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PATIENTS WITH HEART FAILURE – A QUALITATIVE STUDY

by

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DISSERTATION

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for the degree of Doctor of Philosophy at
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Supervising Committee:

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ABSTRACT

PATIENTS WITH HEART FAILURE – A QUALITATIVE STUDY

People living with heart failure manage their diagnosis in diverse ways. The lived experiences of qualitative study participants are valuable for helping healthcare providers understand patient perspectives. When interviewed, the themes expressed by people living with heart failure aligned with the resilience theory by Greene (2002). Healthcare providers can use this theory to guide questions when interviewing people with heart failure and designing effective plans of care for this group of patients. Participants with heart failure were recruited for the phenomenological research project using ResearchMatch.org - an online volunteer organization of people with a variety of healthcare conditions and word of mouth. As a result of their willingness to take part in earlier studies, a few were approached directly. Fourteen individuals consented, provided demographic information, and were willing to engage in semi-structured interviews. The interview data was sorted using an inductive approach. The analysis revealed seven themes: (a) negative reactions of the patient, (b) positive reactions of the patient (with subthemes), (c) self-determination, (d) adherence to doctor's orders, (d) what helps you manage, (e) what makes managing worse, and a (f) sense of humor. These themes and their subthemes align with Greene's (2002) resilience theory. The participants had varying perspectives related to their living with heart failure and how they managed their health condition. New treatment plans can incorporate these findings in novel interventions to build resilience in people living with heart failure. Healthcare providers can incorporate the patients' beliefs and facilitate ways to improve quality of life for patients with heart failure.

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DEDICATION

I dedicate this Ph.D. dissertation to my family and friends who have supported me for the past four years and beyond. I appreciate you all so much! A special dedication to my father, Don Moore, who inspired the idea of this research project to help me to understand the experiences of those living with heart failure so we can one day develop innovative interventions to help improve their lives.

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CHAPTER 1

Introduction

The objective of this qualitative study was to describe resilience in adults with heart failure (HF). Few studies exist that examine resilience in this patient population. The purpose of this research was to explore how older adults with HF manage their diagnosis and to discover common themes that emerged that suggest resilience as a coping mechanism. Findings will add valuable information about how these patients manage daily life with HF. Learning more about the lived experiences of people with HF

can contribute to the development of effective therapies to build their resilience and improve their quality of life.

Background and Significance of the Problem

Almost six million people in the United States (U.S.) have HF and more than 900,000 people are diagnosed yearly (American Heart Association, 2017d). In people over age 65, HF is the leading cause of hospitalizations (Cleveland Clinic, 2021). We can learn from those who are resilient and teach these techniques to others living with HF to improve their quality of life. In the U.S., those older than age 65 with HF have a 30-day hospital readmission rate of 26.9% of total readmission rates, which is the highest among surgical and medical-related conditions (Nair et al., 2020). Cardiac failure overshadows all other organ-related problems in older adults, including cancer, lung, and infection-related diseases (Bellumkonda et al., 2017).

Researchers have emphasized the importance of studying this medical problem to prevent further decline in people with HF (American Heart Association, 2023a; Bellumkonda et al., 2017; Kojima et al., 2019). Considering the population of people with HF may grow in the future, it is imperative to understand the needs of people with HF so they can live their lives to the fullest.

Heart Failure

HF has been defined as a weakened heart that cannot meet the body's demands (AHA, 2023b). This condition affects one to two percent of the worldwide population (Schwinger, 2021). Causes and phenotypes vary dramatically in HF. Possible causes include cardiac injuries such as myocardial infarction, increased afterload or preload, and structural, cellular, and neurohumoral changes.

How Heart Failure is Diagnosed

Diagnosis of HF is made through various methods (Schwinger, 2021). Cellular dysfunction is measured by levels of norepinephrine, a neurohormone, and levels of natriuretic peptides (e.g., N-terminal pro b-type natriuretic peptide, NT-proBNP) that are increased and are shown in lab results (Schwinger, 2021). Several diagnostic procedures are done to diagnose HF, which include a non-invasive echocardiogram, NT-proBNP (blood tests), and diagnostic procedures such as heart catheterization and biopsy (Schwinger, 2021), MRI, chest x-ray, physical exam, and an exercise stress test (AHA, 2017c).

Ejection Fraction Defined

Ejection fraction (EF) measures the amount of blood pumped out of the left ventricle with each contraction (AHA, 2022b). In other words, EF "compares the amount of blood in the heart to the amount of blood pumped out of the heart," which describes how well the heart is delivering blood to the rest of the body (AHA, 2023a). The normal EF is 50-70%. People with HF with preserved ejection fraction, also known as HFpEF, can have a normal EF of 50-70% but due to thickening and stiffness of the heart muscle, the ventricle holds a smaller than normal amount of blood and does not pump enough blood out to meet the needs of the body (AHA, 2017). HF with reduced EF is also called HFrEF and means that 40% or less of the blood in the ventricle is pumped out with each contraction (AHA, 2017). An EF of less than 40% may indicate HF or cardiomyopathy where the heart muscle becomes enlarged, rigid, or thick and, on rare occasions, may result in scar tissue development (AHA, 2022b). In some extreme cases, EF can be very low or very high such as 75%, indicating hypertrophic cardiomyopathy (AHA, 2022b).

Differences Between HFrEF and HFpEF Phenotypes

HFpEF and HFrEF are the two types of left-sided HF. HFrEF, also known as systolic HF, is when the heart muscle cannot contract effectively, resulting in less oxygen-rich blood pumped to the body (AHA, 2022b). HFpEF, also known as diastolic HF, occurs when “the heart muscle contracts normally, but the ventricles do not relax as they should during ventricular filling” due to stiffness (AHA, 2022b).

Types of Heart Failure

Acute right-sided HF may result if the right coronary artery is completely occluded and there are no collaterals. Left-sided HF, HFrEF or HFpEF, is a problem with the pumping ability of the left ventricle, leading to cardiac stiffness. With the failure of the left ventricle, there is an increase in fluid pressure in the lungs. Pumping power is reduced in the right side of the heart. As a result, blood backs up into the body's veins and can cause leg and ankle swelling, congestion, and abdominal swelling in the liver (causing ascites) and GI tract (AHA, 2022b1). It is crucial to determine the type of HF a person has before prescribing treatment (AHA, 2017b).

NYHA Classification of Heart Failure

Patients exhibit symptoms that can be used to help classify how sick they are. For example, patients with HF may have difficulty with everyday activities like walking, climbing up a flight of stairs, or carrying groceries. Some people with HF suffer from fatigue, dyspnea, and coughing (AHA, 2022c). The New York Heart Association (NYHA) classification helps healthcare practitioners determine the severity of HF in individuals (AHA, 2017a; Castro et al., 2019; Reuben et al., 2019; Norberg et al., 2014). As observed in Figure 1, the NYHA classification stratifies patients based on the severity of their patients' symptoms while engaging in physical activity.

Figure 1

NYHA Classification

Class I	No limitations with PA
Class II	Slight limitation with PA
Class III	Marked limitation with PA
Class IV	Inability to carry on PA without discomfort, symptomatic at rest.

Note. PA = physical activity.

Adapted from *Classes of Heart Failure* by the American Heart Association, 2017 (https://www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/classes-of-heart-failure). Copyright 2017 by the American Heart Association.

Limitations from Heart Failure

HF limitations include dyspnea, palpitations, and fatigue. NYHA Class I is defined as physical activity with no limitations, Class II is defined as slight limitation during physical activity, Class III is defined as a marked limitation during physical activity, and Class IV is defined as the inability to carry on physical activity without discomfort, and the patient is symptomatic at rest (AHA, 2017a). As the investigator, I asked participants about their symptoms to give context to the progression of their HF condition. The interview guide included specific questions to ask study participants about their symptoms. Questions eight and thirteen are examples of the detail in these questions. Question eight asked, “What physical symptoms do you have related to heart failure and how do they impact your life? (Probe about shortness of breath, fatigue, difficulty walking long distances, attending social events, not being able to do the things they enjoy – travel, picking up/helping with grandkids, etc.) What matters most to you?” Question thirteen asked, “Do you see your condition improve when you follow those directions (self-efficacy concept)? (Have you been able to follow directions from your Dr. and have those things made a difference in living with heart failure)? i.e., do you limit salt and or exercise, and if so, what happens?”

Resilience Concept

Resilience has become a popular word to describe how patients cope with chronic illness; however other terms have been used to describe this concept in the past, such as the ability to bounce back from adversity (Rutter, 1985), coping, managing, and many other descriptors. Earvolino-Ramirez (2007) wrote a concept analysis on resilience and described the history of resilience as a concept. She stated that the beginning literature on resilience evolved from resilience in children who had suffered trauma and later became a concept used for other populations (Earvolino-Ramirez, 2007). The evolution of resilience fell under the umbrella of human behavior theory (Greene, 2002).

History of Resilience

Resilience has been studied in children, specifically those raised under challenging circumstances (Rutter, 1985). Other researchers have described resilience as a reaction to risk, vulnerability, and a protective factor (Greene, 2002). In seminal research on resilience, Rutter (1985), describes how a person’s experiences can shape psychiatric disorders. He states that individual differences in how people respond to life challenges and individual differences in reactions to stressful events can be influenced by genetics and the environment.

Tusaie and Dyer (2004) described the history of resilience as a concept and stated that literature began in the 1800s on this topic. They summarize how resilience evolved from two distinguishable psychological and physiological aspects. Psychological aspects were called unconscious defense mechanisms during the 1800s-1950s, coping (a conscious process) in the 1960s, and protective/risk factors in the 1980s (Tusaie & Dyer, 2004). Concurrently, physiological aspects included the terms homeostasis in the 1920s, emotional stress and morbidity in the 1950s, brain plasticity in the 1970s, psychoneuroimmunology in the 1980’s; then, in the 1990’s, the merging of these psychophysiological concepts resulted in the term resilience being coined (Tusaie & Dyer, 2004). Several researchers agree that resilience is a dynamic process that changes as a person grows and gains more experience in life. How an individual responds to life stresses depends upon the person’s prior experiences (Greene, 2002; Rutter, 1993; Tusaie & Dyer, 2004).

Resilience Defined

Veradhan et al. (2018) define resiliency as a person's ability to recover from a stressor. They also describe resiliency as being pushed into a condition far from their original state of equilibrium while maintaining the ability to function.

Resilience in Chronic Illness

Many researchers have used resilience as a concept to describe how individuals respond to living with chronic illness, and the concept has been adapted to many patient populations

(Battalio et al., 2020; Gheshlagh et al., 2016; Jenson et al., 2020; Manning et al., 2016; Matheson et al., 2016; Tecson et al., 2019). Battalio et al. (2020) and Jensen (2020) examined resilience in patients with chronic physical disabilities. Manning et al. (2016) studied how resilience may alter the effects of chronic illness with age. Matheson et al. (2016) described resilience in professionals working in challenging healthcare environments. Tecson et al., (2019) measured resilience in older adults with congestive HF who were 57-77 years old and found resilience was highly significant for psychological distress and happiness after controlling for demographic, social, and clinical factors.

Other populations that have been studied for resilience include women with chronic diseases such as Sjogren's disease (Priori et al., 2021) and rheumatic diseases (Rojas et al., 2018). Resilience has also been studied in people with cancer (Cohen et al., 2014) and people with colorectal cancer (Chou et al., 2022; Nakazawa et al., 2018). Military members with traumatic brain injury are another population where resilience has been studied (Reid et al., 2018).

Gheshlagh et al. (2016) performed a meta-analysis and a systematic review of the resilience scores of 3,369 individuals living with chronic disease. This meta-analysis revealed differences in how resilience was defined for those with chronic conditions, leading to problems when measuring resilience. These reviewers identified 15 measurement tools that were used across the studies, of which 10 can be used in clinical situations. The reviewers also found variance in the concept of resilience too broad for one scale to measure. Therefore, Gheshlaugh et al. (2016) decided to use percentages derived from the mean scores of the tools they measured.

Several tools were reviewed for the Gheshlagh et al. (2016) meta-analysis, such as the Conner Davidson Resilience Scales with 10 and 25 items, also known as the CD-RISC10 and

CD-RISC25, and the Resilience Scale with 25 items, also referred to as the RS25 (Wagnild & Young, 1993). For example, when using three tools "CD-RISC10 (72.5%), CD-RISC25 (60.5%), and RS25 (66.8%), the scores were expressed as percentages. The highest score (98.6) was found in the European studies, and the lowest (27.5) was found in the Australian studies, 95% CI: 55.6 - 141.5 and 23.7 - 31.3, respectively (Gheshlaugh et al., 2016, p. 4). The reviewers correlate a higher resilience score with greater resilience. The mean score for resilience in patients with chronic disease was 74.6 (95% CI: 51.8 - 97.4), and the mean resilience score for patients with cardiovascular disease was 79.6 (95% CI: 45.8 – 113.3). Findings reveal that the mean scores for resilience in people with chronic diseases were less than those of healthy individuals. However, the reviewers found that resilience can be taught at “any stage of life” (Gheshlagh et al., 2016, p. 1) regardless of age or disease status and suggest the use of educational programs for building resilience in individuals with chronic diseases.

Several researchers in similar studies explored relationships between resilience and other variables. Jones et al. (2019) studied spirituality and resilience in people with spinal cord injuries. Clark et al. (2019) studied the relationship between age and resilience in those with colorectal cancers.

Resilience in Patients with Heart Failure

People with HF handle their diagnosis in different ways. Resilience was defined in a meta-analysis by Fontes and Neri (2015) and has been referred to by various descriptors such as adaptive functioning, coping, self-belief, emotional regulation, and self-efficacy. Fontes and Neri also describe emotional regulation as related to social support. The authors also suggest that as people age, they increase their capacity for resilience.

Resilience as a concept interested me because I wanted to discover what makes a person with a HF diagnosis resilient. The concept is embedded in theories that support a person’s ability to cope with a chronic illness. In the field of social work, it has become a popular concept used to describe how patient populations manage, cope, and live with chronic conditions (Greene, 2002).

Psychological Resilience

Resilient individuals have effective stress management strategies to manage health (Luciano et al., 2020). Thus, resilience can define how well individuals recover from adverse events and sustain a sense of well-being while living with ongoing challenges (Luciani et al., 2020). Whitson et al. (2018) defines psychological resilience as a person's ability to respond favorably in situations of adversity, significant stress, tragedy, and trauma. Several authors hypothesized that if one’s psychological resilience is improved, one will be better able to cope with the demands of a difficult situation or diagnosis (Luciano et al., 2020; Whitson et al., 2018).

Healthcare practitioners can also dive deeper into the stressors that affect people with HF. The patients with HF who have successfully managed self-care behaviors related to their HF can share their strategies with those who struggle to manage their HF. Learning how to best build resilience in patients with chronic health conditions, such as HF, is an area of study that requires further development (Cleveland Clinic, 2021). Before asking patients with HF how they define resilience, it is essential to ask the participants to describe the stressors that they experience. This research is important because psychological thought processes that motivate resilience are poorly understood in this population.

Theoretical Framework

A theory can help to create a framework for questions asked in a qualitative interview (Munhall, 2012). According to Papathanasiou et al. (2013), holistic care treats patients as multidimensional beings who deserve treatment as individuals with mind, body, and spiritual needs. Papathanasiou et al. state that it is essential to consider an individual's psychological, sociological, and physical needs. This project used the resilience theory developed by Greene (2002) as the framework for this research study about the experiences of resilience in patients with HF.

I believed that resilience was a defining factor in how some patients manage their HF diagnosis. In practice, I have seen how people with HF respond favorably to interventions when they have a positive attitude and recognize their past successes. For example, some study participants doing exercise training (walking on a treadmill or riding an exercise bicycle three days a week for one hour) to increase their stamina, state that they feel better, and have more energy since they have been exercising.

Resilience Theory

Within the resilience theory, Greene (2002) defines resilience as "unpredicted or markedly successful adaptation of individual to negative life events, trauma, stress, and other forms of risk; individual variation in response to risk" (p. 339). This theory has four concepts: Autonomy, a sense of coherence, self-efficacy, and competence. Although many have defined resilience as a term for a younger population, Greene discusses resilience in the older adult population and describes each concept in detail. This project's specific qualitative interview questions incorporated the concepts that comprise the resilience theory by Greene.

Concept: Autonomy

Autonomy is one’s capability to combat stress, care for self, and maintain independence as defined by Greene (2002). Autonomy may decrease with age as people depend more on the help of others. Although dependency increases with age, healthcare practitioners realize that older adults want to preserve as much autonomy as possible (Greene, 2002). Autonomy has also been described as being independent in Western culture. However, Greene argues that this idea can be problematic. Greene stated that “everyone, whether they acknowledge it or not, remains relatively dependent even after childhood, and the likelihood increases as one advances toward old age” (p. 279). She encourages healthcare practitioners to realize that dependence and autonomy are interrelated. Often older adults want to remain independent such as living by themselves and continuing to drive. Discussions with patients about what they feel they need to be independent and what they need from others are worthy conversations.

Some individuals may want to feel self-sufficient, as if they do not need the help of others for food, transportation, living environment, or social support. They may not want to burden others, or they may perceive family or friends are too involved in their lives. Support groups can be helpful for these individuals. They can provide social support for those without family or friend networks. Healthcare practitioners can encourage and refer people living with HF to join support groups to fill this need.

Concept: Sense of Coherence

Sense of coherence includes elements that people possess to remain healthy (Greene, 2002). This concept encompasses three components initially developed by Antonovsky (1993). The components include (a) comprehensibility, the ability for one to understand situations, (b) manageability, the ability to manage the demands of situations, and (c) meaningfulness, the ability to find meaning in demands and situations that one encounters. This concept is useful to healthcare practitioners for incorporating a strengths-based perspective of resilience (Greene, 2002).

Greene (2002) mentions a lack of research on resilience in the older population. This could be due to the idea that old age is not typically associated with resilience. Lack of research could be due to a bias towards ageism or discrimination of older adults. However, adults who live long lives will experience loss. These losses, whether they are mental, physical, or social, will create challenges for the individuals (Greene, 2002). The concept of coherence is a trait that people use to remain in a state of health. As Greene describes, three components comprise the concept of coherence: Comprehensibility, manageability, and meaningfulness. These three components were initially formulated by Antonovsky (1993), a medical sociologist who designed several tools to measure the sense of coherence and designed the three components of comprehensibility, manageability, and meaningfulness which Greene incorporated into her resilience theory.

