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UNIVERSITY OF SAN DIEGO
Philip Y. Hahn School of Nursing and Health Sciences
DOCTOR OF PHILOSOPHY IN NURSING

WOMEN'S EXPERIENCES WITH CHRONIC HEART FAILURE

By

Denise M. Boren, RN, MSN, CNS

A dissertation presented to the
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Dissertation Committee

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WOMEN'S EXPERIENCES WITH CHRONIC HEART FAILURE

Abstract

Denise M. Boren, RN, MSN, CNS

Nationwide, approximately 4.1 million Americans suffer from chronic heart failure accounting for estimated direct and indirect costs of over \$21 billion spent annually for health care. The incidence of heart failure has doubled each decade since the 1940's and slightly more men were inflicted with the illness. This trend changed three years ago, with a decline in the overall incidence of heart failure and a slight predominance of the illness in women rather than men. The incidence of this condition was reduced in males nearly three times that of females. Women survive longer after diagnosis, however they are hospitalized more, and they have more symptoms and a poorer quality of life. There is a significant gender gap in scientific and therapeutic progress made with heart failure. Most research and clinical trials were conducted using primarily male subjects, and then findings applied to women. The heightening trends in women with heart failure question whether findings from this research are beneficial for women. Until new scientific and therapeutic advances are developed using research with female participants, women with heart failure are destined to living with their illness and current therapies.

In light of these issues, a grounded theory study was completed that explored women's experiences with chronic heart failure. A postmodern feminist lens informed a critical analysis of the literature, research procedures, methods to achieve rigor, and the discussion of findings. Data collection using participant observation and interviewing

occurred in two major Naval Medical Centers. Dimensional analysis was used as a method of data analysis to generate a theoretical model exploring the phenomenon under study. Two parsimonious dimensions, network and health care emerged as the most salient. A social network was instrumental for women in their journey of finding out they had heart failure, through a process of psychosocial remodeling to living with chronic heart failure. This network was significant in helping women overcome challenges of lifestyle changes, health care and illness management. The heart failure management approach, provider-client relationships and communication influenced women's physical and psychosocial health and satisfaction with their health care. Experiences with health care inspired women to send messages to other women and health care providers as recommendations for improved health care practices and illness management for women with chronic heart failure.

Historical and social perspectives, and gender issues in pathophysiology, therapies and provider-client relationships must inform nursing practice for women with chronic heart failure. Partnerships and multidisciplinary health care approaches, such as a heart failure clinic were popular among this sample and are recommended for women with chronic heart failure. Possibilities for research that stem from this study are vast.

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DEDICATION

This dissertation is dedicated to my parents (now deceased), Lyle and Doris Solem who whole-heartedly encouraged all their children, regardless of gender, to pursue higher education and “do the best that they can”. Their values and beliefs about education laid the foundation for my academic success.

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Many people supported my efforts to make this dissertation possible. First, I would like to thank my husband Tom for his unwavering support of my educational dreams. He managed the household and kept our children and animals safe and happy during my long hours of study and time away from home pursuing my bachelors, masters and doctoral degrees. I have deep gratitude and love for his encouragement and support of my Navy career.

I would like to thank the Navy Nurse Corps for supporting my dreams of pursuing doctoral level education and selecting me for the Duty Under Instruction for Nurses program so that my dreams could become a reality. It was wonderful to be able to go to school full-time to complete the Doctor of Philosophy degree in nursing.

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proposal that I submitted to the Clinical Investigation Departments of the Naval Medical Centers and offered very sound advice to help expedite the approval process. My dissertation committee members were superb role models.

I acknowledge with gratitude Dr. Robin McKenzie and Dr. Harry Tillman for their help during the approval process and data collection phase of my research. I truly appreciate their efforts in getting me started interviewing women enrolled in the heart failure clinic. I also thank LT Clifford Pyne, LT Shari Jones, Judy McLaughlin, RN and Jennifer Bloomquist, RN, MSN for assisting me in the recruitment of participants for my research. I will never forget their willingness to help further research on women with heart failure.

I last, but not least, relay my eternal gratitude to the women that participated in my pilot study and my research on the experiences of women with chronic heart failure. Their open, willing, and courageous spirits are the reason this research was possible. I hope their stories about their experiences with chronic heart failure will improve health care practice and change health care delivery for those suffering from this chronic illness.

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CHAPTER ONE

Phenomenon of Interest

Heart failure has become a significant public health problem. Nationwide, approximately 4,700,000 Americans (2,300,000 men; 2,400,000 women) suffer from chronic heart failure (American Heart Association [AHA], 2001; Connolly, 2000; Riedinger, Dracup, Brecht, Padilla, Sarna & Ganz, 2001), accounting for estimated direct and indirect costs of over \$21 billion spent annually for health care (AHA, 2001; Riedinger, et al. 2001). Heart failure is a major cause of morbidity and mortality and is the most frequent cause of hospitalization and rehospitalization among adults age 65 and older (AHA, 2001; Cobbs & Ralapati, 1998; Connolly, 2000; Riedinger, et al. 2001).

Heart failure is a significant condition for women. In the Framingham cohort, the incidence of heart failure has doubled each decade since the 1940's with slightly more men than women inflicted with the illness (Funk & Krumholz, 1996). This trend changed three years ago (AHA, 1999). For the first time since initial statistical analyses were published, there was a decline in the overall incidence of heart failure and a slight predominance of the illness in women compared to that of men. Women continue to have a higher incidence of heart failure than men in the newest statistics from the American Heart Association (2001). In addition to the changing trends noted in 1999, it was also observed that the reduction in the incidence of heart failure for males was nearly three times that of females (AHA, 1999). Following myocardial infarction, more women (46 %) than men (22%) were disabled with heart failure within six years of the event

(AHA, 2001). Women were hospitalized more often than men with this diagnosis (AHA, 2001; Moser, 1997). Furthermore, although length of survival after diagnosis is greater for women than men, 62.3 percent of total deaths due to heart failure occurred in women versus 37.7 percent for men (AHA, 2001; Riedinger, et al. 2001).

Since the 1970's, there have been major advances in the diagnosis and treatment of acute coronary syndromes, hypertension and valvular disorders that are often the precursors to heart failure. Additionally, the medical treatment of chronic heart failure has been transformed due to better understanding of pathophysiology, advanced techniques for research and new drug therapies (Poole-Wilson, 1997). This extensive research probably contributed significantly to the decline in the incidence of heart failure for men, however when reviewing the cardiovascular literature and research reports concerning studies on heart failure, one has to ask, "where are all the women"?

Feminist historians have argued that history as a story of progress reflects experiences of men, the usual historians and when women's experiences were different they were omitted (Bunting & Campbell, 1994). There is a significant gender gap in historical accounts on scientific and therapeutic progress made with heart failure and in medical and nursing research on cardiovascular disease (Beery, 1995; Fields, Savard & Epstein, 1993; Laurence & Weinhouse, 1994; Richardson, 2001; Wenger, 1997). Most research and clinical trials have been conducted using primarily male subjects and study findings are then applied to women. The American Heart Association (2001) statistics on the worsening trends in women with heart failure seriously question whether the findings from research on heart failure or clinical therapy trials are helpful for women.

New heart failure management strategies including case management, disease management and heart failure clinics have been implemented in some, but not all health care institutions. Current research on these strategies is focused on cost effectiveness or length of stay and rehospitalization of clients. Genders studies looking at clinical outcomes using these strategies have yet to be published. Until new research and clinical trials, and studies examining client outcomes with new heart failure management strategies enroll a sufficient number of female participants, women with chronic heart failure are destined to living with their illness and current medical therapies and/or approaches to management of this condition.

Purpose of the Study

Emphasis in managing chronic heart failure has been placed on improving physiological outcomes. Medical and nursing care is focused on monitoring cardiac, respiratory, nutritional and fluid status (Connolly, 2000; Laurent-Bopp, 1995; Weinberger & Kenny, 2000). Following hospital or health care provider visits, client's are sent home with a list of tasks to maintain their physiological status including taking medications, obtaining daily weights and adhering to dietary and fluid regimens. Although completing the list of tasks is very important in maintaining physical health, women frequently face other issues while trying to manage their illness that are not considered by their health care provider.

Chronic heart failure is a debilitating illness for both genders but may be more consequential for women. Since most research and clinical trials on heart failure focused on therapies to improve physiological status and were conducted using principally male subjects, their benefit and efficacy for women is highly questionable. In this case,

women may live with chronic symptomatology that hinders their quality of life. Also, when women seek health care, they often bring both physical problems and a social context to the encounter (Fields, Savard & Epstein, 1993). Given the time constraints posed on provider-client encounters either during visits to clinics or stays on hospital units, there may be contrasting goals between the health care professional and client that affects the therapeutic relationship, and ultimately the clinical outcome. Additionally, women often have multiple roles, such as caregiving for other family members, that may compete with providing self-care in the management of their illness and their health may suffer (Orth-Gomer & Chesney, 1997). In light of these issues, the purpose of this study was to explore women's experiences with chronic heart failure. The study findings are the basis for further inquiry; a trajectory of research on women with chronic heart failure.

Research Questions

This study investigated the experiences of women with chronic heart failure. The following research questions were explored:

1. How do women find out they have heart failure?
2. How do women experience health care for heart failure?
3. How do women manage heart failure?

Research Method

The research method selected to study women's experiences with chronic heart failure was grounded theory. Grounded theory is a qualitative research approach that originates from the interpretive tradition of symbolic interactionism (Strauss & Corbin, 1990). According to Blumer (1969), the three basic premises of symbolic interactionism include that "human beings act toward things on the basis of the meanings that the things

have for them; the meaning of such things is derived from, or arises out of the social interaction that one has with [others]; and these meanings are handled in and modified through, an interpretive process used by the person in dealing with the things he encounters” (pp. 2).

Grounded theory research is particularly useful for health practitioners where the interaction with the health care system is only one factor in how health care problems are managed by clients (Chenitz & Swanson, 1986). Grounded theory method allowed for exploration, in depth, of women’s interpretation of their experiences of finding out they had heart failure and their adjustment following this discovery. The method also facilitated inquiry into women’s experiences with their health care and in managing their illness. Besides interactions with their health care system, other factors emerged that were instrumental in either facilitating or hindering living with chronic heart failure. Grounded theory makes its greatest contribution in areas where little research has been done (Chenitz & Swanson, 1986), such as with women with chronic heart failure. The rich data from women’s narratives and the generated theories from this research will add to the body of knowledge on women with heart disease. The grounded theories will be tested in future nursing research.

Feminist Research

Feminist research focuses on the experiences of women. Since the purpose of this investigation was to study women’ experiences with chronic heart failure, a feminist lens was used during the research process. This included a feminist critique of the literature and research reports, a nonhierarchical, reciprocal researcher-participant relationship during data collection and the use of a feminist lens during the discussion of research

findings. There are many diverse feminist theories, each reflecting a different philosophical underpinning. A postmodern feminism lens was well suited for this study as it seeks to expose patriarchal power relations in societal institutions such as in the realm of the health care system.

Postmodernism represents a perspective that rejects positivism, the primacy of rationalism, and the possibility of an objective science for search of universal truths; it depicts the radical change in the ways of thinking we inherited from the eighteenth-century European Enlightenment (Rafael, 1997; Waugh, 1998). Postmodernism embraces the value of practical knowledge, attention to the particular, oral discourse and contextualization of knowledge in place and time. Postmodern researchers “are not concerned about the truth of their research product but rather the pragmatic applicability of the results” (Annells, 1996).

Feminist theories enhance postmodern philosophy with its tenets of critique of androcentric bias, focus on gender, and emphasis on interconnectedness of people with others and the universe (Rafael, 1997). Feminism values women’s narratives that are grounded in their experiences of everyday life and implies that women’s health can only be understood fully by an appreciation for their lived experiences (Campbell & Bunting, 1994; Hamilton, 1993; Wuest, 1994). Feminist theory recognizes the link between social, economic, political and cultural contexts of women’s lives and their lived experiences of health and illness (Rafto’s, Mannix & Jackson, 1997). Postmodern feminists critically analyze the women’s experience and the social, economic and gendered conditions that articulate the experience (Olesen, 2000).

Postmodern feminism focuses on gender and critique of social structures and relationships, including discursive practices, where power resides (Rafael, 1997). A feminist critique of the current model in health care is concerned with issues of power; both as it shapes health, illness, and recovery and as it determines access to health and research (Hamilton, 1993). A postmodern feminist lens guided inquiry into women's experiences with heart failure and critical analysis of conditions that help interpret that experience.

Researcher's Perspective

Consideration of researcher's perspective is a distinctive feature of feminist research. Reinharz (1992) contends that feminist inquiry frequently uses the strategy of "starting with one's own experience" (pp. 259). This approach helps define research questions, leads to sources of useful data, assists in building trust with participants and enables the partial testing of findings. The researcher's personal experience can be the very starting point of a study, the source from which the researcher develops questions and finds people to study (Reinharz, 1992). The researcher's point of view or bias will exist in the research question, inquiry and interpretation of data and will greatly affect the analysis of data, and therefore, should be included as part of the study (Bunting & Campbell, 1994; Hall & Stevens, 1991). The researcher's utilization of "self" is fundamental to qualitative research and a resource for the study. If researchers are adequately reflexive about their research projects, they can summon these resources to guide the gathering, analysis, and interpretation of data as well as their own behavior (Olesen, 2000).

Since heart disease in women has been my interest for several years, I must share my perspective and acknowledge my biases. In my personal and professional life, I have always paid attention to the women's issues, including topics in women's health. I am a cardiovascular clinical nurse specialist, and interested in all aspects of heart disease in women. I began to take a real interest in women with heart failure during my Master's program while managing the cases of eight women with that condition. These women had been hospitalized several times for exacerbations of their illness and had many other things in common. They were 60 years of age or older, experienced some symptoms of heart failure while on cardiac medications, and despite their conditions, most cared for spouses, adult children or grandchildren. They cooked, cleaned and cared for others, leaving little time for planning special diets and cardiovascular exercise for themselves. Although they liked their health care providers, the women were not participants in their health care plans. Instead, they tried to understand and follow "orders" and a prescribed plan of care. The provider-client relationships were paternalistic and often involved one-way communication.

I took a different strategy with clients and became health care partners with these women. While caring for the women, I provided health education to their entire families, and encouraged them to use a team approach to completing household tasks. I empowered them to make their own decisions about their health and life-style, and supported efforts to manage their illness in a manner that was conducive to their lifestyle. During an 18-month partnership, there were no rehospitalizations with this strategy. Similar issues have surfaced as I continue to care for women with heart failure.

In my viewpoint, the biomedical model that dominates health care primarily focuses on the physiological status of the client. Most health care professionals provide care in institutions that advocate this model. Their focus is to assess and treat the physiological symptoms of the client's chief complaint, rather than the "whole person". Other psychological or social issues are often not explored or dealt with. Short client appointments and busy, task-oriented nursing units are not conducive to the social context desired by women. Women want to dialogue. The stories of their illness experiences provide rich, meaningful information about their "whole" selves, their health and their ordinary daily lives.

Since beginning my doctoral program, I completed a small research project for a beginning qualitative research class. I interviewed three women about their experiences with heart failure. Many of the same issues appeared in their stories. Two women cared for members of their family and one woman had no family support. In each case, health practitioners directed their health care. One woman verbalized hostility toward her provider's indifference when he would query about her health status, and then state "lets work on one thing at a time". Other symptoms or complaints were not addressed until her next appointment or ignored completely. Another woman disregarded her medical plan except for her medication regimen. Her health care provider labeled her as "noncompliant" and persuaded a family member to "police" adherence. The third woman meticulously followed her medical plan even after her physician tried a new beta-blocker that caused illness and significant edema, forcing her to bed. She "did not want to call and bother her doctor" and waited for her next monthly cardiology appointment to complain about her symptoms. The drug was discontinued. Her health care provider

confided that her heart disease was severe, yet didn't know, after caring for her for two years, that she walked over a block uphill to the bus stop, transferred three times during her bus trip, then walked nearly one block to her clinic appointments. I knew this information after one interview that took just over an hour, and then quickly found a transportation program that suited her.

Following analysis of the women's narratives during this project, three themes about their experiences with chronic heart failure emerged from the data, including (1) dealing with the physiological/physical and psychological challenges of chronic heart failure is an ongoing, uphill battle; (2) a dynamic and fluid process of psychological remodeling moves back and forth from denial to a "new view" of themselves with chronic heart failure; and (3) managing chronic illness is an unending job that takes considerable time and energy. Women's experiences with chronic heart failure are a never-ending struggle.

During the qualitative project, I asked women, "tell me about your experiences with heart failure". Due to problems with health care and management of their illness cited in the raw data, I focused more specifically on these issues in this study, along with queries of their experiences with finding out they had heart failure and the challenges that ensued following the discovery of their illness.

Significance of the Study

Investigating the experiences of women with heart failure is imperative to their health and quality of life. The current model that dominates health care has been biased in its approach to diagnosis and treatment, provision of specialty care, and research of women with heart disease. Until health care professionals recognize this bias and change

practices, and until there are new scientific discoveries in research that includes female participants, women with heart failure are destined to live with current practices and therapies.

The women recruited for this study were beneficiaries of the Military Health System (MHS), thus military relevance is significant to the study. The Military Health System Optimization Plan (Department of Defense, 2000; Tricare Management Activity, 2000) focuses on population health improvement, access and continuity of care, and client satisfaction. This study on the experiences of women with heart failure centers on key issues of interest to the MHS. First, interview questions focused on women's experiences with their health care. Responses identified women's satisfaction with their health care and revealed problems that can be remedied through programs of population health improvement (case management, disease management) or the development of new practice guidelines or programs to improve health. For example, the Navy's only heart failure clinic was highly regarded by participants as successful in providing multidisciplinary health care for clients with chronic heart failure. Second, these women identified gaps in information and education on heart failure and in some cases, a lack of support from health care providers. These deficiencies in health care can be addressed through better educational programs, discharge planning, and referrals for programs that improve health. Finally, population health improvement focuses on health promotion, wellness and readiness of our active duty population. Active duty personnel are responsible for wives or mothers with chronic heart failure. Women's stories about experiences with their heart failure can be the impetus for better health care and illness management and improved clinical outcomes that are likely to significantly reduce stress

and enhance readiness of the service member. An improved program of health or disease management can reduce the active duty member's time away from work, due to frequent hospitalizations or clinic appointments of family members, which require their support. Also, improved programs for family members will reduce stress and improve focus on task for active duty personnel during military deployments.

This qualitative study explored women's experiences with chronic heart failure. Findings from this research are an impetus for developing changes in practice for this client population. The grounded theory generated from the experiences of these women provides a foundation for new guidelines of nursing practice that support women's management of their heart failure, and improve their health and quality of life.

Summary

Nurses frequently see women with heart failure repeatedly hospitalized for exacerbation of their symptoms. Current practices in caring for these women focus on therapies to improve physiological status without consideration for the whole person. Research and clinical trials have excluded women with heart failure, however findings from studies conducted using primarily male subjects are extrapolated to women. Therefore, clinical therapies may be less effective for women. Side effects of medications have been found to be more prevalent in women. In addition, women have multiple roles and other social issues that may compete with their ability for self-care. In light of these issues, the purpose of this study was to explore women's experiences with chronic heart failure. Due to issues with health care and illness management found in a prior qualitative project, the focus of this study was on how women found out they had heart failure, their responses following discovery of this illness, and their experiences

with their health care and in managing their illness. The women were asked, “if you could change health care for women with chronic heart failure, what would you do?” Their responses provided valuable messages for health care providers and other women with heart failure.

CHAPTER TWO

Review of Literature

A number of factors may contribute to women's experiences with health care for heart failure and in managing this illness. This chapter begins with a brief history on heart failure and women, and then describes the tenets of the biomedical model of health care and Foucault's ideas on power as a framework for understanding research and health care of women within this model. Finally, literature and research on what is currently known about women with heart failure is presented.

Historical Perspectives on Heart Failure and Women

The development of the concept of heart failure as we understand it today begins with the myths, stories and writings in antiquity. From 7500 B. C., the Sumerian culture passed on myths to the people who occupied the land, the Babylonians, Assyrians and Chaldeans, and influenced future knowledge of disease and healing. Discovered ancient tablets, scribed in original "Sumerian word" described heart disease in a patient (Brothwell & Sandison, 1967, pp. 202). These tablets are referred to as the oldest medical text in history and are thought to be the earliest written account of heart disease.

Specific descriptions of heart failure emerged 5000 years later in Egypt. Ancient Egyptian writings (hieroglyphs) that have been interpreted into literary works describe Egyptian medicine of the time (Dalla-Volta, 1993; Kalisch & Kalisch, 1995, pp. 3; Leibowitz, 1970, pp. 20). The "Eber's Papyrus", written in 1552 B. C., is the most

substantial medical papyrus and it is the likely source of the first descriptions of the signs and symptoms experienced by persons with a failing heart (Dalla-Volta, 1993).

There is evidence that the women of this era in history developed heart disease. In 1931 pathologists from the University of Buffalo's School of Medicine examined a female Egyptian mummy of the 21st dynasty (1000 B. C.) who was approximately fifty years old (Leibowitz, 1970, pp. 18). Their findings described coronary artery occlusion from fibrous thickening and calcification, a fragile heart and scarred areas within the cardiac muscle. If this woman lived with heart damage this severe for a period of time, it is very likely she experienced heart failure.

Although it can be concluded that women probably suffered from heart failure as far back in history as antiquity, accounts of this condition in women did not emerge in the literature until the twentieth century. Historical medical literature has been a story of scientific progress, vast technical discovery and great advances in health care. With the exception of reproductive health however, historical medical literature has described medical conditions of men.

