

**WOMEN LIVING WITH CORONARY HEART DISEASE: BARRIERS TO CARE**

**by**

**Marilynne Audrey Hogg**

**A Thesis submitted to  
the Faculty of Graduate Studies  
in partial fulfilment of the requirements for the degree  
Master of Nursing**

**Faculty of Nursing, University of Manitoba  
Winnipeg, Manitoba**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
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## ABSTRACT

The myth that Coronary Heart Disease (CHD) is a male problem originated with studies conducted in the 1950s and 60s. Women are not aware of the extent of their risk, yet heart disease is the leading cause of death among North American women. In a 1996 Gallup poll, 67% of doctors did not know that cardiac disease symptoms, warning signs, and diagnosis were different for women. Feminist activities continue to advocate for woman-centered health care.

In this study, a qualitative methodology was utilized. Women with CHD were invited to participate in Focus Groups and describe their experience of living with the disease. Four major themes emerged: Being Heard, Helps and Hindrances, Validation, and Living for the New Me. Findings revealed that there was still evidence of gender bias and that women experienced an array of barriers to care. Support was apparent, but the women voiced a lack of understanding by others of what they were experiencing, especially the depression and extreme fatigue. Staff were caring, helpful and provided necessary information. Fear of dying alone was revealed, which had not been addressed in the literature reviewed. Implications for caregivers included continuing to address gender bias, and focusing on prevention, especially targeting young women. Including families in education programs was suggested to enhance understanding.

**Key words:** women, coronary heart disease, focus group, experience

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## CHAPTER ONE

### Background to the Study

#### 1.0 Introduction

What is life like for those women who are assaulted, but survive an attack, by their number one killer in Canada? Since the women's movement in the 1960s, the focus in many areas of interest and research has been directed to the unique perspective of being female. In the area of health care, it is only in literature of the last 10 years that there has been attention focused on women and cardiovascular disease. It is acknowledged that women are under-treated and under-diagnosed as compared to men, that research has been done on white males, and that diagnosis and treatment of women has been based on the findings of this research. Current research done with female subjects, and comparing men and women, has revealed that anatomy, physiology, risk factors, signs and symptoms of cardiac disease, diagnosis, treatment, recovery and the illness trajectory are all gender specific. Negligible research has been done on the lived experience of women with coronary heart disease.

The literature review did reveal that, although some topics related to cardiac disease in women are receiving much attention in current research, the personal stories of women with coronary heart disease have not been explored in depth. This study gave women an opportunity to articulate their unique perspectives as they discussed various aspects of experiencing coronary heart disease.

### **1.1 Statement of the Problem**

Until recently, research, diagnosis, care, and education of patients with heart disease have all been planned based on the male population, and the outcomes extrapolated in caring for females. CHD in the female population is being recognized as more of a dilemma than previously known. In 2011, the majority of the Baby Boom generation will turn 65, at which time women will outnumber men 3 to 2 (Census of Population Survey, cited in Women's Connection Online, 1990). As more women are diagnosed with CHD in later years, health care workers will be faced with a significantly large, aged group who require attention to their specific needs. At present, not only are their needs not being met, they are unknown.

### **1.2 Purpose of the Study**

The primary goal of the study was to develop an understanding of the unique experience of women with CHD. A secondary goal was to bring the research results to the attention of health care professionals, increasing awareness of, and sensitivity to, the gender-specific needs of females with CHD. A final goal was to disseminate information gathered to women who are, or may be at risk of becoming victims of this disease, and the people who care for and about them.

### **1.3 Significance of the Study**

In consideration of the numbers of women who will be potentially accessing the medical system in the near future with some form of CHD, health

care workers must be cognizant of the particular differences and needs of these patients to intervene efficiently and effectively. We must be prepared to recognize subtle clues, signs and symptoms, and provide supportive, informed care and education. To do this, we must first identify the specific needs of the female patient. By allowing women who have experienced CHD to tell their stories, we become privy to invaluable information that will guide us in our actions. Knowledge of the unique perspective of being female with CHD will allow us to efficiently direct health care resources to meet these needs, especially in this time of health care constraint.

#### **1.4 Conceptual Framework**

Two conceptual frameworks were utilized in conducting the study and analyzing data, the Feminist Framework and the Human Response to Illness Model (Mitchell, Gallucci, & Fought, 1991).

The feminist framework evolved from the social movement in the 1960s. Not only was the authority of the male-dominated medical care system questioned, but there was a growing recognition of women's unique health and body issues (Andrist, 1988). Feminism, as defined by Hamilton (1993) denotes "woman-centered". The goal of feminism espoused by the writer and shared by Kimmel (1989) is not replacement of male hierarchy by female hierarchy, but recognition that women are separate but equal to men. Hall and Stevens (1991) suggested that feminist inquiry is done with the goal of finding answers for women - providing them with explanations that they want and need about

phenomena that impact on their lives. Prior to this, interest in women's health centered almost solely around child bearing.

With this move towards feminist praxis, it was felt that women were empowered towards self determination in health and health care. The goal was to act, not be acted upon. Chinn (1989) described the issue as "the personal is political" (p. 73), that is, every aspect of our personal circumstance as women grows out of and creates, larger political realities in the world. If we change the personal realities, the political realities will also change, and vice versa.

Feminism is grounded in women's own subjective experience of the world. It is important to examine any illness from a feminist perspective because the nurse must assess the impact of the disease on the client and what that means to her as a women (Andrist, 1988). The patient should know what to expect and nurses need to assist her in preparing to cope as she progresses through the illness trajectory. Knowledge is not only emancipatory, but empowering for women as consumers of health care.

Wuest (1994), Hagell (1989) and Morse (1995) concurred in describing our knowledge of humanity as primarily based on the experience of white, middle-class males. Mann (cited in Rodriguez-Trias, 1992) took this stance even further stating that a male-dominated society was a threat to public health. On behalf of not only women, Wuest (1993) bemoaned nursing's acceptance of knowledge based on research in which the white, middle-class male perspective was central (Duffy, 1985; Sigsworth, 1995). This is notable, as up until recently,

women were not considered as significant cardiac patients; female symptoms were thought to be psychological. "Feminist scholarship endeavors not only to describe and interpret phenomena of women's lives but also to raise consciousness and bring about changes in the interest of the women studied" (Hall & Stevens, cited in Bent, 1993, p. 299). Feminism advocates studying women from the perspective of their own experiences to promote understanding of their everyday reality (Chinn, 1989; Chinn, 1995; Webb, 1984).

Barriers to the success of feminism come from women themselves. McDonald (1999) stated that it is seen as particularly unacceptable for women to express anger. Gallos (1994) proposed that women have been socialized to learn the experience of men and accept it as representative of all human experience. Their inability to relate to this reality results in silence to prevent being labelled deficient (Belenky, Clinchy, Goldberger, & Tarule, 1986; Shepherd, 1993).

The Human Response to Illness Model (Mitchell, Gallucci, & Fought, 1991) views an individual's response "to states of illness, and to situational or developmental transitions or crises" (p. 154). Responses in any of these situations can be examined from any or all of four suggested perspectives. A **normal physiologic regulatory response** is described as usual biologic functioning, and is measurable. This response would involve a bodily change to maintain homeostasis, such as increase in pulse rate as a response to chest pain. A **pathophysiologic response** would indicate that the body is no longer

able to maintain compensatory mechanisms. Evidence of this response can be quantified utilizing "instruments of the biologic sciences" (Mitchell, Gallucci, & Fought, 1991, p. 155). In the case of a woman with CHD, angina would result when narrowed coronary arteries become occluded and sufficient collateral circulation had not yet developed to support adequate blood flow to cardiac muscle. In development of collateral circulation, it usually takes 8 to 24 hours for vessels to enlarge, and near normal circulation can occur in approximately one month (Evanoski, 1997). This transition would be evidenced by changes in the electrocardiogram. **Experiential responses** are the ones that were highlighted in this study and include the concept of personal experience as measured by self-report. Many women experiencing angina would be expected to report chest pain, fear, or dizziness. As the women in the study discussed their experiences related to their individual diagnoses of CHD, the true meaning was revealed. The cultural and social meaning of the experience will be shared with the audience. The final response, the **behavioral response**, includes those motor and verbal responses that are directly observable and measurable. Although captured to some extent on audio tape in tone of voice, laughter and inflections, the majority of this response was captured in field notes as facial expressions, gestures, and other visible "language" as the women interacted and contributed to the discussion.

### **1.5 Research Question**

**The question addressed in this study was "What is the experience of women living with coronary heart disease?"**

### **1.6 Description of Coronary Heart Disease**

**Heart muscle requires a constant supply of oxygen and nutrients to carry out its function. These are supplied in the blood delivered by the coronary arteries. Because there are only two major coronary arteries, when these major arteries become clogged or narrowed by the plaques of atherosclerosis, insufficient blood flow to the heart muscle occurs. The resulting pain, a function of inadequate blood supply, is known as angina. Immediate changes in the electrocardiogram may be evident, indicating a lack of blood flow to cardiac muscle. If the blood supply is cut off completely, myocardial infarction occurs. The area of the heart muscle that is deprived of oxygen and nutrients begins to die and permanent damage may occur within 35 - 45 minutes if flow is not restored (Phipps, Long, Woods, & Cassmeyer, 1991). CHD comprises two diagnoses, myocardial infarction (MI), and angina and commonly involves either percutaneous transluminal coronary angioplasty (PTCA) and/or coronary artery bypass graft surgery (CABG). Myocardial infarction has four possible outcomes: immediate death, delayed death from complications (e.g. slowly progressing heart failure), recovery with impaired function or full functional recovery. Women in the last two categories participated in this study.**

## 1.7 Definitions

***coronary heart disease*** - mechanism of damage to heart muscle caused by insufficient blood supply

***myocardial infarction*** - partial or complete occlusion of one or more of the coronary arteries

***angina*** - severe pain around the heart caused by a relative deficiency of oxygen supply to the heart muscle. This is not a disease, but a warning symptom.

***percutaneous transluminal coronary angioplasty (PTCA)*** - alteration of a blood vessel by dilating the vessel using a balloon inside the lumen

***coronary artery bypass graft surgery (CABG)*** - surgical establishment of a diversion of blood from the aorta to a point in the coronary artery that is distal to the obstruction

## 1.8 Chapter Summary

There is a significant and growing population of women who have, or are at risk of developing, coronary heart disease. Two problems have been recognized in relation to this situation. The first is that the magnitude of this problem has not been acknowledged by women or the health care professionals who care for them. The second is that the majority of research in the field of CHD has been carried out on male subjects and the results applied to women. As a result, delays in diagnosis and treatment have occurred and women have not received the personalized care that they require and deserve. This study endeavored to reveal the plight of the female with CHD.

## CHAPTER TWO

### Review of the Literature

#### 2.0 Introduction

The literature review was undertaken to determine the extent of current knowledge related to women with CHD. Computer searches were conducted utilizing Med-Line, CINAHL, ERIC, BISON and the Internet. Primary search terms included coronary heart disease, myocardial infarction and angina, cross referenced to women, experience, diagnosis, and treatment. Numerous publications and videos were obtained from the Heart and Stroke Foundation of Manitoba. A computer search was also conducted at the Winnipeg Public Library that revealed a number of valuable resources. This chapter will synthesize information on related statistics, risk factors, signs and symptoms, diagnostics, treatment, outcomes, and rehabilitation. Information specifically related to women, and comparing men and women, will be discussed.

#### 2.1 The Problem in Perspective

Statistics support the magnitude of female susceptibility to CHD, the leading cause of death among North American women. In the United States, approximately 625,000 women each year suffer a heart attack and 250,000 of these women die. In comparison, 43,600 women die from breast cancer; 242,000 die from all forms of cancer combined (Washington Hospital Center, 1997). "One in eight or nine American women aged 45-64 has clinical evidence of (coronary) disease and this increases to one in three in women 65 and older"

(Wenger, cited in Women's Connection Online, 1997). Harlan (cited in Jonas & Manolio, 1996) revealed that medical care costs associated with cardiovascular disease in postmenopausal women in the United States exceeded \$11 billion per year.