Component of Comprehensibility

Comprehensibility is a trait one uses to understand situations (Greene, 2002). For example, this could mean that a person newly diagnosed with HF learns to accept the diagnosis and then learns how to live with the diagnosis. People with HF may need to educate themselves and ask questions for clarity on this new condition. Healthcare workers are expected to help guide those diagnosed with HF to follow doctor’s orders regarding exercise, diet, and medications and recognize when they are decompensating.

Component of Manageability

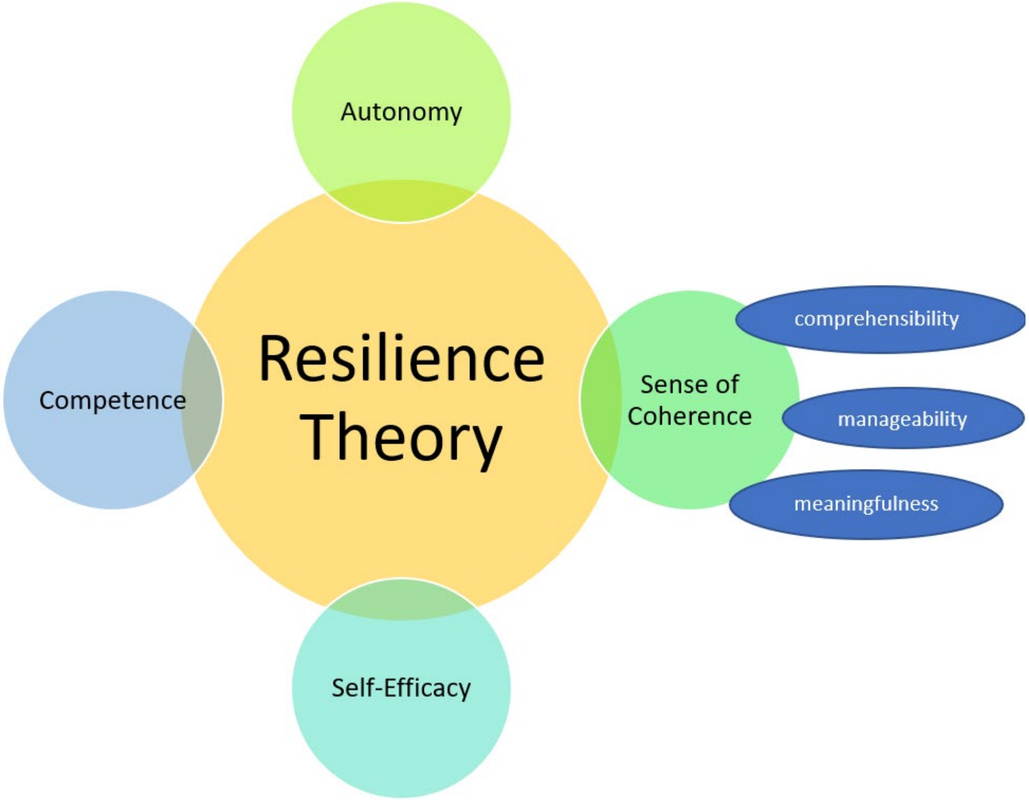
Manageability is a term that Greene (2002) refers to as “the capacity to manage situational demands” (p. 280). To explain this concept further, a person may feel that certain situations or people are helpful, while others may worsen the scenario for the person. Therefore, people learn to recognize what helps them and they avoid the people and situations that worsen their circumstances. For example, the patient with HF may avoid family members who try to control them; they may avoid activities of daily living, such as showering that may result in fatigue. Family and friends who lend a listening ear may be considered helpful to a person with HF and a support group meeting may be an example of an intervention that increases manageability.

Component of Meaningfulness

Greene (2002) defines this term as “the ability to derive meaning from the situations and demands one encounters” (p. 280). An example of this for a person with HF may be learning that if walking to the curb and back to drop off trash requires ten minutes to complete because the person needs to take breaks because of breathlessness, the person will allow time to do specific tasks that were once done in shorter time. Another example is learning to take care of one’s health to live a quality life. A schematic is presented to show how these concepts fit together in the resilience theory by Greene (2002) in Figure 2.

Figure 2

Resilience Theory



Note. This schematic represents the four major concepts of the resiliency theory (Greene, 2002). The three ovals describe specific subconcepts that make up the concept of a sense of coherence. Adapted from *Resiliency: An integrated approach to practice, policy, and research*, by R. R. Greene, R. R. (2002). Copyright 2002 by the National Association of Social Workers.

Concept: Self-Efficacy

Self-efficacy is related to one's belief that he or she can complete goals and tasks effectively (self-efficacy is a 'yes, I can' belief system that a person has, rather than a belief of an initial anticipated result he or she had hoped for). According to Bandura (1977), self-efficacy encompasses whether a coping behavior will be used, the amount of effort expended, and how long this effort will be expended during an adverse event. For example, a client's belief that goals for therapy can be accomplished. Practitioners can encourage self-efficacy by emphasizing strengths, using resources available, and working together to design mutual solutions.

Bandura (1977) explains that a person's efficacy is derived from four information sources: physiological states, verbal persuasion, performance accomplishments, and vicarious experiences. Physiological state refers to one's emotional arousal to stimuli. Verbal persuasion is the idea that people can be led to perform an activity they have not done before, such as exercising regularly. A vicarious experience is watching others overcome challenges with the belief that they, too, can accomplish challenging tasks. Lastly, performance accomplishments can be improved through modeling (watching others improve), repeated exposure, and encouragement (Bandura, 1977). These cognitive processes make up Bandura's theory of self-efficacy, a core concept in Greene's resilience theory.

Commensurate with the Bandura (1977) framework, self-efficacy can be improved in individuals through encouragement and role modeling. Social support is essential to give individuals a way to measure their success. In other words, when others congratulate or provide positive feedback about a change in a person's ability to cope with a medical condition, the individual may feel validated. With self-acceptance and recognition of the ability to manage, an individual may learn to live with a chronic condition and view life differently.

Concept: Competence

Competence is the ability of a person to overcome distress (Greene, 2002). Competency requires the ability to perform psychological, biological, and social activities. Another way of describing competence and resilience is the "ability to function effectively in one's environment, while resilience is the ability to maintain competence in spite of adverse circumstances and resilience being the ability to maintain competence despite adversity" (Greene, 2002, p. 280). Examples include performing chores around the house, cooking, and other instrumental activities of daily living (Greene, 2002). Practitioners should remember that specific competencies, such as driving, may decrease as people age. Still, new competencies such as painting may increase as one retires and has more time for hobbies.

Social workers often use competence to describe how well individuals can cook for themselves and perform chores, which are examples of instrumental activities of daily living (Greene, 2002). People living with HF can also be assessed for competency in activities of daily living such as showering, toileting, and dressing.

A schematic is presented in Figure 2 to show how these concepts fit together in the resilience theory by Greene (2002). The interview questions used in this study were developed from the concepts of Greene's resilience theory. This theory may be supported, expanded, or further clarified as revealed by the study participants' interview data.

Importance of Learning to Live with a Chronic Condition

In a TED talk, J. Suleika (2018) describes her recovery after battling leukemia for four years. Learning how to live beyond a diagnosis is an essential part of recovery and needs to be addressed and recognized by healthcare workers. Suleika stated that her recovery started after she was discharged from the hospital, and she learned to live rather than survive. She made peace with her body's limitations and focused on how to live a meaningful life. This is an example of resilience in a person living with a chronic illness. Individuals with HF can learn ways to exist beyond their diagnosis and to live a quality life. Resilience can facilitate this process. People with HF need to learn ways to live beyond their diagnosis to live a quality life which can be done through resilience.

Aim for Research Study on Resilience

The idea that people with HF can increase their resilience through education and other interventions is inspiring. Little qualitative research has been done to discover how patients with HF feel about their diagnosis and how they handle stressors. I aimed to learn more about how people living with HF view their condition and how they manage their diagnosis. Results from this project may help to develop ways to encourage people with HF to accept living with a chronic condition that waxes and wanes.

Research Questions

The proposed research questions for this study are as follows:

1. How do older adults view their health before, during, and after their diagnosis of heart failure?
2. How do older adults manage living with heart failure?
3. Does having heart failure change the way you deal with challenges?

This project aimed to answer these overarching research questions described in transcriptions of the interviews of participants living with HF. Further probing questions were asked for more detailed answers to these research questions, as demonstrated in the interview guide (Appendix A). The resilience theory by Greene (2002) created the framework for the interview questions. A schematic (Figure 2) represents the four major concepts of the resilience theory. These concepts include autonomy, competence, self-efficacy, and self-coherence, as described earlier. The three ovals depict subconcepts that make up the sense of coherence (comprehensibility, manageability, and meaningfulness).

Method and Its Philosophical Perspective

For this study, I used qualitative phenomenological approach (Munhall, 2012). I, the primary investigator (PI) conducted pilot work and interviewed two people with HF prior to a research study to test the methods. I wanted to find out from the participants' perspective what they considered a good or acceptable life and how they managed their condition. I explored ways people with HF are resilient and plan to use this knowledge later to develop interventions for people with HF to increase their resilience. The phenomenological method was appropriate for this research study because the information was gained from participants' stories and points of view (Munhall, 2012). Although knowledge gained may not be generalizable to all people with HF, it can assist in understanding the resilience of persons with the diagnosis of HF.

Statement of the Purpose

This study aimed to explore how people aged 55 and older with HF manage their illness, in hopes of revealing common themes that suggest resilience as a coping mechanism and discover common themes that reveal resilience as a coping mechanism. This research will add valuable information about how these patients manage daily life with HF and will increase the body of knowledge for all healthcare practitioners to give insight into what is important to these individuals. Discoveries can translate to building more effective interventions that can impact how these practitioners communicate with people with HF. The approach healthcare practitioners use to educate those affected with this disease, meet their current state of understanding and acceptance of their health condition could foster increased adherence to treatment recommendations and contribute to improved quality of life. These practitioners need to educate patients with HF and meet them in their current state of understanding and acceptance of their health condition. By meeting them where they are, the practitioners may increase patients' adherence to treatment recommendations and impact and improve their quality of life.

Phenomenon of Resilience in HF Patients

The phenomenon of concern was resilience in patients with HF. The studied population met the following inclusion criteria: Age 55 and older, self-reporting HF for at least one year, and understanding and speaking English. Exclusion criteria included those who were unable to read and speak English. Additional exclusion criteria included those with a left ventricular assist device, cardiac resynchronization therapy, or cardiac surgery within the last six months, or a separate non-HF life-limiting diagnosis such as end-stage malignancy.

Recruitment of Research Subjects

The proposal included recruiting subjects who expressed willingness to participate through verbal consent. A waiver of written consent was requested and approved by the Institutional Review Board (IRB) for the University of Texas at Arlington to allow verbal consent before interviews because this is a minimal-risk research study. The only information tying the identification of an individual participant to the study was the written consent. An email or letter was sent to each participant prior to the interview with a description of the study's risks and benefits (see Appendix B).

Interview Process and Confidentiality of Subjects

Each participant was scheduled for a telephone interview lasting 60-90 minutes at a time mutually agreed upon by both me and the participant. The interviews were conducted over the phone because the Covid pandemic prevented face-to-face interviews. I conducted the interviews in a private location with a locked door. Participants used a private area in their home environment. Interviews were recorded, and participants were notified of the recording of their interviews. All participant interviews were coded, and no participant names were attached to the recordings or transcriptions. Demographic data were collected separately and were not part of the recording.

IRB Approval

The IRB-approved interview guide included additional probing questions when indicated (see Appendix A). During the interviews, anecdotal notes were recorded on each participant's printed version of the interview guide questions. Recorded interviews were transcribed following the interviews. Interviews were read after transcription to ensure the accuracy of the information. For accuracy, four interview transcriptions were reviewed and validated with the participants who contributed to the interviews. Corrections were made after transcriptions and participant accuracy checks were complete.

The interviews were analyzed and coded by reading and re-reading the transcripts to find common themes and determine meanings and relationships between the discovered themes. Interview and analysis continued with new participants until data saturation occurred and no new themes emerged from the interviews (Munhall, 2012).

Statement of Essential Assumptions

Several assumptions supported the utilization of the Greene (2002) framework as the theoretical framework for this research. The phenomenological approach allowed me to ask HF participants about their experiences which either corroborated or revealed areas that needed more explanation in the resilience theory by Greene. For example, an assumption is that when challenges increase, resilience decreases due to decreased self-efficacy, competence, autonomy, and a sense of coherence (negative relationships). Alternatively, when challenges decrease, a person’s resilience will increase along with increased self-efficacy, competence, autonomy, and sense of coherence (positive relationships).

One of the phenomenological research questions based on the population of interest is: “What are the lived experiences of patients with heart failure who manage stressful situations as they do HF self-care?” This research question led to the formulation of three research questions for this study which were mentioned earlier under research questions. For this particular study, the assumption was that the results from this study would improve the understanding of resilience in people living with HF. By understanding the perspective of these individuals with HF, healthcare practitioners can more effectively treat and educate them, helping them to improve their quality of life.

Summary of Chapter

The people with HF were the focus population and the resilience theory by Greene (2002) was used to assess how people living with HF handle their diagnosis. After recruitment and consent, participants were scheduled, and interviews were conducted. The findings from these interviews can help researchers understand resilience in patients with HF and may lead to interventions to help build resilience in this patient population in the future.

CHAPTER 2

Critical Review of Literature

The literature published to date has been done on various populations of people with chronic diseases. This review covers studies on concepts related to psychological resilience in those with chronic conditions and those with heart failure. CINAHL, PubMed, and Google Scholar databases were searched using the keywords older adults, heart failure (HF), resilience, stressors, causes, mindfulness, and chronic conditions (Gheshlagh et al., 2016; Jin et al., 2022).

Psychological Resilience

Psychological resilience has been studied in many populations. Huang et al. (2019) studied psychological resilience in people who had surgery for breast cancer and Klineova et al. (2020) explored the same concept in individuals with multiple sclerosis (MS). Soliman et al. (2022) mentioned psychological resilience as a "goal of improving walking capacity among older adults known to have substantial residual disability following hip fracture" (p. 3088). The premise for these three studies was that patient outcomes could be improved by increasing patients’ psychological resilience.

Huang et al. (2019) looked at psychological resilience in women with breast cancer after having surgery. Researchers recruited 220 participants, 18-65 years of age, diagnosed with stage I-III breast cancer for a cross-sectional study in China between June and September 2017. Three variables were measured to determine relationships. Psychological resilience was assessed through the Conner-Davidson Resilience Scale (Chinese version), family hardiness by using the Family Hardiness Index, self-efficacy with the General Self-Efficacy Scale, and social support by the Social Support Rate Scale. Positive correlations were found between psychological resilience and total scores for resilience, family hardiness, social support, and moderate exercise.

Huang et al. found participants with higher psychological resilience were diagnosed in earlier stages of cancer (tumor detection). Recommendations from researchers include individualized nursing measures which promote disease rehabilitation which may lead to an improved quality of life for these individuals. This study supports the idea that clinicians need to assess psychological resilience and physical health after breast cancer surgery in women (Huang et al., 2019).

Klineova et al. (2020) sought to determine if psychological resilience was related to better outcomes for non-neurologic populations. They studied 185 people with an early diagnosis of MS and 50 control subjects using the CD-RISC-10. Subjects with MS completed a neurobehavioral evaluation called the MS functional composite (MSFC). The researchers assessed correlational links between the MSFC, CDRS-10, cognitive indices (total, memory, cognitive efficiency), and motor indices (total, gross, fine motor). Better motor and MSFC outcomes were linked to higher CDRS-10 among patients, and the most robust relationships were grip strength and gait endurance (gross motor function). These findings were independent of fatigue and mood. Additionally, CDRS-10 and motor outcomes were highly correlated in healthy control subjects. Klineova et. (2020) identified psychological resilience as a "non-disease-specific contributor to strength and motor endurance" (p. 1111). Klineova et al. concluded that findings from this study suggest that interventions may increase psychological resilience in those with MS, although more research is needed.

In a study by Soliman et al. (2022), the researchers investigated the psychological effects of resilience on walking capacity in older community-dwelling adults who had recently had surgery for a hip fracture. Data were derived from the community Ambulation Project, which included 210 adults > 60 of age with a minimal hip fracture resulting from trauma. Participants completed a six-item Brief Resilience Scale (BRS) to measure psychological resilience at baseline. Study participants were divided into two groups, and the intervention group received 16 weeks of home-based physical therapy. The participants were placed in either a high or low-resilience group. The participants performed three tests at baseline and at 16 weeks, the 4-meter gait speed, the 50-foot walk test, and the 6-minute walk distance. More significant improvements were found in all tests at 16 weeks in the most resilient BRS group compared to the BRS group with the least resilience. Soliman et al. indicated that findings from this study suggest that addressing psychological resilience as part of rehabilitation programs may improve walking capacity in older adults after a hip fracture. These researchers mentioned psychological resilience as a "goal of improving walking capacity among older adults known to have substantial residual disability following hip fracture" (Soliman et al., 2022, p. 3088).

Summary

Several studies (Huang et al., 2019; Klineova et al., 2020; Soliman et al., 2022) support the importance of improved psychological resilience in patients with various conditions such as breast cancer, MS, and post-surgical hip fracture. These researchers encourage healthcare practitioners to assess for psychological resilience in their patients to improve outcomes (Huang et al., 2019; Klineova et al., 2020; Soliman et al., 2022), and interventions may enhance psychological resilience in these populations (Klineova et al., 2020; Soliman et al., 2022).

Psychological Factors Related to Resilience

Many researchers investigated how found psychological factors related to resilience. These factors included well-being (Tecson et al., 2019; Wang et al., 2016), life satisfaction, happiness, and quality of life (Tecson et al., 2019), decreased levels of anxiety, stress, and depression (Love et al., 2021), and mindfulness (Wang et al., 2016).

Tecson et al. (2019) found that resilience may protect the well-being of those experiencing chronic illnesses. These researchers hypothesized that chronically ill adults who were resilient would have higher life satisfaction, quality of life, more happiness, and less psychological distress than people with low resilience. There were 41 participants ages 67 ± ten years surveyed by telephone from March through June of 2017 to measure the effect of resilience on well-being in these individuals. HF was the most common chronic illness (39%). Tecson and colleagues (2019) found resilience to be highly significant for "psychological distress and happiness ($b = -1.91$, $p = 0.002$; odds ratio = 4.71, $p = 0.003$, respectively)" (p. 520) after accounting for social, demographic, and clinical factors. This study supports psychological resilience as a resource for preserving the well-being of chronically ill adults.

