Heart failure: Its impact on women's lives

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HEART FAILURE: ITS IMPACT
ON WOMEN'S LIVES

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A thesis submitted in partial fulfillment
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Graduate College
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December 2001
Thesis Approval
The Graduate College
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August 16, 2001

The Thesis prepared by

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Heart Failure: Its Impact on Women's Lives

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ABSTRACT

Heart Failure: Its Impact
On Women’s Lives

by

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Research has shown women are affected by heart
defailure differently than men, having different risk
factors for heart failure (HF), a higher increase in
mortality per decade, and longer survival after diagnosis.
Women have also been greatly under-represented in studies
of HF. A search of the literature revealed only one
(Swedish) study examining the overall impact of HF on
women’s conception of their own lives.

This phenomenological study examined the changes in
the lives since diagnosis of five women with Stage II HF.
Four one-hour, semi-structured interviews were held with
each. Colaizzi’s steps were used to assess the verbatim
transcripts of the interviews, drawing meanings from the
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ACKNOWLEDGMENTS

Thanks are owed to the patience of my committee chair, Dr. Cheryl Bowles, and the members of my committee, Dr. Susan Michael, Dr. Lori Candela, and Dr. Ann McDonough.

Very special thanks are owed to my mother, Eloise Rhodes, who counts very well to 33, and without whose unswerving love and support I would never have survived the past three years.

My gratitude and love go to the five very special women who opened their hearts and lives to me for this research. And finally, thanks to a very dear friend, Tillie Chaffin (1910 - 2001), whose continuing zest for life is an inspiration.
INTRODUCTION: AIM OF THE STUDY

Phenomenon of Interest: Heart Failure

Heart failure (HF) is a major (and growing) health problem in the United States. Heart failure has been defined in many ways. Dahlen and Roberts (1996) suggest heart failure involves an abnormality of heart muscle resulting in failure when demands are made on the normal muscle that are greater than it can perform. Cohn (1988) states that heart failure is a syndrome in which cardiac output is insufficient for the body’s demands. Heart failure is recognized as a syndrome in which cardiac dysfunction results in decreased exercise tolerance, a high incidence of arrhythmias, and decreased life expectancy.

There are as many as 4.8 million cases of HF in this country at this time (Connolly, 2000), with 400,000 new cases diagnosed annually (Cahalin, 1996). The number of
cases continues to grow, due to advances in treatment and increasing life expectancy.

**Focus: Women with Heart Failure**

Heart failure is heavily researched; however, the majority of studies focus on men, or include only a limited number of women in the sample. For example, examination of 8,876 patients involved in six major HF mortality trials reveals that only 13% were women (Johnson, 1993). Relatively few articles have been written about women and heart failure.

As a result, relatively little is known about women’s response to heart failure. It is known that there are differences between men and women in the incidence, age of diagnosis, risk factors, survival rate, and response to treatment of heart failure. However, very little research reflects women’s perception of their lives with heart failure. A search of the literature revealed only a single study, and that done in Sweden, dealing with this aspect of women and HF.

In this study, the phenomenological approach will be used to attempt to answer the question: How do women with Stage II heart failure perceive their own lives? The
study will attempt to examine and describe, from the patient's perspective, the experience of living with heart failure. An attempt will be made to understand from the participants' descriptions, how having HF has impacted various aspects of their lives, including the mental, physical, emotional, social, and spiritual aspects. The results will hopefully provide a greater understanding, in the words of those women experiencing it, of what it means to live with heart failure. This greater understanding, in turn, will hopefully allow medical caregivers to better meet patient needs in treating them.
CHAPTER 2

EVOLUTION OF THE STUDY

Rationale

Although researchers are beginning to study women with HF more than in the past, there is still a relative paucity of literature dealing with women and heart failure. Only a few dozen articles deal specifically with heart failure’s effects on women’s lives.

For women, HF is an increasing reality: they are hospitalized for HF more than men (Ho, et. al., 1993), live longer after diagnosis (Vaccarino, Chen, Wang, Radford, & Krumholz, 1999), and have a greater increase in mortality per decade of age than men (Ho, et. al., 1993). Thus, the number of women living with heart failure will increase tremendously in the next 20 to 30 years. Yet very little is known about what having heart failure means to the women experiencing it. It is therefore important to learn more about heart failure’s effects on women’s
lives, so that treatment can be designed to meet their needs.

Historical Context

Prevalence

Although many older sources cite two to three million cases, more recent sources indicate there are as many as 4.8 million cases of heart failure in this country at this time (Connolly, 2000). There are 400,000 new cases diagnosed annually, and HF results in more than 900,000 hospitalizations per year (Cahalin, 1996). It is increasingly seen as a primary or secondary diagnosis in patients admitted to transitional care units, home health, and long-term care facilities, as well (Stanley, 1999).

Heart failure is the leading cause of in-hospital deaths and repeat hospitalizations for patients over 65 (Friedman, 1997), and causes the highest reported hospital readmission rate for all patient groups (Hawthorne and Hixon, 1994). In a study by Rich and Freedland (1988), as many as one patient in three was readmitted for HF within 90 days of a prior hospitalization. Another study had similar results: in three to six months, 29 to 36% were rehospitalized, and the 90-day readmission rate of
patients 70 or older with HF was 47% (Vinson, Rich, Sperry, Shah, & McNamara, 1990).

Once HF is diagnosed, the five-year mortality is 60% for men and 45% for women (Dahlen & Roberts, 1995). The Framingham Heart Study found the six-year mortality rate to be 85% for men and 67% for women (Kannel & Belanger, 1994). When a patient is diagnosed with severe (Stage IV) heart failure, the mortality rate at one year is up to 60% (Bennett, Pressler, Hays, Firestine, & Huster, 1997). Furthermore, despite improved treatment and modern technology, there was no appreciable decline in mortality between 1948 and 1988 (Gheorghiade, et. al., 2000).

A Growing Problem

The incidence of HF has been increasing steadily for several years, and this growth is likely to continue. There are at least two reasons for this increase.

First, many patients are surviving cardiac problems which would have been fatal in the past, due primarily to new medicines and new technologies. Second, people are simply living longer. With longer life, many individuals with a variety of heart and lung diseases may well develop HF at some point in their lives (Kannel, Ho, & Thom, 1994; Kannel & Belanger, 1991). According to one source, by 2030, 23% of our population will be over 65 years of age,
with five million older than 85 years (Stanley, 1997). Research has revealed the prevalence of HF doubles with each decade after the age of 50 (Kannel & Belanger, 1991).

**The Cost of Heart Failure**

The most recent sources indicate heart failure costs this country more than 38 billion dollars annually, with more than 23 billion dollars of this due specifically to inpatient hospital care (Dahl & Penque, 2000). In 1992, Medicare paid $2.4 billion for 654,000 hospital admissions for HF alone, and HF is the primary Medicare expenditure for patients over 65. In fact, more than five cents of every health care dollar is spent on this chronic condition (Dahl & Penque, 2000). Another source (Gheorghiade, et. al., 2000) gives the financial cost at $12 billion per year, but this does not include costs related to lost wages or productivity.

These financial figures do not take into account the human costs of the disease: the fluctuations in the ability to function, the burden on the caregivers, the financial burden to individuals and families, and the psychological burden involved in what Baas, Fontana, & Bhat (1997) call "the constant threat of death." Most individuals who die of HF today do so suddenly and
unexpectedly (Gheorghiade, et. al., 2000); at least half of all deaths are sudden (Ballew & Reigle, 1998).

Psychosocial Impacts of Heart Failure

Heart failure affects far more than the physical aspects of the lives of those with the syndrome. In fact, HF has been shown to affect virtually every aspect of these patients' lives. The response to HF varies from patient to patient, but there are some common responses.

Psychological Effects. There is a wide range of psychological adaptations in patients with HF, from cheerful coping to emotional devastation (Freedland & Carney, 2000).

In some patients, Fontana (1996) found patient perceptions of health were positive, reflecting a positive attitude, a powerful will to live, and a self-image that transcended the loss of physical activity. Furthermore, in these patients the level of life satisfaction increased with age. However, some patients also expressed a dichotomy in their treatment: many felt a need to maintain autonomy, but struggled with the feeling of having no control at all.

Subjects are forced to face their own mortality when diagnosed with HF (Baas, Fontana, & Bhat, 1997). They face fears and uncertainty regarding their own future,
their health, and their family's future (Muirhead, et. al., 1992). Patients with HF tend to view their disease as beyond their personal control (Russell, Geraci, Hooper, Shull, & Gregory, 1998).

These patients also find "it can be difficult to come to terms with the reality that one has a serious chronic condition, when the disorder is invisible to others" (Thorne & Paterson, 2000, p. 8).

**Emotional Effects.** According to a study by Hawthorne & Hix (1994), patients with HF experience more mood disturbances than other cardiac patients. There is often an "emotional reaction to the realization that their lives may be shortened by this chronic illness," while some "transcended usual time lines" in achieving developmental tasks (Baas, Beery, Fontana, & Wagoner, 1999, p. 117).

Depression is often a major problem for elderly patients with HF, and this depression is related to an increase in inpatient days and higher mortality at one year after diagnosis (Freedland, et. al., 1991). In a study by Bennett, Pressler, Hays, Firestone, & Huster (1997), hospitalized HF patients reported symptom impact in the emotional area, with depression and worry common. Testing in another study (Dracup, Walden, Stevenson, &
Brecht, 1992) showed HF patients as moderately anxious and moderately hostile, but moderately to severely depressed.

Stress is often high among chronic illness patients. For example, in a study of women with rheumatic arthritis, restrictions in lifestyle caused by the illness was listed as a primary stressor (Revenson & Felton, 1989).

The patients' sense of loss with progress of the disease may manifest as anger, depression, or passivity, with feelings of powerlessness common as well (Letterer, Carew, Reid, & Woods, 1992). Hawthorne & Hixon (1994) also note increased depression and hostility as patients' symptoms increased.

Depression, though, "is by far the most common psychosocial response to the process of decline in health and function seen" with HF (Stanley, 1999, p. 184). Major depression is common in elderly patients with HF, increasing as the HF worsens (Freedland & Carney, 2000). Anxiety related to dyspnea is also common.

Hopelessness is often expressed by these patients (Rideout, 1986). Hopelessness is common among elderly, hospitalized HF patients (Roberts, Johnson, & Keely, 1999). This is seen as due to "repetitive hospitalizations for CHF, an accumulation of physical losses, and a declining ability to care for themselves"
(p. 196), as well as decreasing personal resources. The patients' usual coping mechanisms prove inadequate.

Rideout & Montemuro (1986) found patients with a more positive future orientation, and continued hope and high morale, adapted to HF more effectively than others. Hope is described in this study as "the belief that there is a way out and that with help the individual can manage changes in his being," and morale as "the ability to strive appropriately while still accepting the inevitable" (p. 429). Patients with HF scored similarly to those with chronic respiratory disease. The authors concluded that patients who are more hopeful "maintain their involvement in life regardless of physical limitations imposed by HF" (p. 437).

Craig & Edwards (1983) also emphasize the importance of hope in adapting to a chronic illness, stating that it allows the individual to prepare for a permanent loss of function, while maintaining hope that adaptation to altered function will be possible, even if restoration of function is not.

Social Effects. Rosenblum, et. al. (1993) found HF patients had greater social dysfunction than others, with adjustment to illness best predicted by self-reported functional status, depression, and hostility. Patients
respond to HF in different ways: Fontana (1996) found some patients became increasingly self-absorbed, while others worked harder at familial relationships. However, many patients describe very negative changes in their relationships with friends and members of their extended families (Dracup, Walden, Stevenson, & Brecht, 1992), and described a severe disruption in social functioning (Stewart, et. al., 1989).

In patients with chronic disease, changes in interpersonal relationships often affect close relationships less than more distant ones. Friedman (1997) noted a reduction in social interaction in nonfamilial relationships, especially in older adults. In a study of patients with cancer (Dunkel-Schetter & Wortman, 1982), patients often mentioned changes in interpersonal relationships, though usually in more distant relationships rather than with family. Riedinger, Dracup, & Brecht (2000) noted that an increase in NYHA HF classification was associated with decreased social activity and social life satisfaction.

Social isolation has been noted by several researchers among chronic illness patients. Stanley (1999) noted social isolation may occur as a result of HF's chronic fatigue and problems associated with diuretic
therapy. Jonsdottir (1998), studying patients with COPD, noted social isolation related to difficulties expressing themselves and relating to others. Some described a preference to be alone, coupled with a wish to be seen by others as not different from them. The physical effects of the disease process also affected their ability to go places, be among other people, and participate in recreational activities.

With the decreased sense of control of their own lives, the HF patient may blame others, feeling they have failed or frustrated him or her. There may be an increased inability to trust others. The elderly patient may also have few relatives or friends to help them (Roberts, Johnson, & Keely, 1999). Inadequate social support has been noted as a risk factor for mortality in elderly patients, with or without HF (Freedland & Carney, 2000; Pennix, et. al., 1997; Steinbach, 1992).

In HF patients, absence of social support was significant in one study as a predictor of the endpoint of fatal and nonfatal cardiac events, especially among women (Krumholz, et. al., 1998).

**Role Effects.** Fontana (1996) found role confusion for some HF patients, as their physical limitations increasingly restricted their ability to complete role-
related tasks. For example, one study showed 71% of patients were employed full time prior to the development of HF, but with the disease, only 19% were employed full time, and 8% part time (Baas, Fontana, & Bhat, 1997). Stewart, et. al. (1989) noted a severe disruption in role performance.

Subjects perceiving themselves as unable to perform usual household activities were three times more likely than those considering themselves able-bodied to report anxiety, and almost four times more likely to report depression, and women were more likely than men to experience both anxiety and depression (Stern, 1984). One study showed women were more likely than men to feel guilty about their inability to perform household activities - yet resisted being helped with normal household chores (Boogard, 1984).

Self-image Effects. One study of 691 women with HF showed that fewer than half of women with HF felt they were healthy enough to perform normal activities (Riedinger, Dracup, & Brecht, 2000). The authors noted (p. 606), "Women, as homemakers and caregivers, have traditionally performed activities such as shopping and keeping house. The effect of HF on their ability to continue these tasks may have profound effects on their
feelings of self-esteem." In looking at patients with COPD, Leidy & Haase (1999) noted that physical changes made the activities of daily living (ADL's) more difficult, resulting in diminished feelings of personal integrity and effectiveness. This may be, in part, because patients with chronic disability may focus their sense of identity upon the dysfunctional body component (Price, 1996).

Thorne & Paterson (2000) express the problem in this way: "Chronic diseases that force dramatic changes in biographical course, especially in terms of roles and responsibilities, inevitably challenge identity or self-concept" (p. 8). Stanley (1999) agrees: "Elders frequently find themselves in need of assistance with many activities of daily living, at times they can feel they are a burden to family and friends as the disease process worsens and their dependence on others increases. Instead of being able to give of themselves, they are forced into a situation of being the passive recipient of care" (p. 183), with potentially devastating effects on their self-image.

