1
	Higher Education	8	72.7
Monthly income (ETB)	No income	1	9.1
	1,001–3,000	2	18.2
	3,001–5,000	2	18.2
	5,001–10,000	5	45.4
	>10,000	1	9.1
Occupational status	Farmer	2	18.2
	Gov't employee	4	36.3
	Merchant	1	9.1
	Retired	2	18.2
	Student	1	9.1
	No work	1	9.1
Years with HF	1–3	5	45.4
	4–6	4	36.4
	>=7	2	18.2

Table 2 List of Themes and Subthemes for the Lived Experience of HF Patients

S.no	Themes	Subthemes
1	Impact of HF on patients' daily life	<ul style="list-style-type: none"> • Social life limitation • Decrease physical function
2	Psychological and spiritual experience,	<ul style="list-style-type: none"> • Negative emotion • Depression • Living life inspired by God
3	Economical experience	<ul style="list-style-type: none"> • Direct medical cost • Transportation cost
4	Experiences related to hospital service,	<ul style="list-style-type: none"> • Uncomfortable building setting • Relationships with healthcare professionals.
5	Challenges to getting treatments	<ul style="list-style-type: none"> • Inaccessibility of the cardiac center • Unavailability of medical supply and investigation

Sub-Theme One: Decreased Physical Function

Participants described the impact of HF on their lives living with heart failure symptoms. Most participants reported having limitations in physical function. Almost all participants complained of HF symptoms, particularly physical weakness, fatigue, palpitations, shortness of breath, and lack of energy, which led to difficulty completing their tasks. Some participants said they had difficulty performing daily household activities such as washing clothes, cooking, and taking care of children; these were the most common physical function impairments that participants experienced related to HF. This condition stated as follow:

Before I had heart failure, I took good care of my baby, and washed family clothes, but now I am too tired to take care of my baby and wash clothes. I used to carry small things and feel tired; even holding a small child made me tired, so I could not carry anything. I have limited physical activity. (28 years old p11)

Three participants reported that they were unaware of their condition and felt weak while doing their work; because of this, the community and their family saw them as weak persons, and they did not understand their feelings.

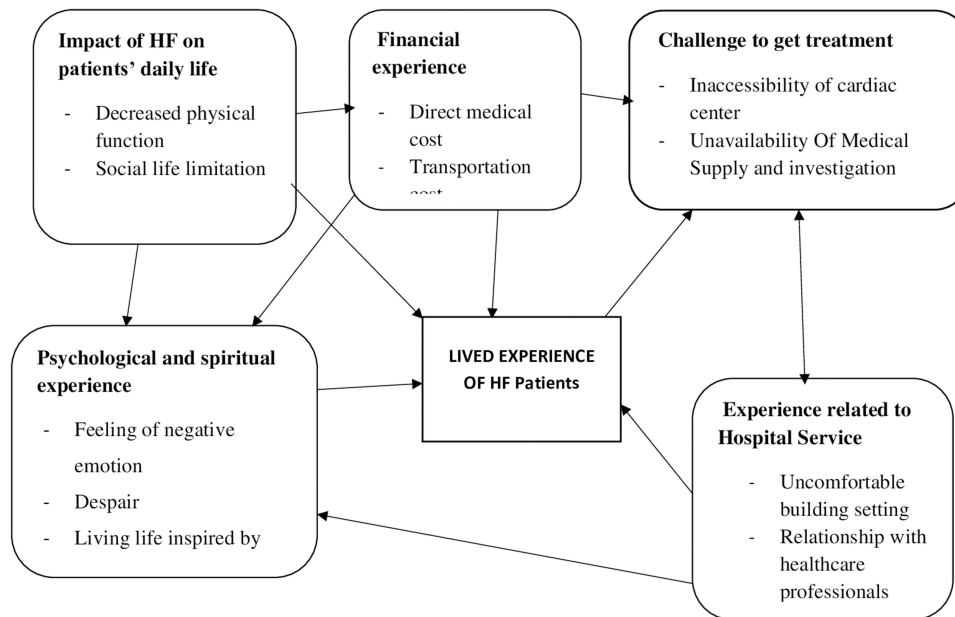


Figure 1 Themes and subthemes of lived experience of adult patients with heart failure in Tibebe Ghion Hospital, Ethiopia, 2023.