Beginning in the late 1960s, the women's movement rejected praise for medical progress and emphasized biases in women's medical care and research (Roy, 1992). The literature focusing on heart disease was predominantly gender-neutral. Articles that discussed heart disease in women were connected to their inability to fulfill homemaking roles until the 1970's (King & Paul, 1996). Some of the biggest and most important research studies on heart disease failed to enroll a single woman. For example, the 1982 Multiple Risk Factor Intervention Trial, a long-term study of lifestyle factors related to cholesterol and heart disease included 13,000 men and no women (Dietrich & Cohan,

1992, pp. 12; Laurence & Weinhouse, 1994). In 1988, the Physician's Health Study that concluded taking an aspirin a day might reduce the risk of heart disease included 22,000 men and no women (Laurence & Weinhouse, 1994; Steering Committee of Physician's Health Study Research Group, 1988). In another instance, the Harvard School of Public Health study that investigated a possible link between caffeine consumption and heart disease included over 45,000 men and no women (Dietrich & Cohan, 1992, pp. 12; Laurence & Weinhouse, 1994). Although the National Institutes of Health (NIH) recommended in 1986 that women always be included in research funded by NIH grants, and audit in 1990 found that little had been done to implement this policy (Laurence & Weinhouse, 1994). It was at this point that women political leaders, outraged by the audit findings, brought the issue of gender bias to the forefront. Dr. Bernadine Healy, the first woman director of the National Institutes of Health, offered the following quote on gender bias:

"Being different from men has meant being second-class and less than equal for most of recorded time and throughout most of the world...it is not surprising that women have all too often been treated less than equally in social relations, political endeavors, business, education, research and health care" (Healy, 1991).

Research and health care for women has primarily focused on reproductive health. Studies on heart disease in women are becoming more prevalent, however, a significant gender gap continues to exist in the research and health care of women with heart failure (Beery, 1995; Fields, Savard & Epstein, 1993; Ghali et al., 1998; Kimmelsiel & Konstam, 1995; Laurence & Weinhouse, 1994; Moser, 1997; Petrie, et al., 1999; Wenger,

1997). Gender bias in health care and research may, in part, be rooted in the philosophical foundation of the biomedical model of health care.

The Biomedical Model of Health Care

The foundation of biomedicine holds an extreme insistence on “hard” versus “soft” science and a “discomfort with dialectical modes of thought” (Kleinman, 1995, pp. 30). It’s rise in status and power came after World War II. Advancement of medical science and technology became paramount over healing the sick; biology came to be viewed as a more basic substance than complaints or narratives of sickness as it could be observed (Kleinman, 1995).

Objectivity is the hallmark of the biomedical model’s approach to research and health care. Health care providers are “expected to decode the untrustworthy story of illness as experience” and replace it with objective data that are based on verifiable measurements (Kleinman, 1995, pp. 32). In spite of the limited progress in the treatment of chronic illness, the medical profession is regarded by its members as “a scientific, technological program of continuous progress in the acquisition of knowledge and deployment of powerful therapeutic operations” (Kleinman, 1995, pp. 34). Biomedicine is practiced in bureaucracies, the rule of efficiency governs the time spent during provider-patient encounters, and patients are mere consumers of the institution’s services. Biomedicine has become bureaucratic, political, materialistic and above all, a very powerful model for health care. Medicine, nursing and other health care professions all work under the umbrella of the biomedical model of health care.

Power and the Health Care of Women

The work of Foucault and his analytics of power provide a useful framework for understanding research and health care of women within the biomedical model. His work is consistently cited in literature describing philosophical underpinnings of postmodern feminist research (Hall, 1999; Rafael, 1996; Rafael, 1997; Waugh, 1998; Weedon, 1987). Foucault describes power as “a web of unequal relationships set up by political technologies which underlie and undercut the theoretical equality posited by the law” (Dreyfus and Rabinow, 1982, pp. 185). Rather than residing in individuals or groups, power is a web of power technologies operating throughout society (Rafael, 1996). Within his theory, the term “technologies” is given to his ideology that knowledge and power are inseparable (Dreyfus and Rabinow, 1982, pp. 194; Kritzman, 1988, pp. 107; Rafael, 1996).

In analyzing power, Foucault looks to historically specific discursive relationships and social practices within a society or institution in order to uncover those regimes of power and knowledge that have produced and sustained the existing power relations (Dreyfus & Rabinow, 1982, pp. 187; Weedon, 1987, pp.107). Discourses are “ways of constituting knowledge, simultaneously with social practices, forms of subjectivity and power relations; they constitute the nature of the body, mind and emotions of the subjects which they seek to govern” (Weedon, 1987, pp. 108).

In Foucault’s theory, the meaning of gender is both socially produced and variable between the forms of discourse. Social meanings are produced within social institutions and practices (Dreyfus & Rabinow, 1982, pp. 187). From the beginning of the eighteenth century, women’s bodies were given meaning by and became subject to

modern medical science. Medical writings of the time illustrated that women were viewed as reproductive organs. One quote stated “women are treated for diseases of the stomach, liver, kidneys, heart, lungs, etc.; yet in most instances, these diseases will be found on due investigation to be, in reality, no diseases at all, but merely sympathetic reactions to the symptoms of one disease, namely, a disease of the womb” (Laurence & Weinhouse, 1994, pp. 14). Women were also subject to a process of hysterization that attributed their psychological and emotional maladies to their reproductive organs (Weedon, 1987, pp. 108). This discursive production of the nature of women’s bodies was central to the patriarchal subjection of women and their exclusion from research, diagnostic procedures, and specialty care for heart disease.

In Foucault’s (1982, pp. 208) thinking, people are objectified or made into subjects by dividing practices, scientific classification and subjectification. Dividing practices are those that differentiate one group from another; one group is considered less valuable than the other and may be excluded based on those differences (Rafael, 1996). Exclusion of women from research and clinical trials due to their various hormonal states and cycles is an example of dividing practices. By claiming women’s hormones can affect study results, women are ignored, men are studied and those findings extrapolated to women.

In regard to gender, scientific classification refers to the generation and institutionalization of gender knowledge that accentuates or mythicizes differences between men and women, providing information that men are supreme (Foucault, 1982, pp. 208; Rafael, 1996). For example, the myth that heart disease is a man’s disease

dominated earlier medical literature and resulted in gender bias in research and the assessment, diagnosis and treatment of women with heart disease (Wenger, 1997).

Subjectification is a phenomenon typical in oppressed groups, in that they assimilate the attributes, practices, and values of groups that dominate them (Foucault, 1982, pp. 208; Rafael, 1996). Historically in health care, the conception that women somaticize emotional issues as physical illness has led health care providers to ignore their complaints and prescribe psychoactive medications instead. In fact, approximately 70% of tranquilizers and antidepressants are prescribed and taken by women (Beery, 1995; Fields, Savard & Epstein, 1993). In cases of heart disease, women are more frequently thought to have psychiatric or other noncardiac causes for their chest pain, even those women with positive nuclear cardiac scans (Fields, Savard & Epstein, 1993). Women come to believe their physical symptoms are “in their head” and take the psychoactive medications prescribed to help their psyche. These three conditions that objectify people can be currently found in the research and health care practices involving women.

Current Status on Women and Heart Failure

The following sections are a review of the current literature and research on heart failure and women. Consistent with feminist research, sections that present research findings in the review of literature are followed by a critique.

Epidemiological Research and Women With Heart Failure

The Framingham Study was initiated in the 1940's and tracked the natural history of heart failure in subjects for over 50 years. The first reports of this study in the 1970's described epidemiological findings in relation to gender for the first time in the medical

literature on heart failure. Researchers have continued to follow the original Framingham population and their offspring in longitudinal investigations.

In 1948, the Framingham Heart Study researchers enrolled 5209 subjects (55% women), ages 28-62 years, in a prospective study that evaluated medical histories, physical examinations, laboratory tests, including blood chemistries and EKGs at two-year intervals (Ho, Anderson et al. 1993; Ho, Pinsky et al. 1993; Kannel, 1997). In 1971, 5135 children (51% women) of the original study cohort were entered in the Framingham Offspring Study to become part of a 9405 subject study that evaluated survival after the onset of heart failure. The median length of follow-up of participants was 14.8 years. During this period, 331 men and 321 women (652 participants) developed heart failure. The mean age of onset of heart failure was 70.0 years (range 32-95 years) and women were slightly older at the time of diagnosis than men (71.9 years versus 68.1 years; $p<.001$). The 652 subjects were followed for a mean of 3.9 years after onset of heart failure (range 0 days to 35.8 years; SD 5.4 years) and 551 deaths occurred (84%). It was found that more women than men with heart failure had co-existing hypertension and diabetes mellitus. The median survival time after the onset of heart failure was 1.6 years for men and 3.17 years for women and a 5-year survival rate was 25% for men and 38% for women. In this study, survival was worse for women with diabetes or left ventricular hypertrophy. Results showed that mortality increased with advancing age in both genders.

Bourassa, Gurne, Bangdiwala, Ghali, Young, Rousseau, Johnstone & Yusuf (1993) reported that investigators enrolled 6273 patients with heart failure in the Studies of Left Ventricular Dysfunction (SOLVD) Registry over 14 months. After a one-year

follow-up, analyzed data indicated that mortality directly related to heart failure was higher in women (12%) than in men (9%). Besides female gender, factors related to one-year mortality or hospital admission for heart failure included age, ejection fraction, diabetes mellitus, and atrial fibrillation.

Philbin & DiSalvo (1998) studied 45,894 (25,915 women) patients discharged from New York State hospitals with a primary diagnosis of heart failure. They found that women were older and had a higher prevalence of hypertension and diabetes. The use of cardiology specialists, most procedures, and intensive care units was lower in women. Women had longer length of stay (LOS), higher hospital charges, lower in-hospital mortality rates, increased rates of discharge to skilled nursing facilities and more post-discharge home care. In a recent study, Haldeman, Croft, Giles & Rashidee (1999) found that among men and women hospitalized with heart failure, men had twice the prevalence of invasive cardiac procedures, as did women.

Burns, McCarthy, Moskowitz, Ash, Kane and Finch (1997) examined a variety of outcomes at six weeks, six months and one year following hospitalization for heart failure to determine gender differences among 519 patients (205 men and 314 women) 65 years or older. Results showed that women were older, poorer, less often married and had a higher incidence of hypertension and diabetes. No significant differences were found between men and women in their ability to perform activities of daily living, perception of health as poor to fair, receipt of formal care and rehospitalization rates. Twenty-five percent of patients were rehospitalized within six weeks, 33% by six months and 50% by one year. Again, among this cohort, more women survived (all p values were .035 or

less). Specifically, by one-year post discharge, 65% of women versus 52% of men had survived.

In order to determine whether increased prevalence of heart failure in women, compared with men, was due to a difference in the left ventricular (LV) pressure/volume relation, Mendes, Davidoff, Cupples, Ryan, & Jacob (1997) retrospectively compared clinical characteristics, left ventricular ejection fraction (LVEF), and end-diastolic pressure and volume in 586 women and 1081 men. Findings showed that compared to men, women were older, had more hypertension, diabetes and symptoms of heart failure. In spite of this, they had a better mean LVEF. Women had lower LV end-diastolic volumes than men, but had similar LV end-diastolic pressures. This study suggests that diastolic dysfunction is one mechanism that may cause more frequent heart failure symptoms in spite of better preserved LV systolic function in women.

Recent data from the Flolan International Randomized Survival Trial (FIRST) showed that women with advanced heart failure lived twice as long as men, even after adjusting for age, race, weight, duration of heart failure, exercise capacity, dobutamine use and gender (Adams, Sueta, Mikai, O'Connor, Schwartz & Koch, 1999; Husten, 1999; Richardson, 2001). The study sample included 359 men and 112 women. Women with a non-ischemic etiology for their heart failure lived three times longer than men; for women with ischemic heart failure the advantage was only half as large.

Critique of epidemiological research. Throughout the years, there have been numerous epidemiological studies conducted that examined heart failure. Most of these studies included primarily male subjects or if both men and women were included, analyses did not include separation of gender. Since the women's movement in the

1960's and 1970's, researchers have become slightly more cognizant to gender bias issues in cardiovascular research, particularly epidemiological research.

The percentage of women included in the cited studies ranged from 31% to 61%. These studies (particularly the more recent research) have improved representation of women and may have the statistical power (not stated in the articles) to make meaningful comparisons between men and women. The results consistently show that women are slightly older, have co-existing hypertension and diabetes, and longer survival rates following diagnosis of heart failure. In addition, these women had higher mortality rates, were poorer, and although they had increased LOS and higher hospital charges, they received fewer specialty services, procedures and diagnostic tests. They did receive more post-discharge skilled nursing or home care.

Clinical Trials and Women with Heart Failure

Several major heart failure clinical trials have included women, however their responses to the studied medications were not examined and compared with responses of men except for one study. Packer, Bristow, Cohn, Colucci & Fowler (1996) reported findings of the Carvedilol Heart Failure Trial. In this study, efficacy of the beta-blocker carvedilol versus a placebo with background therapy of diuretics, digitalis and ACE-inhibitors was tested in 1094 men and 256 (23%) women. Overall mortality was 3.2% with carvedilol versus 7.8% with the placebo. Mortality for women was 3.1% with carvedilol versus 9.6% with the placebo.

Secondary analyses of the Cooperative North Scandinavian Enalapril Survival Study (CONSENSUS) and the SOLVD trials were conducted to study gender differences in mortality (Kimmelstiel & Konstam, 1995; Moser, 1997; Richardson, 2001). In the

CONSENSUS study, results showed that after 6 months, mortality was reduced by 51% in men and 6% in women taking the ACE inhibitor enalapril. In the SOLVD study, women taking enalapril experienced lower hospitalization rates and lower reductions in mortality than men. Women comprised 30% of the sample in the CONSENSUS study and 20% in the SOLVD trial.

In their analysis of outcome data from 30 heart failure studies, Garg and Yusuf (1995) found similar benefits in men and women treated with ACE inhibitors. Their combined sample included 5399 men and 1587 women. Results showed combined outcomes of total mortality and 5399 men and 1587 women. Results showed combined outcomes of total mortality and hospitalization for women were 20.2% in the experimental group who received ACE inhibitors and 29.5 in the control group. For men in the experimental group, combined mortality and hospitalization rates were 22.9% and rates in the control group were 33.2%. Their findings were different from other studies in that men had slightly higher mortality and morbidity rates. The percentage of women in this combined sample was only 29 percent.

Critique of clinical trials. Based on the small percentage of female subjects included in the cited clinical trials, one has to wonder about the validity of the research. How applicable are the results of these clinical trials to women? If men are experiencing a three-fold reduction in incidence of heart failure and lower mortality and hospitalization rates than women (AHA, 1999), maybe these wonder drugs are not effective in women. Additionally, ACE inhibitors have been proven to be efficacious in persons with left ventricular dysfunction. Studies have shown that heart failure in women is often caused by a diastolic dysfunction. Benefits of ACE inhibitors in persons with diastolic

dysfunction are questionable. The standard care for heart failure (digoxin, diuretics, ACE-inhibitors) is less effective in improving symptoms of heart failure due to a diastolic dysfunction (Guerra-Garcia, Taffet & Protas, 1997). Clients have poorer functional status and quality of life.

Peripartum Cardiomyopathy

Peripartum cardiomyopathy is a rare (1 per 3000 live births) and poorly understood condition that develops in temporal relation to pregnancy (Oakley, 1997; Reimold & Rutherford, 2001). The disorder was vaguely defined until 1997 when the National Heart, Lung, and Blood Institute (NHLBI) workshop standardized a definition (Pearson, Veille, Rahimtoola, Hsia, Oakley, Hosenpud, Ansari & Baughman, 2000). The definition of peripartum cardiomyopathy is “the onset of cardiac failure with no identifiable cause in the last month of pregnancy or within five months after delivery, in the absence of heart disease before the last month of pregnancy” (Reimold & Rutherford, 2001, pp. 1). The hallmark findings for this illness are a left ventricular systolic dysfunction and an ejection fraction less than 45 percent (Reimold & Rutherford, 2001).

Women that develop peripartum cardiomyopathy have variable outcomes. In some women, the initial severity of clinical findings improves rapidly and returns to normal and other women deteriorate quickly and require heart transplantation or die (Reimold & Rutherford, 2001). Still others live with cardiac dysfunction for several years and may slowly improve over time. If this condition persists six to twelve months after initial diagnosis, subsequent pregnancies are contraindicated. Women with peripartum cardiomyopathy appear to have better survival (94% in 5 years) than men and women diagnosed with cardiomyopathy from other causes (Felker, Thompson, Hare,

Hrukan, Clemetson, Howard, Baughman & Kasper, 2000). This is likely due to the low frequency of coexisting chronic disease or comorbidities and the young age of the women at the time of the discovery of their illness (Ford, Barton, O'Brien & Hollingsworth, 2000).

Critique of peripartum cardiomyopathy. In reviewing the literature, it was found that research studies regarding this condition are few and focus on physiological variables or clinical trials of anticoagulant therapy used to prevent thrombus during pregnancy. Nursing research appears nonexistent. This particular group of women with heart failure is vulnerable to psychosocial concerns and significant family issues due to their youth and the adjustments their family is required to make following diagnosis. This is a rich area for research.

Heart Transplantation in Women

Heart transplantation has become a viable treatment for heart failure. The number of women undergoing heart transplantation is significantly lower than the number of men. In the most recent reports from the United Network of Organ Sharing (UNOS, 2001), women represented 25.5% of heart transplant recipients from 1996 to December 31, 2000. Of the 4223 patients registered for heart transplantation on the national Transplant Waiting Lists as of June 30, 2001, 952 (22.3%) are women (UNOS, 2001). The percentages of women receiving heart transplantation and waiting for a heart donor is much lower compared with other solid organ transplant listings (Smith & Brozena, 1997; UNOS, 2001) and parallel the low percentages of women enrolled in the major heart failure clinical trials.

There is little reported on gender differences in relation to heart transplantation. Aaronson, Schwartz, Goin and Mancini (1995) investigated whether gender bias occurred in the transplant selection process at a single cardiac transplant center. They prospectively evaluated 386 individuals (295 men and 91 women) less than 70 years of age and found that female gender was independently associated with rejection for heart transplantation (odds ratio, 2.57; $p=.01$). The reason for rejection was explored and it was found that 29% of women and 9% of men refused transplant. They concluded that underrepresentation of women among heart transplant recipients was due to decreased willingness of women to undergo transplantation rather than gender bias in selection of transplant candidates.

Wechsler, Giardina, Sciacca, Rose & Barr (1995) completed a retrospective analysis to study factors affecting mortality after heart transplantation at one medical center. The study sample included 379 patients (75 women and 304 men) that survived the first 48 hours post-surgery. They found that women had decreased survival rates (64% for women versus 76% for men) and increased risk for rejection. Women were at risk for death when receiving hearts from donors exposed to cytomegalovirus (CMV +) and after receiving monoclonal antibody therapy (OKT3). The risk for death was highest for women who were not exposed to cytomegalovirus (CMV -) and were transplanted with CMV + donor hearts without receiving OKT3 induction therapy. The authors concluded that CMV is a potential factor that identifies increased risk for mortality following heart transplantation and factors that influenced survival in women did not appear to be problematic in men.

Critique of heart transplant research. Who shall live when not all can live?

Childress asked this question in 1970 when donor hearts were in short supply compared to demand (Childress, 1997, pp. 15-18). In response to the question and based on the percentages of women heart recipients or those on waiting lists for heart transplants, the answer is “not usually the women”. The selection process for heart transplantation has historically been prejudiced and biased. In 1984, the Task Force on Organ Transplantation was initiated to develop fair selection criteria for recipients (Beauchamp & Childress, 1994, pp. 381). They excluded criteria such as social value, race and gender as unjust but retained debatable criteria including age, lifestyle, social support and other psychological attributes. Although the task force set up a federal program for funding of heart transplants to the financially needy, many centers require cash deposits that exceed what the majority of potential candidates can pay.

It is interesting to note that Aaronson, et al. (1995) reported 29% of women who met criteria for selection for transplant refused placement on a waiting list for a donor heart. Reasons for refusal were not solicited. Since women are poorer and have less adequate health insurance and transplant imposes an enormous financial burden on patients and families, it seems likely that reasons for refusal may be due to an unwillingness to incur large debt and impose on family finances. The investigators also found that only patients with health insurance were accepted for transplantation, patients that were accepted were less likely to be insured by Medicaid, and rejected patients were commonly in the lowest income levels. The percentage of women without health insurance, insured by Medicaid and in the lowest income levels is high. Besides finance and insurance issues, age and social support may also play a role in higher numbers of

women refused for transplant. Women with heart failure tend to be slightly older and less often married (Burns, et al., 1997). Also, at the age most women would be considered for transplant, they are probably primary care givers for parents, spouses, children (peripartum cardiomyopathy clients) or grandchildren. It is possible they refused the transplant due to the considerable time needed for preliminary care prior to transplantation and recovery following surgery. Based on all these issues, I have to disagree with the conclusion that gender bias did not play some part in higher rejection rates. The underlying reasons for rejection (finances, insurance, social support and age) are riddled with issues of gender bias.

Because of the severe shortage of donor organs, patients selected for heart transplantation are those expected to benefit the most in terms of survival and quality of life. Mortality and rejection rates are higher in women and this may influence decisions not to select women for heart transplantation. No major gender differences in quality of life after heart transplantation have been found (Smith & Brozena, 1997). The reasons for higher mortality and rejection in women demands further research.

Nursing Research and Women With Heart Failure

Nurses have written review articles and conducted research on heart failure, however, similar to medical literature, they failed to look at differences based on gender until recently. Moser (1997) published the first review article on heart failure in women in a nursing journal and stimulated interest in nursing research that has either focused on women or included gender differences in relation to their illness. Since Moser's (1997) publication, Richardson (2001) wrote a second review article that provides an update on

the research/clinical trials on heart failure that included women. Only four research studies on women with heart failure were found in the nursing literature.