Quality of Life Effects. In a study by Dracup, Walden, Stevenson, & Brecht (1992), HF patients described their quality of life (QOL) as significantly compromised.
Quality of life decreases, in part because of decreased functional ability related to HF symptoms, but also due to decreased perceptions of health status, which diminishes life satisfaction and feelings of well-being (Bennett, Baker, & Huster, 1998). Most male and female patients with severe HF reported decreased social and leisure activities (Mayou, Blackwood, Bryant, & Garnham, 1991). Internal resources such as hope, spirituality, optimism, self-esteem, and humor were found to be extremely important in terms of enhancing HF patients' QOL (Baas, Fontana, & Bhat, 1997).

Cognitive Effects. In one study of female HF patients, many reported symptoms of cognitive impairment, in some cases severe. However, the authors were reluctant to draw conclusions from the study due to the small sample size and the self-reporting of impairment (Bennett, Baker, & Huster, 1998).

Freedland & Carney (2000) noted that the decreased blood flow and hypoxemia of HF can cause diminished level of consciousness, confusion, and memory impairment, and that the patient's mental status may also be affected by loss of sleep secondary to HF's paroxysmal nocturnal dyspnea and orthopnea.
In a study by Bennett, Pressler, Hays, Firestine, & Huster (1997), hospitalized HF patients reported strong symptom impact in the cognitive area. Decreased attention span and memory loss were frequently reported, possibly related to cerebral hypoperfusion secondary to diminished cardiac output. Cognitive dysfunction and confusion were inversely related to QOL in another study (Hawthorne & Hixon, 1994).

Testing in the Studies of Left Ventricular Dysfunction (SOLVD) trial showed a significant decline in cognitive functioning, progressing with decline in HF from Stage I to Stage II and III, particularly in attention-concentration tasks (Gorkin, et. al., 1993). Thought processes may become irrational, causing “difficulty articulating desires and thinking about future goals” (Roberts, Johnson, & Keely, 1999, p. 196). However, Barroso (1996) noted, chronic illness sufferers find a more positive attitude if they plan for the future (with some long-term goals), and focus their energies in a cause they are interested in.

**Spiritual Effects.** Spiritual well-being is an important internal resource for those who must adjust to uncertainty related to chronic illness (Landis, 1996).
Spirituality facilitates coping in times of stress and illness, and influences psychological well-being (Carson & Green, 1992; Miller, 1985; Soeken & Carson, 1987). Landis (1996) found that as spiritual well-being increased, problems related to living with a chronic illness decreased.

Different researchers have interpreted findings regarding spirituality differently. For example, there are differences of opinion among researchers as to whether spirituality enables a person with chronic illness to find meaning in the experience, and this allows him to come to terms with the illness, as Fife (1994) described, or whether spirituality results from attempting to cope with the illness, as described by Ragsdale, Kotarba, & Morrow (1994).

Causes of Heart Failure

According to Cahalin (1996), heart failure can be related to valve dysfunction, or to blocking of inflow to or outflow from the heart. However, the most common cause is abnormal muscle function, which can occur for many reasons. Chronic heart failure is primarily due to cardiomyopathy, congenital abnormalities, renal insufficiency, or the changes of aging. Acute heart failure, on the other hand, is due primarily to
hypertension (HTN), coronary artery disease (CAD), myocardial infarct or ischemia, cardiac dysrhythmias, pericardial effusion/myocarditis, pulmonary embolus or pulmonary HTN, or spinal cord injury (Cahalin, 1996). One study found HTN and CAD are responsible for more than 80% of clinical events related to HF (Ho, Pinsky, Kannel, & Levy, 1993). Certainly, HTN is a major cause: in fact, one study (Rengo, et. al., 1996) showed 75% of patients affected by HTN develop some degree of HF!

**Signs and Symptoms of Heart Failure**

Common signs and symptoms of heart failure may include dyspnea, tachypnea, paroxysmal nocturnal dyspnea, orthopnea, peripheral edema, cold/pale/or cyanotic extremities, weight gain, hepatomegaly, jugular venous distension, crackles (rales), tubular breath sounds and consolidation, a cardiac S3, sinus tachycardia, and decreased exercise tolerance/physical work capacity (Cahalin, 1996). Palpitations, sleeplessness, and angina are common; however, fatigue and dyspnea on exertion are the most common symptoms (Friedman, 1997). Increased heart size is seen on a chest Xray, and ejection fraction (cardiac output) is decreased. In addition, there is often pulmonary edema.
All body systems can be affected by HF. Changes can be seen in the cardiovascular, pulmonary, renal, neurohormonal, musculoskeletal, hematologic, hepatic, pancreatic, nutritional, and biochemical areas.

The Classification of Heart Failure

In diagnosing heart failure, terms like "mild, moderate, and severe" are used, but are nonspecific and of limited use clinically. The New York Heart Association (NYHA) classifications are commonly used. These classifications also have problems. They are not very discriminating, and as Cohn (1988) states, the NYHA classification "is dependent on the patient's report of limitations of exercise capacity without adequate regard to his or her lifestyle" (p. 100). Nevertheless, the NYHA is the most commonly used way of classifying heart failure patients, and will therefore be used in this study.

The NYHA classification is as follows:

I diagnosed with heart failure based on cardiac changes, but having no symptoms regardless of level of activity

II symptoms with ordinary activity (such as fatigue, dyspnea, palpitations, angina); slight activity limitation
III symptoms with less than ordinary activity; no 
symptoms when at rest; marked limitation with 
daily tasks
IV symptoms are experienced with any type of 
physical activity, or even at rest

Women and Heart Failure

Women have been severely underrepresented in research 
on heart failure. As previously noted, an examination of 
six major HF mortality trials included only 13% women 
among its subjects (Johnson, 1993). Relatively few 
articles have been written about women and heart failure. 
(Hereafter, “women” will refer to women over 60 years of 
age.)

It is known that the incidence of coronary heart 
disease is lower overall in women (Ho, et. al., 1993), but 
greater than that of men by age 75 (Friedman, 1993). 
Women are significantly older than men when diagnosed with 
HF (72 vs. 68 years) (Kimmelstiel & Konstam, 1995). Women 
are more often admitted to the hospital for HF than are 
men (Ho, et. al., 1993).

Heart failure is more frequent in women after a heart 
attack (48% for black women, vs. 22% for black men; 26% 
for white women, vs. 17% for white men), six months after 
infarction. This higher rate of heart failure is true,
even though the women have less systolic dysfunction than men at the same point in their recovery. Researchers suggest the higher incidence of heart failure in women may be because of a higher number of baseline predictors of mortality, such as: higher frequency of reinfarction, older age of women at time of infarction, and greater prevalence of HTN and diabetes mellitus (DM) among women (Johnson, 1993; Tofler, et. al., 1987; Wenger, 1985). Heart failure in women is itself recognized as a risk factor for myocardial infarctions in women (Hendricks, Goodman, Stein, & Carnes, 1999).

The primary risk factors for women and men have been found to be different. Hypertension and DM are the primary risk factors for women, while ischemia seems to play a more important role in men (Kimmelstiel & Goldberg, 1990; Ho, et. al., 1993; Johnson, 1993; Kimmelstiel & Konstam, 1995; Martensson, Karlsson, & Fridlund, 1997, 1998). As many as 78% of women diagnosed with HF have a prior diagnosis of HTN (Ho, et. al., 1993). Valve disease is also more common as a cause for HF in women (Opasich, et. al., 2000). Chronic obstructive pulmonary disease (COPD) is a slightly greater risk factor for women than for men, but smoking is a more significant risk factor for men than for women, according to one recent study.
Atrial fibrillation in patients with HF increases risk more in women than in men (Johnson, 1993), and is more common in women (Benjamin, et. al., 1998; Gottdiener, et. al., 2000; Opasich, et. al., 2000).

Women tend to live longer after a diagnosis of HF than do men (Vaccarino, Chen, Wang, Radford, & Krumholz, 1999). In part, this may be because myocyte death in HF is initially less extensive in women than in men (Guerra, et. al., 1999), adding to the longer overall survival rates. Estrogen use in aging women also increases survival (Reis, et. al., 2000).

One study (Pinsky, Jette, Branch, Kannel, & Feinleib, 1990), relating heart disease symptoms with disability in older patients, found that "not only did a greater percent of women report disabilities compared to men, but they reported being disabled in more activities than men" (p. 1365).

Women have a much greater increase in mortality per decade of age than do men (61% to 27%, respectively) (Ho, et. al., 1993). This may be related to the findings in two major clinical trials where mortality and morbidity outcomes were examined by gender. In these two trials, it was found that beneficial treatment effects of many
medicines appear to be less in women than in men. For example, males treated with enalapril (Vasotec) had a 51% decrease in 6-month mortality, women only a 6% decrease. In another study, captopril (Capoten) decreased risk of death 22% in men, but only 2% in women (Johnson, 1993).

In addition, it appears that treatment of women is not always comparable to that given to male patients. One study (Ayanian, Weissman, Chosan-Taber, & Epstein, 1999) indicated, on implicit review of medical records by physicians, that women received worse cognitive care than men for HF, and worse quality of care. For example, "physicians were less likely to record findings from the initial cardiac exam in women than in men" (p. 1265). Women also had lower sickness-at-admission scores for HF.

Even though they are living longer, women's quality of life, like that of men, diminishes with HF, due to the progressive nature of the disease and its symptoms, their decreased energy and increased fatigue, unwanted dependency, and forced early retirement (Dracup, Walden, Stevenson, & Brecht, 1992; Friedman & King, 1995; Bennett, Baker, & Huster, 1998). Increased dyspnea is directly associated with decreased quality of life for many women with HF (Riedinger, Dracup, & Brecht, 2000). Fatigue is a
major problem for them, and is related to other physical symptoms. Many women adapt to fatigue by simply no longer doing those things they find most fatiguing (Friedman, 1995).

Women with HF are noted to have better support systems than men with HF. If a spouse/caregiver dies, women are more likely to get needed assistance from a network of friends (Friedman, 1997b). Men have a more difficult time finding a replacement for a primary caregiver.

**Perceived Justification for Studying Women with HF**

Despite the literally thousands of articles on heart failure available in the literature, relatively few deal with women with the syndrome. Very few articles deal with what having HF means to women, and how it affects their lives. Yet heart failure is a very serious problem for increasing numbers of women, and women live longer with HF than do men. Effective treatment of these women requires adequate knowledge of the impact of HF on their lives.

**Study Problem and Purpose**

The problem is that there is insufficient knowledge of what having HF means to the women experiencing it. In this study, the phenomenological approach will be used to
attempt to answer the question: How do women with Stage II heart failure perceive their own lives?

Stage II patients were selected in part because at this stage, HF is beginning to affect their ability to accomplish the tasks of their daily lives, yet not so severely as at later stages. Therefore, these participants are more able to tolerate the required time for interviews involved in this study. In addition, because the effects of the disease are not yet severe, these are often women living at home, still very much involved in the work, home care, and other daily activities of their lives prior to diagnosis with HF.

In addition to the fundamental question of how women with Stage II HF perceive their lives, related questions include: (1) How does having HF affect these women's lives? (2) What changes have resulted since the diagnosis was made? (3) In what ways has having HF affected them in their relationships to others, their work life, their daily activities, their outlook regarding life and the future, their view of themselves?

Assumptions, Biases, Perceptions

I worked with patients experiencing HF and other cardiac problems for two years in Louisville, Kentucky. During that time, I became increasingly aware of the
downward spiral of HF, and the impact it had on patients' lives.

Based on those two years, and the knowledge and experience accumulated since that time, I have several assumptions and biases. Among these:

1. I believe older women experience HF uniquely.
2. As a health professional, I believe knowing how HF affects women matters.
3. I believe most HF patients lack adequate knowledge about their disease.
4. I believe HF has a major impact on women's lives.

Additional Historical Context

Knowledge about HF has increased greatly in the past 50 years. As knowledge of many disease processes has grown, it has been discovered that other diseases such as hyperthyroidism and diabetes mellitus can lead to heart failure, as can alcohol or cocaine abuse, and some infectious or inflammatory processes. Hypertension, severe anemia, arrhythmias, CAD, and even (in some patients) pregnancy can be risk factors. In addition, knowledge has increased about various forms of damage to the heart itself, such as ischemic heart disease, valve dysfunction, damage to heart muscle (e.g., secondary to a myocardial infarction), congenital heart disease,
cardiomyopathy; any of these can result in heart failure (Aronow, Ahn, & Kronzon, 2000; Ballew & Reigle, 1998; Cahalin, 1996; Gheorghiade, et al., 2000; Gottdiener, et al., 2000; Kimmelstiel & Goldberg, 1990; Stanley, 1999).

There have been numerous recent advances in diagnosing and treating HF. Tools for diagnosing heart failure and the degree of dysfunction include new laboratory tests (Shamsham & Mitchell, 2000), medical imaging, and new types of medications (Connolly, 2000; Gheorghiade, et al. 2000; Michael & Parnell, 1998; O'Connor, Gattis, & Swedberg, 1999; Sonnenblick, 2000). Various types of surgical options are also available (Dimengo, 1998).

Nonpharmacologic treatment has also improved. For example, there is an increased understanding of the importance of nutrition and diet for heart failure patients (Kendler, 1997; Connolly, 2000). The renal response to decreased cardiac output is to retain sodium. Thus, most HF patients are put on a 2-gram sodium diet, although with severe volume overload, an intake of less than 2 grams is necessary (Lenihan & Uretsky, 2000). It is especially important to avoid "binge" salt eating, which can lead to "acute circulatory congestion and
episodes of decompensation" (p.1102), with the potential for long-term adverse effects on left ventricular function (Cohn, 1988). Fluid restriction is generally not necessary, if the patient is stable on standard HF treatment (Lenihan & Uretsky, 2000).

Vegetarian diets are known to be healthiest for the heart; increased fiber is important, and an adequate intake of B6, B12, and folate is vital because of their role in preventing problems with homocysteine. Coenzyme Q10 (CoQ10) intake has been found to be important because HF patients have been shown to have depletion of CoQ10, and supplementing with CoQ10 gives symptom relief (Kendler, 1997).

Practitioners understand that it is necessary for HF patients to stop smoking. Smoking cessation is especially important because nicotine increases myocardial demand and increases systemic vascular resistance, potentially further compromising ventricular function (Freedland & Carney, 2000). It is also important for these patients to stop drinking or drink no more than one drink per day (because of alcohol’s cardiotoxic effects), to weigh daily, and to get flu and pneumonia shots to avoid illnesses that can worsen HF.
Isotonic exercise - rather than bedrest - has also been found to be important for heart failure, improving function and decreasing symptoms. Rehabilitation programs are available to help patients determine what level of exercise works best for them (Cahalin, 1999; Oldridge, 1997). Moderate exercise has been shown to improve QOL in patients with mild to moderate HF (Freedland & Carney, 2000).

Obese patients should try to lose weight, as obesity complicates treatment of the HF patient, through the increase in cardiac workload. However, weight loss should be through a moderate restriction in calories and a gradual approach in elderly patients, to avoid nutritional deficiencies (Lenihan & Uretsky, 2000).

Heart failure patients should also minimize their use of NSAIDs (except low-dose aspirin), because in heart failure patients, NSAIDs can increase the odds of hospital admission. One study indicated NSAID use may be responsible for 19% of hospital admissions with HF (Page & Henry, 2000).

Perhaps most importantly, health care professionals now place more responsibility on the heart failure patient, for self-monitoring and compliance with the treatment regime. However, this in turn puts greater
responsibility on the practitioners to educate and re-educate these patients so they have the information they need for appropriate self-care, and to closely monitor their condition. In addition, patients must be provided with additional information as their disease process advances, to help them cope with the changes.