Em...They (family) informed me that you are weak while I was working my work. My pain was not appreciated by the family. It made me depressed. Even when I started work, I used to cough, feel tired, and produce blood-tinged sputum. The only way feel better when I rest, and the community consider me that I am weak and can't do work. But the cause of that was heart failure that made me weak. The disease slowly weakened me. (28-years-old p3)

Most of the participants reported Dyspnea, chest pain, and fatigue that were limiting to perform activities such as climbing steps, doing sports, and standing long periods of time on their work, and walking long distances. One participant mentioned feeling tired when walking up the building steps to his medical appointment, which is why he needed someone else's help. Additionally, some of the participants reported that physical symptoms of heart failure, such as chest pain, cough, and shortness of breath, led to poor sleeping patterns.

...Ever since I found out that I have heart failure, it has affected my physical activity. For example, I cannot run within the ward as I need to go where I am currently working. I was relocated to a less busy department because I cannot do my work effectively, which requires energy. Even if I start working when I feel comfortable, I cannot do more work because I feel shortness of breath, chest pain, a cough, and a feeling of tiredness. At the same time, I cannot sleep better if I sleep without a pillow (crying); it's hard to breathe and my breathing is fast, and I'll have nocturnal dyspnea. I cannot sleep. If I am in an upright sitting position, I can sleep better. (33-years-old P5)

Observational result: during interview period I saw some of the study participants had difficulty climbing the steps in hospital during their medical follow-up visit and they need help getting to the cardiac clinic because the patients were unable to walk on their own, they were wasted and chronically sick looking. They complained dyspnea and tachypnea when they climb building steps.

Sub-Theme Two: Social Life Limitation

Although most participants lived with their families, their social lives were limited due to disease condition. Most participants felt that their social interactions with former colleagues, friends, and family members were limited. These limitations in social interaction resulted from due to their physical weakness, economic constraints, as well as dietary restriction and emotional stress. Most of the study participants were experiences negative social life, such as social isolation, decreased social interaction, and negative social judgment. Additionally, most study participants could not walk long distances to participate in community ceremonies like weddings and Christmas, and they could not participate in common community work because they felt tired/fatigued while walking long distances and doing labor work. Hence, most of the time they isolated themselves in community ceremonies, which led to limited social interaction. Stated as follow:

There is always social interaction between people everywhere and, all times, but my health condition limits me in social interaction and leaves a significant gap in my social life. For example, when I go to a café or restaurant with my friends, they order coffee or other alcohol and drink it. I sit and enjoy with them without drinking coffee or alcohol because my heart condition prevents me from doing so (a sad feeling). My heart failure conditions prevent me to maintain a social life. When I am invited to someone's house in ceremony, I get frustrated to go to ceremony because I do not eat what healthy people eat, I do not drink what people drink. As result I do not usually attend invitation ceremonies. (61-years old-male participant)

This study results showed that some participants had positive social outcomes, such as family, friends, and colleagues who offered social, psychological, and financial support, enabling them to access timely medical care, they also received advice and inspiration from other HF patients and healthcare professionals. Participant Stated as follow:

Ah... my family, my husband, my mother, my brothers, and friends are always there to help me. Since my monthly salary does not cover medical expenses, my families are always by my side, covering my medical expenses and mentally strengthening me. I can't even afford medication for two weeks on my salary, and I have good social contacts with my doctor, who gives me excellent care during the follow-up examination. (39 -years- old female p10)

Theme Two: Psychological and Spiritual Experience

This theme emerged from three sub-themes namely: feeling of negative emotion, depression, and living life inspired by God. Most participants were diagnosed with heart failure for the first time their reaction was a negative emotion such as bad feeling, sadness, anxiety, hopeless, depressed, cry, and frustrated experience. This negative emotion was maintained by their spirituality.

Sub-Theme One: Feelings of Negative Emotions

Almost all participants reported that living with heart failure brought intense emotions. Most of the study participants frequently expressed negative emotions, such as anxiety, fear, anger, crying, dissatisfaction, and loss of hope because of the severity of their disease condition, social life limitations, and economic constraints. Most participants experienced anxiety, worry, and hopelessness due to the symptoms of heart failure, a poor disease prognosis, the occurrence of emergency events, high medical expenses, and the inability to engage in activities as they had previously.

