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Anny Ashiq Ali
Aga Khan University

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AGA KHAN UNIVERSITY

School of Nursing and Midwifery

CONCEPT OF HEALTH-RELATED QUALITY OF LIFE AMONG PEOPLE WITH HEART FAILURE IN KARACHI, PAKISTAN

By

ANNY ASHIQ ALI

Student of Master of Science in Nursing (MScN)

A thesis submitted in partial fulfillment

of the requirements for the degree of

[***Master of Science in Nursing***]

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25th October, 2023

Aga Khan University

School of Nursing and Midwifery

Submitted to the Board of Graduate Studies

In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

Members of the Thesis Evaluation Committee appointed to examine the thesis of

Anny Ashiq Ali

Find it satisfactory and recommend that it be accepted

K. Ajani

Supervisor, Dr. Khairulnissa Ajani

Ambreen Gowani

Ms. Ambreen Gowani, Thesis Committee

Dr. Zainab Samad, Thesis Committee

External Examiner

25th October, 2023

Declaration

I declare that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university and to the best of my knowledge it does not contain any material previously published or written by another person, except where due reference has been made in the text.

The editorial assistance provided to me has in no way added to the substance of my thesis which is the product of my own research endeavours.

(Signature of Candidate)

25th October, 2023

Dedication

I would like to dedicate this thesis to my husband Mr. Amirali, and beloved parents, Mr. Ashiq Ali and Mrs Mumtaz Ashiq Ali, and my in-laws Mr. Bahadur Ali and Mrs Dilshad. It was their constant support, love, encouragement, sacrifice, and trust that helped me achieve this milestone in my life. Their unconditional love support and patience enabled me to complete this journey and fulfil my dream of pursuing higher studies.

I also dedicate my thesis to my daughters Amierah and Izna; I dedicate this work to them with the hope that it serves as a testament to the importance of pursuing dreams with determination. They have been my inspiration, and I am dedicated to providing you with an example of what can be achieved through dedication and a strong support system.

I would not have been able to complete this journey and fulfil my academic goals, without the support of all of them.

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Lastly, I would like to thank my family and friends for their infinite prayers, love, and affection, which enabled me to achieve this milestone in my life.

Thank you all

List of Abbreviations / Acronyms

AKUH	Aga Khan University Hospital
AHA	American Heart Association
CVDs	Cardiovascular Diseases
CHF	Congestive Heart Failure
DM	Diabetes Mellitus
HRQoL	Health-related quality of life
HF	Heart Failure
LMICs	Low- and middle-income nations
NYHA	New York Heart Association
NCDs	Non-Communicable diseases
WHO	World Health Organization
AHA	American Heart Association
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Abstract

Background

Non-communicable diseases (NCDs), including cardiovascular diseases, are a leading cause of global mortality. The mortality rate for cardiovascular diseases is on the rise, with 80 % to 86 % of fatalities, particularly in low- and middle-income countries, including Pakistan. Among NCDs, heart failure (HF) is a condition for which there is no cure, and patients rely on supportive treatments to maintain their quality of life. HF not only affects physical well-being but also has far-reaching consequences on the emotional, social, and cognitive aspects of life. In the context of Pakistan, where unique healthcare, sociocultural, and economic factors prevail, the assessment of Health-Related Quality of Life (HRQoL) is crucial for HF patients. This understanding is especially significant in Pakistan so that the relevant interventions can be tailored to address these specific aspects of HRQoL for HF patients in the country.

Purpose

This study aimed to explore and understand the in-depth meaning of HRQoL among HF patients in a tertiary care hospital, at AKUH, Karachi, Pakistan. By conducting in-depth interviews and engaging with the patients, this research aimed to uncover the shades of their daily struggles, aspirations, and adaptations.

Method

A qualitative interpretive design was used to study heart failure patients’ perceptions of their HRQoL. Through the Purposive sampling technique, 14 Heart Failure patients were selected from the outpatient department of AKUH. In-depth semi-structured interviews were conducted until meaningful information was achieved. A manual content analysis technique was followed to analyze the data.

Finding(s)

The study's findings revealed two major themes. Theme one, "Heart Failure Patients' Perception about Health," highlighted participants valuing good health, the role of good health for maintenance, and the prioritization of well-being. Participants underscored the significance of health as a precious asset, emphasizing how HF had transformed their perception of good health and motivated them to take active measures to maintain it. The second theme revealed, "Attributes of HRQoL in Heart Failure," participants detailed how HF had reshaped their roles, necessitated dietary adaptation, influenced their social and family relationships, and led them on a journey of acceptance. This theme highlighted the diverse impact of HF, from reshaping daily responsibilities to adjusting to dietary restrictions and managing changes in social and family relationships.

Conclusion

This study provides insights into how HF patients in Karachi perceive and experience HRQoL. The findings emphasize the multifaceted nature of HRQoL, highlighting the importance of addressing physical, emotional, social, and cognitive aspects to improve the well-being of HF patients in Pakistan. This study contributed to a better understanding of the cultural context and individual perspectives on HRQoL, which can inform patient-centered care and interventions to enhance the quality of life for HF patients in Pakistan.

Keywords

Heart Failure, Patients, Health-related quality of Life (HRQoL), Perceptions, Attributes, Pakistan.

Table of Contents

Title Page .... **Error! Bookmark not defined.**
Declaration iii
Dedication iv
Acknowledgments v
List of Abbreviations / Acronyms vi
Abstract vii
  Background vii
  Purpose vii
  Method vii
  Finding(s) viii
  Conclusion viii
List of Tables xii
List of Figures xiii
List of Appendices xiv
Chapter One: Introduction 1
  Background 1
  Study Significance 5
  Study Purpose 5
  Research Questions 6
  Summary 6
Chapter Two: Literature Review 7
  Search Strategies 7
  Literature Review on HF 9
  Measuring HRQoL in HF patients 15
  Gap Analysis 16
  Conclusion 17
Chapter Three: Methodology 24
  Study Design 24
  Study Population and Setting 25
  Sample and Sampling Strategy 25
  Eligibility Criteria 26
  Inclusion Criteria 26
  The study population was adult HF patients. 26
  Exclusion Criteria 26

Participants' Recruitment Process 27
Study Duration 27
Data Collection Tool 28
Demographic tool 28
Semi-structured interviews 28
Pilot Testing of the Interviews 29
Data Collection Procedure 29
Data Analysis 30
Data Organization 30
Reading and Reflecting 31
Data Coding 31
Categories and Themes 31
Representation of Data 32
Study Rigor 32
Credibility 32
Dependability 33
Conformability 33
Transferability 34
Ethical Considerations 34
Summary 35
Chapter Four: Results and Findings 37
Demographic Characteristics of the Study Participants 37
Content Analysis of HF Patients' Interviews .... **Error! Bookmark not defined.**
Theme one: HF Patients' Perception About Health 42
Category: Value of Good Health 42
Category: Perception about Good Health for Maintenance Purposes 44
Category: Prioritization of Well-Being 45
Theme two: Attributes of HRQoL of HF. 47
Summary 54
Discussion 56
HF Patients' Perceptions about Health 56
Attributes of HRQoL of HF 61
Strengths of the study 68
Limitations of the Study 69
Recommendations 69
Clinical Practice 70

Nursing Education......70
Nursing Research......71
Summary of the Chapter......72
Conclusion of the Study......72
References......74
List of Appedices......85

List of Tables

Table 1. Extraction Table for Literature Review..18

Table 2. Demographic Variables (Quantitative Variables)..38

Table 3. Demographic Variables (Qualitative Variables)..38

List of Figures

Figure 1. PRISMA Flow Chart 8

Figure 2. Themes, and Categories 41

Figure 3. Theme One with its Categories 42

Figure 4. Theme Two with its Categories 47

List of Appendices

Appendix A. Infromed Consent English Version 85

Appendix B. Infromed Consent Urdu Version 89

Appendix C. Study Guide English Version 92

Appendix D. Study Guide Urdu Version 93

Appendix E. Demographic Form English 94

Appendix F. ERC Approval 95

Appendix G. Permission Letter 96

Chapter One: Introduction

This chapter includes a detailed background of the study. It also highlights the significance of the study, particularly in developing countries. Additionally, this chapter describes the purpose of the study and research question and in the end the summary.

Background

Long-term health conditions, commonly referred to as Non-Communicable Diseases (NCDs), are illnesses that have an expanded course and make steady progress. The term "NCDs" has been broadened to encompass a diverse range of health conditions, including hepatic, renal, and gastroenterological diseases, endocrine, hematological, and neurological disorders, dermatological conditions, genetic disorders, trauma, mental disorders, and disabilities such as blindness and deafness (Budreviciute et al., 2020). The development of the majority of NCDs is impacted by a combination of inherited traits, surrounding conditions, and bodily processes. NCDs are not transmissible directly from one person to another.

NCD cases have increased in Western nations as a result of rising life expectancy. NCDs are now the main cause of mortality, morbidity, loss of independence, and public health expenses. The WHO reports that NCDs are the largest cause of mortality globally, accounting for 71% of all annual fatalities. Cardiovascular diseases (17.9 million yearly deaths), malignancies (9.0 million), respiratory illnesses (3.9 million), and diabetes (1.6 million), are the top four NCDs that cause the most fatalities (Budreviciute et al., 2020). However, the World Health Organization (WHO) states that lifestyle changes could prevent or delay 30–50% of malignancies and 80% of heart illnesses, strokes, and Type 2 DM (Irani et al., 2022).

As per the NCD Country Profiles 2014 by WHO, Pakistan is grappling with a twofold burden of communicable diseases (38%) and non-communicable diseases (49%). The leading

10 causes of illness and death in Pakistan are attributed to NCDs, which are also thought to account for 77% of age-standardized fatalities. In Pakistan, it is common to have diabetes, hypertension, malignancies, and other NCDs (Rafique et al., 2018).

Heart Failure (HF) is a chronic and advancing ailment that hampers the heart's capacity to effectively circulate blood. It is a prevalent and growing health problem worldwide, affecting an estimated 26 million people globally (Jessup et al., 2016). HF can result from various underlying factors such as coronary artery disease, high blood pressure, diabetes, and valve abnormalities. The symptoms of HF include breathlessness, fatigue, swelling of the legs and ankles, and reduced exercise tolerance. The intensity of symptoms can range from mild to severe, and HF can be classified into different stages based on the New York Heart Association (NYHA) functional classification (Jessup et al., 2016).

Among non-communicable diseases (NCDs), cardiovascular diseases (CVD), which are often used equivalently with heart disease, are increasingly becoming a significant factor in global mortality rates (Al-Mawali, 2015). Cardiovascular diseases (CVDs) are the main factors responsible for increasing the worldwide burden of disease, accounting for the highest number of deaths annually, surpassing even the combined mortality from cancer and chronic respiratory diseases. According to estimates in 2012, 17.5 million deaths worldwide were categorized as CVD showing 31% of the total mortalities. Approximately 7.4 million of these deaths were linked to coronary heart disease (CHD), while 6.7 million were related to stroke. The disorder is quite common in both Western and Eastern nations. However, the majority of cardiovascular disease (CVD) fatalities, accounting for more than 80%, occur in countries with low and middle incomes (Al-Mawali, 2015). A significant proportion of deaths are attributed to CVD and a substantial quantity of individuals are affected by them and these happen in lower and middle-income countries due to various health and infrastructure constraints. Its co-morbidities may affect how people self-care, their quality of life, and how often people end up in hospitals.

The American Heart Association (AHA) estimates that 2.2% of Americans have HF, compared to 1.26 to 6.7% in Asian nations (Shahid et al., 2020). According to AHA, as per the Heart Disease and Stroke Statistics Report of 2016, it was estimated that approximately 5.7 million individuals had HF and that HF was responsible for one million hospital stays during that period (Shahid et al., 2020).

According to the most recent research, the mortality rate of cardiovascular disease is increasing worldwide, with 80 % to 86 % of fatalities occurring in low- and middle-income nations (LMICs). Moreover, 82 % of the 16 million fatalities caused by non-communicable diseases (NCDs) occur in LMICs, with CVD accounting for 37 percent of these deaths (Barolia & Sayani, 2017). The prevalence of HF is rising in Asian nations as well. It was found to range from 0.5% to 12.7% in Southeast Asia, with greater rates observed in older persons and those with comorbidities, including diabetes and hypertension (Gupta et al., 2018). According to the WHO country profile (2014), data indicates that in Pakistan, 25.3% of individuals had high blood pressure (BP), 19% had cardiovascular diseases (CVD), and 3% were affected by another type of health condition (Naseem et al., 2016). Moreover, heart disease has a substantial financial impact on Asian nations as well; according to one study, managing HF in India costs over US$1.8 billion annually (Mishra et al., 2018).

HF is a critical ailment for which there is typically no treatment. But when the problem is controlled with HF treatments and lifestyle modifications, many individuals with HF have full, productive lives (Ewnetu Tarekegn et al., 2021). Moreover, health care is changing worldwide, therefore every individual who is at risk of CHF or having, must modify their lifestyle and know about their health-related quality of life.

A study on the health-related Quality of Life (HRQoL) was conducted in Ethiopia. It discovered that patients with HF had lowered levels of well-being or satisfaction in life across the board, particularly in the area of physical health, suggesting that they are aware of how their health is influencing their HRQoL (Ewnetu Tarekegn et al., 2021). A nation that exhibits elevated levels, or ranks among the countries with the highest rates of heart disease is India in which it was estimated that 7.3 million people died from acute myocardial infarction in just a year 2015. This study, which investigates the well-being and overall life satisfaction of myocardial infarction survivors in India, is the most extensive report available, considering the observed differences associated with age, gender, and the effectiveness of interventions aimed at enhancing quality (Mohanan et al., 2019).

The patients' HRQoL is greatly impacted by HF, which also causes severe morbidity and mortality HRQoL is a broad term that refers to how patients perceive the effects of their condition overall. It indicates, at the very least, social, emotional, and cognitive, as well as physical, functioning (Mohammed Assen Seid, 2020). HRQoL is important for patients' awareness about self-care and how they describe their QOL needs to be understood in the context of their culture. According to WHO, an individual's perspective of their life, concerning their aims, expectations, standards, and priorities is influenced by their culture and value systems (Lamesgin Endalew et al., 2021). Each person has a different view on HRQoL, which is influenced by multiple dimensions, like physical, emotional, and social aspects, and these are important in the promotion of patient-centred care.

Study Significance

HF is incurable, and the goal of the treatment is to slow down the symptoms and promote well-being. People with HF live a restricted life. They often describe their life as imprisoned by the illness (Gowani et al., 2017). The feelings of restraint and limitations are common among people with HF across different parts of the world as HF impacts all aspects of a person's life. However, the perceived impact may be different for different people regarding the HRQoL. In general, there is a shortage of global evidence about how people with HF living in different contexts define their HRQoL. To expand the HRQoL of people with HF it is important to assess their HRQoL using valid and reliable tools. However, most of the HRQoL tools in HF have been developed in the West and are based on the Western population, they may or may not necessarily reflect the aspects of HRQoL that the people with HF uphold in the Pakistani context. Also, this phenomenon has not been explored in the context of Pakistani people with HF. Therefore, it is difficult to ascertain if the Western HRQoL is suitable for use in Pakistan unless an understanding is developed about the definition of what HRQoL means for people with HF in this context. It is therefore imperative to explore how HF patients in the Pakistani context define/perceive their HRQoL. This study provides basic knowledge regarding the HRQoL of people with HF in Pakistan. It has helped in understanding the attributes of HRQoL of people with HF in this context. Moreover, some of the similarities and differences in the meaning and outlook of HRQoL of people with HF in different contexts and the potential applicability of HRQoL tools in the context. In this way, the study has paved the way for a step-by-step approach to understanding and improving the HRQoL of people in Pakistan, through subsequent studies.

Study Purpose

The objective of the study was to explore and understand in depth the meaning of HRQoL among HF patients in a tertiary care hospital, at AKUH, Karachi, Pakistan.

Research Questions

- How do HF patients perceive the concepts of HRQoL?
- What attributes indicate the HRQoL of people with HF?

Summary

This chapter explained the concept of HRQoL in HF patients. This study helped identify the perceptions and experiences of HF patients. With an elevation disease burden, restricted access to treatment, and major economic and social repercussions, HF has a significant impact on LMICs. There is an urgent need to provide access to inexpensive and efficient therapies, enhance healthcare systems, and implement preventative measures that address the social factors of health, to lessen the burden of HF in LMICs.

Therefore, it is crucial to investigate how HF patients in the Pakistani setting define and interpret their HRQoL. The findings aid in comprehending some of the characteristics of HRQoL in the context of patients with HF in Pakistan. The study identifies the HF patients' perceptions about their HRQoL in various circumstances, including in the context of Pakistan's similarities and differences, and indicates the usefulness of possible HRQoL measures in the context of Pakistan.