With all the improvements in diagnosis and treatment, there is still very little known about the overall impact of HF beyond the physical in the lives of those who have it. That is the foundational reason for this study.

Relevance to Nursing

A phenomenological study of female patients with HF is highly relevant to nursing, for a number of reasons. First, in this country almost $38 billion dollars a year is spent on HF patients, over five cents of every health care dollar (Dahl & Penque, 2000). Yet this is done generally with no consideration of the meanings those affected by HF attribute to their lives and the care they are getting. As Munhall (1994) suggests, to spend this much money "without reflection as to meaning is utter foolishness if not insanity" (p. 179).

In other words, the U.S. is spending billions of dollars treating men and women with heart failure with no
consideration of what they desire, what they hope treatment will accomplish, or what they hope to be able to do in their lives despite the demands that HF makes on their bodies. Yet from the time nurses begin nursing school, they are taught to involve the patient in his or her own care, to take into account in planning care the wishes and needs of the patient. How can this be done without determining from the patient what those wishes and needs are? This study will attempt to determine more clearly how women with Stage II HF perceive their lives. By better understanding their perceptions, information may be gained which will help practitioners better meet the needs of these patients.

Second, the study is relevant to nursing because the population is aging, and the incidence of HF is rising. Thus, most nurses and nurse practitioners will, sooner or later, work with women with heart failure.

Third, according to the American Nurses Association (1980), the phenomena of concern to nurses are human responses. Yet little is known about women’s responses to HF. Practitioners are dedicated to helping meet patients’ needs, yet have very limited knowledge about the needs of women with HF from their own perspective.
Experiential Context

I worked for slightly over two years with cardiac patients in Louisville, Kentucky. During that time, I saw the same HF patients readmitted numerous times for the same medical problems, consisting primarily of increased shortness of breath and fluid retention. I began to ask why this was happening.

I became aware also, from talking to patients, how depressing this constant round of rehospitalizations was for them. One patient, tears in her eyes, told me, "My husband wants to take me for two weeks in Mexico. It's a trip I’ve dreamed about for years. But I can’t go – I never know when I’ll need to go to the hospital."

I also became aware of a remarkable lack of information and knowledge about their own illness among these patients. One woman, diagnosed three years earlier, and in the hospital for the fourth time in that calendar year, told me she had never even been told what HF is, and (until I gave her some written information) had never been aware there were things she could do to keep herself out of the hospital.

My growing frustration with the situation these patients faced led to my interest in establishing a clinic specifically for heart failure patients, where there would
be close monitoring, adjustments of medications as needed, and continuing education and re-education of the patients—on diet, exercise, medications—whatever they needed.

I came to realize, however, that with all my knowledge of the costs and causes and diagnosis and treatment of heart failure, with all my familiarity with its symptoms, I have at best a very limited idea of what having heart failure means to the patients themselves. I simply don't know what the experience is of living day in and day out with a failing heart.

Realizing my lack of real understanding became the reason for the research involved in this study. I chose to work with female patients simply because the research studies on women are so much less numerous than those on men.

Because the interviews involved in the study make some physical demand on the participants, I elected to work with women with Stage II heart failure: they are less limited in ADL's than are women at later stages. In addition, I wished to work with women who are still living at home, functioning reasonably well on a daily basis, yet beginning to feel the effects of heart failure in their daily lives. Stage II participants met these requirements.
CHAPTER 3

METHOD OF INQUIRY (GENERAL)

Introduction to Phenomenology

Phenomenology is a qualitative research approach, but is also an approach to living and learning, a way of thinking. Its focus is on "lived experience" - on learning what an experience means to a human being living within that experience. It seeks to understand what being means, what it means to be human, and to help find ways of "achieving greater humanness" (Munhall, 1994, p. 3).

Phenomenology is a philosophy, interested in the question, "What is the meaning of being human?" It is based in philosophy. Its focus is always on the meaning to human beings of their experiences. Munhall (1994) suggests we can study the meaning of being human only by studying what human beings do and how they interpret what they do and attach meaning to it. The phenomenologist must
respect the individual's interpretation of an experience as that individual's reality.

Thus, phenomenology is based on a profound respect for the individual, the individual's experience, and the meanings the experience has for the individual. Yet, by speaking with several individuals with exposure to similar experiences, the researcher also seeks to interpret the experience, to draw out its essence, and thereby to enable the reader to understand "the deeper significance or structure of the lived experience being described" (Munhall, 1994, p. 18). Van Manen (1990) agrees: phenomenology attempts to gain "a deeper understanding of the nature or meaning of our everyday experiences..." (p. 9).

Background of the Method

The roots of phenomenology can be traced back to Aristotle, Plato, and Descartes. Kant occasionally used the term to distinguish objects/events in human experience from objects/events as they are in themselves. Hegel (1977) described phenomenology as the way in which individuals can know "mind" as it actually is by studying the ways in which it appears to them (Van Manen, 1990).
However, Husserl is generally seen as the father of phenomenology as used in this study: a descriptive method and a human science movement based on philosophy and human science thought. Husserl saw phenomenology as a way to describe how the world is made and experienced through conscious acts. It requires a "bracketing" of any of the researcher's preconceptions or beliefs, in order to describe only what the researcher is given through immediate experience. Husserl developed the idea of the lifeworld, the "everyday world" in which humans live and which they generally take for granted.

This idea of a lifeworld led to a more existential form of phenomenology, as presented by Heidegger. Heidegger suggested phenomenology is a study of the ways of humans "being in the world," and felt that the things of the world must speak for themselves. He also felt it was impossible to separate the interpreter from those experiencing and describing the phenomenon. Therefore bracketing, in his view, was not possible.

Merleau-Ponty further developed the phenomenological approach to research. He stated (1962, p. vii), "Phenomenology is the study of essences," meaning that phenomenology must always ask the question of what the meaning of something is. Phenomenology requires learning
a new way of looking at the world in immediate experience, and (p. xii) "the same demand for awareness and the same will to seize the meaning of the world as that meaning comes into being." Thus, phenomenology "offers accounts of experienced space, time, body, and human relations as we live them."

Phenomenology has been utilized in numerous fields, including sociology, psychotherapy/psychiatry, and education.

Rationale for Choosing the Method

The purpose of this study is to determine how women with Stage II heart failure perceive their own lives. Phenomenology is a qualitative method appropriate for this study.

Many aspects of women's lives are changed by having HF. The limited relevant literature supports this view. Phenomenology is a method to explore such questions as: How are these women's lives changed? How do these changes affect them? Do they retain hope? How do they adjust to the changes? How are they affected in their social and familial relationships, in their employment, in their roles, in their outlook, in their self-image?
Phenomenology is uniquely suited to answering some of these questions. As Burns and Grove (1997) state, "The broad question that phenomenologists ask is 'What is the meaning of one's lived experience?' Being a person is self-interpreting, therefore the only reliable source of information to answer this question is the person" (p. 71).

Phenomenology is an inductive, descriptive approach, which seeks to understand the response of human beings to experiences - to describe the experience as it is lived by the participants, and from their perspective rather than the researcher's. The interest is not just in the experience, but in the meaning of that lived experience to the person experiencing it. If, as Burns and Grove (1997) state, "the only reliable source of information...is the person" (p. 71), then it is important to know what women experience living with HF, by asking them to describe it.

Yet phenomenology is "rigorous, critical, systematic investigation of phenomena," intended to determine "the essence of the lived experience" of the phenomenon in question (Streubert & Carpenter, 1999, p. 48). Each person has his or her own reality - yet in talking to several participants, allowing them to describe their experience in living with HF, common themes may emerge -
the beginning of "grasping the essence" of the experience. Phenomenology deals with the whole person, not just their physical condition. Because HF affects far more than just the patient's body, the method is appropriate. Phenomenology makes no assumptions about what the experience means to the participants, but simply allows them to speak for themselves.

Phenomenology as an approach to research emphasizes ordinary, day-to-day experiences of life. But instead of doing so in what Munhall calls "sailing-through-life-without-reflection," phenomenology allows reflection to better understand the ordinary experiences of daily life.

Nursing, like phenomenology, focuses on the individual and his or her free will. Free will is based on the idea that the individual's acts are based on experience, with the individual acting with autonomy and self-determination, and seeking to fulfill his or her human potential. Each individual is unique, experiencing his or her own "reality." Thus, each individual may interpret an experience differently, and ascribe a different meaning to it than any other individual. Phenomenology acknowledges human beings as unique individuals. Each person's subjective experience is valued and described. The meaning of an experience is
that person's meaning, not a meaning assumed or assigned by the researcher (Munhall, 1994).

Van Manen (1990) suggests that the ultimate aim of phenomenological research is "the fulfillment of our human nature: to become more fully who we are" (p. 12). Phenomenology is the study of being, and beings exist in situations called lived experiences. Munhall (1994) emphasizes that "Through studying these lived experiences of other human beings, we may come to understand what it means to be human. If we understand such meaning, our consciousness is expanded and the possibility of becoming more fully human presents itself" (p. 46).

Phenomenological research then becomes "a caring act: we want to know that which is most essential to being" (Van Manen, 1990, p. 5). Phenomenology offers an appropriate way to study "that which is most essential to being."

Outcome of the Method

It is hoped that the results of this study will provide a clearer understanding and appreciation of what having heart failure means to the women experiencing it. This understanding will be gained through a review and interpretation of the actual descriptions of the
experience by the participants. The reader will have the opportunity to read a description of the participants' experience, in their own words.

Sources to Be Followed

Colaizzi's basic steps of phenomenological research (1978) were utilized for data analysis. Colaizzi's steps are as follows:

1. Repeatedly read and re-read all of the participants' descriptions, to gain a feeling for the whole.
2. Extract significant statements and phrases which pertain directly to the phenomenon being studied.
3. Formulate (spell out) meanings from these significant phrases and statements.
4. Cluster these meanings into themes. Note any discrepancies, which may indicate additional themes.
5. Integrate results into an exhaustive description of the phenomenon.
6. Formulate this exhaustive description into as comprehensive and unequivocal a statement of identification as possible.
7. Validate results by returning to participants with the statement of identification/description of the phenomenon.
It should be noted that these steps are ongoing throughout the research: meanings are drawn out of each subsequent interview, and added to the overall; themes emerge and are verified or negated by subsequent interviews; the description changes as more data are accumulated.

While Colaizzi’s basic steps guided this study, the works of Munhall (1994) and Van Manen (1990) were used to “fill in the detail” of the “how to do” the individual steps. In particular, some of Munhall’s suggestions regarding interview techniques and considerations were incorporated, while some of Van Manen’s suggestions regarding how to write up the findings were used.

Translation of Concepts and Terms

The language used in phenomenological research often includes terms not commonly used, or not commonly defined as used in these studies. Therefore, a brief “translation” of some of these terms is indicated.

Bracketing is “the act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world” (Van Manen, 1990, p. 175). The purpose of bracketing is “to set aside our own beliefs for a period of time so that we can ‘hear’
and 'see' as undisturbed as is possible by our own knowing. This unknowing allows for openness and also allows us to converse with participants without attempting to validate our own presuppositions and beliefs" (Munhall, 1994, p. 62). In short, to the extent possible, the researcher sets aside his/her own beliefs and presuppositions about what the results will be, in order to (1) let the participants' words speak for themselves, (2) not influence the responses given by participants, and (3) not impose his/her values or beliefs on data collection and analysis.

Consciousness is defined by Merleau-Ponty (1962) as sensory awareness of and response to the environment. It is "existence in the world through the body. The unity of mind and body becomes a means of experiencing... A person cannot step out of consciousness and be sure of anything. The world is knowable only through the subjectivity of being in the world" (Munhall, 1994, p. 14-15). Consciousness is "the only access individuals have to the world" (Munhall, 1994, p. 37). Ideally, the outcome of a study from the perspective of consciousness is "raised" consciousness: the reader begins to understand things previously hidden. "At any point in time and for each individual, a particular perspective or consciousness
exists based on the individual's history, knowledge of the world, and perhaps openness to the world" (Munhall, 1994, p. 15). Experience and perception are our modes of consciousness, our way of being aware of the world and what is happening to us.

**Embodiment** is possible through our consciousness: the person is aware of being in the world, and through the body gains access to the world. "We feel, think, taste, touch, hear, and are conscious through the opportunities the body offers" (Munhall, 1994, p. 15).

**Essence** is "the inner essential nature of a thing, the true being of a thing.... Essence is what makes a thing what it is (and without which it could not be what it is)" (Van Manen, 1990, p. 177). Basic essence, the grasp of the very nature of something, is, according to most phenomenologists, accessible to phenomenological research. Van Manen (1990) states, "A good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way" (p. 39). A good phenomenological study will allow the reader to "grasp the essence" of an experience, to
begin to understand it from the perspective of those experiencing it.

**Intentionality** is defined by Van Manen (1990) in this way: "the act of researching-questioning-theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it.... Phenomenology calls this inseparable connection to the world the principle of 'intentionality'" (p. 3). Van Manen further defines it (p. 182) by saying, "All human activity is always oriented activity, directed by that which orients it.... We are not reflexively conscious of our intentional relation to the world. Intentionality is only retrospectively available to consciousness.... It is not possible to experience something while reflecting on the experience."

Intentionality, then, is "the way we choose and find ourselves to be present in the world" (Van Manen, 1990, p. 182).

**Intersubjectivity** occurs "whenever two people engage in interaction or one person hears another's interpretation of experience.... The dialogue is essential, and the intersubjective meeting space, where one person listens and the other person tells his or her story is the heart of the study" (Munhall, 1994, p. 37-38).

Intersubjectivity is "the verbal and nonverbal interplay..."
between the organized subjective worlds of two people, in which one person's subjectivity intersects with another's subjectivity.... The real point here is that individuals do not know about anyone else's subjective world unless they are told about it” (Munhall, 1994, p. 64). The phenomenological researcher approaches the participant as a student. The researcher does not and cannot know what the experience is like for the participant, and can gain that knowledge only by the participant's willingness to describe and reveal the experience.
CHAPTER 4

THE METHOD OF INQUIRY: APPLIED

Sample

The sample of participants was composed of five women aged 60 to 90 years, who self-reported that they had been diagnosed by their cardiologists with Stage II heart failure, or, if the patient was uncertain of HF Stage, stage was determined by the researcher through limited physical examination and questions regarding ADL’s. It was a purposive sample, drawn from a variety of sources: direct referrals from friends, indirect referrals through a participant already involved in the study, and those who volunteered following presentations at senior centers.

Primary requirements for the participants were: they must be diagnosed with Stage II heart failure, age 60 or older, female, diagnosed by their M.D. at least six months prior to the interview, English speaking, and able to express themselves well verbally.

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Setting

The setting of the interviews with participants was determined by the individual participants themselves. The majority of the interviews were held in the participants' homes, but the choice of setting was theirs. The homes were preferred, for two reasons: (1) at home, the participants probably felt most comfortable and natural, and their sense of ease may have translated into better, more informative interviews; and (2) it allowed the interviewer a glimpse into the living environment of the participants, permitting a fuller understanding of and connection with their lives. However, in one participant's case, interviews were held in a quiet corner of a senior center where she spends most of her time.