Ehh... when I was living with heart failure, I faced a lot of psychological pressure. What I have told you that I had no job, and wanted to do more work, but I could not do extra work because of my disease condition. Due to this, I am under economic pressure not only me but also my families are under economic pressure. I felt a great sense of frustration and despair. When I see them (family) not being fulfill their needs, it makes me sad, and depressed. (63-year-old p1)

Although most participants experienced negative emotional a result of their heart failure, some participants experienced positive emotions; they said that they did not feel ill and perceived themselves as healthy and happy, accepting the condition of the illness and having a positive attitude despite their diagnosis. Participants had high hopes of recovering from their disease. P2 stated as follow:

When I was first told that I had heart failure, it caused me psychological distress. But later, when I realized that it was a more serious illness than heart failure and I started to convince myself to accept my illness, my psychological pressure was minimized, and I did not feel much. I am happy because I am dealing with health professionals that helped me get out of depression. I had less mental pain because I believed in God and my family was with me in every step, and I gradually recovered. (61- year- old p2)

Sub-Themes Two: Despair

Participants said they had dreams and inspirations for the future even before they were diagnosed with heart failure. However, some participants reported feeling emotionally unstable, losing their vision of their future life, and feeling hopeless and disgusted, which worsened their depression. For example, two female participants were exposed to severe mental illness. They were depressed when doctors informed them that there was no chance of future pregnancies. These conditions narrate as follow:

My psychology was seriously affected. For example, I was told that I could not give birth. As a human being, I used to have dreams that I would have a family of my own. My inability to give birth hurt me and I lost hope for my future. I am anxious, um...I have lost weight, and I do not sleep well anymore. I am under depression. (33-years-old p5)

Most participants felt depressed. The reasons for the depressions were the perceived decrease their role and function within families, as well as the inability to fulfill their family needs was their major concern.

I am a farmer, but I have never been able to do my farm work as efficiently as my friend. As a result, my family faces financial difficulties and I am unable to meet their needs, which causes me depressed and hopelessness. (56-years-old p6)

Sub-Theme Three: Living Life Inspire by God

Almost all participants had similar religious beliefs. Participants explained that religion alleviates their pain and provides acceptance and belief in God's will to stay alive and hope for healing through God's help. Most participants used specific words to describe their relationship with God, such as "God willing, thank God", in relation to their current health status,

while most participants said that spiritual support was noted as a coping mechanism following HF. Engaging in religious practices, such as praying, fasting, and reciting religious quotes helped individuals make sense of their health. Participant explained this situation as follows:

I believe that my faith has kept me alive until now. I did not believe at first that I would still be alive with my illness. I see that money is not enough to save lives; Only God can heal me from heart failure. (61 years old p2)

However, some participants stated that living with HF affects their spiritual life where some practices of their religion like fasting may affect their heart failure treatment in a negative way. To live in a strong religious condition considered an important thing for the participant to live in peace. But not being able to participate in a religious activity such as unable to fast, praying, baptize related to the impact of the physical symptoms. Due to the impaired physical condition of the participant and the routines nature of the treatment made it difficult for them to continue with their religious commitments.

Participant explored as follow:

Being sick has made me weak in my religion. The Christmas fast has begun. It was a fast that everyone fasts, but I couldn't fast because I took medicine every day after eating breakfast. When people go to places that bring blessings, I can't go because I feel tired after a long distance. For these reasons, I have resumed some spiritual activity. (33- years-old p5)

Theme Three: Economical Experience

The economic experience of the participant caused by HF was given priority in this finding as this was pre-dominant theme across all the interviews. This major theme gave rise to two sub-themes, namely, direct economic experience and transportation.

Sub-Theme One: Direct Medical Cost Experience

Almost all participants reported that they face financial problems during the diagnosis and during the treatments. Most of the participants in this study felt that their medical costs were high. Most of them cost a lot of money for regular doctor visits, Laboratory tests, medications, and frequent hospitalization. This expressed by participant as follows:

Ah... after I became a heart failure patient, I went to the hospital frequently for follow-up and took a lot of medicine. I am requested to have laboratory tests and other heart failure tests. Because of this, I must spend a lot of money as I am under financial constraints. (28-years old p11)

In this study, three participants use community-based health insurance, but are not satisfied and do not fully cover their medical expenses with free medical care. Because most heart failure drugs were not available in public hospitals. Most of the time, they get their medicines from a private pharmacy, and the price is double or more. At the same time, due to physical limitations, the participants no longer undertake the original work, which greatly reduces their economic income and makes it more difficult for them to pay their medical expenses. This can lead to interrupt their follow-up visit. So that some of them were covered their medical expenses by sell their assets like houses, farming land, cattle, and borrow money from other people to have their medication. These have influenced the living conditions of their whole family. As expressed by participant as follow:

I used to have CBHI, but community health insurance did not cover my medical expenses fully. I bought it at a private pharmacy because there is no enough medicine for heart failure in the hospital. Currently, I spend more than 1000 birr on each checkup and my mother has to borrow money for my treatment, but the loan taken for my treatment has not been repaid yet. It's been a month since I stopped treatment because I can't pay for it. (21-years-old p8)

These findings were obtained using in-depth interviews, which correspond to an observational check list the results as follow:

An observational finding: During an interview, one participant reduced his prescribed drugs from four to two; the reason he mentioned was lack of money to buy all types of medicine. Because most heart failure medications were out of

stock in the public hospital, at the same time he could not buy drugs from a private pharmacy. I saw the effect of a shortage of money to get heart failure treatment. Furthermore, I observed two individuals refusing cardiac tests, like EEG examinations; the reason they explained was that the EEG machine was not available in the government hospital and that they could not afford it in a private facility.

Additionally, because of the financial constraints of the disease, two participants reported that they were unable to fulfill their family needs and school fees due to increased medical expenses.

I had four children who were studying at a private school, but now I cannot cover their school fees with my medical expenses. I have sent them to government schools. My heart disease has put a lot of financial pressure on my family. The treatment costs were extremely high. Every month, I spend more than 4,000 birrs on medicines and examinations. (39- Years -old p10)

Sub-Theme Two: Transportation Cost

Most participants complain transportation cost from the treatment center to home and to return to the treatment center during their medical follow-up visit was so expensive. The participants complain that one reason for problems with transportation was the place they come from. Many of the participants traveled a great distance each month for follow-up. In addition, the country's current economic instability has increased transportation costs, in which participants overpay for transportation, food, and beds at each medical follow-up visit. As stated, as the follows:

Heart failure has put a lot of economic pressure on me and my family. I have to travel a long distance for my medical follow-up visits every two months because of this; I spend a huge amount of money for transportation, food, and bed service, especially at the movement transportation cost too expensive, cars do not get as you need because of country political instability. (28 years- old p11)

Theme Four: Experience Related to Hospital Service

Living with heart failure needs routine contact with the health service unit for the better treatment of the condition. Within this theme, there were two sub-themes, namely Uncomfortable building setting and relationships with health professionals.

Sub-Theme One: Uncomfortable Building Setting

We obtained this result through an observation checklist and triangulation with in-depth interviews. Heart failure is one of the chronic cardiovascular diseases for which Tibebe Ghion Hospital offers services in its outpatient clinic. Follow-up care for patients with heart failure took place in two OPDs on the first floor; the hospital structure is not comfortable for heart failure patients and other chronically ill patients. Since the building does not have operable elevators, this was the most difficult situation for most heart failure patients climbing the steps since the heart clinic was on the first floor of building. At the same time, there was a shortage of a separate cardiology OPD room in the hospital that was constantly serve only for heart failure patients; For this reason, cardiac follow-up care for patients with heart failure is only offered once a week. As a result, patients had to wait at least 1 hour and 20 minutes to receive service; some even got service the next day. Some respondents also mentioned that there is not enough waiting place and cleansing schedule not comfortable for us heart failure patients. As a result, most patients had this experience with hospital service during their follow-up visit. The participant stated as follow:

...Since I started cardiology follow-up at this hospital. We heart failure patients are treated together with other patients, which is a problem for us heart failure patients. We need special care because we are weak. Additional hospital facilities, such as hospital building systems, were not comfortable for us because the examination room is on the first floor, which is difficult for us to climbing and down in each movement. In addition, there are delays in the service, which is why we must wait a long time to the gate service. This may be due to the lack of OPD, and the large number of patients in same appointment day. (28 years- old - p11)

Sub-Theme Two: Relationships with Healthcare Professionals

In this study, participants described both positive and negative feelings related to their interactions with healthcare professionals. Most participants were satisfied with the medical care. And express their gratitude to the medical staff they have given us from God. They describe heart failure is urgent and critical, making it difficult to survive without get intensive medical support from healthcare professionals. This condition stated as follow:

From what I have seen, the help of the professionals is amazing for us. When I come to the appointment, they ask me what the new problem is; they ask me what is wrong; they give me advice; they send me home with good hopes; and I have nothing to say. The nurses and the doctor are all very good to me. (56 –years- old p6)

Most respondents describe that the care they received from their healthcare professionals was excellent. They thanked the doctors and nurses who spent more time providing information and instruction on medication adherence, dietary changes, and psychological counseling as part of their medical follow-up. Most participants emphasized the importance of a trusting relationship with the healthcare professionals and the care they provide, which is crucial for their recovery process and future hope. Status as follow:

Surprisingly, the service I received from nurses, doctors, and other health professionals was good. My doctor and nurses saved my life. I am friends with health professionals; I ask any question about lifestyle, and medication side effect. They provide lifestyle advice and direction. We are friends. So the support from the professionals is good. (29-year-old p7)

However, some participants complained that they lack regular follower of their care with whom they confide their problem, making them less positive about the care they received by different doctors. At the same time, most participants complained about delays in care from healthcare professionals, which negatively affected their relationship. Expressed as follows:

When I go to the hospital for a medical follow-up visit, Doctors are not always available; they change frequently. At each follow-up visit, I was treated by different doctors. If the doctor knows you well and knows all about your problems, he will always treat you well. The cardiologist has never seen me; the files have been read; doctors were treating me by phone call; I have never seen a senior cardiologist treating the patient directly. I have been in treatment for a year, and as a result, I have felt uncomfortable and dissatisfied with the services provided. But thanks to money, I can see everything in a private hospital. (30-years-old p4)

Some participants describe dissatisfaction with the coordination of care in the hospital as well as individual health personal interactions with patients. Expressed as follow:

I have observed certain professionals (doctors, nurses) treat people based on their appearance. Every patient has his own identity. As a result, patients must be treated as patients, not by color. When I asked my nurse if my medical card had been entered in the cardiac OPD? She replied that I was not your cardholder. This kind of behavior is not expected from health personal, and I have seen a professional problem here. (33- years- old P5)

Patients during interview time had good interpersonal relationships with health professionals. However, among the participants, some patients had no good communication and interaction with the doctor because they were unable to afford all the medications the doctor prescribed due to shortage of money and refused the medicines prescribed by the doctor. Most heart failure patients waiting doctor for an average of 1:20 hours.

Theme Five: Challenges Related to Get Treatment

All participants face different challenge they live with heart failure disease. The challenges to get HF treatment were the main theme described by two sub-themes such as inaccessibility of cardiac center, and unavailability of medical supply and investigation.

Sub-Theme One: Inaccessibility of Cardiac Center

Tibebe Ghion specialized hospital has no well-known cardiac service unit access and no access to the cardiac center. As a result, most study participants reported the problem of accessing standardized cardiac care. They came to Tibebe Ghion

Hospital from far away through the referral system but did not receive treatment especially valvular heart failure patients who need cardiac surgery. They did not access cardiac surgery in Tibebe Ghion Hospital. Even they have the financial ability to cover medical expenses. For example, two study participants said they were referred to Black Lion Hospital for heart surgery due to the inaccessibility of the heart center but did not go because they could not afford the medical costs. As a result, most heart failure patients continue to suffer without receiving adequate treatment. In addition, being referred from one hospital to another and not having access to a nearby service unit or having to travel long distances increased participants' direct and indirect costs. The participants in this study describe their experiences as follows:

Because of the inaccessibility of the cardiac Center at Tibebe-Ghion Hospital, I have been informed that treatment will refer to Black Lion Hospital. But Black Lion has not started cardiac surgery yet, so I've been told that you can get treatment at a private cardiac center, but that is not cover by my financial means. It has put a lot of pressure on me and my family's finances to earn money for medical treatment. (33 -years -old p5)

Additionally, stated as follow:

Because of the unavailability of an angiograph in Tibebe Ghion Hospital, I was referred to Black Lion Hospital, but at that time Black Lion was not organized treatment center. Since it was not available, as result i was forced to do it at a private hospital, but the cost I was asked for angiography was more than 200,000 Ethiopian Birr. Because of this, I could not gate the treatment. (61-years-old p2)

Observational result: Tibebe Ghion Hospital encourages the reception and care of heart failure patients, but there is still shortage of organized cardiac unit and treatment center, there is shortage of cardiac OPD, and there is no isolated cardiac unit or department. There were no available advanced cardiac tests in the hospital like angiography, EEG, and other lab investigation.