Canadian statistics reported by the Heart and Stroke Foundation (1999) mirrored those of the United States (Appendix A). "By the year 2015, almost half of all women in Canada will be aged 45 years or over, which means a large contingent will be in the heart-disease...prone years" (Heart and Stroke Foundation of Canada, 1997). Each year, heart disease claims the lives of almost 40,000 women (and almost an equal number of men) (Appendix B), while breast cancer is responsible for approximately 5,000 female deaths. Health care costs associated with coronary heart disease for both sexes is estimated at \$7.8 billion a year.

In spite of the prevalence of cardiac disease, only 7% of women in the United States viewed heart disease as their greatest health threat (American Heart Association, 1997). 61% of American women polled cited cancer when asked which disease they should fear most (National Council on the Aging, 1997). In Canada, 86% of women were unaware that heart disease and stroke presented the most serious threat (Heart and Stroke Foundation, 1999). Not only women were uninformed. This lack of awareness was widespread and contributed to the problem. In a 1996 Gallup survey (Libov, cited in Women's Connection Online, 1997) half of the doctors polled cited breast cancer and

osteoporosis as the greatest health risks for women over the age of 50.

Researchers have identified unique female attributes for risk factors (Giardina, 1998), gender based therapeutics (Woosley, 1998), physiology (Romeo, 1995), perception of risk (Legato, Padus, & Slaughter, 1997), attention to symptoms (Dempsey, Dracup, & Moser, 1995), self care actions (Hartweg, 1993), and recovery rates following CABG surgery (Sauve & Fortin, 1996). In the past, women have been excluded from clinical trials related to the study of CHD, or studied in small numbers. As a result, their treatment has been based on data gathered from men, in spite of the fact that crucial gender differences do exist (Bennett, 1993; Caves, 1998; Pinn, 1992; Romeo, 1995). The Women's Health Research Foundation of Canada was created in 1983 to address this type of disparity, but progress is slow. Even today, although women comprise more than 50% of Canada's population, less than 5% of medical research focuses on women's health (Nurscene, 1997). Dr. Bernadine Healy (Beery, 1995) suggested that this is due to the continuance of the Renaissance idea that "Man is the measure of all things". This was reinforced in studies such as that conducted by Smith, Hicks and Heyward (1991) who constructed an instrument to evaluate knowledge of CHD and its risk factors, to direct an in-hospital teaching program. It was tested on 93 male subjects. Begin (1998), speaking as a feminist, chided researchers who did not want women in their study "because of their plumbing problems" (p. 7). She described a review conducted by Dr. Margrit Eichler and Dr. Elaine Borins in the New England Journal of Medicine in

1989. They selected 160 articles and evaluated four dimensions of sexism: gender insensitivity, androcentricity, double standards and overgeneralization. They found much evidence of bias, in the titles of articles, the language used, choice of research variables and construction of control groups. This was supported in the research design and methodology used, data interpretation and treatment recommendations. In the United States, the National Institute of Health established the Office of Women's Health Research in 1990 and in 1991 The Women's Health Equity Act was introduced to Congress (Beery, 1995). This was done in the hopes of beginning to address the problem of gender bias, as Maxwell (1994) cautioned, research must take a true feminist perspective, not just "add women and stir" (p. 26). Flavell (1994) supported gender-differentiated research as the solution to "decades of gender and age-exclusive research that have failed to produce results which can be generalized with any certainty to older, female populations" (p. 18). Evolving research on women, as well as comparing men and women, has revealed that there are many gender specific manifestations and considerations that need to be taken into account by health care professionals at every stage of their contact with women who have, or are suspected of having, CHD.

The substance of the literature review was that coronary heart disease has many gender based differences, in the anatomy, physiology and pathophysiology, risk factors, signs and symptoms, knowledge and education, diagnosis and treatment, and recovery.

## **2.2 Anatomy, Physiology and Pathophysiology**

Wingate (1997) noted that women have smaller and lighter hearts, lower body mass index (a predictor of left ventricular function), experience a greater left ventricular mass with aging, have a smaller cross-sectional area in their coronary arteries and have a lower cardiac volume. Women have lower left ventricular end diastolic pressures and volumes and a higher ejection fraction and rate of ejection than men (Wenger, 1992; Wingate, 1997). The resting ejection fraction is higher than in males (Laurienzo, 1997), but in 30% of women, the ejection fraction does not increase with exercise (Higginbotham, Morris, Coleman, & Cobb, 1984; Romeo, 1995). Ejection fraction is the relative amount of blood (expressed as a percentage of blood at end-diastole) ejected during each systole (Laurienzo, 1997), usually 60 - 70%. The resting electrocardiogram of the female has a shorter P-R interval and QRS duration. (Laurienzo, 1997). Differences also exist in oxygen transportation and delivery, a result of lower oxygen consumption, lower hemoglobin levels, and smaller blood volume.

CHD in females develops differently than in males, often progressing over a much longer period of time, and with symptoms that may be more subtle. MI in men demonstrates circadian variation, occurring three times more frequently in the morning and usually within four hours of awakening (Hendel, 1990). In women, a seasonal variation is noted with increased incidence of MI in the autumn and winter. Infarction has also been shown to occur in 83% of women while at rest with no precipitating factors.

## **2.3 Risk Factors**

Although there are some similarities shared by both sexes with regard to risk factors, there are epidemiologic differences between the sexes that need to be considered, including hormonal and psychosocial factors (Rankin, 1992; Redberg, 1998). There is a growing interest that is fueling investigation of non-traditional risk factors. An overview of some of the differences in the risk factors of particular significance to women is presented.

### **2.3.1 Family History**

Generally, family history of MI in a first degree relative is a significant predictor of premature CHD (before age 55). This relationship was found to be even stronger among women, who were five times as likely to develop early CHD. The daughters of these women were found to have twice the risk of CHD compared to sons (Allen & Blumenthal, 1998; Arnstein, Buselli, & Rankin, 1996). This susceptibility emphasizes the importance of targeting young women when developing educational programs about risk factors and the ability to modify them, as prevention is preferable to intervention.

### **2.3.2 Age**

Susceptibility to heart disease increases with age, and Wenger (1998) stated that heart disease was recognized as a disease of older women, affecting one in three women over the age of 65. Generally, women were affected at approximately the same rate as men, although they developed CHD approximately 10 - 15 years later than men, starting at age 45 (Turner, 1994).

As the population ages, the actual number of women who die from heart disease increases (Appendix C). In the year 2000, 50 million American women will be older than 50 years of age (American Heart Association, 1997). Gender related differences related to CHD were found to diminish with advancing age (Corrao, Becker, Ockene, & Hamilton, 1990).

### 2.3.3 Diabetes

Prevalence of diabetes increases with age. Oparil (1996) noted that diabetes is a more critical risk factor for CHD in women than men, cancelling the protective effect of gender. Barrett-Connor, Cohn, Wingard and Edelstein (1991), in a follow-up to the Rancho Bernardo Study, found that women with diabetes had lower high density lipoprotein (HDL) levels compared to women without diabetes, and the differential was greater than that measured in men. Results from the Nurses' Health Study (Colditz, Manson, & Hankinson, 1997) showed that maturity onset diabetes increased risk of CHD by three to seven times. As well, women over the age of 45 are twice as likely as men to develop diabetes. For women over the age of 65, Finn (1998) found that the risk of death from diabetes was more than triple that from breast cancer yet the women did not take the threat seriously.

Obesity, or even a modest adult weight gain, can trigger the development of diabetes as a result of insulin resistance. Wishner (cited in Finn, 1998) stated that 80% of people with type 2 diabetes are obese. The risk is greatly enhanced if obesity is paired with a family history of diabetes. It is speculated that there is

a notable relationship between diabetes and body profile. Women generally have more body fat than men, and tend to carry this excess weight centrally, thus an increased amount of fat metabolism occurs near the liver (Finn, 1998). Even a weight loss of 10 pounds can make a significant difference for the individual with type 2 diabetes. The problem occurred when the woman was counselled to lose a large amount of weight and gave up because the target was overwhelming (Finn, 1998).

Exercise makes muscle more sensitive to glucose, and as muscle mass increases, there is more capacity for storing glucose. As a result, physical activity can prevent onset, and impact on progression of, type 2 diabetes. Benefits of associated weight loss and positive self-esteem are noted.

Norman (cited in Finn, 1998) stated that women with type 2 diabetes have higher rates for "virtually every risk factor for heart disease" (p. 169) including body mass index, obesity, hypertension, cholesterol, low density lipoprotein (LDL) and less physical activity. Rewers (cited in Finn, 1998) found two reasons for these higher rates. First, diabetes removes the protective effect of estrogen (improved cholesterol levels and blood lipid ratios). Second, renal disease, a complication of diabetes, has been implicated in affecting lipid metabolism, although the specific mechanism is not currently known. "The person with diabetes and renal disease has 30 times the risk of heart disease" (Finn, 1998, p. 170).

Generally, depression is twice as common among women, than

among men, and the incidence increases with age (Finn, 1998). An association between depression and diabetes has been noted, although it is not known whether the cause of depression in women with diabetes is different from the cause of depression in women without diabetes. It is known that depression often results in increased food intake and lack of exercise. Having diabetes may lead to the depression due to fear, anger and feelings of hopelessness. Sluggishness and lethargy due to hyperglycemia may contribute to the depression. A cycle results that must be broken. Gavin (cited in Finn, 1998) proposed diabetic education as the solution to the dilemma of diabetes and its relationship to CHD, although noting that women, as caregivers, not caretakers, have an especially difficult time placing a priority on self-care. "It is just a cultural reality that men can more easily put their needs first" (Norman, cited in Finn, 1998). Women are also unlikely to have an external support system which would facilitate attendance at educational sessions.

#### **2.3.4 Smoking**

Murdaugh (1990) found that smoking was a significant factor in women who had heart attacks before the age of 40. Smoking alone accounted for 50% of all heart attacks (Women's Health Clinic, 1999). Older women who smoke were at five times greater risk for sudden death than non-smokers (Hanson, cited in Romeo, 1995). Smoking posed a hazard because it induced tachycardia and constricted blood vessels, increasing cardiac workload (Kra, 1996).

In young women, who have increasing rates and volumes of smoking, this

compounded other risk factors, such as obesity, sedentary lifestyle, and use of estrogen for birth control. Even though today's oral contraceptives contain lower levels of estrogen, when combined with other risk factors, use increased likelihood of having an MI two- to four-fold (Romeo, 1995).

Flavell (1994) identified that women who smoke tend to have lower HDL levels. These women were found to have increased platelet aggregation and elevated fibrinogen levels (contributing to clotting) and cigarettes have demonstrated an antiestrogenic effect. Smoking has also been implicated in the development of early menopause (by up to 3 years) (Rimmer, 1993), hypertension, elevated cholesterol levels and reduction of available oxygen to the heart. The good news is that CHD risk declined within months of smoking cessation and within 3 to 5 years, CHD risk reached the level of non-smokers (Mosca et al., 1997).

#### **2.3.5 Diet and Cholesterol**

Cholesterol is important in our body's metabolic activities. Naturally occurring cholesterol is a white, waxy substance, manufactured primarily by the liver. The Heart and Stroke Foundation are attempting to inform the public that it is the high fat in food (saturated and trans fat) and not the cholesterol in food that produces a high blood cholesterol level. There are two different forms of cholesterol, low-density lipoprotein (LDL), often referred to as "bad" cholesterol, and high-density lipoprotein (HDL) or "good" cholesterol. LDL is the form of cholesterol that builds up on artery walls, interfering with blood flow

(atherosclerosis). LDL is decreased by ingesting foods low in saturated fats or dietary cholesterol and increasing soluble fibre intake. HDL takes excess cholesterol back to the liver for excretion from the body and can assist in removing some of the atherosclerotic buildup in blood vessels. HDL can be increased by not smoking, by exercising, ingesting monounsaturated fat (olive oil) and avoiding saturated fat (palm or coconut oil). Both are controlled by maintaining a healthy weight. Dietary antioxidants (vitamin C, beta carotene and vitamin E) are suggested as promising agents in helping to reduce the risk of heart disease (Merck Frosst, 1998).