A qualitative study was completed by Martensson, Karlsson and Fridlund (1998) with the specific aims of identifying how female patients with heart failure conceived their life situation. Twelve women from a county clinic in Sweden were interviewed and five themes emerged from their stories: feeling content with their past life and present life situation; feeling a sense of support and encouragement from those in their environment; feeling a sense of physical and social limitation due to fatigue and lack of energy; feeling anxiety; and feeling powerlessness over their life situation. Although these women accepted their disease and were satisfied with the support and encouragement they received from healthcare providers, family and friends, they were frustrated with the limitations heart failure imposed on their work capacity, social activities, and ability to care for others. They felt they were a burden to those around them. This led to feelings of anxiety and powerlessness.

Bennett, Cordes, Westmoreland, Castro and Donnelly (2000) used focus groups to identify symptoms experienced by clients with heart failure and self-care strategies used by these clients in managing their symptoms. Clients that participated in this study included 16 men and seven women with a mean age of 60 years. In this sample, 14 of the men and none of the women were married. Eleven of the clients, all men, were enrolled in a heart failure clinic. The other 12 clients' received care at a general medicine clinic.

Although all participants experienced the common symptoms of heart failure, such as shortness of breath, swelling, chest pain, tiredness and decreases in concentration, attention and memory, the study found that there were symptoms that were more

troubling for women. Women more frequently experienced shortness of breath while bending over and had more difficulty bending over than men while doing household tasks. Also, all the women in the study reported the problematic sensations of hearing their heart beat and feeling it pounding while lying on their left sides and were unable to sleep on that side. Women were likewise more apt to verbalize feelings of fear, depression, worry and thoughts of death that interfered with the ability to sleep at night for fear they would not awaken. Although loss of interest in sexual activities and performance problems were common in men, women reported that they had not experienced any changes in sexual desire; in fact, all women thought they would be sexually active if they had a partner.

Strategies for self-care in managing heart failure were very similar for both men and women. Changing the level of physical activity, including a slower pace with rest periods, breathing exercises for shortness of breath, and setting up medication schedules were common approaches used by participants. The study found that most men had wives to do the driving and the household tasks, where the women had to rely on siblings and children for assistance. The women in the study noted it was helpful to meet other women with heart failure and showed interest in continuing groups for support and education. A study limitation cited by investigators was the large number of patients who declined to participate. In particular, they experienced difficulty recruiting women into the study because they lacked transportation.

Quality of life is a fairly recent concept in research on heart failure. It is an important research outcome, and is emerging as a clinical measure to direct the treatment of clients with heart failure (Moser & Worster, 2000). Like most other studies, samples

in the research on quality of life and heart failure are composed primarily of men. Since research on the quality of life in women with heart failure was scarce, Bennett, Baker and Huster (1998) completed a pilot study that examined the relationships of symptom impact, perceived health status, perceived social support, and overall quality of life in 30 women that were recently hospitalized with heart failure. Findings report that women with heart failure have high physical symptom impact, poor perceived health status and impaired quality of life. Symptoms of fatigue and dyspnea were especially common in this sample of women. Women with higher symptom impact or poorer physical health status had an impaired quality of life. Neither emotional symptom impact nor mental health status correlated with quality of life. Increased physical symptom impact was associated with increased perceptions of social support, indicating that as physical symptoms worsen, social support increases. Further study on the quality of life and women with heart failure was recommended.

A more recent study evaluated gender differences in quality of life in a sample of 1382 patients (691 men and 691 women) with heart failure (Riedinger, et al. 2001). The study was a secondary analysis of quality of life from the SOLVD trials. Women were matched with men within three years of age and within four ejection fraction percentage points. It was found that women had significantly worse quality of life ratings for intermediate activities of daily living (ADL) and social activity than men did. These differences could not be explained by age, EF, comorbidity or severity of illness. The results of this research were consistent with findings from Bennett's et al. (1998) study.

Critique of Nursing Research. The sample size in Martensson, Karlsson and Fridlund's (1998) study was small, however the criteria for "saturation" were met at this

number. The percentage of women (26%) recruited in the Bennett, et al. (2000) study is consistent with other studies in the literature, but unlike other studies, a reason for the small sample of women is presented. The social role ascribed to women emerges from the data in both studies; women are workers, social beings and caregivers and feel frustration and anxiety when they cannot fulfill that role. Although the caliber of social support is different for women, they go on with managing their illness without complaints. It is interesting that none of the women in the Bennett, et al. (2000) study were enrolled in a heart failure clinic. This is another example where women are not provided specialty services.

The studies on quality of life in women with heart failure are a great beginning to studying women and comparing for differences with men. The findings of the pilot study by Bennett, et al. (1998) confirmed the need for further research on quality of life in women with heart failure. Riedinger and colleagues (2001) followed up on this research with their secondary analysis from the SOLVD trials that established women have a poorer quality of life compared to men. The sample size and the number of women represented in this study strengthen the findings.

Ageism and Women with Heart Failure

Older women's health has been neglected in health care curricula and in research studies, and this gap has had harmful effects on delivery of health care to elderly women (Butler, Collins, Meier, Muller & Pinn, 1995). Although policy-makers makers have recognized this and begun to act on the lack of health care research and training in chronic illness, change has been slow.

Among health care providers, there is a need to understand where there are differences between men and women in etiology, progression of disease, and responses to interventions, such as preventive measures, therapy and drug dosages (Butler, et al. 1995). Because of age and hormone status, older women may have different responses to therapy than men or younger women. Older women have not been included in health care research. Public law states that women cannot be excluded from clinical trials, yet the exclusion criteria are so rigid that it is nearly impossible to find older women who meet the criteria. As a result, studies are conducted on a highly selective sample, and then used in women who have multiple comorbidities and take several other medications. Older women are very willing to participate in research and clinical trials; rigid exclusion criteria and lack of transportation are barriers to enrollment (Bennett, et al. 2000; Butler, et al. 1995).

There are a couple studies that have been conducted that enrolled exclusively women or discussed gender differences between men and women. As part of a larger longitudinal, community-based study, Krumholz, Butler, Miller, Vaccarino, Williams, Mendes, Seeman, Kasl & Berkman (1998) reviewed medical records of 292 subjects (168 female; 124 male) ages 65 years or older to determine whether emotional support (measure of the presence of intimate contacts) was associated with fatal and nonfatal cardiovascular events in elderly patients hospitalized with heart failure. Comprehensive psychosocial assessments of subjects were done at intervals during the larger, longitudinal study. Psychosocial data for this study were based on interviews that occurred most directly before hospitalization for heart failure. After adjustment for demographic factors, clinical severity, comorbidity and functional status, and social ties,

the absence of emotional support was associated with a significantly higher risk (odds ratio, 3.2; 95% confidence level, 1.4 to 7.8). The test for interaction between emotional support and gender was significant ($p = .01$). In this fully adjusted model, the odds ratio for women was 8.2 (95% confidence interval, 2.5 to 27.2) compared with 1.0 (95% confidence interval, 0.3 to 3.3) for men. The investigators concluded that among elderly women hospitalized with heart failure, the absence of emotional support, measured before admission, was a strong, independent predictor of occurrence of fatal and nonfatal cardiovascular events in the year after admission.

Friedman and King (1995) interviewed eighty women who had been hospitalized for heart failure during the previous 12 months to examine the contributions of physical symptoms versus psychological factors to their fatigue with this illness. The researchers found that fatigue was more related to other physical symptoms such as sleep difficulties, chest pain, dyspnea and weakness, than to psychological factors.

Critique of elderly women studies. The number of studies that compare elderly men and women with heart failure are minimal. The exclusion of women from clinical trials is high among the elderly due to the strict eligibility criteria, yet once approved by the Federal Food and Drug Commission, these drugs are prescribed to elderly women. Women report more drug side effects than men do; for this reason, women should be a mandatory part of research (Laurence & Weinhouse, pp. 71).

Friedman and King's (1995) study provides evidence for health care providers that physical symptoms in women with heart failure are valid complaints. It would interesting to note how many of these women with their complaints of fatigue,

sleeplessness, chest pain, dyspnea and weakness were convinced they needed psychoactive medications, rather than therapies to reduce their physical symptoms.

Other Qualitative Research on Clients with Heart Failure

Two qualitative studies that included women participants examined experiences with heart failure. Lough (1996) used a grounded theory approach to discover processes in the post-discharge management of 25 elderly clients (12 men; 13 women) with congestive heart failure. Data was collected through semi-structured interviews that were conducted within two weeks of discharge and ranged from 30 to 60 minutes long. Constant comparative analysis revealed major themes and a conceptual model was developed. The core concept was ‘a tentative situation’ that was characterized by three processes including ups and downs associated with illness management, caregiver issues and quality of life challenges. The ups in illness management included having family and friends and pride in self-care and the downs were the daily impact of the illness and uncertainty about management of therapies. Caregiver issues were of dependency and the client as a caregiver too. Quality of life challenges included feelings of hopelessness, self-blame and uncertainty about life. The researcher also completed trajectory phasing based on the work of Corbin and Strauss (1988; 1991) and found participants in three phases including stable, unstable and downward. From findings in this study, the researcher recommended interventions of “supportive assistance, counseling, meeting emotional needs and teaching” (pp. 9).

Stull, Starling, Haas and Young (1999) used Strauss and Corbin’s (1990) grounded theory approach to understand the process of becoming a patient with heart failure. The authors characterized this process as identity formation. Twenty-one

participants (17 male; 4 female) were interviewed (the spouse was interviewed in more than half of the cases) in the examining room of a cardiology clinic as part of their regularly scheduled appointment. The main theme that emerged was identity formation. This concept was characterized by five distinctive phases including crisis event, diagnosis, response to diagnosis, acceptance and adjustment and getting on with life. The researchers concluded that becoming a patient with heart failure is a process of searching for meaning related to their illness, and taking on a new identity and appropriate role behaviors. Recommendations from findings included support with identity formation through education.

Critique of other qualitative studies. The studies focused on very pertinent questions about the experiences of clients with heart failure. Lough's (1996) study had better representation of women participants. It would be interesting to compare responses of men and women for differences. The recommendations of support and education in both studies are needed in the realm of health care in a managed care environment.

Innovative Strategies to Manage Heart Failure

Heart failure is a complex illness that requires an integrated approach for optimal management. Several management programs have been developed and described in the recent literature. Programs include case management models (Blaha, Robinson, Pugh, Bryan & Havens, 2000; Morrison & Beckworth, 1998), partnership models (Dunbar, Jacobson, & Deaton, 1998; Welsh & McCafferty, 1996), education models (Cline, Israelson, Willenheimer, Broms & Erhardt, 1998; Dunbar, Jacobson, & Deaton, 1998), disease management models (Albert, 2000; Brass-Mynderse, 1996; Fanarow, Stevenson,

Walden, Livingston, Steimle, Hamilton, Moriguchi, Tillisch & Woo, 1997), team management (Grady, Dracup, Kennedy, Moser, Piano, Stevenson & Young, 2000; Venner & Seelbinder, 1996) and heart failure clinics (Grady, et al., 2000; Lasater, 1996; Paul, 1997; Smith, Fabbri, Ramdas, Ferry, Heywood & Pettis, 1997; Urden, 1998; Venner & Seelbinder, 1996). Nurses play a vital role in heart failure management programs as managers/directors or coordinators/facilitators of health care.

Studies of Heart Failure clinics/management models were aimed at measuring cost effectiveness, rehospitalization rates, functional status and quality of life (Fonarow, et al. 1997; Hanumanthu, Butler, Chomsky, et al. 1997; Lasater, 1996; Smith et al. 1997). Research has found that these programs have significant reductions in mortality, readmission rates (53 to 85%) and costs per patient (nearly \$10,000). Improvements were also found in NYHA functional status, adherence to therapies and quality of life. Like other research on heart failure, less than 30% of subjects in these studies were women.

Conclusion

Women with heart failure are slightly older, have co-existing hypertension and diabetes, and longer survival rates than men. They are hospitalized more, have longer lengths of stay and higher hospital charges, yet they are poorer and less insured. They receive fewer specialty services, including enrollment into the heart failure clinics that provide education and emotional support, in addition to physical care. Evidence suggests women's physical complaints are often ignored and they are given psychotropic medications instead of therapies to reduce physical symptoms. They are more often

unmarried and an absence of emotional support is a strong predictor of fatal or nonfatal cardiac events.

Women with heart failure have been largely excluded from research and clinical trials, yet therapies tested on men are prescribed to women. Additionally, a diastolic dysfunction may be the underlying cause of their heart failure, yet they receive therapies that have questionable efficacy for this disorder. Clients with a diastolic dysfunction often have a poorer functional status and quality of life. Few women meet the eligibility criteria or are considered for and agree to receive a heart transplant that could increase their functional status and quality of life.

Besides their chronic physical symptoms and reduced functional status, frequent side effects from prescribed medical therapies, and poor quality of life, most women with heart failure are being cared for in a system that has been historically biased toward their gender. In approaching their health care provider, women often bring not only their physical problems, but also a social context with concerns about family, work, economics and demands of their gender roles. They want to talk about their illness experience. The biomedical model of health care generally dismisses client experiences and focuses on physical symptoms and objective data to form a diagnosis and decide on treatment.

Based on these conclusions, it was imperative to explore women's experiences with heart failure. With all the physical and social obstacles these women face in their daily lives, insight to their experiences with health care and in managing their illness is valuable evidence for changing health care practice. The grounded theory that emerged from their stories will be the basis for designing programs to improve their health and quality of life. The dimensions that were discovered during the research process are

essential in developing research instruments for use in quantitative research of women with heart failure.

CHAPTER THREE

Methodology

Grounded theory was selected as the method for development of a theory on the experiences of women with chronic heart failure. Grounded theory is a research method developed by sociologists Glaser and Strauss (1967). Pragmatism and symbolic interactionism are the theoretical underpinnings of grounded theory (Strauss & Corbin, 1990). Symbolic interactionism focuses on meanings that people ascribe to events through interaction or experience (Blumer, 1969; Robrecht, 1995; Wuest, 1995).

A grounded theory is inductively derived from the study of the phenomenon it represents (Strauss & Corbin, 1990, pp. 23). It is a general methodology of qualitative research for constructing a working and dynamic theory that is grounded in data regarding the phenomenon under study (Strauss & Corbin, 1998). Grounded theory methods consist of systematic inductive guidelines for collecting and analyzing data to build theoretical models that explain the collected data (Charmaz, 2000). Theory evolves through a continuous, reciprocal interplay of data collection and analytical interpretations of data. Researchers use analytical interpretations of data to focus further data collection as they refine their developing theories.

The method of dimensional analysis by Schatzman (1991) was selected for the analysis of data collected from women with chronic heart failure. Dimensional analysis is informed by the core ideas and practices of grounded theory, but differs in that the aim of the analysis is to discover people's interpretation and meanings of phenomenon within

their social world, rather than the discovery of basic social processes (Robrecht, 1995; Schatzman, 1991). Like grounded theory, the process of discovery through dimensional analysis is embedded in symbolic interactionism, where analytical thinking is “governed by and reflective of one’s interaction with the data” (Robrecht, 1995, pp. 170; Schatzman, 1991). The researcher’s analysis focuses on events in the natural setting where interactions occur between human beings.

Natural analysis and dimensionality are important tenets of the dimensional analysis method. Natural analysis is conceptualized by Schatzman as “a normative cognitive process generally used by people to interpret and understand problematic experiences or phenomena” (Kools, McCarthy, Durham & Robrecht, 1996, pp. 314; Schatzman, 1991). This process is learned through early socialization and becomes a “schema that can be subsequently used to structure and analyze the intricacies of phenomena of ordinary life” (Kools, et al. 1996, pp. 314). Scientific analysis is an extension of natural analysis. Dimensionality is a cognitive attribute and a distinct process of natural analysis that allows an individual to derive meaning through interpretation of the different attributes of a phenomenon or situation; these attributes are referred to as dimensions (Kools, et al. 1996; Schatzman, 1991). Past knowledge and experience are integral parts of the individual’s thinking during natural analysis.

Along with traditional qualitative research and grounded theory methods, dimensional analysis proposes that data is collected primarily through semi-structured interviews, observation and field notes (Kools, et al. 1996; Robrecht, 1996; Schatzman, 1991). Sampling starts with an initial pool of participant’s, and then is guided by findings from concurrent data analysis during data collection. In addition to dimensional

analysis, the constant-comparative method of data analysis guides the development of a grounded theory (Straus & Corbin, 1990).

Dimensional analysis consists of three phases including designation, differentiation, and integration (Kools, et al. 1996; Schatzman, 1991). During the designation phase, dimensions are generated from the initial data. The purpose of dimensionalizing is to identify, name and label dimensions and properties noted during data collection and to expand data by asking the question, “What all is involved here?” A critical mass of dimensions is assembled and assessed during this phase. In the differentiation phase, data are limited and analysis becomes more direct and focused. An explanatory matrix is used to reconstruct and explain participant viewpoints of the phenomenon. A central dimension is selected and other dimensions are arranged on the explanatory matrix. The central dimension serves to provide purposeful orientation for subsequent inquiry and guides the remaining data analysis. During the integration phase, limited data is collected through theoretical sampling and analyzed as a means of verifying the validity of the emerging theory. When sufficient data saturation and depth of conceptual linkage has been reached and described, theory generation is complete. The final explanatory matrix tells the theoretical story of the phenomenon under investigation.

Feminist Research and Grounded Theory Methodology

Feminism is a perspective or theme, not a research method (Bunting & Campbell, 1994; Reinhartz, 1992). During conduct of the study on the experiences of women with chronic heart failure, I operated with a dual vision, as a feminist scholar and a grounded theorist with the goal of developing nursing theory from women’s experiences.

Feminist research is guided by feminist theory. Feminist researchers use a multiplicity of research methods for conducting research with the goal of creating social change that will benefit women or other marginalized groups (Wuest, 1995; Bunting & Campbell, 1994; Reinharz, 1992). Feminism assumes all women are legitimate knowers and are the most knowledgeable about their own particular experiences. Attributes of feminist research are that it includes small samples, participant observation, in-depth interviewing and gender-neutrality (Kleffel, 1994). Other guiding principles for feminist epistemology include concepts of reflexivity, nonhierarchical relationships between the researcher and the participants, mutual participation between participants and researcher, and recognition of the oppressive nature of social structures and ideologies (Bungay & Keddy, 1996).

Feminist postmodern research is designed to benefit participants and has transformational potential; knowledge is elicited and analyzed to alter oppressive, exploitative conditions within society (Rafael, 1997; Hall & Stevens, 1991; Cook & Fornow, 1990, pp. 80). Feminist postmodern research analyses existing “truths”, and challenges acclaimed constructions of basic concepts of power, knowledge, truth and gender that influence our social arrangements (Wuest, 1995; Allen & Barber, 1992).

Grounded theory is consistent with postmodern feminist epistemology in the recognition of multiple explanations of reality, the examination of influence of social structures on the interactional process, and the idea that theory as process is consistent with changes over time (Wuest, 1995). There are other common epistemological underpinnings of feminist theory that are consistent with grounded theory. First, feminist theory states women’s experiences are a legitimate source of knowledge; the participants

are experts about their own experience. In grounded theory methodology, the investigator through theory development interprets the voices of the people studied; the basic tenets of symbolic interactionism reflect a respect for the persons' subjective interpretation of social experience as a source of knowledge. Second, the grounded theory aim of discovering social process within social structure that involves deeply grounding personal and practical experiences, closes the distinctions between the personal and political, theory versus practice; dichotomies that are considered artificial in feminist epistemology. Since dimensional analysis will be used in this study, the aim will focus on understanding meanings of interactions occurring within social structures, rather than extracting a basic social process; therefore supportive of Wuest's premise that both traditions merge the personal and political. Finally, both feminist epistemology and grounded theory accept researcher bias. Grounded theorists are biased by accepting responsibility for their interpretation of the data (Wuest, 1995; Strauss & Corbin, 1998). In feminist research, the values of the researcher may influence every stage of the research, including problem selection, development of research questions and analysis of the data. Due to the degree of bias permitted, feminist researchers must conduct ongoing self-critique and clarification of personal values and remain committed to the techniques of grounded theory.

Adequacy of Inquiry

Methods to achieve rigor in feminist postmodern research should be reflective and congruent with the philosophy underpinning the research study (Rafael, 1997; Hall & Stevens, 1991). In an effort to meet requirements of "good science", researchers have developed some criteria to achieve rigor that are grounded in modernistic assumptions

and parallel those used in positivistic research. Researchers must exercise judgement in applying standards of rigor in feminist research.

According to Hall and Stevens (1991), the best way to evaluate feminist research is to use “standards of rigor that reflect the adequacy of the whole process of inquiry, relative to the purposes of the study, rather than on standards that focus on the reliability and validity of measurements within the study” (pp. 20). Adequacy of inquiry looks at research processes and outcomes, searching for cogency, grounding, justifiability, relevance and meaning. There are a number of elements to consider in ensuring adequacy in qualitative research. Although all are important, I selected standards that were appropriate for feminist postmodern research including (1) reflexivity; (2) rapport, honesty and mutuality, (3) coherence; (4) complexity and (5) naming.