Chapter Two: Literature Review

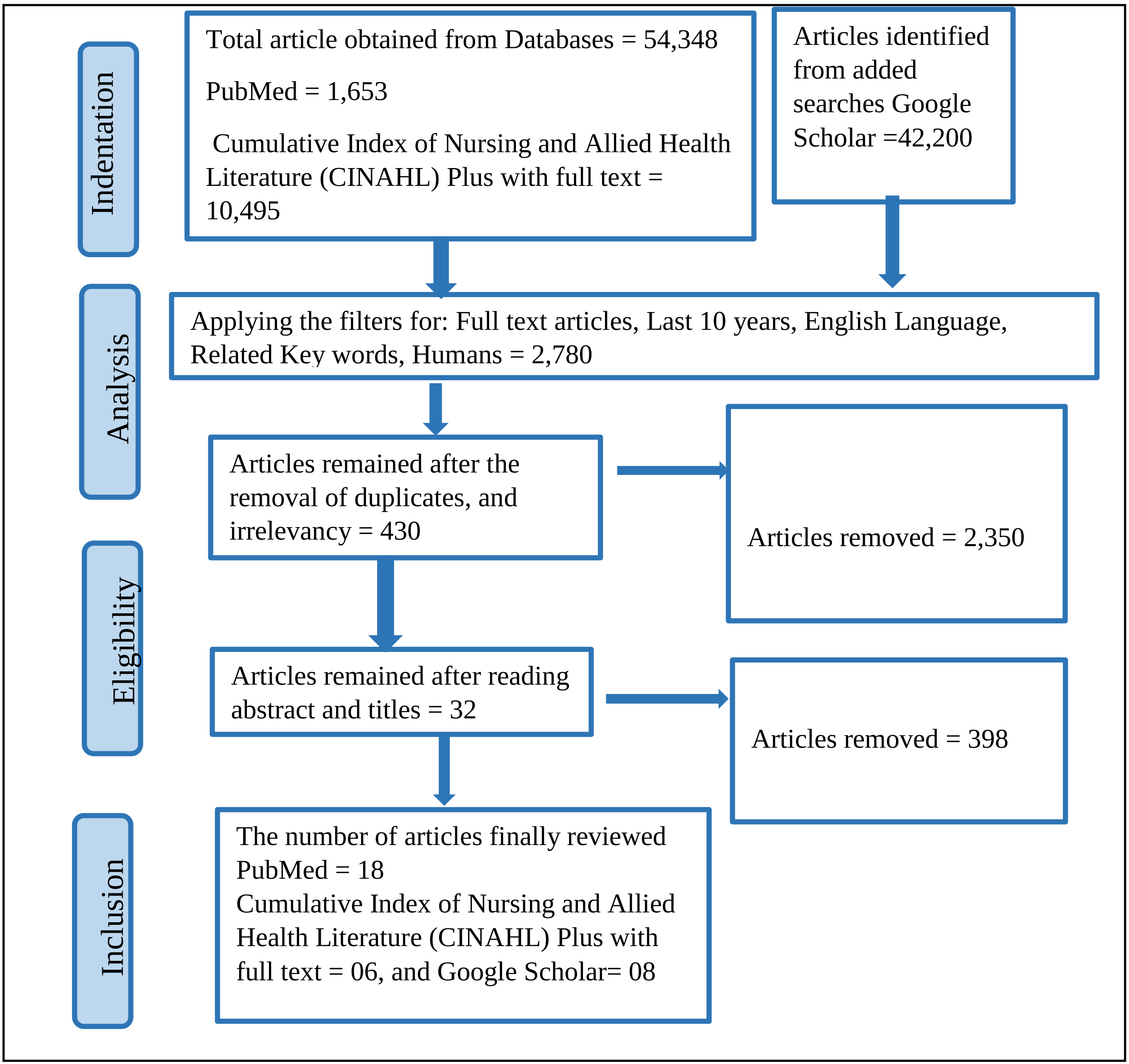
This chapter includes the search strategy and a detailed literature review regarding HF patients' health-related quality of life. This chapter is divided into parts, the first part will include the search strategy, the second part show the PRISMA flow chart, the third part will discuss the literature searched, the fourth part will cover the gap analysis, and the last part concludes the chapter.

Search Strategies

An organized search strategy was meticulously crafted to retrieve relevant literature from PubMed, CINAHL, and Google Scholar. Given the variability in syntax and indexed/MeSH terms across these databases, the search terms were adapted to each database's unique requirements. Boolean operators AND/OR were employed to effectively combine the keywords. For PubMed, MeSH terms were utilized, ensuring alignment with the database's indexing system. In CINAHL, subject headings specific to nursing and allied health were incorporated. Google Scholar, being a more comprehensive search engine, required a more flexible approach, and search terms were adapted to accommodate its broader indexing. To illustrate, the keywords included were "Concepts of HRQoL" OR "HRQoL" OR "Health-related quality of life" AND "Heart Failure" AND "Pakistan," properly combined by Boolean operators. In PubMed, MeSH terms were mapped for "Health-related quality of life" and "Heart Failure," whereas in CINAHL, database-specific subject headings were used. The initial search yielded a total of 54,348 articles across the three databases. To refine the results and ensure relevance, a set of filters was applied, including full-text availability, the last ten years, related keywords, and studies involving humans. This process resulted in the shortlisting of 2,780 articles. Articles were further scrutinized based on relevance, and those deemed irrelevant or duplicates were excluded. The final selection of 32 articles for review was based on careful evaluation of titles, abstracts, and backgrounds. Notably, the majority of the identified studies were qualitative or mixed-method studies, aligning with the research focus. Systematic reviews and meta- analysis were included and letter to editor and editorial were excluded.

This detailed approach ensured a comprehensive and precise search strategy that considered the nuances of each database, adapting to differences in syntax and indexed/MeSH terms for an exhaustive retrieval of relevant literature.

Figure 1. PRISMA Flow Chart



Literature Review on HF

Non-communicable diseases (NCDs), such as diabetes, hypertension, and obesity, provide significant risks for developing cardiovascular diseases (CVDs) (Sanchis-Gomar et al., 2016). Over the past few decades, the worldwide burden of NCDs has considerably increased, with CVD being the leading cause of death in developed and developing nations (Roth et al., 2020). Globally, 17.9 million people died from CVD in 2019; the majority of these deaths happened in low- and middle-income countries (World Health Organization, 2020). The fact that many people with NCDs also have other CVD risk factors, such as hypertension, dyslipidaemia, and obesity, further increases the burden of CVD (Sanchis-Gomar et al., 2016).

A primary cause of mortality and morbidity around the globe, cardiovascular disease (CVD) accounts for about 31% of all fatalities (Roth et al., 2020). There are significant clinical ramifications of the connection between CVD and NCDs. The high frequency of concomitant CVD, which can have a considerable influence on morbidity and mortality, is one of the major problems in managing patients with NCDs (Sanchis-Gomar et al., 2016). Hence, when managing patients with NCDs, healthcare professionals should take into account any potential effects that these NCDs and their therapies may have on CVD risk. According to the descriptive cross-sectional study, HF is a significant, worldwide health issue and the main cause of hospitalization for both young adults and those above 65 years, therefore, their mortality, morbidity, and readmission rates increase day by day. Around the world, low- and middle-income nations account for 80% of CVD fatalities. Since 26 million persons, globally, suffer from HF, it is one of the most prevalent cardiovascular diseases (AbuRuz, 2018).

There could be many reasons for the readmission or reoccurrence of the symptoms. According to the AHA, “heart disease and Stroke Statistics Report (2016), the estimated prevalence of HF was 5.7 million, and an estimated 1 million hospital stays were attributable to HF" (Mueed et al., 2020).

The epidemiology of HF in Western nations has been the subject of numerous investigations. The prevalence of HF was found to be rising in Europe in 2020, with a significant load on hospitalization rates and mortality (Triposkiadis et al., 2020). A retrospective study was conducted, which showed the prevalence of HF was shown to be rising in the United States in 2021, with a significant burden on healthcare expenses and outcomes (Ohori et al., 2021).

A retrospective cross-sectional study has been conducted in Australia, which concluded that the causes of HF in Western nations have also been the subject of numerous investigations. Obesity, hypertension, and diabetes were identified as major risk factors for HF (Alhawassi et al., 2018). Moreover, medication regimens can get even more complicated with age, severity, and underlying diseases, which makes it difficult for patients to follow them. A prospective cross-sectional study conducted in Thailand showed that though the prescribed pharmacological therapy for individuals with HF is successful, adherence to therapies is still insufficient, which lowers treatment effectiveness. Medication adherence and quality of life share a direct and proportional relationship (Silavanich et al., 2019). Furthermore, countless drugs, long-term and complicated medication regimens, inadequate attention from healthcare professionals, lack of health insurance, and inability to get to appointments are all variables that have been linked with non-compliance in HF patients.

A cross-sectional survey has been conducted. The research showed that HF incidence could be significantly predicted by factors related to the physical, emotional, and social quality of life. Moreover, a lesser quality of life was linked to a higher chance of developing HF (Li et al., 2019).

HF incidence has also been connected to stress and mental wellness. According to a review paper, HF prevention should include stress reduction, as chronic stress was linked to an elevated risk of HF incidence, as there is a relationship between depression and CVD (Shao et al., 2020). Moreover, a retrospective study has been conducted in Iraq, which showed that behavioural changes can occur due to sleep problems. HF incidence has also been connected to sleep problems; sleep apnea raises the risk of developing HF. Hence, treating sleep issues should also be a part of HF prevention (Ahmed et al., 2017). The incidence of HF has also been linked to diet and nutrition. Furthermore, a diet high in red and processed meat was linked to an elevated risk of HF incidence, a heart-healthy diet should be promoted as a means of preventing HF (Ashaye et al., 2011).

A cross-sectional study has been conducted in Iran, which examined the outcome of medication adherence on the HRQoL of patients with HF. Medication adherence was found to be positively associated with improved HRQoL scores. Patients who followed their medication regimen had a greater overall quality of life. To enhance the HRQoL of patients with HF, the researchers advised healthcare professionals in LMICs to give priority to medication adherence education and support (Sadeghiazar et al., 2022). These results demonstrate the critical role that medication adherence plays in enhancing the HRQoL of HF patients in LMICs.

A more recent study carried out in Nigeria in 2021, looked at how comorbidities affected the HRQoL of people with HF. Additionally, individuals with HF frequently had comorbid conditions like diabetes and hypertension, which had a serious detrimental effect on their HRQoL. The study suggested that to improve the general well-being of HF patients, healthcare professionals in LMICs should give priority to preventing and managing comorbidities (Adamu et al., 2022). The results highlight the need of taking into account how comorbidities affect the HRQoL of HF patients in LMICs.

In Pakistan, the frequency of HF is substantial, placing a significant strain on healthcare resources and costs (Ansari, 2018). According to a 2019 study, the prevalence of HF is rising in Japan, where it has a significant negative impact on hospitalization rates and healthcare expenses (Tsutsui et al., 2019).

Hypothetically, QOL can include a diverse variety of elements and dimensions. Functional ability, role functioning, functional capacity in different roles like physical actions and the attainment of belief system, the amount and performance of community engagement, emotional health, physiological sensory experiences, pleasure, living circumstances, overall happiness, and the demands for fulfilment are all included in this. The elements characterizing QOL in this context also include sex, socioeconomic position, age, and generation. As a result, QOL is a complicated set of interdependent objective and subjective dimensions (Megari, 2013).

Hence, the patient's perceptions towards the quality of life have a direct effect on their health and positive outcome after suffering from HF. The fundamental goal of HF care is to extend the life of HF patients by preserving physiological stability and enhancing HRQoL. An institutional-based study was conducted in Ethiopia, which showed that HF patients' participation in daily self-care behaviours, including medication compliance, symptom monitoring, and lifestyle changes, have a significant impact on the disease's course. Despite improvements in HF care and hospitalization, death attributable to HF continues to rise. (Mohammed Assen Seid, 2020).

The Quality of Life (QOL) of HF patients has been demonstrated to be impacted by a wide range of socio-demographic, physiological, and psychological aspects. Age, sex, marital status, social support, education, and culture are only a few of these variables (AbuRuz, 2018). Even though QOL and HRQoL are frequently used to refer to the same idea, they differ from one another. A descriptive cross-sectional study has been conducted in China concluded that QOL is a wide term that encompasses all facets of human existence, whereas HRQOL is more focused on the consequences of sickness and, more particularly, the impact of therapy on QOL (Lin et al., 2013).

A broad term, HRQoL comprises aspects relating to physical, mental, emotional, and social functioning. A cross-sectional survey has been conducted in Spain which concluded, that a higher level of education is linked with achieving a better level of HRQoL and education is the process of acquiring information, skills, attitudes, and behaviours that might affect one's health and welfare (Gil-Lacruz et al., 2020).

HRQoL includes how a clinical condition and its treatment affect a person's capacity for daily tasks, emotional state, and social interactions. The significance of HRQoL as a patient-centred outcome measure in healthcare has been highlighted in several studies (Stull et al., 2020). It has been demonstrated that HRQoL can give important insights into how a health condition and its treatment affect patients' lives, including their preferences for and adherence to treatment regimens. In addition, measuring HRQoL might encourage patient-centred treatment by facilitating shared decision-making between patients and healthcare professionals.

In addition to the absence of diseases or disabilities, a condition of complete physical, mental, and social well-being is referred to as being in good health (Hussain et al., 2013). Moreover, as health and quality of life are impacted by a person's experiences, beliefs, expectations, and perceptions, these factors also determine how one perceives.

It is crucial to evaluate the HRQoL of persons with HF to comprehend their demands and create effective therapies. In persons with HF, physical functioning is a critical component of HRQoL. Individuals with HF frequently encounter restrictions in their ability to move, climb stairs, or perform home duties. These restrictions result from symptoms like dyspnea, weariness, and a decreased capacity for exertion. A randomized controlled trial study was conducted in the United States to determine physical health and HRQoL connect with HF. The findings demonstrated a substantial relationship between physical functioning and HRQoL, suggesting that people with greater physical functioning also had improved HRQoL. This finding emphasizes how crucial physical health is in preserving HRQoL in people with HF, and enhancing their physical performance to improve HRQoL in people with HF (Mack et al., 2021).

Emotional functioning may be significantly impacted by HF as well. Anxiety, depression, and other emotional problems are frequent in HF patients. These emotional disturbances can lower social functioning, and increase hospitalizations, and death rates while also having a detrimental effect on HRQoL (Alharbi et al., 2022).

Another crucial component of HRQoL in patients with HF is social functioning. Due to the physical restrictions and emotional complications of their condition, patients with HF frequently experience social isolation. Less social support, more hospitalizations, and worse mortality rates can all result from this isolation. A cross-sectional study conducted in Japan found that HRQoL in HF patients was highly correlated with social functioning. Patients with higher social functioning ratings, likewise, had higher HRQoL ratings. The purpose of this study was to determine whether social functioning and HF patients' HRQoL are associated. This finding emphasizes the significance of social functioning in controlling the HRQoL of chronic HF patients (Kusunose et al., 2017).

Another concern is how HF may affect a person's relationships and social life. It was discovered that HF patients felt socially isolated and cut off from their social networks, which can worsen their symptoms and lower their quality of life (Xia & Li, 2018). Similar findings were made in a review paper in which, the social functioning domain of the SF-36 revealed a substantial drop in social QoL in HF patients when compared to baseline (Choi et al., 2019). These studies demonstrate that the interpretation and outlook of HRQoL in people with HF may vary depending on the situation. However, important aspects that affect HRQoL in people with HF include physical functioning, emotional functioning, and social functioning; depending on the circumstances, these factors' respective weights may change.

In one study, HF patients' HRQoL scores were lower across many areas, including role restrictions brought on by physical health, mental wellness, and physical functioning (Jegier et al., 2021). In addition, another review article also concluded that social support was found to be favourably linked with HRQoL in individuals with HF in another study (Mai Ba et al., 2020).

According to a randomized controlled trial study, hospitalizations accounted for a sizable amount of the overall healthcare costs experienced by individuals with HF (Armstrong et al., 2020). Lastly, it is impossible to ignore the financial burden that HF has on both individuals and healthcare systems.

Measuring HRQoL in HF patients

The Minnesota Living with HF Questionnaire (MLHFQ) proved to be an accurate tool for evaluating HRQOL in patients with HF, The MLHFQ can be used to assess HRQOL in patients with HF and to spot areas of impairment that need to be addressed (Bilbao et al., 2016).

In addition, a review article investigated the usefulness of the European Quality of Life-5 Dimensions (EQ-5D) tool in patients with HF across 20 nations. According to the study, patients with HF from various nations and cultural backgrounds could assess their HRQoL using the EQ-5D as a valid and trustworthy tool. According to the authors, patients with HF can have their HRQoL assessed in a variety of settings using the EQ-5D (Romiti et al., 2020).