Sub-Theme Two: Unavailability of Medical Supplies and Investigation

Nearly all participants complained that there was difficulty in gate most prescribed heart failure medications in the hospital. They get most of the prescribed medication in private pharmacies or at Red Cross. Furthermore, most participants complained shortage of lab investigation, and imaging like EEG and Echo in hospitals, so they were forced to do their examination in private hospitals, which posed the challenges for the patients during their treatment. As Participants narrate:

Most of my drugs prescribed by doctors are not available in public hospitals. Even some medicines are available in government hospitals, but they are still expensive. I bought most of my medication from private pharmacies. If I buy them from private pharmacies, the price doubles and I cannot afford to buy all the medicines that the doctor prescribed. I remember being charged 31 birrs for a single tablet of medicine, which surprised me. For example, in this month I have medicine for one month only. After one month, I do not know how I can buy a medication because I have no money to purchase my medication. All these challenges I faced because of being HF patient. (63- years- old p1)

Observational finding: During the interview, I confirmed there were lack of access of cardiac medications in the hospital dispensary and drug store. Many cardiac medications were stock-out in the hospital. Specifically, metozoline, propranolol, and sildenafil cardiac medicine most of the time were not available in hospital. For example, during an interview time one participant reduces his prescribe drugs from four to two drugs since he could not afford to buy it. Because most heart failure medications were out stocked in public hospital pharmacy, he cannot buy drug from a private pharmacy. Additionally, the hospital did not provide necessary lab investigations such as lipid profile, TSH, T4, T3, and nitrate tests. Due to this, most participants were obligated to buy drugs and do their lab investigations from a private pharmacy, exposing them to extra costs.

Discussion

This qualitative phenomenological study explored the lived experience of adults with heart failure who had follow-up at TGSH. The impact of HF on patients' daily life, psychological and spiritual experience, economic experience, Experience

related to hospital service, and challenges to getting treatment as the main themes including other sub-themes. Many of these study participants expressed profound changes in their lives because HF symptoms affected their usual roles like physical activities, social life, and spiritual activities, which led to psychological distress. We found that participants experienced financial constraints related to high medical expenses, job loss, and physical limitations in their work.

In this study, most participants reported that HF and its associated symptoms had a negative impact on their everyday life, such as decreased social contact, social role or function limitations within their family and community and decreased physical function.

According to this study, the impact of HF on participants' physical dimensions was described in terms of reduced physical function, activity restriction, and reduced mobility. Most participants with heart failure suffered from decreased physical function. Most participants complained of physical weakness, shortness of breath, fatigue, and a lack of energy. These symptoms had a negative impact on their daily life, their ability to engage in social events, and their ability to carry out their usual tasks after being diagnosed with heart failure.

Also, they reported that their HF symptoms, particularly nocturnal dyspnea, palpitations, decreased energy, and lack of power, were limiting their ability to perform physical activities such as climbing steps, playing sports, doing labor work, standing for long periods at work, and walking for long distances. Which is similar to the study conducted in Sweden,²⁹ The patients noted that their physical activity had decreased since their heart failure diagnosis. They mentioned certain activities they used to do but could no longer do, so they had to live more quietly. This similarity may be due to the seriousness of the disease.

In our study, the impact of HF on social life was described in terms of changes in social relationships and isolation. Most participants explained that heart failure affected their social life and reduced their participation in society. They face a range of negative social experiences, including social isolation, limited participation in social activities, and negative social judgments. Most participants had a limited social life due to physical inactivity, financial constraints, and emotional distress.

At the same time, due to dietary restrictions or change of lifestyle causes participants' social life were decreased and they felt misunderstood and disrespected by their parents and friends. Which is similar study conducted in Italy and USA,^{30,31} shows that the restriction in social life can be due to various factors, including lifestyle changes, financial constraints, anxiety, and physical limitations due to shortness of breath and fatigue. Sometimes patients refuse to attend social events due to physical limitations or emotional distress. Participants reported an inability or limited ability to participate in social events and limited opportunities to connect with friends and family. This similarity may be due to dietary changes and economic constraints.

Despite social life limitations, the results of this study show that participants had a good relationship with their family after a diagnosis of HF. Most participants had positive social support, such as financial support, psychological support, and motivation from their family, friends, society, and health care providers. This is supported by a study conducted in Kenya,³² Family, friends, and church members provided social support to heart failure patients. Social networks provided a sense of community where patients could share their experiences and receive encouragement to alleviate their distress. In contrast to our findings, a study in Denmark found patients with HF reported that a lack of family support because they lived alone. Patients said there was no need to ask neighbors or friends for support, leaving support. The struggling physically, financially, and emotionally, making it difficult to navigate their care alone. Participants were dissatisfied with the inadequacy of social, familial, governmental, and healthcare.²⁹ These different findings may be due to the socio-cultural differences between the two study areas participants.

