Issues and Concerns of Individuals Living with Heart Failure

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Abstract

Five million people in the United States have heart failure and approximately 550,000 new cases are diagnosed each year. About 22 percent of men and 46 percent of women will develop heart failure within 6 years of having a heart attack. The purpose of this thesis was to explore the issues and concerns of individuals living and coping with heart failure. Three participants volunteered to be in this grounded theory research study. Data collection and classic comparative analysis involved in-depth interviews, field notes, and theoretic memos. The core category was Learning to Live with HF and supporting categories were Maintaining Normalcy, Planning Ahead, and Changing Lifestyle. Participants often experienced loss of intimacy with loved ones or family members and were intimidated with discussing the topics with those outside of their comfort zone. Implications for nurses must include that some individuals with HF strive to maintain normalcy and thus may minimize their symptoms. These findings cannot be generalized to all individuals with heart failure.
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To My Husband and Children
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Chapter I

Issues and Concerns of Individuals Living with Heart Failure

Approximately 5.2 million people in the United States have heart failure, and about 550 thousand new cases are diagnosed each year. More than 287 thousand people in the United States die each year with heart failure. In fact, 1 in 5 persons die within one year of diagnosis and approximately 50% die within five years (Wingate, 2007). Hospitalization rates rose from 402,000 in 1979 to 1,101,000 in 2004 (CDC, 2006 National Hospital Discharge Survey). Heart failure is the most common reason for hospitalization among people on Medicare (CDC, 2006).

The most common causes of heart failure are coronary artery disease (CAD), hypertension or high blood pressure, and diabetes. About 7 of 10 people with heart failure had high blood pressure before being diagnosed, and 22 percent of men and 46 percent of women will develop heart failure (HF) within 6 years of having a heart attack. According to the American Heart Association (AHA), the estimated annual costs of care for HF in 2003 were $24.3 billion dollars, and in 2006 the CDC estimated the direct cost for HF in the United States to be at $29.6 billion dollars. Heart failure is more prevalent in African Americans and the elderly populations. The following graph, Table 1, outlines trends in hospitalizations for HF by age group from 1979–2004 in the United States (CDC, 2006).
Heart failure is a progressive disorder in which damage to the heart causes weakening of the cardiovascular system. Over time, high blood volumes cause remodeling of myocardial tissue increasing the heart’s size and further impacting its ability to adequately eject blood (Romeo et al., 2006). It manifests by fluid congestion or inadequate blood flow to tissues. Heart failure progression is usually caused by an underlying heart injury or inappropriate responses of the body to heart impairment (Romeo et al., 2006). After heart impairment, increasing the functional ability usually can be improved with medications.

Heart failure is a cumulative consequence of all insults to the heart over an individual’s lifetime, and being aware of the disease process and how individuals cope is imperative for holistic nursing. Nurses need to be able to recognize if their client is exhibiting signs and symptoms of “ineffective coping” associated with HF. Nurses also need to educate the individual in symptom management and coping methods (Ackley & Myers, 2003).
Pathophysiology of Heart Failure

Heart failure is a general term used to describe several types of cardiac or myocardial dysfunction that result in inadequate perfusion of tissues with vital blood-borne nutrients (Ignatavicius & Workman, 2006). There are different types of HF that are dependant upon origin and can be caused by infarction, ischemic heart disease, hypertension, valve disease, or other disease processes. Unfortunately it is a vicious cycle associated with increased contractility, preload, and afterload.

Increased contractility, preload, and afterload contribute to the development of an enlarged heart and worsening HF by stimulating other compensatory mechanisms. The compensatory mechanisms of baroreceptor stimulation, renin-angiotensin-aldosterone stimulation, sympathetic nervous stimulation, increase of preload and afterload only cause the cycle to start again, or worsen, and further increases oxygen need (Ignatavicius & Workman, 2006). In turn, this process will decrease tissue and organ perfusion.

Types of Heart Failure

Left heart failure, or congestive heart failure, has two subgroups: systolic heart failure and diastolic HF. With systolic HF there is inadequate cardiac output to perfuse vital tissues, and diastolic HF results from decreased compliance of the left ventricle and abnormal diastolic relaxation (Ignatavicius & Workman, 2006). This problem leads to an increased left ventricular end diastolic pressure in where blood will then back up into the pulmonary circulation causing pulmonary edema (Ignatavicius & Workman).

Right heart failure results from the backup of blood into pulmonary circulation in which the right ventricle is not prepared to compensate for the increased workload (Ignatavicius & Workman, 2006). If this continues, the right ventricle will dilate and fail.
High-output failure is the inability of the heart to adequately supply the body with blood-borne nutrients, despite adequate blood volume and normal or elevated myocardial contractility (Ignatavicius & Workman).

Compensatory Mechanisms

Compensatory mechanisms maintain cardiac function initially; however they will eventually add to the progression of HF (Davis, 2002). There are three compensatory mechanisms: sympathetic nervous system, renin-angiotensin-aldosterone system, and eventually ventricular remodeling will begin to take place.

Sympathetic nervous system. Decreased cardiac output and decreased systemic blood pressure lead to baroreceptor activation in the left ventricle, aortic arch, and carotid sinus. The stimulation of baroreceptors causes the vasomotor regulatory center in the medulla to be stimulated, leading to the activation of the sympathetic nervous system (SNS) (Ignatavicius & Workman, 2006). Once stimulated, the SNS increases the release of catecholamines (epinephrine and norepinephrine), causing vasoconstriction.

The sympathetic nervous system is the first compensatory mechanism to be activated in individuals with HF. Stroke volume increases to maintain cardiac output, and the peripheral vasoconstriction will increase the vascular resistance, afterload, and augment the preload (Davis, 2002). The vasoconstriction then increases afterload, blood pressure, and heart rate which does have the benefit of maintaining blood pressure and improving tissue perfusion in low output states, but ultimately leading to ventricular remodeling (Ignatavicius & Workman). According to Davis, over time this will lead to increased oxygen consumption by myocardial tissue, cardiac arrhythmias, and even death.
Renin-angiotensin-aldosterone system. Myocardial dysfunction causes a decrease in the perfusion to the kidneys; the renin-angiotensin-aldosterone system (RAAS) activation will cause an increase in sodium and water retention, a foundation for increased preload and afterload (Ignatavicius & Workman, 2006).

Preload is the end-diastolic stretch of the heart muscle in the ventricle and is approximately equal to the end-diastolic volume or pressure (Venes, 2001). Afterload, on the other hand, is the force that impedes the flow of blood out of the heart (Venes). If the preload and afterload increase continue, they will contribute to ventricular remodeling of the heart and cause an increase in contraction force, further increasing cardiac output (Ignatavicius & Workman, 2006). Because the myocardial tissue responds to the increased workload as an injury, it mounts an immune response causing more inflammation and damage, contributing to the progression of HF (Ignatavicius & Workman).

Ventricular remodeling. This process involves hypertrophy of the myocardium from prolonged activation of the sympathetic nervous system and RAAS (Davis, 2002). When the muscle mass increases, the configuration of the ventricles change, and pump performance is impaired.

These compensatory mechanisms give the basis for increased consumption of oxygen resulting in an increased need for oxygen. The myocardial oxygen reserve will deplete over time and manifestations of HF will develop (Ignatavicius & Workman, 2006).
Manifestations of Heart Failure

Heart failure manifests signs and symptoms of dyspnea, orthopnea, cough, fatigue, decreased urine output, and edema. Heart failure affects the muscles of the heart, renal system, gastrointestinal (GI), gastrourinary (GU), pulmonary, and circulatory systems. GI complaints are usually from fluid congestion of the liver causing engorgement and eventually hepatomegaly (CDC, 2006). GI and renal symptoms are from congestion and the stimulation of the renin-angiotensin-aldosterone system affecting tissue perfusion. All of these organs and systems combined affect the adequate functioning of the circulatory system. The quality of life and life expectancy of individuals with HF can be improved with early diagnosis and treatment (CDC).

Common signs and symptoms exhibited. Individuals with HF will commonly exhibit symptoms such as abnormal respiratory rate, altered mental status, dyspnea, cool skin, and fatigue (Micromedex, 2006). Other symptoms may include loss of appetite, weight gain, peripheral edema, cyanosis, increased blood pressure, and respiratory crackles. If someone with HF exhibits any symptoms that are of concern, this person should contact a physician or emergency department (Micromedex).