A patient's value system, beliefs, and views, as well as other factors related to a patient's quality of life, should be considered while measuring improvements. This is because perceptions about overall health state and life happiness, in contrast to functional capacity, are qualitative and cannot be verified. These views can be compared and contrasted with actual measurements of social function, role transitions, and other factors.

Each person perceives HRQoL differently and is impacted by a variety of physical, emotional, and social variables. The standardized measurement of HRQoL is seen to benefit from the promotion of treatment plans. It emphasizes the viewpoint of the patient and thus might highlight regions that require special attention. This makes it easier to reach collaborative conclusions and assures that the patient's preferences are considered when making management decisions (Lamesgin Endalew et al., 2021). Clinical manifestations and the disruption they cause in the form of repeated clinical events and their effects, such as hospital readmissions, complaints, the amount of treatment needed, and changes in activities to manage the condition, can all have an impact on the quality of life.

Gap Analysis

The literature stipulates the Quality of Life (QOL) of HF patients is impacted by a wide range of socio-demographic, physiological, and psychological aspects, age, sex, marital status, social support, education, and culture are only a few of these variables. Another crucial component of HRQoL in patients with HF is social functioning. Due to the physical restrictions and emotional complications of their condition, patients with HF frequently experience social isolation. Hence, is important to know the patient's perspective regarding the quality of life. However, the perceived impact may be different for different people.

To improve the HRQoL of people with HF it’s important to assess their HRQoL using valid and reliable tools. However, most of the HRQoL tools in HF are developed in the West and they may or may not necessarily reflect the aspects of HRQoL that the people with HF uphold in the context of Pakistan. It is, therefore, imperative to explore how HF patients in the Pakistani context define/perceive their HRQoL to understand the attributes of HRQoL in this context. Also, since this phenomenon has probably not been explored in the Pakistani context, it is difficult to say if the Western HRQoL is suitable for use in Pakistan unless an understanding of what HRQoL means for people with HF in Pakistan. This study explored the basic knowledge regarding the HRQoL of people with HF in Pakistan. It has thus paved the way for a step-by-step approach to understanding and improving the HRQoL of people in Pakistan, through subsequent studies.

Conclusion

This chapter provided an in-depth overview of HF and the Health-related quality of life of HF patients. In conclusion, non-communicable conditions (NCDs) are significant risks for developing cardiovascular diseases, and the Quality of Life (QOL) of HF patients is impacted by various socio-demographic, physiological, and psychological aspects.

Moreover, health and quality of life are influenced by a person's experiences, beliefs, expectations, and perceptions, and these factors contribute to the concept of HRQoL. Social functioning is also a critical component of HRQoL for HF patients. To improve the HRQoL of people with HF, it is important to assess their HRQoL using valid and reliable tools. However, most of the HRQoL tools in HF are developed in the West, and it is necessary to explore how HF patients in the Pakistani context define/perceive their HRQoL to determine the applicability of these tools in this context. The study of HRQoL of people with HF in Pakistan provides basic knowledge that can pave the way for improving their HRQoL through subsequent studies.

Table 1. Extraction Table for Literature Review

Author/Year of Publication	Study Design	Sample/Finding	Place of study
AbuRuz, M. E. 2018	Descriptive Cross-Sectional Design	A total of 200 patients with heart failure were enrolled using convenience sampling from March to August 2017. The Arabic Version of the Hospital Anxiety and Depression Scale was utilized to assess levels of anxiety and depression. The study's findings indicated that individuals with heart failure experience a low quality of life along with elevated rates of anxiety and depression.	Jordan
Ahmed, M. D., et al 2017	Prospective & Retrospective Study	The study enrolled a total of 122 patients with heart failure. The findings emphasized the importance of prioritizing behavioural changes as a primary preventive measure for heart disease. Furthermore, exercise emerged as a crucial and fundamental factor in this regard.	Iraq
Alhawassi, T.M., et al 2018	Retrospective Cross-Sectional Audit	503 aged patients were recruited. Antihypertensive-related adverse drug reactions were common among hospitalized aged patients, increase awareness can help in prevention and decreasing the risks.	Australia
Ansari, M. Z. A. 2018	Review Article	According to this review, the HF rate is extensive and has a major strain on healthcare resources.	Pakistan
Armstrong, P.W., et al 2020	RCT	The study involved the recruitment of 789 participants who were divided into three groups. The aim was to investigate the impact of Vericiguat compared to Placebo	Kansas

		on the quality of life (QoL) in patients with Heart Failure and Preserved Ejection Fraction (HFpEF). The results indicated that treatment with Vericiguat did not lead to an improvement in the physical limitation score as measured by the KCCQ tool.	
Choi, H.-M., et al 2019	Review Article	This review concludes that the advances in diagnostic modalities and treatment regimens for HF improved the outcomes of HF patients.	Korea
Ashaye, A. et al 2012	Prospective Cohort Study	This article studied 21120 Healthy men, and it is concluded that the consumption of red meat has an association with an increased risk of HF.	Brigham
Gil-lacruz, M., et al 2020	Cross-Sectional Survey	A total of 244 individuals were enrolled in the study, and it was determined that attaining a higher level of education is associated with attaining a higher level of Health-Related Quality of Life (HRQoL).	Spain
Alharbi et al 2022	Cross-Sectional Survey	In Saudi Arabia, a cross-sectional study was conducted, involving the recruitment of 246 patients with heart failure. The participants had a mean age of 56.7 years, with 80% of them being male. The study findings indicated that assessing Health-Related Quality of Life (HRQoL) aids in reducing both physical and emotional concerns across all education levels.	Saudi Arabia
Jegier, et al 2021	Expert Opinion Paper	Heart failure patients' HRQoL scores were lower across some areas, including role restrictions brought on by	Poland

		physical health, mental wellness, and physical functioning.	
Lamesgin Endalew et al., 2021	Cross-Sectional Study	A consecutive sampling technique was used to select a total of 421 patients with myocardial conditions for the study. The results unveiled that psychological factors play a more substantial role in impacting the Health-Related Quality of Life (HRQoL) compared to physical and environmental factors.	Ethiopia
Lin et al., 2013	A Descriptive Cross-Sectional Design	A total of 145 participants were enlisted, and the study concluded that pain, fatigue, disrupted sleep, and distress were prevalent symptoms linked to the functional status and quality of life (QoL) among the patients.	China
Mack et al., 2021	RCT	A total of 31 patients were recruited for the conduction of the study. Moreover, 15 pairs of family members were recruited. In this study Health literacy level was measured and concluded that Technology-based interventions and evidence-based practices showed positive health outcomes and promoted active learning.	US
Mai Ba et al., 2020	Review Article	The review revealed that transitional care interventions should be initiated at admission including early detection of disease and its management to increase safe transition.	Review Article
Megari, 2013	Review Article	This paper aims to study QoL and HRQoL in chronic conditions and the importance of their impact to receive positive outcomes and better HRQoL.	Greece

Mueed et al., 2020	Qualitative Inquiry	500 patients were recruited and in-depth semi-structured interviews were conducted the result concluded that lifestyle modifications and self-care management help to minimize readmissions among HF patients.	Pakistan
Ohori et al., 2021	Retrospective Study and Observational Study	198 patients were recruited through a consecutive sampling technique and revealing the statistics of HF have a significant burden on healthcare expenses and outcomes.	Helsinki
Adamu et al., 2022	Cross-Sectional Study	376 hypertensive patients were recruited and the results concluded that old age, duration of antihypertensive drugs, and low social support have inverse proportion with HRQoL.	Ethiopia
Sadeghiazar et al., 2022	Cross-Sectional Study	A total of 273 participants were enrolled in the study, and the findings indicated a correlation between medication adherence, acceptance of illness, and the quality of life among patients.	Iran
Sanchis-Gomar, Perez-Quilis, Leischik, & Lucia, 2016	Review Paper	The purpose of this paper is to provide an overview of the prevalence, mortality trend, overall prognosis, and incidence of acute coronary syndrome (ACS), a condition that is connected to coronary heart disease (CHD). This evidence highlights the need for primary prevention strategies to be implemented globally.	Spain
Seid, 2020	Institutional based study	At Gondar referral hospital, a total of 284 patients with heart failure were selected for the study. Data was collected through structured questionnaire interviews.	Ethiopia

		The results revealed that a significant number of heart failure patients experienced a low Health-Related Quality of Life (HRQOL) due to factors such as their residential areas and their level of self-care practices. The study concluded that it is crucial for patients with heart failure to comprehend the benefits of self-care practices in order to improve their quality of life and slow down the progression of their disease.	
Romiti et al., 2020	Review Article	This review article presented the key points that gender differences between symptoms and comorbid in terms of the clinical result of HF.	Review Article
Roth et al., 2020	Review Article	This review article presented the findings that in recent decades, there has been a significant rise in the global prevalence of non-communicable diseases (NCDs), with cardiovascular disease (CVD) emerging as the primary cause of death in both developed and developing countries.	USA
Triposkiadis, F., Xanthopoulos, A., Parissis, J., Butler, J., & Farmakis, D., 2020.	Review paper	This paper provided an explanation that heart failure (HF), a prevalent condition primarily affecting older individuals, is becoming increasingly prevalent. The expenses associated with HF-related medical care are substantial and projected to escalate significantly in the coming years. The interaction between cardiovascular aging, specific risk factors, comorbidities, and disease modifiers contributes to the development of HF in older	Europe

		individuals from Western countries, regardless of the left ventricular ejection fraction (LVEF).	
Silavanich, V., Nathisuwan, S., Phrommintikul, A., & Permsuwan, U.,2019.	A Prospective Cross-sectional Study	A total of 180 patients were enrolled in the study, aiming to examine the association between medication adherence and the quality of life in individuals with heart failure. The study findings revealed a positive correlation between medication adherence and the overall quality of life among the patients.	Thailand
Li et al., 2019	National Cross-sectional Survey	A national representative sample of 109,551 individuals was chosen to assess the connection between metabolic syndrome (MetS) and its components with cardiovascular disease (CVD). The findings demonstrated a significant association between MetS and CVD.	China
Shao et al., 2020	Review Article	In this review paper, the author summarized current research on the common pathways between depression and CVD in this review. These results have significant therapeutic ramifications for developing additional strategies for the early detection and treatment of one or both disorders.	China

Chapter Three: Methodology

This chapter describes the research methodology that was used in the study to explore and understand in depth the meaning of Health-related quality of life (HRQoL) among HF patients, in Karachi, Pakistan. The chapter describes the study design, the rationale for using that design, the study population, the study setting, and the rationale for choosing this setting, the study sample, the sampling process, inclusion and exclusion criteria, the recruitment method, sample size, data collection, data analysis, study rigor, and ethical considerations undertaken in this study.

Study Design

A qualitative interpretive design was used to study HF patients' perceptions about their HRQoL. A qualitative interpretive study was considered most suitable for this research because it explores and interprets the day-to-day reflections and perceptions (framed from the day-to-day experience) of the people who live with HF. Hence, the participants shared their perceptions of HRQoL, and the researcher interpreted the aggregated information to develop a contextual sense of the meaning of HRQoL. The interpretive approach was well-suited for this study as it allowed for an in-depth understanding of the patients' experiences, perspectives, and the meanings associated with HRQoL.

According to Polit and Beck (2012), the interpretive approach relies heavily on conducting in-depth interviews with individuals who have firsthand experience of the phenomenon being studied. In this methodology, questioning and observation play crucial roles as tools for uncovering and fostering a deep and nuanced understanding of the phenomenon under investigation. Moreover, interpretive studies delve into personal experiences, recognizing the active role of interpretation by the participants and the researchers. Furthermore, they acknowledge the link between thoughts, feelings, and communication while recognizing the challenge of fully grasping an individual's unique perspectives. Consequently, researchers may infer meaning from individuals' verbal expressions, including emotional states (Creswell & Creswell, 2017).

Study Population and Setting

The study was conducted at the Aga Khan University Hospital outpatient cardiac clinic, a tertiary care hospital in Karachi, Pakistan. This being a JCIA accredited hospital, provides medical, allied, and surgical and allied services. Furthermore, the hospital is fully equipped with cutting-edge technology and offers a wide range of services. The outpatient cardiology units at AKUH receive around 40-50 cardiac patients per day, under the 14 cardiology consultants. The study population was adult HF patients, from the study setting, who were eligible according to the inclusion criteria for the study.

Sample and Sampling Strategy

The study was commenced in March 2023, after obtaining written approval from the Aga Khan University Ethics Review Board and the Ethical Research Committee (2023-8165-23834). Purposive sampling was used to collect the data, the study participants were selected based on certain qualities and characteristics. The study's aimed to recruit adult patients with heart failure (HF) by considering individuals aged 35 to 75 years, encompassed those with a confirmed diagnosis of HF, irrespective of gender. The inclusion criteria were designed to observe the spectrum of the youngest patients with heart failure. While age was not explicitly mentioned, it was included to capture this specific population. Despite heart failure being commonly associated with older age, a deliberate lower age limit was incorporated to investigate its occurrence in younger individuals. The selected age range was purposefully chosen to align with the prevalence of heart failure, excluding age groups where the disease is less prevalent. Conversely, exclusion criteria comprised individuals currently experiencing HF symptoms during the initial interaction. This technique facilitated the researcher to recruit participants intentionally, who were willing to share their perceptions and experiences, ensuring detailed information on the phenomenon of interest (Campbell et al., 2020; Etikan et al., 2016).

Bernard (2013), believes that a sample size of 10- 20 essential research participants is sufficient to find and grasp the major difficulties in any study about lived experience. As a result, the sample size for this study was estimated to be 12-15 participants (Bekele & Ago, 2022). Saturation was achieved in 13 participants, after which no new information emerged from the data and there was redundancy. However, one more interview was conducted to validate data saturation. Thus, a total of 14 participants were interviewed for the current study. Saturation is the point where the researcher observes the repetition of the information (Polit & Beck, 2012).

Eligibility Criteria

The participants of the study were recruited according to the given criteria.

Inclusion Criteria

The study population was adult HF patients.

- Participants of ages ranging from 35 to 75 years were considered eligible
- Participants who had a confirmed diagnosis of HF.
- Both males and females were included in the study.
- Participants who were willing to give voluntary consent and have their interviews tape-recorded.
- The participants who could speak and understand Urdu or English.

Exclusion Criteria

- The Participants who were experiencing the symptoms of HF (shortness of breath, fatigue, ankle swelling) at the time of initial interaction and data collection.
- Participants suffering from untreated malignancy.

- Participants with documented psychiatric illness.

Participants' Recruitment Process

The researcher followed the following process for the recruitment of the study participants. Written approval (Appendix G) was acquired from the Medical Director and Nursing Director of the public tertiary care hospital and the institution's Ethical Review Committee (Appendix F). Following this, the researcher wrote an email for approval to the Nurse Manager, department administrator, and the head nurse of the study unit, to gain access to the study participants. As it was difficult to access participants without medical assistance, a consultant of cardiac medicine and the unit nurses were involved in the process of recruitment of the participants.

The researcher collected the daily appointment list from the Unit Receptionist of the study unit to identify possible candidates who met the inclusion criteria. Following that, with the help of an assigned nurse, the potential participants were contacted on the day of their visit and were provided with information regarding the study's background, purpose, and significance. Participants were then personally approached by the researcher and were selected considering the inclusion criteria and maximum variation. After they showed a willingness to participate, the interview was recorded. For in-person interviews, a conference/private room in the clinic was booked where the interviews were taken, a place to maintain confidentiality.

Study Duration

The data collection procedure was started in mid-March 2023 and ended at the end of June 2023. The total duration of the study was eight months, from March 2023 to October 2023, which included thesis compilation.

Data Collection Tool

For data collection, the researcher developed a demographic questionnaire and an interview guide, to conduct in-depth interviews with the participants.

Demographic tool

The demographic tool comprised questions related to participants’ age, gender, marital status, level of education, occupation, religion, years of marriage, number of family members, and monthly income (Appendix E). The researcher ensured the inclusion of participants from different age ranges (e.g., 35-75 years), gender (both males and females), educational status (e.g., high school diploma or higher), years of marriage, occupations, and monthly household income to explore their HRQoL after the diagnosis of HF.

Semi-structured interviews

According to Burns and Grove (2010), semi-structured interviews allow the study participants to share their feelings and experiences related to the phenomenon of interest, irrespective of any boundaries. They involve a dialogue between the researcher and the participant, which is directed through a study guide and complemented by probes (DeJonckheere & Vaughn, 2019).

The interview guide consisted of eight open-ended questions inquiring about participants’ opinions about their health, life, and limitations in daily activities after diagnosis of HF. The participants were also asked to share their perceptions about their HRQoL (Appendix C). Moreover, certain planned and unplanned probes were also used during the interview to obtain depth and richness in the participants’ responses. According to the participants’ comfort, the responses were provided by them in English and Urdu (Appendix D). Throughout the interviews, the researcher consistently recorded field notes simultaneously, to capture the non-verbal gestures and emotions exhibited by the participants. This aided in aligning the verbal data with their non-verbal cues.