In this study, most participants experienced negative emotions such as anxiety, fear, hopelessness, despair, frustration, bad feelings, anger, and depression due to physical symptoms of illness, financial constraints, reduced social functioning, loss of independence, and restricted daily activities. Most participants were anxious and afraid due to the poor prognosis and sudden onset of illness. Some participants experienced depression symptoms such as bad feelings, loss of interest in socializing, and hopelessness, resulting in a decrease in their role in the family because of the disease. Which is similar to the finding of the studies conducted in Sweden, Italian, and UK,^{30,33–35} Participants with HF reported negative feelings related to the early stages of the disease, such as anxiety, despair, and nervousness caused by the perception of physical symptoms and work restrictions. The depression that was also experienced could be connected to the decreased physical capacity.

In addition, participants in our study felt worry, hopelessness, frustration, and dependency because of future uncertainty, and decreased their role in family/social life, which is in line with the study conducted in Bahrain,³⁶ participants expressed a mix of feelings, including sadness about their current health, frustration, helplessness, anger, regret, and a sense of hopelessness about their future as their social roles are changing. As a result, the basic symptoms and physical deterioration associated with severe heart failure could be met. This similarity is probably due to the poor prognosis of the disease condition and their physical function, social life, economic income, and health status that may not be consistent with what they had previously.

Despite the negative emotional expression, the results of this study show that some participants who live with HF have high hopes to recovery or have positive emotions such as a positive attitude, happiness, and hope to recover from the disease and accepting their illness. Participants perceived something positive to expect will happen in the future. A few participants did not feel sick despite their diagnosis; they felt healthy because they were inspired by God. Participants thought their spiritual activity would be enhanced after becoming ill. Which is supported by a study conducted in China,³⁷ Some participants showed a positive mindset, reflecting positively on their experiences, looking to the future with optimism, and expressing confidence because they believed that, with God, everything would be fine. This similarity in results may be due to the hope they had in the modern medical treatment they received and they use of spirituality for positive emotion in both study areas.

The results of this study show that because of heart failure, almost all the participants experienced strong relationships with God and relied on their faith in God. They expressed that after the situation of disease occurred in their lives, they experienced praying and feeling hopeful with the help of God. They used prayer to avoid stress while living with stress and depression. Which is similar study conducted in Bahrain and Kenya,^{32,36} All participants shared similar religious beliefs. All reflected on their experiences and drew on their religious beliefs and their faith in God's will to sustain them. Being faithful and trusting God was a privilege for the participants. Believing that there is always a possibility of being cured by God gave them the hope and strength to continue. The similarity of this study may be due to the fact that incurable heart failure patients believed they could live longer only by placing their trust in God the two studies area participants.

In this study, economic constraints were a major finding. Most participants faced direct medical and transportation costs. Most of the study participants described heart failure as a scary, severe, and terrible disease due to the increased cost of treatment. For this reason, they were in a state of economic crisis; not only themselves but also their families were under economic pressure. Limited participants' ability to perform daily activities, job loss, and expensive medical expenses due to a disease condition or the lifelong nature of the disease were the most common causes of financial constraints among participants. Which is similar to studies conducted in China and Singapore,^{38,39} Most patients in the study felt their medical costs were enormous. At the same time, due to physical limitations the patients can no longer carry out their original work, which severely reduces their economic income and makes it more difficult for them to pay the medical costs. In addition, similar study conducted in Kenya,³² Being sick is to be poor. If you are sick, you cannot work, and if you cannot work, you cannot afford the medicines you need. High healthcare costs limit the financial resources available to meet family needs. This similarity may be due to functional limitations preventing them from completing their work; job loss and recurrent hospitalization increase medical expenses.

Some of the participants in this study were retired governmental officers, farmers, and had no work according to their reports. Even though they had community-based health insurance, heart failure drugs were unavailable in governmental hospitals, which increased their medical expenses related to their treatment, and there was no cardiac service unit facility in the study participants' residence. Additionally, some participants expressed problems related to transport costs because they had to come to the cardiac follow-up visit every month from a long distance. As a result, some participants interrupted their regular follow-up visits. Which is similar study conducted in Thailand,³² Healthcare costs reportedly limited the financial resources available to cover other household needs, like rent and school fees. Patients unable to afford transportation missed hospital appointments, disrupting continuity of care. This similarity may be due to long-term high medical costs for treatment, recurrent hospitalization, job loss, and lack of financial support from NGO and government for heart failure patients.

In contrast, two participants in this study had no problem with the financial costs of heart failure treatment. When they were asked why they had no problem with medical expenses, they replied that their medical expenses were covered by their family, friends, and the National Health Insurance. Which is similar to a study conducted in Malaysian,⁴⁰ the integration of peer and family support can lessen the burden on costly healthcare resources. This similarity may be due to good socio-cultural support trained in low and middle-income country.