Gaining Access

Initial contact was made directly to the participants. The first participant was a direct referral through a faculty member at the University. The next two were indirect referrals, brought into the study by the first participant. The final two were respondents to the invitation to participate which followed presentations on heart failure at two senior centers.
General Steps

Initial Meeting with Potential Participants

The initial meeting was held at a site of the patient's choosing: their home, in four cases, and a senior center in one case. At this time all participants were fully informed regarding the purpose of the study and what was expected of them as a participant. They were again invited to participate, and upon agreement, were asked to sign an informed consent and set up a time for the first full interview.

The Interviews

Four semi-structured interviews were held with each participant, the number of interviews determined in part by whether or not new information continued to emerge with additional interviews (i.e., if a saturation point was reached). A Grand Tour question began the initial interview: In what ways has having heart failure affected your life? Thereafter, the interviewer spoke as little as possible. Silence was utilized to encourage further elucidation of an area from the participants, and additional questions and comments were used only to keep the interview focused or to clarify information already given by the participants.
Each interview lasted no more than one hour; with the 90-year-old participant, interviews were shortened to 45 to 50 minutes. The length of each interview depended both on the information forthcoming, and on the strength, endurance, and willingness of the participants. Close observation of the participants was maintained during the interviews, so that opportunity for termination of the interview could be offered at the first indication of fatigue. As noted above, open-ended questions were kept to a minimum, as the purpose of the interviews was to let the participants describe their lives in their own way and in their own words.

All interviews were audiotaped, with the full knowledge and consent of the participants. It was explained to participants that the purpose of the audiotapes was to insure that transcription of the interview was accurate and verbatim. Furthermore, all tapes were identified only by codes, with no personal identifying information on them, and only the researcher had access to the tapes.

Colaizzi's Steps

Once the interviews were transcribed, Colaizzi's steps (1979) were followed for data analysis:
1. The participants’ interviews, as transcribed verbatim, were read and re-read many times. This was done both to get a feeling for the whole, and to “immerse” the researcher in the data.

2. Significant statements/phrases were extracted from the transcribed interviews: statements and phrases directly related to the experience of living with heart failure on a daily basis.

3. Meanings were drawn from these selected statements and phrases.

4. The meanings were “clustered” into themes, alert for discrepancies which might suggest additional themes.

5. These themes were used to create as complete a description as possible of the experience of living with heart failure.

6. This description was formulated into as clear a statement of identification as possible.

7. The researcher took the description back to the participants to be sure it was as correct and thorough as possible. If additional information was forthcoming from participants, it was incorporated into the study.
Methodological Rigor

In a qualitative study, as in any research, it is necessary to demonstrate the soundness of the project. All research, according to Lincoln and Guba (1985) must respond to certain questions: (1) How truthful are the findings - and judged by what criteria? (2) How applicable are the findings to another setting/group of people? (3) How sure is it that the findings can be replicated, using the same participants and the same concept? (4) How certain is it that the findings reflect the subjects and inquiry, rather than the researcher's biases?

Lincoln and Guba (1985) suggest four criteria that must be met in qualitative research: credibility/validity, transferability, dependability, and confirmability. In addition, bracketing has been added.

Bracketing. To the extent possible, the researcher should set aside preconceptions regarding the outcomes. The researcher should attempt to suspend personal beliefs, to approach the participants with what Munhall (1994) calls an "attitude of unknowing" (p. 54), to allow the participants' descriptions alone to create an understanding of what living with heart failure is like. This required setting aside any assumptions or
presuppositions about living with heart failure, so the participants could speak in their own words, not the researcher's. It also involved the researcher becoming fully attuned to and conscious of personal beliefs, in order to determine what the experience is for the participants.

Initially, bracketing was done before interviews even began. The researcher examined personal prejudices and beliefs, recording them in a log. For example, the researcher found beliefs about the elderly had to be examined, as well as beliefs about those with chronic illnesses. These beliefs were based in the researcher's own life experiences with these groups of people. As interviews proceeded, and additional beliefs and experiences were revealed, these also had to be bracketed. In short, bracketing occurred throughout the entire process of data collection and analysis, as the researcher's own biases and presuppositions were revealed through self-examination or brought to light by information received during the interviews.

In bracketing, the researcher discovered numerous presuppositions regarding females with heart failure, which were set aside during the interviews (and most of which proved false). Among these: that the women would
undergo frequent hospitalization even at Stage II; that they would be frustrated by the rehospitalizations and their inability to prevent them; that they would have a significant lack of knowledge regarding their own condition; that they would have received or sought little education regarding heart failure from medical personnel or other sources; and that they would be hopeless, helpless, and dependent.

**Credibility and Dependability.** A major means of establishing credibility is to see whether participants recognize findings as true to their own experiences (Yonge & Stewin, 1988). Credibility of the results therefore was determined through validation of the results by the participants. The researcher returned to each participant with copies of the results, allowing them at least three days to review them. All participants were then asked two questions: (1) Is this description of heart failure accurate to your life experience? (2) Is there any important aspect of living with heart failure which has not been described here, based on your experience? All participants recognized the findings as true to their own experience, and none suggested additions or changes. Their validation of the results as written established the credibility and thus the dependability of the results.
(Lincoln and Guba (1985) state there can be no dependability without credibility.)

**Confirmability/reproducibility.** As the transcribed interviews were read and re-read, as words and phrases were singled out and grouped, and as themes emerged, an audit trail was developed. The audit trail allows another researcher to verify that, utilizing the same raw data, he/she would arrive at the same themes. The audit trail records activities over time, and shows the evidence and thought processes that led the researcher to the reported findings. The interviews were transcribed verbatim on the left half of the page, with each line numbered. The right half of the page was left blank, for singling out words and phrases considered significant (i.e., coding). As themes or groupings emerge, they were identified and clustered on a separate paper by interview number, page and line number. An experienced phenomenological researcher was given copies of two interviews and an audit trail, and concluded she was able to arrive at the same themes as reported in this study.

**Transferability** of the results is the responsibility of the reader: to determine if the results fit their situation (Lincoln & Guba, 1985; Sandelowski, 1986).
Human Subject Considerations

Human Subjects Approvals

Approval to conduct the study was obtained from both the Nursing Department and UNLV Human Subjects Review Boards prior to data collection.

Informed Consent

The purpose of the study was discussed with participants, and the informed consent form was signed by those willing to participate at the initial meeting with potential participants. (See Appendix I.)

Entry and Departure

Initial contact with potential participants was made directly with the first participant, based on a referral by a University faculty member. Initial contact with the next two participants was at the first participant’s home, and at her invitation to two friends with heart failure. Initial contact with the remaining two participants was through their voluntary contact following presentations at two senior centers. At the initial meeting with each potential participant, the study’s purpose and direction was explained, arrangements for the interviews that were satisfactory to the participants were determined, and the Informed Consent was reviewed and signed. This was a time of mutual assessment between researcher and potential
participants, during which the researcher evaluated the patient’s ability and ease of communication and degree of openness, and the participant determined the trustworthiness of the researcher and her own willingness to talk with the researcher.

Departure was a two-step process. Initial departure occurred when a saturation point was reached in the interviews with each participant - i.e., a point where information was repetitious. With all participants, this point was reached late in the third or during the fourth interview. However, because validation of the results was needed, the researcher had additional contact with the participants. Once data were analyzed and themes had emerged, a comprehensive description of living with heart failure was formulated. The resulting description was brought back to each participant to verify that it adequately captured her experience, and to allow for revision if any participant wished to provide additional information.

Confidentiality

Participants were assured that all information they gave would be confidential, and would be reported in the study only in ways which would guarantee their privacy.
Emotional Response

Occasional tears during an interview were assessed by the researcher to be therapeutic. None of the participants appeared emotionally upset as a result of the interviews. The researcher was supportive and alert for such a circumstance, and prepared to offer to terminate the interview for that day. The researcher was also prepared to offer referrals to four counseling centers with sliding scale fees, if participants indicated any intense emotional reactions during the interviews.
CHAPTER 5

RESULTS

Heart Failure - or Aging?

Because of the age of the participants in this study, it could be argued that at least some of the changes reported were due simply to aging. This topic was addressed directly with participants: Consider all the changes you have described. Do you feel they are due to your age, your heart disease, or to some other cause? The consensus was that although some of the changes might be due to aging, much or most of what they were experiencing was attributable to their heart disease. Beatrice expressed best their response:

I regret that I have slowed down so much, but I can’t even blame it on my heart, totally on my heart. It’s just my age has slowed me down, also. So it’s like a double whammy. Two things slowing me down instead of one.
An Overview of Results

All five women participating in this study were deeply affected by having heart failure. They identified its effects in every aspect of their lives: physical, mental, emotional, social, spiritual, and financial. Some were more deeply affected than others in various ways, but all felt the impact of the disease process on their lives. In addition, the sole married participant discussed sexual effects related to HF, which are therefore discussed in this chapter. Because they were of real concern to the participants in this study, participant comments regarding medical care they have received are also presented.

After extensive analysis of the data presented by the five participants, the results of this study appear to fall into the following four main themes: Acknowledging Losses in Their Lives, Accepting the Losses, Changing Their Lives, and Deepening Relationships. Each of these four themes had various sub-themes, as indicated in Table 2, p. 132. The results are presented in the following pages under these four major themes, with each sub-theme addressed.
Acknowledging Losses

All five women spoke of losses they had experienced due to their heart failure, and in many cases, it was apparent they grieved for what was lost. The losses affected many areas of their lives: the loss of physical capacity (addressed as the sub-theme of A Decrease in Physical Activity), the decrease in social activity (the sub-theme of A Narrowed Social Life), the loss (or threat of loss) of control of their own lives (the sub-theme of A Concern with Maintaining Control), the decrease of easily-achieved happiness (the sub-theme of Working on Being Content), and the decrease of finances (the sub-theme of Living on a Tight Budget). For all five women, these five sub-themes were spoken of repeatedly during the interviews.

A Decrease in Physical Activity

All five women were heavily impacted physically by heart failure. All complained of symptoms they experienced: all mentioned decreased strength and energy, shortness of breath, and fatigue. Four of the five spoke of edema, occasional chest pain, and sleeping with more than one pillow. Two mentioned sleep problems, and two spoke of arrhythmias. All spoke of an increased awareness
of their own bodies, and three mentioned an increased feeling of vulnerability to other illness.

All five participants spoke of extremely active lives before heart failure. One of the women had gone from taking part in five activities at the Senior Olympics, to requiring 15 minutes to walk approximately two blocks. All spoke of the difficulty of the transition from very active lives to lives much more limited by their physical conditions.

"Abigail" stated, "Heart failure slowed me down, and I can't be as active, I can't go places like I did. I can't do the things I used to do. I get so upset with myself, 'cause I want to do things." "Dorothea" complained, "I start all these jobs, and before I'm halfway through, I'm wondering why I started them. Life is an effort. It's miserable to be like that, because I want to do so much." And "Esther" finds, "Living at a retirement home is about all I can manage and still feel a sense of well-being and satisfaction."

Some of the women spoke of having to now consider aspects of their activities which would have been irrelevant in the past. One woman expressed it in this way:
I want to go, but... there's things I never had to think about before. I would have said, Sure, and just left. But now, it's the heat, and the crowds, and do I have to climb hills when I get there, do I have to go up stairs when I get there?

A Narrowed Social Life

All five women spoke of changes in their social lives necessitated by their changing physical condition. All spoke of the need to limit their social lives because of diminished energy and strength, and increased fatigability.

Abigail can no longer visit her daughter's home because of the number of stairs in the split-level home. She describes her social life as "nothing" now, and says, "It's gotten really narrow." Esther finds her social life restricted primarily to the retirement home where she now lives.

Beatrice and Charlotte made deliberate choices to change their social lives. Charlotte deliberately chose to discontinue seeing some friends, because they were practicing a lifestyle (smoking/drinking/overeating) she could no longer live. She sought new friends among her volunteer area and the church, and says she "met a whole new crop of people. Where were these people hiding?"

However, her biggest deliberate change socially came when
she and her husband moved from the Midwest to a Western state and established a new home, requiring development of a whole new circle of acquaintances and friends. She attributes this move completely to her heart disease.

Beatrice likes living alone. She states, "It's nice to go home and have it quiet!" She spends a part of five days a week at a senior center, but when there, is selective in the activities in which she takes part. A strong and independent woman, she says, "I don't call myself a social person as such"; she chooses solitude over company.

Dorothea is the most isolated of the five women, much of it because of her own actions and her own choices. She has closed many past social outlets. For example, she no longer does volunteer work, because of uncertainty regarding how she will feel physically from day to day. She finds visitors too tiring now, and because of the physical demands, no longer enjoys traveling. At times, she deliberately avoids people. She also self-isolates when she is depressed (much of the time) or tired. Most of her social activities are loner activities, though sometimes in a room with others. She goes to movies, the casino, or bingo alone. She also reads, knits, and paints.
A Concern with Maintaining Control

All of the women spoke of mental changes since their heart failure was diagnosed. In particular, they spoke of memory loss and decreased ability to concentrate. They did not always attribute these changes solely to the heart failure. Two felt the mental changes were also due in part simply to aging, and one recognized the possible effects of a stroke on her mental abilities.

The five women all expressed concern with maintaining control of their own lives. The loss they experienced in this area had to do with perceived or threatened loss of this control.

Abigail fears a loss of mental abilities. Her response is to work hard (and successfully) at maintaining her intellect. She continues to read magazines and books, though she uses talking books at times to protect her failing eyesight:

I read, I read a lot of magazines, and I read books. I listen to the news, and I get the paper. I keep up with the news, I keep up with politics. You shouldn’t let your mind vegetate.

Two of the women spoke of concerns at what they see as a loss of control of their own lives. Charlotte noted a forced dependence, about which she is ambivalent:
A little thing like taking a car away, and not even having that independence to say OK, I’m going to get in the car and go somewhere - now I don’t. But even as a small child, I never liked restraints of any kind, you can’t do this, you can’t do that, you know, and I always tried to say, Oh, yes I can!

She speaks of hiding her physical symptoms from her husband, and of terrifying dreams. But most difficult for her is her reliance on a mechanical device, over which she has no control at all:

The vulnerability I feel is that there is a machine inside of me that is really taking over my heartbeat. What if there’s a malfunction, what if it stops, will I get to the hospital on time before my heart just completely stops beating?

Dorothea finds her physical symptoms cause her to feel a loss of control:

I’m not used to not being in control. The dizziness terrifies me. I’m so afraid. Once it starts to go, once the room starts going around, I... you don’t have any control. That’s a horrible feeling. I hate that feeling. I always took care of things.... Heart failure has changed my sense of control. I’m not as secure as I was. I’m worried I won’t be able to do for myself, and have to ask for help.

The other two participants, however, stress the ways in which they maintain control of their own lives. Their emphasis is on keeping their minds sharp (both read

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extensively), doing things they can control, and making their own choices.

Beatrice speaks of the satisfaction of working (18 hours a week) at the senior center, and of enjoying the responsibility involved in her work. One method she uses to maintain control is to maintain privacy. She has chosen not to inform her children she has heart failure. She has confidence in her own ability to cope, saying, "I just knew that I could overcome this - not that my condition would go away totally, but I just knew that I could handle it." She also maintains control by making her own choices about major changes in her life. For example, she chose to stop driving recently, when she felt it was time, and is maintaining her independence by finding alternate means of transport.