In a systematic review by Love et al. (2021), the researchers reviewed 34 studies to find evidence of associations between individual-level psychological, behavioral, biological, and social/cultural variables with resilience in patients with cardiovascular disease. In 23 studies, the reviewers found inverse relationships between psychological factors (anxiety, depression, and stress) and resilience. Evidence for associations between resilience and behavioral or social/cultural were scarce. Four studies on biological factors found associations between young adults with low-stress resilience and early diagnosis of heart failure, coronary heart disease, and stroke. Therefore, these studies support the need for further studies on the relationships associated with variables and resilience (Love et al., 2021).

In a correlational study, Wang et al. (2016) examined the relationship between psychological resilience, well-being, and the level of mindfulness in randomly selected patients with inflammatory bowel disease (IBD). They had 134 people who had IBD fill out three questionnaires, the Five Facet Mindfulness Questionnaire (FFMQ), the CD-RISC, and the

General Well-Being Schedule (GWB). Wang et al. found psychological resilience positively correlated with well-being and mindfulness level. Therefore, these researchers concluded that psychological resilience partially mediates between overall well-being and mindfulness level. They found that people with IBD can experience frustration with the inconveniences of their disease process and may adopt negative coping strategies. These findings suggest clinicians can help improve these individuals' happiness or indirectly enhance their psychological resilience through the nursing process of assessment and intervention. Some interventions mentioned to increase psychological resilience include mindfulness techniques such as noticing body sensations, thoughts, feelings, and their environment (Wang et al., 2016).

Summary

Love et al. (2021) stated that resilience may improve health in those with cardiovascular disease and that complex relationships between variables and resilience need to be studied in this population and in vulnerable people such as women and ethnic minority groups. Love et al. emphasized that research is necessary to develop interventions to improve resilience in these groups with cardiovascular disease. Wang et al. (2016) also encouraged interventions to strengthen resilience in patients with IBD. Tecson et al. (2019) mentioned journaling and mindfulness, modules, or other self-directed reflection activities, and modules done in group settings as interventions to build more resilience. Many of these factors can influence resilience.

Resilience in Chronic Disease and Conditions

Researchers have looked at various populations of people with chronic illnesses such as people with chronic physical disabilities (Battalio, Tang, & Jensen, 2020), IBD (Dai et al., 2022), systemic lupus erythematosus (SLE; Garcia-Carrasco et al. (2019), chronic kidney disease (Garcia-Martinez et al., 2021), patients with HF and people with chronic conditions (Gheshlagh et al., 2016; Jin et al., 2022). People with autoimmune heart diseases such as Sjogren's syndrome, rheumatoid arthritis, and SLE were studied by Rojas et al. (2018). Phillpou et al. (2022) looked at patients with IBD, and Reid et al. (2018) studied people who had a traumatic brain injury and how resilience was associated.

Battalio et al. (2020) investigated resilience in 1,574 people with chronic conditions such as spinal cord injury, MS, muscular dystrophy, and postpolio myelitis in a longitudinal survey study in the U.S. The researchers hypothesized temporal associations between four functional domains (depression, anxiety, physical function, and social role satisfaction) and resilience. The 1,574 participants received and filled out two questionnaires three times a year. Functional domains were measured using the short form of the Patient Reported Outcome Measurement System (PROMIS), and the CD-RISC-10 was used for assessing resilience. The researchers used cross-lagged path models and found significant reciprocal relationships between all functional domains, except physical function, with resilience. The findings from this study suggest resilience is a strong predictor of social and psychological function over time in people with chronic physical disabilities but not a prospective predictor of physical function (Battalio et al., 2020).

Dai et al. (2022) conducted an associational study on inpatients with IBD. The researchers examined the relationships between resilience, quality of life, and social support. From September through December 2019, a convenience sample of 249 participants in Hunan province in China completed three surveys. These tools were Resilience Scale For Inflammatory Bowel Disease to assess for resilience, the Short Health Scale for quality of life, and the Social Support Rating Scale to evaluate social support. The researchers found that resilience needs to be enhanced in this patient population. Factors influencing resilience included where people lived, for example, rural areas, and social support. Findings suggest that resilience increased when people lived in nonrural areas, utilized social support, and improved their quality of life (Dai et al., 2022).

Garcia-Carrasco et al. (2019) examined associations between resilience, socioeconomic factors, and depression symptoms in women with SLE. Sociodemographic characteristics included age, socioeconomic level, occupation, marital status, number of family members, and education. The researchers performed a cross-sectional study with 123 women aged 34-54 with SLE and 132 age-matched control subjects. The researchers used various tools such as the Graffar method, the Systemic Lupus Erythematosus Activity Index 2000 (SLEDAI-2K) for disease activity, SLICC Damage Index, and Spanish versions of the Resilience Scale of Wagnild and the Young Depression Scale. Garcia-Carrasco et al. found no differences in the scores for resilience between the two groups. Women in the SLE group had higher scores on self-efficacy and a negative relationship between resilience and depressive symptoms. There was no association between resilience and socioeconomic factors in those with SLE. This study suggests resilience is essential to evaluating women with SLE (Garcia-Carrasco et al., 2019).

Garcia-Martinez et al. (2021) performed an associational study on people with chronic kidney disease who had received hemodialysis for over six months. The researchers looked at correlations between resilience, quality of life, and clinical, sociodemographic, and hemodialysis routine variables related to perceived stress. This study was a cross-sectional design with 144 patients from a community in Spain. The researchers used three tools for their study: the CD-RISC, the Kidney Disease Quality of Life 36, and the Perceived Stress Scale 10. Resilience, employment status, and quality of life were significantly related to perceived stress. Stress was negatively associated with health-related quality of life and resilience. Comorbidity and age were not significantly associated with stress. Resilience was one of the main predictors of perceived stress from the perceived stress scale 10 scores. Results from this study suggest interventions to promote resilience may improve perceived stress in those with chronic kidney disease (Garcia-Martinez et al., 2021).

Gheshlagh et al. (2016) hypothesized that resilience attenuates stress caused by disease and health problems. The researchers sought studies discussing resilience's attenuating effects on chronic disease to perform a meta-analysis and systematic review. In 15 of the studies, they found significant mean resilience scores in 3,369 patients with cardiovascular disease, cancer, and other diseases. They found higher resilience scores equal better functional and physical outcomes in these individuals. The reviewers explained the more lethal the disease that the person had, the more resilience was needed to mitigate the adverse effects of the disease. Gheshlagh et al. also discovered resilience, along with feelings of capability and control, helped the person feel that they had control over their chronic condition and increased their ability to manage. For example, the patients reported feeling capable of managing their condition by taking their prescribed medication and preserving their recommended diet. The reviewers found that employment status, resilience , and quality of life were significantly ($p = 0.003$ or less) to related to perceived stress in people with chronic disease. These findings are pertinent to the qualitative study on resiliency among HR patients as these patients typically have more than one comorbidity that they need to learn to manage. The findings from this study support the need for educational strategies to increase resilience in heart failure patients and others with chronic conditions (Gheshlagh et al., 2016).

Jin et al. (2022) performed a meta-analysis and systematic review of 20 studies published between January 2000 and July 2020, that included a total of 9,269 people with 11 different chronic conditions. The reviewers wanted to quantify the association between self-care and resilience among those with chronic conditions. Jin et al. found definitions of resilience and self-care shared some core concepts, and there was a positive relationship between self-care and resilience across various chronic conditions. In addition, the reviewers found interventional studies identified bidirectional relationships between self-care and resilience. Therefore, self-care interventions, such as resilience training, could improve patients' resilience in those with chronic diseases (Jin et al., 2022).

Manning et al. (2016) conducted a secondary data analysis study of 10,753 adults with chronic disease, ages 51-98, from 2006 to 2010. Data was collected for a U.S. based health and retirement study. The researchers hypothesized that people with higher levels of resilience would have fewer disabilities. They also hypothesized that resilience would moderate the effects of disabilities after a chronic disease diagnosis. Findings supported higher resilience, decreased limitations of activities of daily living, and decreased limitations of instrumental activities of daily living in those with chronic diseases. Manning et al. found that improved resilience mitigated harmful effects for those with chronic illness. These researchers support interventions to increase resilience in this population.

Priori et al. (2021) researched relationships between Sjogren's syndrome in women and resilience. The researchers recruited 74 women aged 18 to 80 years old with Sjogren's syndrome and 74 age and gender matched control subjects. The participants completed surveys for Sjogren's disease damage, activity, symptoms, fatigue, anxiety, depression, and general health. An inverse relationship was found between mood disorders such as depression and anxiety and resilience. More resilience was correlated with a higher quality of life, less fatigue, a more active lifestyle, and improved general health. No significant differences between resilience and age, disease, and sociodemographic characteristics were noted. In addition, no significant associations were found between resilience and damage from Sjogren's syndrome, disease activity, duration of disease, or sociodemographic features. This study supports the exploration of resilience in women with Sjogren's syndrome (Priori et al., 2021).

Rojas et al. (2018) evaluated clinical outcomes and resilience in 188 female patients with autoimmune rheumatic diseases. The researchers used individual interviews, focus groups, and chart reviews to collect data on patients with conditions such as SLE (*n* = 70), rheumatoid arthritis (*n* = 51), Sjogren's syndrome (*n* = 32), and systemic sclerosis (*n* = 35) in this cross-sectional analytical study. They also collected data about demographic characteristics and lab variables (patient-reported outcomes) and utilized the BRS Scale to measure resilience. Lower resilience was associated with age less than 48 years in patients with SLE, systemic sclerosis, and rheumatoid arthritis who were in a low socioeconomic group. Participants who were older than 50 had resilience scores that were higher, irrespective of socioeconomic class. Disease activity did not influence resilience. One observation from this study included women with systemic sclerosis who had high resilience scores, were physically active, and had a high socioeconomic status. The findings of this research support the idea that these patients experience resilience influenced by socioeconomic status, age, and possibly by exercise (Rojas et al., 2018).

Philippou et al. (2022) conducted a cross-sectional study with patients with IBD and examined the relationships between anxiety, depression, and resilience. Their sample included 288 people with IBD who completed the Generalized Anxiety Disorder 7 (GAD-7) to measure anxiety, the CD-RISC to capture resilience, and the Patient Health Questionnaire-9. High resilience was associated with lower anxiety. "For every 1-unit increase in the CD-RISC, the

GAD-7 score decreased by 0.04 units" (Philippou et al., 2022). Further research is recommended to evaluate a decrease in depression with increased resilience in this population. These findings suggest greater coping mechanisms in those with IBD that have high resilience, which may buffer the development of anxiety (Philippou et al., 2022).

In a cross-sectional study by Reid et al. (2018), researchers looked at retrospective data from a traumatic brain injury repository of U.S. members who had been screened at a primary care visit and were positive for mild traumatic brain injury. The researchers assessed for associations between adversity, resilience, reporting of post-traumatic stress symptoms, and post-concussion symptoms between February 2015-August 2016. The sample consisted of 165 people who had filled out four inventories, the CD-RISC, the Trauma History Screen, the Neurobehavioral Symptom Inventory, and the PTSD [Post-traumatic Stress Disorders] CheckList – Civilian Version. The researchers found CD-RISC and Trauma History Screen scores were significantly correlated with Neurobehavioral Symptom Inventory and PTSD CheckList. These findings suggest resilience was associated with less reporting of post-concussion symptoms, and adversity was associated with more reporting of symptoms, as hypothesized by the researchers. Results from this study suggest that healthcare providers screen for cumulative adversity in their patients to identify individuals at risk for poor outcomes. Also, findings suggest interventions that increase resilience may ameliorate PTSD symptoms and post-concussion severity (Reid et al., 2018).

Summary

Many concepts have been studied concerning resilience in individuals with chronic illnesses. Several researchers found resilience to be inversely related to anxiety (Battalio et al., 2020; Mungase et al., 2021; Phillipou et al., 2022; Priori et al., 2021) and depression (Battalio et al., 2020; Garcia-Carrasco et al., 2019; Philippou et al., 2022; Priori et al., 2021). A positive relationship was found between resilience and quality of life (Dai et al., 2022; Garcia-Martinez et al., 2021). Many studies encourage interventions to improve resilience (Dai et al., 2022; Garcia-Martinez et al., 2021; Gheshlagh et al., 2016; Jin et al., 2022; Manning et al., 2016; Rojas et al., 2018; Reid et al., 2018).

Resilience in Patients with Cancer

Several studies reviewing resilience were done on people with cancer (Chou et al., 2022; Clarke et al., 2019; Cohen et al., 2014; Franjic et al., 2021; Mungase et al., 2021). Other variables assessed were depression (Clark et al., 2022; Cohen et al., 2014; Mungase et al., 2021) and quality of life (Clarke et al., 2014; Franjic et al., 2021). Mungase et al. (2021) looked at sex differences in patients with cancer regarding resilience. Several researchers recommended strategies to increase resilience (Chou et al.,2022; Cohen et al., 2014; Franjic et al., 2021; Mungase et al., 2021).

Chou et al. (2022) performed a cross-sectional study examining resilience in 416 people with colorectal cancer. They recruited patients from Northern Taiwan at two medical centers between September 2017 to April 2019. Inclusion criteria for participants were diagnosed within the last five years with stage I to III colorectal cancer , spoke Chinese, were aware of their diagnosis, and gave written informed consent. Chou et al. (2022) used many different tools to assess specific variables: the Resilience Scale for resilience, the Fatigue Symptom Inventory (for fatigue), the Symptom Severity Scale (for the severity of symptoms), and depression by the Epidemiological Studies Depression Scale. The researchers used additional tools to measure self-efficacy for coping with spiritual well-being (Functional Assessment of Chronic Illness and Therapy-Spiritual Well-Being Scale) and cancer diagnosis (Cancer Behavior Inventory). The results of a revised structural equation model used for analysis in this study support depression as a partial mediator between resilience and protective factors. Therefore, those with high resilience had higher protective factors (purpose, perseverance, equanimity, self-reliance, and authenticity). Practice implications include that oncology nurses should assess protective factors, resilience, and depressive symptoms in those with colorectal cancer (Chou et al., 2022).

Clarke et al. (2019) explored the relationship between resilience in patients and the quality of life in 98 patients who had been treated for head and neck cancer. The study was a retrospective analysis where the researchers analyzed patient records. The CD-RISC was used to measure resilience, and quality of life was measured by the University of Washington Quality of Life Questionnaire (UW-QoL). Results from this study showed a significant correlation between scores from resilience and QoL. Higher resilience scores were associated with a better QoL, strengthening the idea that improved resilience may improve quality of life (Clarke et al., 2019). Clarke et al. stated that using assessment tools such as the CD-RISC and the UWQoL may help clinicians refer patients to appropriate services leading to better health outcomes.

Cohen et al. (2014) conducted an exploratory cross-sectional study with 92 people who had colorectal cancer. The study included individuals aged from 27-87 years with a mean age of 58 who were in either stage II or III colorectal cancer . The researchers wanted to assess mediating factors of resilience on age and emotional distress in patients with colorectal cancer . The researchers used the Brief Symptoms Inventory with 18 items to measure anxiety, depression, and somatization. They also used Wagnild and Young's Resilience Scale, demographic and disease details, and a cancer-related problem list. Findings from this study were that higher resilience and decreased emotional distress were associated with male gender, older age, and fewer problems related to cancer. This study supports increased care provider support for patients with low resilience scores (Cohen et al., 2014).

Franjic et al. (2021) performed a cross-sectional study with 200 participants with colon cancer in Bosnia and Herzegovina between April 2019 – June 2021. The researchers used a questionnaire for demographics, a CD-RISC to evaluate resilience, and the WHOQOL-BREF Quality of Life Questionnaire to measure quality of life. Resilience had a significant positive relationship with quality of life (mental health, physical health, the environment, and social relations). Single patients had higher levels of resilience than those who were divorced, married, or widowed. Patients treated with surgery and chemotherapy had higher levels of resilience than those treated with other therapeutic methods. However, the researchers found no statistically significant evidence between resilience and cancer stage or sociodemographic factors. Clinical implications for healthcare workers are that interventions that enhance resilience in this patient population may be beneficial and may provide holistic care (Franjic et al., 2021).

In a prospective cross-sectional analytical study by Mungase et al. (2021) with 100 patients (62 women and 38 men) with cancer undergoing radiotherapy, the researchers assessed the relationship between anxiety, stress, depression, and resilience. Participants were recruited from two rural hospitals in India. The researchers evaluated resilience with an abbreviated version of the CD-RISC and used the Depression Anxiety Stress Scale to measure stress, anxiety, and depression. They also used a demographic questionnaire for age, sex, occupation, number of children, religion, and marital status. After analysis, these researchers found only gender, anxiety, and resilience were predictive of depression. Findings from this study revealed depression and anxiety were positively related to psychological stress and negatively related to resilience. Results indicated that male patients had significantly higher resilience, and female patients experienced significantly more depression, anxiety, and stress. Lessons learned for clinical practice support healthcare workers using interventions to increase resilience and preventative strategies for depression and anxiety in these patients (Mungase et al., 2021).

Summary

Cancer patients endure many challenges, and as stated in several study reports, researchers encourage healthcare providers to use strategies to increase psychological resilience in this patient population (Clarke et al., 2019; Chou et al., Mungase et al., 2021). Two studies found quality of life greater in those with high resilience (Clarke et al., 2019; Franjic et al., 2021). Several researchers discussed how their patients' resilience needs to be assessed (Chou et al., 2022; Clarke et al., 2019; Cohen et al., 2014; Mungase et al., 2021). Overall, resilience has been studied in various cancer patients, and lessons learned may be helpful in other patient populations.

Resilience in Heart Failure

Two studies specifically focused on resilience in people with HF (Chang et al., 2017; Heo & Kim, 2020). The researchers of these studies examined different variables related to resilience in people with HF, such as depression and self-care (Chang et al., 2017). Heo and Kim (2020) examined the relationships between resilience, self-care, and Type-D personality. van Rijn et al. (2023) examined the relationship between self-care and resilience in patients with HF.

Chang et al. 2017 performed a cross-sectional study to discover the associations between resilience, depressive symptoms, and self-care in individuals with a HF diagnosis documented by an echocardiogram. They recruited 201 patients with HF between the ages of 30-90. The researchers used various tools to measure each of the variables for their study: resilience through the Chinese version of the Resilience Scale, self-care through the Self-Care of HF Index, and depression through the Beck Depression Inventory. This study showed that resilience moderated the effects of depressive symptoms on self-care maintenance in patients with HF with moderate to high resilience levels. Those with low levels of resilience did not show self-care confidence as a mediator of depressive symptoms, leading to a lesser ability to carry out self-care maintenance. Chang et al. stated that disease management and support groups might be beneficial to improve self-care in patients with HF who have adequate levels of resilience. In addition, researchers of this study suggest that healthcare practitioners effectively communicate and intervene with strategies in these patients with HF. By targeting symptoms of depression, healthcare practitioners can use interventions to influence self-care confidence in patients with high and moderate levels of resilience (Chang et al., 2017).