Acute exacerbations. The American Heart Association (2007) recommends individuals with HF seek care immediately if they have increased trouble breathing, cannot sleep or rest because of breathing difficulty, increased dizziness, or have signs or symptoms of a heart attack. These signs and symptoms may include the following: chest pain or discomfort that spreads to the arms, jaws, or back, nausea, trouble breathing, and sweating.
When the physician suspects HF, Micromedex (2006) recommends the following: a chest X-ray to observe for vascular redistribution, ventricular hypertrophy, and (less commonly) interstitial infiltrates. It also recommends a Brain Natriuretic Peptide measurement to determine HF. Any measurement above 400 pg/mL is suggestive of HF. A 12 lead Electrocardiogram (EKG) should be performed, and individuals with HF will exhibit typical findings of Q waves, ischemic ST-T waves, atrial fibrillation, and cardiac conduction abnormalities (Micromedex). A two-dimensional echocardiography with Doppler is essential for evaluation of the functional and structural changes underlying or associated with HF (Micromedex).

If it is suspected that the individual is hypoxic, pulse oximetry should be monitored to evaluate for impending respiratory failure. The individual should maintain a pulse oximetry saturation of at least 90% (Micromedex, 2006).

Thomson Micromedex (2006) recommends assessing individuals with suspected or known HF for anemia, by a complete blood count (CBC), because it may cause exacerbation, or mimic high-output HF. Known individuals with HF should have a variety of labs drawn: urinalysis for proteinuria; Values of 0.5-1 g/day are common in individuals with acute pulmonary edema and concomitant HF (Micromedex). Sodium Serum levels of 132-135 mEq/L in individuals with HF are low, and these individuals tend to have higher 60-day mortality rates than clients with normal levels; abnormal Magnesium Serum levels appear to be associated with increased mortality in individuals with HF. Serum Potassium levels for individuals with HF need to range from 4.5 to 5.5 mmol/L because hypokalemia is associated with increased mortality (Micromedex).
Thomson Micromedex also endorses that individuals with HF obtain a Serum Creatinine lab to evaluate renal blood flow function.

*Risk Factors for Heart Failure*

Coronary Artery Disease (CAD) is the most common cause of HF in the United States today. This is also known as Atherosclerosis, or blocking of an artery wall by cholesterol-lipid-calcium deposits (Venes, 2001). Risk factors for CAD include smoking, high cholesterol, hypertension, and diabetes (Romeo et al., 2006). CAD is any vascular disorder that narrows or occludes the coronary arteries (Heuther & McCance, 2006). CAD causes diminished myocardial blood supply until deprivation impairs myocardial metabolism enough to cause ischemia, leading to a heart attack.

Hypertension, or high blood pressure, is a risk factor for CAD and also is a risk for stroke, peripheral vascular disease, or kidney impairment. The long-term increased blood pressure damages the walls of the systemic blood vessels (Heuther & McCance, 2006). Prolonged vasoconstriction within these vessels stimulates thickening and will cause permanent narrowing.

Cardiomyopathy, or a disease of the heart muscle, can be a causative factor for CAD and can be from a genetic cause, a viral infection, or a consumption of toxins such as lead or alcohol (Romeo et al., 2006). The following factors also can play a role in determining who will be affected with HF: family history of HF, diabetes, marked obesity, drug abuse, and failure to take prescribed medications, large salt intake, and sustained rapid heart rhythms (Romeo et al.). Many other conditions can actually simulate HF symptoms: lung impairment, anemia, kidney impairment, and pericardial disease, though this is rare (Romeo et al.)
Individuals living with HF can improve their quality of life, outcome, and the heart’s functional ability by taking prescribed medications as recommended each day and implementing the prescribed lifestyle changes. Some medicines that are used to treat HF include ACE inhibitors, diuretics, positive inotropes, and beta blockers. Individuals with HF can reduce their dietary intake of salt (sodium), increase daily physical activity, and be aware of and tell their health provider about their HF symptoms to build a solid beginning for treatment of symptoms and progression control of HF (CDC, 2006). Individuals with HF must record daily weight and inform their health care provider of significant changes in weight. Depression, anxiety, and stress can also aggravate HF (CDC).

*Impacts on Lifestyle*

Individuals with HF must make many adjustments in their lifestyles. These changes include: prescribed medical regimens, dietary restrictions, activity recommendations, and drug therapies. Ultimately individuals will need to alter their daily lives by balancing activity and rest to maintain energy. According to Ignatavicius and Workman (2006), many individuals with HF experience oliguria (decreased urination) during the day, angina, confusion, restlessness, dizziness, tachycardia, palpitations, and pallor, weak peripheral pulses, cool extremities and may have an irritating nocturnal cough. Because these individuals have impaired gas exchange, they unconsciously may limit their activities in response to fatigue or dyspnea and may not realize how physically limited they have become (Ignatavicius & Workman).

There may be some loss of physical intimacy with a spouse or partner because of the decreased ability for sexual activity. The diagnosis of HF often means stopping or at
least limiting sexual activity until the exacerbation is under control (AHA, 2006).
Depression and anxiety rates are also high in individuals with HF since they have increased work of breathing and have many limitations placed upon them (AHA).

*Treatment, Medications, and Education Materials*

Individuals with HF are usually on a plethora of medications to reduce the workload on the heart, increase contractility, decrease fluid volume overload, and improve quality of life. Individuals, staff, and nurses need to recognize medication indications and side effects. It is the nurse’s responsibility to educate, or continue educating, the individual with HF on diet modifications, activity, environment tolerances and intolerances, and the importance of attending rehabilitation sessions.

This segment will identify five major medicines used for individuals with HF, the indications and side effects of those medicines, rehabilitation programs, and client education materials. Individuals with HF should be urged to use a written medicine schedule for complicated regimens (Grady et al., 2000). They should also be taught the name of each medication with the purpose, dosage, frequency, and significant side effects of the medication.

*Diuretic medications.* Individuals with acute HF and moderate to severe volume overload and/or pulmonary edema should be started on intravenous loop diuretics (Micromedex, 2007). Diuretics can relieve pulmonary and peripheral edema more rapidly than any other drugs used for HF and are the only drugs that can adequately control fluid retention in individuals with HF. Individuals with only mild overload may be given a Thiazide diuretic. Thiazides also can be used to augment the effect of loop diuretics. Because of the risk for hyperkalemia, potassium-sparing diuretics should be used with
caution during acute management of HF for clients on ACE inhibitors (Micromedex, 2007).

**Vasodilators.** Vasodilators are first-line agents in most individuals with acute HF. Although a normal systemic blood pressure may exist, tissue hypoperfusion can co-exist in many individuals with acute HF as a result of poor forward flow and/or increased afterload (Micromedex, 2007). Vasodilators can reduce ventricular filling pressures, myocardial oxygen consumption, systemic vascular resistance, and ventricular workload. In addition, vasodilators can increase stroke volume and cardiac output (Micromedex).

**Nitrates.** Nitrates are used in individuals with acute HF; nitrates reduce pulmonary congestion without an increase in myocardial oxygen demand or a compromise of stroke volume. Nitrates produce only venodilation at low doses; however, at higher doses, nitrates cause venous and arterial dilation, including the coronary arteries (Micromedex, 2007). Nitrates exert balanced venous and arterial vasodilation, reducing left ventricular preload and afterload while not impairing tissue perfusion. Intravenous nitroglycerin is an effective vasodilator used to relieve pulmonary congestion in individuals with acute HF. Intravenous Nitroglycerin (IV-N) requires frequent dose titration and may cause dose-dependent hypotension. Blood pressure monitoring is indicated during the administration of nitroglycerin, which can also be administered orally, by inhalation, or via buccal mucosa (Micromedex).
Positive inotropes. Intravenous (IV) positive inotropes (digoxin, dobutamine, or milrinone) may be used to relieve symptoms and increase end-organ function in individuals with advanced HF (low output syndrome), especially in those with marginal systolic blood pressure (less than 90 mmHg), symptomatic hypotension despite adequate filling pressures, and/or unresponsiveness to, or intolerance of, IV vasodilators (Micromedex, 2007).