Pilot Testing of the Interviews

Pilot interviews improve the interview process and allowed the researcher to modify to the interview questions and probes based on the participant’s level of understanding. A semi-structured interview guide, consisting of open-ended questions and probes, was utilized to guide the interviews. Additional spontaneous probes were incorporated, as needed, during the interviews. Two pilot tests were conducted with the recruited participants, resulting in minor adjustments in the interview guide. The revised version was found to be easily understandable by the participants. The pilot testing participants and their interviews were excluded from the final study.

Data Collection Procedure

The data were collected from March 2023 to June 2023, after obtaining approval from the Aga Khan University Ethical Review Committee. The participants were allowed to decide whether they wanted to be interviewed before or after their doctor’s appointment. The interview duration of all the participants was ranged from 30-40 minutes, with an average duration of 35 minutes.

The participants were selected from the daily appointment list, which was obtained from the Unit Receptionist of the study unit. Their eligibility was checked by reviewing their medical records and confirming the HF diagnosis. The selection of specific patients for the study was purposive, considering factors such as age, gender, educational status, and type of HF, to ensure a diverse and representative sample.

The selected participants were personally approached by the researcher. During their clinic visit, the researcher approached them, explained the study's purpose and significance, and highlighted the potential contribution of their experiences. The researcher tried to build rapport and establish trust with the participants, addressing any concerns or questions they had regarding the study.

To convince the participants to join the study, the researcher emphasized the importance of their unique perspectives and insights in advancing knowledge in the field of HF. It was highlighted to them that participation was voluntary and their confidentiality would be maintained by, ensuring the privacy and anonymity of the participants. The researcher conveyed that their involvement would contribute to improving the understanding and management of HF, potentially benefiting other patients in the future.

During the study, the researcher employed therapeutic communication techniques. When interacting with the participants, the researcher attentively listened to the participants, and expressed empathy and understanding with the participants' experiences and emotions. Moreover, the researcher used reflective statements to validate and confirm participants' feelings and experiences, and reassured the participants about maintaining their confidentiality. Furthermore, the participants were given the choice to discontinue the interview at any moment if they experienced any discomfort or distress. Additionally, written informed consent (Appendix A & B) was obtained from each participant in the study on the same day. The researcher audio-recorded all interviews with the participants’ consent.

Data Analysis

Data Organization

Firstly, after conducting each interview, the researcher secured the participants’ data in a locked cabinet, while the recordings of the interviews were saved in a password-protected folder to maintain the confidentiality of the participants. Participants were provided an identification number (ID#) to maintain their anonymity. The interviews were first transcribed in the Urdu language and then translated into the English language by the researcher, with the help of a language expert. Transcribed interviews were read two-three times to further understand the participants' perspectives and to develop the researcher's reflections on the overall meaning of the transcription. The researcher identified the general ideas that the participants presented, and the tone of their voices. This helped the researcher understand the depth of meaning and added to the credibility of the information collected (Creswell, 2013). All the interviews were organized in a Microsoft Word document as text-based data.

Reading and Reflecting

The researcher read and reflected upon the transcripts several times, and compared each of them with the audio recordings to understand and identify the key concepts from the data. The researcher also reviewed the reflective notes that were written soon after each interview, which helped the researcher to eliminate the researcher's bias and to understand the sense of the data as a whole (Palaganas et al., 2017)

Data Coding

Coding is an essential process in qualitative data analysis. It is a deductive process of breaking down data into smaller units that reflect the participants' responses to the question under study (Stuckey, 2015). For this, the researcher made three columns: participants' narratives, codes, and categories. From the narratives, each single idea was aggregated under the columns of codes, which lead to multiple codes emerging from the participant's responses.

Categories and Themes

The formed codes were further analyzed and grouped based on similarities and differences. Through this process, categories were developed. These categories were further grouped to develop the themes. Major themes, which emerged from categories were thus identified. These themes drew an analytical conclusion from the data, initially presented in the form of codes. Reviews of the thesis committee were obtained at each step of data analysis, to have a complete, accurate, and fair interpretation of results (Creswell, 2013). A detailed description of themes is given in the result section.

Representation of Data

The researcher displayed the demographic data in a tabular form to comprehensively present the study findings. Whereas, the themes were presented in a hierarchical form, where major themes were divided into categories and assisted through participants' narrations, for thorough reporting and understanding of the study findings.

Study Rigor

Rigor is maintaining the trustworthiness of the research during the process of data collection, analysis, and interpretation. Lincoln and Guba (1985), have described the criteria for maintaining the trustworthiness of qualitative inquiry. This includes credibility, dependability, and confirmability and transferability. This framework was followed during data collection, analysis, and interpretation, to achieve trustworthiness.

Credibility

It refers to the truthfulness of the data findings. Credibility was maintained throughout the study, as the researcher herself collected the data and performed analysis. Moreover, the researcher encouraged the participants to share their experiences honestly, without any hesitation. Furthermore, during the interview, the researcher repeatedly used rephrasing to confirm what the participants wanted to say, used probing to explore the maximum possible information from them, and took written notes where required. Besides, the participant's non-verbal expressions (laughter and sighs) were also observed and were mentioned in the researcher's field notes, to ensure the rigor of the study.

Dependability

Dependability in a qualitative study, is about evaluating the consistency in data analysis (Lincoln & Guba, 1985). The researcher ensured dependability by cross-checking the organization and documentation of the data. Moreover, the researcher re-listened to the recordings and re-read the transcripts to make sure that the analysis was comprehensive. Furthermore, the thesis supervisor and the committee members were also involved throughout the process of data analysis.

Confirmability

Conformability in a qualitative study is about evaluating the content of the data through member checks, audio audits, and participant checks (Lincoln & Guba, 1985). The researcher in this study ensured the objectivity of the research results by maintaining field notes and reflections, thereby preserving conformability. Participant check and confirmability procedures were conducted with utmost consideration for participant confidentiality. Any adjustments or corrections made during the participant check were handled with sensitivity to ensure the continued trust and privacy of the participants.

Furthermore, a systematic and sequential approach was employed to analyze the data, and the resulting findings were extensively deliberated with the thesis committee to ensure that the researcher's own biases were bracketed. Lastly, to uphold the integrity of the findings, each theme and category were substantiated with participants' narrations. The researcher used bracketing, by writing reflections, to minimize the role of conflict and the influence of the researcher’s values on the participants’ views (Polit & Beck, 2012). As the researcher’s background includes cardiac nurse and dealing with heart failure patients which could shape my perspective on the topic of HF and HRQoL. While providing expertise, this background might also introduce certain biases, and it is essential to acknowledge and address these influences to maintain the integrity of the research.

As researcher assumed the position of an observer and facilitator during the study, responsible for conducting interviews and analyzing the data. This involvement could have influenced the data collection and interpretation process. Maintaining awareness of this role is crucial for transparency and understanding the potential impact on the study outcomes. Acknowledging personal biases is a fundamental aspect of maintaining objectivity. Researcher strived for impartiality, preconceived notions about the significance of HRQoL in heart failure patients may have influenced the framing of questions and data interpretation. Reflecting on these biases is necessary for a more comprehensive understanding of the study's context.

Transferability

It refers to the applicability of the data findings in other similar settings with other respondents. With regard to this study, the transferability of the data may be uncertain because it was conducted in only one private tertiary care setting. However, the researcher-maintained transferability through the use of a purposive sampling technique, which helped in selecting participants with maximum variation and allowed the researcher to explore information through multiple experiences. Moreover, a detailed explanation of the study processes has been provided to assist future researchers in replicating this study in their context.

Ethical Considerations

Firstly, the research proposal was sent to the thesis committee for approval. Following that, approval was taken from the CMO of the Aga Khan University Hospital (Appendix G). Lastly, permission was taken from the ERC board of AKUH (Appendix F).

Before the interview, the participants had given written consent after reading the form outlining the objective and goals of the research. Everyone participated voluntarily, and no one was interviewed without their permission. Since feelings and behaviours are a concern, confidentiality was maintained. There were no potential harms, risks, or threats to any participant. In fact, the participants often felt better when they talked about their experiences with illness. None of the participants experienced any fatigue or complications that could have stopped the interview process.

Before recording any of the participants' statements, verbal approval was obtained from them. Their personal information was kept confidential. Moreover, confidentiality was maintained, as the names of the participants were kept confidential throughout the study period by assigning an ID to each interview. The researcher used pseudonyms to identify participants throughout the study.

The hard copies of the data collected were kept in a safe private lockable place, and the data in soft copies was saved with a strong safety password in the computer. The collected data was only shared and discussed with the thesis supervisor and the members of the committee and then the data was coded. For discarding data, the researcher obeyed the disposing policy of the AKUH. Although taking part in the study did not directly benefit the participants, and the study did not offer any incentives, they had the opportunity to express their emotions and discuss their experiences, all of which helped in improving clinical services.

Summary

In conclusion, the chapter has described the research methodology employed in the study. The study utilized a qualitative interpretive study design to explore the phenomenon of interest. It was conducted at the outpatient cardiac clinic of a private tertiary care hospital in Karachi, Pakistan. Through purposive sampling, a total of 14 participants completed the demographic tool and the semi-structured interview. Creswell's steps for data analysis were followed, and rigor was maintained throughout the process. Lastly, the chapter described the ethical considerations of the study.

Chapter Four: Results and Findings

The purpose of this chapter is to present the data analysis findings regarding concepts of HRQoL among HF patients in Pakistan. The chapter provides the demographic characteristics of the research participants and an analysis of the findings in the form of themes, categories, and codes related to the study questions.

Demographic Characteristics of the Study Participants

The study sample comprised n=14 Patients with HF (HF) coming to the outpatient Department of Cardiology, of the Aga Khan University Hospital, Karachi, Pakistan. Their mean age was 64.21 years, with a standard deviation of ± 6.86. Of these, 42.9% (n=6) were male and 57.1% (n=8) were female HF patients. Moreover, the data was obtained from married 78.6% (n=11), unmarried 7.1% (n=1), and widowed 14.3% (n=2) patients. They were married for a mean of 35.35 years, with a standard deviation of ± 13.93. The participants' mean number of children was 3.5, with a standard deviation of ± 2.07. The mean household income was 75,714 PKR, with a standard deviation of 34,521.

The education level of the participants was primary education 35.7% (n=5), intermediate 28.6% (n=4), diploma/degree holders 21.4% (n=3), secondary education and no formal education 7.1% (n=1) (each). With regard to occupation, most of the patients were aged and retired, 42.9% (n=6), followed by housewives, 28.6% (n=4), while non-working patients were 21.4% (n=3). Islam was dominant as a religion among the participants, 92.9% (n=13), followed by Christianity, 7.1% (n=1). Most of the participants were living in a joint family, 64.3% (n=9), while some of the participants, 35.7% (n=5), lived in a nuclear family.

The overall descriptive analysis for quantitative variables is presented in Table 1.0 and for qualitative variables in Table 2.0.

Table 2. Demographic Variables (Quantitative Variables)

Demographic Variables	**Mean**	**Standard Deviation**
Age	64.21	6.86
Years of Marriage	35.35	13.93
Number of Children	3.50	2.06
Total Household Income	75,714	34,521

Table 3. Demographic Variables (Qualitative Variables)

Demographic Variables	**Number of Participants (n)**	**Percentage (%)**
Gender		
Male	06	42.9
Female	08	57.1
Marital Status		
Married	11	78.6
Unmarried	01	7.1
Widowers	02	14.3
Level of Education		
No Formal Education	01	7.1
Primary Education	05	35.7
Secondary Education	01	7.1
Intermediate	04	28.6
Diploma/Degree	03	21.4

Religion		
Islam	13	92.9
Christianity	01	7.1
Occupation		
Housewife	04	28.6
Retired	06	42.9
Non-Working	03	21.4
Working	01	7.1
Type of Family		
Joint Family	09	64.3
Nuclear Family	05	35.7

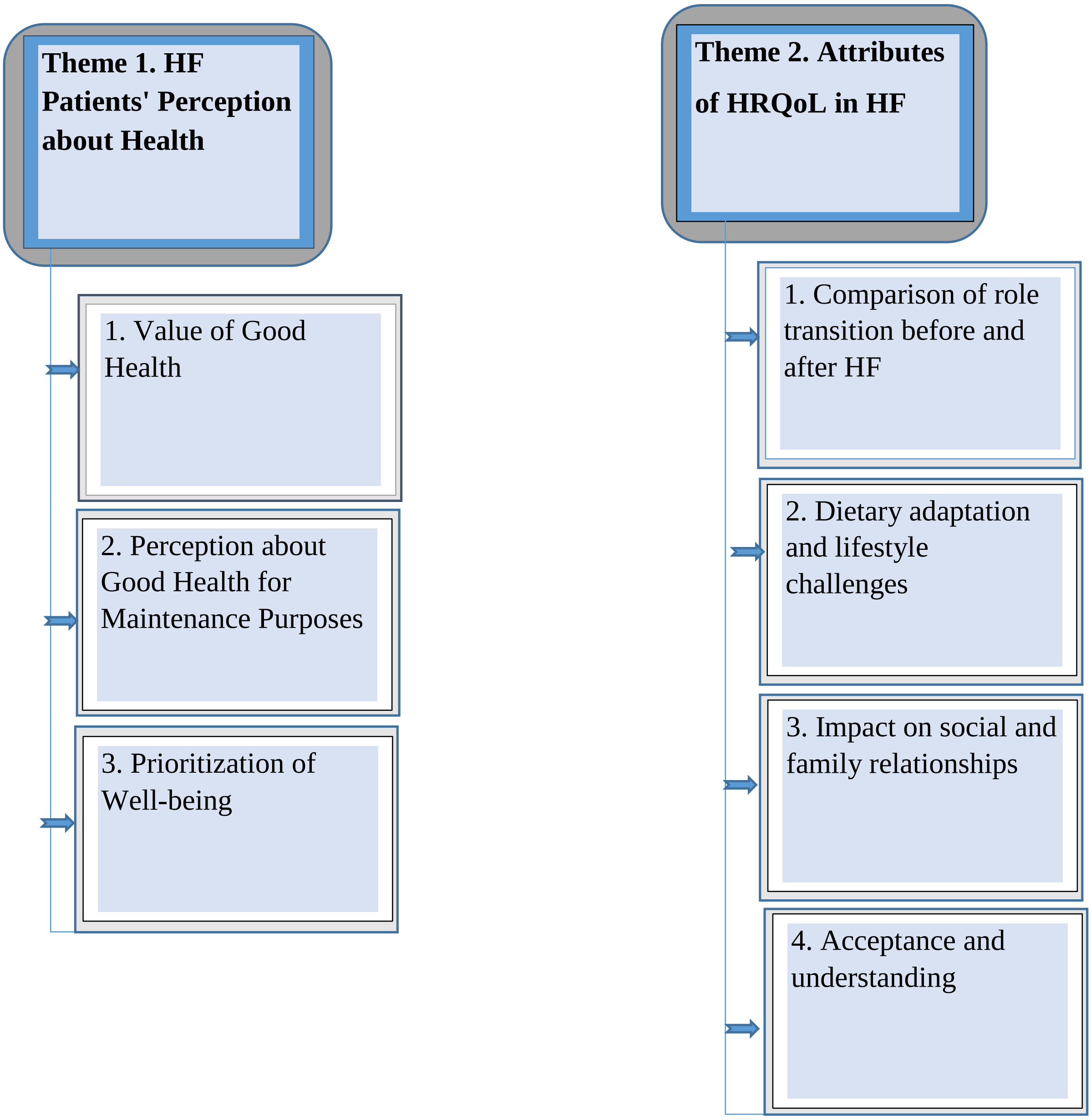
Themes

The content analysis of the data resulted in the development of multiple codes from the participants’ narratives. Similar codes were then compiled together to develop categories. These categories were the merged to develop themes, to have clearer understanding of the phenomenon. A total of two themes emerged, according to the study questions. Theme one “HF Patients' Perception about Health", emerged from the categories, the value of good health, perception of good health for maintenance purposes, and prioritization of well-being. Theme two “Attributes of HRQoL in HF”, emerged from the comparison of role transition before and after HF, dietary adaptation and lifestyle challenges, impact on social and family relationships, and acceptance and understanding.

In this chapter, the categories are explained comprehensively and are supported by quoting the participants’ appropriate narrations from the data. Participant’s narrations have been provided to support each theme and category. Moreover, to promote the clarity of the text for the readers, the researcher has corrected all the grammatical errors have been corrected without altering the actual meaning. Furthermore, in the interest of maintaining participants' confidentiality, their narratives were anonymized through the pseudonyms and numerical codes. Consequently, when presenting participants' quoted responses, a combination of pseudocodes and numerical identifiers was utilized, such as *HFP-01*.

The concept of HRQoL of HF patients was explored. The themes and categories that emerged are illustrated in Figure 2.0.