In a descriptive, cross-sectional study, Heo and Kim (2020) sought to find out if there was a relationship between resilience, self-care, and Type D personality in patients with HF. They recruited 90 patients with HF ages $\geq$20 in South Korea. Type D personality was defined as "the tendency to be vulnerable to negative emotions and the tendency to suppress self expression consciously in social interaction" (Heo & Kim, 2020, p. 2). Resilience was studied using the Cardiovascular Disease Resilience (CDR) tool and self-care by the European Heart Failure Self-care Behavior tool. Type D personality was measured by the Type D Personality Scale-14. and the researchers found significant correlations between resilience and self-care. They found full mediation effects from resilience on the relationship between self-care behavior and Type-D personality. Therefore, the greater the resilience, the better the self-care behavior (Heo & Kim, 2020).

In a cross-sectional study, van-Rijn et al. (2023) conducted a study measuring the association between resilience and self-care behaviors. They recruited 68 participants and used the 2-item Patient Health Questionnaire, the Self-care of Chronic Illness Inventory (self-care maintenance, self-care monitoring, and self-care management), and the Resilience Evaluation Scale. The researchers found an association between self-care maintenance with $b = 0.24$, 95% CI [0.03-0.96] (van Rijn et al.), but no significant relationships between resilience and self-care monitoring (noticing symptoms such as fluid retention and weight changes), or self-care management (changing medication management for fluid retention). These researchers suggest further longitudinal studies to measure cause-effect relationships (van Rijn et al., 2023).

Summary

Few studies have been done on resilience in people living with HF. Heo and Kim (2020) examined relationships between Type D personality, resilience, and self-care behavior. The researchers defined Type D personality as the tendency to be susceptible to negative emotions and to consciously suppress self-expression in social situations.

Heo and Kim (2020) found that resilience had a statistically significant ($p < .001$) mediating effect on self-care in individuals with a Type D personality. They noted, “Type D personality was found to be more frequent than the non-D type personality in heart failure patients who are in the final stages of cardiovascular disease” (Heo & Kim, 2020, p. 6).

Chang et al. (2017) also studied self-care in relation to resilience in people with HF. They found resilience had a moderating effect on the relationship between depression and self-care. Researchers from both studies encourage more research on resilience in those with HF (Heo & Kim, 2020; Chang et al., 2017).

Resilience Tools in HF Research Studies

Researchers have used resilience tools to measure levels of resilience. The CD-RISC (Conner &Davidson, 2003) is a tool with 25 items, with each item containing a scale of 0-4;

higher scores reflect greater resilience. The CD-RISC is a tool that has been widely used in research studies and has sound psychometric properties (Conner & Davidson, 2003). The BRS (Smith et al., 2008) has six items that range from strongly disagree to strongly agree. Questions on the scale ask about a person’s ability to bounce back from setbacks. When interpreting results from the BRS, higher scores equal higher levels of resilience (Smith et al., 2008).

Researchers used several different resilience tools in their research studies. The CD-RISC was used in seven studies (Battalio et al., 2020; Chang et al., 2017; Clarke et al., 2019; Franjic et al., 2021; Garcia-Martinez et al., 2021; Mungase et al., 2021; Philippou et al., 2022; Reid et al., 2018; Wang et al., 2016). The version Chang et al. (2017) used was in Chinese. The BRS was used in two studies by Rojas et al. (2018) and Soliman et al. (2022). Heo and Kim (2020) used the Cardiovascular Disease Resilience tool. Although researchers often used tools such as the CD-RISC and the BRS in studies, they did not measure the lived experience of those with HF.

Summary

Few tools have been used in chronic conditions and patients with HF. Researchers used the CD-RISC (Conner & Davidson, 2003) and the BRS (Smith et al., 2008) in patients with chronic disease and HF. The Cardiovascular Disease Resilience tool was specifically designed for people with a cardiovascular diagnosis.

The Gap in the Knowledge Base for Resilience

The results of these research studies point to a need for understanding the experiences of people living with HF. Many similar concepts have been studied in patients with chronic conditions, such as quality of life (Clarke et al., 2019; Franjic et al., 2021), well-being (Chou et al., 2022; Wang et al., 2016) and opposing concepts, such as depression (Chou et al., 2022; Mungase et al., 2021) and anxiety (Cohen et al., 2014; Mungase et al., 2021). Topics researched on people with HF include well-being (Tecson et al., 2019; Wang et al., 2016), quality of life, life satisfaction, happiness, and physical distress (Tecson et al., 2019).

Resilience is a topic that requires more research on individuals with HF. There is a need for more qualitative research to discover the self-management of patients with HF and how they are coping with their illnesses. Qualitative interviews with HF patients asking how they handle their challenges are valuable research methods to help healthcare practitioners learn techniques to increase resilience in this population. Little qualitative research has been done regarding resilience in these individuals. Through interviews, researchers may find possible interventions for building resilience in people with HF. Designing effective interventions to improve self-efficacy can help patients with HF by increasing their skill in recognizing and managing their HF progression.

Summary

Although many studies have measured resilience (Battalio et al., 2020; Gheshlagh et al., 2016; Manning, 2016; Tecson et al., 2019), little qualitative research has been done that explores resilience within the HF population and discusses how people living with HF manage their illness. Therefore, the gap in research is understanding the lived experience of resilience in people living with HF. This chapter reviewed the extant literature about what is known about people with chronic diseases and the HF population regarding how they manage their HF condition.

CHAPTER 3

Methods and Procedures

The qualitative method of phenomenology I used will be described in detail. This chapter will outline the methods and design for this study. The recruitment of participants, sample details, interview guide questions, rationales, and thematic analysis will be described.

Phenomenology: Philosophical Foundations

I used a phenomenological qualitative approach. The philosophical foundations of phenomenology are based on concepts that Munhall (2012) and Cresswell and Poth (2018) defined. Munhall illustrated phenomenology as a way researchers come to know the lived experience of people. A challenge for researchers using phenomenology is to forget their previous individual experiences and listen as if the information gathered from interviews is being heard for the first time. Therefore, not allowing bias to sway the researcher’s perceptions (Munhall, 2012). First, researchers need to discover the specific issues people living with HF are experiencing.

Cresswell and Poth (2018) describe transcendental phenomenology as a method to portray the shared life experiences of those who have lived with a specific phenomenon. These authors state that interview information is developed into a textual and structural description by placing interviewees' experiences in context.

This qualitative research method is appropriate to advance knowledge about the lived experience of resilience in persons with HF. The environment shapes people’s experiences and views; no two people have the exact same experiences. Still, discovering concurrent themes among people with the same condition can suggest underlying shared experiences and mechanisms leading to an improved understanding of the phenomena.

Investigators trained in qualitative methods are taught to forget preconceived notions about the outcomes they expect to find and be open to the unique stories told by participants (Munhall, 2012). At the same time, I examined comments from participant interviews in light of the concepts described in the resilience theory (Greene, 2002) for fit.

The Rationale for the Use of Phenomenology

This research method was feasible because the quantitative method does not answer how a person living with HF is coping. Phenomenology was the best fit for the data as I was trying to collect because it emphasized descriptive data collection. Thematic analysis is a large part of the qualitative method. Phenomenology is a method that helps researchers describe personal stories and encounters of people living with a specific phenomenon (Munhall, 2012), such as resilience.

I had access to patients with HF from previously completed studies and the ability to recruit participants through word of mouth and HF support groups. Up to 25 participants were expected to be interviewed to describe their experiences with HF and how they manage stressful situations as they manage their HF self-care. Participant interviews stopped when no new themes were discovered. There was a potential for bias by the limitation of participants after saturation was reached. Interviews were read repetitively and analyzed and reanalyzed. Data analysis for themes is an iterative process and was repeated until no more new themes emerged from the data. Findings were examined within the context of other extant literature on this topic.

The qualitative research method is especially suited to research questions involving the lived experience of individuals living with a phenomenon (Cresswell & Poth, 2018). Cresswell and Poth (2018) advocate the qualitative technique of writing about common themes found in the data collected from interviews instead of simply reporting the findings without a thematic context. Themes were derived from the interview data and then compared to the resilience theory

(Greene, 2002). The qualitative method helps researchers uncover new knowledge through in-depth interviews of study participants and the detailed descriptions in the findings (Munhall, 2012, p. 509). The qualitative researcher used a deductive approach for thematic analysis, from a general premise to a specific conclusion (Gray, Grove, & Sutherland, 2017). Throughout the interview, general questions (Appendix A) helped guide more specific and probing questions.

Identification of Sample

The population studied consisted of self-described patients with HF recruited through support groups for patients with HF or by word of mouth. Participants were recruited from patient support groups in north-central Texas or by word of mouth and through ResearchMatch.org, an organization of volunteers who want to share their experiences and participate in research ((See Appendices for recruitment posters and online post). Therefore, this was a convenience sample.

The inclusion criteria for participants included age 55 and older, who had a diagnosis of HF for at least one year (self-report), and spoke English. The age range for this study was based on the knowledge that patients with HF are typically between 57 and 101 years (Denfeld & Lee, 2018; Reeves et al., 2017).

Exclusion criteria included having a left ventricular assist device, resynchronization, and cardiac surgery within the last six months. Also excluded were those with a separate non-HF life-limiting diagnosis with a six-month prognosis, such as cancer, end-stage chronic obstructive pulmonary disease, or end-stage renal disease. People with these conditions may not give a clear picture of a person living with HF because their other comorbidities prevent their ability to focus on symptoms of HF.

Sample Size and Saturation

After the recruitment of participants, a copy of the consent form was emailed or sent by U.S. mail if the participant did not use email. Interviews were conducted by telephone at a time negotiated between the participant and the interviewer. The consent form was discussed with each participant to describe in detail the interview process, possible risks, and benefits of the study before starting the interview. A waiver of written consent for all study participants was approved as part of the IRB approval process.

The sample included up to 25 participants until saturation of themes was reached, and the researchers discovered no new themes. Cresswell and Poth (2018) recommend 15-25 participants for a phenomenological study to find saturation of themes. The sample size recommended for phenomenological studies varies according to the source.

Munhall (2012) stated that there is no set number, but a researcher should continue interviewing participants until no new perspectives are revealed. In other words, researchers should find saturation of information with common themes. However, others have defined specific numbers of participants for this type of research study. Morse (1994) recommended six study participants and Creswell and Poth (2018) state that five to twenty-five participants are helpful for a phenomenological study. Moser and Korstjens (2018) recommended less than ten participants for phenomenological research but caution that researchers carefully consider this advice. Participants were recruited, interviewed, and transcripts were analyzed until no new themes were discovered. All interviews were reviewed, and it was determined that no new themes emerged from the last four participant interviews signifying that saturation had occurred.

Data Collection

After approval from the IRB, I began recruiting participants. I was approved to recruit through support groups of a local rehabilitation facility. I attended meetings online or in-person and discussed this study, the need for subjects, compensation ($10/hour), and the benefit of helping to gain valuable insight into how persons living with HF handle their diagnosis. I emphasized that the outcome of this study was to help gain knowledge that will encourage the development of interventions and education that could help this population although I did not develop interventions with this study.

I primarily recruited from an online volunteer organization called ResearchMatch.org which is an online organization consisting of researchers, volunteers, and community collaborators conducting research. This organization allows people from a variety of backgrounds and ages who live within the continental U.S. and Puerto Rico to volunteer for research projects and clinical trials. I set up an account and recruited subjects who stated they had HF and were at least 55 years old, and spoke English. I recruited five to ten subjects at a time to gather subjects for this study. After potential subjects responded on the website that they were interested in this study, I emailed them a consent form. After subjects accepted the verbal consent, I scheduled interviews with the ResearchMatch.org participants.

Description of Setting

I conducted interviews in a private office with the door closed. The participants were in a quiet place in their own residence or a similar location. Privacy for the interviewer and interviewees (study participants) decreased distractions and encouraged study participants to share their thoughts and feelings.

Discussion of Data Collection Method

Demographic data of the study participants were collected, such as age, race, ethnicity, the highest level of education, employment status (part-time or full-time, retired, or unemployed), living situation, method of payment for healthcare, and other chronic diseases. These items are listed in the interview guide (Appendix A).

Semi-structured interviews included probing questions to add more detailed explanations from the participants. In qualitative research, it is helpful to encourage the participants to share more about their experiences to help the researcher to gain a deep understanding of their lived experiences (Munhall, 2012). The beauty of interviewing in this manner is to obtain rich data and to add to the existing knowledge of the phenomenon of persons living with HF. Each study participant had a specific vantage point and helped me understand their core needs.

Interview Guide Questions

The research questions were kept in mind when I created the interview guide. The research questions were:

1. How do older adults view their health before, during, and after their heart failure diagnosis?
2. How do older adults manage living with heart failure?
3. Does having heart failure change the way you deal with challenges?

The first research question broadly defined how participants viewed their condition and encouraged them to explain how their perception of their HF diagnosis changed over time. The idea of a possible change in perspective is highlighted in interview guide questions one through five which will be described. The second research question slightly overlaps research question number five and is a concept of manageability that is included in many of the interview guide questions (numbers 5 through 12 and 14). I wanted to find out how participants were managing HF. The third research question was more comprehensive about how people living with HF handle challenges in general after their diagnosis with HF. In other words, I wanted to explore if the HF diagnosis changed how they react to events or situations that cause them stress and was threaded through interview guide questions 10 and 14.

The interview guide included the participant code number signified by the qualitative (research study) about people with HF and then a number, for example QHF01. I recorded the date, time, and setting of each interview. Participants were told “thank you for agreeing to participate in this study”, reminded that they could stop the interview at any time, and that the interview was being recorded. I also reminded participants to try to avoid using specific names or any identifiable information in the interviews and that any names would be redacted in the final transcript of the interview.

I asked demographic variable questions at the end of the interview and the recorder turned off to avoid bias when recording the interview (Appendix A). Demographic questions included race, ethnicity, highest level of education, employment status (full time, part time, unemployed, or retired). Race and ethnicity information may help provide a clear picture of the study population. Participants’ level of education and employment status can further describe the sample of subjects and to help define their background situations that may influence how they answered interview questions.

Other demographic questions included the participants’ living situation (living alone, or with others, and who they live with). They were also asked how they pay for their medical treatment (insurance or other) and if they had any other comorbidities such as diabetes, lung disease, kidney disease, high blood pressure, lack of or decreased feeling in their feet, and stroke.

These demographic questions help provide a more detailed description of the participants who were interviewed and how living conditions, financial situations, and comorbidities shaped their responses.

The participants were then asked to respond to fifteen questions. The written form of each question includes the concepts from the resilience theory by Greene (2002) in parentheses to show how each question linked to the theory (Appendix A): The investigator started the audio recording here.

"I would like to learn more about your experiences as a person living with heart failure. Think about when you first found out about your heart failure diagnosis. Tell me about your experiences."

- How do you feel you are doing living with heart failure? With this question, I hoped to find out the person's perspective of how they are currently coping living with HF.

1) Were you hospitalized when you found out? Did that make a difference? [Did this hospitalization make you feel like your diagnosis was real?] (Sense of coherence - comprehensibility and autonomy)

This statement helped to guide the general questions asked of each participant with the subtheme of a sense of coherence – comprehensibility and the theme of autonomy in mind. The purpose of this question was to define if the person was hospitalized, in a clinic, or some other place when they learned of their diagnosis. The latter part of the question was to help define whether the participant was affected by the location when they found out about their diagnosis. For example, if they were hospitalized for an exacerbation of their HF, the situation may have made them feel the gravity of the diagnosis. I also wanted to discover if they found out about their diagnosis another way. With these questions I sought the initial feelings of participants when they were first diagnosed with HF. I used the theme of autonomy to further describe how people with HF were able to combat stress and how they were able to manage caring for themselves and maintain independence.

- What were you thinking at that time? (Sense of coherence – comprehensibility)
    - What thoughts were going through your head? (Sense of coherence – comprehensibility)

I asked these questions under the resilience theory (Greene, 2002) theme of sense of coherence – comprehensibility (to get more insight about how each participant felt at the beginning of their diagnosis). In addition, I wanted to know how they were processing what was happening to them.

Question number two was “Overall, how has the experience of being a person with heart failure been for you?” (Sense of coherence – meaningfulness). The purpose of asking about meaningfulness was to understand the participant’s view of the demands of their diagnosis and how they found meaning in their lives. This question encouraged participants to further describe what was most important to them.

Question number three was “How long have you had heart failure?” (Sense of coherence – comprehensibility). I asked this question to gain an understanding of how each participant viewed the length of time they have lived with HF, the impact of their HF diagnosis, and how it may have changed over time.

Question number four was “How has your daily life changed since your diagnosis? (Are there things you cannot do any more or you need help with?) [such as bathing, dressing, housekeeping, and preparing meals]” (Sense of coherence – comprehensibility, competence). This question helped I gain perspective about how participants experienced daily life and if the diagnosis of HF caused any limitations with activities of daily living or instrumental activities of daily living.

Question number five was “tell me about how you feel about having a diagnosis of heart failure? (Emotional changes you have had?; Sense of manageability and competence). These questions helped me to discover if the participants had any emotional changes with their diagnosis of HF and how they managed them.

Question six was “Is there anything you do that gives you a feeling of control over your treatment or symptoms? Tell me what you do?” (Competence – manageability). This question allowed participants to expand upon how they responded to their symptoms related to HF and if anything helped them to cope with their HF. Examples include following their doctor’s orders, exercising, or social support.

Question seven was “Has anyone treated you differently after your diagnosis? Tell me about that?” (Sense of coherence - manageability). This question was to help me discover if the participant felt bias from anyone after their diagnosis which may have caused them additional stress. The participants were encouraged to give examples and to express how they responded.

Question eight was “What physical symptoms do you have related to heart failure and how do they impact your life? (Probe about shortness of breath, fatigue, difficulty walking long distances, attending social events, not being able to do the things they enjoy – travel, picking up/helping with grandkids, et cetera; Sense of coherence - manageability and competence). I included this question to learn how participants’ physical abilities may have changed with the diagnosis of HF. The premise for this question was to find out if the participant was able to overcome any distress (psychological, social, or biological distress) and if the participant was motivated to do activities they enjoy.

What matters most to you?” (Meaningfulness). This part of question eight was key to find out if there were reasons or people that helped motivate participants to have meaning in their lives such as taking care of themselves according to recommendations provided by healthcare providers so they could travel or spend time with their family.