Esther also maintains control by choosing to change, even before change becomes necessary. She always looks at her options before choosing, although she states, "At this age, I realize it is important to reflect, and discuss options, before making decisions; equally important is to acknowledge that sometimes there are no options." She feels making her own choices about her life - even about living in the retirement home - is a vitally important part of maintaining control: "I think it makes a
difference when you get to choose... Probably the choice of my own is the core of my happiness and cheerfulness, or at least the chance of choosing what I feel I am able to do."

Thus, all five women spoke of the importance to them of maintaining control of their own lives. Loss of this control is seen as a threat, and all five fight to maintain their own independence and autonomy.

**Working on Being Content**

Four of the five women spoke extensively of fighting negative emotions in connection with their heart failure. All five mentioned encounters with depression, two mentioned anger, and four mentioned having to deal with fear. They found a loss of easily-achieved happiness in their lives. Abigail expressed this well: "I don’t think I’m as happy as I was. You have to work on being content, and before this, I didn’t have to do that."

**Depression.** Abigail occasionally fights depression, but says, "it don’t last long. I’ve never been that kind of person. When I do get upset, I try to think of all the good things I have." Beatrice mentions that depression would be easy, with the losses, enforced dependency, and diminished physical capacity she faces each day, but refuses to be a "poor me" person, saying, "I try to stay ‘up’." The enforced dependency is difficult for her: "It’s
very humbling in this respect. I have spent my life helping other people, doing their grocery shopping, taking them to the store, and all of a sudden, it's about face."

Charlotte fights depression. She attributes this to thinking about her health too much, and fearing that something serious will go wrong. Her depression is also based in her guilt over no longer contributing financially to the family coffers, and her resultant feelings of uselessness: "I felt like I was just nobody, I'm a vegetable. You know, what am I going to contribute here?"

More than any of the other women, Dorothea fights depression. In large part, her depression is a continuation of her grieving process for her late husband, who died almost ten years ago, but who was, according to Dorothea, the only person in her life to whom she was ever special, the only person in her life who ever loved her. Her depression, unlike that of the other women, is a continuing, daily struggle, and has the earmarks of a true clinical depression. She is tired all the time, finds life "overwhelming," sees nothing to look forward to in life, and finds joy in very little. She says, "I'm not there at all. I'm existing, but that's all." On Zoloft now, she finds decreased intensity of feeling and fewer
tears than in the past. Nevertheless, when asked to describe herself, she says, “Deep down, I’m very unhappy.”

Anger. Charlotte spoke of her anger at what she saw as the unfairness of her disease, her feeling of “Why me?”

I blame my job, the job I had before, and the stress from my condition, more than the risk factors. There are a lot of people that were overweight, like I was, and who smoked, at my age. And they didn’t suffer heart attacks. I don’t know why me, at such a young age. I get very upset about it.

Dorothea also spoke of anger, but hers was directed at the limitations imposed by heart failure and by her age. She described herself as irritated, frustrated, and resentful of her inability to do all she wants, her irritation at physical symptoms, and her dislike of the restrictions the symptoms cause, saying, “I’m unhappy about the restrictions, I’m unhappy that I get tired so fast. I think I’m irritable a lot, only at myself, not... I guess at life, at getting old.”

Fears. Four of the five women spoke of a loss of feeling safe, and having to deal with far more fear than they ever had before heart failure. Charlotte and Dorothea both speak of this fear as being greater than any they had ever experienced: Charlotte says, “I never had that much fear before,” while Dorothea states, “I never had the fear
that I have now.” Abigail and Charlotte both speak of a fear of death, while the other three emphasize they have no fear of death. Charlotte, Dorothea, and Esther all spoke of a fear of pain associated with their heart disease, a fear of additional surgery or complications they had not yet seen.

All five women speak of a fear of becoming a burden to other people; this is a major concern to all of them. They very much want to maintain their independence, to make decisions affecting their own lives right up to the point of death. Beatrice says she just hopes she “never has to be a burden, physically or financially.” Charlotte says, “I don’t want to become a vegetable, you know, that my husband would have to take care of.” Dorothea says, “That’s when the heart thing bothers me, that I will become incapable of taking care of myself, or doing things the way I want to do them. I just don’t want to be a bother to anybody.” And Esther emphasizes she does not want to have to live with her children.

At times, fear was counterproductive for two of the women. Dorothea avoids going to the doctor, because she feels nothing will be done: “They said with my heart condition and my diabetes, I’m not a good candidate for surgery, so what’s the point in finding more?” Charlotte
also avoids going to the doctor because of fear: "I started having symptoms, but I never went to the doctor because I was afraid."

**Living on a Tight Budget**

The final area of loss which the women acknowledged was financial. All five women spoke of learning to be careful with their money, of "trying to teach my dollars to have more cents," as Abigail put it. Abigail speaks of feeling freer of financial worries than in the past, since she no longer has to worry about house or yard maintenance, taxes on her house, utility bills, or car insurance. However, she has to budget strictly, and is trying to make ends meet just on her Social Security without dipping into her small nest egg any more than she has to.

Beatrice, a proud women, says, "I would not consider myself poor. I put myself in the low income bracket. But I have what I need. It's amazing as you get older how you find out what you don't need." It becomes clear that she must watch her money closely: she buys "one new top and one pair of pants a year," and on at least two occasions, she mentioned that so far (emphasis hers), with her insurance, she can afford her medications.
Dorothea considers finances a private topic, which she doesn’t discuss even with her children. However, she expressed a great awareness that she is no longer making money, and what she has now is all she has or will have.

Esther is on a tight budget, and is grateful for her good health, as assisted living would severely cut into her savings. So far, she says, she can afford the retirement home, "if it doesn’t change too much, and they don’t raise the rent too much." She has less than $300 a month to pay for "telephone, outings, gas, insurance for car, licenses," and all other expenses. (Fortunately, her medications are free through her late husband’s military benefits.) She notes, "The co-pays of $10 mount up." There is no more casual spending on anything.

It could be argued that these four women, living on the fixed income of retirees, would be on tight budgets regardless of whether they had heart failure or not. However, Charlotte’s loss of financial security is directly attributable to her disease. To pay her medical bills and keep their daughter in college, they had to sell their Midwest home. To move to the West, they were forced to cash in her husband’s 401k. She has very real concerns about their lack of reserves:
OK, here we are, up in our, almost retirement age. I can't go back to work. Sold our 401k. The only thing we have to fall back on is a $200,000 life insurance policy. This is all we have to our names, and the house, and the car, and the dog. We don't have anything put away for retirement.

The picture is clear: all five women have suffered very real losses in connection with their heart failure. These losses are physical, mental, social, emotional, and financial. They acknowledge these losses and speak of them freely. For some, there is still grief at times over what they can no longer do. However, in most cases, these five women have found ways to accept the losses and go on with their lives.

Accepting the Losses

All five women have learned acceptance of their lives as they now experience them. Some found this acceptance more easily than others. All spoke of times when they still resist the limitations, particularly the physical limitations they face, but continue on a day-to-day basis to practice acceptance. Their acceptance fell into three sub-themes: Allowing Unfinished Tasks, in which they spoke of their acceptance of physical limitations, Accepting
What Is, the mental “shifting of gears” required, and A Focus on the Positive, the emotional change necessitated in order to accept the losses heart failure has brought.

Allowing Unfinished Tasks

For the five women in this study, acceptance of their losses included allowing things to be unfinished, or at least allowing them to be finished in far longer than the time frame they would have liked. All of the women commented on learning to do this. Abigail spoke of always having a project, but not always getting it done. When it doesn’t get done, though, she says it just carries over to the next day, and she doesn’t get upset about it. Oh sure, she says, sometimes she gets a little frustrated, “but that’s life. There comes a time when you have to slow down, whether you want to or not.”

Beatrice sees letting things go as a matter of learning her own limits, and says she now knows her limits and has quit pushing so much. Esther comments on the very noticeable change in her attitude: “It almost seems like I was reborn with a different attitude. If it doesn’t get done today, well, the world doesn’t fall apart…. I don’t drive myself any more. So it doesn’t get done. The world doesn’t come to an end.”
Accepting What Is

All five participants were practicing acceptance of life as it is now. Two of them spoke extensively about it, as almost a mental exercise. Abigail spoke of her inability to travel extensively as she had in the past:

I traveled to Europe. I’ve been to Germany and France, Italy and Switzerland, and then to Greece. I wish I’d gotten to Egypt, but (shrugs) I’ll just forget about that. I’ll just travel on TV.

Her acceptance of how things are now extends to many areas:

My daughter moved. So I have friends that’ll take her place, you know. Things change.

I could have done things differently ...

... In the end I guess I adjusted. It’s just how things fall into place.

It’s not so bad living here. I can be just as happy here, and - you can be lonesome in a crowd. So I think this is as good as it gets.

Beatrice also spoke about a simple acceptance of life as it now is:

It doesn’t bother me emotionally. Either you can do it or you can’t, that’s just the way it is. No, I don’t get depressed over things that I can’t do... How do you cope with changes? You just do it... As seniors, we have all learned to live with circumstances to a certain degree. And again, I’ve learned to adjust to this circumstance.
A Focus on the Positive

Closely tied to the mental acceptance of life as it now is for these women, all have found ways emotionally to come to terms with their losses and their disease process, and with the negative emotions engendered. In discussing this, three of the five women mentioned the prayer of St. Francis: "God grant me the serenity to accept the things I cannot change"; one woman had a plaque with the prayer on her kitchen wall as a daily reminder.

All of the women suggested an emotional acceptance of their lives as they are now. Three of them spoke of this specifically. Beatrice, in particular, uses terms like, "That's the way the cookie crumbles," and "Life goes on" to indicate her acceptance. She states,

You mentally adjust. If you can't do something, you might as well be patient about it. It's accepting - that's a part of patience... This is where I am, and I'm content. I'll do the best I can with it.

Charlotte also specifically spoke about acceptance. She mentioned the change from an independent life to a far more dependent one, and that she wishes she could do some things better, but "it's a matter of acceptance. I think I like the way things are. When you weigh it all out, I think I do."
Even Dorothea, who fights severe depression, speaks of acceptance: "I guess maybe I’m accepting things better…. I’m very grateful that I have today, and that’s all. I think it’s the first time I really recognized that I really like the way it is…. If you don’t, you would change it."

Charlotte, Dorothea, and Esther all have found a new appreciation of small blessings. Charlotte finds “just simple things are interesting to me now. I’m much happier and more content, I’d say.” Dorothea strongly appreciates the comforts she finds in her home, and Esther has learned the blessing of desiring very little: "I don’t want things. I’d rather have friends, and conversation, and enough to live on, but that’s all, and I’m happy as a bug in a rug."

Abigail finds a focus on the positive has helped her come to terms with her life now; she surrounds herself with the positive: “I try to read positive books, and I try to stay around positive people, and I play uplifting music, and I pray.” She also has a strong will to fully live her life: “Some of these people, they just sit. I want to live.”

Abigail and Esther both speak of happiness as a conscious choice on their parts. Esther says,
So I have a good outlook on life. I’m just happy. I’m generally cheerful, happy with my life, and not distressed, not worried.... I’m more cheerful than I had ever been in my life. And it’s because I’m happy, I think. I specifically made a choice to try to be cheerful. But it’s no effort now.

Abigail also speaks of happiness as a choice, and one which in her opinion, is available to everyone, but not chosen by some people:

You can choose to be unhappy. You can choose to be miserable. And you can choose to try to make people miserable. But nobody can make you miserable if you won’t let ‘em. Right?

Accepting the Losses, then encompasses acceptance by these women of the reality that they are physically unable to do what they could in the past. Acceptance involves a mental “shifting of gears” and an emotional component of learning contentment with what one has. All five of the women have, to a greater or lesser extent, learned acceptance.

Changing Their Lives

All five women faced significant losses in their lives due to their heart failure, and all five learned to accept these losses. However, a simple acceptance of loss was not enough. In order to continue to have lives meaningful to themselves, they also had to find ways to
change their lives. These changes can be found in five sub-themes: Choosing Easier Ways, in which the five women discuss learning to do things differently physically; Changing the Focus, in which they discuss making needed mental changes; Depending on Others, speaking of social alterations; Searching for Answers, in which three of the women discuss spiritual changes; and Considering Financial Choices, in which they deal with financial changes.

**Choosing Easier Ways**

All of the women recognized heart failure required some lifestyle changes. All now watch their nutrition, including salt intake, and all recognize the need for exercise and do what they can. In fact, the youngest participant changed her life the most: she used to work in a high-stress job, smoked two to three packs of cigarettes a day, ate a very high fat diet, and did not exercise at all. She can no longer work for pay (but does volunteer work), does not smoke, is very careful of her low-fat, low-salt diet, and exercises for almost an hour a day.

Although most of the women expressed little difficulty with activities of daily living (ADL’s), all of the women spoke of finding new, less energy-demanding ways to accomplish the tasks they faced each day. One spoke of rotating her clothing so she rarely has to do laundry,
using Paratransit for door-to-door transportation, and wearing wigs to decrease exertion.

Two of the women spoke of how difficult it is to slow up: Dorothea says, “It’s very, very hard for me. I try to lay down for a while, but... I just can’t. I can’t waste time. I have to have accomplished something today.” But, as Beatrice says, “It is difficult to slow up when you are geared a certain way.”

The women have learned to substitute those things they can do for those they can no longer do. As one woman said,

There’s a few things I can’t do, but... I try to substitute things I can do. I don’t play golf any more, I don’t swim miles, I don’t wallpaper. But I do paint, I read, I do the things I can do.

Several of the women spoke of letting others perform certain tasks for them. Abigail spoke of the help given by her weekly laundrywoman: “Now when I need something, I’ll send Elsie, the lady that does my washing. She’s my legs.”

All five women spoke of planning ahead more than they would have in the past. They also spoke of pacing themselves, and of the ways in which they pace their lives now. Charlotte is, perhaps, less regulated in her pacing (she rarely makes lists, for example), but expresses the approach well:
Here now, I don’t really have a routine. Any day can be anything I want, basically, within reason. I pace myself. After all, I have all day to get it done! I only do a little bit every day.

Changing the Focus

Changing their lives meant changing their mental focus for these five women. All five learned to change the focus in their lives, in order to deal mentally with the changes brought by heart failure. However, for each woman, this change of focus took a different form.

Abigail has learned to focus on what she can do, rather than on what she can’t. For example, in speaking of how far she can walk before it’s an effort, she said, “When you and I walked to the library, I got out of breath, didn’t I? But I could still go” (emphasis mine). She focuses on remaining fully involved in life: “I think I’m as active as I want to be. I don’t want to just sit like those people do, and I’ll find things to do.” Abigail also uses self-talk extensively to refocus on the positive.

Beatrice has learned to stress the positive. She recognizes the body-mind link, and speaks of being “up” mentally when she is “up” physically. She has established a “pattern” of diet, sleep, and medicines that works well...
for her, and is careful not to disturb it. She proudly calls herself a survivor:

I’m a survivor. I regret that I have slowed down so much.... But hey, there’s no pain associated with it.... So I’m slowed down. I’m a survivor and I live with it.... I don’t have to go down with the ship.