Antiarrhythmics. Antiarrhythmics are used for atrial fibrillation (AF) or ventricular arrhythmias and are a common complication in individuals with HF:

AF is compromised of decreased cardiac output, increase myocardial oxygen demand, decrease coronary perfusion, impair both cardiac contraction and cardiac relaxation, and induce atrial thrombosis formation with an increased risk of embolization. Ventricular arrhythmias are responsible for a significant portion of the (sudden cardiac) deaths in clients with HF. (Micromedex, 2007, ¶ 3)

Activity Guidelines

Individuals with HF may benefit from moderate physical activity to help the myocardial muscle, or heart muscle, get stronger. Most people find that exercise improves their symptoms, reduces stress and boosts energy levels. Regular physical activity also may lead to other important health advantages, including weight control, weight loss, better circulation and blood pressure, and lower cholesterol levels (AHA, 2007).

Individuals with HF should not perform isometric exercises that require holding the breath, bearing down, or sudden bursts of energy (AHA, 2007). Also patients should
avoid lifting weights and competitive or contact sports, such as football and not engage in activities that cause chest pain, shortness of breath, dizziness, or lightheadedness (AHA).

Individuals with HF may feel like resting more and will need to match their activity to the amount of energy they have (Micromedex, 2006). Nurses will want to allow clients to rest during the day as needed. Staff and nurses will need to group tasks to lessen interruptions.

Cardiac rehabilitation. Cardiac Rehabilitation Programs (CR) are supervised programs of increasing exercise, mental support, and training, allowing individuals with heart conditions to resume normal activities (AHA, 2007). After a heart attack, individuals who participated in CR had better survival rates than those who did not (Clark et al., 2005). Clark et al. reported that individuals who participated in CR had improved quality of life and improved ability to carry out daily activities.

There are obstacles impacting individuals’ participation in CR programs. These include “lack of referral, lack of insurance reimbursement, limited access, and clients’ lack of desire to change lifestyle” (Aude et al., 2006, p. 56).

Diet Guidelines

Nurses will need to educate individuals with HF about eating a healthy diet as directed by their caregiver. They need to understand the importance of monitoring their weight, via daily or weekly weights, because weight gain can be a sign of worsening HF (Micromedex, 2006). They need to call their caregiver if they have gained three or more pounds in one day, or five pounds in one week (AHA, 2007).

Heart failure affects all systems of the human body and all the systems in turn affect the heart. By looking into the pathophysiology of HF, it is easy to relate the
relationships between the body systems and how important monitoring one system can affect another. As nurses we are researchers, scientists, and investigators for our clients and treatment begins with our continual assessment.

*Diet modifications.* The AHA recommends a 2 gm sodium diet for individuals with HF; however, most individuals find it unpalatable (Grady et al., 2000). The AHA also has diet and lifestyle recommendations for cardiovascular disease risk reduction. These heart healthy modifications also apply for individuals with HF.

AHA (2007) recommends a balanced caloric intake and physical activity to achieve or maintain a healthy body weight, eating a diet rich in vegetables and fruits, choosing whole-grain and high-fiber foods. Individuals with HF need to consume fish, especially oily fish, at least twice a week, limit the intake of saturated fat to less than 7% of calories, trans fat to less than 1% of calories, and cholesterol to less than 300 mg/day. To do this choose lean meats and vegetable alternatives, select fat-free, 1% and low-fat dairy products; and minimizing intake of partially-hydrogenated fats. Individuals with HF also need to minimize the intake of beverages and foods with added sugars and choose and prepare foods with little or no salt. Grady and associates (2000) recommend avoiding alcohol because its acute ingestion depresses myocardial contractility in individuals with known cardiac disease.

*Education Materials*

The American Heart Association (2007) has several recommendations from nutrition and exercise to teaching individuals with HF how the heart operates. Grady et al. (2000) advises teaching individuals with HF a clear and simple explanation of the
pathophysiology of the heart and HF. Nursing staff can utilize education materials online by accessing several sites. For example, the Mayo Clinic (2006) has heart healthy recipes that range from appetizers, breads, main course, salads, desserts, sauces, sandwiches, and soups. AHA also has tracking tools that allow individuals with HF to follow their health, nutrition, and fitness levels.

With all of the important considerations individuals with HF must make to decrease their symptoms and improve outcomes, nurses can educate them on various medication side effects and indications. Nurses may also educate on diet, activity, environment tolerances and intolerances, and the importance of attending rehabilitation sessions. Nurses can access needed information online that individuals with HF can understand and be able to access themselves. Nurses have the ability to give individuals with HF the proper tools to manage symptoms to improve their outcomes.

**Ethical Decisions**

Individuals with HF have the option of trying to receive a heart transplant with no guarantee of actually receiving one before it is too late. There are devices available to help with pacing and left ventricular assistance, but being able to afford these devices is questionable because most are from 20 to 40 thousand dollars and up (AHA, 2006).

Sometimes keeping the person comfortable may become more important than trying to prolong his or her life. The individual with HF and his or her family members should be involved in these decisions. Much can be done to provide compassionate care, relieve symptoms, and maintain the person's dignity (Merck, 2007). Death and dying involve decision making in which emotions are elevated, and families should always take into consideration the dignity of their loved one.
Heart failure can cause death suddenly and unexpectedly, without worsening symptoms. Consequently, when possible, individuals who have HF should prepare an advance directive identifying the type of care desired in case they are no longer able to make decisions about their own care (Merck, 2007).

Heart failure affects many people for whom nurses can improve outcomes and symptom management. Educating individuals with HF about risk factors, manifestations, impacts on lifestyle, and alternative therapies may improve symptoms. Nurses can also educate and provide compassionate care during the dying process for the families.
Chapter II

Review of Research

This section will review research materials related to HF. Each critique pertains to HF in either quantitative or qualitative aspects of nursing in hopes of improving or creating the capacity to develop nursing knowledge, improve nursing practice, support the design of nursing systems, or enhance education and professional accountability in healthcare practices.

*Depression*

According to De Jong and associates (2005), anxiety and depression are strong determinants of health status and are important factors for individuals with HF. The principal findings according to the New York Heart Association (NYHA) HF classification (classification depicts to which degree of HF the individual has) anxiety and depression strongly and independently predict health status. Of these predictors, clinicians routinely assessed only NYHA classifications, creating a major gap in the assessment and management of health status for individuals with HF (De Jong et al.). De Jong and associates’ finding supported that failure to identify and treat anxiety and depression may result in a lost opportunity to improve the individual’s health status.

De Jong and associates (2005) designed a randomized clinical study to determine the optimum disease management strategy needed to improve outcomes in individuals with HF. They questioned whether quality of life was dependant upon health status, functional status, or symptom burdens. Participants were chosen based upon recent hospitalizations with their risk for re-hospitalization. Within the first week of discharge, a cardiovascular nurse would visit the individual’s home, read the questionnaires, and
Initiate actigraphic monitoring. Actigraphic monitoring is a way to quantify physical activity in the individual’s home environment by having him or her wear a device that is somewhat like a watch (De Jong et al.). Health status was conceptualized as health related quality of life (HRQL) by using the Minnesota Living with Heart Failure Questionnaire (LHFQ). The Minnesota LHFQ assessed the validity and reliability using Cronbach’s α and the measurement was 0.91 (De Jong et al.). Symptom burden was measured using the Dyspnea-Fatigue Index (DFI), which assessed the degree to which dyspnea and fatigue impacted daily living. According to the Cronbach’s α for the DFI, this sample was at a rate of 0.83. Health perception and emotions explained significantly more variance in HRQL than sociodemographic and clinical variables. HRQL was lower in individuals with either depression or worse status of NYHA Class (De Jong et al.). De Jong and associates found that the better NYHA Class and the higher the anxiety, the greater the actual physical activity level. Also, emotional variables explained more variance in functional status better than the other variables (De Jong et al.).

Nurses do need to assess and treat psychosocial parameters to improve health status and survival for individuals with HF. De Jong and associates identified that depression is under-recognized if nurses only use clinical judgment in individuals with HF. Another important factor this research study acknowledged is that most clinicians neither routinely assess depression in individuals with HF even though depression rates are up 70 to 78%, and only half get treatment (De Jong et al., 2005, p.160).