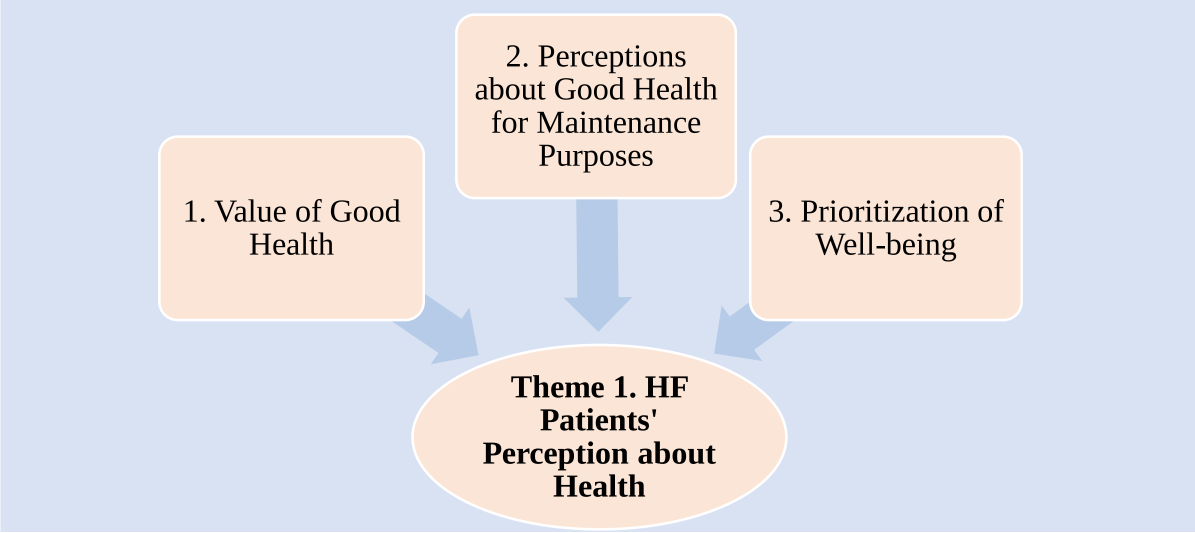
Figure 2. Themes, and Categories



Theme one: HF Patients' Perception About Health

In this theme, the researcher explored the patient's perspective regarding overall health and their views on their health. The researcher started with general questions first about health and then moved toward their perception about health change as a result of their experience with HF. Moreover, since HF affects multiple domains of an individual’s life, it was significant for the researcher to explore the perspectives and significance of health after having HF. The three major categories under this theme are reflection and value of good health, perceptions about good health for maintenance, and prioritization of well-being.

Figure 3. Theme One with its Categories



Category: Value of Good Health

Many participants reflected on their health journey, and many mentioned individuals who are in better health but facing more severe medical issues. This contrast fostered a sense of gratitude in them for their well-being**.** Moreover, some participants had also begun to notice how their physical health was connected to their mental and emotional well-being. Realizing this connection, they realized that staying healthy had positive effects on their state of mind too. Additionally, three of the participants also shared that good health had a ripple effect. For example, they stated that when we take steps to stay healthy, we inspire others to do the same. Our choices and behaviours can be motivating examples for friends, family, and even our communities. By valuing our health, we contribute to our well-being and also take care of others. Moreover, one participant recognizing the significance of good health acknowledged its unparalleled contribution to preserving and enhancing the very essence of life itself by stating,

> Health is very important, extremely important. Health is everything in life. Health means keeping oneself fit and active. Staying healthy is about living life the right way. It's like having a special gift, so I don't take it lightly. Being in good health means I can make the most out of life. (HFP-01)

The analysis of data also reflected that some participants showed gratitude to Allah (God) for the blessings they had received after going through the disease process and how their health was improving after experiencing this challenge. As one of the participants shared, “I am grateful to Allah (God) that I am alive. Whatever Allah (God) has granted us we have to accept it and modify our lifestyle to accept this challenge” (HFP-05).

A few of the participants reflected on their understanding of the importance of good health. They expressed that it is comparable to having a key to a happy life, and it is a valuable asset that requires careful attention. One of them expressed:

> I have realized how important it is to stay healthy. It's like having a key to a happy life that you must take care of. My health feels like a special present, and it reminds me to be grateful and take good care of it. Seeing my health as a gift makes me thankful and determined to keep it safe. (HFP-03)

Other than health being a blessing, the participants shared that being healthy is important. It is like the foundation that supports everything in life. They can do everyday tasks easily, spend time with their family, and find happiness because they are in good health. They think of it as a valuable gift that is more than just living a long time, it is about living a better, more fulfilling life. As one of the participants stated, “Good health is like the base of everything. It lets me enjoy normal things, be with family, and feel happy. It is a special gift that is not just about living longer, but about living better" (HFP-10). Moreover, many participants acknowledged the value of life and chose to live it fully, cherishing each moment. As one participant stated, 'Every day is a chance for me to live a happy life” (HFP-11).

The above-identified participants' narratives demonstrate that health is paramount in shaping an active life.

Category: Perception about Good Health for Maintenance Purposes

The majority of the participants shared insightful perspectives that extended beyond their well-being. They viewed their health as intertwined with the health of those around them, fostering a sense of responsibility to maintain it. While sharing their experiences, the participants showed their emotions through tears and grimaces. Additionally, some of the participants, shared their perspectives, that the idea of health was less personal and more of a shared duty; this was especially noticeable in people who thought about their partners. One of the participants stated, “Being healthy is not just for me. It is for those I love too. Taking care of myself is like taking care of them" (HFP-01). Another participant also mentioned:

> After my HF diagnosis, I learned how important it is to make healthy choices. It is not just about me; I must stay well. I work hard to keep myself healthy because I want to feel better and be there for those I care about. (HFP-04)

Moreover, most of the participants believed in the primacy of health over all else. Individuals also acknowledge the significance of timely interventions as delayed medical attention can lead to deterioration in health. One of the participants stated:

> Five years ago, I discovered that I suffered from HF. At that time, I neglected my symptoms, did not go for check-ups and medical tests, and took only painkillers. I spent that night in pain and this occurred for two consecutive nights. Later I realized that I should be taken to the hospital and I did not pay proper attention to my health. (HFP-09)

Overall, most participants emphasized making good decisions and working hard to take care, both for themselves and their loved ones. They also recognized the importance of seeking timely medical attention.

Category: Prioritization of Well-Being

In this category, the participants showed that they cared about their health. They realized that taking care of themselves would help them chase their dreams, especially with regard to their kids. They made sure that they visited the doctor regularly, took medicines as needed, and avoided over-the-counter drugs. This shows that they became responsible and serious about their well-being. Most of the middle-aged participants expressed this perspective. One of them said, “I focus on my health because it gives me the energy to chase my dreams, especially for my children. Going for checkups regularly is important to me"(HFP-02). However, older participants showed more concern about their well-being and showed a more responsible approach to self-care by seeking professional guidance. As one of the participants stated, “I make sure to take my prescribed medications seriously, and I have learned to avoid using over-the-counter drugs without taking advice from my doctor"(HFP-06).

A few participants reflected on the positive changes in their daily routine they began prioritizing proper sleep and exercise. One of the participants stated, “I have changed my daily routine to include enough sleep and exercise, and I am making conscious lifestyle adjustments” (HFP-08). Similarly, one more participant expressed, “I am also consciously working on adjusting my lifestyle for the better"(HFP-09).

Moreover, some of the participants also showed contentment and appreciation for the current situation, with a renewed perspective on life. As one of the participants shared, “I had been given a second chance at life. It made me more grateful and motivated to care for myself, as health is the backbone of a fulfilling life” (HFP- 10).

The analysis also revealed that proactive health habits were considered important for reasons other than physical health. The participants stated these practices had a good impact on their mental and emotional states, hence improving their general quality of life, helping them make healthy choices daily, and empowering them to live life to the fullest, with energy, confidence, and a sense of control over their health. Two participants thought that investing in their future well-being, by adopting these habits, guaranteed that we could enjoy life's events and difficulties with resilience and vitality. As one of the participants stated:

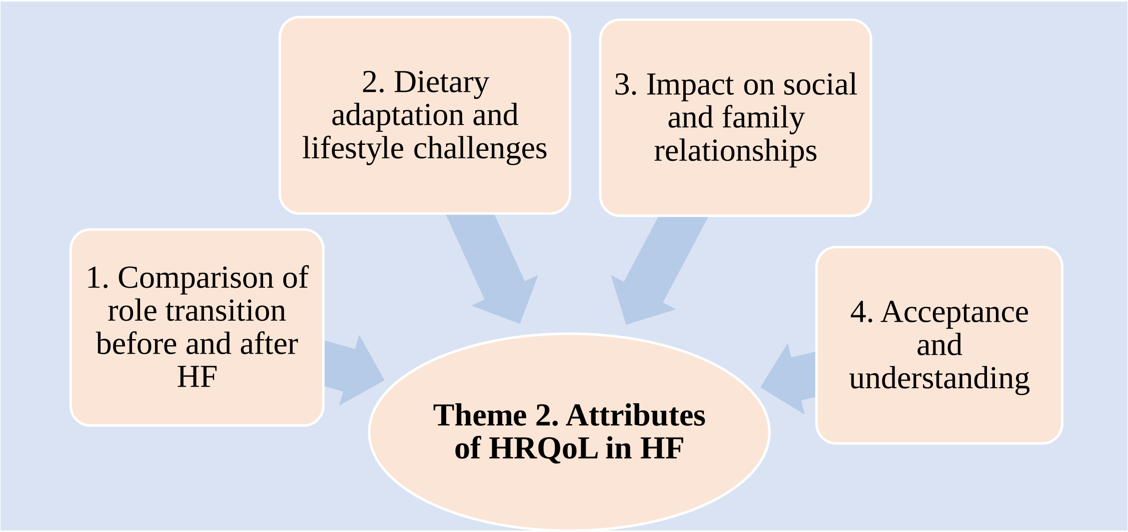
> To maintain good health, despite having HF, it is important to adopt healthy habits in our daily lives. Regular exercise, a balanced diet, and seeking sufficient medical care. These steps are towards our well-being, we can prevent potential health issues and ensure that we are equipped to handle any challenges that come our way. (HFP-13)

The recognition of personal care and prioritizing of well-being are driven by knowledge-seeking, self-care, and up-to-date lifestyle choices.

Theme two: Attributes of HRQoL of HF

Under this theme, individual perspectives regarding HRQoL and its holistic approach to their life after experiencing HF were explored. Every participant articulated a different opinion and a different viewpoint about their life in a different way, with mixed feelings. The four major categories that emerged from the participants' narrative showed how roles change before and after HF, challenges in lifestyle and diet adaptation, how relationships are impacted, and the journey of acceptance.

Figure 4. Theme Two with its Categories



Category: Comparing Role Transition before and after HF.

In this category, many participants expressed feelings of frustration and sadness due to the limitations that HF had imposed on their physical abilities. One of the participants stated, "HF has brought a lot of frustration and sadness. I feel limited in doing my household work, like cooking, and washing. It needs strength which I do not have. I experienced shortness of breath when I stand for a prolonged time" (HFP-01).

Most of the participants narrated that they were facing difficulty in performing their Activities of Daily Living (ADL) due to their physical limitations and this affected their emotional and mental health. One of the participants expressed “I cannot take care of household chores like before; I find it challenging to carry out certain tasks that were once manageable for me” (HFP-03). Similarly, one more participant narrated, “I have difficulty in performing small tasks because I have a constant fear of consequences” (HFP-05).

Some of the participants showed their frustrations with their social boundaries through their narrations. One participant showed concern by saying “I cannot go anywhere, not meet anyone, even not engage in social activities. I am stuck because of my illness” (HFP-07). And, one participant shared, “I have my nephew's marriage next week but due to this disease and symptoms, my children were not allowing me to attend because they are afraid of my sickness and worsening of my symptoms” (HFP-09).

Moreover, female participants expressed their anxiety and fear related to their family, particularly with regard to their responsibility towards their family. The majority of the female participants expressed that their responsibility as a mother was hindered after having HF. As one of the participants stated, “As women, we are the pillar of our family, we have to take care of ourselves. After HF, I always used to worry when I became sick because there was no one to take care of my family. Nobody was there for cooking cleaning, and my children, my husband also became worried about my health” (HFP-13). Moreover, some participants expressed how their illness impacted their families and increased their burden in different ways. One participant stated,

> The main problem is that my illness is causing trouble for my family and because of this, I also feel tired and get annoyed easily. I do not have the energy to do any work, and I do not enjoy talking anymore. It is not just that, the financial side is also tough. After having HF, it has been hard to handle expenses and manage money properly. (HFP-10)

Additionally, one of the participants expressed, “I used to go my shop and work a few hours to help my son financially, but now, due to this illness, I am unable to travel by bus and am not able to work properly. I feel bad that I cannot help my son financially, and I have become a burden on them” (HFP-14). As already mentioned, good health is a gift of God and good health brings the gift of enjoying life freely and having independence and self-sufficiency. Most of the participants expressed that good health was more than a physical state. It empowered them to be independent and formed the foundation of their existence. One of the participants stated:

> My life has undergone significant changes. Previously, I used to live a normal life and do my work on my own but now I have to depend on my family members, and mostly my daughter-in-law, for everything, as I feel fatigued and lethargic sometimes, so I am not able to do any household chores. (HFP-09)

While a few participants expressed their limitations and compared their freedom with their past. As expressed by one of the participants,

> I feel a mix of emotions when I think about the past, as I had the freedom to go anywhere, it was a wonderful feeling I had without any limitations. But now I feel restricted and unable to enjoy the same level of freedom. (HFP- 08)

Overall, the above-stated participants’ narratives show that individuals had varied views regarding their role transitions in different aspects before and after having HF.

Category: Dietary Adaptation and Lifestyle Challenges

In this category, most of the participants shared that they had adjusted their lifestyles and dietary habits in response to their health conditions. They mentioned in detail the various ways they had adapted to navigate their daily lives. Moreover, they expressed that they adapted themselves according to their health conditions, by making deliberate choices in both their diets and overall lifestyles. This involved modifying eating habits, incorporating exercise routines, and embracing wellness practices to maintain a balanced and healthy way of living. One of the participants stated,

> I realized that I needed to make some changes to feel better. So, I started looking at what I eat and how I live. I began choosing foods that were good for me, even if they were not what I used to eat. And you know what? It's not just about food. I started doing exercises that my body could handle and finding ways to relax my mind. It is like I am adjusting my life to fit my health needs, and it's helping me feel better, overall. (HFP-05)

Similarly, one of the participants verbalized, “I have to monitor my fluid intake and limit the salt intake to avoid swelling and shortness of breath and need to follow the strict medication regimen and it is challenging for me” (HFP-04). While one of the participants expressed exercising their intentional efforts to control their health by suppressing desires, by stating,

> At first, it was tough because I loved eating certain things. But then I realized that those things were making my health worse. So, I learned to control those cravings. It is like I am telling myself that my health is more important than that moment of indulgence. (HFP-06)

Additionally, the findings of the study revealed that the participants felt restricted in terms of outdoor activities and mobility. This limitation led to a sense of confinement, highlighting the impact of health conditions on their overall lifestyle and experiences. As stated by one of them:

> I used to love going out and doing things, but my health doesn't allow me to be as active as before. It is like I am confined to my home more often. I miss being

> outdoors and doing things freely, but I have learned to find joy in simple moments indoors. It is a different way of living, but I'm adapting. (HFP-03)

All in all, the majority of the participants depicted flexibility and self-control. Their dedication to regulating their well-being and pursuing a healthy existence is demonstrated by how they adjust their dietary changes and lifestyle changes.

Category: Impact on Social and Family Relationships

Under this category, most of the participants talked about their connection with families and friends after HF. The majority of the participants were worried about their future and felt unsure about their purpose in life due to the illness. Some of the participants also verbalized that they were not as valuable as before. HF had made them dependent on their family and they felt being left out of regular activities. One of the participants stated,

> Since my heart got weaker, I have felt closer to my family and friends. But it is not easy. I worry about what will come next, and I do not always know what I am supposed to do anymore. And there are times when I feel like I am not as important. (HFP-02)

Similarly, another participant stated, “I struggle to stay focused on my daily tasks. And I worry a lot that if I walk too much, I might suddenly feel pain" (HFP-04). Moreover, some participants expressed how their illness impacted their families and increased their burden in different ways. One participant stated, “The biggest issue is that my illness is affecting my family, and along with the impact I have become lethargic and irritable. I do not feel like doing any work, I do not like to talk anymore” (HFP-09).

Some of the participants verbalized that HF didn’t just affect the body, but also the mind and emotions. One of the participants reflected,

> I remember, how heart problem made me not just tired physically, but also made me feel sad and worried. I used to be active and happy, but now I feel different. It is like my body and mind are not working together (HFP-08).