Question nine was “Do you have family members, friends, or neighbors that help you? Tell me about that? (For example, do they help you get to appointments, cook meals, clean house, set up your pillbox, help with refills?)” (Sense of coherence - manageability). I asked this question to find out about social support and specifics about how these people helped participants to cope with their diagnosis of HF.

Question ten was “Do you have family members, friends, or neighbors that make things worse for you? Tell me what that looks like.” (Sense of Coherence - manageability). This question was for subjects to elaborate on whether people made it difficult for them to manage living with HF. This question was used to ask participants about their psychological stressors and how they handled them.

Question eleven was “Are you in a support group for heart failure? Tell me about that? Why did you decide to join? (If they say no) Are you aware of any support groups? Any reason you chose not to join a support group?” (Sense of coherence – manageability). I wanted to find out if participants sought social support beyond their family and friend connections and why or why not they sought this support.

Question twelve was “How do you feel you are doing with your health care provider’s recommendations? (Such as weighing yourself daily, walking daily, monitoring salt intake?)” (Sense of coherence – manageability). This question helped to define if subjects followed their doctor’s orders and what degree they followed them.

Question thirteen was “Do you see your condition improve when you follow those directions” (self-efficacy concept)? (Have you been able to follow directions from your Dr. and have those things made a difference in living with heart failure)? i.e., do you limit salt and or exercise, and if so, what happens?” This question allowed participants to expound on their experiences of heart failure management and the outcomes of their compliance to doctor’s orders.

Question fourteen was “How have you handled setbacks in the past before your heart failure diagnosis? How do you handle setbacks now?” (Sense of coherence – manageability, competence, and self-efficacy). This question provided participants with an opportunity to discuss how they have historically reacted to stress and how they handle stressful situations currently. These questions were designed to help me understand the subject’s self-efficacy or the person’s ability to resist stress or produce intended results effectively.

Question fifteen was “Is there anything else you think we need to know?” (Comprehensibility). As the final question, this allowed participants to further elaborate on anything discussed previously or discuss any new information that they wanted to share.

Discussion of Procedure

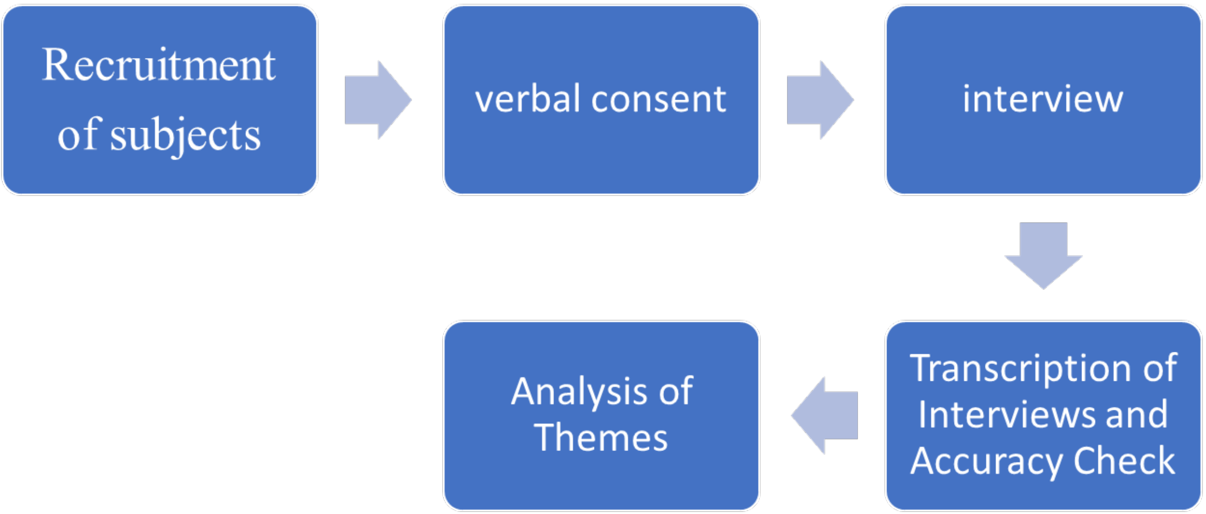
The interviews took 60 to 90 minutes. Participation in the study did not cost the participants any money. The participants were given a $10 gift card per hour for their participation after the interview's conclusion. Each interview was labeled with a participant number, such as QHF01 (Qualitative Heart Failure 01). Interviews were audio recorded and then transcribed after they were complete. The finalized interview questions and prompts are included in Appendix A. The original audio recordings will be destroyed according to the IRB protocol upon completion of this project. Every precaution possible was taken to prevent a breach of confidentiality. If participants used proper names, the names were redacted from the transcript before analysis and archiving.

Presentation of Ethical Considerations

A research study protocol was submitted and approved by the IRB of the university. The following procedures were followed to ensure the confidentiality of study participants. After recruiting participants, I emailed each participant a copy of the consent form. I used only my student email for all digital communication with participants. If the participants did not have or use email and if participants preferred, I mailed a copy of the consent form to them via U.S. Mail. Data analyzed from this research study only consisted of de-identified data, which will be published in a future manuscript. Subjects were notified about the plan for their de-identified data to be included in future publications at the time of their consent to the study.

Figure 3

Brief Flowchart of the Procedure



There was no alternative if subjects did not want to participate in the research study. Subjects who participated in the study were informed that they could discontinue the study at any time during the consent process. The consent stated the possibility of the participants feeling discomfort during the interviews regarding their health condition. Participants were given time to regain their composure. If participants experienced any adverse events or psychological distress during the interview and needed to talk to someone about their feelings, they were referred to a support group or website with resources for persons living with HF. No participants notified me of any discomfort during any interview.

Procedure for Qualitative Data Analysis

I transcribed all interviews promptly after they were recorded. After transcriptions were completed, they were verified to ensure accuracy. Four transcripts were reviewed with the respective participants randomly to confirm that the transcription accurately captured their verbatim words. I analyzed each transcript before proceeding to the next interview and subsequent transcript. The last step of the process was to describe the themes and discuss any relationship between the themes to the resilience theory by Greene (2002).

Inductive analysis with NVivo 12 Pro (QSR International) software program was used to analyze interview data. I used coding to capture themes in the data. The themes from the resilience theory by Greene (2002) were described previously in Chapter One under the Theoretical Framework header. Additional themes were found to help further define the existing themes in Greene’s theory.

Assumptions for Analysis

Assumptions for this study include that people living with HF will develop resilience in managing their illness and that they can articulate their experiences fully. Data collected from this study may help future scientists design strategies for persons living with HF to increase their resilience. Findings from this study may improve their chances of bouncing back from setbacks such as hospitalizations by increasing their awareness of changes that are needed relative to their HF diagnosis.

Lastly, incorporating the resilience theory with new themes in planning care for patients with HF will improve their quality of life. For example, one new subtheme discovered under the theme of self-efficacy was ‘following doctor’s orders.’ A healthcare provider could ask persons with HF how they follow the doctor’s orders and review the current treatment regimen. The healthcare practitioner could ask the patient to explain (teach back method) what has been discussed to ensure they comprehend the correct recommendations. If the patient interprets these instructions accurately according to the healthcare practitioner, the patient may have fewer rehospitalizations and admissions to the hospital. An example would be when a patient calls the doctor because of a weight gain of two to three pounds in 24 hours or five pounds in a week (AHA, 2022b). The healthcare practitioner might change something about the patient’s plan of care to prevent the patient from a preventable hospitalization (AHA, 2022b).

Storage of Research Data

As the primary investigator, I stored interview data on an encrypted password-protected One Drive folder created and owned by the faculty advisor, who shared it with me. I kept anecdotal notes from the study participants to highlight pauses, attitudes, vocal tones, and anything specific to each individual during the interviews. Notes captured the distinct differences in each interview to emphasize particular nuances rather than general responses (Munhall, 2012).

Maintenance of Rigor and Credibility

All transcripts were reviewed for accuracy after transcription and compared to any anecdotal notes the interviewer took during the interviews. Four transcripts were chosen randomly and were reviewed with the participants who provided that interview for accuracy. The names of individual participants and their demographic data were stored separately in an Excel file in a password-protected One Drive file. Only the faculty advisor and I had access to this information to ensure confidentiality.

Chapter Summary

A detailed description of how I performed data analysis, storage, and maintained confidentiality of data for this research study has been described. I transcribed, read, and analyzed all data and made corrections for accuracy. Each question from the interview guide was described in great detail with rationales to explain why I chose these specific questions. Each interview question has a theme in parentheses from the resilience theory by Greene (2002) to show how the questions reflect the theory.

CHAPTER IV: RESULTS

In this chapter the investigator describes findings and results from this study. Demographic variables are described and themes and subthemes from interviews are defined and how they support or do not support Greene's Resilience Theory (2002).

Results

Each of the seventeen patients who stated they had been diagnosed with HF and agreed to participate in an individual interview which was recorded. The investigator read and reread the transcripts through an iterative deductive process to identify common themes determined in the proposed methods in Chapter 3 of this dissertation. Three interviews were not included in the study because the participants identified themselves as patients with HF, but they did not fit the criteria for HF. They described the symptoms of heart disease rather than HF. They did not have the common symptoms of HF, such as shortness of breath or fatigue, and they did not know their ejection fraction. One excluded participant had a heart transplant. Another person had a heart attack, and one said he had a mitral valve problem. The final sample size was fourteen after the three were removed. No new themes were discovered in the interviews of the last four participants which signified data saturation.

Demographic Variables

The demographic variables included age, sex, race, ethnicity, employment status, highest level of education, insurance or other coverage, and participants' comorbidities. Each participant was asked these questions at the end of the interview to prevent bias during the interview. Additionally, these questions were not recorded as part of the transcription to protect the confidentiality of the participants. All data are stored in a password-protected folder owned by the faculty advisor and shared with the investigator.

The specific demographics of the participants were as follows: Average age was 67.1 years (SD = 6.5), five were male (35.7%), and nine were female (64.3 %). Twelve participants were White (85.7%), and two were Black (14.3%). All fourteen were non-Hispanic. The employment status of the individuals in the study varied; seven were retired, two were unemployed (one on disability), two worked part-time, and three worked full-time. Five participants had college experience, four had a bachelor's degree, two had attended graduate school, and three had a master's degree. Eight participants had medical insurance, and six had Medicare (Table 2). Comorbidities varied among the participants, including diabetes (*n* = 8), lung disease (*n* = 5), kidney disease (*n* = 3), hypertension (*n* = 11), neuropathy (*n* = 7), and stroke (*n* = 2). Table 2, Demographic variables, shows that most of the participants were White, had some level of college, were retired, living with a spouse

The investigator recruited participants in various ways. No particpants were recruited from rehabilitation facilities, through UTA faculty contacts, or in the community. Four participants were recruited from previous research studies at the University of Texas at Arlington. The remaining 10 participants were recruited from ResearchMatch.org, an online database of volunteers with many different medical conditions from the contiguous United States and Puerto Rico who were interested in participating in research studies.

Table 1

Where Participants Were Recruited (n = 14)

Participants	**Number**
Rehabilitation hospital	0
UTA faculty	0
Community	0
Previous research subjects from UTA	3
Research subject from another research study at UTA focused on the same population	1
ResearchMatch.org	10

Note. UTA = The University of Texas at Arlington

The inclusion criteria for this research study were people aged 55 and older, self-report of heart failure for at least one year, and able to read and speak English.The specific demographics of the participants were as follows: average age was 67.1 (SD = 6.5), five were male (35.7%, n = 5), and nine were female (64.3 %, n = 9). Twelve participants were Caucasian (85.7%, n = 12), and two were African American (14.3%, n = 2). All fourteen were non-Hispanic. The employment status of the individuals in the study varied: seven were retired, two were unemployed (one on disability), two worked part-time, and three worked full-time. Five participants had college experience, four had a bachelor's degree, two had attended graduate school, and three had a master's degree. Eight participants had medical insurance, and six had Medicare (Table 2). Comorbidities varied among the participants, including diabetes (8), lung disease (5), kidney disease (3), hypertension (11), neuropathy (7), and stroke (2). Table 2 shows that most of the participants were Caucasian, had some level of college, most were retired, living with a spouse or other family members and paid for treatment with either insurance or Medicare.

Table 2
Demographics Summary (n=14)

Demographic Variable	***n* (%)**
Sex	
Male	5 (35.7)
Female	9 (64.3)
Age (years)	67.1 (6.5)
Race	
White	12 (85.7)
Black	2 (14.3)
Ethnicity (Non-Hispanic)	14 (100)
Employment Status	
Retired	7 (50)
Unemployed	2 (14.3) (One on Disability)
Full-time	3 (21.4)
Part-time	2 (14.3)
Highest Level of Education	
Some College	5 (50)
Bachelor's	4 (28.6)
Some Graduate School	2 (14.3)
Master's Degree	3 (21.4)
Insurance or Other	
Insurance	8 (57.2)
Medicare	6 (42.9)

Note. *SD – Standard deviation percentages may not add up to 100 due to rounding.

Procedures

Each participant received a consent form to review by email or by United States mail if the individual did not have email prior to scheduling an interview. All of the participants had access to email. After obtaining verbal consent from the participant over the telephone, I conducted the interview the individual for 25-90 minutes in a private office. The participants were instructed to use a private place in their residences to participate in the interviews.

Were the Research Questions Answered?

The research questions were:

1. How do older adults view their health before, during, and after their heart failure diagnosis?
2. How do older adults manage living with heart failure?
3. Does having heart failure change the way you deal with challenges?

The first research question, *"How do older adults view their health before, during, and after their heart failure diagnosis?"* was answered in a variety of ways. Before their diagnosis, many participants said they did not exercise or monitor their diets. Some participants said they changed their diets dramatically and started eating better, for example, consuming fewer carbohydrates, more salads, and more water. Others indicated that they watched their salt intake and followed their doctor's orders about fluid restriction. Overall, participants were more aware of their symptoms and health issues than before their diagnosis. During the process of HF diagnosis, most participants expressed initial feelings of denial followed by acceptance.

In some cases, it took participants up to a year to come to terms with how their lives would be different. Many started to exercise to try to improve their condition. One participant commented after talking with the cardiologist:

> He said, 'you're free to do what you feel like you can do,' so I walk the dog, but we also, we also go to the gym once a week, uh, and hopefully that will increase to twice a week, but we've been, you know. We, we've started at the gym before COVID" (QHF09).

Research question two, *“How do older adults manage living with heart failure?”* received robust responses and garnished the most data. Participants stated they had family and friends that helped them. One participant related difficulties brought on by the family trying to help but not agreeing on how to help. Another participant discussed how her husband and son did not always get along although they all lived under the same roof: “Well, there's a conflict with the personalities sometimes and, uh, that's very stressful for me, ya know? Can’t we all just get along?” (QHF08). An example of how family helped was, “I have a great support system, you know, we have two children and their wives, and our grandchildren. We have three grandchildren. They're all very supportive” (QHF05).

Another example of the importance of social relationships was demonstrated in this statement by a participant:

> I go out to lunch once in a while with my girlfriends, and when they have (a) birthday, in fact, I was just out on Monday with a group of girls and then on Fridays a birthday party. We get together, but like when, when, when there is a function, I will go” (QHF02).

Several participants mentioned having a good healthcare team to help them manage HF. Another common thread throughout several interviews was learning to pace activities to prevent fatigue and shortness of breath. A few participants ordered groceries online to be delivered and had people clean their houses:

> Oh, it's been, well, of course, it's limited my, my ability to do a lot of things and, uh, as a matter of fact, right now, I have a lady that comes over three days a week for five hours a day to do my laundry, and dishes, and floors. You know (it) limits my abilities because I can't do for (myself what a) normal person (could) do. (QHF08)

Responses to research question number three varied. Interestingly, the answers from participants for research question number three, *“Does having heart failure change the way you deal with challenges?”* was about how participants felt they dealt with setbacks after their HF diagnosis. Their responses to challenges were often the same as before their HF diagnosis. For example, one participant said, “Um, I usually I just work my way through” QHF04. Another participant said, “my family member(s) always, you know, overreacted to everything, and so I just go the opposite way just because, just because I think it's wise too, you know” (QHF05).

Thematic Analysis

Transcriptions of the interviews were read and reread for common themes. The themes from the interviews correlated with the concepts from the resilience theory by Greene (2002). However, I discovered new themes that described those responses in greater detail. Study participants' perspectives were better understood by incorporating these new themes and facilitated learning how they viewed their coping abilities to manage HF (Table 3).

Table 3

Greene’s Resilience Theory (2002) Themes and Subthemes

Resilience Theory Concepts and Subconcepts	New RelatedThemes and Subthemes
Autonomy	-
Competence	
	Reaction of Patient
	Negative Reaction (Subtheme)
	Positive Reaction (Subtheme)
Self-Efficacy	
	Self-Determination
	Adherence to Dr’s Orders
Sense of Coherence	
Comprehensibility (Subconcept)	
Manageability (Subconcept)	
	What helps you manage?
	What makes managing worse?
	Sense of Humor
Meaningfulness (Subconcept)	

Note. Resilience Theory (Greene, 2002) concepts and subconcepts are in the left column. New themes and subthemes found that support these concepts and subconcepts are in italics on the right (they were not in the original Resilience Theory by Greene, 2002).

Autonomy Concept

Being able to maintain independence was mentioned by several participants.

> Yeah, if I have everything that I need I'm at home, you know it, it's, it goes even as far as if I know I'm, I'm not feeling well or I'm having a moment, I will even pay my bills, if that makes sense, because I don't, I don't know what's gonna happen in the next few days. So, on the onset, that's one of the things that flashes into my mind how, how I'm gonna deal with work. Um. Changing with, you know, changing my schedule around. It's those, it's those kinds of things. That as long as I know work is taking care of, you know, my medication is taken care of, home taken care of, that gives you more self-control. (QHF04).

Some expressed discouragement that they could not do chores or tasks as they would like to but tried to manage what they could do. "I used to drive to New York, but I've gotten so that I can't drive that long a period anymore, which is upsetting for me 'cause I would go to my daughter's myself." (QHF06).

Another idea expressed by many was the idea of gauging one's energy level to make sure they did not wear themselves out further by doing too much:

> It's a constant battle daily, uh, because you, it's just, how you feel and uh, like I say, some days are better than others. And I might have a pretty, pretty good feeling when I get up in the morning whether I'm gonna be able to get much done. (QHF15).

Table 4 provides additional responses.