When clinicians do assess for depression and anxiety, they use their own tools instead of one designed specifically for individuals with HF (De Jong et al., 2005).
Examples of tools they should use for assessing anxiety and depression are the following:

Brief Symptom Inventory, State-Trait Anxiety Inventory, Hamilton Ratings Scale for Anxiety and Depression, Beck Depression Inventory, or the Hospital Anxiety and Depression Scale (De Jong et al.).

De Jong et al. (2005) did not identify how many participants were involved in the study to assess health status yet did identify that only baseline data were analyzed. The research used SPSS to analyze the data. Overall De Jong and associates presented the research well and in layperson’s terms with the tables understandable and easy to follow. De Jong and associates did a nice job with reliability and validity in comparing their results with other works. They did recommend that because anxiety and depression are modifiable, to use cognitive-behavioral interventions, stress management, biofeedback, and medication therapy can be used to reduce anxiety and depression in individuals with HF.

*Hope in Heart Failure*

According to Rstoen et al. (2005), it is not the severity of HF, but the number of comorbid diseases and self-assessed health problems that influence hope in individuals with HF. Perhaps focusing on what brings meaning or hope will allow healthcare providers insight into what individuals with HF wish for. Rstoen and associates’ research discovered that hospitalized individuals with HF had higher hope levels than did healthy adults in the general population. They related the increased hope levels to a personal shift in internal values or standards that may be a reflection of adaptation from a life-threatening chronic disease, or a response shift. A response shift is defined as “a change
in the meaning of one’s self-evaluation of quality of life as a result of change in values or internal standards” (Rstoen et al., p. 422).

Rstoen et al. (2005) described hope in hospitalized individuals with HF and evaluated the influences of demographic and health-related variables on hope. They used a descriptive, cross-sectional study in which ninety-three individuals with HF participated, and 441 subjects were included in the analysis. Five participants with HF were excluded from the analysis because less than 80% of the Herth Hope Index was completed. Statistics were analyzed using SPSS software for Windows, and if 40% of values were missing the respondents were not included in the hope analysis. Hope was measured by using the Norwegian version of the Herth Hope Index, which is a scale based on the definition of hope. It contains twelve items measuring various dimensions of hope (Rstoen et al.).

Individuals with HF scored highest on the individual hope item with statements like, “I can recall happy/joyful times” (Rstoen et al., 2005, p. 422). Rstoen and associates speculate that the older and unhealthier individuals with HF may be, the more concerned they are with the past than with the future.

This research overall was very well done, easy to understand and read. Tables and graphs were easy to follow and flowed nicely. This article was compared with other research and made comments about what areas are in need of further research.

Nurses are often goal orientated, encouraging their clients to reach for milestones (Rstoen et al., 2005). Perhaps encouragement, reflection, and recollection would be more helpful for individuals with HF since they do tend to focus on the past and recalling past successes as a way to nurture hope (Rstoen et al.).
The following research study described the issues and concerns related to symptom management and coping mechanisms of HF individuals. A nursing researcher at the University of Texas at Austin, no author (2006), estimated that one-third to one-half of hospital re-admissions for HF could be prevented with better education about symptoms, medications, and diet. Many factors such as a change in lifestyle or medications can help or prevent HF and can be applied at any stage (University of Texas at Austin, 2006).

Class and Functional Status

New York Heart Association (NYHA) HF classifications were developed in 1928 for use as an essential criterion for comprehensive cardiac diagnosis. It consists of a two-part grading process that summarizes clinicians’ judgments regarding degrees of physical activity and data that are received from specific measurements of cardiac structure and function (Coyne et al., 2006). The specific classifications suggest that the individual’s physiologic status provides information on capacity; limitations in physical activity describe functional performance, and individual symptoms accompanying activity offer insight into cardiac reserve (Coyne et al.). NYHA classifications promote uniformity that is essential to the consistent application across clinical and research settings when referring to cardiac structure and function (Coyne et al.). The NYHA classification descriptions are as follows,

Class I indicates people with heart disease who have no limitation in engaging in ordinary daily activity. Class II denotes people whose ordinary daily activity is slightly restricted by heart disease symptoms. They are comfortable at rest; however, ordinary activity may result in
fatigue, palpitations, dyspnea or angina. Class III consists of people whose ordinary daily activity is markedly restricted by heart disease. They are comfortable at rest, but very minimal activity exertion results in aggravating symptoms. Class IV indicates people who have difficulty performing any daily activities. Symptoms of heart disease are present even at rest and any activity will cause discomfort. (Hsing-Mei, 2007).

Coyne et al. (2006) provided evidence that the NYHA classes work by the efficacy outcome in controlled trials, despite differences in conceptual meaning and the wide variability associated with its measurement.

Doctors' Perceptions

In 2002 a research group focused upon the development of palliative care for individuals with HF. Hanratty et al. concluded that a greater consideration should be given to the care of individuals dying of HF. Also, the roles of doctors and nurses in different specialties should be clarified. They also specified that there is a need to reshape the services provided for individuals with HF. Improvements are needed with the coordination and continuity of medical care between hospital discharges for individuals with HF that are going back into the community (Hanratty et al., 2002).

Hanratty et al. (2002) collected research data via a focus group over 80 minutes using two each of general practitioners and consultants in cardiology, geriatrics, palliative care, and general medicine. The focus group session was audio taped, transcribed, and analyzed using the principles of constant comparison and then checked for final interpretation. Emerging themes and categories were identified independently, and an agreement was reached by discussion (Hanratty et al.).
The focus group discussed the future in terms of funding palliative care for individuals with HF and agreed upon enhanced roles for nurses. They saw the nurse as someone who could follow individuals into the community after their discharge from the hospital and liaise between primary and secondary care, ensure that treatments were adhered to, and mobilize support. This would reduce the number of hospital readmissions and improve disease management for individuals with HF once back into the community (Hanratty et al., 2002).

Client Perspective

Alexander et al. (2004) identified four elements of the inpatient experience that hold the greatest opportunities for improving the quality of care provided to individuals with HF: client involvement in decision making, staff response to concerns voiced during the hospital stay, staff sensitivity to the inconvenience of HF and hospitalization, and emotional/spiritual support (Alexander et al., 2004). They also identified the unique preferences and needs of individuals with HF that are not being adequately addressed during hospital stays and offered practical suggestions for making routine HF management more client-centered.

Sample data were collected from returned client satisfaction surveys from December 2001 to November of 2003. Data were split into two time periods with one group containing 5224 surveys from individuals with HF and the other group containing 6531 sample surveys. Surveys were taken from 40 different states across all 9 American Hospital Association Regions (Alexander, et al., 2004). A standardized mail-out/mail-back methodology was used to collect client perceptions of care. Survey questions were
presented as 10 subscales representing a central dimension of the care experienced (Alexander et al.).

According to Alexander et al. (2004), the instrument’s reliability and validity surpassed accepted standards for sound scale construction. They concluded their study with the addition of complementary client-centered steps to the clinical pathway for HF, which would optimize the quality of care of the whole person, enhance the hospital experience, and improve client outcomes (Alexander et al.).

The research piece was very well written and organized with all tables, graphs and outlines functional and informative. This study included the reliability and validity of the instruments used with the resources, reasons, and suggestions for improving care for individuals with HF.

Nurses should try to ascertain the extent to which each individual would like to be involved in treatment decisions, as it can vary greatly. Another suggestion would be to give individuals enough information for them to be comfortable to make informed decisions, regardless of their decision-making preference.

Removing Boundaries

Despite expert medical care, individuals with HF experience significant losses in their lives related to the inability to carry out many activities previously done with ease. This is due to the extreme lack of energy and/or breathlessness which causes them to be housebound and ultimately leads to isolation and loneliness (Horne & Payne, 2004). Horne and Payne addressed that the palliative care needs of individuals with HF are similar to those living with cancer, yet there are fewer services available to them.
Horne and Payne (2004) used a prospective qualitative design to make up for the lack of descriptive knowledge on the needs and experiences of individuals living with end-stage HF. They also used purposive sampling to recruit clients who had a clinical diagnosis of HF confirmed via echocardiogram. Twenty individuals consented, 11 had NYHA class 4, seven had class 3, and two were class 2. Data were collected between October 2001 and March 2002. The interview design was an open semi-structured format which enabled clients to elaborate on their experiences and views. The interview was audio taped to enhance analysis and labeling of main themes and categories. Horne and Payne also used field notes and a research diary to improve analysis of data.