They also highlight the importance of getting support from family and friends. As one of the participants stated: “Having people who love and comfort me when I am upset or facing tough times really helps me feel better and stronger. It is like having a big warm hug when I need it most” (HFP-10). Additionally, a few participants also stated that social connection can significantly contribute to their well-being, and nurturing these relationships and engaging in meaningful social interactions can positively impact their health holistically. One of the participants verbalized, “Having a support system, whether it is through family, friends, or community, provides emotional support and a sense of belonging and can help reduce feelings of loneliness or isolation” (HFP-06).

Overall, this category emphasizes the importance of relationships and the home environment in people's health journeys. Immediate circles of support, reassurance from loved ones, and the interconnection of family happiness help to promote well-being.

Category: Acceptance and Understanding

In this category, the majority of the participants shared their experiences of finding solace and strength in close relationships. Many of them emphasized the invaluable support provided by their family and friends, which reassured and empowered them. One of the participants stated: “I feel lucky to have my family and friends by my side. They give me the strength I need to deal with my health issues" (HFP-02). Some participants spoke confidently about relying on their spouses and families. They were confident about getting spousal and family support and expressed their feelings as such. As one of the participants stated: “My husband, children, and daughter-in-law supported me a lot. My son has also been there for me but my husband, has supported me the most” (HFP- 04). Similarly, others noted that companionship and family ties helped divert their attention from illness and brought them happiness. Another participant verbalized, “My daughters are my support. I spend time with my children and grandchildren, and they consistently divert my focus from my illness, bringing me happiness" (HFP-07).

Moreover, participants also discussed the methods that they used to deal with the adjustments and uncertainty brought on by their medical problems. These coping strategies included looking for emotional support and living in the present to develop resilience against difficulties. As one of them articulated, “I used to be stressed about the future, but that only worsened things. Now, I concentrate on the present, planning small joys daily. When overwhelmed, I reach out to loved ones for support” (HFP-06). A few participants also verbalized the feeling of happiness and well-being; one of them stated, “When we're happy and our families are with us, it's easier to take care of ourselves and enjoy life. And where we live also matters for our health” (HFP-09).

Furthermore, participants mentioned the proactive steps that they took to navigate their changed lives, including focusing on positivity, educating themselves about HF, and accepting their feelings. This acceptance, in turn, improved their mental well-being. As one of them articulated, “I decided to take control and learn about HF. I read and asked questions to know how to manage it better” (HFP-11).

Participants also verbalized their strong determination and resilience in carrying out their ADLs. Despite the challenges posed by their health conditions, they demonstrated an unwavering persistence to follow their everyday routines. This determination reflected their inner strength and willingness to persevere and maintain a sense of routine in their lives. One of the participants stated:

> Dealing with HF's limits was tough. It got me frustrated and sad when I couldn't do my usual things. But I learned to adjust, find new things that make me happy, and stay positive. I found stuff I can still enjoy, even if I have to do it differently now. (HFP-014)

Moreover, a few participants reported finding solace in the present moment. They shared their efforts about appreciating life's immediate joys, creating a source of emotional comfort. One participant stated,

> When we think about good things, it makes us stronger inside. It's like a special power that helps, even when things are hard. We can feel peaceful and enjoy happy moments. And you know what? Being thankful isn't just good for our hearts, it helps our bodies too. (HFP-012)

For some participants faith and prayer played a significant role in finding peace and purpose after experiencing HF. One of the participants narrated, “After HF, my faith and prayers became my support. They gave me a sense of peace and helped me see a purpose in everything. (HFP-07)

This category shows how participants deal with their feelings while surviving HF. They keep going despite challenges, taking care of themselves, and thinking about life's meaning. They use mindfulness to stay clear-headed and find comfort in the present moment. Their resilience and emphasis on the present moment intensely illustrate the influence of relationships and coping strategies in shaping their experiences with HF.

Summary

This chapter began by providing the demographic details of the participants. The perceptions of patients with HF regarding their health and how they manage it after diagnosis were explored along with the strategies, they adopted to prioritize their well-being.

Furthermore, the chapter presented findings related to their post-illness experiences. The attributes of health-related quality of life were discussed through a comparison of pre-and post-HF experiences, highlighting challenges faced by participants. Their understanding and level of acceptance were revealed through their narratives.

Chapter five: Discussion

This chapter discusses the study's key findings from the in-depth interviews of HF patients (HF)in the cardiac outpatient department of a private tertiary care hospital in Karachi, Pakistan. The findings are based on the perceptions and attributes regarding the health-related quality of life (HRQoL) in HF patients in the light of empirical literature. Moreover, the chapter also includes the study’s strengths, limitations, and recommendations. This study was based on two research questions and it aimed to explore the concept of HRQoL as perceived by the HF patients and the attributes that indicate the HRQoL of people with HF. The study findings are discussed under two themes.

HF Patients' Perceptions about Health

In this theme, the researcher explored the patients' perspectives about overall health and their views on their health. The three major categories under this theme are: reflection and value of good health, perception about good health for maintenance, and prioritization of well-being.

The present study showed that the views regarding their quality of life influenced the patients ‘health and the favourable effects on their QOL, following HF. The primary objective of caring for individuals with HF is to prolong their lives by maintaining their physiological balance and improving their overall HRQoL. The concept of HRQoL serves as a crucial measure for evaluating how diseases, conditions, or disabilities affect the physical, mental, and social aspects of a patient's well-being (Arab-Zozani et al., 2020).

In the context of HF patients in Pakistan, the present study has shed light on several crucial findings. First of all, a recurring feature in the participants' stories was their overall sense of appreciation for what they had. This sense of appreciation, deeply rooted in the Pakistani cultural setting, which is supported in the religious realm, was not merely an emotional response but a powerful coping mechanism. Participants expressed profound gratitude for each day of life, despite the challenges that they faced. They thought of appreciation as something essential for a happy life, like a valuable asset that they needed to take good care of. A similar study has also supported these concepts, as a positive outcome after disease, such as a new philosophy of life, greater appreciation of life, changes in personal properties, and improvement in relationships with family and friends (Cooke et al., 2009). One more study also shows that Gratitude is essential for improving and maintaining well-being and the overall quality of life (Ahmad et al., 2019). Social support and coping styles were found to partially maintain the relationship between gratitude and well-being (Chih-Che, 2016). Another study indicates that self-esteem partially controlled the relationship between gratitude and well-being (Lin, 2015).

An important finding that emerged from the study was the interconnection between physical health and mental and emotional well-being. This study indicates that good health exerts a favourable influence on various aspects of individuals' lives. It suggests that when individuals experience positive physical health, it contributes to a more favourable overall well-being. This interconnectedness implies that improvements in physical health not only alleviate the burden of illness but also extend to fostering positive mental and emotional states. However, an extensive literature search indicates the need for further exploration to fully understand the underlying mechanisms and implications of this relationship, emphasizing the complexity of factors at play and the importance of continued research to inform comprehensive healthcare strategies. There are some studies that can be linked with the current study results that increased levels of frailty, anxiety, and depression have been found to be associated with a decline in the quality of life among patients with HF (Uchmanowicz & Gobbens, 2015). Moreover, the results of one more study, conducted in Serbia, show that poor HRQoL is linked with an increased possibility of cardiac mortality and HF-linked readmissions (Erceg et al., 2019). And so, a more comprehensive understanding of these interconnections and their implications could pave the way for already developed interventions and support systems that enhance the overall well-being of HF patients in Pakistan.

In the current study, a prominent concept that emerged was the exploration of the concept of "the meaning of health." Despite expressing unhappiness with the limitations imposed on their lifestyles by their illnesses, patients actively engaged with their conditions. This active engagement proved to be the primary coping strategy employed by the study participants in response to their illnesses. Farsi (2015), showed that patients' experiences with their sickness and therapy helped them reach a higher degree of growth and sublimity, despite their acknowledged dissatisfaction with the constraints that their disease imposed on their lifestyle The importance of health, therefore, transcended the individual and extended to the collective, reinforcing the concept that ‘health is a shared duty’.

Beyond being seen as a blessing, participants emphatically emphasized the paramount importance of good health. In the Pakistani context, participants held views that health forms the foundation upon which all other aspects of life depend. Good health enables them to effortlessly perform daily activities, cherish quality time with their families, and find genuine happiness in their lives. Furthermore, the findings of the present study are supported by a study conducted by Howell et al. (2007), which suggests that immediate changes in health have a stronger association with an individual's current emotional state, while long-term health outcomes are more closely linked to enduring well-being traits.

Moreover, the research findings emphasized the significance of timely intervention to prevent delays in treatment and to avoid complications and dependency. The participants recognized that prompt medical attention was crucial in managing their condition effectively.

This realization underscored the priority that they placed on their health. Their insightful perspectives extended beyond their well-being. They viewed their health as knotted with the health of those around them, fostering a sense of responsibility to maintain it. While sharing their experiences, they expressed the idea of health as being less personal and more of a shared duty; this was especially noticeable in people who thought about their partners. One of the studies is congruent with these findings; and shows that health dimensions were thought to affect each other, and physical and mental health dimensions were selected as the most important items (Lee et al., 2016).

Furthermore, the study revealed that HF patients in Pakistan actively sought positive changes in their daily lives. These changes were driven by a desire to improve their overall well-being, maintain their health, and cultivate contentment. The participants' resilience and determination in the face of adversity were truly commendable. One of the scoping reviews revealed that patients with HF have a hard time detecting and differentiating symptoms, which might lead to readmission if appropriate treatment is not provided (Riegel et al., 2021)

The participants in the current study exhibited a profound concern for their health, recognizing its pivotal role in pursuing their aspirations, particularly concerning the well-being of their children. This sense of responsibility and seriousness manifested in their consistent adherence to regular doctor visits, prescribed medications, and avoidance of non-prescription drugs. These findings align with a cohort study conducted in the USA, which underscored the importance of self-care maintenance activities, such as medication adherence and dietary sodium restriction, in managing HF (Lee et al., 2015)Similarly, an institutional-based study in Ethiopia highlighted the significant impact of daily self-care behaviours, including medication compliance, on the course of HF (M. A. Seid, 2020).

Within the Pakistani context, our study participants certainly exhibited a strong commitment to improving their daily routines, highlighting a holistic approach to well-being. They displayed resilience in the face of challenging HF symptoms, which catalyzed positive lifestyle changes. However, no particular study was found that talked about the holistic approach being affected, but a descriptive cross-sectional study found that sleep problems were the most burdensome symptom, and they were linked to lower HRQoL, along with worse functional status and reduced overall symptom burden (Zambroski et al., 2005).

In Pakistan, where HF patients encounter a unique set of challenges and cultural nuances, it is imperative to recognize the significance of this holistic perspective. The emphasis on a well-rounded approach to health, encompassing not only physical symptoms but also mental, emotional, and social well-being, underscores the need for tailored healthcare strategies that address the multifaceted needs of individuals living with HF in Pakistan. This approach recognizes that improving the overall quality of life extends beyond symptom management, to encompass the broader spectrum of well-being.

The present also revealed a sense of contentment and appreciation for the current situation, accompanied by a renewed perspective on life. These findings match those from a study conducted in South Asia, which emphasized the role of personal connections, including those with healthcare providers, family, and spirituality, in shaping self-management approaches and reflecting individuals' desires to maintain balance and autonomy in managing their chronic conditions (Ambreen Tharani et al., 2023).

Furthermore, the analysis of the findings of this study showed the broader advantages of proactive health habits that extend beyond physical well-being but hold particular relevance within the context of Pakistan. The relevance lies in the fact that by adopting proactive health habits, individuals cannot only improve their physical health but also positively impact their mental and emotional well-being. In the context of Pakistan, where the cultural and societal aspects play a significant role in overall well-being, such proactive habits can empower individuals to lead healthier, more fulfilling lives, fostering a sense of control, confidence, and energy, ultimately improving their overall quality of life.

Further, the analysis showed that these practices exerted a positive influence on the mental and emotional states of HF patients, ultimately contributing to an enhancement in their overall quality of life. These outcomes resonate with a prospective interventional study conducted in Pakistan, which highlighted a robust connection between physical functioning and HRQoL, thereby reinforcing the essential role of physical health in safeguarding the quality of life among individuals grappling with HF (Mack et al., 2021). This shows the importance of adopting comprehensive healthcare approaches in Pakistan that recognize the holistic relationship between physical and emotional well-being in HF patients, aiming not only at extending life but enhancing its quality as well.

The current study underscores the significance of personal care and prioritizing well-being among HF patients in Pakistan. This recognition is driven by knowledge-seeking, self-care practices, and informed lifestyle choices, reflecting the multifaceted nature of managing HF within the unique cultural and healthcare context of Pakistan. These insights emphasize the importance of personalized healthcare approaches that can contribute to the holistic well-being of HF patients in our country.

Attributes of HRQoL of HF

The comprehensive findings from the current research on the concept of HRQoL among HF patients in Pakistan, reveal a multifaceted landscape of experiences and challenges. The narratives of the study participants have unveiled a range of emotions, physical limitations, and coping mechanisms that collectively provide valuable insights into the unique healthcare context in Pakistan.

One significant aspect that emerged from the present study is the sense of frustration and anger experienced by HF patients. The burden of managing a chronic condition, coupled with the associated physical limitations, often leads to frustration and anger. These emotions reflect the challenges patients face in maintaining their health and well-being within the constraints of their condition. In one of the studies, it has become apparent that the presence of depressive symptoms in patients with HF not only escalates their susceptibility to heightened morbidity and mortality but also exerts an unfavourable impact on their adherence to recommended therapeutic interventions (Kato et al., 2011). Moreover, one other study emphasizes how crucial physical health is in preserving HRQoL in people with HF, and in enhancing their physical performance to improve HRQoL in people with HF (Mack et al., 2021). It is crucial for healthcare providers and policymakers in Pakistan to acknowledge and address these emotional challenges in the care and support provided to HF patients.

Additionally, the present study highlighted the struggle of patients in balancing their responsibilities and adjusting to dietary and lifestyle restrictions. The fear and anger that can be associated with these restrictions underline the need for patient-centred approaches that offer practical guidance and support in managing HF while maintaining a meaningful life. A descriptive qualitative study, conducted in three teaching hospitals in Pakistan, also reported that in the initial stages, individuals exhibited adherence to the prescribed dietary and exercise protocols, primarily driven by their concerns regarding potential disease-related suffering. However, as time progressed, some individuals experienced a sense of burden and a potential decline in motivation (A. Tharani et al., 2023). Similarly, another study validated these findings but also emphasized that participants recognized the importance of limiting fluid intake, while being less informed about the necessity of restricting their salt consumption to manage their HF (Ming et al., 2011). These insights underline the dynamic nature of managing HF in Pakistan and the need for ongoing support and education for patients. It becomes clear that addressing the challenges associated with dietary and lifestyle restrictions, as well as sustaining patient motivation over time, is a crucial aspect of HF care in Pakistan.

Within the context of Pakistan, our study explored the adaptation of individuals to the transformative impact of HF on their daily lives. This exploration encompassed their willingness to regulate their priorities and their personal experiences in coping with altered physical capabilities, necessitating the development of innovative strategies for managing everyday tasks. A similar study emphasizes the structural facets of this adaptation process, highlighting the complexities of modifying the characteristics of daily activities, the ongoing need for meticulous planning to effectively manage these activities, and the crucial role of external support networks in successfully navigating the demands of daily life (Pihl et al., 2011). These shared insights show the universal challenges faced by HF patients, irrespective of geographical boundaries. Acknowledging the need for adaptable strategies and support is vital in Pakistan, as it can lead to a more patient-focused approach to HF care and improve the quality of life for those dealing with this condition.

Furthermore, the study's emphasis on the importance of meticulous planning and external support resonates deeply within the Pakistani cultural context. Pakistani families often play a central role in providing support and assistance to individuals dealing with chronic illnesses, portraying the significance of familial and communal bonds in managing HF. This study highlights that the impact of chronic HF extends beyond the individual affected and touches the lives of their families as well. Several participants in this study shared how their illness had financial implications and increased the burden on their families in various ways. This reflects the findings of a similar study, which concluded that patients with chronic HF and their spouses often encountered challenging situations where the patients that they were felt burden on others due to their reliance for assistance in daily life, which was worrisome (Pihl et al., 2011).

Moreover, another study yielded similar results, emphasizing that participants' role disruptions and the perceived burden on their families, coupled with an inability to contribute financially, led to reduced self-esteem (Ming et al., 2011). In light of these findings, it becomes evident that a comprehensive approach to HF care in Pakistan should not only focus on the individual patient but also consider the broader familial and societal context. Such an approach can contribute to a more holistic and effective strategy for enhancing the HRQoL of HF patients and their families in Pakistan.

Moreover, a recurring concept emerged wherein many participants described significant life changes that resulted in a shift from independence to dependence on family members. This shift was primarily attributed to symptoms like fatigue and lethargy, which often made daily activities challenging. These findings are in alignment with existing literature, where individuals with HF not only face substantial physical limitations and sudden health deteriorations, but are also required to manage intricate treatment routines, adhere to strict self-care practices, and adapt to lifestyle alterations that profoundly affect their daily existence (Pyo et al., 2021). Consequently, both the experiences shared by our study participants and the insights from existing literature underscore the multifaceted and impactful nature of HF in the lives of individuals in Pakistan.