Table 4
Autonomy Concept from Greene's Resilience Theory

Concept	**Participant Quotes**
Autonomy	And that was part of that mind shift at that point in time. I also made the decision it was time for me to take care of myself. (QHF07). Yeah, I do, I take a strong role and I, and I try to, you know, I'm, I'm on top of all of my medications. I'm always trying to reduce the amount of medication I'm taking if it's, you know, logical and, um, so, you know, I do what I can within the, you know, the limits of reasonableness, I guess. (QHF09). I'm, I try to be as independent as possible. (QHF11)

Competence Concept

Competence has been used to describe one's ability to overcome distress and perform adequately in psychological, biological, and social activities (Greene, 2002). "Ya know, it almost makes me sound selfish, but um, once you put your health first, actually it's better for everybody else too." (QHF07). Another participant described how he cleaned house "like kind of, or after break things down and do a little bit, a little bit, a little bit, it takes me, you know, a, a, a ton of time to get something done." (QHF11). Another person commented, "I still get winded, and if I do too much too fast, I can still, you know, uh, I have to sit down and make sure I catch my breath, and then I'm OK, and I'm back up going and doing." (QHF10). Table 5 provides additional responses.

Table 5
Competence Concept from Greene's Resilience Theory

Concept	Participant Quotes
Competence	The ADLs [activities of daily living] I'm still doing all by myself. (QHF11). Because you do different things. I think I learned (over) time that I had to adjust. My, if it was the fluid, even know my ankles went real big, they would be bigger, but not like you would normally expect. Um, I with the help of doctors and stuff they taught me how to, um, juggle the Lasix and then I also have to take potassium with it. (QHF07).

The Reaction of Patient – New Theme

This theme was discovered when participants would describe how they responded to their diagnosis, limitations because of HF, or frustration with others (family members and other patients with HF in cardiac rehab programs or support groups). This subtheme was further divided into 'positive reactions' and 'negative reactions.' A positive outlook helped some live more fully rather than focusing on their limitations. They appreciated what they could do each day. A negative reaction was a coping mechanism for some who stated they lacked social support or the ability to do what they enjoyed. Table 6 provides additional responses.

Table 6
Reaction of the Patient

Concept	Participant Quotes
Reaction of Patient – New Theme	"Houston, we have a problem." QHF01 "So, um, but the bottom line. I was in denial" QHF07.

Positive Reaction Subtheme

This subtheme describes how people have an optimistic outlook on life and can cope with changes.

"Even though I was scared, I was relieved too, at the same time 'cause I had, you know, an answer." (QHF12).

> Well, (long pause) I, I handled them as good as I could, um, and I did have problems with the children and then with my husband at one time and, um, but I always I never gave up. I always got myself out of it with, with work and just determination. It wasn't, it wasn't easy all the time, but I, I'm not a depressed person, really. (QHF02).

Some participants had a "push through" mentality, like this participant:

> I can usually tell when I get up in the morning what kind of day I'm gonna have. Um, and then I take my, I weigh myself daily to see if the fluctuation in weight with the fluid and uh, then I take my blood pressure (to) see if I'm out of rhythm 'cause I have A-fib, uh, and uh, the A-fib usually comes along because uh, I just uh, I don't know. I just (have) that dragging feeling that you get with heart failure, um, and um, but I still, you know, I don't let it stop me. (QHF15).
>
> Another example of a positive attitude is this quote by QHF10:
>
> I do not let myself get this 'I'm so tired, I can't do this.' Now, if I sit down to watch a movie, or if I have worked really hard in the kitchen, or I've been running around a lot

> doing different errands and stuff. You know, I can sit down and do something, you know. But no, you don't let (it); you stay active. (QHF10)

Table 7 provides additional participant responses.

Table 7

Positive Reaction Subtheme

Concept	Participant Quotes
Positive Reaction Subtheme	““Yes, I did have a little more things (faith) in the medical profession at that point, but I knew that as long as I, I stuck with the regimen (pause), that I have a normal life.” QHF16. I think it's good for me just to do things. Sometimes when you don't feel good it's easier to say, to have somebody else do things for you. I need I really need to do as much as I can myself. QHF02. At first, believe it or not, I was relieved because I've been a year and a half trying to figure this out and it was like, I'm not crazy after all! There really is something wrong with me! QHF12.

Negative Reaction Subtheme

This subtheme reveals how some people can view their lives with a negative outlook on life and or problems. ‘It's very frustrating trying to navigate and realize that this is my life now, and having to learn to deal with it, deal with it as best I can” (QHF12). One respondent gave a detailed description of the fear she was living with after her diagnosis. “Ohhh, well, I've lived alone most of the time, so it was just really, really, really, really, really scary. It's just not knowing, like, it's like at first, every little symptom or sign, I thought I was dying (she laughs) (QHF16). Another expressed her fear after the realization of her diagnosis “I was shocked 'cause when you see heart failure, that's scary. That, those two words (heart failure).”

One individual described feeling depressed “Cause, uh, well when you don't feel well, you're trying to work, you just feel like the world is coming down on you.” (QHF04). Another person explained how they felt anxious “Uh, it's had it's ups and downs. Um, it has given me, well it (HF) and the other diagnoses, have given me, or created in me a lot of anxiety.” (QHF11). Table 8 provides addition responses.

Table 8
Negative Reaction Subtheme

Concept	Participant Quotes
Negative Reaction Subtheme	“But on days I’m feeling a little tired or, or just really tired, and I need to go lay down, and it gets to be aggravating to think, you know, I can’t do more.” QHF12 It the beginning like, like I said, I was um. They haven't given me like a, I don't know, it was a prognosis of like the, they said the average person survived like seven years post diagnosis. That was scary. Like the first seven years was really awful. QHF16.

Self-Efficacy Concept

This theme defines one’s ability to resist stress or produce intended results. An example of this would be a person believing they can accomplish their goals for therapy. This concept is reflected in an attitude of believing in oneself. Table 9 provides some participant responses.

Table 9
Self-Efficacy Concept from Greene’s Resilience Theory

Concept	Participant Quotes
Self-Efficacy	“I actually have a journal that I bring into her that shows my daily weights, blood pressure. I guess daily weights, blood pressure, and my glucose, and my weight.” QHF11 Yeah, yeah, yeah, it definitely gives me those clues and it's strange that now the older I get because I wanna continue to live. Uh, that I’m balancing out even more so and, and, and do the right thing and try my best to do the right thing for longevity's sake. QHF04.

Self-Determination Theme

Self-determination was a subtheme repeatedly shown in interviews about how patients with HF forged ahead with life events despite their diagnosis. This subtheme could be considered a surrogate marker for self-efficacy. One person stated she continued attending social gatherings as best as possible.

> I'll go to social functions, and if, if I feel like I'm getting tired, or it's wearing me out, or something, I'll just, I'll just tell (them) I'm not feeling good. I go home. But, uh, I generally try to hang in there. (QHF08).

Some participants wanted to have a proactive role in their medical care.

> You guys keep giving me all this potassium because you're having a hard time controlling the potassium. I understand that potassium can affect your heart in a small range, but I'm seeing them come back through. QHF07).

Another HF participant told a story about her self-determination to climb a massive stairway on one of her vacations.

> And I made it to the top. It took me about 15 minutes, but I made it, and then coming down is a little bit hard too, but, uh, you know, I was just determined that I'm doing some things, and doing differently, and doing (things) that I wanna do. (QHF10).

Another participant illustrated her self-determination:

> I'm tougher. I'm like, uh, for and a lot of people tell me, how my friends (comment) ‘I don't know how you deal with what you deal with (it).’ I do it number one 'cause I have to if I wanna be here. So, you just, you, you soldier on. I mean, there are those moments where you just curl up in a little ball and just cry, cry, cry, but, you know, you gotta get up and keep going. And that’s how I feel about heart failure. You get up and keep going one step at a time. (QHF04)

Table 10 provides additional participant responses.

Table 10
Self-Determination Theme

Subtheme	Participant Quotes
Self-Determination	“To get up and exercise even though I don't want to. You know, but you know, it's just kind of one of those, like you take vitamins, yeah, you're (gonna) go exercise, you know?” QHF05 That’s a place where I need, I want to try to improve. I'm wanting to get off of the Furosemide, uh and back to a homeostasis, if

	you will, with, with that bodily function rather than relying on the drug. QHF09 Adherence to Doctor’s Orders Theme

Adherence to Doctor’s Orders Theme

In this subtheme, the investigator noticed several participants remarked whether they followed their doctor’s recommendations. For example, one participant stated: The thing that they say is do what you enjoy, you know, keep track of, of things that you think are critical, keep it, keep in touch with us. Let us know if you have any questions or whatever and, but no, he just said, you know, ‘don't just sit at home and, and be worried,’ you know. (QHF05).

Another person described how she did what she could to follow her doctor’s orders but felt overwhelmed:

> Like, like I can tell the doctor I guarantee you that I'll check my blood pressure at least three or four times a week. I'm not gonna say every day. Uh, the weight I do, I do, do that every day. That's the only thing that I do every day, and the blood sugar every day. (QHF04).

This participant emphasized the importance of following the doctor's orders:

> The only way I have any control over this is to keep up with my doctor visits, all the medication, and the stress test, and the, they've done the, uh, thing where they do the MRI on your, your legs and arms and everything, to check out your veins. So, I mean that, that's the only way I can battle it. It’s just doing what the doctor says. (QHF08).

Both self-determination and adherence to doctor orders subthemes support the Greene’s concept of self-efficacy in the Resilience Theory. See Table 11 for additional responses.

Table 11

Adherence to Doctor's Orders Theme

Sub-Theme	Participant Quotes
Adherence to Doctor's Orders	Yes, I do watch it and I don't, we don't eat a lot of cold cuts anymore, like they have a lot of salt. We got away from that, but, and I don't salt a lot. I do put a little bit of salt in the food, but now that my husband cooks, he puts nothing in there. So, I do have to salt a little bit, but I try not to put too much on. (QHF10). The only way I have any control over this is t*o* keep up with my doctor visits, all the medication, and the stress test, and the, they've done the, uh, thing where they do the MRI on your your legs and arms and everything, to check out your veins. So, I mean, that, that's the only way I can battle it. Is just doing what the doctor says. (QHF08).

Sense of Coherence Concept

The theme 'sense of coherence' has been described as ways people remain healthy and it is divided into three subconcepts: comprehensibility, manageability, and meaningfulness, according to the Resilience Theory (Greene, 2002). Examples of a sense of coherence include help around the house from others and anything that helps them. "Like for cleaning, laundry, and cooking. I hire people to do those things for me. Well, there's a service that will send someone to help you for the day. They can help me bathe." (QHF16).

One participant knew the amount of blood pumped out during each contraction: "My ejection fraction was 15%" (QHF01). Considering that the normal ejection fraction is between 50 and 70 (AHA, 2022b), this person knew how severe their HF problem was. Additional participants' responses are in Table 12.

Table 12

Sense of Coherence Concept from Greene's Resilience Theory

Concept	Participant Quotes
Sense of Coherence	"So, I knew what to expect when I found out that I was (having surgery); all that didn't scare me." QHF01

Comprehensibility Subconcept

Greene (2002) defined comprehensibility as “the ability to understand a situation.” One participant who was a retired pilot stated, “but, yeah, that's the hardest thing. I couldn't fly. The other thing is I was involved in ranching and farming. And, uh, I had to take off. I couldn't do normal things you do working with cattle.” (QHF01).

Some participants talked about being realistic about what they could accomplish around the house, such as chores. “And also, whatever doesn't get done will get done another time. I'm not that picky anymore like I used to be.” (QHF02).

Table 13
Comprehensibility Subconcept from Greene’s Resilience Theory

Subconcept	Participant Quotes
Comprehensibility	“And this came out of left field. And, uh, I had no idea. It was, it was overwhelming at first. And at first, it was like it was surreal. And (husband) I kept it to ourselves for probably two or three years. We didn't tell (any of the kids), we didn't tell anybody, and we just kept it to ourselves, like well, we're gonna see what we're dealing with, what this is.” QHF10 “He said, ‘Oh no,’ he said ‘no you won't, you won't die from this. You’ll, uh, die from somethin’ else,' but he acted like, ya know, it’s gonna really affect your quality of life.” QHF12

“It was after I went to a cardiologist in XXXXXX, which is about 2 hours away, they completely reassured me and said, you know this is treatable. Yes, you're in heart failure. Yes, your output is not great, but you can live a long, you know, healthy life with heart failure.” (QHF05).

One participant, QHF05, described how he learned to accept help from others when before his diagnosis, he was the one who often helped others. He stated this was a change in perspective for him.

> And then once I saw how, you know, people were doing the same thing that I used to do, you know, eager to help and, ya know, no problems, and no stigma, or anything, then it was like 'OK, maybe it wasn't as bad as I imagined [he laughs]. (QHF17)

Manageability Subconcept

This subtheme describes how people with HF find things or people that help them manage their condition or cause barriers for them to managing their disease process. Under the subtheme of manageability, the following subthemes were discovered:

- What helps you manage? (Others that help, watching diet, weighing daily, etc.).
- What makes managing worse? What things or people feel like they are barriers to your managing well?

The subthemes for manageability were labeled for comments from study participants about how they coped living with heart failure. Some participants mentioned they were supported by family members and friends, and others said they wanted to live longer to be there for their families. Several participants noted that they limit their activities and rest more during the day to reduce exhaustion. By noticing increased symptoms such as shortness of breath, they stated they could conserve energy. A few examples of not managing well include people with HF pushing themselves beyond exhaustion and lack of social support. These situations make people with HF feel they cannot cope well with their condition. One participant stated that it took him days to recover when he pushed himself to do things when he felt tired. These examples further explain Greene's (2002) theory of manageability:

- Sense of humor: (light-hearted attitude/comments)
- What matters most (what is most important to individuals in life?)

A sense of humor helped a few people with HF to handle their diagnosis light-heartedly, so they did not focus too much on the daily struggles of their condition. 'What matters most' was one of the questions in the interview guide, and several participants stated they considered their families and friends their social support system that helped them to manage. See Table 14 for additional participant quotes.

Table 14

Manageability Subconcept from Greene's Resilience Theory (2002)

Subconcept	**Participant Quotes**
Manageability	"Well (I can) I dress myself. It's, I have, you know, it exhausts me, but I can dress myself, and I can shower myself." QFH02 "I don't get worked up or upset and very easily" QHF06 And the other thing I was active doing my yard and all that kind of stuff. I still do it and I do two my neighbors elderly ladies and I do theirs just to help them out and it's also part of my exercise routine. It doesn't bother me because If I were to get tired or hot, I just come inside cool off, right. QHF01

After further analysis, I decided that these examples fell under the concept of manageability in Greene's resilience theory (2002). Rather than noticing new themes unrelated to the resilience theory, I found themes that supported the concepts in Greene's theory.

What Helps You Manage? (Theme)

This subtheme describes how people with HF manage their disease. Some mentioned following their doctor's orders and limiting activities based on energy levels. Others mentioned social support from family and friends and eating healthier diets. Lastly, some said their basic personality was optimistic and non-reactive to stressful life events. Some examples include: "I always draw back, and also, I grew up in a military family. And one of the things you're taught, even as (a) child, you know, in public, you hold your emotions, you do." (QHF01).

> Having little grandkids. They're just my joy, and they are really an incentive for me too, and you know, be around for a while, right? But I don't know. Some days, when I feel better, I feel like more optimistic. (QHF02)

Another example was:

> We go with the kids to the store or to lunch, and my daughter-in-law is really good about, uh, she knows. As long as I have a shopping cart to hold on to, I'm fine. And, uh, nobody really excludes me from anything. (QHF02)

See Table 15 for additional participant quotes.

Table 15
What Helps You Manage? Theme

Theme	Participant Quotes
What helps you manage?	“I've dealt with elderly parents that had to take care of them in Hospice situations, and so I knew a lot of what to expect once I found out. And also, I had a backup that most people don't have. I have my family - there are a lot of nurses and my family.” QHF01 I still get winded, and if I do too much too fast, I can still, you know, uh, I have to sit down and make sure I catch my breath, and then I'm OK, and I'm back up going and doing. (QHF10)

Limiting activities

Several participants discussed how they learned to limit their activities to preserve energy. “I may change what I do, and I am the housekeeper. Um, it's not like I have help to do that, um, so there are certain things that I just won't do, and second of all, I'm too tired” (QHF07).

> I just do things slower now. Like at one time, you know, I could clean my whole, my whole apartment, things like that. And there's times when I can only do a little bit of that, of one room. And that's how I tackle it, everything, you know. (QHF04)

Social Support

Several people mentioned social support to help them manage around the house. One participant described how her fiancé helped around the house “he's highly entertained! He, there’s no lack of things to do for, he helps around the house a lot.” (QHF08). Some described their healthcare providers as their social support.

> Yeah, yeah, yes, they, they definitely helped, and are helping me, have helped me with the quality of life, and it's, it's so, so important. It's so, and I know the doctors and nurses and things are out there to mentally help you get through things. (QHF04)
>
> I knew who was in my corner 'cause those people were still here. Now, I have some really good friends that have been around for 30-plus years. That's why I said try, try not to lean on people because, you know, they've been through it as much as I have, and it's, it's, it's hard to see a friend go through what they go through. Ya know, friends are like family (laughs). So yeah. But, yeah, I have, I have a support system that‘s, um, that’s pretty good. I wouldn't trade any of them in for a thousand people, the five or six people that they're there for me. I wouldn’t trade them in for a thousand people. (QHF04)

Another research participant described how a local group of college students helped her with challenging tasks.

> They do light housekeeping, or they helped me with a lot of activities. And when I moved in here, I had students, and I put stuff on the dining room table. They would pack it up and put it in boxes and load up my car, so I could drive it to Goodwill or wherever. (QHF06)
>
> One participant described her fiancé helping with cooking “I was able actually to make the meals still about I would say about 3-4 months ago, but now um he usually sometimes we do it together. And I sit down while I drop something, but he does a lot. He got so good at cooking that I let him. (QHF02)

Eating Healthier

Several participants mentioned eating healthier diets to improve how they felt. An example was from a person who had lost forty-five pounds, and she described how she did it: *“*I just eat better. Like I don't choose the starches. I don't choose the breads. I don't choose the sweets. I'm eating better vegetables. I'm eating better meats, leaner meats, and drinking tons of water.” (QHF10). Another participant stated, “and I don't eat desserts, and I don't eat, I cut, I don't eat carbs much. I eat vegetables and eat meat mostly.” (QHF06).

Optimistic Attitude

Some individuals expressed optimism as an attitude of making the best of living with their HF condition. They described a change in attitude after their diagnosis. One subject said, "And being kinder to myself. I quit trying emotionally, if I can't do something, like what I want to do, it's not working out like it is, but try to forgive myself." (QHF07). "I didn't expect it, and nobody does expect to be in this shape and when they're just 60, but there's always somebody out there worse than I am." (QHF12).