Reflexivity

Feminist research should be robust and reflexive; researchers should examine their values, assumptions, and motivations to see how they affect each step of the research process (Hall & Stevens, 1991). The researcher-participant relationship is a hallmark in feminist inquiry; the researcher and the research participant jointly construct knowledge. The concept of reflexivity in feminist research means that the researcher’s values, assumptions and motivations are made explicit and there is continuous reflection and assessment of how the researcher participates in creating and interpreting research data. In my research, my values, assumptions and motivations were made evident to participants as I described my perspective as a health care provider and researcher of women with heart disease. My experiences in caring for women with heart failure and my values and beliefs about the current model of health care were known by the

participants. Documentation of notes and memos during data collection and analysis, and written self-reflection of my values and thinking and their influence on the analysis of data provided an audit trail of my research. The researcher-participant relationship was checked during data collection and analysis for mutual influences that affected the nature of responses. Since bias is allowed in feminist research, conflicting realities may coexist in continuous reflection on the research process. When this phenomenon occurred during the data analysis, I kept focused on data, rather than my evaluation of the data.

Rapport, honesty and mutuality

Rapport, honesty and mutuality are essential in feminist research to ensure the sufficient depth and scope of data collection and analysis (Hall & Stevens, 1991). Rapport involves trust and openness in the researcher-participant relationship and can be evaluated by the depth and specificity of information shared, verbal and nonverbal indications of comfort during the encounter, and willingness to fully participate in the interviews. Honesty means that the participants believe there are no hidden agendas or unethical practices during the research process. Mutuality refers to an egalitarian relationship between the researcher and the participant that promotes free expression about one's experiences. Egalitarian relationships were established through mutual sharing, encouragement of free expression and the undivided attention of the researcher in listening to the women's stories. An expression of caring about women's daily lives and their personal struggles in managing their illness served to strengthen rapport, trust and mutuality. Most participants looked forward to telling their story. If they were anxious initially, a warm, open greeting and an introduction to my perspectives as a health care provider and researcher, and to the goals of my research, aided in reducing

that anxiety. Nearly all participants were very vocal, open and trusting as they told me about their experiences of living with chronic heart failure.

Coherence

Coherence is a criterion that gauges the unity in the research account derived from all interview data, field notes and theoretical memos in the research process (Hall & Stevens, 1991). Conclusions from the research are coherent if they are founded in the raw data, systematically connected in a logical discourse, and faithful to the participant's sentiments, stories and behaviors conveyed during their interviews. During analysis of the data, continual questioning was used to ensure my analytical interpretations communicated the meanings of the raw data. Reflections on coherence were documented in notes and memos.

Complexity

Measures of adequacy of inquiry in feminist research should incorporate the degree that the research reflects the complexity of reality (Hall & Stevens, 1991). Women's actions and interpretations of their experiences are affected by the contexts in which they occur. In this postmodern feminist inquiry, analysis of the data focused on the daily lives of participants and the influences that the health care system had on them.

Naming

Naming is a standard of adequacy that ensures the active voices of the participants are heard in the research account (Hall & Stevens, 1991). In feminist research, naming addresses women's lives in their own terms and generates concepts through words directly expressed in their narratives. In my research, the memos, notes, and the data analysis findings and discussion writings all have the directly expressed words of

participants. With the criteria of naming, the reader should see the link between the participant's words and the researchers thoughts and analysis.

Human Subject Considerations

The research study was approved by the University of San Diego Committee on the Protection of Human Subjects (Appendix A) with support of the two Naval Medical Centers where participants were recruited for this research. A research proposal also went through an expedited review for scientific merit and the protection of human subjects at both Naval Medical Centers. Approval letters are found in Appendix B.

Potential Risks

The potential risks to participants in this study were (1) confidentiality; (2) privacy; (3) physical symptoms of illness during the interviewing process; and (4) emotional symptoms while narrating experiences with chronic heart failure. To ensure confidentiality and privacy, interviews were conducted between the researcher and participant and family members in a private setting that included either a private room in the clinics or at the participants home. Demographic information forms, interview tapes and transcribed copies, memos, and field notes were kept in a locked file that was only accessible to the researcher. Transcribed interviews were numbered and did not identify the participant by name. The risks were fully explained to the participants during the review of a consent form. Participation in the study was entirely voluntary. Consent forms were kept in a locked cabinet separate from other data.

If the participants became tired, emotional, or displayed any symptoms of ill health during the interview, the session was stopped and the participant was evaluated. One participant with stable angina experienced chest pain during the interview. The

session was stopped and she was evaluated. After taking one nitroglycerin sublingually, the pain was relieved. Rescheduling the interview was recommended, however the participant was determined to continue. No further chest pain occurred and the interview was completed.

Potential Benefits

The potential benefits for the women participating in this research study included: (1) a sense of empowerment in having their voices and stories heard; (2) an opportunity to openly discuss their experiences (positive or negative) with the health care system and with managing their illness; and (3) a sense of satisfaction in that sharing their experiences, nurses and other health care professionals will become more aware of their desires and/or needs and more knowledgeable in regard to providing care to women with heart failure. New programs or management approaches may result from study findings. The potential benefits of this study far outweighed the risks. The information gained through this research has enhanced knowledge of what is currently known about women with chronic heart failure. From findings of this research, other studies will be designed to enhance nursing science and a practice model may be developed based on the grounded theory that was formulated.

Gaining Entrée

The Division Head of cardiology at one Naval Medical Center and the nurse manager of the heart failure clinic at the second Naval Medical Center were contacted about the study. They both agreed to support this research and assist with the recruitment of participants. The study proposal was approved first in the facility on the east coast. Prior to traveling there to begin data collection, the nurse manager of the heart failure

clinic was contacted and agreed to start recruitment of participants. The inclusion criterion for potential participants was provided to assist in enrolling informants. Once the study was approved in the facility on the west coast, the clinic nurses in the cardiology clinic were contacted and they agreed to assist in the recruitment of participants for the study. They were provided with the inclusion criteria for participants and with fliers to advertise the study (Appendix C).

Recruitment of the Participants

Prior to arrival to the Naval Medical Center on the east coast, the nurse manager of the heart failure clinic had recruited four women for the research study. The day following arrival, a visit was paid to the heart failure clinic. The women that agreed to be interviewed were called to verify their wish to participate in the study, and the date, time and place for the interviews. Recruitment of other women began with those that had appointments in the heart failure clinic that day. The participants were all interested in the research study and anxious to participate.

The clinic nurses at the Naval Medical Center on the west coast initially called six women and got their approval to be contacted by the researcher regarding the study. They were interested in participating in the study. All six women were called within a week and three were recruited to participate. One woman changed her mind and declined participation, another woman had died and the third woman was hospitalized by the time she was contacted. The day the interviews were to take place for the three participants, they were called to verify the appointments and were queried regarding their health that day to ensure they were feeling well enough to complete the interviews. During this process, it was learned that another participant had died since setting up the interview.

The cardiac rehabilitation nurse was contacted and agreed to assist with recruitment. She provided names and telephone numbers of several prospective participants with chronic heart failure and the clinic nurses called the women for their approval to be contacted about the research study. Once the women were contacted, they agreed to participate in the study, and a date, time and place for the interviews was set up.

The Participants

Fifteen participants were enrolled in the study on women's experiences of living with chronic heart failure. Sampling of women continued until key dimensions emerged from the data and there was sufficient support of each of the dimensions (Strauss & Corbin, 1990). The women were beneficiaries of the Military Health System. Eleven women were spouses of retired or deceased military personnel and four women were family members of active duty military members (two women were spouses, the other two women were mothers-in-law). Eligibility criteria for participation in the study included: (1) female gender; (2) 18 years or older; (3) diagnosis of chronic heart failure; and (4) able to speak, read and understand the English language.

The influence of family and significant others on health-illness behaviors is a consideration for nurses both in practice and in designing research studies (Chenitz & Swanson, 1986). The interviews for grounded theory are particularly fitting for gathering data from natural or multiple units. Often frail/ethnic elders with chronic illness live with extended families (Ebrahim, 1996; Hornung, Eleazer, Strothers, Weiland, Eng, McCann & Sapir, 1998). The women afflicted with chronic heart failure lived with spouses, significant others, and children and grandchildren. Although the focus was on the women's experience with heart failure, family members participated in four interviews.

The participation of family members in an interview enables a richer account of the lived experience (Gilgun, 1992).

Table 1 describes the demographics of the fifteen women participating in the study. The participant's ages ranged from 28 to 76 years old. Eleven women were 55 years or older and four women were younger than age 55. The majority of women were married (9), however many women were widowed (5). Ethnicity was varied among participants; five women were African American, five were Caucasian; three were Asian/Pacific Islander and two were Mexican American. Although two women declared ethnicity as Caucasian, one added that she was also of Japanese ancestry and the other stated she was partially Native American. Of the Asian/Pacific Islander's, one participant was Filipino, another was Japanese and the third woman was Hawaiian. Level of education for the participants ranged from less than high school to master's prepared with most participants (6) in the category of high school diploma or GED. Most participants were retired (10); some retired early due to their disability. Five women classified themselves as homemakers, regardless of age. These women either had a brief work history or always had been a homemaker. Most participants lived with their spouse (8) or other family members (5). Four women that lived with their spouse had other family members (adult children, dependent children and grandchildren) living with them. Women's ejection fractions (EF) were both found in narratives or within their medical record and ranged from 10 percent to 65 percent. Most women had an EF between 21 and 30 percent. The youngest woman had the lowest EF of 10 percent. One woman had a diastolic dysfunction and a normal EF (65%). Functional class was found in medical records. The participant's functional class ranged from class I to class IV;

Table 1

Demographic Information

Participant	Age Range	Ethnicity	Marital Status	Education	Employment	Living Arrangement	EF	FC
001	66-75	AA	Widow	HS/GED	Retired	With family	25%	II
002	56-65	AA	Widow	AD	Part-time	With family	30%	II
003	76-85	AA	Widow	AD	Retired	Lives alone	20%	II
004	46-55	C/NA	Divorced	VT	Retired	With family	20%	III
005	56-65	C	Married	HS/GED	Retired	With spouse	30%	II
006	66-75	AA	Married	Less than HS	Retired	With spouse	27%	III
007	26-35	C	Married	HS/GED	Homemaker	With spouse	10%	II
008	56-65	MA	Widow	2 yrs college	Retired	Lives alone	40%	III
009	56-65	AA	Married	1 yrs college	Homemaker	With spouse	28%	I
010	46-55	A/PI	Married	BSN	Part-time	With family	20%	II
011	66-75	A/PI	Married	HS/GED	Homemaker	With spouse	13%	III
012	25-35	C/PI	Married	HS/GED	Homemaker	With spouse	37%	III
013	66-75	MA	Married	Less than HS	Homemaker	With spouse	25%	II
014	76-85	C	Married	HS/GED	Retired	With spouse	40%	II
015	76-85	C/PI	Widow	Masters	Retired	With other	65%	IV

AA = African American

C = Caucasian

PI = Pacific Islander

MA = Mexican American

NA = Native American

A = Asian

most women were classified as class II. Class I clients are asymptomatic, class II clients have slight limitation of physical activity and symptoms with more than ordinary activity, class III clients have significant limitation and symptoms with ordinary activity and class IV clients experience symptoms at rest (Connolly, 2000).

Data Collection

The participant's selected the site for data collection. The research study and the consent form (Appendix D) were explained to the women and signatures were obtained. A demographic information form (Appendix E) was completed prior to the interviews. The functional classification and ejection fraction items on the demographic information form were obtained from the women and if not known, from their medical record. Before beginning the interviews, the researcher described prior work with women inflicted with heart failure, and how these experiences led to the current research study. Participants were encouraged to share any information they wanted, and that led into the interview questions.

The data for this study was collected primarily through semi-structured interviews lasting from one to two hours. Nine interviews were conducted in a private office or room in either the heart failure clinic or the cardiology clinic and six interviews were completed at women's homes. The interview guide (Appendix F) served as the format for the interview. Although initial questions remained the same throughout the data collection process, probes were changed based on data analysis. Interviews were tape-recorded and then transcribed. The researcher personally transcribed eleven interviews and a professional secretary/transcriptionist transcribed the remaining four interviews. The transcribed copies were reviewed with the audiotapes for accuracy. Participants

were contacted if any clarification of data was needed and they contacted the researcher with additional information they had forgotten to share during the interview.

Observational memos and notes were written following the interviews.

Data Analysis

Data analysis was ongoing during data collection. Techniques used for analysis included dimensional analysis (Schatzman, 1991) and constant comparative analysis (Strauss & Corbin, 1998). The process of data analysis was documented using observational, theoretical and methodological notes described by Schatzman and Strauss (1973). Data analysis began with a line-by-line review of initial transcripts and dimensions were identified and written in a column next to the data (open coding). As data analysis continued, salient dimensions were identified, however the importance of their meaning to the phenomenon was not assigned until later. After approximately five interviews were analyzed, dimensions needing further dimensionalization were identified and a worksheet to study them was generated (selective coding). Once a critical mass of dimensions and their corresponding attributes were established, the explanatory matrix described by Schatzman (1991) was used to explain women's experiences of living with chronic heart failure. During this phase, the dimension of network was the most salient in relation to explaining the phenomenon and a preliminary theoretical diagram was generated. As analysis continued, the concept of health care emerged as a second salient dimension. A final theoretical diagram was developed to explain the relationship of the two parsimonious dimensions, network and health care, to the phenomenon under study. The final configuration of the explanatory matrix was verified through comparative analysis of pilot data collected in the qualitative project and experiential data from prior

extensive experience working with women that have heart failure. Meetings with my dissertations committee were held to discuss the process of data analysis and the findings. According to Strauss (1996, pp. 11), experiential data are essential in qualitative analysis not only for added theoretical sensitivity, but also for credible comparisons and verification in data analysis.

Summary

Grounded theory methodology (Corbin & Strauss, 1998) and dimensional analysis (Schatzman, 1991) were used for developing a substantive theory on the experiences of women living with chronic heart failure. Since the study focused on women, the tenets of feminist/feminist postmodern research were described, along with the methods used to achieve rigor in this study. The research sample was described. The research procedure beginning with obtaining approval for the research from human subjects committees and other agency reviewers and moving on to recruiting participants and collecting and analyzing data was explained.

CHAPTER FOUR

Findings

Network and health care emerged as parsimonious and the most salient dimensions in this study. A theoretical model was developed from the explanatory matrix to illustrate the influence that a social network and conditions of health care had on women's experiences of living with chronic heart failure (Figure 1). A network was instrumental for women in their journey from finding out they had heart failure, through a process of psychosocial remodeling to living life with chronic heart failure. The health care received during each phase influenced the processes of finding out and psychosocial remodeling and the consequence of living with chronic heart failure. As participants moved through the phases, they sought health care for information, support and therapy. Their network was significant in helping them overcome the challenges they faced during lifestyle changes and illness management and it promoted their strengths during the process. Lack of network support led to poor psychosocial health. A network for the women in this study included family, friends, spiritual connections, health care providers and other women with heart failure.

The quality of the health care management approach, provider-client relationships and communication influenced women's physical and psychosocial health and satisfaction with care. Positive experiences with health care led many women to "think what a blessing it is I am doing so well". Negative experiences fostered a focus on illness rather than health and resulted in frustration and less satisfaction with their health

care. Experiences with health care inspired women to send messages to other women and health care providers as recommendations for improved health care practices and illness management for women with chronic heart failure.

Figure 1. Women's experiences of living with chronic heart failure

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The Health Care System as Context

Health care was delivered to women with chronic heart failure in a variety of settings. With their initial symptoms, care was provided in military or civilian emergency rooms, clinics or hospitals. Once diagnosed with heart failure, the participants were referred to military cardiologists or internists or civilian heart specialists for their health care. By the time this study was conducted, all participants were part of the military health care system. The women receiving care at one Naval Medical Center were all enrolled in a nurse managed heart failure clinic.

The other women remained under the care of a cardiologist at the other Naval Medical Center. Some women were referred to clinic nurses for case management, education and titration of the beta-blocker, Coreg. One participant had a case manager to coordinate all health care needs. Another woman also received health care at a local major metropolitan health care center as part of a pacemaker study. A cardiac rehabilitation nurse is occasionally involved in the care of women with heart failure. She normally found clients for education and rehabilitation through admission rosters and marketing her services through fliers and base newspapers. Health care providers rarely referred heart failure clients to classes on heart failure or cardiac rehabilitation. The two participants in this study not enrolled in the heart failure clinic that received the classes and cardiac rehabilitation were registered for other reasons (myocardial infarction and open heart surgery) and their heart failure was addressed as part of their other conditions.

In this study, the health care providers involved in women's experiences with chronic heart failure included physicians, nurse practitioners, other advanced practice nurses, clinic nurses, dietitians, physical therapists and social workers. The women's narratives reflect their experiences with these professionals. The stories told by these women often included both prior experiences with health care and current experiences. The women receiving care in the heart failure clinic often compared their experiences before and after their enrollment.

Finding Out

The journey for women with chronic heart failure began with the process of finding out they had this illness. Finding out began with women experiencing symptoms that moved them or persons in their network toward seeking health care. Once health

care was sought, it was discovered that they had heart failure. The experienced symptoms, pattern of seeking health care and discovery are properties of finding out. The women's narratives frequently revealed very severe symptoms and other conditions that indicated there was a delay in seeking health care for these women.

The presence of heart pain often is a cue to seek health care and several women in this study failed to experience cardiac pain. They did not relate their other symptoms to heart disease. One participant's "silent" pain reduced the significance of her initial symptom experience, "I came out of the shower [at the YWCA] and I had to hang onto the wall and calm myself down just to get a deep breath...I had to sit down and catch my breath but there was no pain". She thought this episode was "a little strange" so after she drove home, she made an appointment with her health care provider and subsequently "that is how I found out what it was...heart failure". Although her elderly mother has chronic heart failure, she was quite perplexed that she developed a cardiomyopathy and heart failure at the middle age stage of her life. She thought it was middle-aged men who got heart disease.

Several women attributed their symptoms to "a severe cold" and delayed seeking health care until they thought they had pneumonia. After ordering chest x-rays and other diagnostic tests, their health care providers found that they had heart failure due to various underlying heart diseases. Other women experienced disbelief or an unawareness that their severe symptoms were related to heart failure. One participant stated, "at first I didn't know that the symptoms I was having was part of congestive heart failure...it was probably explained to me but I am a little nervous around [health care providers] and there are some things you hear and some things you don't hear". Another woman said

she had monthly appointments with her health care provider and during one appointment, “I was complaining that my feet were swollen, my legs were swollen, and so was my stomach...and I said, ‘I don’t understand it’. It was the water...it was caused by water. They took 30 pounds off of me at that time...thirty pounds! It was all water.”

In nearly every woman’s story of finding out, there was some reason for a delay in seeking health care and someone in their network that encouraged or insisted that they get help, particularly their family members. The following narrative describes one woman’s severe symptoms, her initial reaction to minimize her experience and her choice to provide self-care. Her network assisted her in making a decision to seek health care:

I just couldn’t breath and my heart felt like it was beating so fast...real fast, real heavy...like a vice that was real tight up in here and the breathing was real fast and I couldn’t catch my breath. I was at work and I just told [my co-workers] I was going home. They kept talking to me and finally my daughter came to get me and took me to the hospital. For some reason I just didn’t want to go to the hospital. I just thought if I got home, I would feel better if I got the medicine. I think I went to hospital because it was pretty crucial...that’s when they told me I had congestive heart failure.

Another woman had a poor experience during her hospitalization for open heart surgery. Following discharge from the hospital, she was sent home and developed severe complications. Despite the severity of her condition, she wanted to continue self/home care rather than return to the hospital. Health care providers are part of a client’s network and this participant’s home health nurse insisted that she seek health care:

When I had my surgery...I got real swollen, my legs were badly infected. I had green stuff running out and puddles of water on the floor. Puddles of fluid from the swelling and the fluid intake. I would stand up and instantly started dripping from the grafts. My home care nurse told me I had to go in (to the Emergency Room). I told her I wanted to take care of it at home but she said that I had to go in. So I went in...that was when I found out that I had congestive heart failure.

Finding out was different for three participants. These women sought health care, sometimes repeatedly, and their health care provider failed to discover their heart failure. The women experienced tremendous suffering prior to finding out. A twenty-one year old woman was sent home from the hospital even though she weighed more at discharge than she did prior to delivering her baby. She stayed home just one night as “I was swollen huge...I couldn’t breath. I couldn’t sleep in the bed...I had to sit up in a chair. I told my husband ‘I am dying...nobody believes me’...my husband called my [health care provider] and he told him to bring me to the emergency room and he would run some tests to make me feel better”. Fortunately an emergency health care provider noticed her distress, ordered some tests and found out that she had heart failure. She was admitted for intravenous diuretic therapy and lost 40 pounds in one week.

Another participant in her early fifties experienced a comparable episode. This woman had been diagnosed with breast cancer and received radiation and chemotherapy for treatment. She was in remission when her “stomach became big” and she was “having shortness of breath”. During follow-up care for her cancer, she told her health care provider that she thought her swollen abdomen was just constipation. A laxative was prescribed but it didn’t help. She went to see her primary care provider with the same complaints and was placed on different kinds of stool softener. When that didn’t help, she tried to do some exercise, but due to her severe shortness of breath, that idea failed. She returned to her health care provider and stated, “I’m really having a hard time breathing, and I could not even sleep...how come I have this occasional dry cough?” He finally ordered a chest x-ray and found she had “some kind of fluid retention, a fluid within my lungs...they found out I have congestive heart failure”.

A similar story with a thirty-two year old woman revealed she had very severe chest pain intermittently for two to three years and her health care providers failed to explore her complaints until significant myocardial damage had occurred. The following narrative describes her experience:

I kept coming in and coming in and coming in, with this pain...chest pain...crushing...couldn't breathe. I kept passing out. I couldn't walk five steps without having to sit down, and I was breathing so hard I couldn't even catch my breath...it was so excruciating. They finally decided to do a [cardiac catheterization], and [my health care provider] told me when I was going in...just relax...we don't expect to find anything...really. After the test, my [health care provider] said, 'the results [show that] five of your arteries are closed; three of them are 100% closed, and a couple of them are 97% closed. Your heart muscle is dead...the left part of your heart was just deprived of oxygen for such a long time, you know.' And then they took me for another test for heart function and my heart was only functioning 10% (ejection fraction)...and that's the big diagnosis right now...we don't know why it's happening, we don't know why everything is kind of going like it is. We don't know...so I've come to that realization that, okay, that's what I'm putting on my tombstone: 'Here lies [participants name] because [my health care providers] didn't know.'