The research resulted in three main themes and seven sub-themes. The three main themes that individuals had experienced living with HF were a) “can’t do,” b) difficulties in walking and, c) relying on others (Horne & Payne, 2004). “Can’t do” pertained to the simple things we take for granted; walking, bending, driving, climbing stairs, getting to the doctors, or cooking. Difficulties in walking were related to breathlessness or loss of energy. Individuals with HF saw this as an important sense of wellbeing and again presented as a significant loss of wellbeing to the individual (Horne & Payne). Relying on others, whether it is a spouse, family member, friend, or neighbor meant being a burden and caused an emotional impact on the individuals’ lives.

The seven sub-themes were identified as concept of disease; talking about death; keep taking the tablets; feelings and attitudes; hope and hopelessness; symptoms and information needs. Concept of disease was how the individuals related the disease to the effect it had on their lives. Talking about death was hard to discuss, and individuals were asked how they saw their future. Horne and Payne (2004) discovered that many
individuals with HF thought about death daily and shared concerns, yet could not talk about it with their own families. Keep taking the tablets referred to how individuals perceived the necessity to be on medications. Some individuals with HF knew that the medication was crucial to their existence and felt that apart from tablets, there was nothing else that could be done (Horne & Payne). Individuals used descriptive words for feelings and attitudes such as how HF makes them feel imprisoned by their illness, which also caused depression and feelings of sadness. Lack of emotional support compounded a sense of loneliness and isolation for those living alone (Horne & Payne).

Horne and Payne (2004) reported that hopelessness was experienced, sometimes alongside feelings of hope, but for others it was the predominant feeling that individuals just viewed their lives as finished or “simply going.” Individuals reported symptoms as having no strength, constantly feeling tired and lacking energy to do anything. When they felt mentally able to do tasks, they were too tired to even try (Horne & Payne). Other symptoms were shortness of breath, sleeplessness, loss of appetite, edema, nausea, and constipation.

Informational needs were expressed by individuals as wanting better communication from their physicians in the form of explanation, education, and information. According to Horne and Payne (2004), individuals with HF wanted a better understanding of the disease process, the practical limitation, how to get help and how to cope in living with heart failure. They also would have liked some sense of prognosis and wanted to be told the truth (Horne & Payne).
Nursing Implications

Horne and Payne (2004) highlighted the need for more psychological support by providing HF nurse specialists, to reduce hospital readmission, titration of medications and to play a role in providing psychological support for individuals who are emotionally and socially isolated. Nurses would be able to provide the need for someone to listen to life stories and be comfortable in talking to them about dying, including discussions on what gives meaning to their life. Horne and Payne also identified the need for prompt access to social services, early referral to community and financial assistance for individuals with HF.

Evidence based research on HF provides knowledge and forethought into providing holistic care for those individuals who need support from hospital based care into the community. Heart failure symptoms require physiological and emotional support and in reviewing research, nurses are able to identify and establish improved methods to enhance holistic care for individuals with HF. Enhancing care will enable nurses to improve symptom management and outcomes for individuals with HF.

Comfort Theory

The Comfort Theory, written and developed by Kathy Kolcaba, is a holistic guide for practice and research. It presents a way to provide patients and their family holistic care and provides a framework for research proposals. (Continuing Education, [CEU4U], 2007).

The Comfort Theory is based upon holistic nursing. According to Ignatavicius and Workman (2006) the holistic view considers the body, mind, and spirit to be interrelated as parts of a person’s being. Holistic nursing reflects the principle that
people respond, as a whole, to physical, psychological, spiritual, social, cultural, and environmental stimuli" (CEU4U, 2007).

Comfort Theory is defined as “the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts “physical, psychospiritual, social, and environmental” (CEU4U, 2007). Relief happens when a patient has a specific comfort need met. Ease is a state of calm or contentment and transcendence happens when a person rises above problems or pain (CEU4U). Relief, ease, and transcendence are the three types of holistic comfort and form the cornerstone of comfort to build the Comfort Theory (CEU4U).

The Comfort Theory takes into account four contexts of comfort: physical comfort (all bodily senses), psychospiritual comfort (mental, emotional, and spiritual components), environmental comfort (external surroundings, conditions, and influences), and the sociocultural comfort includes aspects of interpersonal, family, and societal relationships (CEU4U, 2007).

Kolcaba designed a grid which cross references the four contexts of physical, psychospiritual, social, and environmental with relief, ease, and transcendence (CEU4U, 2007). In using the grid, the Comfort Theory will tie into the thesis topic, Issues and Concerns of Individuals Living with Heart Failure by understanding what complications HF individuals experience emotionally and physically. Individuals will benefit by being strengthened and having their comfort needs met in the four contexts of the physical, psychospiritual, social, and environmental.

Having individuals with HF strengthened by their needs being met in all aspects of comfort should be what nurses understand and strive for and they should make it an
intuitive part of their assessment, intervention, and evaluation for both practice and research. Nurses need to truly understand comfort levels and address clients’ needs individually. Individuals should be assessed with interventions designed to address all aspects of comfort.

Individuals with HF are at risk for “ineffective coping” because of issues with anxiety control, depression, proper support systems and management of comfort levels. Applying this theory to individuals with HF will enhance their level of comfort, decrease anxiety about the disease process, and help caregivers understand their role in patient comfort care. All individuals should be assessed and cared for by the “Caring Theory” to enhance comfort beyond the altruistic reasons advocated by nursing theorists (CEU4U, 2007).

Nursing Interventions and Guidelines provide ways to understand the correlation between client, physician, and facility. How these interrelate and co-exist is important to determine understanding of holistic care for the individual with HF. In order to maximize client outcomes, guidelines, and interventions need to flow together in an orderly fashion, and the optimal state of health for the individual will be, it is hoped, at a previous state (CEU4U, 2007).

*Traditional Interventions*

HF affects the person’s role in society as well as in relationships; just socializing with friends and family may be a strain (Ignatavicius & Workman, 2006). Most nurses understand the need to discuss with clients their feelings to elicit specific information in assessing their acceptance of and ability to cope with HF. Because Nurses will need to assess previous coping strategies and support systems that have worked well in the past
and should not overlook religious beliefs when looking for sources of support for their clients.

Traditional interventions may be as simple as normal coping mechanisms or an individual’s support system or religious group. Healthcare facilities may be their source for intervention through Cardiac rehabilitation or physical therapy sessions. Because individuals cope in many different ways it is important for nurses accept that not everyone accepts lifestyle changes in the same way.

**Complementary and Alternative Therapies**

Support groups for individuals with HF or other heart conditions at local hospitals or community centers help individuals understand that they are not alone. Participation in structured cardiac rehabilitation programs has been shown to be beneficial; referrals to such programs are not widespread because coverage is usually not provided by third-party payers (AHA, 2006).

Ignatavicius and Workman (2006) report that some clients use complementary and alternative medicine (CAM) to cope with chronic disease and disability. Examples include acupuncture, imagery, music, tai chi, meditation, exercise, and massage.

Researchers have discovered that a 12-minute visit with a dog can help heart and lung function. The 12-minute visit lowered blood pressures, diminished the release of harmful hormones, and decreased anxiety among hospitalized individuals with HF (AHA).

De Jong and associates (2005) do recommend that because anxiety and depression are modifiable, the use of cognitive-behavioral interventions, stress management, biofeedback, and medication therapy to reduce anxiety and depression in clients with HF.
Reiki Touch Therapy

Reiki has been used for preventing disorders, maintaining positive wellness, and helping the healing process. Individuals with HF look to nurses to encourage and to provide holistic care so they will be able to have improved symptom management and quality of life. Individuals with HF who choose to use alternative medicine have unlimited potential to facilitate improved outcomes. Because touch is fundamental to the nursing practice, it is recognized in the Nursing Interventions Classification Code (McCloskey & Bulecheck, 1996). Reiki touch has been used to promote relaxation, reduce pain, and accelerate healing (Whelan & Wishnia, 2003). This research section will identify the origin of Reiki touch therapy, the nature of the therapy, steps in delivering Reiki, nursing considerations, and recommendations.