According to this study, most participants reported that the hospital environment was not comfortable for us heart failure patients. The hospital building has no operable elevators and a shortage of cardiac OPD. Most participants had positive relationships with the HCP and expressed their gratitude for their respect and effective communication with them. Participants also had a trusting relationship with their healthcare provider. Most of them received constructive feedback about their heart failure from medical staff. Which is similar to studies conducted in the UK, Spain, and Norway,^{41–43} Patients generally have very positive things to say about cardiologists and nurses. They also mentioned their valued relationships with nurses. Overall, they felt well supported by the hospital staff, including cardiologists and nurses. This might be similar medical to school ethics and discipline those study areas. Nonetheless, some participants complained that some healthcare professionals were not disciplined, lacked commitment, and were not given all the necessary information, which had a negative impact on patient support and care. This difference may be due to the workload and healthcare professionals' motivation is not being same to provide care to their patients between two study areas.

According to this study, lack of access to most diagnostic services and medicines required in public hospitals posed a further major challenge for patients. Most participants complained that even though they had the ability to pay for the service, there was no alternative access. Many participants had travelled from far distances to access the service, which made it challenging for them to access the service on time.

In addition, patients reported recurrent stock-out of medicines in public hospitals, being forced to find these services in private facilities at high costs or dropping their cardiac follow-up for one month or more due to increased medical expenses. This is similar to a study conducted in Uganda,⁴⁴ Participants expressed their frustration and disappointment at having to travel long distances to health facilities only to find that medicines, diagnostics, and health workers were unavailable. This frustration led some participants to abandon care since they were referred to private facilities where services were unaffordable. Delays at health facilities also hindered access to care. Many participants would miss a full day of work to attend their clinics, and patients were stopping their follow-up due to unavailability and expensive medical costs. This similarity in the findings may be due to limited healthcare resources between the two study areas because both countries are developing country.

Strength and Limitation

One of the strengths of this study is the sampling method the use of heterogeneous purposive sampling, used to capture the widest range of perspectives and possible findings with different backgrounds of participants which allowed the principal investigator to see the data from a different perspective. The limitation of the study was the inability to generalize the findings of this phenomenological study. No matter the phenomenon being investigated, the conclusions derived by the principal investigator apply only to that aspect of reality that was perceived by all participants.

Conclusion

In this study, Phenomenological qualitative study the lived experiences of adults with heart failure were explored. Five main themes and thirty sub-themes were emerged from in-depth interview data: The impact of HF on patients' daily life, psychological and spiritual experience, economic experience, experience related to hospital service, and challenges to get treatment were explored. Participants faced problems of decreased physical function, social life limitations, financial constraints, and negative emotional feelings such as stress, fear, anxiety, hopelessness, bad feelings, and crying related to the diagnosis of HF due to the poor prognosis of the disease and their prolonged state of illness, which made life with heart failure difficult for them. Furthermore, patients faced economic challenges due to the expensive nature of the treatment, and the continuity of the treatment. The study further highlights those patients' social relationships changed after HF diagnosis; their social role and social interaction in the community decreased compared to their previous life. Despite this, participants received good social and psychological support from their families and friends, which could

improve the quality of life for patients with heart failure. In addition, the inaccessibility of the cardiac center and the lack of medication were the main challenges that the participants faced during their treatment. Therefore, we recommended policy makers and concerned stake holders working on patients safety to provide psychological support, economical support, availing medication at hospital and establish accessibility of cardiac centers.

Abbreviations

CVD, Cardiovascular Disease; HCPs, Health care professionals; HF, Heart Failure; LMICs, Low Middle-Income Countries; MRN, Medical Registration Number; RHD, Rheumatoid Heart Disease; TGSH, Tibebe Ghion Specialized Hospital; WHO, World Health Organization.

Data Sharing Statement

All relevant data are within the paper and its supportive information files.

Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) Bahir Dar University, College of Medicine, and Health Science School of public health (protocol No: 548×2022). Informed written consent was taken from each participant after clarifying the study objective and data collection procedure. To keep the confidentiality of participant name was not included in the in-depth interviews instead we used a coding method and keeping it with the principal investigator only. They were also informed of they had the right to withdraw from the study at any time. The participants informed consent included publication of anonymized response and the ethical clearance was based on Declaration of Helsinki.

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The authors declared no competing interests exist.

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