The two youngest women in particular were very anxious to tell their story and several years after these experiences they still have clear recall of the details surrounding finding out. The other woman was a registered nurse and understood the devastating effects that chemotherapy can have on the heart. Like the other health care providers involved in her care, she "didn't know" and therefore was more understanding and forgiving for the delay in the discovery of heart failure in her case.

Psychosocial Remodeling

In response to finding out they had heart failure, the women went through a process of psychosocial adjustment to their new life situation. I labeled this dimension psychosocial remodeling. I see the process of psychosocial remodeling as dynamic and

fluid where participants moved back and forth between phases as their conditions changed or exacerbations and readmissions occurred. The process has three phases including initial response, unfolding enlightenment and a “new view”. After finding out, the women’s initial responses were of fear, disbelief and anguish. Through an unfolding enlightenment they began learning about their illness and revising their perceptions of their new situation. The reality of their new situation came to light and depression plagued several women during this phase. For most women, a revisioning occurred with the support of their network and a “new view” of their illness situation emerged.

Initial Response

Fear was the initial response for all participants in this study. They described finding out as “it was so frightening....so scary”. One participant stated that it was initially “an everyday worry” and she had a “kind of scared feeling all the time”, particularly if she did any type of strenuous activity, such as walking for exercise. The women’s fears encompassed many issues including the return of severe symptoms and reoccurrence of a cardiac event, the “not knowing” what to expect or what to do now that they had heart failure, and of “what is coming” in the future. The initial response of fear was paralyzing for one woman. She described her fear in the following narrative:

[Finding Out] was a little scary...hmmm am I going to self-destruct? It was hard thing to get over...that you have no control over basically. At first it was really scary. I guess it is control...it was something you had no control over. For a headache you can take an aspirin, for a cut you can wrap a Band-Aid but this thing you felt there was nothing you can do about it. It was scary...to have something wrong with you. It was like your body betrayed you or something...every time I got that real shortness of breath or anything...I got real scared and I thought I should just sit down and not move.

This participant's husband recognized this fear and after she was physically stable, he pushed her to move on with living. Like this woman's fear of self-destruction, most other women had a fear of death. One woman stated, "I'm afraid...you never know when you're going to go. I hope I go peacefully".

Other women reacted to finding out they had heart failure with disbelief or anguish. When her health care providers were telling her the results of diagnostic studies and how damaged her heart was, one woman exclaimed, "I just couldn't believe it. It was like I didn't know what they were talking about because I didn't feel like that, but I guess my heart is really in bad shape". Another woman stated that initially the discovery of heart failure did not seem real to her and she questioned why this devastating illness had afflicted her:

I kept thinking it was like a bad, bad dream. It was presented to me, it was shown to me on x-rays and stuff and test results...it still didn't seem like it was real. I guess I was in denial myself. And then, it was Why Me? What did I ever do, you know? I'm doing what I'm supposed to be doing the best way I know how to do and now look.

Another woman developed post-partum cardiomyopathy after her fourth child and was treated for a short while, then essentially recovered, requiring no further medical therapy. Nineteen years later her symptoms returned and it was discovered she had heart failure. Her initial response was total devastation and she "cried and cried". This woman is the primary caregiver for her elderly mother, who was bedridden following a stroke. Her concern for others first at the time of discovery and recommended hospitalization was a common theme in women's narratives, "I cannot stay...I have my mama...what am I going to do with her?" Given her overwhelming stress and flood of tears, emergency health care providers stabilized her and supported her wish to return home to make

arrangements for her mothers care. She later returned to the hospital to be admitted for diuretic therapy. Other women placed the needs and concerns for others first including for their ill spouses, children and grandchildren. One woman was concerned first for health care providers when she delayed seeking health care because “I guess I really and truly didn’t want to inconvenience them if there was nothing wrong...I didn’t want to put anyone out”.

Unfolding Enlightenment

This phase of psychosocial remodeling is when learning and revisioning occur. After their initial response, the participants began to learn the reality of their situation. For some women, teaching had taken place for some time but learning did not occur until they heard the experiences of other women with heart failure. One woman said that she didn’t know her symptoms were part of her illness, “I didn’t put that all together...so when we started the discussion group...you know with the patients with congestive heart failure...then I found out that I wasn’t the only one having this...that this was part of [congestive heart failure]”. Her unfolding enlightenment evolved from this point with the support of other women with heart failure.

Finding out that they had heart failure for several participants was not good news, but nevertheless, it was a relief to learn that their lower level functioning was attributed to an illness. Prior to finding out, they lacked understanding of the cause of the symptoms that had affected their ability to do the things they wanted to do. The inability to do normal household tasks and other activities of daily living made them feel “useless” and it “affected your self-worth in some way”. Once they learned that they had heart failure, they were able to deal with it:

It was really liberating to find out that I wasn't inadequate and I wasn't lazy. That I had a real live honest to God problem that kept me from things that other people could do. But I have learned a lot. I have learned how to deal with it.

During this phase, these women learned that their illness was "something that you are going to have to live with" for the rest of their lives. This was difficult for most women and they went through a period when they were very depressed. One woman got so depressed she "really wanted to kill myself...I did take an overdose...it was so embarrassing. I wish I hadn't done it but I felt so bad". Another woman said she started to get depressed by the whole situation when she realized, "that I couldn't live the life I wanted to live, that I couldn't do the things I wanted to do".

Nearly all the women enrolled in the heart failure clinic have worked through their depression and revised their perception of themselves and their life. They all had supportive networks and most women thought the support group was particularly helpful especially the other women in the group, "we helped each other...we got through the holidays together...it took the stress off". Several women not enrolled in the heart failure clinic remained fearful and depressed about their health and life situation. One woman moved back and forth through the phases of psychosocial remodeling and remained depressed:

I've been from...instead of the bottom of the barrel, under the barrel. From the middle to the top and up and down, up and down. I went to the classes and things like that. This past year I'm like, I can't do this anymore. I went to the aqua-cise program and I stopped doing that. And I just...I shut myself down. Like now, I'm a shut-in basically. I don't go anywhere. I don't like going shopping if I don't have to. I don't want to meet or get involved with anybody. It's just a stab in the back in the end. A little bit of thought deep inside says be cautious, don't do this, don't talk to anybody, don't associate with anyone. Make your family your whole life. Live for the moment.

This woman's network was her immediate family and a couple health care providers. Her mother lived in the area but she rarely saw her. Her friends failed to remain in touch because "they don't want to sit around and wallow in my pity with me". She stated, "nobody called, nobody came over, nobody did anything. And it was like one day they were there, and the next day they disappeared. I was so hurt". The other women that remained depressed had a small network, primarily their immediate family.

A "New View"

Women that reached the "new view" phase revisioned what was normal for themselves with the ever-present limitations imposed by chronic heart failure. One woman's story demonstrated this well when she initially described her situation as "really a disaster", but "[now] I say, 'I'm a normal person'. I don't even consider I have a heart problem. Yeah, I don't think about that...and like I can do the normal things, you know, but I just try not to overdo. I feel like I'm normal".

It was similar for another woman who said it was initially hard to acknowledge her limitations, however she "was able to say to myself, 'okay, this is the way it is, life is not fair, portions aren't equal, deal with it' and I did". She would have preferred that her health circumstances were different, but she was able to come to terms with her illness situation and was able to accept living life with heart failure:

I am not pretending that I wouldn't like a strong heart and my life back cause I liked the life I had created for myself and I was doing pretty well and it is different now...I accepted it...it is what it is and it was what it was.

Another woman described her "new view" with an analogy:

I am not a sick person...what I think I am is a run-down Chevrolet. I love Chevrolets. I am like the old Chevrolet that I had. The clutch went out on it and I drove it slow and I didn't drive it over any hill so I

would go around streets to get to where I wanted to go...but made sure I would not go over any hill. That little Chevrolet lasted a long, long time.

The journey from their initial response to a “new view” was long and hard. Many women relied on their faith to get them through their hardships, “you are supposed to have faith...not fear. You do what you have to do”. Other women wondered why they were still alive after being so sick initially. One woman said it wasn’t her time to die yet and there must be some purpose for her life because “I’m still here”. Another woman thought the only reason she was still alive was because of God. She added, “I have come a long way. But I haven’t done it alone...it is with the help of God”.

For many of the participants, other women with heart failure facilitated their transition through the phases of psychosocial remodeling to their “new view”. During a support group session at the heart failure clinic, one woman listened to another woman say that she was going to have to figure out how to handle her symptoms, manage her illness and move on with living with heart failure. After hearing that, “I said, ‘I am going to figure out how to handle it too’ and I think I have. I feel pretty good...the way I feel now, I think I will be able to plant some flowers this year”.

Living with Heart Failure

The participants thought that life was very challenging with chronic heart failure. The physiological changes within their bodies imposed symptoms and many physical limitations that required lifestyle changes to maintain health. Complex therapeutic regimens required planning, organization and work in order to manage their illness and prevent exacerbation of symptoms and rehospitalization. In addition to these challenges, there were issues with family that were complicated and “really tough to deal with”.

Lifestyle Changes

Changes in lifestyle were necessary for the women with chronic heart failure. It was very difficult to change the pace of their busy lives but their limitations demanded it. Adjusting to limitations was described as “not easy” and “it is hard”. For one woman, “the worst part of [living with heart failure], the very worst part of it all was having to adjust and change my life. That is the hardest thing”. Many of the women lived with adult children either in their own homes or in their children’s homes. Three women moved from other states, leaving their homes, friends and old lifestyle, to live with or be near their children for their support in managing life with heart failure. One woman said the move was very hard as “I raised my children as an only parent in Alaska...I always wanted to go there. I loved it there. It is beautiful and the temperature suited me”. Another woman’s move from Texas was difficult for her because “I love my El Paso”. The third woman left Atlanta after living there twenty years to move in with her son, “it was difficult to leave my life and friends there”.

The lifestyle changes that were mentioned most by women with heart failure were pertaining to their employment and busy social life. One woman stated, “I have always been very active. I have always had a very busy social life and I worked two jobs. I was on the go...I was very seldom home. So now it comes to a screeching halt and it is like...what do I do now?” Nearly all these women worked outside the home prior to discovering they had heart failure and it was very difficult for them to give up their jobs either by resignation or retirement. After discovery and recovering from her initial episode of heart failure, a school nurse returned to work but became ill again and was

rehospitalized. She became concerned for the school children's welfare and decided to retire:

I was one of those persons that went to work every day and I loved my kids and my kids loved me and I couldn't move as fast and my energy level was lessened with this condition and there were three floors to my building and I couldn't see myself denying a kid who was sick on the third floor and needed me...so I decided it was best that I just retire and I did. It was hard.

Similar incidents occurred with other women, "I wish I could work, but I know I can't. I tried, but every time I tried, I would end up in the hospital so I just don't work a full-time job". Some women tried working part-time or volunteering, however after several readmissions to the hospital they stopped working and applied for disability or retirement pay. Only two women worked part-time at the time of their interviews. A registered nurse worked a day or two a week at a skilled nursing facility as "it's better to be at work than at home...I enjoy working more because at work at least you can [interact] with people...you can laugh...you can smile". The social network of colleagues, patients and families was therapeutic for her. The other woman has begun a financial planning business that "is run on my limitations. I can do it when I feel up to it. I can do it on a part-time basis...you pace yourself...I can do it based on how I feel". Although part-time work caused readmissions in the past, this woman was determined that this business would work for her.

The other lifestyle change that was hard was adjustments made in their social life. Several women acknowledged that they were no longer able to walk distances and this posed limitations on "going to places I want to go and doing the things I want to do". One woman stated that taking Lasix held her back from doing the things she wanted to do socially. She said, "I would like to go to the museums or the park and I'd like to go on a

little day cruise, but because I take so much Lasix, it is either take the Lasix during the day when you are up and about or take it at night and not sleep so it is hard to go places because who likes to have accidents...not me”.

Another woman stated that having heart failure was not easy and it has hindered her social life. Her limitations have slowed group activities and her symptoms have concerned those within the group:

I love to bowl and I didn't feel comfortable on a league anymore because I would have to take time...I didn't know when my breathing would change or get those palpitations and I didn't want to subject anybody to those things. I didn't want anybody to worry about whether I felt good so I learned to do things that included myself or another person, but not with a whole group of people.

Other lifestyle changes that were difficult for women were the inability to run and play with grandchildren and “go to church the way I want to”. All women confirmed that household tasks such as cooking, cleaning, laundry and shopping were difficult to do, however they had a network to help them with these responsibilities. Most women that were part of the heart failure clinic lived with extended families in one dwelling. They shared responsibilities and worked together to complete household jobs:

My husband helps me some and right now my son and his daughter is living with us so that makes it easier because she helps with the housework...most of the cooking and the laundry goes between my granddaughter, my son and me. Whoever decides to do it. We help each other with the house cleaning. I do some, they do some...everybody pitches in...[my husband] does most of the vacuuming.

Most women that were not enrolled in the heart failure clinic lived with a spouse or significant other who provided help with housework. Most couples shared responsibilities and divvied up the work, “[My husband] does the vacuuming and the laundry. I do the dishes and the cooking. He does the bathroom...he does a lot of

things”. One husband does “everything...[he] vacuums...cleans the stove, cleans the oven, and all that kind of thing. So I just make a mess!” One woman has a diastolic dysfunction and was unable to walk further than ten feet. Her significant other not only does the household tasks, he “watches me and takes care of me. He’s my caretaker”.

Illness Management

Managing the illness of heart failure was a challenge for the women with chronic heart failure. They had most difficulty with their medication regimen. One woman stated, “the hardest thing I have to do is take all these pills. At one time I had to take 16 pills in the morning!” Others complained that they had a hard time remembering to take their medicines and still others thought changing medications and the side effects were the worst part. One woman said, “they put me on those medications [and] I was feeling really good. And then they introduced a new one...I think every medication that they introduced...my body was adjusting to it. But by the time you adjust to it, there’s a new medication they give you. And my stomach, you know, the discomfort I had with my stomach”. Another common complaint was that they were very tired, yet unable to sleep during the night because they took a diuretic:

Since I take the Lasix I have to go bathroom so often...6, 7 times a night. I toss around, turn around; finally it takes 2 or 3 hours to get to sleep. Then I just finally get to sleep, I got to get up and go to the bathroom. I have not had a good night sleep at all lately. I’m tired. I never have a whole nights sleep. I want to sleep. I mean it. I cannot keep going like this night after night after night.

Another difficulty for these women was changing their diet. They all tried to stay on a low fat and scant sodium diet. For several women, just a trace amount of salt caused “fluid build up” and that exacerbation of their illness sent them to the hospital for readmission. One woman stated, “I either have to not have salt or be in the hospital...I

have put no salt in nothing. It is hard to get used to". They all complained that the allowable food in their diet was tasteless without added salt and spices. A hardship for the Asian/Pacific Islander and Mexican American participants was giving up their ethnic foods. One woman was particularly passionate about her difficulty with the changes in her diet:

[Living with heart failure] is difficult and it is sad. You can eat hardly anything...I think that is a crime because I like to eat! Everything is loaded with salt. And I am not a great cook. I can make nothing without the salt. I just make a piece of meat or an egg or some vegetables. We like to go eat out...you open the menu and there is nothing you can eat. No salt, no garlic, no spices and the flavor's not there. Nothing tastes good and you get tired of it. I miss my Mexican food...I love it. I used to make a lot of dishes but no more. I haven't had bacon [or] a hot dog...I am dying!

Although these women primarily managed their illness, their network assisted them with the most difficult tasks. One woman said, "I was having a hard time figuring out the [medications] so my daughter took over putting them in a seven day pillbox. It really helped." Another woman stated that her husband is "a better cook" than she is so he does a lot of the cooking. To avoid the salt in many processed foods, they cook their dishes from scratch, "instead of canned soup, we make our own soup".

Creative Solutions for Lifestyle Changes and Illness Management

To compensate for the challenges the participants faced daily, they developed creative solutions to cope with lifestyle changes and for managing their illness. One very interesting finding in this study was that all but one of these resourceful women was enrolled in the heart failure clinic. The other innovative woman did not attend a heart failure clinic, but participated in cardiac rehabilitation and several health promotion courses on heart disease. From my observations, these women were focused on health

and moving on with life. A common theme that I heard from them was “I just can’t sit around and do nothing. I have got to keep going” and they found creative ways to live with chronic heart failure. The women enrolled in the heart failure clinic told similar creative solution stories as they were sharing their strategies with other women in the support group. The other women were focused on their illness and limitations, hardships with medical therapy or poor relationships with their health care provider.

Most participants had difficulty either remembering to take medications or keeping them organized due to the volume of pills they took each day. Several women obtained a seven-day pillbox and organized their medicines for the week and that helped them to remember to take their pills as scheduled. One woman had difficulty with side effects from medications and that kept her from leaving the house and doing the things she wanted to do but she found a solution:

[Medications] used to make me very sick and sometimes my pressure would drop. I have gotten so I can work with the medicines. If I have to go out, I take the ones that I can’t delay, and then I take the others when I get home. It works out well.

The prescribed low fat, low sodium diet was described as “tasteless” and very difficult for most women to stay with. One woman stated, “If I want to eat something I know I’m not supposed to have, I’ll take a bite and I’ll throw the rest away. I’ll take a bite of the cookie and throw the rest away. And pretend I ate it. I’m not denying myself anything. That works for me”. Another woman found a way to stay within her sodium limits but added taste to her prepared meals:

They gave me a diet guide to go by. They said low salt but for low salt I use hot sauce. I know you get sodium or salt from the hot sauce but on a 2000 a day calorie diet and I spread one or two teaspoons of hot sauce on my meals and I do not go over the sodium limits they gave me. So that’s how I manage my diet. I use garlic and some herbs but

not too much. I have a grill on my stove...I use it in my house so I don't have to grill my food outside. I also got one of those George Foreman grills to cook with...that is a wonderful thing.

Other women were unable to cook with salt or add salt to any meal and adjusted to their diet without too much difficulty.

Household tasks were challenging for all women but they found a way to get things done. Some women only shopped at stores with the carts for disabled persons. Other women shopped more frequently and get fewer groceries in one trip. For one woman, grocery shopping became a problem when she began experiencing pain in her neck and arm after loading and unloading items from her car. Now after checking out, "[store employees] will load [groceries] for me into the car, then when I get home I only unload the cold stuff, and when my husband or son get home, they do the rest". Several women have family members accompany them on shopping trips and others prefer to have them do all the shopping because "I can't stand in those long lines".

Housework and cooking were difficult for women with heart failure and they advocated, "you have to take shortcuts". One woman stated, "I take a pretty quilt and put it over my mattress to cover it. Then when I go to bed at night, I put a sheet over that and I get another blanket. And during the day I take all that off and the bed looks made".

Another woman thought the worst task she had to do was make the bed. She came up with a solution to improvise:

It would be easier if I had a small bed, but I don't so what I do is I make up the bed and I sleep on one side until it is time to change the sheet, then I go to the other side. There is nobody in that bed but me so it works. When I use both sides of the bed, then I change the bed.

Most women did the cooking, although several women shared that task with their spouses or daughters. One woman said she had to figure out the most efficient way to do

things so she wasn't wasting energy because energy was a problem for her. She stated, "I do most of the cooking. We live in this house and we have got this nice roomy kitchen and I've got a clerical chair and I just whip around the kitchen in this clerical chair. It is what I need to do. It works". In order to save energy, another participant "had some occupational therapy people come to my house and they taught me how to do things efficiently...like slide things around rather than lifting". Another informant had another solution:

I think pacing our work is the answer...just pacing. You know I think that if [family members] don't put pressure on me, I do just fine. What I mean is...like we have set dinner times and that is just fine but [for my husband] to say 'are you going to fix those pants now?' and I say, 'no, you don't need the pants'...I used to fix the pants right now and now I don't. So just to keep that pressure, and maybe control too, down...I don't need to be in control...if it doesn't get done, it doesn't get done. I had to let go of that. It is okay that there is dust on the table...it's okay because if you wipe it off, it keeps coming back.

Most women admitted that they used to clean everything in one day and were quite compulsive about keeping things tidy. As a prior active duty sailor, one woman did "field day" every Thursday while in the service, then continued cleaning from top to bottom that same day of the week for years after she married and left the service. Since becoming ill with heart failure, these women did housework when "I want to or feel up to doing it".

Family Issues

One of the most challenging concerns that women with heart failure had to deal with was family issues. Although chronically ill themselves, several women were caregivers for sick family members. One participant cared for her husband initially at home, then after a rehospitalization for heart failure herself, she placed him in a skilled

nursing facility. Once she felt better, she traveled to the facility to care for him. She stayed all day and into the evening as he wanted her there for the evening meal and until he went to sleep. She stated, “it was tough. I didn’t think of it until now, but most of the times I got sick and went into the hospital were while I was taking care of him”. Since his death, she has been hospitalized very infrequently. Another woman stated that the most difficult aspect of caring for her mother was having her in a skilled nursing facility. She was “worried to death about her” and would go to the facility many times a day to check on her care. Finally, she set up a room for her at home and has become her full-time caregiver. She is determined to care for her mother, “I feel like my mother is my responsibility...she took care of me and now I am going to take care of her”. She insists that she is able to handle her mother’s care. The participant’s daughter helps care for her grandmother on weekends when she is home from college.