For a person over the age of 30, healthy levels are considered to be:

Total cholesterol.....less than 5.2 mmol/L

LDL cholesterol.....less than 3.4 mmol/L

HDL cholesterol.....more than 0.9 mmol/L

Triglycerides.....less than 2.3 mmol/L.

(Becel Heart Health Information Bureau, 1994)

Young women generally had higher high-density lipoprotein levels and lower low-density lipoprotein levels than men, which was associated with a lower risk of heart attack (Arnstein, Buselli, & Rankin, 1996). This changed after menopause, and women's levels exceeded those of men. Hormone replacement positively impacted on cholesterol, reducing risk of CHD.

Holme's (cited in Arnstein, Buselli, & Rankin, 1996) work on cholesterol reduction and impact on cardiac disease excluded women in more than 67% of

the studies, therefore female response to lifestyle changes is unclear.

Medications, such as "statins", which work by regulating cholesterol production in the liver, are available to help in treatment of high cholesterol levels. Although medication may be prescribed, this must be accompanied by dietary changes. Gotto (1998) recommends lipid-lowering treatment in women with CHD, based on the 46% risk reduction in women utilizing pravastatin in the Cholesterol and Recurrent Events (CARE) trial.

Associated with high total cholesterol and LDL, lower levels of HDL, and increased risk of diabetes, is a high triglyceride level. This is the most common type of fat in the body. Although its role as a risk factor for heart disease is unknown, research suggested that high triglycerides may present more of a risk for women than men (American Heart Organization, 1998).

#### **2.3.6 Alcohol Consumption**

Recent research supported the benefits of alcohol (liquor, beer and wine) in moderation in reducing coronary risk. Each beverage type showed evidence for coronary protection, weakest in liquor, strongest in beer in males and red or white wine in females (Klatsky, Armstrong, & Friedman, 1997). Wine contained both antioxidants and phenolic compounds, which reduced the rate of LDL oxidation, platelet formation, and buildup of fat in the arteries. Drown (1997) cited the results of the Nurses' Health Study, which showed a 40% reduction in risk of CHD in women who consumed the equivalent of 12 ounces of beer, one glass of wine or one drink of hard liquor daily. Healey (1998) acknowledged the

benefits of no more than two drinks per day, but recommended that the same benefits could be obtained by other health promoting activities, encouraging non-drinking women to stay that way.

### **2.3.7 Hypertension**

Hypertension results from a narrowing of blood vessels, increasing the pressure required to pump the blood throughout the body. Blood pressure may be increased by stress, obesity, and smoking. Hypertension increased the risk of coronary artery disease three times in males, but four times in females (Flavell, 1994). The increased pressure within vessel walls is suspected of causing trauma and shearing, increasing plaque formation and contributing to progression of atherosclerosis. Women are more likely to be diagnosed with hypertension, and many may be asymptomatic or unaware of the significance of warning signs.

### **2.3.8 Physical Inactivity and Obesity**

Women who are overweight are approximately three times more likely to experience a myocardial infarction than women who are at their ideal weight. Excess weight is also implicated in development of other risk factors, such as high blood pressure, diabetes and high cholesterol. Body mass index, calculated by dividing weight in kilograms by square of height in meters, is the current method of determining overweight (Newton & LaCroix, 1996), considered a risk factor when greater than 23 kg/meter squared (Evanoski, 1997). Obesity is defined by the Heart and Stroke Foundation (1997) as a body mass index

greater than 27 kg/meter squared. Distribution of body fat is an indicator of risk of CHD, in women defined as a waist to hip ratio of more than 0.8 (Caves, 1998; Rimmer, 1993). Weight loss and exercise can help to lower LDL, total cholesterol and triglycerides. Current research (Burghardt, 1999) explored the effects of exercise in preventing the lowering of HDL that appears to occur with menopause. Exercise had direct cardiovascular benefits as oxygen delivery and utilization were enhanced. Additional benefits included weight loss, stress reduction and decrease in blood pressure (Ready et al., 1996). Aerobic exercise was recommended, and as little as walking a mile (15 minutes) a day is therapeutic. Ideally, 30 minutes of walking, cycling, swimming, cross country skiing or any other activity should be carried out 3-5 days each week (Allen & Xu, 1997; Healthwest Consultants, Inc., 1995). Burghardt (1999) stated that in spite of benefits of reducing risk of heart disease, osteoporosis and diabetes, only 38% of women over age 19 engaged in regular exercise. Caves (1998) suggested that this may be due to time constraints and the stresses of women's multiple roles.

### 2.3.9 Stress

In contrast to the male picture of high status, high stress as a risk factor for cardiac risk, Haynes and Feinleib (1980) found that women in "pink-collar" occupations, such as secretaries, with low control, little power, little job mobility, a frequently unsympathetic boss and minimal opportunity to express anger, were twice as likely to develop cardiac disease than women working in white-collar

jobs. Overall, Brezinka and Kittel (1995) found that employed women had significantly higher levels of HDL cholesterol and better dietary habits than homemakers.

Walters (1993) studied Canadian women's perceptions of their health problems and stress was identified as the problem that bothered them the most. Other problems included anxiety, depression, fatigue, and lack of time for themselves. The source of the problem was identified as multiple demands, "being everything to everybody" (p. 399). Arnold (1997) supported this, stating that most women "take pleasure from a broader identity and experience greater psychologic well-being by occupying multiple roles" (p. 568) but in doing so, adopted male standards for success while retaining responsibility for female roles at home. The expectation was that women were wives and mothers first and individuals last. Pashkow and Libov (1993) described this dilemma as being in a "stress sandwich" caught between multiple responsibilities. Women are socialized to be "pleasers" and are torn when divided between a multitude of family and job responsibilities. Elliott (cited in Arnold, 1997) suggested a link between stress (from unexpressed hostility) and the development of CHD. This was supported by Thomas, Smucker, and Droppleman (1998) who described how women kept the anger inside to preserve harmony in a relationship. Fostering this type of response is described as a "psychological foot-binding". In an attempt to become "perfect girls" (quiet, calm and kind), self-silencing results. Fundamental to a woman's well-being was connectedness with others. The fear

was that not only was displaying anger considered unfeminine, there was a chance that such a display would result in "disconnection".

O'Hanlon (1996) studied shiftwork in nurses, a predominantly female profession. Shiftwork was classified as a type of stress, as the body responded to interruption of its biorhythm by "pouring out" stress-related hormones. After adjusting for risk factors, it was found that women working rotating shifts for six years or more had up to a 70% higher risk of heart attack as compared to non shift workers.

#### **2.3.10 Menopause and Hormone Replacement**

Increased female longevity means that women can expect to live almost a third of their lives after menopause (Fishbein, 1992; Flavell, 1994; Villablanca, 1996). At this time of change, physically, psychologically, and often socially, women need to reevaluate their lives and make many significant decisions and changes, not the least being whether or not to take hormone replacements. This may be estrogen, progesterone or a combination. Natural estrogen is produced in the ovary and cessation of ovarian follicle secretion results in decreased production. Estrogen helps protect women from CHD, and osteoporosis; progesterone protects estrogen-takers from uterine cancer. Education is the key in helping women make decisions regarding their use of hormone replacement therapy. Concerns about breast cancer prevent many women from taking estrogens. Gapstur, Morrow, & Sellers (1999) acknowledged the risk but noted that the type of cancer that occurred had a favorable histology.

Hormone replacement therapy not only helps to control hot flashes, and maintain bone density, but the estrogen helps to lower the "bad" and raise the "good" cholesterol, contributing to reduction in women's risk of CHD. Maddox (1992) reported that during the first three years after the onset of menopause, total cholesterol and LDL increased while HDL gradually decreased. Bush, Gambrell, and Miller (1993) reported that increase in HDL occurred in approximately 3 months, while decrease in LDL could occur as early as 1 month after initiating therapy (dramatically, the more elevated the pre-therapy level). They did note that oral regimens often raised triglycerides and transdermal estrogens may produce lesser changes in lipids, possibly because this therapy is metabolized outside the liver. Grady, (cited in Bush, Gambrell, & Miller, 1993) analyzed 32 studies and found an overall 35% reduction in CHD risk in women who used estrogen therapy while other studies reported up to a 50% reduction (Barrett-Connor & Bush, 1991). Sullivan (cited in Barrett-Connor & Stuenkel, 1998) suggested up to an 89% risk reduction from estrogen replacement in women who already have CHD. In conflict with this suggestion, although utilization of hormone replacement therapy at menopause has been shown to reduce risk of cardiac disease in women, Khan (1998) warned that women with heart disease should not start taking hormone-replacement therapy to prevent MI. In the first 4-8 months of treatment, an increased risk for MI was found with certain forms of hormone replacement therapy. To even further complicate the decision to begin estrogen therapy, the Heart and Estrogen/Progestin

Replacement Study (Hulley et al., 1998; Bush, 1998) found no overall cardiovascular benefit to women with heart disease assigned to active hormone therapy. It was proposed that length of time on therapy may be a critical factor, as long term therapy may show a cardiovascular benefit.

Rako (1998) reported that several studies, including the Framingham study, showed that women with premenopausal hysterectomy, even with preservation of one or both ovaries, had a substantial increase in CHD. The Rancho Bernardo study found that even with estrogen replacement, women who underwent bilateral oophorectomy were at risk of "more unfavorable heart disease risk factors many years after surgery" (Rako, 1998, p. 827). Jonas and Manolio (1996) acknowledged that better cardiac risk profiles were seen with hormone use, but suggested that this may be due to the higher socioeconomic status, better medical care and increased health consciousness associated with women who used hormone therapy.

In light of potential serious side effects of estrogen therapy (increased risk of uterine and breast cancer, cholecystitis and venous thromboembolism) as well as annoying side effects (vaginal bleeding and breast tenderness) new therapies are being developed. Selective estrogen receptor modulators (SERMs) (Cole, Flaws, & Bush, 1998) have been introduced that mimic the beneficial effect of estrogen but have no adverse effect on the endometrium as a result of binding properties. This is being promoted as a "safer estrogen" although as a new therapy, this has yet to be proven. As reported by Cole, Flaws, and Bush (1998)

short term studies in women have revealed a significant increase in thromboembolic events.

### **2.3.11 Non Traditional Risk Factors**

Penckofer and Holm (1993) proposed that because there was a marked increase in a man's risk of heart disease as a result of an elevated iron level, iron retention that occurs in nonmenstruating menopausal women may be a relevant cardiac risk in aging women (Naimark et al, 1996). Low iron levels possibly inhibit oxidation of lipids.

Oparil and Oberman (1999) reviewed other non-traditional risk factors currently under scrutiny. Chronic inflammation, indicated by elevated levels of C-reactive protein, was suggested as a factor in the development of coronary atherosclerosis, as well as atherothrombotic events. A dual role for aspirin therapy was proposed, because of its antiinflammatory and anti-platelet properties.

In 1969, children with homocystinuria were found to have concomitant vascular damage by McCulley (cited in Oparil & Oberman, 1999), with death from thrombosis. Homocysteine has been found to potentiate auto-oxidation of LDL, and interfere with elasticity of vessel walls. Dietary supplementation is suggested as deficiencies of vitamin B6 and folic acid, have also been linked with elevated homocysteine levels. This relationship has attracted increased interest although Warren (1999) found that many remain sceptical of the link.