Exercise

A few participants mentioned exercise as a way to manage their HF condition. Some stated walking was helpful, and others said continuing to walk to stay in shape and do things they enjoy, such as traveling. "I just walk. I don't have any, I haven't added anything yet, but I intend to once my body adjusts to the walking. So, I walk about 30 minutes, you know, every day." (QHF05).

What Makes Managing Worse? (Theme)

This theme describes any situations or problems that make managing HF difficult or challenging for participants. Some participants described symptoms they felt difficult to manage that caused them frustration or lack of energy and affected their mood.

> Yeah, so it just never seemed like I can't, I couldn't balance it all out, you know, and how my body would, you know, retained the fluid and stuff. I just never, never, never worked. I just, I just couldn't get it there. I mean, it's still a struggle. (QHF04)

Another example was:

> I just lost my breath. I couldn't breathe. I was walking around the house and my wife and kids are looking at me like 'he's gonna die', you know, 'cause I was, uh, you know (acts like he is wheezing). QHF12

See Table 16 for additional participant quotes.

Table 16

What Makes Managing Worse? Theme

Theme	**Participant Quotes**
What makes managing worse?	I just have to come you know to the best I can I have a really hard time doing things when I'm on my feet. I'm, I'm fine when I'm resting, but when I'm on my feet doing things or carrying stuff I um I get so exhausted. QHF02 (I) was tryin' to say when I felt really bad, just all day long and hardly could do anything. It got depressing, you know? (QHF12)

Lack of Social Support

Social support was an issue for some individuals. Problems arose from disagreements between family members on how to help or lack of support from family and sometimes friends, which was a prevalent theme in the interviews. Some participants experienced a lack of social support or felt they were treated differently after their diagnosis. Others described feeling controlled by their family and friends as in this example from a participant.

"So, yeah, the lack of support from my kids is hurtful" (QHF06). She went on to say, "My daughter in New York, we go to visit her, and she thinks the cure for my problem is just to walk faster in New York City." (QHF06).

When asked about people who made things worse for her, one participant said, "That would be family. Like any time they would try to help me, it would give me a headache". [She laughs.] (QHF16).

Another person stated:

> It would, it would just be way too much, and I just I would rather deal with strangers. I know that sounds weird… it was just kind of like them treating me like a child, and I just could not stand [that]. (QHF17)

Different Treatment After Diagnosis

Some participants stated they felt like others treated them differently after their diagnosis. For example, "I would say, I got upset. People find out you got heart failure, and immediately they treat you like a China doll, you know, you're gonna shatter if you do everything." (QHF010. Another subject commented, "I'd hear comments, and they weren't meant to hurt. But it's like, I couldn't keep up with my family." (QHF07). One participant stated she felt judged by her friends "My dear friends don't walk with me 'cause I'm so cotton' pickin' slow." (QHF07). Another person interviewed tried to explain his condition to others by saying:

> When you tell people stiff heart syndrome, they kind of look at you like, what does that mean? You know, or did you make it up, but you know, it's like, um, what does that mean that you know, they don't know how to react 'cause I don't know what it means, you know? It's just got trying to tell me he's dying. What does this mean? [He laughs because of the confusion of others when he tells them he has stiff heart syndrome] (QHF12).

Family Causing Stress

Some subjects stated they felt others tried to dictate what they should and should not do.

> My sister did, neighbors. I have a neighbor who's a retired urologist, and you know she was sort of want, coming over, you know? 'Don't let him do this, don't let him do that.' And she was correct in some respect, but you got frustrated with it, you know. I, you know, it's also that time getting used to the new diet, and you know everyone was on me about that 'cause I one of the things my sister was in the hospital initially came over and, you know, went through every scrap of food in the pantry, yeah my niece got a lot of good stuff (laughs)! (QHF01)

Another participant stated she was stressed by her fiancé and son arguing: "Well, there's a conflict with the personalities sometimes and, uh, that's very stressful for me, ya know? Can't we all just get along?" (QHF08)

In summary, these more detailed themes under the concept of manageability support the resilience theory and the concept of a *sense of coherence*. Example quotes illustrated how participants either felt they managed situations (or people) that caused them to experience difficulties managing their health condition.

Sense of Humor (Theme)

Humor was used by several patients interviewed. Humor may have helped them to cope with living with a chronic disease. “Well, my, uh, my numbers are looking pretty good now, so they're not fussing at me.” (QHF04). “My neighbor who keeps mowing my yard. I keep telling him not to, and he keeps doin’ it anyway! [He laughs].”

One participant warned, “You don't wanna get heart failure. It's not, it's not, it's all the salt, all the salty things will be taken, all the pretzels, all the salty things will be taken away from you!” (QHF04). This same participant also described how it was challenging to change her habits about shopping for healthy foods. “Oh, I wanted to get some fruit, and some way, I was in there before I knew it, I was on the chip aisle!” (QHF04).

Another participant admitted that services help her “If it weren't for chewy.com, my dogs (would have) starved! [She laughs]” (QHF08). The same person said, “humor is a good way to avoid stress!” (QHF08). See Table 17 for additional quotes.

Table 17
Sense of Humor Theme

Theme	***Participant Quotes***
Sense of Humor	**“**I was counseled by my cardiologist that I should only (cough) ingest a liter and a half worth of fluid a day. When ya know, when I said, good golly Doc, that's not even four beers!” QHF09 Well, my, uh, my numbers are looking pretty good now, so they're not fussing at me! QHF04 One of the nurses told me several years ago ‘the couch is your enemy’! [She laughs]. QHF05

These participants found humor a helpful coping mechanism for dealing with their HF condition. Humor is another example of a subtheme that fits well with the Resilience Theory by Greene (2002) under the subconcept of manageability.

Meaningfulness Subconcept

This theme describes how people with HF feel they can find meaning in the demands of life situations (Greene, 2002). Several individuals stated they want to give back to others with similar health conditions. “So, I want to come away from this if I leave this earth tomorrow knowing that I had some kind of impact on somebody. That's why I agree to do this with you today.” (QHF04). Another idea expressed related to meaningfulness was the idea of accepting limitations.

> I don't want to be limited. I, I don't. I still haven't come to terms to accept that. Sometimes my body, I'm forced to by, you know, how my body reacts, but I, I tend to not accept. (QHF11)

When asked what matters most to you? Participants explained what or who motivated participants to continue to manage HF. Participants shared the people, things, hobbies, or experiences they valued most and what motivated them to live their best lives and take care of themselves.

> My grandkids, my little grandkids. That they sort of, uh, I want to be around for them, so I try my best not to, you know, to do as many things with them as possible 'cause I love those two little guys. (QHF02)

> Being able to interact with family, friends, you know, that's the most important thing and, you know, probably is, but you know, in among that, you know, exercising, you know, being able to do, you know. It's important to me to be able to maintain, you know, my independence. (QHF09)

> To be able to function, to go, and do, and to participate with my family. To participate in events, I enjoy. I'm in several women's groups, Bible study groups, my church group. I wanna do family functions first and foremost, and of course, I'm retired, so I'm not working anymore and, uh, but I, I just wanna be able to (if) somebody calls me on the phone and says, ‘let's go do this,’ by golly, I'm there! (QHF10)

> Just being able to be there for my family and being able to just do, ya know, I'm thankful that I can still do a lot of the everyday things, um, ya know, before this all happened. I was always the person to do for others, and it was really hard for me to accept the fact that I needed help from people for my condition. (QHF17)

See Table X for additional quotes.

Table 18
Meaningfulness Subconcept (Greene's Resilience Theory)

Subconcept	**Participant Quotes**
Meaningfulness	"He said, but you were born with this. He said it's a mild case and he said, but that explains so much, so." QHF10 I've been thinking about ways that I can help 'cause I've been dealing with it for so long. How I can help and kind of like give back to heart failure patients. So, I want to come away from this if I leave this earth tomorrow knowing that I had some kind of impact on somebody. That's why I agree to do this with you today. And I always look for ways of what I can do to get back to me on a limited income and not always feeling good so I decided what people can learn about me and my struggle, will be my way of giving back." QHF04 "So, I knew what to expect when I found out that I was (having surgery); all that didn't scare me." QHF01

Chapter Summary

This chapter contains the study's findings related to the Resilience Theory's concepts (Greene, 2002). New themes and subthemes that support Greene's Resilience Theory (2002) are identified. All of the research questions are answered and described in detail.

CHAPTER V: DISCUSSION

This chapter focuses on the alignment of findings from this study and current literature. The chapter includes the interpretation of the research data, limitations of the study, and research conclusions. I also share its implications for nursing practice and ideas for future studies.

Interpretation

This study differed from previous research on resilience in patients with HF because it focused on resilience in people with HF and how they coped with their diagnosis. The investigator used qualitative methods to discover how those with HF perceived they were managing through patient interviews. This information would have been difficult to find any other way.

Many researchers have used resilience scales to measure resilience in those with chronic illnesses (Battalio, Tang, & Jensen, 2020; Gheshlagh et al., 2016; Heo & Kim, 2020; Manning, 2016; Tecson et al., 2019). This study incorporated interviews to discover patient perceptions.

This qualitative study revealed new subthemes during the interviews of fourteen participants and these could be added to the Resilience Theory by Greene (2002). The new themes fit well with the original themes of Greene's Theory.

Using the theory by Greene (2002) with the expanded themes and subthemes, healthcare providers (HCPs) can interview HF patients and design a care plan collaboratively that could potentially increase their quality of lives. By improving patients' quality of life, they may feel more competent in managing the signs and symptoms of HF, which could help them to be more resilient.

Several participants in the study voiced concerns about not fully understanding their HF condition, treatment, and its progression. HCPs need to ensure that patients are clear about their orders and understand their disease process. Some participants explained how they had experienced exacerbations from HF and did not know how to avoid problems managing it. A few participants voiced concerns about taking medication such as Lasix due to urinary frequency. Others felt like they did not need to take their medications as prescribed because they had a good report from their HCP or did not weigh themselves or take their blood pressure daily.

Limitations

The limitations of this study were that the study participants were a convenience sample and may not represent the population of all patients with HF. Some participants were recruited from previous research studies, but most participants were recruited via ResearchMatch.org. Another consideration one must evaluate is that ResearchMatch.org was used to recruit study participants from all over the U.S. This may increase the generalizability of the results of this study for those living with HF in the U.S, but may not represent those living outside the country.

Another limitation of this study was that the investigator discovered three participants who agreed to participate in this study after reading the consent form had heart disease rather than heart failure. When asked about their symptoms, one excluded participant stated he had a heart attack, and one said he had a mitral valve problem, and the last mentioned a heart transplant. None of them were explicitly diagnosed by a HCP with heart failure. The interviews for this research study were based on self-reports of heart failure and these excluded participants lacked the symptoms of heart failure.

In future study designs, the investigator may define heart failure by cardiac ejection fraction and specific symptoms in the inclusion criteria. However, the discovery that participants could not distinguish heart failure from heart disease is an interesting finding.

Some participants were part of another study conducted at the same site with patients with HF by another investigator. Most participants were recruited from ResearchMatch.org. This organization consists of people with various diagnoses who are interested in participating in research with researchers at institutions across the United States and Puerto Rico. They desire to contribute to the knowledge and study of diseases and health conditions. Self selection bias may affect those who participated in this research study. These participants are possibly atypical of the entire older adult population with HF. Although this site is a valuable resource for researchers, participants may not be representative of all who live with HF.

The majority of participants were White (85.7%), although two were Black participants. These people agreed to participate in the study, but other races could have been represented if individuals identified as such had chosen to participate. This lack of racial diversity was another limitation of this study.

Covid-19 was prevalent during the time of this study so I decided to conduct phone interviews rather than meeting in person. This decision made it easier to recruit participants because few candidates were meeting face-to-face in clinics or support groups. A creative solution to finding participants was the use of ResearchMatch.org online website as a means of recruitment. This organization had well-structured digital presence which was easy to navigate online. Over 300 subjects were potential research participants according to the inclusion criteria. I selected five to ten participants at a time to email and schedule phone interviews. This recruitment method is also a form of selection bias.

Another limitation was that each interview was a one-time event. There were no follow-up interviews. The data collected was a snapshot of the perceptions of participants at a single point in time. If there had been more than one interview with each participant, I might have been able to capture how their perceptions changed over time.

Lastly, it would be more accurate to measure resilience with a validated tool. A resilience tool used by investigators could measure if interventions used had a positive or negative outcome on resilience in participants. Healthcare providers could incorporate interventions that increased resilience in research study participants.

Conclusions

The current study revealed eight subthemes. The new subthemes aligned with the concepts of the Greene (2002) resilience theory as defined earlier in chapter four, include

- autonomy,
- a sense of coherence (subconcepts – comprehensibility, manageability, meaningfulness),
- self-efficacy*,* and
- competence*,*

The new themes, one of which has also subthemes, which reinforced the resilience theory are:

- reaction of the patient (with new subthemes – positive reactions and negative reactions),
- self - determination,
- adherence to doctor’s orders,
- what helps you manage,
- what makes managing worse, and
- sense of humor.

Several interviewees were using elements of the new theme, sense of humor, as a coping mechanism with HF-related difficulties. Participants who demonstrated either a ‘negative’ or ‘positive’ outlook on life, as displayed by their responses to interview questions, were expressing the theme, reaction of the patient. For example, a few participants who described trying to live each day fully were expressing a positive reaction. The several participants who expressed anxiety brought on by their diagnosis, especially within the first year, were articulating a negative reaction. However, these participants indicated they learned how to accommodate their limitations over time and learned how to function with HF.

Several new themes and subthemes can be used describe some of the original concepts from Greene’s resilience theory:

- Manageability (original concept) → What helps you manage? and what makes managing worse? (new themes),
- Self-efficacy (original concept) → Adherence to doctor’s orders and Self-determination (new themes).

The definition of the new theme, what helps you manage*,* was people, things, or attitudes that helped participants cope. The description of the new theme, what makes managing worse, was people, situations, or attitudes that cause difficulties for those living with HF. The what makes managing worse theme is useful in gathering information about multiple medical problems that compound difficulties for those coping with HF.

Interview questions about meaningfulness*,* a subconcept in Greene’s resilience theory, captured what mattered most to participants in the study. This subconcept helped explain what participants deemed most important to live a quality life.

These added themes and subthemes would be beneficial for HCPs to understand the experiences of people living with heart failure. In addition, they could help define what is most helpful in the treatment of these individuals living with HF.

Comparison of Findings with Previous Literature

A discussion about how each new subtheme compares to prior literature clarifies its description. These subthemes align well with the Greene's 2002 resilience theory as demonstrated for each theme.

Reaction of Patients

Several participants expressed a positive reaction in response to their diagnosis. A positive reaction to life events could describe psychological resilience. The concept of psychological resilience was measured by several researchers (Huang et al., 2019; Klineova et al., 2020; Soliman et al., 2022) in chronically ill adults. A negative reaction to a HF diagnosis could be depicted as anxiety, stress, and depression, as mentioned in a study of patients with cardiovascular disease by Love et al. (2021).

Positive Reaction

Participants who expressed a positive reaction to their diagnosis of HF, stated how they tried to change their diet, exercise more, and valued their relationships with their families and friends. Huang et al. (2019) found resilience positively correlated with family, moderate exercise, hardiness, and social support in patients recovering from breast cancer surgery. Findings in the current study supported these positive correlations. Priori et al. (2021) found an inverse relationship between anxiety and depression, and resilience in those with Sjogren's disease. These studies corroborate findings from current research about resilience being on the opposite side of the spectrum from depression.

Negative Reaction

Several particpaants expressed a negative reaction at times to their diagnosis. Some felt they were unable to keep up with their families or friends. Others described feelings that others treated them differently, for example, people telling them what they should or should not do because of their HF diagnosis. These feelings counter the concepts of psychological resilience mentioned by (Huang et al., 2019; Klineova et al., 2020; Soliman et al., 2022).

Love et al. (2021) evaluated four studies in a systematic review that correlated low resilience with early diagnosis of HF, stroke, and heart disease in young adults. This review exemplifies how low resilience can affect health outcomes. Love et al. found some people react to their diagnosis of chronic diseases with biological factors such as anxiety and depression. In the current study, one participant with HF described how his diagnosis affected him and caused him great anxiety. Several other participants discussed how it took them a while to understand that a diagnosis of HF is a lifelong diagnosis and that they would need to change how they lived the rest of their lives. These realizations helped them understand they needed to limit their activity when they had shortness of breath or experienced fatigue, decrease their fluid and salt intake, and notice signs and symptoms of possible exacerbations that could result in emergency room visits or hospitalizations.

The literature described depression as a common concept studied in people with various chronic conditions. Cohen, Baziliansky, & Beny (2014) and Chou et al. (2022) measured depression in patients with colorectal cancer. The study by Cohen, Baziliansky and Beny (2014) recommended increased care provider support for patients with low resilience scores. These individuals are more likely to suffer from depression and anxiety. Chou et al. (2022) found depression to be a mediator between protective factors and resilience. Battalio et al. (2020)

described people with post-poliomyelitis, muscular dystrophy, multiple sclerosis, and spinal cord injury as having reciprocal relationships between depression, anxiety, and low resilience. Garcia-Carrasco et al. (2019) also found a negative relationship between depressive symptoms and resilience in patients with systemic lupus erythematosus.

In the current study, a few participants expressed a feeling of depression which was in line with previous research on chronically ill adults. Some participants commented that they wished they had more energy to keep up with their family and friends or could do things they enjoy, like gardening. However, many participants in the study relayed stories about how they had come to terms with their limitations due to HF and learned to pace themselves according to how they were feeling.

Gheshlagh et al. (2016) found higher resilience scores led to better physical and functional outcomes for individuals with chronic diseases, cardiovascular disease, and cancer. Although the current study did not measure resilience with a tool, many participants stated strategies they had employed to help them cope with their HF condition, which will be described in the subtheme, what helps you manage.

Self-Determination

No literature mentioned self-determination as a theme. Several participants expressed the theme of self-determination in this study. Participants verbalized a fighting spirit to cope with the challenges of living with HF. They stated how they were prepared to follow HCPs recommendations to be able to enjoy their family and friends. Many said they realize they cannot do as much as they used to before the HF diagnosis but have learned to listen to their bodies, take breaks, and rest when necessary. This is related to the one study that discussed exercise's benefits in decreasing fatigue and improving the quality of life in those with congestive heart failure

(Hasanpou-Dehkordi et al., 2020). Some subjects mentioned walking as a way to exercise and to help them feel better, and it could be considered a way participants demonstrated self-determination to improve their quality of life. Although Cohen et al. (2014) did not research the term self-determination, they mention in their research that older adults, with a mean age of 58 years, learned effective coping strategies to handle their chronic illness of colorectal cancer.