Other family issues revolved around absentee husbands either through separation or deployment. After getting breast cancer and going through chemotherapy and radiation treatments, it was discovered that one woman had developed heart failure as a result of cardiac damage sustained from the chemotherapeutic agents. In the midst of all of these issues, her husband went home to the Philippines because he has difficulty being around doctors, hospitals and sick people. This participant said, “he gets so frustrated because he cannot do anything, see? So that’s why he says, ‘well, it seems like you’re doing okay, so maybe I can just go home’. I said, ‘well, it’s fine with me’...I don’t care”. He does assist her financially and he plans to return someday. Her oldest son and his family live with her and they assisted her both domestically and financially.

The younger women in this study are married to active duty military members and they find their husbands deployments very difficult. Besides having to run their entire household, they had the sole care of their children. One woman stated that her husband helps her a lot and “when he is out to sea, things get pretty bad. I have a hard time keeping up and I get real depressed”. The last deployment was particularly challenging as they had just transferred to a new duty station, “It was [very hard] this time because I didn’t know anybody here. The only reason I got up in the morning was to get my daughter on the school bus. It was bad. I didn’t eat at all. I ate a bite of yogurt and that would be it all day. I smoked like a fiend. I couldn’t sleep. Some nights I wouldn’t even go to bed”. Her husband had returned home by the time of the interview and they began building a network with neighbors and friends. Another woman stated that she was repeatedly hospitalized during deployments and since her husband has been on shore duty, she has had no further hospitalizations. Her extended family lives in the area but she does not see them often and her friends have “faded away”. Without the support of their spouses, women whose husbands were deployed felt very alone.

Another family challenge for several women was children or grandchildren, regardless of age, that did not recognize the need to help with household tasks. One grandmother complained that her teenage grandchildren were “lazy” and did not help with household chores. Another woman stated, “the upbringing here is really hard...you cannot get anything from [teenagers]. Not like back home. When they know you are sick, they’ll do everything for you”. She added that her family had adopted Western ways where “they don’t care about you...what you have to do here is really love yourself.

Otherwise, nobody will take care of you. You really have to be strong". One participant with adult children said it was difficult for them to understand that she needed help:

I don't know why I raised them to think I was the Rock of Gibraltar. Even in my weakness moments when I failed them...I have tried suicide and to me that was failing them...even at those moments I was still strong to them because I brought myself above it in spite of the feelings and I think they don't think of me as not being able to do some things...but there is a lot I need help in and I don't know how I do it. I really don't.

One participant with preadolescent children stated that she is very depressed because she was unable to do the activities her children wanted because she is so tired all the time and "the kids are suffering...and they went through a period where they blamed me...[they said] 'Where is our mom? You're not our mom. We want the mom that we used to have, the fun mom, the one that took care of us and did everything with us...Where's that mom?' and it was so hard". The participant added that they were in family therapy and she was thankful for the support the health care providers had given them.

Health Care

Due to the saliency of the dimension health care and its significance in women's experiences with heart failure, the theoretical model was developed to illuminate its relationship to the central dimension network and its influence women's experiences of living with chronic heart failure (Figure 1). The properties of health care, including heart failure management, provider-client relationships and communication were powerful predictors of psychosocial health and client satisfaction with health care. Despite their physiological/physical status, most women with positive provider-client relationships and

constructive communication encounters had enhanced psychosocial health and were more satisfied with their health care.

Heart Failure Management

The heart failure clinic's management strategy included a multidisciplinary approach. A critical care nurse managed the clinic and oversaw the care of the participants. They contacted him if they needed information, referrals or help with managing their illness. During clinic days, the nurses completed assessments and provided nursing care and patient teaching. Physicians were responsible for the medical care of the participants. The dietician and a social worker provided instruction and consultation. The social worker conducted a support group for all clinic enrollees. Participants were referred to cardiac rehabilitation and if they were not able to tolerate the treadmill or exercise bicycle, they attended water aerobics taught by the YWCA.

The participants described the heart failure clinic as very good, fantastic and wonderful, "you just feel very well taken care of...all your needs and everything". Interestingly, some participant's medical care remained the same after they were enrolled in the heart failure clinic, yet they stated, "I feel so much better!" One participant was very pleased with her health care management:

They are concerned what medicines will work with me and about how I feel. Everybody here has a hand in your care...the nurses, the doctors. It is pretty nice! I went to Physical Therapy and they explained to me about the walking and the exercise I need to do. I saw the dietician and she talked with me about what I could eat...low sodium, low fat. They had a support group here...not just for women...and I liked that. It was helpful. We talked about medicines...we talked about diets and the things people were going through so it was helpful.

This woman was diagnosed with cardiomyopathy and heart failure around 1990, yet most learning about her illness took place after enrollment in the heart failure clinic. This was a common phenomenon among the women enrolled in the heart failure clinic that participated in this study.

All women enrolled in the heart failure clinic had very positive comments about their health care management. They thought the nurse was “real caring...the doctors too. They listen and follow my blood pressure and my heart disease”. They also liked the dietician and the social worker and found their services “very helpful” in managing their illness. Cardiac rehabilitation “was great...I thought I am not going to be able to handle this...you know the treadmill...but I did...it helped me”. Many women favored the support group because it was incredibly instrumental in their psychosocial transition of becoming a woman with chronic heart failure and in revisioning their perceptions of living life with this illness.

Experiences with health care management varied for participants not part of the heart failure clinic. One woman with an ejection fraction of just 10 percent was frustrated with the access to her heart specialist, “he seen me once...I tried to make appointments with him and I was told he didn’t have any appointments open and I was like ‘help!’...I had a primary health care provider and I got bad a couple times and [he said] ‘take this medicine and take that medicine’ and I couldn’t get in to see my [heart specialist]”.

Another woman was frustrated with her health care management and although she appreciated her health care providers honesty about the seriousness of her condition, she wished he had been more positive and had offered more encouragement:

[My health care provider] is real knowledgeable but not very informative. He just says you have everything done to you so there is nothing more they can do. You have your pacemaker, your heart is so enlarged and there is nothing else to do for you. So every time I go he says I am fine. He listens to my lungs...no water...if you need me, come back. That's it...never offered much encouragement. He is probably concerned about me...I just never felt that I got what a patient needs. If I ask him to give me something, he never does and that is why I never ask him for nothing or say nothing.

This phenomenon was common in my experiences of caring for women with chronic heart failure. Several of my prior clients wanted to know the truth about their condition but did not want to hear from their health care providers that nothing more could be done for them. Those words squelched their hope and promoted the attitude of giving up and “just waiting to die”, a phrase I heard so often. Even if they knew their condition was serious and their prognosis was bleak, they did not want their health care provider to give up. They would have preferred a positive approach; a plan to adjust therapies or try different medications if symptoms became problematic for them and a hope that new technologies and therapies would become available to help them. They wanted hope rather than hopelessness.

Other participants felt very supported and well cared for. One woman that had a myocardial infarction and subsequent heart failure attended cardiac rehabilitation and the classes on heart failure. She sang praises for her health care provider and others involved in her healthcare management:

[Health care providers] were with me in a second. They treated me like I was a queen. They helped me constantly. I have *never* – and I have been to a lot of hospitals all over the world practically – *never* have I been treated as well. The doctors, the nurses, the corpsmen, the cardiac rehab clinic...were wonderful...it's most unusual. I don't know what kind of system they have down there, but it is tops.

The participants that “loved” their health care providers or those that attended cardiac rehabilitation and classes that supported and assisted them in managing their illness had positive experiences with their health care management.

New therapies and technology were part of many participants health care management. Although not part of the heart failure clinic, one participant was enrolled in a research protocol testing a new biventricular pacemaker. Although she still gets tired as she expends energy, she walks a mile every day “because that’s good for me”. A relatively new medicine that is used for heart failure management is the beta-blocker Coreg. The heart specialists and the health care providers in the heart failure clinic prescribed Coreg to most women in this study. All participants taking this medication had improved functional status and therefore positive experiences with living with chronic heart failure. They all stated that they have been “doing much better since I have been on it”. One woman stated, “it helps...I’m still on a baby dose but it helped [my ejection fraction] go from 10 to 38 [percent]”. Another woman found significant improvement in a short period of time using Coreg:

Now that [my health care provider] gave me a new medication - Coreg...I am very good about doing the dishes and cleaning the stove. Isn’t that sad that it is a big feat, but it is for me because before I couldn’t clean the stove or do the dishes. Now I have been talking up a streak and I am not out of breath. I couldn’t have done that just 3 weeks ago.

Another woman stated that she felt much better on Coreg and there was “just no comparison” with prior therapies:

I can go do other things if I want to. That’s freedom! I went to my cross-stitch shop a couple of weeks ago and I have been going there for four years and I know the lady and I could actually get out of the van and not have to immediately lean down on the counter. And she

said ‘my gosh, what have you been doing?’...she noticed. I cooked a Thanksgiving dinner all by myself. It was wonderful.

Other participants thought they were doing well on their prescribed medical therapies until they started using Coreg, “I felt much, much better...I do things and I am not getting out of breath”.

Provider-Client Relationships

Relationships with health care providers were very important for the women with chronic heart failure. Several women stated that when they sought care for their cardiac symptoms, they were not believed that their symptoms were real or related to heart disease. One woman stated, “women have the same problems as men. It’s a men’s society, and women are just there to have the kids and take care of them. So at the [onset of symptoms], I felt like I was like segregated, you know. I was put in a category of being nuts or just bored or whatever...‘it’s all in your head’...that category. And I didn’t like it. I didn’t like it at all. They wouldn’t listen to me”. After repeatedly seeking care for chest pain and syncope, this woman philosophized:

I don’t fit the criteria, you know. And, you know, [health care providers] practice medicine in the box...they prefer not to go out of the box. They just dump you off to [another service] or whatever, and then they can go on. So they just kind of stabilize you and push you out the door. And I’ve heard everything. I’ve gone in and I heard everything from...you are watching too much TV, you are over-reacting, it’s your time of the month. My husband was at sea and they said, you know, I really think it’s just that you’re really lonely and you’re coming in here for a little attention and some reassurance.

The poor treatment of women came from both male and female health care providers of all types. One woman had a diastolic dysfunction and a very limited functional status. She had difficulty with controlling her weight and an unwelcome reprimand from a female health care provider. This participant fought back:

[A health care provider] scolded me for being overweight. She really scolded...and I never said one word. I let her rant and rave. And when she got done, she said, 'what are you going to do about it?' So I told her I'm going to see another [health care provider]. [She said] 'Well, what do you want to do that for?' I said, 'listen, you're not helping me. I guess you're helping yourself. You got it off your chest. But you're not helping me. So I'll see another [health care provider]. And if that [health care provider] is just like you, I'll see another [health care provider]. I'll just go down the line, because there's going to be a [health care provider] who will listen to me. I walked out. That is no way to act. Good thing I let her know. Hey, you fight the battle of the bulge everyday...you don't have to be smeared into it.

Several women were nervous during provider-client encounters. One woman stated that her pulse rate goes up to 100 beats per minute when she sees her health care provider, "every time I go to [my health care provider], I'm so tense, so I say maybe that's why my pulse rate is like that". Another woman became very nervous during visits to her health care provider and he further reinforced her uneasiness with his comments:

Sometimes I get sweaty and nervous. It is not as bad as it used to be. Sometimes I would be sitting in [my health care providers] office and I would be sweating in the middle of January. I don't know what causes that. I had one [health care provider]...and it was really cold outside...and he asked me 'did you know you were sweating?'...I said 'probably because I am sitting across from you'. And he said 'what is wrong with me?' and I said 'you are a [health care provider]'. I was probably 50 years old then and he said 'kids are suppose to act like that, not grown ladies'.

This woman is now enrolled in the heart failure clinic and is much more comfortable with provider-client encounters, "he doesn't rush me...he is real good. He tells me things and if you got questions he will answer them. I never felt rushed with him".

Several participants have difficulty asking questions of their health care providers. For some women, reasons for this were nervousness or discomfort during the provider-client encounter. One woman did not want to put anyone out, "I wasn't very good with [some health care providers]. Just tell me what is wrong with me, fix it and let me go

home. I mean I have a hard time asking questions...I guess I really and truly didn't want to inconvenience them if there was nothing wrong. I thought maybe they would tell me it was all in my head'. After enrolling in the heart failure clinic, other women with heart failure "helped me with that. Now I do ask questions, 'why am I taking this'? Or 'why am I feeling like this'? So I feel I am coming out of that". The idea of not wanting to inconvenience health care providers came up during an interview in my qualitative project. A participant in that project was started on Lopressor and experienced severe symptoms of heart failure. Despite a significant increase in calf circumference (18 inches) from edema and feeling so ill that she had to remain in bed, she waited nearly three weeks for her next regularly scheduled appointment to tell her health care provider about her symptoms as she didn't want to bother him. Many women in this study had concerns for other first.

The impersonal nature of many health care providers was a concern for these women as well as the women with chronic heart failure that I have cared for and case managed. One woman's words reflected the sentiment of many others:

I don't know what [his] problem is. He is just not a people person. He is not personable. It is all business. If you are a [health care provider], you have to have some kind of bedside manner. [He] just seems like he has too many other patients to look at or he is too busy to deal with you right now...he just doesn't care.

This uncongenial attitude coupled with disbelief that women's symptoms can be attributed to heart disease relays a message of no concern and extends the clients suffering. One woman stated, "the [health care provider] that saw me didn't like me...but I went to her in cardiac failure and she sent me home with a decongestant and a real nasty comment on the fact I had gained five pounds. And I ended up in the

ER...couldn't breath". In my experiences with women with chronic heart failure, disagreeable attitudes and misdiagnoses were common, particularly with younger women.

Communication

Communication with health care providers was a concern for most women in this study. They did not like the one-way communication, lack of explanation or teaching, and not being listened to. One woman thought it was an insult to her intelligence and capabilities:

I am a fairly well read and intelligent person and like to be a participant in my health care management. There are [health care providers] who don't want you to do that. They want to be God and tell you what to do. I don't do well with [health care providers] like that. [One health care provider] doubled my Cosar the first time I saw him and I said 'why' and he said 'because I can'. And wouldn't explain anything to me.

The lack of information and/or instruction about heart failure led to fear and several rehospitalizations for one participant. She stated, "I wish someone would have told me how it was going to be. I wish they had told me more about it. All that I went through, I didn't know anything about that...I was constantly in the hospital...every two to three days...and it was frightening...scary".

The participants that experienced a multidisciplinary approach with their care praised the pattern of communication between them and their health care providers. One woman not part of the heart failure clinic, that had a good relationship with her health care provider and was case managed by the clinic nurses felt very supported and informed. She said, "You get what you want if you ask them. They listen to you too...if you ask for some literature, they give it you. You can study. And they explain

everything to you, also”. The women enrolled in the heart failure clinic had positive experiences with communication and receiving information or instruction. One women thought the reciprocal exchange of information and active listening was “just wonderful”:

They treat me like a real person and they respect me for who I am and what I have done in my life...and they listen to me. I have lived with my body for 53 years and I have been interested in my health care and I have learned about it and I have valuable input of what happens to me and I can manage my own [health care]...that is what I expect from health care providers is to speak to me and talk to me...and that happens here and that is impressive.

Open, reciprocal communication had a positive effect on psychosocial and physical health. One woman stated that if health care providers “listen...like my input...I feel so much better. They don’t argue with me...respect me as a person. That is really, really important to me...they are interested in me”. The women in this study wanted to be heard, respected and cared for as a client with chronic heart failure.

Client Satisfaction

All the participants that were enrolled in the heart failure clinic had very positive comments about their health care. The most favorable attributes found in their narratives were that they felt listened to and really cared for, “[the heart failure clinic] has been good...very good. I am very pleased with it. People listen. They seem to want to do the best. They are concerned what medicines will work with me and about how I feel. Yes. I like it...the people are nice. I like talking to them”. The collaborative philosophy between the staff and the clients was truly appreciated by these women, “I love the people in the heart failure clinic. They listen, they explain, they get my input and if they can’t do something they tell me why. They listen...they like my input”.

One participant really appreciated the heart failure clinic “taking me on and giving a chance to work with the medications...the nurses and the doctors have been really, really good”. Another participant was very satisfied with her treatment:

It is one of the best places I have ever been (heart failure clinic). I haven't been anywhere that treated me more like a person...not a number...treated like a person...that you were important. It means a lot. They make you feel comfortable. I have been coming to this hospital since they first built the old building and I have been treated nice but this was something different. Very different. It means a lot when you are feeling bad and your body ain't doing what it is suppose to be doing and somebody treats you like you are a human being...not just somebody that you do something for and hurry up and finish with you. It makes a big difference.

The participants not enrolled in the heart failure clinic, that were cared for using a multidisciplinary approach were very satisfied with their care. One woman stated the health care providers including doctors, nurses, and hospital corpsman were “lovely, lovely people; hardworking people” and she appreciated the help they provided her. She was particularly in awe of the support given her by the cardiac rehabilitation nurse, “when she listens she gets right up under your face. She doesn't care [about the things around her], she is concentrating on you! She is giving you all of her support”.

Another participant said, “I love my health care! HMOs came out and I didn't go with Secure Horizons and it's a good thing, because that is how I got my [health care provider]. You know, I am perfectly satisfied with [this clinic]. I like my [health care provider] and I dearly love my [primary care provider] because she goes to Luaus. I was going to a luau and I told her “Oh, I can't eat any of my food! She said, ‘you go ahead...just don't make a pig of yourself!’ I love her”.

The participant that is involved in a pacemaker study at a local major metropolitan health care center has a physician-nurse team caring for her. She stated, “I

have a wonderful [health care provider] out there...[also the nurse] is so nice; she's so nice to me. She is wonderful...she's great! She checks everything out...asks so many different questions. I'm lucky to have that kind of nurse. Anytime we need something to find out, we call her, she answers. She calls us and asks 'how you been doing?...how you feeling?' She calls us!"

Messages from Women with Chronic Heart Failure

Through all of their experiences with chronic heart failure, the women in this study have messages for other women and for health care providers. The most prominent message for women was to know their bodies and "if you feel funny, go get checked out. Don't feel foolish. Just go and have them check it out and if they send you home and say you're a little crazy, it is okay. But if it is something, then they find it before too much damage happens". Another participant said that she would tell women, "don't shop until you drop. Just don't over-do it and stick to your diet. And it is good to go out once in a while...just listen to your body and don't over-do. Just know your body and know your limitations and don't do things when you don't feel well". One woman was concerned about the stress women were under:

I think stress causes heart problems. [Women] have to learn how to roll with the punches instead of getting uptight, blowing a fuse, being upset. That is the only thing. When you work hard...a lot of mothers are working today...they walk in that door, the kids are yelling and screaming, their husband wants this, and the dinner has to be prepared, homework has to be done...that is stress. I bet we are going to have more women with heart problems. I think that support is the most wonderful thing that [women] can have, really.

One participant thought women should not focus on their illness, "Tell [women] not to really dwell on that sickness and then let them think that they are as normal...I mean, a

normal human being, and not to worry about the things, as long as you don't overdo what you are supposed to".

The messages for health care providers focused on improving communication skills, especially listening to women and providing more education for women with chronic heart failure. One woman stated that she would like to see "the people who take care of women to listen to them...to really, really listen. And they need to educate and teach along with listening". Another participant agreed and added that she would like "more education for the patients and for the family...maybe videos that women could take home and watch with their families". One participant felt very strongly about getting more information:

What we need is more output...more information and a little brochure does not do it! Maybe get a speaker...someone who has been through it. Get volunteers to come in and tell you 'I have been through this and you are going to go through this'. We need to know what's coming...if I had only known what to expect I wouldn't have spent so much time baffled, and feeling lost and hopeless. I don't know what to expect. Somebody give me answers...I don't get answers.

The women wanted to know more than what is ordinarily taught during educational sessions. One participant said they should know "what do women wear...what kind of clothes are comfortable? Let women know that if you wear something that is stretchy and a little snug, it helps you breath better and it is [more comfortable]...so clothes is an issue...what kind of clothes a woman should wear...we can look pretty and still have heart failure". Another informant added, "I wish I could learn to cook to give food flavor...they do not teach preparation of foods at all. It would be nice to make foods that are not tasteless...that you could actually eat".

Women thought health care providers should “let women be a participant in their care...encourage them to be more open and you need to treat the whole person...it is a holistic thing”. One participant did not like the frequent rotations and transfers of military health care providers. She stated, “I know this is an almost impossible thing in the Navy, but to get the same [health care provider] all the time. You need to establish a rapport with your [health care provider]”. She added, “I wish that there could be more [health care providers] that are more on the...social side”. For another woman, the ability to sleep at night concerned her, “you know one thing I wish [health care providers] could do for me...I wish they could give me good night sleeping pill so I can sleep good. I wish I could sleep good, you know for 8 hours”. A young participant that was passionate about health care providers “knowing” wanted to educate them:

I’d like to educate [health care providers] that practice in the box, that we’re not excluded, you know. We are part of this. More and more women every day are dying from heart disease, which most [health care providers] think that’s a male thing. They need to be educated. They need to get themselves out of that one rut and get up with the world.

Conclusion

Two parsimonious dimensions, network and health care, emerged as the most salient in this study. A theoretical model was developed to illustrate their influence on women’s experiences with chronic heart failure. A network was instrumental in moving women through the processes of finding out and psychosocial remodeling and had significant influence on their emotional well-being, ability to cope and move forward with living their lives with chronic heart failure. Members of the network were influential in the health care received and, in turn influenced finding out and the phases of psychosocial remodeling. The properties of health care management, provider-client

relationships and communication had an impact on the participant's satisfaction with their health care and their experiences of living with chronic heart failure. The women in this study presented advice for other women and recommendations for health care providers; messages for improving illness management and health care.