Kra (1996) identified cocaine abuse as contributing to unpredictable

sudden death that was not dose-related. Cocaine can cause the blood pressure and pulse rate to increase, the arteries to spasm and constrict and has been associated with myocardial infarction and pulmonary embolism. Evanski (1997) identified earlobe crease (genetic) as a risk factor, while increased height was associated with a decreased risk.

The most current release by the Heart and Stroke Foundation of Canada (1999) added exertion in the cold and snow shovelling as risk factors, due to the high myocardial oxygen demands and possibility of intense sympathetic output that may precipitate coronary thrombosis or plaque rupture.

#### **2.4 Signs and Symptoms**

Davidson (1996) warned that women will be misdiagnosed if physicians follow the classic male model for recognizing heart disease. Douglas and Ginsburg (1996) identified evaluation of chest pain as a critical step in treatment of women with heart disease, the point at which women were likely to be treated differently from men. Physicians were also warned to be aware of their own bias in treating women with chest pain (Douglas & Ginsburg, 1996). A woman presenting in an emotional state was less likely to be correctly diagnosed with CHD than a woman presenting with the same symptoms, but with a businesslike affect.

Female patients were more likely to have their symptoms attributed to psychosomatic causes, and ultimately were less likely to be referred for invasive testing (Armitage, Schneiderman, & Bass, 1979; Clancy & Massion, 1992;

**Legato, Padus, & Slaughter, 1997). Romeo (1995) stated that women must seek care when they first experience chest pain and be "clear, objective and persistent in expressing their concerns" (p. 176). Historically, women have been socialized to dependency, not seeking knowledge, and letting others, especially males, assume the role of decision maker (Collier, 1982). In today's health care system, consumers, and especially women, need to be empowered to advocate for themselves and take an active role in their health care.**

**The Heart and Stroke Foundation (1999) provided a succinct summary of the problem of why heart disease is such a threat to women:**

- It is the #1 cause of death**
- Women think heart disease only happens to men**
- Women put their families' health before their own**
- Women don't know the warning signs and often don't seek medical advice until their condition becomes serious.**

**Typical symptoms experienced by both men and women (Ross & Sachs, 1996) included chest pain, nausea, sweating, shortness of breath, and fluttering or rapid heartbeats. Women described chest tightness, more likely to radiate into the jaw or giving a feeling of fullness in the throat. As well, women experienced chronic breathlessness or waking up at night with shortness of breath, chronic fatigue that was overwhelming and unusual, as well as blackouts and edema, especially of the ankles and/or lower legs. Men were more likely to experience dramatic signs and symptoms, while the woman's symptoms were**

inclined to be vague, confusing and only involved chest discomfort (Pedwell, 1995).

The Heart and Stroke Foundation of Manitoba (1999) cautioned women to take note of the **early warning signs of heart disease** they may experience. A physician should be consulted regarding pain or discomfort in the chest that comes on with activity and goes away with rest, shortness of breath or unusual tiredness with activity, or notice that activities that used to be easy have become difficult. **Warning signs of heart attack** in women included:

- a vague discomfort in the chest that does not go away with rest, or sudden severe, crushing chest discomfort that may move to other parts of the body
- heaviness, pressure, squeezing, fullness, burning, tightness or other discomfort in chest, shoulder, arm, neck or jaw that does not go away
- unusual pain that spreads down one or both arms
- shortness of breath, pallor, sweating or weakness
- nausea, vomiting and/or indigestion
- feelings of extreme anxiety, denial or fear

Experiencing any of these signs would warrant seeking emergency help right away. It is this initial time period that was most crucial if interventions were to be effective, as occlusion of a coronary artery rapidly progressed to irreversible myocardial necrosis, usually within 4-6 hours (Hendel, 1990).

Doehrman (1977) reported that over one half of all deaths following MI occurred

within the first 4 hours of onset of symptoms. This was more significant considering that Dracup and Moser (1991) found, on average, patients delayed 4 or more hours before seeking health care. Thrombolytic therapy was most effective when initiated within 90 minutes of onset of symptoms, with little effect after approximately 6 hours (Dempsey, Dracup & Moser, 1995). Wenger (1992) reported that the benefits of thrombolytic therapy were even greater in elderly patients, but Hsia (1998) found that, in general, women were less likely to receive thrombolysis. Even though women were more likely to have bleeding complications, the advantages equalled those found in men (Amsterdam & Legato, 1993). Consultation with physician or spouse has been found to increase delay in seeking treatment at a medical facility, while consultation with a coworker or friend decreased delay. Women were consistently found to have longer delays than men (Caves, 1998; Hendel, 1990). Reasons for delay included not recognizing symptoms or thinking they were not significant, believing they would go away, as they had done so in the past, denial, commitments and concern for others. Women's concern for others most often caused delays in their seeking and receiving treatment (Caves, 1998), including critical thrombolytic therapy.

## **2.5 Knowledge and Education**

In many cases, women were unaware of the risk factors (Frame, 1999), ignored the significance of risk factors, or only became aware of their control over risk factors after the diagnosis of CHD. Hill (cited in Women's Connection

Online, September 10, 1997) suggested that this low level of awareness regarding cardiovascular risks may be due in part to the myth "that women don't get heart disease", and if they do, "it's only old ladies who get it" (p. 1). To draw attention to the significance of heart disease in women, Charlotte Libov, women's health activist, initiated Women's Heart Health Day (February 1) in 1995 and this yearly initiative continues.

Chan (1990) reviewed the literature on cardiovascular patient teaching, and found few studies that focused on the self-perceived learning needs of post-MI patients. It is noteworthy that Smith, Hicks, and Heyward (1991), in developing a coronary heart disease knowledge test exclusively studied 93 males. The few studies found in the literature that did explore information needs of patients (men and women) with cardiac disease utilized the Cardiac Patients Learning Needs Inventory (Ashton, 1997; Gerard & Peterson, 1984; Karlik & Yarcheski, 1987; Wingate, 1990). This tool directed the study participants to rank a list of educational topics or information needs, proposed by caregivers. No study was found that elicited personal information needs exclusively from women diagnosed with coronary heart disease.

An interesting relationship was established by Brezinka and Kittel (1997) linking low socioeconomic status with an increase in CHD incidence and mortality, moreso in women than men. It was speculated that low social class and low educational attainment were associated with an unhealthy lifestyle, including an unhealthy diet, less physical exercise, higher blood pressure and

more smoking. Increasing women's level of education is proposed as a method of reducing CHD risk. Follow-up in the Framingham Heart Study showed that women with less than eight years of schooling had almost four times the risk of developing CHD as women with more than 12 years of education (Eaker, Johnson, Loop, & Wenger, 1992).

Allen (1999) studied women one year after by-pass and found that pre-surgical risk factors remained unchanged. She speculated that women considered themselves "fixed" and because of a false sense of security or lack of teaching were unaware of their continued risk for subsequent disease. The shift from acute to chronic cardiac disease produced a new array of disabilities, and this required patients to more actively participate in their own care (Wenger, Cleeman, Herd, & McIntosh, 1986). Ornish et al. (1990) conducted the Lifestyle Heart Trial to determine whether patients sustained lifestyle changes once discharged and what effects these changes had on regression of coronary atherosclerosis. The women in the study made moderate lifestyle changes yet showed more overall regression than men, some of whom made significant lifestyle changes.

Dodge (1969) was credited with conducting the first investigation of patients' perceptions of their information needs. Karlik and Yarcheski (1987) replicated this study and their results supported the Dodge study findings. Nurses identified knowledge related to medications as priority while patients focused on risk factors that could lead to another heart attack. Both parties

agreed that knowing what to do when chest pain occurred was critical. It is interesting to note that some studies reported patients preferring teaching from physicians rather than nurses (Dodge, 1969; Gerard & Peterson, 1984; Karlik & Yarcheski 1987). Ashton (1997) supported this preference in women, but found that male subjects preferred teaching from the nurse. None of the studies identified the gender of the nurses or the physicians providing the teaching.

The Women's Heart Health Survey (Naimark, Tate, & Turner, 1999) found that women were most interested in nutritional information, learning about heart disease and risk factors. The need for programs specifically for older women and those with low levels of education was also identified.

Wingate (1990) acknowledged discrepancies in educational priorities between nurses and patients, and cautioned that a needs analysis should be performed to provide individualized teaching. As lengths of hospital stay decrease and patients' acuity levels increase, it has become critical to focus on what is possible for the staff to teach and what is reasonable for the patient to learn (Chan, 1990; Steele & Ruzicki, 1987; Thomas, 1994). Duryee (1992) found that use of audio-visual materials was preferable to giving patients written material, although research has shown that patients only retain half of the information given. This was improved by providing written material in addition (Raleigh & Odtohan, 1987).

## **2.6 Diagnosis and Treatment**

Although improving (Chan, Cox, & Anderson, 1996), recent literature

(Schulman et al., 1999) continued to report that women have significantly less access to major diagnostic and therapeutic procedures as well as coronary artery bypass grafting (CABG) and percutaneous transluminal coronary angioplasty (PTCA) (Ayanian & Epstein, 1991; Jaglal, Goel, & Naylor, 1994; Steingart et al., 1991). Canadian women were three times less likely than men to be referred for PTCA and five times less likely to be referred for CABG (Barry, 1993), possibly because of poorer outcomes with advanced age. Penque et al. (1998) noted that women were referred for PTCA and CABG later than men, and as a result, tended to be sicker, with unstable angina, congestive heart failure, hypertension and diabetes. Schwartz et al. (1997) found that women had worse functional health outcomes, and physical health status worsened significantly in the first year after the cardiac event. This only strengthened the need to focus on primary and secondary prevention of CHD.

On initial presentation, Steingart et al. (1991) found that men were twice as likely to undergo cardiac catheterization and bypass surgery. This disparity was less apparent after women had undergone cardiac catheterization, and rate of bypass surgery became equivalent to that of men. The diagnosis of CHD was more of a challenge in women because of gender differences in clinical presentation (Mosca et al., 1997), and decreased or varied accuracy of diagnostic tools. Chest pain was not of great diagnostic value, as reported in follow-up of the Framingham study, because although women tended to experience chest pain more often than men, it rarely progressed to MI (Travis,

Gressley, & Phillippi, 1993; Wenger, 1990). The Myocardial Infarction Triage and Intervention Project found that 90% of women with MI did present with chest pain, as did men, but unlike men, the women were more likely to present with epigastric discomfort, dyspnea, nausea and fatigue (Mosca et al., 1997). In contrast, in Rankin's study (cited in Beery, 1995) 46% of women with acute MI had no chest pain, presenting with shortness of breath (80%) or epigastric pain (20%) It is not uncommon for postmenopausal women to exhibit typical angina, a positive response to treadmill stress testing and coronary arteries that are angiographically normal. This has been termed Syndrome X, and was first described by Kemp in 1967 (Futerman & Lemberg, 1993). The precise mechanism is unclear, but it is suggested that this is due to an abnormal neurohumoral tone, producing impaired vascular response during exercise. Angina occurs when vessels are unable to increase blood supply to meet the demand (Zell & Reis, 1996).

Unfortunately, Beery (1995) reported that "women's complaints have been consistently attributed to mental rather than physical problems" (p. 427) and added that physicians tended to see women's complaints as trivial (Belgrave, 1993). Legato and Colman (cited in Beery, 1995) described the stereotype of women as whiny, and hysterical. Men, in contrast, are assumed to be stoic, so if they complain, they must really be sick. Belgrave (1993) concluded that there were overall gender disparities in health care treatment, actually describing these as discrimination. Gauthier (cited in Belgrave, 1993) suggested that, based on

the stereotypical role of the housewife, women might be subject to "burdensome waits for care" as their time was seen as more flexible.

Gender specific considerations are important when deciding types of diagnostic testing for women. Kwok, Kim, Grady, Segal, and Redberg (1999) warned that not only have the methods for performing many of the tests been developed using men (Beery, 1995), but the interpretation of results was established based on data obtained from males (Belgrave, 1993).