Origin of Reiki touch. This touching to heal has been recorded for thousands of years. The Tibetans possessed a “deep understanding of the nature of spirit, energy and matter, using this knowledge to heal their bodies, harmonize their souls and lead their spirits to an experience of unity” (Baginski & Sharamon, 1985, p.15). These same concepts emerged in India and, later, appeared in Japanese, Chinese, Egyptian, Greek, and Roman cultures. Knowledge was usually preserved by the mystery schools, available only to priests or spiritual leaders, and passed on by word of mouth (Miles & True, 2003).

Reiki is composed of two Japanese words: “Rei,” which means the Higher Power or God’s Wisdom, and “Ki,” meaning life force energy (Whelan & Wishnia, 2003). Reiki began with the Tibetan Sutras 3000 years ago and was reintroduced into Japan in the 19th century (Stewart, 1995). The Sutras contained the keys to healing, which claimed to
activate and direct universal life energy and would enable one to channel this energy
(Whelan & Wishnia).

Nature of Reiki touch. Reiki involves light touch over different parts of the body in an ordered sequence. Hands are the conduit of the universal energy that goes naturally to any area of the recipient’s body where needed. The specific hand placement is taught as part of the Reiki student’s education (Whelan & Wishnia, 2003). Mantras and symbols are used to activate the students’ ability to channel universal life energy and empower their ability to act as conduits in the healing process (Whelan & Wishnia).

Yogis and Buddhists believe that one’s wellbeing depends on a healthy balance in the body’s subtle energy fields. These fields consist of a network of energy lines called meridians in Chinese acupuncture. The points which these lines intersect are spinning energy centers called chakras or wheels. The chakras distribute universal energy along the network of energy lines throughout the whole body. Using photography we now have the ability to see the energy field that exists in the dermal layer of connective tissue. The chakras vibrate at a higher frequency than the dense lower frequency physical body. They flow through, surround, and extend from the human body (Whelan & Wishnia, 2003, p. 210).

Models in bioelectromagnetism, quantum physics, and super string theory are consistent with Asian scripture in suggesting that vibration may have a role to play in health and disease (Miles & True, 2003).
Reiki delivery. There are three levels of education or degrees of Reiki. During the first degree, the beginner learns the history of Reiki, instructions on basic Reiki hand positions, and receives attunements that activate practice for this level. The second degree of Reiki involves attunements unique to this level and absentee healing. During absentee healing the practitioner and patient are not together. It is usually not over the phone. The third degree (master level) has several stages and prepares to teach the practitioner for Reiki Master training. This level of education lasts one year while the student works as an apprentice learning to transmit energy and subsequently teach Reiki to others (Whelan & Wishnia, 2003).

There are 3 tiers of Reiki practice: Individuals who use Reiki for themselves, family, and friends; licensed or unlicensed health care professionals, either offering full Reiki treatment or combining Reiki with other modalities, and hospital-affiliated and community-based programs offering Reiki treatment or training.

(Miles & True, 2003, p. 64)

Reiki can be used anytime, any place, for any condition, even HF. In addition, when used on a conscious patient, the experience is relaxing and pleasant, increasing patient comfort, enhancing relationships with caregivers, and possibly reducing side effects of procedures and medications. Caregivers and nursing staff who routinely distress clients to administer needed medical care, express gratitude for a tool that minimizes client discomfort (Miles & True, 2003).

Clients receiving Reiki will go into a deeply relaxed state also referred to as the healing state. The conscious mind is invited to rest, giving the unconscious mind free rein
to do its healing work more efficiently. Reiki blocks and the disruptions are cleared away and replaced with life force energy, establishing free flow of Ki through the energy channels in the body (Miles & True, 2003).

**Nursing Considerations**

Although Reiki can involve skin contact, it can be done with clothes on by placing the hands six inches above the body, or at a distance with the use of symbols (Bennett, n.d.). It is suggested that hand positions be discussed with the client before Reiki treatment to ensure comfort with the approach taken. This form of energetic touch is noninvasive and falls easily within the scope of nursing practice if the nurse is properly trained (Kendall, 2001). There is currently no licensing for Reiki, and there are no professional standards so certificates also have no meaning (Miles & True, 2003).

**Benefits and Risks**

As a nursing intervention, Reiki touch therapy has frequently been shown to provide therapeutic and symptomatic relief for clients. Reiki has the ability to soothe even clients undergoing painful procedures, and it is not uncommon for clients screaming with intractable pain to become composed within 5-10 minutes of receiving Reiki touch (Miles, 2004). According to Kendall (2001),

> the outcomes of Reiki exhibit improved response of the central nervous, endocrine, and immune systems; improved sense of well-being; improved active coping; promotion of relaxation and natural sleep patterns; and reduction of pain, anxiety, depression, and insomnia. (p. 57)
All of these outcomes from Reiki touch will benefit individuals with HF to improve quality of life. In 2005, the Harvard Heart Letter identified that Reiki can lower heart rate and diastolic blood pressure. Miles (2004) also reported that Reiki appears to enhance the effectiveness of other interventions.

Reiki is used increasingly in conventional medical settings because of strong anecdotal evidence. Clients are also using it on their own because there are no known contraindications (Miles, 2004). With proper training, touch therapies remain a very low risk, low cost intervention, and within the scope of nursing practice (Wardell & Engebretson, 2001).

Practitioners believe Reiki has the potential to rebalance the biofield at the deepest vibrational level, thereby removing the subtle causes of illness while enhancing overall resilience. Because Reiki is a holistic modality that supports overall healing and wellbeing, it is not possible to predict how quickly specific symptoms may respond. Generally, in addressing chronic conditions, such as HF, a minimum of four complete treatments is advised (Miles & True, 2003).

With the known benefits individuals can receive when having Reiki touch, with the low cost and no known risks involved, it would be beneficial for individuals with HF to try Reiki touch. For individuals with HF, Reiki therapy modality is dependant on the persons receiving the therapy and what they are expecting. Because so much speculation comes with any alternative therapy, educating clients is important before any new therapy is started. For individuals with HF, if improving their quality of life and decreasing manifested symptoms are important, then trying Reiki touch may improve both.
Chapter III
Methodology

Purpose of Grounded Theory

Grounded theory methodology can be used to identify, on a more qualitative level, what are the issues and concerns or basic social process for individuals with HF. It is important for healthcare professionals to know what issues and concerns affect individuals with HF in order to address them more effectively and improve quality of life.

This type of research uses the constant comparative method for analyzing the data and constructing a theoretical model (Leedy & Ormrod, 2005). Grounded theory discovers concepts and hypotheses rather than tests or replicates hypotheses (Fain, 2004). Grounded theory ultimately focuses on an individual’s actions and interactions related to a particular topic.

Sample and Setting

This was a qualitative study using grounded theory to identify basic social processes among individuals with HF. Participants diagnosed with HF were recruited by postings that were placed at local senior centers and local cardiology offices. Volunteers contacted the researcher via phone to discuss the research of study and set up the mutually agreed upon time to meet. The sample included three volunteers with HF stage greater than II. Participants were one female and two males all of whom were caucasions, ages (65-78). Of these three participants, all had a history of smoking, all had family history of heart disease, two had chronic high blood pressure, one had full time use of oxygen, while one had nocturnal oxygen use.
The collection of data was in a private location where the individual was most comfortable. Each participant chose to have the interview take place in his or her home where he or she could answer questions that pertain to issues and concerns about living with HF.

**Confidentiality**

Each participant completed informed consent and received a copy with the researcher's information. The researcher upheld the code of ethics for the protection of human subjects and was also certified by the National Institutes of Health. This research study received approval by the Carroll College Institutional Review Board. Confidentiality was maintained during data collection by assigning pseudonyms to each participant. Data will be secured via lock box for five years, then destroyed.