CHAPTER FIVE

Discussion

The purpose of this study was to explore women's experiences with chronic heart failure, specifically their experiences with health care and in managing their illness. Two parsimonious concepts, network and health care, were the most salient dimensions in women's narratives about living with this illness. Other qualitative studies have described person's experiences with living with chronic illness, however the focus was on both genders with any type of chronic illness, including chronic heart failure.

A classic study by Corbin and Strauss (1989; 1991) on experiences with chronic illness was conducted over several years. Their key theoretical concept was trajectory, a term that represents the physiological development and the work involved in managing chronic illness, the impact the illness has on their lives, and the changes that are required for both the clients and their families when living with their new situation. The trajectory framework implies that chronic illness has "a course that varies and changes over time" (Corbin & Strauss, 1991, pp. 156). A trajectory has several phases during the course of chronic illness.

The stories of the women with heart failure began with the process of finding out. This process was similar to the crisis or acute phase of a trajectory. A crisis phase of a trajectory is a life-threatening event requiring emergency or critical care and an acute phase is active illness or complications requiring hospitalization for management (Corbin & Strauss, 1991). Most women with heart failure in this study had a crisis event that

alarmed either them or someone within their network to summoning emergency medical care and they were hospitalized. Other women became acutely ill and either sought care at a clinic or made an appointment with their health care provider after the initial symptoms improved somewhat. Another phase within the trajectory framework is “stable” where the illness course and the symptoms are controlled by the therapeutic regimen (Corbin & Strauss, 1991). At the time of the interviews all women were in the stable phase physiologically or physically, although a few women had more limitations than others due to their underlying heart disease, comorbidities or medical regimen.

Trajectory management shapes the illness process (Corbin & Strauss, 1991). Within the trajectory framework, the client and their families, and health care providers all have a part in managing chronic illness and all have different positions on how the illness should be managed. In this study, the women with heart failure and the persons in their network, including their health care providers, worked toward managing the illness. Conflicting positions on illness management sometimes occurred, particularly between the client and her health care provider. One participant was prescribed dosages of medications that were intolerable due to the side effects. Although she complained to her health care provider, the dosage remained the same as her physiological health status improved. The participant defied orders and took a reduced dosage to diminish the side effects and feel better. She stated that she “takes what feels good for me...I know they are the [health care provider], but I know my body...I know what makes me feel terrible and what makes me feel right”. Conflicting positions affect the provider-client relationship.

Davis and Magilvy (2000) studied the experience of chronic illness by rural older adults. Descriptive ethnography method and analysis revealed six themes: managing daily, support from faith and family, balance through negotiation, self-care, belonging to community, and finding meaning in life. Similar themes were found in this research on women with heart failure. In both studies, the participants were faced with the ongoing challenges of managing their illness. Chronic illness was work and it affected every aspect of the participants' lives. Unlike Davis and Magilvy's (2000) study, the research on women with chronic heart failure explored strategies to manage their illness. The women enrolled in the heart failure clinic had creative solutions to managing their illness that they shared with others. The theme self-care was prevalent in both studies as participants wanted to remain independent and take care of their selves to feel healthy.

Another similar theme was support from faith and family. In both studies, faith and family were a major support system. Davis and Magilvy (2000) also found the close-knit rural community provided support to their participants. In this study on women with heart failure, the network was a central dimension and not only included family, friends and faith, but also extended to health care providers and other women with heart failure.

The "overarching theme" in Davis and Magilvy's (2000) study was finding meaning in life. Their participants learned to find meaning and a new understanding of what was important and worth seeking in life. Although not exactly the same, a similar process occurred with the women in this study. The women with heart failure went through a revisioning process that led them to a "new view" of what was normal for them with their illness.

Other qualitative studies that had some similarities to this study were presented in chapter two. Stull's, et al. (1999) research found that becoming a patient with heart failure was a gradual process of taking on a new identity. The five phases that emerged from their data were similar to the process of finding out and psychosocial remodeling in this study. The first phase was the crisis event, which was similar to the crisis phase in a trajectory (Corbin and Strauss, 1991) and a means of finding out in this study. The crisis event typically involved severe shortness of breath, requiring emergent and critical care. Like the women with heart failure, some participants in Stull's et al. study (1999) attributed their symptoms to pneumonia and had large volumes of fluid (30 pounds of body weight) removed through diuretic therapy. Their second phase, diagnosis, was similar to discovery of heart failure in the women of this study. During this phase, meaning or a label of heart failure was attached to participant's symptoms.

The first reaction or response to their diagnosis or discovery of heart failure was fear in both studies. In Stull's et al. (1999) study, the participants experienced uncertainty during this phase. In the current study, the women with heart failure reacted with disbelief and anguish over the discovery of their new illness. The next phase for these women was unfolding enlightenment where they learned about heart failure and many experienced depression. In Stull's, et al. (1999) study, the next phase was acceptance and adjustment to their limitations. The final phase was getting on with life where participants took on a new identity and moved on with living with the illness of heart failure. This phase was similar to "a new view" in the process of psychosocial remodeling where the women with heart failure accepted their illness and revised what

was normal for them in their new situation. Most women moved on with living with heart failure.

Lough (1996) began her study following the crisis or acute event that led to the hospitalization of participants with heart failure. She began with the transition from hospital to home and focused on the participant's management of their illness. In her study, participants were frequently rehospitalized like the client's in Corbin and Strauss' (1991) sample and the women with heart failure in this study. Concepts that emerged in Lough's (1996) study that were similar to the themes or dimensions in the other research on chronic illness and heart failure included support system, self-care, uncertainty and challenges. Another concept that surfaced in her research was quality of life and caregiver issues. Participants worked to achieve a good quality of life in all studies cited.

Like the women with heart failure in this study, some of the participants in Lough's (1996) study were caregivers for their spouses. Caring for a spouse was very difficult for the participants in both studies and frequently led to rehospitalization for exacerbation of symptoms. Other women in this study cared for children and grandchildren. Caring for teenage children was very difficult due to their lack of input to household tasks and expectation that they should be cared for (fed and cleaned up after) by their mother or grandmother. Babysitting and caring for small grandchildren was very rewarding for most women with heart failure. They loved the interaction and company the children provided and enjoyed being part of "raising" their grandchildren. For most women, the caregiver role was reciprocal; their children assisted them with living life with heart failure and they, in turn, assisted their children with childcare while they worked outside of the home.

There are other similarities in the nursing studies cited in chapter two and this study. The social support from family, friends and healthcare providers and the frustration with limitations among the participants in Martensson, Karlsson and Fridlund's (1998) study on how female patients with heart failure conceived their life situation was found in this study. The women with heart failure received major support from persons in their network and that helped them to deal with their limitations, lifestyle changes and illness management.

In Bennett's et al. (2000) study that explored symptoms of heart failure and strategies for self-care, the women informants verbalized feelings of fear, depression and worry that interfered with their sleep. The women with heart failure in this study also verbalized fear during their first reaction to the discovery of their illness, and depression during the phase of unfolding enlightenment when they were learning about their illness and reality set in. The biggest complaint regarding sleep interference was frequent trips to the bathroom due to diuretic therapy. Bennett, et al. (2000) also found that participants had to change their lifestyle and daily routine. Like the women in this study, they had to change their activity level, slow their pace and set up medication schedules. The women in Bennett's et al. (2000) study completed interviews as part of a focus group and found it very helpful to meet other women with heart failure. Following data collection, they wanted to continue their groups for support and education. The women enrolled in the heart failure clinic in the current study found that other women with heart failure in their support group were very helpful and wholeheartedly advocated support and educational groups for women with heart failure.

There are many differences between the studies cited and this research. All but one study had significantly more male participants than females. One study researched only women with heart failure (Martensson, Karlsson and Fridlund, 1998). In addition, most researchers analyzed their data without separating gender and findings were reported based on the total sample. Bennett et al. (2000) studied both men and women, but analyzed and reported data on both genders. The current study solely focused on women with heart failure.

There were other differences specific to each study. Corbin and Strauss (1991) studied persons with all types of chronic illness, rather than focusing specifically on heart failure. Their research focused on the physiological/physical trajectory of chronic illness. The depth of their study was greater as research had taken place over several years and their sample size was large. The current study had more breadth as it focused extensively on health care, in addition to other experiences with heart failure including illness management and strategies for self-care.

Davis and Magilvy's (2000) study also focused on all types of chronic illness and no specific gender. The context of their study was a rural community so their research focused on being part of that community and the relationships between the people that lived there. They also examined how roles and responsibilities were negotiated among the chronically ill persons and others in their environment. Their study had a cultural component, as 67 percent of their sample was Hispanic.

Stull, et al. (1999) and Lough (1996) studied clients with heart failure, however their analysis and findings were not gender-specific. The participants in both studies all had personal health care providers and were not enrolled in any type of heart failure

clinic. Stull, et al. (1999) examined the process of becoming a patient with heart failure, from the crisis event to getting on with life. Martensson, Karlsson and Fridlund's (1998) study was similar as it focused on perception of their life situation with heart failure. Their study centered on women only. Lough (1996) focused on the management of the illness of chronic heart failure. Bennett, et al. (2000) studied symptoms and strategies for self-care and reported findings for both men and women. This research explored those areas and went further to study strategies for living with heart failure and women's experiences with their health care. The breadth of the current study is distinct. In addition, compared to Stull, et al. (1999) and Martensson, Karlsson and Fridlund's (1998) research, the depth of inquiry for this study was greater or the women with heart failure may have been simply more revealing during data collection. The data supporting the phase of unfolding enlightenment (the learning that took place) was not found in the other studies. Besides the breadth of this study and depth of certain phenomenon within the study, the context for many participants was different than all other studies cited. This is the first qualitative study that explored women's experiences with their health care within the context of a heart failure clinic.

A Network and Women with Heart Failure

The literature reports evidence that a relationship exists between social networks and health (Bowling, 1994; Chin & Goldman, 1997; Krumholz, et al., 1998; Rennemark & Hagberg, 1999; Sluzki, 2000; Moser & Worster, 2000). A network is defined as "social relationships that surround a person, their characteristics, and the individuals perception of them" (Bowling, 1994, pp. 1). Few studies have been completed that examined social support and women with heart failure. As cited in chapter two,

Krumholz, et al. (1998) conceptualized social support as the presence or absence of emotional support (someone to discuss problems with) and as instrumental support (someone to help with daily tasks). When looking at gender differences, they found that the absence of emotional support was significantly associated with higher fatal and nonfatal cardiovascular events in women and not men, the year after an initial admission for heart failure. Support from a social network then may improve survival of women with heart failure.

An assumption of Rennemark and Hagberg's (1999) research on social networks was that women's health behavior would be more strongly related to a social network than men's. Measures for characteristics of a social network, reported symptoms, subjective health and health care utilization found that none of the health related behaviors were bivariately associated with a social network for men. For women, there were no significant differences for those who lived alone versus those who lived with others and health related behaviors. Women had more symptoms and more depression and tension with poor social support. In addition, more satisfying social networks for women were related to better subjective health, more frequent consults with health care providers and less symptoms.

A network was the central dimension in the current study as the participants family, friends, health care providers, spiritual connections and the other women with heart failure that they were associated with, were mentioned in virtually every narrative and were influential in their experiences with heart failure. The women that had strong social networks moved through the process of psychosocial remodeling and moved on with living life with heart failure. They adjusted to the lifestyle changes and were coping

with the challenges of being a person with heart failure. They knew their bodies and figured out how to manage their illness. The women with small or poor social networks had struggled with depression and had difficulty with illness management due to their sadness; this resulted in exacerbation of symptoms and frequent readmissions to the hospital. Living with heart failure was difficult for these women without the support and encouragement of a social network.

Different persons in the network influenced positive outcomes for women with heart failure. The young women were very connected to their spouses and had no readmissions while their active duty military husbands remained in port on shore duty. They had difficulty during deployments, particularly because they lacked other persons in their social network. Military life often leads to frequent transfers and separation from family, friends and other persons in a social network. Also, having chronic heart failure as young women was very difficult. Friends within their social network could not understand why they declined to participate in many strenuous activities. One woman stated that she wanted to plan activities with her friends, however she easily became tired and they had difficulty understanding why she was unable to do the things other women that age were able to do.

Despite their supportive network of family, friends and spiritual connections, some women that enrolled in the heart failure clinic had a significant improvement in their knowledge, attitude and health status only with the support of other women with heart failure. These women had better subjective health and enjoyed coming to the heart failure clinic for their health care. Their focus was on health rather than illness. They supported one another and shared creative strategies for managing their illness and living

with chronic heart failure. Contemporary feminist theorists have proposed that women learn to know their selves and what is important in their lives through relationships with others (Lauver, 2000). Through interaction with other women within a support group, many women moved through the process of psychosocial remodeling to a “new view” of who they were with chronic heart failure. In addition, with interaction and support of other women, several women experienced empowerment and were able to overcome fears and passive behavior in dealing with health care providers. According to Lauver (2000) “relationships are central to women’s psychological development and integration, to women’s empowerment, and to women’s social roles”.

In this study, other women that had supportive family, friends, and spiritual connections, but lacked support from their health care providers or support groups were doing well physiologically/physically, however they reported they felt depressed. Disease severity has been shown to be unrelated to emotional distress including depression (Denollet & Brutsaert, 1998). Women come from a social context; they are social beings. The importance of supportive health care providers and of identifying with other women that have heart failure was instrumental for positive psychosocial health and physiological/physical outcomes in women enrolled in the heart failure clinic or those attending cardiac rehabilitation and health promotion courses with other persons with heart failure. Nobody in a network will understand the experiences of living with heart failure better than others inflicted with this illness and these women related to that connection and support.

Family issues. Family was one element in the social networks of women with chronic heart failure. Most families were very involved in the health maintenance and

illness management of the participants. For most women, the relationship with their families was reciprocal. The women received help in the form of living spaces, transportation or help with household tasks from family members and in turn, provided help with cooking, light cleaning and childcare. For most families, the sharing of responsibilities was working very well. The families of participants were part of the studies cited in the discussion section, however, similar to this study, they were not the primary focus of the research.

The other issues with families included difficulties with children of younger participants, adult children failing to understand the needs of their mothers with chronic heart failure and the women in this study serving as caregivers for their ill spouses. There is little in the literature that specifically focuses on these issues. In Lough's (1996) study on the ongoing work of older adults with heart failure after hospitalization, three participants were caregivers to their spouses. These women, like the women in this study, were concerned for their spouses needs first and often were readmitted to the hospital due to the fatigue and lack of self-care as their lives revolved around providing care for their husbands. This area of research, on family issues of women with chronic heart failure, is a wide open and necessary for addressing the whole person and providing holistic health care.

Health Care and Women with Heart Failure

Health care was another salient dimension that was related to the central dimension of network and emerged from women's narratives about their experiences with chronic heart failure. Experiences with health care weaved through women's stories from finding out they had heart failure through living with chronic heart failure. In

nearly every woman's story, there was a delay in seeking health care for various reasons. Although common cardiac symptoms were always present (shortness of breath, diaphoresis, vomiting), many women had an absence of chest pain and did not attribute their other symptoms to heart disease. In epidemiological studies that have included women, they were more likely than men to experience silent or unrecognized myocardial infarction [35% versus 27%] (Wenger, 1997) and they may sustain more myocardial damage due to the long delays in seeking health care because the lack of pain. The women with coronary artery disease as the underlying cause of their heart failure in this study had ejection fractions that ranged from thirteen to forty percent, demonstrating an inefficient pump that may be the outcome from heart damage due to myocardial infarction. Several other women attributed their symptoms of heart failure (shortness of breath, chest discomfort, fatigue) to an upper respiratory infection or bronchitis and delayed seeking health care until they thought they had pneumonia. In a recent qualitative study exploring the meaning of illness for women with coronary heart disease (Rosenfeld & Gilkeson, 2000), a delay in seeking health care was a prevailing theme in woman's narratives. This study validates those findings.

Health care providers failed to discover heart failure in three women that participated in this study. The women were young and sought help repeatedly for their symptoms. They were all finally diagnosed with heart failure and survived to tell their stories, although one woman experienced significant heart damage during her ordeal. The myth "heart disease is a man's disease" is a perspective still present in the minds of health care providers (and the general public). Literature on heart disease and women has been available for over a decade and a public law requiring that women be included in

research on heart disease was passed in 1994 (Laurence & Weinhouse, 1994; Wenger, 1997). Several years have passed and many women still are not diagnosed with heart disease when they present with classic symptoms and they suffer considerably until their illness is discovered. Perspectives on heart failure in women are slow to change, regardless of the evidence that women are plagued with this illness along with men. Foucault's ideas on dividing practices and scientific classification are evident here; women's symptom narratives were differentiated from men's and ignored, as gender knowledge mythicizes heart disease to be a disease of men. This was clearly demonstrated when a 32 year old participant repeatedly sought medical care for "crushing" chest pain. Diagnostics for heart disease were not completed, as she was a young woman. The perspective of many health care providers is that young women do not get heart disease, young men do.

The journey through the process of psychosocial remodeling was difficult for women with chronic heart failure. The component of health care that helped participants the most was classes on heart failure, diet and medications, and cardiac rehabilitation, and an organized support group of other persons with heart failure. For many women, learning did not take place in their health care providers office or exam room, nor did they learn during hospital stays or discharge planning. The setting or the situation was too stressful for learning to take place. When they returned to the medical center to attend formal classes, meet with clinic nurses or assemble with a support group, learning began for many women. The journey through the process of psychosocial remodeling moved forward.

Participants that attended the heart failure clinic or those that attended formal classes and cardiac rehabilitation but were not enrolled in a heart failure clinic, were very satisfied with their health care management. The women that had a good relationship with their health care provider or were case-managed by the clinic nurses were also happy with the management of their illness. Informants that were dissatisfied with their health care management had difficulty relating to their health care provider or difficulty with access to care.

The provider-client relationship means a great deal to women with heart failure. When health care providers are business-like, impersonal, or have the attitude that they have done all they can for their client (given up), women become frustrated and unhappy with their health care, regardless of its quality. One participant in the pilot qualitative project that was conducted stated her health care provider had gone through a transition. She always thought that he was an excellent heart specialist, but over several years he told her there was nothing more that could be done for her and that was “very depressing”. Since then, her primary health care provider has maintained her health. She has survived, but recently had an admission to the hospital for severe chest pain. Her heart specialist saw her again and rather than tell her that there was nothing more that could be done for her, he stated, “lets adjust your medications and see if that helps”, and he brought her diagnostic films to his colleagues for viewing, in hopes that they might think of some other therapy that he could try. The caring he displayed changed this woman’s whole attitude about her health care. She was aware that her condition was serious but she did not want her health care provider to give up. Women with chronic heart failure can survive for several years and they want to live that time with hope rather

than hopelessness. New technologies and advances in science are rapid and new discoveries may surface in their remaining years.

Communication between health care providers and their clients is detrimental to a positive relationship. The women with heart failure easily sensed both verbal and nonverbal cues from their health care providers. One distinct signal was “I am too busy” and these women felt that they were bothering their health care providers. Additionally, many health care providers place themselves in a position of power or authority over their clients. They feel they are the experts in their client’s health care, and orders, directions and instructions must be followed to maintain health. They do not solicit input or dialogue with their clients and often get perturbed when a woman says, “I know my own body and I do not feel right with all those pills you gave me”. In cases such as this, women get labeled as difficult or made to feel their symptoms are “all in their head”. These messages from health care providers are frustrating and humiliating for women and they will avoid seeking health care for fear they are being bothersome or they are going to be told their symptoms are not real. Foucault’s idea of subjectification is operating in these cases; women come to believe their symptoms are “in their head” and fail to seek health care and bother their health care provider with symptoms that are not real.

In the current study, women enrolled in the heart failure clinic learned to become more assertive and ask questions of their health care provider. They also learned that they were consumers, the providers were paid for their services, and they had a right to health care. They were taught that symptoms should be explored, regardless if examination findings are negative, as early treatment prevents myocardial damage. In this study, one woman wished to pass on this message to other women with heart failure.

In the biomedical model, health care providers rely on objective data from vast technology to decide on a diagnosis and therapeutic regimen for their clients. One woman in this study complained that viewing an echocardiogram was more important to her health care provider than listening to her story and completing a history and physical examination. Another woman stated that she was not diagnosed with heart disease for close to three years because she did not fit the criteria outlined in the cardiology textbooks. She repeatedly sought care for chest pain and syncopal episodes, but her subjective symptoms and illness narratives were ignored, as her age and gender were not what was typical for diagnosing heart disease. Still other women reported “nasty comments” and reprimands regarding their weight; the focus of the health care provider was on the weight scale rather than the client’s description of her health status. Women may have come a long way since feminist movements, but there is still poor treatment of women in health care institutions. It is hard to fathom male clients having to contend with these issues.

Carvedilol therapy. Despite the small numbers of women in clinical trials, it has been reported that the beta-blocker carvedilol (Coreg) had some promising results on the mortality of women (3.1% with Coreg versus 9.6% with placebo) using this drug (Packer, et al. 1996; Richardson, 2000). Evidence of improved ejection fraction and regression of left ventricular hypertrophy is substantial with the use of Coreg. Women in this study that were taking Coreg found that their symptoms decreased and functional status increased within three weeks of beginning this medication. One woman thought she was doing well with other therapies until she started Coreg therapy. Her symptoms have decreased and her functional status has improved significantly with this drug. Reports on

Coreg have been focused on mortality. This study validates an improved functional state when using this drug.

Implications

Based on study findings, several implications for nursing education, practice and research have been identified. Messages or recommendations from the women with chronic heart are discussed in this section. A conclusion section follows the implications.

Education

Nursing education. Gender differences in the care of women with heart disease has been neglected in both medical and nursing curricula, and this gap in knowledge is evident in women's narratives in this study. The younger women presented with the classic symptoms of heart disease or heart failure and their health care providers did not know that they could be inflicted with this illness. Not knowing delayed the diagnosis, caused considerable suffering for all women and had negative effects on the outcome of one woman.