The basic electrocardiogram (EKG), produces a graphic record of the heart's electrical activity and when done at rest, can aid in diagnosing ventricular enlargement, arrhythmias, and pre-existing muscle damage (Pashkow & Libov, 1993). Women normally exhibited a higher resting heart rate, higher frequency of heart rate fluctuation and, although not highly significant, there were many differences in the electrical waveforms of the EKG (Wingate, 1997). In addition, women had unrecognized MI more frequently than men and an increased incidence of non-Q wave infarctions (Hendel, 1990).

Stress testing in women (treadmill or exercise EKG) records the heartbeat during exercise, as some cardiac problems only occur with physical stress. This test is less specific and sensitive than in men, partly because women are less likely to achieve an adequate heart rate response, and because they are more likely to have repolarization abnormalities. Women also increase their stroke volume during exercise by increasing the end-diastolic volume. Laurienzo (1997) reported high rates of false positive results, up to 67% in women with normal

coronary arteries. Women on hormone replacement therapy may exhibit ST segment depression, a false indication of cardiac disease. Naturally occurring estrogen has been found to produce a digoxin-like response. Chaitman (cited in Pashkow & Libov, 1993) described studies where women have undergone random exercise electrocardiogram testing and had abnormal results at various times throughout their menstrual cycle. Wellens (1999) has shown diagnostic value in adding right precordial leads to the standard 12 when ST segment deviations are recorded. Steingart et al. (1991) and Wenger (1990) suggested that stress testing might be perceived as less beneficial in women partly due to the misconception that chest pain in women is likely a benign symptom.

In exercise, or stress, echocardiography, images of the heart at rest are compared with those after exercise. Changes indicative of cardiac disease can be seen, but images of actual coronary arteries are not visualized. Exercise echocardiography appeared to be more specific and had the benefit of being cost effective (Mosca et al., 1997). Laurienzo (1997) did not find gender differences in the response to the test, with few false positive results in both sexes.

Thallium stress testing combines an exercise stress test with a nuclear scan and can show damaged areas of the heart and uncover difficulties with cardiac contraction. A small amount of radioactive material is injected into a vein and a camera scans the material as it is "taken up" by healthy areas or not taken up by damaged areas. One difficulty was attenuation artifact (Wenger, 1992),

that is, breast tissue in women, especially if excessive, diffused the radioactive energy of the thallium and it appeared that it was not being absorbed. This led to a false impression that coronary artery disease existed. Adjusting the results for smaller ventricle size in women has been shown to improve accuracy (Kwok, Kim, Grady, Segal & Redberg, 1999).

Coronary angiography, also known as cardiac catheterization, is considered the "gold standard" of diagnostic testing. Dye is usually injected into the femoral artery and x-rays are taken to show how the dye makes its way through the coronary arteries. Areas of stenosis or complete blockage can be identified and this assists in planning appropriate interventions. This is a more invasive procedure, more costly, requires booking of operating room staff and does have some serious potential complications, such as reaction to the dye, bleeding and hematoma. An overnight stay in the hospital might be required to observe for these complications.

After MI, women have higher mortality and morbidity than men and are more likely to experience reinfarction or die within a year. Those undergoing CABG or PTCA had significantly higher mortality rates than men, possibly due to a worse risk profile, severity of disease at diagnosis, anatomy, delay in treatment or presence of diabetes, hypertension or other non-cardiac co-morbidities (Nohria, Vaccarino, & Krumholz, 1998). Half of all post PTCA deaths were due to procedural complications, which were a particular problem for women (Malenka et al., 1999). Women's hearts and coronary vessels are smaller than

those of men which possibly impacts on surgical outcomes, since size of cardiac surgical instruments are based on male anatomical proportions. The arteries, being smaller, are more easily occluded and possibly procedures requiring cannulation are more difficult and complicated. Long term survival, however, has been found to equal that of men (Brezinka & Kittel, 1995).

Most infarctions resulted when an occlusive coronary thrombus formed on an ulcerated atherosclerotic plaque (Kristensen, Ravn & Falk, 1997). After menopause, women experienced an increase in fibrinogen, factor VIII and PAI-1, which made them more susceptible to atherosclerosis (Mayo, 1997). The benefits of aspirin, due to its role in preventing platelet aggregation, are under scrutiny and, so far, women appear to be less responsive to this therapy (Nohria, Vaccarino, & Krumholz, 1998). Kadar (1994) described the Physician's Health Study, a five year study on the effects of aspirin in preventing cardiovascular disease conducted by researchers from the Harvard Medical School. Subjects were 22,071 men and no women (Schroeder, 1992). Manson et al. (1991) studied women taking one through six aspirin weekly and demonstrated a reduction in the risk of a first MI, but concluded that further study was required in a larger group of women in a randomized trial. Although it appears that there is a need for anticoagulation to prevent CHD, concerns have been expressed that women are being treated with a therapy that, so far, has unproven results in this population (Beery, 1995; Oparil, 1996). Woosley (1998) defined gender based therapeutics as "the application of the known differences between males and

females to individualize (medication) therapy based upon a patient's gender" (p. 21). It is not enough to adjust dosage based on body size. The Women's Health Study (Hennekens, 1998), assessed the benefits and risks of low-dose aspirin as well as vitamin E in the primary prevention of cardiovascular disease and cancer. In 1997, the Heart and Stroke Foundation of Canada released a position statement on aspirin administration that supported ingestion of aspirin (160 - 325 milligrams) by patients experiencing acute onset chest pain which may be cardiac in origin. It is described as "as effective as thrombolytic therapy given alone in reducing morbidity and mortality". In spite of the known benefits to a low cost, high outcome therapy, Schwartz et al. (1997) reported that women were not as likely as men to be discharged on aspirin and could offer no explanation for this finding.

## **2.7 Recovery**

Carhart and Ades (1998) cited reduction in mortality, increased exercise tolerance, diminished angina and dyspnea, improved blood lipid levels and an overall improvement in psychosocial well-being as benefits of cardiac rehabilitation. Cardiac rehabilitation was defined by Smyrski (1998) as:

the sum of activities required to ensure patients the best possible physical, psychological and social conditions to allow them, by their own efforts, to regain as normal as possible a place in the community and to lead an active productive life. (p. 1)

Fleury, Kimbrell, and Kruszewski (1995) studied the process of

rehabilitation in patients diagnosed with CHD, finding that experiences affecting the recovery of women received minimal attention. Women were not referred to cardiac rehabilitation programs at the same rate as men (Carhart & Ades, 1998; Jensen & King, 1997). In cardiac rehabilitation programs, women had lower participation rates and higher dropout rates than males (Eaker, Johnson, Loop & Wenger, 1992; Moore, Ruland, Pashkow, & Blackburn, 1998; Mosca et al., 1997). Hartweg (1993) reviewed self care of women and found that, overall, they were more likely than men to engage in health promotion activities, such as health responsibility, exercise, nutrition and interpersonal support. On the practical side, decreased attendance could be a result of having limited means of transportation to get to the programs, or having fewer financial resources to allow attendance. Reduced activity tolerance is typical in women and perhaps they just do not feel well enough or physically able to attend due to comorbidities (Rankin, 1992; Romeo, 1995). Women beginning cardiac rehabilitation were found to have lower exercise tolerance (4.1 metabolic equivalents or METS) compared to men (5.5 METS), had decreased aerobic capacity, and reached a lower percentage of their predicted maximal heart rate (Carhart & Ades, 1998). A MET is the energy equivalent of an individual at supine rest and equal to an oxygen intake of approximately 3.5 ml per kg of body weight per minute (Boogard, 1984). Another possible reason for lack of participation is that women in this age group have not been socialized to engage in physical activities that involve "working up a sweat", especially in the company of men, and are

uncomfortable in the typical rehabilitation environment (Arnstein, Buselli, & Rankin, 1996). Lack of time and energy, having fulfilled household and caregiver roles, with less support from spouses has also been proposed as a barrier. Young and Kahana (cited in Angus, 1996) found that for women, marriage was not synonymous with caregiving support. "A primary determinant of motivation in health behavior change consists of the personal meaning of life experiences to the individual" (Fleury, Kimbrell, & Kruszewski, 1995, p. 475). To assist the woman in initiating and maintaining risk-reducing behaviors, it is first essential to understand her perspective and then identify motivating factors. Major themes in their work included fear, uncertainty, information seeking behaviors, and a need to critically examine previously held values and beliefs.

Hawthorne (1994) found that women tended to minimize the experience of CABG, viewing it as another inconvenience of aging, whereas men viewed it as a major life crisis. For women undergoing cardiac surgery, the core variable was "preserving the self" which meant struggling with role-related behaviors and interpersonal relationships (King & Jensen, 1994). The process involved several phases: waiting, getting there, surviving, being there, and moving on. Each woman moved through these phases in her own way, facing her own unique barriers, and utilizing individual coping strategies. Interestingly, in this study women again defined "self" in terms of domestic role expectations, role performance and relationships with others. Domestic roles may be difficult or impossible to manage to any extent and this perception is bound to result in

feelings of failure (Jensen & King, 1997). Women typically experienced more discomfort at the mediastinal incision (Hawthorne, 1994), suffered from fatigue and if older, may have had comorbidities that prevented successful resumption of household chores. Caves (1998) stressed the need for support and education regarding modification of traditional roles, especially during convalescence. Discharge teaching should describe housework as a form of exercise, which must be resumed gradually (Cronin, Logsdon, & Miracle, 1997). It should also be stressed that, even though some lifestyle modifications may be necessary, women can return to their normal daily activities for the most part.

Moser (1997) stated that although little is known about the unique stresses women encounter after MI, higher levels of anxiety and depression (Pinneo, 1984), more guilt in relation to their disease, difficulty resuming social activities, and increased marital difficulties and life changes were reported. Women were less likely to return to work (Romeo, 1995), and those who did, did so later than men. This observation may be clouded by the fact that many women, experiencing CHD later in life, were closer to, or already in retirement. Many women in this cohort did not work outside of the home, and return to work equated with resuming household chores. As opposed to men who benefit from social contacts and supports in the workplace, women working at home were more socially isolated and lack support.

Baggs and Karch (1987) researched women and sexuality. Historically, women had been reported as less likely to resume sexual activity, and those who

did reported less satisfaction. It was proposed that this was partly due to lack of information about resumption of female sexual activity, as women were excluded or only included in research activities in small numbers. There was also an assumption by some health care providers, that women were no longer interested in sexual activity. Baggs and Karch (1987) only found that 10% of the women in their study reported lack of interest.

Although there are many similarities in the illness trajectory of women who experienced MI and CABG, a critical difference was identified by Flynn and Franz (cited in Jarsma, Kastermans, Dassen, & Philipsen, 1995). The patient post MI lived with whatever chronic debilitating sequelae exist, while the bypass patient had been given a "new lease on life". In either case, cardiac patients lived with fear (Thomas, 1994); fear of recurrence and/or fear of death.

Even though happy to be home, women may feel insecure and vulnerable away from the "safe" hospital environment. Fatigue and depression were common experiences (Pinneo, 1984). Although social interaction may be beneficial, withdrawal from family and friends was not uncommon due to lack of energy. Artinian and Duggan (1995) stressed the importance of educating families and support persons about what to expect and how to best meet the needs of female patients. The value of nurses providing phone follow-up, post discharge, especially for women, was stated.

## **2.8 The Female Role**

For most of this century, although it was recognized that cardiac disease

did occur in women, this was only considered significant when it interfered in their most important roles, childbearing and homemaking (King & Paul, 1996).

The question that remains is why do women respond the way they do? Many women still believe that heart disease only happens to men. Women tend to ignore the signs and symptoms, partly from fear, and partly because they are so enmeshed in the caregiver role. Pedwell (1995) noted that when a man was in the physician's office, the wife was sitting beside him making notes on how to care for him. Typically, a woman went to the doctor alone. Women had difficulty reducing risk factors, were reluctant to pursue treatment, and even abandoned the thought of undergoing lifesaving surgery because of their commitment to caregiving responsibilities. Pedwell (1995) wondered how "women can be so big-hearted to everyone - but themselves" (p. 71).