She is a strong and independent woman, with little patience with those who complain about their aches and pains, saying, “There’s no use bothering anybody else with my miseries, you know.” Her focus is on maintaining her independence and living life her own way. As she puts it, “My children tell me I’m stubborn. I said, I’m not stubborn, I said, I’m determined!” At this time, at least, Beatrice feels she has control of her life, “me and the Lord,” and although she tires more quickly than in the past, “I don’t plan on the rocking chair getting me.”

For Charlotte, changing the focus was a literal thing: to get past the effects of heart failure, she had to learn to change the focus from herself to others. As she put it, “I just stopped thinking about me, and I just went out there and helped other people.” Working with the Church bazaar “got my mind off me, and I started volunteering, doing a lot of volunteer work” for a disabled group, and later for other groups. She has found a reason for her survival in her volunteer work: “And then

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I thought, well, I'm definitely here for some reason, I'm going to help someone's life out, I'm going to do something useful." She speaks of her new (since heart failure) idea of what is important in life: "Make every day count."

For Dorothea, changing the focus meant focusing on her inner strengths, in order to deal with the forced choices of heart failure. She takes pride in her own independence, and says, "I don't think I want anyone to make decisions for me, not yet, anyway." She is confident of her own ability to cope: "When you get to the bottom, there's nowhere else to go but up. And I know that I can handle it. Isn't that something?" She has established firm beliefs and boundaries in her life, and works to maintain them. She has little patience with those who focus on their aches and pains, and laughs when she talks about this:

When you get older and you live alone, you do worry more about your aches and pains more. But you can't dwell on it.... When I used to babysit my granddaughter... people would say to me, Are you babysitting again? I'd say, You know what? She doesn't know her cholesterol, she doesn't know her blood pressure, she's not living on a fixed income, she's a pleasure to be with!

Focusing on her own inner strengths has enabled Dorothea to deal with real and potential forced choices: the
possible loss of her home in the future, asking others for help, being forced to deal with her own advancing age.

Dorothea finds life complicated, but is aware she has the choice of how to respond to it:

If you don’t like your life the way it is, you change it. Every day you get up, you have a choice, to be a bitchy old lady, or you can be fine. I have a choice every morning.

And ultimately, she finds satisfaction in that: “I think we live the way we want to live. And I’m living here and making my own decisions, and I think deep down, that’s probably the way I want it.”

Esther’s change of focus has been “simplification and order” in her life. One form simplification has taken in her life has been to become well acquainted with the manager of her bank and with people in her insurance office, because “they know so much, and they can make life so much easier for you.” She does not wish to be encumbered by “things”:

I was just so happy that I could move here, and not have to bring all my furniture with me, try to stuff it in... There’s practically this, just this (waving her hand to encompass the contents of the room), and my car, that I have to worry about.

The focus on order and simplification extends to all areas of her life. She arranges her clothing so she has to
do laundry only once a month. She shreds papers and bills every two to three months to avoid clutter, and dresses in tans, whites, and blacks to simplify coordination of clothing and accessories. Once or twice a year she goes through her belongings and disposes of some of them. She has rid herself of all but one credit card.

She has a will made, and has made funeral arrangements. Thus, as she says, "I think I've done about as much as I can do on that, to try and simplify it for anyone coming after me."

Each of the women has found her own way of doing it, but all five have found ways to change their focus, and thus refocus their mental energy in ways more productive in dealing with their heart failure. Abigail focuses on what she can do, Beatrice on the positive, on maintaining her independence, and on continuing to be "a survivor." Charlotte has found her focus on others gives her a new purpose and direction in life. Dorothea has learned to recognize and utilize her inner strengths in coping with the changes she must face, and to use humor to help her deal with the changes. And Esther has learned to bring order and simplification to her life. In all five cases, they have used different approaches; in all five cases,
they have achieved the same result: a mental balance which allows them the ability and the flexibility to change.

Depending on Others

All of the participants spoke at some point of enforced dependence, most of them negatively, preferring to maintain their own independence. However, when speaking of the social impact of heart failure, they spoke of depending on others in good ways in their social lives, and particularly when speaking of their support systems. There is, in fact, an increased reliance on others.

Abigail knows others will help when she is fearful: "There's help out there." She willingly counts on her insurance-provided helper (her "legs"), the canine therapy providers who have "adopted" her, and a support group at the retirement center. She also describes an extensive support system inside and outside the retirement center. In the past, she indicates, her dependence would have been much more strongly on her family, but with them unavailable, she has found other sources of support.

Charlotte, in her life before heart disease, was too busy working to have much of a social life. Now, though, she is probably the most "people person" of the five women. She says, "When you're in the company of others, you have a tendency to forget about yourself...." She
credits friends heavily in her recovery from her heart attack and stroke: "I think having friends that care about you is the best medicine in the world. I don't know what I would have done without it." She recognizes others' role in coping with her disease, in exercising with her, and in helping her relax. And she depends heavily now on her extensive network of friends and family as her support system.

In the past, Dorothea has attempted to completely separate herself from others. However, even Dorothea, for all her self-isolation, recognizes her need for others, saying such things as, "I'm alone, I need a friend," and "I have no one to talk to." She speaks of wishing others were there when she doesn't feel well, and of getting lonesome.

Searching for Answers

Spiritually, most of the women have not changed extensively with their heart failure. However, they indicate they are, perhaps, more open to examining new ways of looking at spiritual matters. Esther does not find answers to her spiritual questions in organized religion.

She sees herself as essentially a fatalist, and states her philosophy of life is, "Que sera, sera. What will be, will
be." Still, she is unwilling now to close herself off from any possible answers. She has been attending church more, goes to a weekly Bible study (a new development since her heart disease), and when in trouble or pain, has often found answers in the Bible. She believes there is an overriding pattern to all of life, but states "it is beyond my ability to comprehend." She is unimpressed by Biblical miracles, feeling, "We live in a sea of miracles."

Beatrice finds herself more open to different viewpoints, albeit basically within the Christian faith. She feels she could probably be equally comfortable in church with any of three of four different denominations.

Abigail, oldest of the participants at 90, has also become the most adventurous in studying other ways, despite being "a Catholic and a Christian." Her diminished physical condition has given her more time to read, and she browses in many philosophies, currently reading Pierre de Chardin, Thomas Merton, Pana Chopa, and Kahlil Gibran. She believes strongly in reincarnation (although uncertain what the Catholic Church's response to that would be). She is beginning a study of astrology, and is open to parapsychology, seeking to develop her own psychic abilities (which she describes as strong when she was a
child, but ruthlessly suppressed by her mother). She also speaks of developing herself spiritually through reading books of philosophical meditations (not necessarily religion-tied), and of listening to tapes of nature sounds to bring herself into a greater communion with the earth and all that surrounds her.

**Considering Financial Choices**

The final way in which the five participants have learned to change their lives involves the financial area. Again, in this area, four of the five women are living on a fixed (retirement) income. The planning they are doing is necessitated at least in part by the realities of living on a fixed income, and the reduction in options that results.

Dorothea says, "If it got right down to it, and I had to sell the house, that's gonna keep me much longer than I'm gonna be here." Still, she has looked into the cost of living in a retirement home. She unfortunately has much of her money invested in stocks, but is waiting for the market to recover. At that point, she says, she will invest her money in something she understands better: second trust (real estate) deeds. Abigail has also considered what would happen if her money runs out, and
realizes that with her lack of resources, she would be forced to go on Medicaid.

Esther has best thought through her options should her finances become insufficient. She has considered a small hotel, or life in small outlying towns where the cost of living is less. As she says, "So these are all solutions that... I may need to, I may not need to, but I would be very happy in any of these situations. And I would still be able to choose. I guess that's what I'm trying to do."

Deepening Relationships

The women in this study found their relationships changing: both their relationships with other people, and with God. Although they had curtailed relationships with some former acquaintances, they spoke of deeper and more meaningful relationships with those with whom they still interacted. The change in their lives in this area, then, had both a social and a spiritual aspect. The social aspect is reflected in the sub-theme Reaching Out to Others, the spiritual aspect in the two sub-themes Living Their Beliefs and Deepening Their Faith.
Reaching Out to Others

Abigail recognizes her social life is more curtailed than in the past. Nevertheless, she also recognizes: "I’m having as much social life as I want to have. I don’t have it; the fact is, I’m not able to have it." But she reaches out to many people, in many ways. She writes letters and e-mails to many people, plays Bingo, goes out with friends occasionally and with great joy, calls friends to keep in touch, and attends parties at the retirement center. She has a less extensive circle of friends than in the past, but speaks lovingly of those she still has.

Beatrice is not a highly social person, but has friends of more than 20 years, with whom she interacts on almost a daily basis at the senior center she attends. Although she dislikes feeling dependent, she recognizes this group of friends as people she can call on for help if she needs it. She enjoys interacting with them, and summarizes, "We fill our day with what we like to do."

Charlotte speaks freely of the importance of friends in her life. However, she emphasizes even more strongly the strengthening of family ties that has resulted from her illness. She speaks warmly of her husband’s support, his refusal to blame her for their tight finances, his
willingness to uproot his life and move for her sake, and
his assumption of the role of sole provider. She
emphasizes the importance of family in her life, speaking
lovingly of her daughter and son-in-law, her stepson and
grandchildren, and even of her husband’s ex-wife! She
also depends heavily on her dog:

Besides my husband, my dog is my best
friend and companion. We exercise
together every day by walking, and
after bypass surgery, I believe they
should pass out dogs instead of the
mended heart pillows. A dog will
give you back so much more.

Dorothea has also found a real friend in her dog:

“Patrick, my dog of four months - I’m not alone any more....
I don’t know how I lived eight years by myself.... I can
tell Pat anything. That’s the nice part. He never tells a
soul.” Her dog has been very good for her socially: she
recognizes she talks more when someone’s around, even the
dog, and she finds he forces her to leave the trailer
every day to walk him, increasing her contact with others
in the neighborhood. In this past four months, Dorothea
has begun to reach out to others: she is working at
building a new friendship, and is even going to try
something new: she is going to run a crafts class in a
month.
Esther sees a distinct improvement in her relationship with others, since her heart failure began. She described it this way:

It almost seemed like I was reborn, with a different attitude. I was pretty intolerant. If you're stupid, and you won't listen, I don't want anything to do with you. Now, you can be just as stupid, dumb, and it doesn't matter. And I just feel kindly toward you.... And I can't imagine myself this way. I think it's wonderful. At least I'm more human.

Esther also described the therapeutic effects of the interviews involved in this study, saying, "There's a healing power in opening up and confiding in someone. Well, actually, I think this has helped me, you know, talking with you, and confiding in you. And I feel perfectly comfortable in doing it."

**Living Their Beliefs**

Spiritually, Abigail describes herself as "a Catholic and a Christian," explaining that, unfortunately, she doesn't believe all Catholics are Christians. Asked to define how she would demonstrate that she is both Catholic and Christian, Abigail said, "You know, I think in life, you're supposed to help each other, wherever you can. Well, I try."

Other participants agree that speaking of their beliefs means little, if their lives do not reflect what
they believe. Beatrice says, "I can see it is a very big world. I'm just a grain of sand, but in my little swatch, I do what I can, I do my best, for myself and others." She believes faith is to be lived out: "I've always believed actions speak louder than words." She speaks of people's response to her actions, and their resulting respect for her faith.

Dorothea hates the ritual of formal religion. However, in the Church of Religious Science, she has found a philosophy of life that works well for her. She explains the church emphasizes the value and worth of each life, and encourages learning from mistakes and going on, rather than guilt. She believes in a Supreme Being, and that each of us has a right to believe in a different way. She states the philosophy she follows does not believe in criticizing people, but in "treating people the way you'd like to be treated." She attempts to apply this philosophy in her life, summarizing it in this way:

I won't argue with anyone, but I know what I think. And I know what's right for me; I don't know what's right for you. I know what bothers my conscience and what doesn't. But I don't know what bothers yours.
Deepening Their Faith

Abigail speaks of a deepening relationship with God, but attributes it to aging: "I think as you get older, you feel like you’re drawing closer to God, which you are, you know... everybody gets closer to the grave every day."

Beatrice’s faith in God is deep and central to her life. Faith allowed her to overcome the bitterness of a divorce, and faith has enabled her to change. It has helped her get through tough times: "It’s possible to let yourself get overwhelmed physically or mentally, and it’s just backing off and, hey, saying a prayer, and things will turn around." Turning to her faith is automatic for her in troubled times: "I’m not really discouraged, I guess I’m just more upset by it. Just enough that I’m going to give the problem to God. That’s His problem."

Asked what she has learned spiritually from having heart failure, she says, "Well, it’s only firmed my belief that God’s in charge. I put it into Your hands, Lord, and that’s just about what it amounts to."

Beatrice speaks extensively of a deepening of her faith with heart failure. She says she now studies her Bible almost daily, that her relationship with God has "grown to be a closer relationship," that heart failure
"has enriched my spiritual life," and has increased the rate of her spiritual growth.

Charlotte also spoke of a deepening spiritual life with heart failure. She indicates living with heart failure has taught her to "take the time to smell the roses." She speaks openly of her frequent use of prayer, when her symptoms make her afraid, and at other times, and of answered prayer ("There is a God, I'm telling you!"). There is an element of "hope of heaven, fear of hell" in her faith, but Charlotte also speaks of a change in her relationship with God: "I feel much closer... spiritually, just feeling closer. You start listening to the liturgy of the mass, for one thing. [Before heart failure] I wouldn't listen to the Gospels. And I started doing that." She speaks of drawing closer also to others in the church. Perhaps most important to her, church "gives me a strong sense of belonging to a special group, as one of God's children."

Additional Findings

In addition to the four major themes and sixteen sub-themes discussed previously in this chapter, there were additional findings which will be discussed in this chapter. These include the sexual impact of heart
failure, and their view of the medical care they receive.

The Sexual Impact of Heart Failure

Only one participant was still active sexually: Charlotte, age 60, who is married. She spoke extensively of the problems sexually since her heart failure began:

The only thing I noticed, I used to love the bedroom, but that’s changed... I don’t think it’s so much fear. I don’t think I’m going to have a heart attack.... I noticed a big change, lack of interest....It just wasn’t important to me any more. And I wish I could find out why. I love my husband.... Can you tell me what you think it is? Is it the medication?

Because there was only one participant who was sexually active, there was no one with whom to compare these findings.

The Participants’ Views of Medical Care

Four of the five participants had something to say about the medical care they have received. Very little of it was complimentary.

Concerns regarding HMO coverage. Charlotte had this to say: “You’re almost afraid to get ill. Are you going to be taken care of properly? Are you going to get the cheap little mechanism, or are you going to be put over there in the corner?”

Dorothea’s complaint was twofold with her HMO. She had to change her primary physician, and every time she
goes in, she ends up seeing a different doctor. Thus, no doctor really becomes familiar with her and her needs. In addition, she found the HMO cancelled tests her doctor said she needed. She said, "How do they expect you to have any confidence in the doctor? They override her, and she’s your doctor, well, where do you go, you know, what do you do from there?"

Concern regarding the quality of care. Charlotte compared the quality of care here to that where she lived before. In the Midwest, she was checked every three months and had pacemaker checks every month; here she is checked annually, and has pacemaker checks every three months. As she states, "I’m very scared of health care here; I felt very secure with my doctor back in [the Midwest]." She adds, the state she came from "has great health care, especially cardiac health care. Maybe they have good health care here, but I’m not too familiar with it." She also points out that here she feels like "I’m my own doctor, taking care of myself."