**Data Collection**

The research involved audio taped in-depth interviews, collecting of life stories, daily coping mechanisms, observations, field notes, and theoretical memos. An interview guide was used that consisted of several questions relating to the topic of HF which stimulated conversation and the individual's memory. The guide was sent to the participant a week before the scheduled interview, allowing time for thought on issues that might be related to HF. Informed consent was obtained before starting the interview process, which was required by the Institutional Review Board of Carroll College. The audio taped interviews were transcribed word for word and were stored in a locked box with the audio tape and Informed Consent until its time of disposal for the confidential protection of the participants involved in the study.
Data Analysis

The analysis process began with listening to the audio tapes, reading the transcripts line by line, and coding each in the context of the participant's description. Grounded theory analysis uses the constant comparative process of identifying similarities and differences within the data, and from participant to participant and draws data which is likely to offer insight, enhance understanding, and provide a meaningful guide to action (Corbin & Strauss, 1998). Theoretical memos were developed to further conceptualize concepts and emerging categories. Once categories were identified, relationships were connected among between each of the categories, and a core category was identified. Quotes were used to validate the categories.
Chapter IV

Results

Learning to live and cope with HF was answered by the core category of Learning to Live with HF and supporting categories of Maintaining Normalcy, Planning Ahead, and Changing Lifestyle. The core category of Learning to Live with HF and supporting categories are presented along with quotes to validate these findings.

Core Category: Learning to Live with HF

All participants talked about learning to live with HF and were emotional when talking about what HF meant for them. Learning to Live with HF was described by participants as the lifestyle changes of activities, symptoms, worries about their disease getting worse, being on oxygen, and managing medications. They asked themselves if their breathing would get worse, not better. They all were upset or cried during the interview process, and they all said, “It is something I have to deal with.” Participants are continually learning to live and accept the daily shortness of breath, sleep disturbances, weight gain from the edema, weight loss from taking Lasix, diet changes, and the daily embarrassment of catching up to the person they are walking with.

Changing Lifestyle

Participants are continually changing their lifestyle in accordance with their symptoms, as a way to manage those symptoms. All participants self-educate after receiving medications or diagnostics from their health care providers. Some ways they self-educate are related to improving their diet, increasing their activity, self-care, having an awareness of their daily oxygen needs, planning oxygen needs during travel and activity, recognizing a need for rehabilitation services, and support groups. They all
wanted to be active, and they knew it is good for them regardless of the difficulty of activity intolerance, ankle edema, shortness of breath, and cold intolerance.

The following three participants’ names were changed to protect their identity.

Mr. Hunt changed his lifestyle by stopping the places he frequented—the bars in which he and his wife played in a band. That meant changing long time friendships. He and his wife now play in a different band that no longer subjects them to drinking and second-hand smoke.

Mr. Hamilton is seventy-eight, wears oxygen, and he is still a part of the National Ski Patrol. He also frequents the local ski hill though ankle edema affects how often he is able to ski, but he manages the edema by taking Lasix.

Mrs. Campbell has limited her travels, her exercise, and her amount of driving due to her shortness of breath and fatigue she said:

I look for ways to make it more manageable; I guess is the word I want,

I don’t know. You just do. Just keep on keeping on. That’s how I figure out. And I’m already taking everything that anyone has ever remotely suggested that I do. So, I’m still here.

_Maintaining Normalcy_

All participants show signs of maintaining normalcy in their daily lives. They all minimize their symptoms and/or problems associated with HF and they all said, “It is something I have to deal with.” Two of the participants tended to stay at home instead of going into town.
Mr. Hunt stated, “It is something I have to live with; I don’t have a choice.” Mr. Hunt now has a different group of friends and lifestyle. He has chosen another hobby of flying model airplanes which gives him a large group of support.

Participants tried to stay in good spirits for their family, though inside they may not be so high spirited. Mrs. Campbell stated, “Everyone has problems, and I’ve tried not to magnify mine. I try to minimize. I find that’s the best way to do it. If you think about it too much, it’s too difficult.” She also said, “You accept what comes and you handle it the best way you can.”

Mr. Hamilton had a year and a half when he could not ski, and it was a big disappointment for him. His ejection fraction was 24%, limits his exercise ability. He has to work out in the yard with oxygen on, go to town with oxygen on, go skiing with oxygen on, and even travel with oxygen on. Mr. Hamilton has to sleep with a Bi-Pap machine on, and he stated:

Wearing it at night is not very romantic, I think. But I think over a period of time between medications and I don’t know, maybe some of these other factors, it has been probably age, well, the libido, if you want to call it, is not really there. I wouldn’t say that it’s gone, but it’s . . .

Mr. Hamilton then trailed off as if he did not know what to say.

Planning Ahead

Two of the participants needed to plan for oxygen needs during travel, activities, and exercise. Mr. Hamilton is on continuous oxygen at four liters and will increase the liters as needed. Mr. Hamilton explained:
I’ve gotten used to planning to have, you know, taking so many cylinders to such and such a place or that. But the other thing is I bought a concentrator, so that makes travel a lot easier. You don’t have the big old concentrator to lug around, so that works out very well.

He also has frustration with the oxygen cord getting caught on things around the house. Mr. Hamilton stated, “My biggest challenge I have is planning what I want to do in terms of oxygen. And buying this Inogene One has taken a lot of that away.” Mr. Hunt wears oxygen during periods of napping, and when he is short of breath, so his frustration with oxygen is limited.

Activity Intolerance

Mr. Hunt has to wear oxygen with increased activities such as exercise and yard work because he experiences shortness of breath with the increased activity. Mr. Hunt explains:

I have a hard time slowing down, because I’ve done everything on the run all my life. Even walking. She had to run to keep up, and any more, why, she’s waiting for me. And I have a little problem with that.

Mrs. Campbell complained of fatigue from lack of sleep. She was up urinating from taking Lasix and lost seven pounds of fluid, leaving her tired and shaky the next day. Mrs. Campbell talked about taking Lasix the night before and stated:

. . . which leaves me not really at my best this morning. I call it my “all gone” feeling. Tired. A little bit shaky, and a little bit . . . a deep breath doesn’t feel good. But if you want to go and live, why, you have to do it.
She used to be more active in hiking, and as she has gotten older, she has unconsciously adjusted to not doing those types of things anymore. She said

“When you huff and puff, you don’t take on as many things like that where you know you are prone to. It’s not pleasant.” I spend more time huffing and puffing than I used to, and it’s... I’ve learned to breathe differently when I go up a flight of stairs. It took me a while to figure out that you just have to.”

Her main complaint has been that she is always cold and has a hard time keeping warm: “I literally can’t put enough clothes on so that I’m warm and comfortable if I’m out there. Like if the wind is blowing I’m sunk. I am frozen solid when I get back.” Mrs. Campbell also described:

I don’t drive anymore than I have to anymore, and I only go on short trips and things like that. And I don’t go unless I’m feeling well, so I don’t know if I would make the effort or not. I really don’t know. I live in beautiful country. I should be walking up and down my avenue. I used to do it when I first retired, but I got out of the habit...

Mr. Hamilton talked about skiing and why he was unable to go for so long and explained why he had to limit his activity:

I’ve skied for years. So I didn’t ski the balance of that year because I had started going through a raft of tests and medications and everything else, and it wound up, it still wasn’t really fully sorted out until about mid-season. . .mid ski season the next year, so that next year I didn’t ski either. And that was probably the biggest disturbance to me, you know.
All participant experienced role changes and adaptations related to their HF symptoms. All of the participants are finding ways to cope and the following table refers to a framework for Learning to Live with HF with the sub-categories that pertain to the findings of the research study.
Table 2. Framework for Learning to Live with Heart Failure
Learning to Live with Heart Failure

Physically, HF is characterized by a slow deterioration in physical functioning that often results in repeated hospital admissions. Individuals with HF experience devastating functional losses and a variety of psychosocial, socio-economic, and emotional concerns, such as increased depression and loss of employment, that affect their overall quality of life (Bosworth et al., 2004). Physical function plays a major role in perceptions of QOL for individuals with HF, and research suggests that other domains, particularly mental well-being and other psychosocial factors are equally crucial to QOL (Bosworth et al.). For participants in this study, decreased socio-economic status, changes in traditional household roles, and deteriorating physical functioning forced role adaptation. These changes also caused anxiety with alterations of body concept.