Harriet Braiker, a psychologist, has described the female counterpart, Type E, to the hypercompetitive Type A male personality. This "Type E" woman strives to be everything to everyone and in her own estimation is never doing enough. She measures herself against "cruelly perfectionistic standards of what she thinks she 'should' be able to do, or what she imagines others expect of her" (Braiker, cited in Heart and Stroke Foundation, 1996, p. 10). Women were more likely to exhibit this type of personality because they tended to define success in terms of relationships (Abbey, cited in Heart and Stroke Foundation, 1996, p. 10). This can involve putting everyone's needs ahead of their own and taking the blame for anything less than perfection. Social norms have established women's

role in terms of caring for others (Gilligan, cited in Banister, 1999). Caring for self challenges this norm and is difficult as this is often perceived as selfish. Women need to realize that they have a responsibility to engage in self-care activities, to value oneself. If this is not achieved, the outcome was that the woman's own health tended to become a low priority (Thomas, 1997) and frustration and resentment may result.

Moore (cited in Arnold, 1997) observed that women post MI worried about who would maintain the household after discharge. Male patients reported no anxiety in relation to household maintenance. Arnold (1997) found that most women lacked energy and felt abnormal when they could not resume performing household duties. Not only was this frustrating and frightening, but the women experienced loss of personal value and self-confidence. Johnson and Morse (1990) found that women were more inclined to "bend the rules" and engage in housework, rather than feel dependent and watch others do "their" work. There is a frustration experienced during the healing period, at being trapped between the sick role and previous roles. Boogard (1984) identified feelings of guilt as a result of inability to perform household activities, yet the women resisted accepting help. Women actually put themselves at risk of reinfarction in their attempt to resume household activities on return home.

Smith (cited in Thomas, 1997) defined health as the ability to perform one's socially defined roles successfully. Risk of role dissatisfaction was greater for women than men. MacKenzie (1993) discovered that after discharge, women

identified a new role, Heart Patient, as a priority. This attention to one's own needs is critical to survival. Toobert, Strycker, and Glasgow (1998) described women at greatest risk for discontinuing supervised exercise programs, as unable to be "selfish" about their own health. This puts a negative connotation on an admirable redirection of priorities. Wingate (1995) suggested that the experience of MI forced women to evaluate their lives and make changes that would enhance their quality of life.

In spite of their need, women in Johnson and Morse's study (cited in Arnold, 1997) discouraged attention after an MI, possibly because they were more familiar and comfortable with the role of caregiver rather than care receiver. Men in the same study welcomed attention. This male tendency to encourage nurturing, a visible validation of being loved, was also described by Johnson and Morse (1990). Hildingh, Fridlund, and the MISS-W Study Group (1997) identified that women received the most social support from children, parents or siblings and secondarily from spouse and intimate friends.

Arnold (1997) speculated whether the higher rates of depression seen in women after MI were related to the disease process or reflected generally higher rates of depression in women. Either way, she noted that women usually did not seek help, but tended to generally withdraw from those offering support "with a protective disagreeable response that wards off any who dare intrude" (p. 570). Overzealous helpers had to be fought off to regain independence (Johnson & Morse, 1990).

Thomas (1997) proposed that nurses and health care professionals counsel women to strengthen their boundaries, verbalize when their caregiving capacity is overdrawn and do not hesitate to seek assistance and support as needed. Efforts should also be directed towards increasing women's awareness of the benefits of continued participation in cardiac rehabilitation programs, after discharge, for physical and psychological benefits (Mickus, 1986).

## 2.9 The Experience

Considerable research has been done on the experiences of CHD in men, but little has been done to investigate the experiences of women. The challenge to physicians, and the frustration for women, is that so often they present differently from men, with vague signs and symptoms and diagnostic methods may present an unclear picture. Angus (1996) described coronary events as epiphanies in the lives of women, "where the realities of their everyday lives and activities intersect with their altered health requirements" (p. 9).

Syndrome X has been used to identify a population of mostly postmenopausal women who presented with exertional angina, positive exercise testing but angiographically normal coronary arteries. Although these women did not typically respond to antianginal therapies they showed no reduction in long-term survival rates. The good news is that awareness has increased and women in the late 1990's benefited from "prompt and more intensive evaluation of chest pain syndromes... with better selection and utilization of noninvasive diagnostic procedures (Wenger, 1998, iii).

Primary prevention is the preferable option in both sexes. In women, approximately two thirds (compared to half of the men) who experienced sudden death due to CHD exhibited no warning symptoms prior to the event (Mosca, et al., 1997). They also had a higher fatality rate following their first MI. Women developed chest pain more often than men, experiencing angina as the initial sign of CHD, although it rarely progressed to MI (Dustan, 1990).

A problem consistently reported throughout the literature is the difficulty women experienced being heard, and although this is improving as awareness increases, it is still a problem. The Canadian Women's Health Test, a nationwide survey of Canadian women conducted in 1995 (Pedwell, 1995) revealed interesting data related to the doctor-patient relationship. Forty-three percent of women had changed physicians because their doctor "talked down" to them or treated them like children. The Commonwealth data (Legato, Padus, & Slaughter, 1997) supported women's experience of paternalistic or dismissive attitudes from physicians. Doctors typically interrupted the patient within the first 18 seconds of the visit (Beckman, cited in Allen, Gilchrist, Levinson & Roter, 1993), reinforcing the need to be persistent and act as one's own advocate. People are usually more passive when they are sick, so it is suggested that the patient bring someone along to act as advocate.

The problem of lack of support was upheld by Allen et al. (1993) who found that women did not receive the same quality of care as men, primarily because their complaints were less likely to be taken seriously. Zaret, Moser,

and Cohen (1992) encouraged women to use the checklist provided by the American Heart Foundation (Appendix D) and discuss these issues with their doctors.

Little is known about the psychological aspects of CHD in women (Eaker, Johnson, Loop, & Wenger, 1992) or differences in the post-CABG recovery experience in men and women (Artinian & Duggan, 1995). La Charity (1997) studied the experiences of postmenopausal women diagnosed with coronary artery disease. These women reported misdiagnosis of symptoms, anger at themselves for failing to recognize the disease, fear, and stress at not being able to resume care-provider roles within the family. Much discussion centered around their diminished energy and physical activity, leading to difficulties as they could not resume housework and were hesitant to solicit assistance with chores. Following MI and cardiac surgery, the recovery trajectory was found to differ significantly for women and men (Boogard, 1984, Hawthorne, 1994). Men allowed themselves to rest and recover while women resumed household work soon after discharge. Rankin (1989) found that female role demands added significant stress during their recovery period. Her advice to women at hospital discharge is that "they not remove their bathrobes or get dressed in street clothing until they know they are recovered....wearing a bathrobe seems to authorize neglect of household responsibilities" (Rankin, 1993, p. 247). Fleury, Kimbrell, and Kruszewski's (1995) study of women following a cardiac event had similar findings, and participants described the process of healing as "a struggle

through the uncertainty" (p. 477). The authors characterized this process as moving through three stages: surviving, originating and patterning balance, each with their own distinct challenges and goals. Possibly women found this period especially difficult as they were generally older, tended to live alone and may have had limited financial, physical and psychosocial support (Legato & Colman, 1991; Penque et al., 1998). Male patients tended to be younger and usually were cared for by a spouse (Rankin, cited in Hawthorne, 1994).

Benson, Arthur, and Rideout (1997) conducted a phenomenological study of the experience of 14 women post MI. Four major themes evolved; validation, perceived gender differences, role expectations/role tensions and helps and hindrances to recovery. Validation included sharing experiences about hospitalization, recovery and managing the challenges. It was important for these women to relive critical portions of the experience and be reassured that they were normal. Perceived gender differences included not being taken seriously by physicians, and being treated differently, because of "having a man's illness in a man's world". Clearly role difficulties resulted from disparities in expectations women had for themselves as opposed to the expectations they felt others had for them. Inability to immediately resume previous activities related to caregiving produced dissatisfaction. In recovery, helpful behaviors were described from health care professionals but the inability to overcome feelings of powerlessness was troubling.

Helpard and Meagher-Stewart (1998) utilized a grounded theory approach

to study eight women between the ages of 61 and 87 years, with acute exacerbations of CAD at 2 and 4 weeks post discharge. Two major themes emerged. The first, Finding a Voice, consisted of composing a new self and a new way of life, which was a complex and individual process. This involved being heard, listened to and understood. The second, Struggling for a New Self, comprised four subcategories. Living with loss included both physical and psychosocial losses: tolerance for physical activities, peace of mind (waiting for the pain to start), being devalued and disrespected because of age, personal control, and independence. An inability to fulfil their caregiving and homemaking responsibilities made it necessary to rely on support from others, which they felt they did not deserve. It was reaffirmed that marital status did not ensure support, and the women received more support from significant others. In conforming to tradition, women resumed homemaking and caregiver roles as a way of exerting personal control over family activities in a quest for both stability and identity. Silence was part of the traditional patriarchal society. The women in the study did not feel entitled to express their emotions, needs and desires, seeking privacy to have a little cry as they did not think it was fair to burden anyone. Wuest (1993) found that the more strongly a woman identified with her responsibilities as caregiver, the more difficult it was to comply with the restrictions during convalescence. Women appeared to need to sacrifice for their spouses, as described by one woman who did not like to see her husband vacuuming, because she worried more about his heart than hers. Striving for

respect involved wanting to be valued, and seeking feelings of self worth. Blending the gaps encompassed blending and resolution of perceived and/or actual losses, traditional societal expectations and the desire for self-discovery and respect. They were reconstructing their own realities and resolving the instability caused by the cardiac event and subsequent changes required.

LaCharity (1997) utilized a qualitative, descriptive approach to study the experience of 12 postmenopausal women diagnosed with coronary artery disease (CAD) and discovered four major themes. Experiencing the effects of the diagnosis of CAD included dealing with fatigue, self-esteem issues, emotional responses (anger, fear and guilt) and shifts in major concerns after the diagnosis. Managing lifestyle changes, again revolved around household duties, exercise, diet, weight control and stress reduction. Identifying support systems included being able to share experiences and be heard. Physicians were found to be the least supportive, always appearing busy and not explaining tests, results, or plans for care. Adapting and coping was based on acceptance. These women had to develop strategies for adjusting to living with the illness, both on the physical level and emotionally.

## **2.10 Chapter Summary**

The literature review revealed that in the last century, throughout North America, there has been much research conducted and much attention focused on every aspect of cardiac disease. It is only in the 1990s that this interest expanded to include those women who were acknowledged as victims of CHD.

Their specific needs are now being identified, and aspects of CHD unique to women are being studied and treated as significant. Lay publications, specifically women's magazines (Rogers, 1998), abound with detailed information ranging from risk factors to critique of diagnostic testing methods, written in easily understood terms. Women are being empowered as advocates in their own care. The area that has received little attention is in the description of the experience in personal terms. The stories of the victims have not been heard in any detail. We currently do not know what having coronary heart disease means to a woman. The intent of this study was to reveal the individual insights, coping strategies, difficulties encountered, thoughts and feelings, gaps in treatment and education that can be utilized or considered in treating subsequent patients. The diagnosis and treatment of women with CHD reveals significant gaps. In consideration of the numbers of women who will be potentially accessing the medical system over the next 30 years with some form of CHD, health care workers must be cognizant of the particular differences and needs of these patients. We must be prepared to recognize symptoms, and provide supportive, informed care and education. To do this, we must first identify the specific needs of the female patient.