The study's findings illuminate a significant aspect of participants' lives, wherein they tend to avoid social gatherings and often confine themselves to their homes due to concerns about worsening their physical symptoms and potential complications. This apprehension is noteworthy in the light of research, which suggests that individuals with weaker social connections tend to have a poorer prognosis in cases of cardiovascular disease (Nicole et al., 2016). Moreover, it has been shown that social support plays an important role in predicting the prognosis of heart disease (Barth et al., 2010). However, further investigation is required to determine whether HF can lead to social isolation and feelings of loneliness. A salient finding from the current study revolves around the sense of restriction experienced by participants concerning outdoor activities and mobility. This limitation is reflected in similar findings in a study that underlines how individuals with chronic heart conditions, akin to those in the present study, often experience a significant life transformation. This transformation involves reduced engagement in daily activities, such as work and social interactions, and significant alterations in dietary habits (Ming et al., 2011). It is evident that this transformation can lead to a sense of confinement, underscoring the profound impact of health conditions on their overall lifestyle and experiences.

However, it is crucial to recognize that the current study also unveiled a remarkable sense of resilience and adaptability among the majority of participants. Despite the restrictions they faced, they exhibited notable flexibility, self-control, adaptability, and self-discipline. This resilience shows the strength and determination of HF patients in Pakistan, who strive to maintain their quality of life and well-being, even in the face of substantial challenges. This highlights the importance of a balanced approach to patient care that acknowledges the challenges they face while nurturing their resilience.

Moreover, the study also uncovered a prevalent sense of reduced self-esteem among participants, which they attributed to their heightened dependence on familial assistance and occasional exclusion from routine daily activities due to their HF condition. This sentiment aligns with a similar finding from a qualitative study conducted in Birmingham United Kingdom, , which emphasized the valuable practical and emotional support provided by family and friends (Thornhill et al., 2008). Expression of uncertainty about the future and questions the purpose of life and their experience underscores the importance of incorporating psychosocial support and counselling services into the healthcare system for HF patients, in Pakistan. Addressing these emotional and existential concerns can significantly enhance HRQoL.

In the present study, several participants expressed discomfort with their reliance on others, feelings of guilt for not being able to contribute to daily tasks, and, at times, a sense of being overwhelmed by the assistance they received. These sentiments mirror findings from various other studies (Friedman, 1993; Olano-Lizarraga et al., 2022; Saunders, 2012). Suggesting that the complex emotions surrounding dependence are not unique to the present study but are part of the broader experiences of HF patients. Moreover, the observed sense of reduced self-esteem and the intricacies surrounding dependence on family and friends among the Pakistani population may be deeply rooted in cultural and societal factors. In Pakistan, where family bonds hold immense importance, the perception of relying heavily on loved ones may impact one's self-worth. Additionally, constraints related to limited access to specialized care, awareness, and support systems, compared to Western countries, can compound these feelings of dependence.

Simultaneously, the study findings highlighted the significance of receiving support from family and friends. Several participants expressed that social connections can profoundly contribute to their overall well-being, emphasizing the importance of nurturing these relationships and engaging in meaningful social interactions for holistic health benefits. The existing research has also shown that children and other family members cannot fully substitute the level of support that a spouse can offer, in terms of home assistance. The support system, particularly the spouse, plays a pivotal role in home management and sustaining a high quality of life (Mårtensson et al., 1998). These new insights provide fresh perspectives on the indispensable role that spouses play in the well-being and daily life of HF patients. While the body of recent literature may be limited, these unique findings emphasize the necessity for further exploration and recognition of comprehensive care and support strategies tailored to the Pakistani cultural context. Such strategies should take into account for the vital role that spouses and social connections play in enhancing the HRQoL of HF patients in Pakistan.

The current study further showed that HF patients in Pakistan often turned to spirituality, sand spousal and family support as sources of solace and strength. These support systems play a pivotal role in helping patients navigate the emotional and physical challenges associated with their condition. Recognizing the significance of these support networks and integrating them into healthcare strategies can contribute to a more holistic approach to managing the care of HF.

In the current study, the findings also revealed that the majority of participants shared their experiences of finding solace and strength in close relationships. They emphasized the invaluable support provided by their family and friends, which reassured and empowered them. This is in line with a study conducted in Iran, which also yielded similar findings, highlighting that those who were well-adjusted to life's general circumstances, especially challenging situations, had more tranquillity, happiness, overall well-being, and fulfilling relationships (Ahmad et al., 2019).

Furthermore, the participants in the study discussed their coping strategies for managing the uncertainties and adjustments brought about by their medical conditions. These strategies revolved around seeking emotional support and developing resilience to effectively confront difficulties, while maintaining a focus on the present moment. Previous studies also suggest that the acceptance of an illness represents a pivotal factor influencing the outlook of individuals with HF (Obiegło et al., 2016). The participants also described the proactive steps that they took to navigate their changed lives, including focusing on positivity, educating themselves about HF, and accepting their feelings. Another study yielded similar findings, emphasizing that understanding these determinants can aid in optimizing patients' abilities and promoting their self-reliance (Iqbal et al., 2010). This suggests that individuals who have experienced HF have gradually come to terms with the necessary lifestyle modifications over time. These factors offer not only emotional solace and strength but also essential coping strategies to navigate the challenges associated with the condition. Incorporating these insights into healthcare strategies can lead to a more patient-centred and holistic approach to HF management.

This discussion highlights the need for a comprehensive and culturally sensitive approach to managing HF in Pakistan. Recognizing the financial and emotional burden on families, providing support for patients' shifting roles, and addressing the challenges associated with daily life are critical aspects that healthcare providers and policymakers should consider. By acknowledging and addressing these multifaceted impacts of HF, an effective strategy can be developed to improve the HRQoL of HF patients and their families in Pakistan. By acknowledging and building upon their strengths and adaptability, healthcare providers can work collaboratively with patients to enhance their HRQoL and empower them to lead fulfilling lives within the confines of their health condition.

Strengths of the study

The strengths of the study are as follows:

- As per the researcher’s limited knowledge, this is the first qualitative study in the context of Pakistan, where the concept of HRQoL was explored among HF patients through their perspectives.
- The results of this study revealed the importance of health among HF patients; moreover, the concept of HRQoL and its attributes among them has been explored.
- This study has provided a foundation for HF patients to understand their HRQoL and how to improve their quality of life after suffering from HF.

- The intentional inclusion of diverse participant groups, although it is noteworthy that the participants appeared to share similarities in age and marital status. Despite this apparent homogeneity, the deliberate consideration of various demographic factors, such as ethnicity, socioeconomic status, and educational background, ensures a nuanced exploration of perspectives.
- The study provides a base for future research on the HRQoL among HF patients and e for exploring their concepts, in the Pakistani context.

Limitations of the Study

The limitations of the study are as follows:

- The findings of this study cannot be generalized to other clinical settings or populations with different backgrounds, such as government or secondary care hospitals, as this study was only limited to one clinical setting of a private tertiary care hospital in Karachi, Pakistan, due to limited time and budget.
- Since the study primarily focused on patient perspectives, it may not provide a comprehensive view of HRQoL; additional research, involving healthcare providers and caregivers, could offer a more holistic understanding.
- The sexuality domain was not thoroughly explored, representing a notable gap in the study's scope.
- The study only explored the experiences of HF patients attending the outpatient clinic, while the perceptions of HF patients who were admitted were not investigated.

Recommendations

Based on the findings of this study, the following recommendations are proposed for different domains.

Clinical Practice

- Healthcare practitioners should conduct holistic assessments of HF patients, considering their physical, emotional, and social well-being. This comprehensive evaluation will enable a more patient-centered approach to care.
- Psychosocial support should be incorporated as an integral part of HF care. This includes providing counseling services, support groups, and resources for managing emotional challenges.
- Healthcare care staff should offer structured and ongoing education to HF patients and their families and ensure that they have a clear understanding of their condition, treatment options, self-care practices, and the importance of regular medical check-ups in the outpatient setting.
- Enhance collaboration among healthcare professionals, including nurses, physicians, dietitians, and social workers, to provide comprehensive care. A multidisciplinary approach can address the multifaceted needs of HF patients.
- Advocate for the integration of tailored assessments and the active involvement of advanced practice nurses in routine clinical evaluations, ensuring a more nuanced and specialized approach to patient care.

Nursing Education

- Encourage interprofessional education initiatives that bring together nursing, medical, and other healthcare students. This collaborative learning can prepare future practitioners for team-based care.
- Emphasize the development of effective communication skills that prioritize patient-centered care. Nursing staff and other HCPs should be trained to engage in empathetic and open dialogues with HF patients and their families.

- Design and implement focused educational programs tailored for healthcare professionals, aiming to enhance their knowledge and skills in specific areas. Disseminate these programs to ensure widespread access and participation, fostering continuous professional development within the healthcare community. Include cultural competency training to prepare HCPs for providing care to diverse populations of HF patients. Understanding of cultural barriers can enhance the quality of care.

Nursing Research

- Since the study explored the perceptions and experiences of HF patients attending out-patient departments, in Pakistan, regarding the concept of HRQoL and its attributes, the exploration of the same phenomenon for in-patients is recommended.
- Further research should aim to provide a more comprehensive understanding of the specific attributes of HRQoL in HF patients, enabling the development of targeted interventions and strategies to enhance their quality of life.
- Addressing the noted limitation related to the sexuality domain, future research could dedicate specific attention to the exploration of this aspect. This could involve incorporating specialized instruments, conducting focused interviews, or collaborating with experts in sexual health to ensure a thorough investigation of this important domain.
- Future research could implement randomized controlled trials to evaluate the effectiveness of specific nursing interventions. This would involve randomly assigning participants to different groups, allowing for a rigorous examination of causal relationships between nursing interventions and outcomes.

Summary of the Chapter

This chapter explored the findings of a qualitative study conducted among HF patients in Karachi, Pakistan. It identified two main themes: "HF Patients' Perception of Health" and "Attributes of HRQoL in HF." The study emphasized the significance of good health, gratitude, and family support for these patients. It also highlighted challenges related to role adjustments and lifestyle changes. Further, the chapter discussed the study's strengths, and limitations, and offered recommendations for clinical practice, education, and future research. Overall, it underscored the importance of patient-centred care and improving HRQoL in HF patients in Pakistan.

Conclusion of the Study

This study is probably the first qualitative interpretive study conducted in Pakistan that explored the concept of HRQoL in HF patients. This study was based on two research questions: “How do HF patients perceive the concepts of HRQoL in Karachi Pakistan? And, what attributes indicate the HRQoL of people with HF in Karachi, Pakistan?” The findings of this study illuminated several crucial insights with respect to the perceptions and experiences of HF patients regarding their HRQoL. Two overarching themes emerged from the data analysis: "HF Patients' Perception of Health" and "Attributes of HRQoL in HF."

This study has shed light on the lived experiences and perceptions of HF patients regarding their HRQoL. The findings emphasize the intricate interplay between physical health, mental well-being, and interpersonal relationships in shaping HRQoL among HF patients. The insights gained from this study have significant implications for clinical practice, clinical education, and nursing research, as discussed in the recommendations. Ultimately, this research has contributed to a deeper understanding of the challenges and opportunities in improving HRQoL for HF patients in Pakistan.

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List of Appendices

Appendix A. Informed Consent English Version

Title of Study: “Concept of Health-Related quality of life among people with Heart Failure in Karachi, Pakistan”.

ERC application No: **8165**	**Dr. Khairulnissa Ajani** Assistant Professor & Assistant Dean AKU-SONAM **Thesis Supervisor** Khairulnnisa.ajani@aku.edu **+92 21 3486-5411**
Ms. Anny Ashiq Ali MScN Student, AKU-SONAM **Co-Investigator** anny.ashiq@scholar.aku.edu Contact number: 03222033639	**Ms. Ambreen Gowani** Senior Instructor AKU-SONAM **Co-Supervisor** ambreen.gowani@aku.edu **+92 21 34865283**

Introduction:

I **Anny Ashiq**, student of Master of Science in Nursing (MScN) at the Aga Khan University School of Nursing and Midwifery (AKU-SONAM). As part of my thesis, I am interested in conducting a study to determine the “Concept of Health-

Related quality of life among people with Heart Failure in Karachi, Pakistan" in Cardiac clinic of outpatient department (OPD) at AKUH.

Purpose of the study:

The purpose of the study to explore and understand the depth of the meaning of HRQOL among heart failure patients in tertiary care hospital at AKUH Karachi Pakistan.

Procedure:

As a participant your interview will be conducted where you are requested to answer the questions. The questions are divided into two parts: **Demographi**c details and the questions about concept of HRQOL in depth from the heart failure patients in cardiac clinic out patient department (OPD) AKUH. Your participation in this research is voluntary. If you consent to participate then the date, time and venue for the interview will be decided based on your availability and convenience. The interview will be conducted as per your preference of language, i.e., English or Urdu. The interview time is expected to be 40-60 minutes. Simultaneously, the interview will be recorded.

Possible Risk:

There are no potential harms, risk, or threats to any participants associated with this study. You might feel a sense of distress for being interviewed. To relief your discomfort and to enhance the comfort you will be allowed to ventilate about it. Also, you have right to refuse answering any question that you are not comfortable to answer. You can also refuse to continue with the interview.

Benefits:

There will be no monetary compensation provided to you for your participation**.** This study is for academic purposes only.

There will be no direct benefit to you, but your participation is likely to help us explore the concepts of health-related quality of life and factors facing by heart failure patients and addressing their issues specifically in Pakistan, so that it may serve as the initial step for timely intervention in the future.

Financial considerations

There is no payment to participate in this study and will not receive any payment for participation.

Right of refusal to participate and withdrawal

You do not have to take part in this research if you do not wish to do so and choosing to participate will not affect in your care. You may stop participating in the interview at any time you may wish. If you are uncomfortable answering any question, you have the right to refuse.

Confidentiality:

Your privacy will be ensured throughout the duration of the study. Moreover, all the collected data will be kept in locked cabinets, and data in soft copies will be secured by a password. The data will only be accessible to the principal investigator and committee members. However, the monitoring and evaluation team of human ethics committee, AKU may review the data for quality assurance.

Right to ask questions:

If you have any queries or questions related to the study or consent form, kindly contact Ms. Anny Ashiq Ali at Aga Khan University School of Nursing and Midwifery on cellphone number:**03222033639** or email address: anny.ashiq@scholar.aku.edu

Authorization

I have read and understand this consent form, and I volunteer to participate in this research study. I understand that I will receive a copy of this form. I voluntarily choose to participate, but I understand that my consent does not take away any legal rights in the case of negligence or another legal fault of anyone who is involved in this study.