Beatrice speaks of her last visit to the doctor. She had been feeling more fatigued than usual, and asked about it, but had to demand to get blood tests she felt she needed to see if there were other reasons than her heart
failure for her fatigue. She feels the doctor is too ready to attribute all her problems to her heart failure.

Abigail tells of having her entire blouse soaked through the carelessness of a nurse removing wax from her ear. She believes care for humans is often less caring than care for animals: “[On TV] they have emergency vets, and they have dogs that have been injured, or people bring sick dogs... I think those dogs get better treatment than humans do.”

**Concern that doctors don’t listen.** Dorothea says, “I haven’t been to a cardiologist now for, like two years, I guess. But I find that it’s very hard to convince a doctor that you’re not feeling well. I can’t pull it off, so I’m a little discouraged about it.” She states, “When I go, I always walk away disappointed. Just like, Oh, well, and nobody listens, anyway.” She adds:

> I like the ones that come into the room with the paper up in front of them, and they’re flipping through, and talking to you, and when they leave the room, you don’t even know what they look like - that has happened to me. I have no idea what he looks like, and he has no idea what I look like!

**Concern regarding the lack of time spent.** Three participants commented on how little time they were given at appointments. Beatrice said, “I talked to my doctor.
That’s where I was yesterday. Thirty minutes, I left here, and thirty minutes, I was back, and saw the doctor in there.” Dorothea says she doesn’t understand their attitude: she wouldn’t have made the appointment and then waited weeks to get in, if she didn’t think it was important. She concludes, “I feel like I’ll just get better on my own. That’s about what I feel.” She adds:

I had one doctor, a lung specialist. He kept me waiting two hours. I had taken Xrays in to him. He never mentioned them, whether he got them, or whether he saw them. He wasn’t in the room two minutes, and he was gone.

Abigail also complained about the lack of time she got at the doctor’s, although she seasoned her comment with humor: “I’d make an appointment, and before he had both feet in the door, one would be going back out! And he’d give you about five minutes...”
CHAPTER 6

SUMMARY, DISCUSSION, CONCLUSIONS,
AND IMPLICATIONS

Summary

The problem addressed in this study was that there is insufficient knowledge of what having heart failure means to the women experiencing it. The phenomenological approach was used to attempt to answer the question: How do women with Stage II heart failure perceive their own lives? Four semi-structured interviews were held with each of five participants. Colaizzi’s steps for data analysis were followed, and four major themes emerged: Acknowledging Losses in Their Lives, Accepting the Losses, Changing Their Lives, and Deepening Relationships.

Discussion - a Comparison with Previous Studies

In her 1996 study, S. R. Michael wrote of “Integrating Chronic Illness into One’s Life”. She found
four themes emerged in speaking with patients with chronic
diseases: Confronting Loss, Fluctuating Emotions, Making
Changes, and Gaining Control of an Altered Life Direction.
In many ways, this study was a confirmation of her
results, even though her study included no participants
with heart failure. Many of the findings were similar:
Dr. Michael speaks of physical and social losses, of
negative emotions including frustration, anger, fear, and
depression, of changing the routine and adding new
routines, and of seeking support, learning about the
illness, and finding meaning in life with the disease.
There are parallels with the results in this study, in all
of these areas; certainly, the five women in this study
would recognize much about their own lives in Dr.
Michael's study. However, in this study, there was more
emphasis on acceptance of the changes and on deepening
relationships, both of which emerged as major themes.

Jonsdottir (1998) found the people she spoke to were
discontented with their current situation physically, but
felt unable to change the situation. Her participants did
not consider different approaches to their lives, their
disease, or their ways of interacting with others. Leidy
and Haase (1996) found the opposite to be true. With
their participants, when the probability of discomfort in
doing something was seen as high, the person considered alternate ways of doing that activity, or dropped it. And rather than giving up, some participants simply let some activities go and moved on to other satisfying, but less demanding, activities. The participants in this study resembled the participants in the Leidy and Haase study far more than those in Jonsdottir's study. They were not passive observers, but active participants in their own lives. They actively sought alternatives when symptoms interfered with desired activities, and found less energy-demanding ways to accomplish almost anything they really wanted to do.

Leidy and Haase's study (1996) also found planning was much more necessary to the participants in their study, in order to accomplish tasks within their recognized limitations in capacity. All five of the women in this study spoke of planning ahead more than they would have in the past. Similar to the findings of Leidy and Haase, these five participants also spoke of the need for pacing of tasks, in order to minimize negative physical effects, and of learning to pace themselves based on the negative effects of given levels of physical demands.

The two primary mental changes mentioned by the participants in this study were memory loss and difficulty
concentrating. This is similar to previous studies. Memory loss was noted by Bennett, Pressler, Hays, Firestine, & Huster (1997), Freedland & Carney (2000), Bennett, Baker, & Huster (1998), while difficulty concentrating was noted by Bennett, Baker, & Huster (1998), Bennett, Pressler, Hays, Firestine, & Huster (1997), Gorkin, et. al. (1993). Only one participant in this study mentioned occasional irrational thought processes, similar to those reported by Roberts, Johnson, & Keely (1999). It should be noted, however, that the women in the current study did not always attribute mental changes solely to their heart failure. Two felt the mental changes were also due in part simply to aging, and one recognized the possible effects of a stroke on her mental abilities.

In a study by Roberts, Johnson, & Keely (1999), elderly HF patients had trouble expressing their desires or thinking about future goals, but attributed the lowered sense of external control to others having failed him or her. This was not found in the present study. Participants recognized difficulties in maintaining control of their own lives, but recognized this primarily as the result of their physical condition. The two women who felt some degree of loss of control of their own lives
seemed similar to findings in Fontana's study (1996), where the author spoke of the patients' dichotomy: a need to maintain autonomy, coupled with the feeling of having no control at all.

In Leidy and Haase's 1996 study, most COPD patients described some form of altruistic activity, contributing to the welfare of others, and finding activity on behalf of others a source of great satisfaction. In the current study, Abigail, Beatrice, and Charlotte all have found satisfaction in attempts to reach out to and help others.

Forbes (1999) found older adults with chronic illnesses often found a recognition of their own strengths because of their illness. This was true to some extent for all five participants in this study, but especially true for Dorothea. For her, a discovery of her own inner strengths proved to be a building block for acceptance of her condition, and for building a life despite her illness.

Numerous studies have spoken of stress, passivity, anger, and hopelessness among heart failure patients; only anger and stress were mentioned by the participants in the current study, and neither was a major factor in their lives. The fear of death, noted by Baas, Fontana, & Bhat (1997) was expressed by two of the five participants. The
previous literature (Freedland, et. al., 1991; Bennett, Pressler, Hays, Firestine, & Huster, 1997; Dracup, Walden, Stevenson, & Brecht, 1992; Letterer, Carew, Reid, & Woods, 1992; Hawthorne & Hixon, 1994; Stanley, 1999; Freedland & Carney, 2000) has described moderate to severe depression as a major problem in these patients' lives. All five participants in this study had experienced some depression, but it was severe for only one participant. For the other four participants, depression was not identified as a continuing problem. Four of the five participants in this study refused to give up hope. All recognized the changes of heart failure were permanent, but they were determined to continue to be involved in life regardless of the limitations they faced, a decision Rideout and Montemuro (1986) found vital to better continued functioning.

In the social arena, heart failure patients have been described in the literature as having a high degree of social dysfunction (Rosenblum, et. al., 1993; Stewart, et. al., 1989). A decrease in social activity has been noted (Riedinger, Dracup, & Brecht, 2000), with several researchers noting social isolation (Stanley, 1999; Jonsdottir, 1998). Jonsdottir (1996) found some patients became more self-absorbed, others turned to their
families, but some had very negative changes in their relationships with some friends and family members (Dracup, Walden, Stevenson, & Brecht, 1992). Many found it necessary to curtail relationships with more casual and distant relationships in favor of closer ones (Friedman, 1997; Dunkel-Schetter & Wortman, 1982). Researchers have also noted the importance of social support. Inadequate social support has been noted as a risk factor in elderly patients (Freedland & Carney, 2000; Pennix, et. al., 1997; Steinbach, 1992).

All five women in this study spoke of changes in their social lives necessitated by their changing physical condition. All spoke of the need to limit their social lives because of diminished energy and strength, and increased fatigability. They spoke of their support systems, and, in some cases, of their increased dependence on others. And they continued to reach out to others, though this took different forms.

The study most similar to the current study is the Swedish study of Martensson, Karlsson, and Fridlund (1998), reported in their article “Female Patients with Congestive Heart Failure: How They Conceive Their Life Situation.” In their phenomenographic study, the authors interviewed 12 females, diagnosed three to 24 months prior
to the interviews, aged 65 to 83, and including five patients at Stage II, five at Stage III, and two at Stage IV heart failure. Because this was the sole study found during the search of literature which dealt with the entire life experience of women with heart failure, it will be reviewed in some detail in this chapter.

The first theme that emerged in the Martensson study was Feeling Content. Participants in the current study also spoke of accepting their current situations, and of being content with their lives as they now live them. The second theme in the Swedish study was Feeling a Sense of Support. All five women in the current study also spoke of strong and meaningful support systems, on which they depend.

Martensson, Karlsson, and Fridlund's third major theme was Feeling a Sense of Limitation. Women in this study also spoke of the physical and social limitations they face as a result of their heart failure. The fourth theme in the Swedish study was Feeling Anxiety. A constant state of anxiety was an important factor among the women in the Swedish study, but was much less a concern to the women in this study. The American women spoke of some fears and concerns, but for four of them, these fears and concerns were not a driving force in their
lives, nor did they result in the strong sense of insecurity spoken of in the Swedish study.

Martensson, Karlsson, and Fridlund's final theme was Feeling Powerless. Although the American women in the current study recognized they were powerless to change the basic fact of their heart failure, all had moved to limit its progression through lifestyle changes. They fought for control of their own lives, and refused to accept the possibility that they were powerless to influence what happens to them. Unlike their Swedish counterparts, they did not describe themselves as feeling worthless, or a burden (although becoming a burden to others is a concern for all five).

In part, at least, the differences may be due to the fact that the Swedish study included women in Stages II, III, and IV of heart failure, while this study was limited to women in Stage II. As their disease progresses, the women in the American study may possibly become more anxious and feel more powerless over time.

Conclusions

The Findings

Acknowledging Losses. The five women in this study faced numerous losses in their lives. Foremost among
these losses was the increasing physical debility they experienced secondary to their heart failure symptoms. Because of their diminished energy, shortness of breath, and easy fatigability, all found their previous level of vigorous activity extremely diminished. They provided extensive descriptions of their former lives, and all acknowledged the impossibility of living as actively as they had in the past.

A sense of loss of control of their own lives was mentioned by two women, and all spoke of an increased effort necessary to maintain control. Three felt they were successful in doing so, although they used differing methods to accomplish it. Those who felt they were still making the choices that affected their lives were most satisfied with their control.

All five women spoke of a diminished social life. Some social activities were simply no longer physically possible. The women spoke of having to consider the logistics of social occasions (energy/physical demands) before determining whether to attend activities. They spoke also of deliberately curtailing certain relationships.

All five mentioned fighting depression at some point, in connection with their heart failure. However, contrary
to previous research, for only one of the five was depression a continuing or serious problem. Also unlike the results of previous studies, four of the five did not speak at all of being highly anxious or stressed, although two expressed a fear of dying and/or pain due to complications of their heart disease, and four of the five expressed concern regarding becoming a burden to those they love.

All five mentioned living on very tight budgets. In the case of four, this is attributable to their ages: they are retired and living on fixed incomes. For the fifth participant, the tight financial situation is due to her no longer being able to "contribute to the family coffers," a circumstance which causes her guilt and decreases her self-esteem, by her own report.

Accepting the Losses. Perhaps because they have lived so long with their heart failure, the five women were generally able to accept the losses heart failure had brought to their lives. (Four of the five had been living with heart failure for five to ten years. The fifth was diagnosed only two years ago, but at 90, was already experiencing a "slowdown" in her life, which heart failure had simply exacerbated.) For all of them, there are times
of frustration when they are physically unable to do all they want to do, but they ultimately accept these limitations — if only because their symptoms will not allow them to do otherwise, as in Dorothea's case. Most of them, though, echo Beatrice's statement: "That's life. You adjust to it."

There was a kind of mental "shifting of gears" involved in the acceptance, from Abigail's "I'll just travel on TV," to Beatrice's "Either you can do it or you can't, that's just the way it is." For all of the women, accepting life as it now is has already occurred, but also continues to be a daily challenge.

All of the women were learning "the serenity to accept the things [they] cannot change." Several spoke of learning contentment with their current situation. Acceptance for them is both a mental and an emotional exercise. Even Dorothea speaks of "the first time I really recognized that I really like the way it is." They spoke of counting their blessings, and their appreciation of small things.

**Changing Their Lives.** All five women spoke of finding new, less energy-demanding ways to accomplish physical tasks, and of giving up certain tasks as simply"
being beyond their energy and strength now. They spoke of the necessity of allowing time to rest, and of the vital importance of pacing themselves in all they do now. They found their lives less spontaneous than in the past, because they found an increased need to plan ahead in achieving physical goals. They have learned their own physical limits with heart failure, and work within those limits. However, unlike the participants in Jonsdottir’s study (1998), they have been quick to consider new ways of doing things, and not just in the physical area. For example, socially they simply found satisfying (but less demanding) activities to be involved with. They do not always find the transition easy, but they find it both necessary and possible.

In adjusting to the demands and uncertainties of heart failure, all five women changed their mental focus, though each did so in her own unique way. One learned to focus on what she is still able to do, rather than on her limitations. Four of the five have learned to focus on the positive. Three have turned their focus very much outward in altruistic pursuits. Charlotte, in particular, finds her purpose in life now is tied to her volunteer work. One participant has learned to focus on her own inner strengths, while another has learned to simplify her
life. All have found ways of adjusting that work for them.

Although all of the women found dependence which was forced on them distasteful, and all fought fiercely to maintain their own independence, they also acknowledged the necessity of depending on others for things they can no longer do (e.g., Abigail's use of her laundry/cleaning woman as her "legs"). They freely recognized the importance of others in their support systems.

Three of the women were open to change spiritually. Esther, a self-described "doubting Thomas," has been exploring some more traditional ways of learning about God. Beatrice sees the possibility of meaningful worship in many churches. And Abigail, the oldest participant, has been exploring many spiritual avenues, within and outside of traditional religion.

The changes four of the five women have made financially, in trying to consider how to plan for tomorrow, are probably not a function of change due to heart failure. Rather, they are considerations any elderly person on a fixed income would have to make. The fifth woman, Charlotte, was torn from full employment to full retirement overnight by cardiovascular disease. Because her illness depleted their financial reserves, she
and her husband must plan for tomorrow in order to be able to retire comfortably.

Deepening Relationships. All five women spoke of ending some relationships, primarily with acquaintances who were not close friends, because of the limited energy they had to devote to relationships. However, all also spoke of deeper and more meaningful relationships with those they stayed in touch with. Even Beatrice, the most reserved of the five, has friends of 20 years at the Senior Center she attends. Charlotte stressed the deepened relationship with her family. Dorothea, the most isolated of the five, has nevertheless developed a loving relationship with her dog that means a great deal to her. And Esther speaks of being more open to others, more tolerant of their foibles, and more caring toward them.