## CHAPTER THREE

### Methodology

#### 3.0 Introduction

**Question: What is truer than the truth?**

**Answer: The story**

**(Old Jewish Saying, cited in Krueger, 1998, p. 103)**

**A focus group is a qualitative method, appropriate to use when existing knowledge of a subject is lacking (Powell & Single, 1996). It is composed of individuals with shared key characteristics pertinent to the study. In a focus group, people are encouraged to tell their stories.**

**This chapter will include a description of the methodology, sample, setting, data collection method, process of analysis and ethical considerations.**

#### 3.1 Research Design

**A qualitative study, utilizing the focus group method of data collection, was undertaken to explore the experiences of women living with Coronary Heart Disease. The premise of the focus group is that "group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview" (Sim, 1998, p. 346).**

**Krueger (1988) cited three major advantages to the use of focus groups:**

**1) The focus group is a socially oriented research procedure, and one that should be effective in producing rich data when used with this population. The benefit of this group synergy, is much like a brain-storming session (Gray-**

Vickrey, 1993) in that the interaction between participants illustrates dynamics of attitudes and opinions (Morgan, 1998).

2) The format allows the moderator to probe. Unlike a questionnaire type of data collection that is rigid and set, the focus group allows further investigation and clarification of a particular avenue of discussion. This method also allows the group to explore unanticipated areas and fosters spontaneity (Sim, 1998).

3) Focus groups have high face validity. Study results are presented in a manner that is easily understood and illustrated by use of direct quotations and examples as provided by the participants.

An additional advantage for participants was that this study gave women an opportunity to articulate their unique perspectives as they discussed various aspects of experiencing coronary heart disease. Gulanick and Keough (1997) suggested that a focus group affords the participants an opportunity for "cathartic verbalization of problems and opinions, for peer-problem solving and for giving and receiving support" (p. 25).

This method is non-limiting, open-ended and facilitates discussion on a specific topic (the experience of being a woman with CHD) in a non-threatening environment. As the members interact with each other, they verbalize ideas, perceptions, fears, and offer their own unique perspective of a shared experience. The dynamic nature of the interaction allows participants to explore, freely exchange ideas (Millar, Maggs, Warner, & Whale, 1996) and provide qualitative insights into the personal experiences of individuals (Gulanick &

Keough, 1997). Information generated is validated both verbally and non-verbally by participants, assisting the researcher to identify essential themes in the data.

The focus group is typically composed of no more than 12 participants who have certain characteristics in common (Morgan, 1993). It is recommended that focus groups be conducted until no new data is garnered, which may depend on the homogeneity of the group, but typically data saturation occurs after three to four sessions (Carey, 1995; Krueger, 1994; Morgan, 1998; Stewart & Shamdasani, 1990), as illustrated by Sim (1998, p. 349) (Appendix E). Participants should also not be expected to address more than eight to ten questions in the usual one to two hour focus group session (Gulanick & Keough, 1997; Kingry, Tiedje, & Friedman, 1990). Although focus group data is not usually generalizable, because of the typical small sample size, results can be used to stimulate interest in the topic, and generate further research.

### **3.2 Population, Sample and Setting**

The population for this study consisted of women residing in the city of Winnipeg, and the rural Interlake Region, who had been diagnosed with CHD, including MI and angina, or who had undergone PTCA or CABG. There were no specific time frames imposed on the diagnosis. The women were over 18 years of age, able to read, write and speak English and were not in-hospital patients at the time of the focus group sessions. They consented to having the discussions that they participated in audio taped.

A purposive sampling method was utilized as a particular group was being studied. Subjects initially were recruited from the Cardiology Clinic in the Adult Ambulatory Care Department at Health Sciences Centre. Posters were placed in the Clinic notifying women attending appointments of the existence of the project (Appendix F). Staff in the clinic made patients aware of the project and provided those interested with a pamphlet (Appendix G), explaining the study and inviting them to participate. Patients could contact the researcher for further information or to join one of the focus groups. The researcher reviewed the disclaimer (Appendix H) with subjects either in person or verbally over the telephone. Potential participants were sent a copy of the disclaimer, an outline of the discussion guide (Appendix I), letter confirming the date, time and place of the focus group session (including a map) and they received a reminder phone call the day before the session. Women who attended one of the focus group sessions were reimbursed for parking or transportation charges incurred and refreshments were provided at the beginning of the session.

Physicians and staff in the Clinic received letters informing them of the details of the project (Appendix J). Staff were provided with a suggested script to utilize in introducing the patients to the researcher (Appendix K). Because interested patients would possibly ask questions of the staff before deciding to contact the researcher, a short informational session was offered, for those staff members who required more detail. On a random basis for five months, the researcher reviewed charts of those patients who would be seen the following

day in clinic, and those eligible for participation had a pamphlet placed on the chart. This pamphlet was given to the patient by a staff member.

Difficulty was encountered as only two participants were recruited from the Cardiology Clinic, and therefore several organizations were approached about the possibility of recruitment from their population. These included the Women's Health Clinic, The Council of Women of Winnipeg, a Heart to Heart Group (rural), The University Women's Club, and the Menopause Clinic at Health Sciences Centre, all of which yielded no participants. Four participants were garnered from The Gwen Sector Creative Living Centre for Seniors, four from The Gordon Howard Seniors Centre (rural) and 12 from the Kinsmen Reh-Fit Centre. Six participants were recruited by word of mouth. In each case, a proposal was submitted to the agency, a presentation was done to inform staff about the study, ads were placed in facility newsletters and posters were placed throughout the physical structure. Pamphlets were distributed by staff, except at the Reh-Fit Centre. The researcher took a more proactive approach and for eight weeks, attended Cardiac Rehabilitation classes as well as fitness and exercise classes in an attempt to identify and approach women who would be eligible and willing to participate in the study. Once women from any of the settings consented to participate, the same methodology was utilized as previously described for the Cardiology Clinic. A total of 28 women participated in the study. Three focus groups were held in the library of the Reh-Fit Centre, two were held in the Board Room of the Gwen Sector Seniors Centre and one

was held in the common room of a Seniors Apartment Complex in Selkirk, Manitoba. None of the women were known to the researcher.

Organization of focus groups required much coordination of dates and times as conducting an effective group depended on the availability of subjects willing to participate. One also considered last minute drop-outs when anticipating number of participants.

### **3.3 Data Collection**

The focus groups were conducted by the researcher. Six focus groups were conducted of approximately 60 - 90 minutes each in length. At the beginning of each focus group session, participants either submitted or completed a demographic questionnaire (Appendix L). Discussions were audio taped and field notes were compiled during each focus group session noting the group dynamics and atmosphere (tone, nonverbal communication, humor, emotions). Using dictaphone, verbatim transcripts of the discussions were typed by a secretary. The researcher was provided with the data on a computer disc as well as in hard copy.

### **3.4 Data Analysis**

Preliminary analysis of data occurred after each focus group session. Initially, during the first focus group, the role of moderator in this setting was new, and the session was quite directive, although it generated rich data. As the moderator gained expertise, conversation from the participants was guided and informal discussion was promoted, encouraging discussion of related topics, as

well as those contained in the Discussion Guide. Demographic information was compiled to provide a descriptor of the participants involved in the study. The data was analyzed, with frequent reference to field notes taken during the sessions, to identify particular themes that emerged over the course of the interaction.

Because of past experience with qualitative data analysis software, the researcher chose to use a manual method of data analysis. Russell and Gregory (1993) suggest that each researcher must decide the method of data analysis that personally "fits", and recognize the benefits and burdens involved in using either a qualitative computer program or manual method. Although the manual method was time consuming, the researcher chose to invest time in data analysis rather than in dealing with a computer program. Analysis was guided by a suggestion from David Morgan (personal communication, February, 1999) who warned that analysis should be kept simple, especially for the novice. Mary Anne Casey (cited in Krueger, 1998) described a "question-by-question" method that helped to organize the data in a logical format. Strauss and Corbin (1998) provided the final advice, stating that there is no wrong way to analyze data as long as the researcher is organized and consistent.

The transcripts from each group were kept in a binder, but separated by dividers, numbered from one to six. Once the focus groups had reached data saturation the complete transcript was read over twice, to become familiar with the data. Questions were identified, named according to topic, organized, and

responses were "removed", and typed into a computer file. A hard copy of these responses was generated, again reviewed and the data gradually reduced by combining and reorganizing responses into color-coded groupings. Categories of data emerged, which were then regrouped by subject, content or topic. With frequent re-reading, Themes emerged, which were then named.

The manual method involved "cutting and pasting" on the computer, and reviewing the hard copy, using colored highlighters to identify content categories that evolved through frequently revisiting raw data. Emergent categories were examined and compared to identify themes suggesting major domains of subjects' experiences.

Content analysis (Krippendorff, 1980) and data reduction methods, suggested by Zemke and Kramlinger (1985) and Krueger (1998) included:

- a) generating a list of key ideas, words, phrases and actual quotes that reflect the sentiments of the focus groups
- b) formulating categories and linking these with ideas and quotes that fit most appropriately, as well as substantiating the category
- c) clustering the categories and subtopics and identifying themes.

Study results were presented in a manner that was easily understood and illustrated by use of direct quotations and examples, as provided by the participants.

### **3.5 Reliability and Validity**

Reliability is the extent to which consistent administration of an instrument

will produce the same or equivalent results (Nyamathi & Schuler, 1990). It is recognized that reliability is in question when using focus groups, as replication of the results would be difficult. Data gathered would vary, depending on the individual leading the discussion, and the personal stories of participants involved.

Messick (cited in Carey, 1995) defines validity as “an integrated, evaluative judgment of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of inferences and actions based on test scores and other modes of assessment” (p. 489).

Because of the very nature of focus groups, subjects responding to each others' conversation, it is doubtful that the exact information would be gathered in repeated focus groups. This replicability is a critical component of validity. Nyamathi and Shuler (1990) stated that focus groups have high face validity because of the credibility of comments derived from participants. Carey (1995) supported this notion, as information gathered can be considered “an accurate representation of the perceptions of reality for the group members” (p. 489), therefore it is valid. If consistent information is gathered from several groups, it can be “cautiously” generalized to groups of similar nature. Nyamathi and Schuler (1990) propose that because of issues related to reliability and validity in qualitative research, a better measure of rigour would be credibility, strengthened when descriptions or interpretations of the experience are recognized by the participants.

### **3.6 Ethical Considerations**

**The study received Ethical Approval from the University of Manitoba Nursing Ethical Review Board as well as Access Approval from the Research Impact Committee at the Health Sciences Centre in Winnipeg, Manitoba.**

**Participants received a copy of the disclaimer, which was reviewed with the researcher. The disclaimer explained the focus group process and outlined what was expected of participants. Volunteering to participate in a focus group session indicated that consent was obtained. Participants were reassured that their participation was voluntary and that they could withdraw from the study at any time without fear of repercussions. This was communicated on the poster, in the disclaimer, in the letter of confirmation and verbally at the beginning of the focus group session.**

**The researcher, the Thesis Chair (Dr. Barbara Naimark) and the transcribing secretary were the only individuals who had access to the gathered data. This was communicated in the disclaimer. It was stressed to participants that they would only use first names when communicating in the focus groups, and if necessary to highlight individual responses in data analysis, presentations or publications, a pseudonym would be utilized. Outside of the focus group, individuals would not be identified by name.**

**Confidentiality was maintained by limiting access to names of participants as well as the data gathered. The participant's name, address and phone number only appeared on the paperwork required to organize individuals into**

appropriate focus group sessions. This information was seen by the researcher alone. During the focus group, participants were identified by first name on their name tags and only first names were utilized in the discussion session. The secretary transcribing the taped interactions only heard first names revealed and had no access to any other personal information.

Initial lists of participants, coded lists of pseudonyms used to identify participants in transcribed data, field notes, along with data on computer disc and hard copy will be stored, in a locked file at the researcher's home for seven to ten years, at which time the research-related information will be destroyed.