Changing Lifestyle

Long-term lifestyle adjustments for people living with HF often include the following: modifications in diet and activities, adherence to a complex medication regimen, and the need to monitor symptoms (Hardin & Hussey, 2003). Participants made major lifestyle changes such as diet, medications, smoking cessation, and activities. Traveling has to be planned out carefully considering portable oxygen, activity intolerance, including calculating the effort involved using stairs, length and intensity of walking. Physical health, maintaining normalcy, and social functioning are important components to perceptions of health to those that live with HF. Successful management of individuals with HF often embraces long-term lifestyle adjustments by the clients and
their families. The individual accomplishment of lifestyle adjustments is dependant not
only on the person with HF but also on his or her support system (Hardin & Hussey,
2003).

Cleland and associates (2005) offered home telemonitoring for individuals with
HF as a way to reduce admissions, hospital days, and mortality rates. Telemonitoring
individuals with HF has the potential to involve patients more in their care, assist in
titration of medication, improve compliance, and help providers identify early signs of
worsening HF and its precipitating factors (Cleland et al.).

* Becoming educated. * Participants all described that they did not receive adequate
education pertaining to HF, exacerbations, resources, or their medications. All
participants reported that they educated themselves on these topics and learned through
living with HF.

Educating individuals with HF is most effective when it takes place over time,
addressing their educational barriers as appropriate. According to the *Journal of the
American Medical Association* (2004), educational offerings may vary but also should
include information on, activity, diet, medications, medical follow-up, weight
monitoring, and symptom management.

Individuals with HF may be provided with education by various health care
professionals such as physicians, nurses, dieticians, and pharmacists (*Journal of the
American Medical Association*, 2004). Educational programs have been shown to reduce
hospitalizations and improve quality of life for individuals with HF.

* Exercise. * Another factor shown to improve the quality of life for individuals with
HF is exercise training. Rees and associates (2004), have shown that exercise training
improved exercise capacity and quality of life in patients with mild to moderate HF in the short term.

The importance of individuals’ participating in a cardiac rehabilitation program is seen not only through the increased support they receive from others attending, but through the advances in exercise tolerance. Joyner (2004) addressed the issue of exercise tolerance of individuals with HF. Because these individuals have poorly perfused skeletal muscles with limited oxidative capacity and dysfunctional metabolism to begin with, the renal vasoconstrictions observed during exercise are profound. The renin-angiotensin system and the related renal response with mild physical activity cause a constant activation of this system (Joyner). A vicious circle of inappropriate regulatory responses is initiated that originates in the muscles. The blood flow to the muscles is further limited creating a worse situation than before.

Self care. Participants educated themselves on medications, cardiac rehabilitation, and oxygen usage. They found that self-care through diet and exercise programs helped them and understand their own HF diagnosis. Participants described symptoms of edema, shortness of breath, and frustration with the use of oxygen equipment. One of the participants used a Bi-pap machine at night; one used continuous oxygen during the day, while another only used oxygen for naps during the day.

Because HF increases mortality, it has a dramatic effect on patients’ functional ability and quality of life. Patient involvement in treatment and outcome demands the skill, expertise, and education of a nurse. The nurse must be involved in the initial assessment and the coaching process (Hardin & Hussey, 2003). It is recommended by Hardin and Hussey to use the Synergy Model because it is readily adaptable to the acute
care or critical care setting when patients are critically ill. The nurse can link his or her own competencies to the patient’s characteristics as needed.

Cleland et al. (2005) identified a one-in-four chance that an individual will be re-hospitalized or have subsequent death due to HF within 12 weeks. According to Hardin and Hussey (2003), HF has a dramatic effect on the functional ability and quality of life of individuals. This is seen through recurrent hospitalizations that are preventable. Hardin & Hussey also identified factors that contribute to preventable hospitalizations: inadequate patient and caregiver education, poor symptom control, insufficient social support, and inadequate discharge planning.

Maintaining Normalcy

Today’s healthcare environment mandates that individuals with serious diseases live in their homes. This causes the need for acute and critical care settings to reach out to their patients in their home setting, not only to assist them in maintaining quality of life but also to decrease the number of hospital readmissions. This situation is especially valid for patients with HF.

Minimizing HF symptoms. Participants downplayed symptoms and tried not to stress family members during their exacerbation of symptoms. One participant stated that he would walk 2 miles a day with his spouse. Later he was unable to walk from the house to the car, and then he finally admitted to his spouse that he needed to go to the hospital. This was used as a coping mechanism as well as to maintain normalcy.

Bosworth (2003) reported that their patients were acutely aware that the physical symptoms they experienced also affected their loved ones; they often ‘downplayed’ discomfort to protect a family member from concern.
Because people with HF experience shortness of breath and tend to restrict their activities, this can reduce their amount of fitness further, making their symptoms worse (Coats et al., 2004).

**Social support.** Participants often feared being a burden to their family and friends. The results of this study highlighted the influence of role loss for individuals with HF. These individuals often found they were unable to work and contribute to the family as they had before dealing with HF. They had lost friends that they once had for many years and jobs that they could no longer keep up with. Role Definition is described by Levinson (1969), as “A person’s attempt to structure his social reality, to define his place within it, and guide his search for meaning and gratification” (Manning, 1969, p. 71).

**Sexuality and sexual intimacy.** Participants were emotionally upset when discussing loss of intimacy with spouse due to the medications, oxygen, fatigue, and shortness of breath. Participants changed social roles or lost those roles completely. Two participants stayed home most of the time with the exception of planning ahead several days to go into town. One participant kept up with golfing, skiing, and going to dinner with friends, regardless of his oxygen requirements.

According to Bosworth et al. (2003), all of their patients also spoke on the subject of frustration about the loss of their ability to participate in usual work or social roles and its negative influence on overall quality of life. Also, a number of these men discussed specifically how the loss of abilities impacted their expected masculine roles in their household including their loss of sexual intimacy. In addition to expressions of negative emotions, they heard many examples of coping and compensation. Coping included both
positive and negative coping mechanisms for the present and preparation for the future (Bosworth et al.).

Planning Ahead

Planning ahead was an issue for all participants in the research study. Individuals with HF have many concerns related to their health and what precipitating factors could lead to an exacerbation during an outing or extended travel. Individuals with HF must take precautions when traveling and must be prepared for all arising circumstances. For the three participants in this study oxygen needs were of the most concern.

Traveling with oxygen. Individuals found it difficult to prepare needed oxygen requirements when traveling. Traveling requirements differed among the three participants dependant upon oxygen needs to begin with. To travel overnight they needed to understand their oxygen requirements for multiple days. They found it time consuming and fatiguing to prepare and travel with oxygen.

Nursing Implications

 Individuals with HF experience the following concerns: (a) role adaptation of patients, (b) the effect of shortness of breath on activities of daily living (c) increased anxiety, (d) loss of functional ability, and (e) loss of sexual intimacy. Patients often experience loss of intimacy with loved ones or family members and are intimidated with discussing the topic with those outside of their comfort zone. Nurses must be aware that some individuals with HF strive to maintain normalcy and thus may minimize their symptoms. Education may play an important role in symptom management in addition to their changing lifestyle. When nurses are involved in the lives of their patients on a daily basis, they understand how HF affects daily coping and how shortness of breath, fatigue,
and edema affects their daily lives. The nurse should also understand how to help the patient cope with feelings associated with the diet changes and exercise regimes.

Recommendations for Future Research

There are no evidence based protocols for activity tolerance. There is a need more evidence-based practice studies (EBP) on symptom management including non-pharmacologic management such as Reiki therapy. There is also a void of research related to exercise, the amount or type and its impact on HF. There was a lack of EBP or clinical guidelines to assist healthcare personnel in educating individuals with HF before discharge from the hospital or clinical setting. The following areas of research would be helpful in improving the outcome of individuals with HF: (a) symptom management and sexuality, (b) symptom protocol and guidelines, (c) non-pharmacologic therapies, (d) programs to facilitate role adaptation, (e) nurse-managed HF clinics, and (f) support groups for those who live with HF.

Summary

Learning to live and cope with HF was answered by the core category of Learning to Live with HF and supporting categories of Maintaining Normalcy, Planning Ahead, and Changing Lifestyle. Learning to Live with HF was described by participants as the lifestyle changes of activities, symptoms, worries about their disease getting worse, being on oxygen, and managing medications.

The prevalence of HF will continue to grow as our society increases in age and more comorbid conditions exist. As healthcare providers it is essential to identify ways to improve the QOL of this growing population.
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