Name of participant (Printed or Typed): ___________________

Date: ____________________

Signature of participant: _______________________

Date: _____________________

Signature of Principal Investigator: ________________________

Date: ____________________

Name and Signature of the person obtaining consent: ___________________

Date: ______________________

For Participants unable to read

Witness:

I have witnessed the accurate reading of the consent form to the potential participants, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Witness Name: _____________________ Participant's Thumb Print: __________________

Signature: ___________________________

Date:________________________________

Appendix B. Infromed Consent Urdu Version

تحریری رضامندی

مطالعے کا عنوان: کراچی، پاکستان میں حرکت قلب رک جانے کے حامل مریضوں میں صحت سے متعلق معیار زندگی کا تصور

اخلاقی جائزہ کمیٹی درخواست نمبر:8165	**ڈاکٹر خیرالنساء اجانی،** اسسٹنٹ پروفیسر و اسسٹنٹ ڈین، آغا خان یونیورسٹی اسکول آف نرسنگ اینڈ مڈوائفری **مقالہ کے سپروائزر** khairulnnisa.ajanni@aku.edu +92 21 3486 5411
آنسہ عینی عاشق علی طالبہ ماسٹر آف سائنس ان نرسنگ آغا خان یونیورسٹی اسکول آف نرسنگ اینڈ مڈوائفری **شریک تحقیق کار** anny.ashiq@scholar.aku.edu رابطہ: 0322 2033 639	**آنسہ عنبرین گوانی** سینئر انسٹرکٹر آغا خان یونیورسٹی اسکول آف نرسنگ اینڈ مڈوائفری **شریک سپروائزر** ambreen.gowani@.aku.edu رابطہ: +92 21 3486 5283

تعارف:

میرا نام عینی عاشق علی ہے اور میں آغا خان یونیورسٹی اسکول آف نرسنگ اینڈ مڈوائفری میں ماسٹر آف سائنس ان نرسنگ کی طالبہ ہوں۔ اپنے مقالے کے حصے کے طور پر، میں آغا خان یونیورسٹی ہسپتال میں آؤٹ پیشنٹ شعبے کے کارڈیاک کلینک میں " کراچی، پاکستان میں حرکت قلب رک جانے کے حامل مریضوں میں صحت سے متعلق معیار زندگی کے تصور " کا تعین کرنے کے لئے ایک مطالعہ کررہی ہوں۔

مطالعے کا مقصد:

مطالعےکا مقصد ثانوی درجےکی دیکھ بھال کے ہسپتال آغا خان یونیورسٹی ہسپتال، کراچی، پاکستان میں حرکت قلب رک جانے کے حامل مریضوں میں صحت سے متعلق معیار زندگی کے معنی کی گہرائی سمجھنے اور اس کی چھان بین کرنا ہے۔

طریقہ جات:

مطالعے کا مقصد حاصل کرنے کے لئے، آپ سے ایک انٹرویو میں شریک ہونے کی درخواست کی جاتی ہے جس میں آپ کو حرکت قلب بند ہونے کے بارے میں چند سوالات کے جوابات دینے کی دعوت دی جاتی ہے۔ یہ انٹرویو ہماری مشترکہ اتفاق رائے سے کلینک میں واقع ایک آرام دہ جگہ پر کیا جائے گا۔ اگر انٹرویو کے دوران آپ کسی بھی سوالات کا جواب نہ دینا چاہیں تو آپ ان کے لئے نہیں کرسکتے ہیں اور میں دوسرے سوال پر چلی جاؤں گی۔ ماسوائے میرے بہ حیثیت ایک تحقیق کار اور انٹرویور کوئی موجود نہیں ہوگا۔ انٹرویو کا پہلا حصہ شماریاتی تفصیلات اور آغا خان یونیورسٹی ہسپتال میں آؤٹ پیشنٹ شعبے کے کارڈیاک کلینک میں حرکت قلب رک جانے کے حامل مریضوں میں صحت سے متعلق معیار زندگی کے تصور پر تفصیلی سوالات پر مشتمل ہوگا۔ اس تحقیق میں آپ کی شرکت رضاکارانہ ہے۔ اگر آپ شرکت پر رضامند ہوتے ہیں تو آپ کی دستیابی اور آسانی پر مبنی انٹرویو کی تاریخ، وقت اور جگہ کا فیصلہ کیا جائے گا۔ انٹرویو آپ کی تجویز کردہ زبان میں کیا جائے گا یعنی انگریزی یا اردو میں۔ انٹرویو کا ممکنہ دورانیہ چالیس سے ساٹھ منٹ ہوگا۔ اس کے ساتھ ساتھ، انٹرویو ریکارڈ بھی کیا جائے گا۔

ممکنہ خطرات :

اس مطالعے سے منسلک کسی بھی شرکاء کو کوئی نقصان، خطرہ یا خوف کا اندیشہ نہیں ہے۔ اسکے علاوہ آپ کو کسی بھی سوال کا جواب دینے سے انکار کا حق حاصل ہے جو آپ کے لئے تکلیف دہ ہو۔ آپ انٹرویو جاری رکھنے سے بھی انکار کرسکتے ہیں۔

فوائد:

آپ کی شرکت کے لئے آپ کو کوئی مالی معاوضہ فراہم نہیں کیا جائے گا۔ یہ مطالعہ صرف اکادمی مقاصد کے لئے ہے۔

آپ کو براہ راست کوئی فائدہ حاصل نہیں ہوگا لیکن آپ کی شرکت سے حرکت قلب رک جانے والے مریضوں میں صحت سے متعلق معیار زندگی کے تصور ات کی اور ان کو درپیش عوامل کی چھان بین میں ہمیں مدد حاصل ہونے کا امکان ہے خاص طور سے پاکستان میں ان مریضوں کے مسائل پر توجہ دینے کا، تاکہ یہ مستقبل میں بروقت علاج کے لئے ابتدائی قدم ثابت ہوسکے۔

مالی معاوضہ جات:

اس مطالعے میں شرکت کے لئے آپ کو کوئی ادائیگی نہیں کی جائے گی۔

شرکت سے انکار اور دستبردار ہونے کا حق:

اگر آپ نہ چاہیں تو آپ کو اس تحقیق میں حصہ لینے کی ضرورت نہیں ہے اور شرکت کا انتخاب نہ کرنا آپ کی دیکھ بھال پر اثرانداز نہیں ہوگا۔ اگر آپ چاہیں تو انٹرویو میں اپنی شرکت کسی بھی وقت روک سکتے ہیں۔ اگر کسی سوال کا جواب دینے میں آپ کوئی بے چینی محسوس کریں تو آپ کو جواب نہ دینے کا حق حاصل ہے۔

رازداری:

آپ کی خلوت مطالعے کی تمام تر دورانئے میں یقینی بنائی جائے گی۔ اس کے علاوہ، آپ سے اکٹھا گیا تمام معلوماتی مواد مقفل کیبنٹ میں رکھا جائے گا اور اس مواد کو سافٹ کاپی میں پاس ورڈ کے ذریعے محفوظ کیا جائے گا۔ اس مواد تک صرف مرکزی تحقیق کار اور کمیٹی کے ممبران کو رسائی حاصل ہوگی۔ البتہ، آغا خان یونیورسٹی کی اخلاقی جائزہ کمیٹی کے نگرانی اور جائزہ ٹیم معیار کی یقین دہانی کے لئے مواد کا جائزہ لے سکتی ہے۔

سوالات کرنے کا حق:

اس مطالعے سے متعلق یا رضامندی فارم سے متعلق آپ کوئی سوالات کرنا چاہیں یا کوئی استفسارات ہوں تو براہ مہربانی آنسہ عینی عاشق علی سے ، آغا خان یونیورسٹی اسکول آف نرسنگ اینڈ مڈوائفری میں، سیل فون 0322 2033 639 پر یا ای میل anny.ashiq@scholar.aku.edu سے رابطہ کیجئے۔

اجازت نامہ

میں نے اس رضامندی کے فارم کو پڑھا اور سمجھا ہے ، اور میں رضاکارانہ طور پر اس تحقیقی مطالعے میں حصہ لیتا ہوں۔ میں سمجھتا ہوں کہ مجھے ا س فارم کی ایک نقل فراہم کی جائے گی۔ میں نے رضاکارانہ طور پر حصہ لینے کا انتخاب کیا ہے ، لیکن میں سمجھتا ہوں کہ اس مطالعے میں شامل کسی بھی شخص کی غفلت یا دیگر قانونی غلطی کی صورت میں میری رضامندی کسی بھی قانونی حق سے محروم نہیں کرتی ۔

شرکت کنندہ کا نام: ____________________ دستخط: ____________________
تاریخ: ______________

مرکزی تحقیق کار کے دستخط: ________________________ تاریخ: ______________

Appendix C. Study Guide English Version

Interview Guide

Research Project:

Exploring the concepts of health-related quality of life for patients with Heart Failure

Interview questions:

1. In your opinion, what does health mean to you?
2. Tell me about your experience after diagnosing heart failure?
3. What are your perceptions about health-related quality of life in a person's life?

   Probes:

   - what gives your life quality?
   - Have you ever heard the term health-related quality of life?
   - What does it mean to you?
   - What do you think it's component?

4. How do you feel about your general health after diagnosing with heart failure?

   Probes: Tell me your experiences, how did heart failure affect your overall life or activities of daily living? Physical, social, and psychological.

5. How did heart failure affect your life?
6. What is it like to be living with heart failure?
7. What aspects of your life are most affected by your illness?
8. What are your challenges while living with heart failure?

Appendix D. Study Guide Urdu Version

انٹرویو گائیڈ

تحقیقی پروجیکٹ: حرکت قلب رک جانے کے حامل مریضوں میں صحت سے متعلق معیار زندگی کے تصورات کی چھان بین

انٹرویو کے سوالات:

1- آپ کے رائے میں، آپ کے لئے صحت کیا معنی رکھتی ہے؟

2- حرکت قلب رک جانے کی تشخیص ہوجانے کے بعد مجھے اپنے تجربے کے بارے میں بتائیے؟

3- صحت سے متعلق معیار زندگی کے بارے میں آپ کے کیا احساسات ہیں؟

چھان بین:

- آپ کی زندگی کو کیا چیز معیار پیش کرتی ہے؟
- کیا آپ نے کبھی صحت سے متعلق معیار زندگی کی اصطلاح کے بارے میں سنا ہے؟
- آپ اس کو کن معنی میں لیتے ہیں؟
- آپ اس کا جزو ترکیبی کیا سمجھتے ہیں؟

4- حرکت قلب رک جانے کی تشخیص ہوجانے کے بعد آپ اپنی عام صحت کے بارے میں کیسا محسوس کرتےہیں؟

چھان بین:

اپنے تجربات کے بارے میں بتائیے، حرکت قلب رک جانے کی بیماری نے آپ کی جملہ زندگی یا روزمرہ رہن سہن کے سرگرمیوں کو متاثر کیا ؟ جسمانی، سماجی اور نفسیاتی طور پر۔

5- حرکت قلب رک جانے کی بیماری نے آپ کے معیار زندگی کو کیسے متاثر کیا ہے؟

6- حرکت قلب رک جانے کی بیماری کے ساتھ رہنا کیسا ہے؟

7- آپ کی بیماری سے آپ کی زندگی کے کون سے پہلو سب سے زیادہ متاثر ہوئے ہیں؟

8- حرکت قلب رک جانے کی بیماری کے ساتھ آپ کو کن چیلنجز کا سامنا ہے؟

چھان بین:

سرگرمیوں کی ، غذا، سماجی زندگی ، خاندان کی زندگی

Appendix E. Demographic Form English

Socio-Demographic Tool

Research Project:

Exploring the concepts of health-related quality of life for patients with Heart Failure

Serial Number ________________________

Interview Date: _______________________________

Interview start time: __________________________

Interview end time: ______________________________

Ethnicity: ________________________

Gender: (please tick)

Female ☐ **Male** ☐

General Demographic Information

Age: ☐ years

Level of Education: ☐ No formal education ☐ Primary education

☐ Secondary Education ☐ Intermediate ☐ Diploma/Degree

Occupation: __________________________________

Religion: _____________________________________

Marital Status: ☐ Married ☐ Unmarried ☐ Widowed

Years of marriage: _________________________________

Number of children: ________________________________

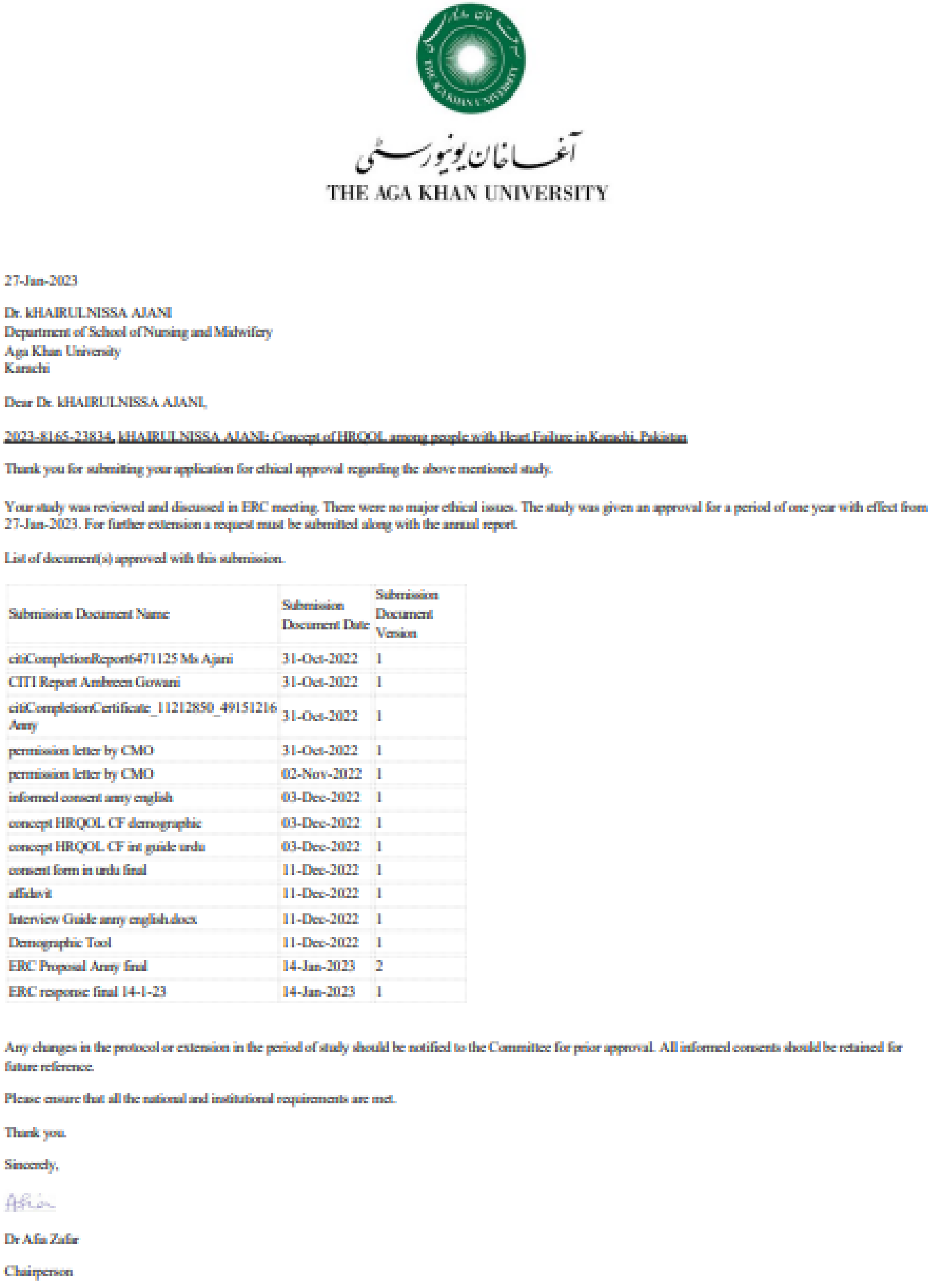
Residence: __________________________________

Occupation: ________________________________

Total Household Income: _________________________________

Type of family: ☐ Joint Family ☐ Nuclear Family

Appendix F. ERC Approval



آغا خان یونیورسٹی
THE AGA KHAN UNIVERSITY

27-Jan-2023

Dr. kHAIRULNISSA AJANI
Department of School of Nursing and Midwifery
Aga Khan University
Karachi

Dear Dr. kHAIRULNISSA AJANI,

2023-8165-23834, kHAIRULNISSA AJANI: Concept of HRQOL among people with Heart Failure in Karachi, Pakistan

Thank you for submitting your application for ethical approval regarding the above mentioned study.

Your study was reviewed and discussed in ERC meeting. There were no major ethical issues. The study was given an approval for a period of one year with effect from 27-Jan-2023. For further extension a request must be submitted along with the annual report.

List of document(s) approved with this submission.

Submission Document Name	Submission Document Date	Submission Document Version
citiCompletionReport6471125 Ms Ajani	31-Oct-2022	1
CITI Report Ambreen Gowani	31-Oct-2022	1
citiCompletionCertificate_11212850_49151216 Amy	31-Oct-2022	1
permission letter by CMO	31-Oct-2022	1
permission letter by CMO	02-Nov-2022	1
informed consent amy english	03-Dec-2022	1
concept HRQOL CF demographic	03-Dec-2022	1
concept HRQOL CF int guide urdu	03-Dec-2022	1
consent form in urdu final	11-Dec-2022	1
affidavit	11-Dec-2022	1
Interview Guide amy english.docx	11-Dec-2022	1
Demographic Tool	11-Dec-2022	1
ERC Proposal Amy final	14-Jan-2023	2
ERC response final 14-1-23	14-Jan-2023	1

Any changes in the protocol or extension in the period of study should be notified to the Committee for prior approval. All informed consents should be retained for future reference.

Please ensure that all the national and institutional requirements are met.

Thank you.

Sincerely,

Dr Afia Zafar

Chairperson

Appendix G. Permission Letter

آغا خان یونیورسٹی
THE AGA KHAN UNIVERSITY

Dated: October 25, 2022

Title: Concept of HRQOL among people with Heart Failure in Karachi, Pakistan

Principal Investigator: Dr. Khairulnissa Ajani
Assistant Professor, School of Nursing
Aga Khan Hospital
Karachi

The above-entitled study is a descriptive interpretive qualitative study in the Aga Khan University Hospital, Karachi.

As Chief Medical Officer at the Aga Khan University Hospital, Karachi, I approve the above named study to be conducted within the Hospital, following required approvals and maintaining compliance with all Institutional ethical and regulatory requirements

Asim F. Belgaumi,
Professor, Pediatric Hematology & Oncology,
Department of Oncology.
Chief Medical Officer,
Associate Dean for Clinical Affairs
Aga Khan University Hospital.

Stadium Road, P. O. Box 3500, Karachi 74800, Pakistan
Telephone: +92 21 3493 0051, Fax: +92 21 3493 4294 / 3493 2095, Website: www.aku.edu