In living out their beliefs, the five women also find themselves drawn closer to others. Abigail speaks of the necessity of helping one another, Beatrice of living her life so that her faith is seen by others because of her actions. Dorothea speaks of treating others better and an increased tolerance because of her beliefs.

Three of the five women also spoke of deepening their relationship with God because of their heart failure.
Charlotte speaks also of the "strong sense of belonging" she finds in her faith, while Beatrice speaks of a "closer relationship" with God.

A Statement of Identification

No aspect of women's lives escapes the impact of heart failure. It causes immense losses in many areas of life, and requires tremendous changes in many aspects of daily living. Yet, drawing on inner resources of great strength and courage, these women learn to find contentment in their lives. They discover ways to create productive lives and deeply meaningful relationships, within the boundaries imposed by heart failure.

Strengths of the Study

The primary strength of the current study lies in the phenomenological approach. The women describe their experience of heart failure in their own words. Because they were willing to open their lives to the researcher, a picture of those lives emerged. In initially reviewing findings of each woman's interviews with her, the researcher received comments such as the following. Abigail stated: "That sounds real good. You hit it right on the head. I think you did very well for me. That suits me... that's me."
Beatrice concluded: “I think that pretty well covers it.” Charlotte stated: “That sounded wonderful. You sounded it out in just little words. Perfect! That’s very good. You know, when you pull all this together, it makes sense, it really does. I don’t know how you pulled all that complex stuff together like that.”

Dorothea stated: “That’s right. That’s right. I’m surprised at how much you picked up, because I think I just talk.” And Esther stated: “Yes, exactly. Absolutely. You’ve captured it very well, very, very well. I’m amazed you got all that, out of all these thousands of words....”

Three of the women told the researcher they had found the interviews therapeutic, allowing them to voice thoughts and ideas which in some cases they had not previously shared with anyone.

Limitations of the Study

Researcher’s lack of expertise. The researcher’s lack of expertise at phenomenological interviewing almost certainly affected the study, particularly in the earlier interviews. After reading over the transcripts, the researcher found there were too many leading questions, and inadequate use of silence. In addition, during initial meetings with participants, when the informed consents were signed, the researcher may have
inadvertently suggested a direction for the interviews. When asked what they were to talk about, participants were told by the researcher, "any way heart failure has affected your life - physically, mentally, socially, whatever." Although expansion of the interviews into financial and sexual areas was unexpected, it is possible the participants would have gone in still other directions, were it not for the inadvertent "guidance" given in those initial meetings.

The age of the participants. Participants were widely spread in age, from 60 to 90, with three of the five over 80. While this is not a limitation in and of itself, two of the older participants suggested, perhaps correctly, that at least some of the physical and mental changes under examination were probably due as much to aging as to the effects of heart failure. The study would perhaps have been stronger with a narrower age range, such as 60 - 75 years, or 55 - 70 years.

Duration of diagnosis. Four of the five participants had been living with diagnosed heart failure for five years or more. Many of the changes in their lives caused by heart failure were thus "old hat" to them, and memory of the initial impact of those changes may therefore have been blunted. Again, the study might have been stronger.
with participants who had been diagnosed for a shorter period of time, such as six months to three years.

Marital status. Only one participant was married and sexually active. The other four were widows (3) or divorced (1). Thus only the married participant currently had a close family member living with her, and only she was sexually involved. In these ways, her situation was unique among the participants. There was no one with whom to compare the impact of heart failure on sexual activity. In having help immediately at hand in her home, she also expressed less frustration regarding undone or poorly done chores than did the other women. The study would have been strengthened by having at least one other participant whose situation was similar to hers.

Implications

Women with Stage II heart failure may be far more resilient than suggested by earlier research. However, most prior studies have involved males, or males and females, or (if on females alone) have included women at all stages of heart failure. The results are therefore not directly comparable in most cases.

The five women in this study, all at Stage II, openly acknowledged the losses caused by their heart failure.
However, all five showed amazing strength and resilience, not only in accepting their losses, but in building productive lives within their capabilities, and with an emphasis on the positive. They fought for independence and control of their own lives, and to a large extent, attained it. They have achieved what Elizabeth Lindsey (1996) calls "health within illness." The resulting sense of contentment and well-being has been recognized as an important internal resource in adjusting to chronic illness (Landis, 1996), and an important factor in maintaining health (Barroso, 1996). These five women made necessary changes to their lifestyles early in the disease process, and since that time, with their focus on living rather than their illness, have lived for two to ten years with heart failure with minimal progression of the disease.

If nurses and other medical personnel can foster a positive focus in their patients with heart failure, encouraging them to take charge of their lives and their illness, this is likely to positively affect both their physical and mental health, giving a better quality of life. If this positive focus is engendered early in the disease process, at Stage II, it may continue to have a therapeutic influence as their heart failure progresses.
Suggestions for Future Research

A replication of this study should be done involving a larger number of women diagnosed three years or less with Stage II heart failure, and aged 60-75 years. This would allow further verification of the results of this study, while bypassing limitations of this study.

A longitudinal study, with these or other women, would be of interest to determine the effects of heart failure on women’s lives over time, as the disease progresses from Stage II to later stages.

A Final Word

It is appropriate to this study that the final word be a participant’s. Charlotte asks:

Why do they call it heart failure? Why not heart weakness? I mean, why do they call it heart failure? Heart failure sounds so final, you’re going to die. How about weakness? Maybe with weakness, you’ll live a long time. It’s so final. I just don’t like that term.

Her words are echoed in the lives of the participants in this study. All five are too busy living their lives as fully as their symptoms allow to focus on dying at this stage.
Appendix I

Informed Consent
Informed Consent

I have been asked to, and now agree to participate in the study ("Heart Failure: Its Impact on Women's Lives") conducted by Diane L. Rhodes, a graduate student in the Department of Nursing at UNLV, regarding women's experience of living with heart disease. The purpose of this research is to increase the understanding by medical providers and others of the experience of living with heart disease. I give this consent with the understanding that:

1. My participation in this research will involve being interviewed by the researcher two to four times over a maximum of a two-month period. These interviews will last about an hour each, and will be held at a place of my choosing. I understand that these interviews will be audiotaped, and my name will not appear on the tapes. All communications during these interviews will be considered part of the study. There will be no payment for these interviews, nor will there be any cost to me except that of my time.

2. All information revealed in the interviews is confidential. Confidentiality will be maintained at all times, and no one will know of my participation in this study except the researcher and myself, unless I myself choose to reveal it. Quotations I make during these interviews may be used, but my name or identity will not be used.

3. It is my understanding that talking about my heart disease may make me sad or upset. If I feel the need for assistance, I will be encouraged to seek help from my physician or from a mental health provider. The researcher will provide me a list if requested. The potential benefit to me of being involved in the study is the opportunity to describe how heart disease has affected my life. Talking about experiences and feelings is often helpful, and talking about my disease may be of help to me. In addition, the information I provide may also help health care providers better understand how heart disease affects women's lives.

4. I understand I have the right to drop out of the study at any point, by informing the researcher I no
longer wish to participate, and doing so will in no way affect my medical care. My participation in this study is strictly voluntary.

5. I understand that I will be asked to look at the researcher’s summary of what was learned during the study, and to indicate in what ways I agree or disagree with the summary.

6. It is my understanding that the audiotapes/transcripts of the interviews will be kept in a locked file cabinet at the researcher’s home for 3 years, then destroyed. Audiotapes and transcripts will have no identifying information. No one else will have access to them.

7. I have had the opportunity to ask questions and clarify any areas unclear to me in regard to this study, and have no further questions at this time.

8. I have the right to ask questions at any point during the interviews. I can ask such questions by contacting the researcher, Diane Rhodes, through the UNLV Nursing Department (895-3360). If I have questions regarding my rights in this study, I can contact the Office for the Protection of Research Subjects at UNLV at 895-2794.

9. I may request a copy of the results of the study by contacting the researcher. I understand that the results of this study may be published, and that no identifying information will be used in publication.

Signed

__________________________________ Date

Witnessed

__________________________________
Appendix II

Tables
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Marital Status and Living Arrangement</th>
<th>Risk Factors</th>
<th>Family Cardiovascular History</th>
<th>Comorbidities</th>
<th>Signs &amp; Symptoms</th>
<th>Number Of Meds</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Abigall&quot;</td>
<td>64</td>
<td>Widow Retirement Home</td>
<td>Hypertension (HTN); arrhythmias history (hx); multiple pulmonary emboli; obesity; heavy family cardiac hx</td>
<td>Mom - several strokes (CVA's); Dad - died of heart attack (MI); Sister - valve replacement; Brother - died of MI; Sister - died of heart or CVA</td>
<td>Osteoarthritis</td>
<td>Short of breath (SOB) with exertion; sleeps with 2 pillows; edema; excessive fatigue; sleeplessness; dry cough; decreased exercise tolerance &amp; work capacity</td>
<td>10 (6 prescription (Rx) &amp; 4 vitamins)</td>
</tr>
<tr>
<td>Participant</td>
<td>Age</td>
<td>Marital Status and Living Arrangement</td>
<td>Risk Factors</td>
<td>Family Cardiac-vascular History</td>
<td>Comorbidities</td>
<td>Signs &amp; Symptoms</td>
<td>Number Of Meds</td>
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<tr>
<td>&quot;Beatrice&quot;</td>
<td>64</td>
<td>Divorced In own Home</td>
<td>Mitral Valve insufficiency; enlarged heart; arrhythmias; heavy family cardiac hx.</td>
<td>Mom- coronary artery disease (CAD); heart-related death; Dad-died of MI; Brother-multiple heart surgeries, valve problems, heart-related death</td>
<td>Osteo-arthritis</td>
<td>SOB with exertion; edema; excessive fatigue; decr. exercise tolerance &amp; work capacity; palpitations</td>
<td>10 (5 Rx &amp; 5 over-the-counter (OTC))</td>
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<tr>
<td>Participant</td>
<td>Age</td>
<td>Marital Status and Living Arrangement</td>
<td>Risk Factors</td>
<td>Family Cardiovascular History</td>
<td>Comorbidities</td>
<td>Signs &amp; Symptoms</td>
<td>Number of Meds</td>
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<tr>
<td>&quot;Charlotte&quot;</td>
<td>60</td>
<td>Married In own Home</td>
<td>Early meno-pause w/o hormone replacement therapy; CAD; high cholesterol &amp; triglycerides; history MI &amp; stroke; arrhythmias hypothyroidism; heart surgery (3-vessel bypass &amp; pacemaker); history heavy smoker; history obesity &amp; high stress; heavy family cardiac history; history poor nutrition</td>
<td>Dad- 1st heart attack (MI) at 34, died of heart attack at 66; Pat. Grandfather - died of MI at 50; brother- died of MI at 34; aunt- MI x2, now in HF</td>
<td>None</td>
<td>Short of breath w/ exertion; sleeps w/ 2-3 pillows; arrhythmias; chest pain w/ exertion; excessive fatigue</td>
<td>11 (8 prescription &amp; 3 over-the-counter)</td>
</tr>
<tr>
<td>Participant</td>
<td>Age</td>
<td>Marital Status and Living Arrangement</td>
<td>Risk Factors</td>
<td>Family Cardiovascular History</td>
<td>Comorbidities</td>
<td>Signs &amp; Symptoms</td>
<td>Number of Meds</td>
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<tr>
<td>&quot;Dorothea&quot;</td>
<td>81</td>
<td>Widow In own home</td>
<td>HTN; chest pain; arrhythmias; diabetes mellitus; family cardiac hx; pacemaker 1996</td>
<td>Mom- died HF; Dad- died HF. Has no sibs.</td>
<td>Depression; growth in rt ear; osteoarthritis</td>
<td>SOB w/ exertion; tachypnea; paroxysmal nocturnal dyspnea; sleeps w/ 3-4 pillows; edema; excessive fatigue; decr. exercise tol. &amp; work cap.</td>
<td>6 taken regularly, plus 4 taken occasionally</td>
</tr>
<tr>
<td>&quot;Esther&quot;</td>
<td>78</td>
<td>Widow Retirement home</td>
<td>HTN; hx. Rheumatic heart dz → valve prob; enlarged heart; CAD; angioplasty 1991; 82-pack-year smoking hx (quit 1979); heavy family cardiac hx.</td>
<td>Mat. GF- died of MI; Mom- died of MI; Dad- died of CVA; sister- died of HF at age 66</td>
<td>Deaf, rt. ear; possible TIA 1999; skin ca; hx cataract surgery</td>
<td>SOB w/ exertion; edema; excessive fatigue; decr. exercise tol. &amp; work capacity; chest pain</td>
<td>8</td>
</tr>
</tbody>
</table>
### TABLE 2

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
</table>
| Acknowledging Losses        | A Decrease in Physical Activity  
                              | A Narrowed Social Life  
                              | A Concern with Maintaining Control  
                              | Working on Being Content  
                              | Living on a Tight Budget |
| Accepting the Losses        | Allowing Unfinished Tasks  
                              | Accepting What Is  
                              | A Focus on the Positive |
| Changing Their Lives        | Choosing Easier Ways  
                              | Changing the Focus  
                              | Depending on Others  
                              | Searching for Answers  
                              | Considering Financial Choices |
| Deepening Relationships     | Reaching Out to Others  
                              | Living Their Beliefs  
                              | Deepening Their Faith |
Appendix III

Questions Used in Interviews
Questions Used in Interviews

Basic Question

The first question asked of all participants was this: In what ways has having heart failure affected your life?

Other Questions

Other questions (and variations of these questions) asked of all or most participants included the following:

1. Can you tell me about your life before heart failure was diagnosed? (Describe your life before your heart disease. Compare your life before the symptoms of heart failure, as compared to now.)

2. What physical symptoms have you had?

3. Describe “exercise” for you today.

4. What do you miss most? (What would you like to be able to do that you can’t do because of physical problems? What kinds of things would you be doing, if you felt like you could?)

5. What has changed since heart failure symptoms began? (What are the greatest changes you’ve seen in your life, since this started? If you compare yourself as a person, pre and post heart problems, how are you different?)
6. Tell me about your nutrition now. (Describe a normal day’s diet for yourself.)

7. What is your philosophy of life?

8. Describe a typical day in your life. (How would you describe your schedule, in a week? Describe an ordinary day to me.)

9. How would you describe your support system?

10. What is your outlook on the future? (What do you see in the future for yourself?)

11. What do you think are your major coping mechanisms? (How do you cope with the changes? What coping mechanisms from the past have helped you cope with heart failure?)

12. What kinds of choices do you make in your life now? (You describe your current life as one of “making adjustments.” Can you tell me more about the kinds of adjustments you’re talking about?)

13. I’m a good fairy, and *Poof!* You’re now completely cured, completely sound in body. What would you do? (What would you change about your life if you could change anything?)

14. What are your feelings about death?

15. What kinds of things do you worry about? (What causes you the most stress now? What do you fear now?)
16. How often do you see the doctor now, and how does that compare to the time before heart failure?

17. What have you learned from having heart failure?

All of these questions were asked of at least three of the five participants; most were asked of at least four. However, it should be noted that most questions during the interviews were not these "pre-planned" questions, but were questions which emerged in response to information offered by the participants. The questions listed in this appendix were prepared in advance, for use as necessary in keeping the interviews flowing.
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