Adherence to Doctor's Orders

Many participants in this study described the theme, Adherence to doctor orders**.** Several subjects commented on adhering to their doctor's orders to reduce symptoms such as shortness of breath, swelling, and fatigue. The investigator discussed self-management by adhering to or following doctor's orders with participants, and this study found several participants followed orders given to them in general. Several stated they did not always watch their diet and did not manage their blood pressure every day. Adherence to doctor orders was not a concept reported in the literature associated with resilience and those with chronic conditions.

What Helps You Manage

Management of HF refers to one's ability to live with a chronic condition and avoid exacerbations and hospitalizations. In the literature, researchers measured well-being and happiness (Tecson et al., 2019), but many did not ask specific questions about What helps you manage.

Many participants found limiting activities, good social support, eating a healthy diet, and having an optimistic attitude helpful in coping with HF. Patients with HF have similar limitations as others who live with chronic diseases. Improving psychological resilience was discussed in several articles by researchers who studied those with chronic illnesses (Battalio et al., 2020; Huang et al., 2019; Solisman et al., 2022; Tecson et al., 2019; Wang et al., 2016).

Limiting Activities

In a study by Manning et al. (2016), the investigators found resilience negatively associated with limitations in activities of daily living and instrumental activities of daily living. This longitudinal study was about how resilience could prevent the onset of new chronic conditions and subsequent disability.

In the current study, participants said they limited activities because they were conserving their energy for things they wanted to do. For example, cleaning the entire house was not important if they wanted to have enough energy to visit grandchildren later in the day. Techniques such as paying attention to how fatigued you feel are a way to moderate activities in those living with HF.

Social Support

Many participants relayed stories about family friends helping them after their diagnosis with housework, meal preparation, medication management, and encouraging adherence to treatment recommendations, being available to listen to them. Tecson et al. (2019) echoes these concepts, who also mentioned social support for people with chronic conditions through assistance with errands and emotional support.

Huang et al. (2016) mentioned moderate exercise, self-efficacy, and family hardiness as positively correlated with psychological resilience in post-surgery patients after having breast cancer. Tecson et al. (2019) found happiness and resilience were positively correlated in those with chronic conditions. Social support is discussed in a few studies (Dai et al., 2014; Huang et al., 2019). They conclude that social support is associated with resilience in patients with chronic diseases (Dai et al., 2014; Huang et al., 2019).

Eating Healthier

Diet was not discussed in the literature in relationship with resilience in patients with HF or chronic conditions. However, one could argue that healthier dietary habits can affect overall health (American Heart Association, 2021). Several study participants were excited to talk about how they had lost weight after learning how to cut back on salt and prepare simple foods. Some said they were not aware of the importance of diet, living a healthy life and how an unhealthy diet can contribute to many health problems.

Optimistic Attitude

One study by Tecson et al. (2019) linked happiness to resilience in chronically ill adults. Several participants in the study laughed or made jokes during the interview, indicating they may have a lighthearted attitude. Self-efficacy was another concept that reflected resilience in a study of women recovering from breast surgery (Huang et al., 2019). However, psychological resilience was higher in women with tumors detected in earlier stages of breast cancer (Huang et al., 2019).

Exercise

Several participants in this study described how they had started walking and felt better as a result. A study by Soliman et al. (2022) with patients recuperating from hip fractures found an improved walking distance and speed and increased resilience scores after 16 weeks of therapy. Hasanpour-Dehkordi et al. (2020) described a 24-week exercise training intervention as beneficial to those with Class II and III congestive HF to have a better quality of life and decreased pain and fatigue. These findings support how exercise improved patients' feelings about their health in this study’s participants.

What Makes Managing Worse

The investigator used the theme, What makes managing worse, to find out how participants with HF perceive situations or people that exacerbate their condition. Some examples included a lack of social support and being treated differently after their HF diagnosis. Researchers in the literature used terms such as psychological distress (Tecson et al., 2021) or low-stress resilience (Love et al., 2021) as opposite terms for resilience.

Lack of Social Support

Dai et al. (2014) described people with irritable bowel disease (IBD) living in rural areas as a condition causing a lack of social support. The researchers explained that people with IBD living in the rural areas have less access to hospitals and medical resources, which was correlated with lower resilience. A few participants in the current study spoke about family members living far away and feeling less supported by them. Some did not have many family members or friends and learned to rely on services such as home grocery delivery or hired people to help them if they had difficulty getting out to run errands or prepare food.

Treated Differently After Diagnosis

A few subjects said they did not like their friends and family treated then differently after their diagnosis, which caused them additional stress. They wanted to continue to exercise or eat what they wanted, and others told them to reconsider their choices. This concept was not reflected in the literature, but it could be that these questions were not asked in previous studies.

Participants described psychological distress, such as feeling anxious and depressed due to family members who disagreed on how to handle their diagnosis. A few participants stated they were being treated differently. They described people treating them like they were children and telling them they should not do things like climbing a ladder. Participants also stated others sometimes treated them like they were fragile, like a China doll. Some participants indicated that family members were not there for them or that their HCPs were not checking in on them or giving them guidance about when to call the HCP for potential problems.

Sense of Humor

Humor is a method that some participants use to cope with difficulties. Few studies reviewed discussed people utilizing a sense of humor as a coping strategy for chronic illness. However, several participants in this study described the importance of using humor as a technique to handle living with a chronic condition in this study. They joked when answering interview questions and stated that humor helps them to cope with their diagnosis. Humor enabled them not to focus on their difficulties and to enjoy life to the best of their ability. There may be some overlap of the theme sense of humor and optimistic attitude (subtheme).

Meaningfulness

Meaningfulness, a subconcept of the theme, Sense of coherence, was discussed in this study when participants interviewed stated what or who motivated them to find ways to live with their HF diagnosis. Many research studies used tools asking participants about psychological behaviors such as depression and anxiety but did not ask about what motivates people living with chronic diseases to live their lives to the fullest and manage their disease processes. However, Chou et al. (2022) measured the concept of purpose as a protective factor and found purpose to be highly correlated with resilience in patients with colorectal cancer.

Other Variables Influencing This Study

Variables such as the age of the participants, the fact that this was a cross-sectional study, and the amount of time each participant had lived with HF may have influenced how they responded to questions and processed their health condition. For example, a person recently diagnosed may respond with a more emotional answer than someone diagnosed many years in the past.

Ages of Participants

Compared to other studies on people with HF, this study had participants between 55 and 77 with a mean age of 67.1 (SD = 6.5). Love et al. (2021) performed a meta-analysis with participants who had cardiovascular disease. Four studies measured biological factors and discovered low stress resilience in young adults (18 or above) related to an early diagnosis of heart failure, stroke, and coronary heart disease. Results from other studies had participants of varied ages. Chang et al. (2017) had participants ages 30-90. Heo and Kim (2020) recruited subjects ages $\geq$20. van Rijn et al. (2023) conducted a study with participants eighteen years old and older who had HF.

The current study may have had participants with more comorbidities due to being older than the participants in other studies reviewed for resilience and HF previously mentioned with younger participants. Therefore, the current study's participants may possibly reflect the opinions of older people living with HF rather than the participants in the general population below age 55.

Cross-sectional Study

Other studies looked at participants over more than one time point (Battalio et al., 2020; Manning et al., 2016; van Rijn et al., 2023). These one-time interviews were conducted over a 25 to 90-minute period. People may be more open to deeper discussions about how they feel over time and after multiple conversations about living with HF, especially after gaining the trust of the researchers.

Time of Participant Diagnosis with HF

The amount of time after diagnosis may have influenced the results of participants as well as the structured interview guide questions. For example, the interviewer asked participants question number five, which was, “tell me about how you feel about having a diagnosis of heart failure. (Emotional changes you have had?).” This question did not name depression or anxiety specifically; therefore, participants may have felt reluctant to share if they had experienced these feelings. One participant who was recently diagnosed with HF described depression and anxiety. A person newly diagnosed with HF (within the last year) may react differently than someone diagnosed with HF for several years. A new diagnosis may bring uncertainty about the future and insecurity about handling HF. In contrast, someone who has had HF for years may have time to process and learn coping strategies to live with their diagnosis, although this was not always the case with participants interviewed for this study.

Implications for Nursing Practice

After completing this descriptive qualitative research study, the investigator found that how education is delivered by HCPs to those with heart failure about their condition, limitations, and future expectations may need to be evaluated. Sometimes patients are trying to process the diagnosis they have been given and get overwhelmed by new information about their condition. The timing and delivery of information may need to be studied and could lead to better compliance with HCPs' orders.

Additionally, patients with HF need encouragement to work with HCPs to develop treatment plans that incorporate their desires for a quality life and what is important to them. Including these as part of the treatment plan, patients with HF can build resilience through self-efficacy, a sense of coherence, autonomy, and competence. Greene’s 2002 resilience theory can be used as a framework to build resilience. Future HCPs can use this theory and expand upon it to include ‘what matters most’ to patients with HF, encouraging a ‘positive’ outlook on the future, a sense of humor, and more descriptors of how well they believe they are managing their HF. The purpose of adding these suggested themes and subthemes would be for HCPs to incorporate these ideas into care plans for patients with HF with the outcome of improved quality of life and resilience.

Implications for nursing practice include lessons learned from patients with HF, which may help develop nursing interventions to improve resilience in the HF patient population. Themes noted in interviews include all of the concepts mentioned previously (autonomy, self-efficacy, competence, and sense of coherence) and new themes and subthemes, which include reactions of patients (positive and negative reactions), self-determination, adherence to doctor’s orders, what helps you manage, what makes managing worse, and sense of humor.

Qualitative methods were helpful for this investigator to find out what matters most to patients with HF so their desires can be incorporated into the plan of care for each patient and HCPs can connect with patients on a level they can understand. HCPs can discuss with patients how they can manage their symptoms so they can do what they enjoy most (what matters most). In other words, this research's findings may help HCPs communicate effectively with patients with HF, changing how patients manage their HF. Interviewing patients with HF can improve outcomes with individualized care plans. The result will be that patients will be more able to follow their HF treatment regimens if they help create them based on what they consider most important, which can lead to a better quality of life.

Recommendations for Additional Nursing Research

I hope to help develop effective therapies to manage patients with HF, build their resilience, and help them have an improved quality of life. HCPs could incorporate interview questions related to resilience through a validated tool with their patients to assess their level of resilience and offer supports to help improve their health outcomes.

Interestingly, a few participants proposed various ideas to increase resilience during this study. For example, one participant mentioned that community education classes on healthy eating and preparing meals would greatly help individuals with heart failure. Two other participants recommended dietary counseling as part of their treatment to help them lose weight, lower their blood sugar, and have more energy. Although these ideas sound promising, they are not innovative or new. Community education classes and dietary counseling have not been well attended in the past and are not typically paid for by payors (Professional Nutritional Consulting, 2022).

Ideas for Future Studies

Future studies the investigator would like to focus on include increasing resilience in patients with HF by increasing their self-efficacy and skill in recognizing and managing their HF progression. Additionally, she would like to study the mechanisms for resilience in patients with HF who have successfully managed their lives after their diagnosis (Varadhan et al., 2018). No studies reviewed discussed how family and friends could provide social support to encourage patients to continue exercising. Longitudinal studies are needed to show how resilience can be cultivated over time in patients with HF. Additionally, this investigator would like to examine cultural differences in managing heart failure and how to incorporate nutritional counseling and education for patients with HF from diverse cultural groups. These ideas would be beneficial, especially since two participants described changing their diet as a turning point for successfully managing their HF symptoms, decreasing their hemoglobin A1C, and helping with weight loss.

Another idea for future study includes how patients with HF interpret information given to them and whether they apply what they have learned to decrease trips to the ER and hospitalizations. In the future, this investigator would also like to explore how physical deficits might be overcome through exercise after psychological resilience has improved through interventions. An intriguing idea is to investigate whether resilience is a static term or constantly changing. Additionally, she would like to investigate interventions to increase resilience in vulnerable populations. HCPs could use a multipronged approach to increase resilience in chronically ill patients to improve their psychological resilience. They could do this by using tools to measure patients' resilience and interviewing them to determine what motivates them to follow HCP s' orders and monitor their signs and symptoms.

Future investigators could use resilience tools to quantify a baseline of resilience and then inform patients in areas where they lack knowledge or understanding of their disease process, management, and treatment. After education, researchers could use the same tools and interview questions to measure how patients have improved their resilience. Future researchers could use these strategies to be included in a mixed-methods study to show differences before and after the educational intervention.

Chapter Summary

Implications for nursing practice and ideas for future study have been described. Improving resilience for patients with HF is an essential part of the care for this population of patients. Viewpoints from patients with HF have been described along with new themes that can be incorporated as part of the care planning between HCPs and patients with HF. Improved quality of life and increased resilience for these patients could result from the findings of this study.

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APPENDICES

Appendix A

Qualitative (Phenomenology) Interview Guide: Lived Experience of HF Patients

Participant Code Number______________________________

Date/Time____

Location_(Setting)_____________________________________

Thank you for agreeing to participate in this study. As a reminder, this interview will be recorded. You may stop the interview at any time. Please try to avoid mentioning specific names or other specific information about people you know.

- Age: ________________ Gender: Male / Female
  - **a)** Race
  - **b)** Ethnicity
  - **c)** Highest level of education
  - **d)** Employment status (Full time/ Part-time/ Retired or unemployed)
  - **e)** Living situation (live alone or with others? If you live with others, who do you live with?)
  - **f)** How do you pay for the treatments you receive for your health condition (heart failure)? Do you have insurance or other coverage? If so, what kind? Does it cover everything? [If they say no, "Is that a significant burden for you?]
  - **g)** What other chronic illnesses do you have if any such as diabetes, lung disease, kidney disease, high blood pressure, lack/decreased feeling in your feet, stroke?

(Start audio recording here) I would like to learn more about your experiences as a person with living with heart failure. Think about when you first found out about your heart failure diagnosis. Tell me about your experiences.

- How do you feel you are doing living with heart failure?

1) Were you hospitalized when you found out? Did that make a difference? [Did this hospitalization make you feel like your diagnosis was real?]

- What were you thinking at that time?

2) Overall, how has the experience of being a person with heart failure been for you?

3) How long have you had heart failure (Probe)?

4) How has your daily life changed since your diagnosis? (Are there things you cannot do any more or you need help with?) [such as bathing or dressing and such as housekeeping and preparing meals]

5) Tell me about how you feel about having a diagnosis of heart failure? (Emotional changes you have had?)

6) Is there anything you do that gives you a feeling of control over your treatment or symptoms? Tell me what you do?

7) Has anyone treated you differently after your diagnosis? Tell me about that?

8) What physical symptoms do you have related to heart failure and how do they impact your life? (Probe about shortness of breath, fatigue, difficulty walking long distances, attending social events, not being able to do the things they enjoy – travel, picking up/helping with grandkids, etc.) What matters most to you?

9) Do you have family members, friends, or neighbors that help you? Tell me about that? (For example, do they help you get to appointments, cook meals, clean house, set up your pillbox, help with refills?)

10) Do you have family members, friends, or neighbors that make things worse for you? Tell me what that looks like?

11) Are you in a support group for heart failure? Tell me about that? Why did you decide to join?

(**If they say no**) Are you aware of any support groups? Any reason you chose not to join a support group?

12) How do you feel you are doing with your health care provider's recommendations? (Such as weighing yourself daily, walking daily, monitoring salt intake?)

13) Do you see your condition improve when you follow those directions (self-efficacy concept)? (Have you been able to follow directions from your Dr. and have those things made a difference in living with heart failure)? i.e., do you limit salt and or exercise, and if so, what happens?

14) How have you handled setbacks in the past before your heart failure diagnosis? How do you handle setbacks now?

15) Is there anything else you think we need to know?

Appendix B

Lived Experience of Heart Failure Patients

Lived Experience of Heart Failure Patients

UNIVERSITY OF
TEXAS
ARLINGTON

Share Your Experience!

We are researchers at the University of Texas at Arlington, and we would like to hear about your experiences with heart failure. You can help us by sharing how you have managed your heart failure.

You are invited to participate in this study if you are:

- 55 years or older
- Have been diagnosed with heart failure for at least one year
- Speak English

Participants will be interviewed one time and the interview will last 60-90 minutes. You will receive a $10 gift card per hour for your time. Interviews will be conducted by phone. We will require verbal consent for audio recording prior to starting the interview.

Please contact Elisa Stehling (primary investigator), at 817-907-5892 or elisa.stehling@uta.edu if you would like to learn more.

Appendix C

Lived Experience of Heart Failure Patients

Lived Experience of Heart Failure Patients

UNIVERSITY OF
TEXAS
ARLINGTON

Share Your Experience!

We are researchers at the University of Texas at Arlington, and we would like to hear from those who have experienced heart failure. You can help us by referring someone you know who has managed heart failure.

They are invited to participate in this study if they are:

- 55 years or older
- Have been diagnosed with heart failure for at least one year
- Speak English

Participants will be interviewed one time and the interview will last 60-90 minutes. Participants will receive a $10 gift card per hour for their time. Interviews will be conducted by phone. We will require verbal consent for audio recording prior to starting the interview.

Please have them contact Elisa Stehling (primary investigator), at 817-907-5892 or elisa.stehling@uta.edu if they would like to learn more.

Appendix D

Lived Experience of Heart Failure Patients

Poster

Research Study

Lived Experience of Heart Failure

Share Your Experience!

We are researchers at the University of Texas at Arlington, and we would like to hear about your experiences with heart failure. You can help us by sharing how you have managed your heart failure.

You are invited to participate in this study if you are:

- 55 years or older
- Have been diagnosed with heart failure for at least one year
- Speak English

Participants will be interviewed one time and the interview will last 60-90 minutes. You will receive a $10 gift card per hour for your time. Interviews will be conducted by phone. We will require verbal consent for audio recording prior to starting the interview.

Please contact Elisa Stehling (primary investigator), at 817-907-5892 or elisa.stehling@uta.edu if you would like to learn more.

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Appendix E

Message for Participant Recruitment on Researchmatch

Lived Experience of Heart Failure

Share Your Experience!

We are researchers at the University of Texas at Arlington, and we would like to hear about your experiences with heart failure. You can help us by sharing how you have managed your heart failure.

You are invited to participate in this study if you are:

- 55 years or older
- Have been diagnosed with heart failure for at least one year
- Speak English

Participants will be interviewed one time and the interview will last 60-90 minutes. You will receive a $10 gift card per hour for your time. Interviews will be conducted by phone. We will require verbal consent for audio recording prior to starting the interview.