Education must begin with the historical accounts and social perspectives that preceded what is known about heart disease and women today. The gender bias that has occurred throughout history should be taught in schools of nursing, and at continuing education offerings and seminars so prospective health care providers can change this practice. For instruction on heart failure, discussions should include gender issues in pathophysiology, prescribed therapeutic regimens and the effect of provider-client relationships on client knowledge and illness management. Professional knowledge is the basis of practice and based on the latest epidemiological trends of women with heart failure, knowledge is lacking. One participant in this study wanted to educate health care

providers about women with heart failure. She sent a very strong message that if women, regardless of age, have symptoms of heart disease, ignore the criteria from cardiology textbooks and explore those symptoms.

Client education. Messages from the women with heart failure advocated for more education and information for clients. Information on heart disease can be provided to women at health promotion fairs, information booths set up in health care facilities and at places where women gather. Nurses can speak at women's group meetings about heart disease, assess risk factors and provide consultation for health promotion. Educational videos can be shown in beauty salons as women get their treatments and services. To capture the readership of women's journals, nurses can publish articles about all types of heart disease in women.

Education about heart failure is also necessary for women and should be provided as part of any health promotion information given to women. Many women in this study had their first episode of heart failure without any prior symptoms of heart disease. In addition, young women need to be educated about cardiomyopathies and coronary artery disease. The number of young women inflicted with these illnesses may be small, however early intervention can make a significant difference in outcomes. If women know the symptoms and consequences of these illnesses, they will be less likely to delay seeking health care. Educational videos can be shown in clinic waiting rooms and free educational seminars can be offered to women at health care institutions. Knowing about heart disease in women can reduce disability and save lives.

Practice

Besides the considerable work involved in managing the illness of heart failure, women are faced with overwhelming physiological and psychological changes. Their lifestyle and daily routine goes through changes due to new limitations and work required for maintaining their health. This is a difficult transition for them. Women with heart failure need education and support from health care providers. A common theme in the messages from women in this study was a need for more information, education and support. Education should go beyond diet and medications, to meal preparation, selection of clothing for comfort and strategies for energy conservation during daily living. Support groups were very valuable for the women in this study and should be part of every health care plan for persons with chronic heart failure.

Traditional health care practices have been paternalistic, in that they have placed unequal power and lack of control on clients. Clients are expected to follow their health care plans after a short educational session in an office or exam room, or during discharge teaching at the time of their release from the hospital. Once they return home, they have difficulty managing their illness and quickly become overwhelmed. This leads to frustration, overload and for one woman in this study, readmission in just three days. Due to the complexity in managing the illness of heart failure, clients need open, reciprocal communication and an empowering relationship with their health care provider so that they can work together to facilitate health care goals. Clients' expectations for care during visits to their health care providers were demonstrated in a study by Kravitz, et al. (1994). In their sample, 71% of clients favored being able to discuss their ideas on managing their health with a provider. This compares with providing a medical history

(49%), getting a physical exam (55%) or receiving diagnostic tests (52%). Clients are clearly emerging as desiring a partnership in conducting their health care. This recommendation of being a participant in their health care was a message from women with heart failure in this study.

There are a number of innovative ways to deliver health care to women with heart failure. The nurse managed heart failure clinic was very popular with the participants in this study. They particularly liked the approach the health care providers took in ensuring good provider-client relationships through listening, educating and providing support. They liked the access to care as they could telephone or page the nurse manager and get a very quick response and advise on how to proceed with their problem. If they needed to be seen prior to the next clinic day, arrangements were made for care. Other nurse managed heart failure clinics have nurse practitioners as providers with a physician as the medical director. They have shown to be very cost effective as admissions to the hospital are significantly reduced. Outpatient costs increase, but client satisfaction is increased per preliminary studies. A heart failure clinic is a desirable program for the Military Health System Optimization Plan as it focuses on population health improvement, access and continuity of care, and client satisfaction. It also provides the support of health care providers and other women for those clients who have a spouse that is deployed. Clients are monitored and remain healthier so unexpected trips to the emergency room are reduced, along with an active duty service members time away from work to provide transportation and support for their sick loved one.

The multidisciplinary team and ongoing monitoring and care of clients are important to successful management of chronic heart failure. In addition to the heart

failure clinic, this can be accomplished in a variety of ways. Management teams that consist of cardiologist, advanced practice nurse, social worker, dietician and cardiac rehabilitation are popular in some geographic areas of the United States. The team works together to manage the client's illness. Client participation depends on the health care provider. Case management is another approach to managing heart failure. A case manager coordinates the client's care in a continuum from hospital to home and beyond. The hallmark to any approach to health care was revealed in the women's messages; listen to women, provide information, reassurance and support rather than a prescription for anti-anxiety medications and empower them to be a participant in their health care.

Research

The possibilities for nursing research that stem from this study are vast. Of particular interest are the family experiences of young women with heart failure. These women had special issues with family, including the transition problems when family members have to adjust to changes in lifestyle because their spouse and mother has heart failure. It is very difficult for the typical teenager to have a parent who is chronically ill. Another rich area for research is the experiences of women with peripartum cardiomyopathy. Their special needs as young women with babies and perhaps, small children need to be identified through qualitative inquiry. Study of the family experiences with a wife/mother inflicted with this illness can provide data to assist health care providers better serve these clients and their families.

Research on the provider-client relationship is recommended, as this concept is the core of successful treatment of women with heart failure. A tool was developed that measures healthcare partnership (Boren, 2000) that can be used to measure the quality of

the partnership between the client and their health care provider. This tool specifically measures the attributes connection, reciprocity, sharing and integration, and synergy in the provider-client relationship. In a heart failure clinic, it could be studied along with health status, quality of life and client satisfaction. In a recent study by Kim (2001), therapeutic alliance was found to be 46% of the variance when measuring patient satisfaction in adult clinic clients. This is a significant finding for the provider-client relationship, and for women as the sample was 80 percent female.

Tools for the dimension network can be developed or existing instruments can measure the quality of a social network and the impact of social support on the outcomes for women with heart failure. There have been studies on social support and heart disease, but not with women with heart failure (Moser & Worster, 2000). It would be interesting to find out who in the social network made the biggest difference in the outcomes of women with heart failure. In the current study, the other women with heart failure were a significant support to the participants.

A number of interventions can be measured in the heart failure clinic, team management and case management programs for managing heart failure. The effectiveness of educational approaches or content and health outcomes is one example. Other areas for research with this population include quality of life, coping, impact of cardiac rehabilitation on functional status, health beliefs, and the effect of healthcare partnerships on health status. Women from various ethnic groups and social class require further study.

Conclusion

Through a feminist lens, this study explored women's experiences with chronic heart failure. Grounded theory and dimensional analysis were the methods used for this research. A theoretical framework was developed with two parsimonious concepts, network and health care, that were the most salient dimensions in women's stories. A social network was instrumental in the processes of finding out they had heart failure and through psychosocial remodeling where they revisioned their lives as women with chronic heart failure. The system of health care, approach to management of heart failure and the attributes of the provider-client relationship were influential in achieving positive physiological/physical and psychological outcomes, and client satisfaction with their health care.

The implications for nursing education, practice and research are vast. A gap in knowledge about heart disease and women still exists after its fruition over a decade ago. Gender differences regarding this illness are recommended topic in the formal and continuing education of all health care providers. Approaches to managing chronic heart failure should include the multidisciplinary team as the nucleus of any program of health care, including heart failure clinics, health management teams and case management models. A model of healthcare partnership (Boren, 2000) should be the foundation of any health care program for women with chronic heart failure. The provider-client relationship is a key issue for providing care to these women. Recommendations for nursing research included qualitative study of families with wives, mothers or grandmothers inflicted with chronic heart failure; exploration of healthcare partnerships,

quality of life, patient satisfaction and health status in women with chronic heart failure; and intervention studies on approaches to managing this illness.

The gender gap in research and health care of women is slowly narrowing, thanks in part to Dr. Bernadine Healy, the first woman director of the National Institutes of Health (NIH). She initiated a major study to examine health problems of women. The Women's Initiative is a \$500 million, 10-year research project that studies diet, supplements, and hormone therapy and their role in the prevention of heart disease. In addition, NIH has a policy that requires inclusion of women in clinical trials, which now is a matter of public law. The FDA has established guidelines that recommend inclusion of women in drug studies. Every nurse should encourage women to participate in research on heart failure and women. Topics for women with heart failure are unending.

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Memorandum

6500
KCA
26 Mar 01

From: Head, Clinical Investigation Department (CID)
To: CDR Denise Boren, NC, USN, DUINS

Subj: OFFICIAL APPROVAL OF AN **EXPEDITED** CLINICAL INVESTIGATION
PROGRAM STUDY, CIP #S-01-017, TITLED **"WOMEN'S EXPERIENCES
WITH CHRONIC HEART FAILURE"**

Ref: (a) NAVMEDCEN SDIEGOINST 6500.4E
(b) NAVMEDCEN SDIEGOINST 6500.5D

Encl: (1) **Approved version of CIP Study**
(2) **Revisions to the protocol**

1. Your research protocol (enclosure (1)) has been approved for initiation as of this date. Your protocol has met the requirements of references (a) and (b) and has been approved by the Scientific Review Committee (SRC) and has been determined as minimal risk by the Committee for the Protection of Human Subjects (CPHS). **A Progress Report will be required in February 2002.**

2. Articles/abstracts for publication must be submitted to the CID Medical Editing staff. They will assist in their preparation, will ensure proper acknowledgment of BUMED as sponsor, will obtain command approval and submit them to journals and publications.

3. Changes to the protocol (i.e., increasing/decreasing subjects or budget, addition/deletion of investigators, and changes in protocol procedures) must be submitted to CID for approval (enclosure (2) prior to initiation.

4. Please note that although your study has been locally approved and you may begin, the Navy Clinical Investigation Program (CIP) includes a second level review process by the CIP office at the Naval School of Health Sciences in Bethesda, MD. This review may generate concerns, which will be addressed to you in a memo from CID. The memo will require a response from you to CID within 30 days.

5. Sincere best wishes for a successful research project. For assistance, please contact the Research Program Administration office at 532-8125/36.

J. M. KELSO

Appendix C

ATTENTION

WOMEN WITH HEART FAILURE

Would you like to participate in a research study titled “**Experiences of Women with Chronic Heart Failure**”? If so, please contact the nurse researcher conducting the study:

**CDR Denise Boren, NC, USN
RN, MSN, CNS**

Phone: (760) 631-7304

Email: dmsboren@pacbell.net

If you decide to participate in the study, you will complete a demographic information form, then participate in an interview that focuses on your experiences with your health care and in managing your illness of heart failure. The interviews will be done at your convenience and at a place selected by you. The approximate time you will spend participating in this research study will be 1 ½ hours. Your story about your experiences with heart failure could benefit all women with this condition if new guidelines for practice are developed based on the results of this study.

ENROLL TODAY!!

Appendix D

**NAVAL MEDICAL CENTER
SAN DIEGO, CALIFORNIA 92134-5000****CONSENT BY A SUBJECT FOR VOLUNTARY
PARTICIPATION IN A CLINICAL INVESTIGATION
(RESEARCH) STUDY**

1. I, _____, have been asked to voluntarily participate in a research project entitled, "**Women's Experiences with Chronic Heart Failure**", being conducted at the Naval Medical Center, San Diego by a nursing researcher/doctoral candidate from the Hahn School of Nursing and Health Sciences, University of San Diego, CA. I understand the nurse researcher is an active duty Nurse Corps officer assigned to the Department of Nursing Research while attending school full-time.
2. The purpose of this research project is to explore women's experiences with their health care and in managing their illness of heart failure.
3. I understand that my participation in this research project will be for a period of 1½ hours.
4. The procedure(s) for this project include completing a demographic information form, then participating in an interview by the nurse researcher. I understand that the researcher will use my medical record to obtain clinical information (NYHA heart failure classification). I understand that the interview will be tape-recorded and that the researcher will take the tape with her. Once she transcribes the interview, the tape will be destroyed.
5. Up to 30 participants are expected to participate in this study. The total number will be determined when key information has come from and been supported in the women's stories.
6. There are no anticipated risks or discomforts to me from my participation in this study. My confidentiality will be protected. I understand that should I become tired, emotional or ill, the interview will stop. We will reschedule at another time. If my illness requires medical care, I will be referred to my physician or if emergent, to the nearest hospital.

Subject's Initials: _____

CPHS/IRB Approval Stamp/Seal Required

7. I understand that my participation in this research project may not be of direct benefit to me personally. However, the results of this study may help the investigator gain important knowledge about the experiences of women with their health care for heart failure, and in managing their illness of heart failure or aid in the future health care of women with heart failure.

8. I understand that I will not be financially compensated for my participation in this study.

9. The alternate procedure(s) or course of treatment, should I decide not to participate in this research study, has been explained to me as follows: I will continue my current health care plan, as decided on by my doctor and me.

10. In all publications and presentations resulting from this research study, information about me or my participation in this project will be kept in the strictest confidence and will not be released in any form identifiable to me personally. However, I realize that authorized personnel from the Navy Medical Department and from the Food and Drug Administration (FDA), where applicable, may have access to my research file in order to verify that my rights have been adequately protected.

11. If I have any questions regarding this research study, I may contact **CDR Denise Boren at (760) 631-7304**. If I have any questions about my rights as an individual while participating in a research study at the Naval Medical Center, San Diego, I may contact **CDR Kenneth Earhart, MC, USN, Chairman, Committee for the Protection of Human Subjects at (619) 532-8125**, or **CDR John M. Kelso, MC, USN, Department Head, Clinical Investigation Department at (619) 532-8127**. If I believe that I have been injured as a result of my participation in this research study, I may contact **CDR L. McNees, JAGC, USN, Naval Medical Center, San Diego, Legal Department, at (619) 532-6475**.

12. I understand that my participation in this project is entirely voluntary and that my decision not to participate will involve no penalty or loss of benefits to which I am entitled under applicable regulations. If I choose to participate, I am free to ask questions or to withdraw from the study at any time. If I should decide to withdraw from the research project, I will notify **CDR Denise Boren at (760) 631-7304** to ensure my timely removal from the study. My withdrawal will involve no prejudice

Subject's Initials: _____

CPHS/IRB Approval Stamp/Seal Required

to my future health care or any loss of rights or benefits to which I am otherwise entitled. Any new significant finding developed during the course of this study which might affect my willingness to continue participation will be communicated to me.

13. I understand that I am making a decision whether or not to participate in the research project above. My signature indicates that I have had the information presented to me, have had the opportunity to ask questions about the research and my participation, and agree to participate in the study. Further, my signature indicates that I have been provided with a copy of this consent document and a copy of a document entitled, "California Experimental Subject's Bill of Rights."

SIGNATURES AND DATE SIGNED: PRINTED OR TYPED IDENTIFICATION:

_____
Patient / Subject   (Date)

_____
Name / Status / Sponsor's SSN

_____
Witness   (Date)

_____
Name / Grade or Rank

_____
Researcher/Investigator (Date)

_____
Name / Grade or Rank

Subject's Initials: _____

CPHS/IRB Approval Stamp/Seal Required

**NAVAL MEDICAL CENTER
PORTSMOUTH, VIRGINIA 23708**

**CONSENT BY A SUBJECT FOR VOLUNTARY
PARTICIPATION IN A CLINICAL INVESTIGATION
(RESEARCH) STUDY**

1. I, _____, have been asked to voluntarily participate in a research project entitled, **"Women's Experiences with Chronic Heart Failure"**, being conducted at the Naval Medical Center, Portsmouth by a nursing researcher/doctoral candidate from the Hahn School of Nursing and Health Sciences, University of San Diego, CA. I understand the nurse researcher is an active duty Nurse Corps officer assigned to the Department of Nursing Research, Naval Medical Center, San Diego while attending school full-time.
2. The purpose of this research project is to explore women's experiences with their health care and in managing their illness of heart failure.
3. I understand that my participation in this research project will be for a period of 1½ hours.
4. The procedure(s) for this project include completing a demographic information form, then participating in an interview by the nurse researcher. I understand that the researcher will use my medical record to obtain clinical information (NYHA heart failure classification). I understand that the interview will be tape-recorded and that the researcher will take the tape with her. Once she transcribes the interview, the tape will be destroyed.
5. Up to 30 participants are expected to participate in this study. The total number will be determined when key information has come from and been supported in the women's stories.
6. There are no anticipated risks or discomforts to me from my participation in this study. My confidentiality will be protected. I understand that should I become tired, emotional or ill, the interview will stop. We will reschedule at another time. If my illness requires medical care, I will be referred to my physician or if emergent, to the nearest hospital.

7. I understand that my participation in this research project may not be of direct benefit to me personally. However, the results of this study may help the investigator gain important knowledge about the experiences of women with their health care for heart failure, and in managing their illness of heart failure or aid in the future health care of women with heart failure.

8. I understand that I will not be financially compensated for my participation in this study.

9. The alternate procedure(s) or course of treatment, should I decide not to participate in this research study, has been explained to me as follows: I will continue my current health care plan, as decided on by my doctor/nurse and me.

10. In all publications and presentations resulting from this research study, information about me or my participation in this project will be kept in the strictest confidence and will not be released in any form identifiable to me personally. However, I realize that authorized personnel from the Navy Medical Department and from the Food and Drug Administration (FDA), where applicable, may have access to my research file in order to verify that my rights have been adequately protected.

11. If I have any questions regarding this research study, I may contact **CAPT Robin McKenzie at (757) 953-7849 or CDR Denise Boren at (760) 631-7304**. If I have any questions about my rights as an individual while participating in a research study at the Naval Medical Center, Portsmouth, I may contact **Chairman, Institutional Review Board or the Head, Clinical Investigation and Research Department at (757) 953-5939**.

12. I understand that my participation in this project is entirely voluntary and that my decision not to participate will involve no penalty or loss of benefits to which I am entitled under applicable regulations. If I choose to participate, I am free to ask questions or to withdraw from the study at any time. If I should decide to withdraw from the research project, I will notify **CAPT Robin McKenzie at (757) 953-7849 or CDR Denise Boren at (760) 631-7304** to ensure my timely removal from the study. My withdrawal will involve no prejudice to my future health care or any loss of rights or benefits to which I am otherwise entitled. Any new significant finding developed during the course of this

study which might affect my willingness to continue participation will be communicated to me.

13. I understand that I am making a decision whether or not to participate in the research project above. My signature indicates that I have had the information presented to me, have had the opportunity to ask questions about the research and my participation, and agree to participate in the study. Further, my signature indicates that I have been provided with a copy of this consent document.

SIGNATURES AND DATE SIGNED: PRINTED OR TYPED IDENTIFICATION

_____ Patient / Subject (Date)	_____ Name / Status / Sponsor's SSN

_____ Witness (Date)	_____ Name / Grade or Rank

_____ Researcher / Investigator (Date)	_____ Name / Grade or Rank

Appendix E

Women's Experiences with Chronic Heart Failure

Demographic Information

Participant Identification Number (interview #): _____ Date: _____

Please circle the appropriate responses in each category below:

Age:

1. 18 – 25
2. 26 – 35
3. 36 – 45
4. 46 – 55
5. 56 – 65
6. 66 – 75
7. 76 – 85
8. Over 85 years

Ethnicity:

1. White/Caucasian
2. Black/African American
3. Asian/Pacific Islander
4. Mexican American
5. Other _____

Living Arrangement:

1. Live with spouse
2. Live with other family members
3. Live alone in house/condo/apartment
4. Live alone in an assisted living facility

Ejection Fraction:

1. 0-10
2. 11-20
3. 21-30
4. 31-40
5. Other _____

Marital Status:

1. Single
2. Married
3. Divorced/Separated
4. Widowed

Educational Status:

1. Less than high school
2. High school diploma or GED
3. Vocational/military school
4. Associate degree
5. Bachelors degree
6. Graduate degree

Employment Status:

1. Full-time
2. Part-time
3. Retired
4. Volunteer

NYHA functional class:

1. Class I
2. Class II
3. Class III
4. Class IV

Appendix F

Women's Experiences with Chronic Heart Failure

Interview Guide

Note: Interview questions will be directed to the participant, however family members are welcome to participate in the interviews. Prior to beginning the interviews, family members will be informed that the focus of the study is on the experiences of the participant. If they choose to participate, they will be asked if they have anything to add following the participants response to the interview question. If the participant gives short answers or provides little information due to timidity or style, the family member will be invited to provide further information. For example, if asked "what prompted you to seek help for the symptoms you were having?" and the response is "my daughter called the doctor", the daughter will be asked what her mother was experiencing at the time and what prompted her to call the doctor.

Interview Guide:

1. Tell me how you found out you had heart failure.

Probes:

- When was this?
- What symptoms did you have?
- When did you decide to seek help for your symptoms?
- What prompted you to seek help?

2. Tell me what it is like for you to live with chronic heart failure.

Probes:

- What symptoms do you have?
- What limitations do you have?

3. Tell me how you care for yourself on a daily basis.

Probes:

- What is your typical day like?
- What help do you have?
- If none, what would you do if you needed help?
- How would you decide you needed help?

4. Tell me about your health care for heart failure.

Probes:

- When was the last time you went to the doctor or nurse for your heart failure?
- What prompted you to go?
- What did the doctor or nurse do?
- What did the doctor or nurse tell you?
- Did the doctor or nurse prescribe any therapies or medications? If so, what?
- Did the doctor or nurse place you on a special diet? If so, what can you eat/drink on your diet?
- What did the doctor or nurse tell you about your activity level?

5. If you could change health care for women with heart failure, what would you do?

** Once the first three interviews are analyzed, new or additional questions will be developed based on the data.