There were no anticipated risks to participation in the focus group. If a participant had recalled a negative experience and suffered emotional distress at any point, she would have received support within the context of the focus group. The researcher would also have provided an opportunity for individual support after the focus group. If a participant had withdrawn from the focus group while it was in session, a follow-up telephone call would have been initiated by the researcher to ensure the participant's well-being. None of these occurred.

Three potential benefits to subjects were identified:

1. Being able to contribute to the knowledge base of health care practitioners in caring for other women with coronary heart disease.
2. Having the opportunity to discuss their personal journey and vent their feelings and frustrations, suggest changes and approaches for the health care system, share positive or negative outcomes that may have resulted from

the experience, give advice to others who are going, or may go through, the same experience.

3. Gaining the support and empathy of a group of cohorts, and possibly resolving outstanding issues of their own, by having the opportunity to discuss their experience surrounded by women who shared their diagnosis.

The only burden or cost to subjects envisioned was the planning and energy required to attend the session and participate in the discussion. It took approximately 15 minutes to complete the demographic survey and another 10 minutes to review the discussion outline. In addition to travel time, participants were required to contribute no more than 90 minutes of their time to the actual focus group.

### 3.7 Chapter Summary

In six Focus Groups, a total of 28 women participated in a discussion of their experiences with Coronary Heart Disease. These discussions were audio taped, and transcribed into hard copy for data analysis.

## CHAPTER FOUR

### Findings

#### 4.0 Introduction

The goal of the study was to develop an understanding of the lived experience of women with CHD. The literature review revealed some of the differences between men and women with CHD, and highlighted perspectives and problems unique to women. The need for research dedicated to exploring many aspects, but in particular the personal perspective of women who have CHD, was demonstrated. A qualitative study utilizing the Focus Group method was conducted and four main themes emerged in analyzing the transcripts of the conversations: Being Heard, Helps and Hindrances, Validation, and Living for the New Me. The information gathered falls into the experiential and behavioral perspectives of the Human Response to Illness Model.

#### 4.1 Demographic Profile

From January, 1999 until September, 1999 a total of 28 women with CHD each agreed to take part in one of six focus groups conducted. The focus groups contained from four to six participants and lasted from 60 to 90 minutes each. Although the study was widely advertised, response was not as enthusiastic as anticipated. The women who did take part in the study were articulate and wanted to be heard. Participants were recruited in Winnipeg, Manitoba, from the Cardiology Clinic at the Health Sciences Centre (2), the Gwen Selter Creative Living Centre for Seniors (4), the Kinsmen Reh Fit Centre

(12), and by word-of-mouth (6). Four participants were recruited from the Gordon Howard Seniors' Centre in Selkirk, Manitoba.

All women wrote, spoke, and had no difficulty understanding English. They described themselves as White Canadians, with a variety of cultural heritages. Ages ranged from 47 to 88 years, with a mean of 64.6 years and a mode of 78. Ten of the women were married (35.7%), 3 were single (10.7%), 12 were widowed (42.8%) and 3 were divorced (10.7%). Level of education varied, with 7 having less than high school, 10 with a high school diploma, 2 with technical training, 2 with registered nurse diplomas, 2 with teachers certificates, and 5 with university degrees. Only 4 were presently employed outside the home.

The value of knowing approximate yearly incomes, as reported, was in question, as only half of the group chose to respond. Those who did reported a range of \$5,000.00 to \$50,000.00 yearly, with a mean of \$26,284.98 and a mode of \$20,000.00. I received many comments from the women verbally and on the demographic forms they submitted, wanting to know why I was asking their income, and wondering about the significance of this data. Some of the comments were actually quite hostile. This was the only time that I was faced with any type of mistrust, as the women were willing to share any other information with me. Seniors, especially women living alone, had been targeted by a police campaign that was focused in the Interlake region at the time of the study. Vulnerable persons were being warned about efforts to defraud them of

money, and possibly this made the women wary. I explained that income was a typical question to ask, to help describe the population being studied, but reassured them that they did not have to respond if they were uncomfortable revealing this information. If the incomes were true, many of the women were living well below the poverty line, and this would have had a significant impact on their being able to follow the lifestyle dictated by having a cardiac condition.

Fourteen of the women lived alone, one lived with a daughter, 11 lived with a spouse or significant other and two lived with siblings (sisters). Nineteen resided in a house, four in apartments, one in a condominium and four in seniors' apartments. Diagnoses varied and overlapped, with some women reporting several of the offered options. One woman was unsure of her diagnosis, while others listed chest pain (6), coronary artery bypass graft (CABG) (6), heart attack with CABG (1), chest pain with percutaneous transluminal coronary angioplasty (PTCA) (2), heart attack (5), PTCA (1), chest pain, heart attack and PTCA (2), heart attack with PTCA (1), chest pain with heart attack (1), heart attack with PTCA and CABG (1) and chest pain with heart attack, chronic ischemic heart disease with CABG x 2 (1).

Length of time from diagnosis, and/or the coronary event, ranged from 6 months to 31 years, with a mean time of 7 years. Twenty-one had a family history of CHD, six did not, and one participant did not answer. Those with a family history reported a strong family history with many members afflicted with a wide range of cardiac diagnoses.

Two of the women were pre-menopausal, 24 post-menopausal and two did not respond. None of the 28 smoked. By verbal report, seven of the women had been or were presently on hormone replacement therapy, and two were presently studying the available information and deciding on a course of action. They were unsure if they wanted to engage in hormone therapy, because of fears related to risk of breast and uterine cancer. If they did choose to start hormone therapy, they were weighing benefits of the patch as opposed to the oral route.

Demographic information and diagnoses are summarized in Tables 1 and 2 respectively. Fortunately, in spite of the range of ages and variety of diagnoses and backgrounds, discussion was easily forthcoming. Even the women who had experienced the cardiac event several years prior had no difficulty recalling details, and did not hesitate in their contributions to the discourse.

#### 4.2 Themes and Categories

##### Being Heard

Being heard was a main theme that was evident throughout the experience, from diagnosis to rehabilitation, and in some instances, was cited as a source of anger and frustration. There were four categories within this main theme: Heeding Your Body, Finding Your Own Voice, Convincing the Gatekeepers, and Telling Others.

### Heeding Your Body

Some of the women, recognizing classic signs of cardiac disease, sought help immediately. They described chest pain, shortness of breath, and pain radiating down their left arm. Others were not sure of the nature or significance of what they were feeling. In retrospect, many of the women expressed anger or disbelief at their response, when describing their initial experience of coronary problems. They were able to give a detailed account of the symptoms they noted, and the signs they exhibited. Reports of nausea, heartburn, back pain and throat tightness were common. They offered a variety of reasons in attempting to explain their actions. Some of the women did not want to be a bother, and tried to ignore the problem, hoping it would go away:

I sat up all night at home in misery because I didn't want to wake my husband up.

I told the kids, I am going to lay down, I'm not feeling well. Don't tell your dad. That's what I always say, don't tell your dad.

I was really scared when I was sitting up all alone, which is, at night, I think it is the worst time.

I wasn't gonna tell anybody. I figured I can heal myself. But it got so bad, it came oftener, this chokey feeling...it was burning me right up to here. It was 1:30 after midnight. I quickly phoned the emergency and they said they would send someone out. I said no, there was too much snow in my yard, so I said no, I'll drive myself in. They said, are you okay, are you sure? I said sure and then I got stuck, but I got out and I drove myself in and then they said that I had a heart attack.

This last scenario only served to illustrate how hard some of these women fought to retain their independence.

Some of the women reacted with denial, even though there was

ample evidence that something significant was wrong.

I was exercising at Reh-Fit and I had this huge pain in my right arm, massive pain, heavy and I thought....I must have been lugging too many groceries.

In spite of the fact that this woman had easy access to expert care, she chose to ignore the "massive" pain. She drove herself home.

I felt a tightness in my chest, I felt quite strange. I kept thinking it was the hiatus hernia, though in the back of my mind I had heart.

I was making coffee, all alone in the kitchen and I had this huge pain in my chest and I was gasping. I thought, I don't have time for a heart attack. So I stopped, stood very still, and it passed.

In hospital they put all kinds of stuff on me and they said I had a heart attack, but I was okay. I wanted to go home because I didn't feel it anymore. It just came and went.

I could feel numbness but I didn't have pain. I couldn't believe I was having a heart attack, and in fact I asked the doctor if this was a warning. He jumped all over me and said it's not a warning, it is a heart attack. Come on, pay attention.

The consensus seems to be that if you do not acknowledge that something is wrong, whatever is going on will go away and everything will go back to being normal. These women, even though they knew in their minds that what was going on was cardiac in origin, could not face the consequences of admitting that they had cardiac problems. The fear of the unknown was worse than the possibility of dying. One of the women, in retrospect, just said "How stupid can you be?".

Another woman described her experience as "mind over matter". She was experiencing a "firm chest pressure" that she thought was indigestion. Her

friends tried to get her to go to hospital, but she was unyielding - "I am not having a heart attack". As she was driving home, she debated:

Should I go there (to St. Boniface Hospital). It was closed because of the flood, and I was wondering if I should go there or not, but all of a sudden the car just turned like my head and body took over and I went there.

Others just did not know that what they were feeling was indicative of

**CHD:**

Severe chest pain, numbness in the arm, I thought I would recognize that. I had different symptoms all the time, pressure in my chest and a feeling of anxiety. I thought I pulled a muscle or something.

I felt the moisture on my forehead and I just didn't feel right.

When I think of it, I used to get this pain here (points to sternum) but I just thought it was something I ate, but I felt pretty well.

There were a couple of nights when I had to sit up in bed a lot because I couldn't breathe. I couldn't catch my breath. Apparently that was the heart attack.

It's funny that I used to have such bad heartburn, but I haven't had heartburn once since I had my heart attack.

Many of the women reported signs and symptoms that were not typical, or commonly attributed to heart disease although frequently seen in females:

It feels like your bra is too tight, like somebody's got their hands squishing you all around your bust. You feel like if you take your clothes off, you feel better. It wouldn't hurt so much.

I felt this funny nausea and I was uncomfortable during the night. I felt like I couldn't burp.

I had trouble breathing and I never have trouble breathing. The breathing was something different. I just couldn't get breath in my nose.

I had the pain in the back, none in the chest, none in the arms, all in the back.

The pain was all in the back, there was no pain in the front at all, all completely in the back. Like I caught a cold in my back. So I went and took a hot bath.

Several of the women were surprised that they had their myocardial infarctions at rest, believing that this would only occur with strenuous exercise.

I had done my morning walking and was sitting in the kitchen reading the paper and drinking my coffee.

I was out playing bridge. I came home, went to bed and all of a sudden I had this feeling in my chest.

I get my angina when I'm doing nothing. I'm watching TV and I get this pain and I take a nitro and it is gone. I never had it while I was overdoing anything.

Only one woman reported that when she experienced angina, it was just like "a pressure between my shoulder blades". Several of the women described suddenly passing out with no warning signs. Knowing that the audience could appreciate her analogy, one participant described her chest pain as "not comfortable, but it wasn't like being in labor".

### Finding Your Own Voice

Participants in the study unanimously agreed that no matter how difficult, assertiveness was an essential component in receiving the necessary attention from the health care system. One of the women went to her doctor for a year and a half, and was very frustrated as she was continually told that there was nothing wrong with her heart, even though she intuitively knew better. Many women had a similar experience and the solution for many of these women was to seek an opinion from a variety of physicians until someone was found who

would listen:

**If you're not getting satisfied, get a second opinion. I was sent for tests...but there was never anything done. I didn't get any help with my problem until I changed doctors.**

**...and if they aren't listening to you, pursue it, go to someone else. Go to somebody because you could be in trouble, you're the one that has to get this looked after.**

**There were also reports of physicians who listened, but in disbelief. One woman had a guaranteed method of getting her doctor's attention:**

**The doctor couldn't tell what was the cause of my chest pain and he put me on nitro pills and nothing else. I kept telling him I just pass out when I take those nitro pills. I don't think he believed me. I was in his office one day and .. got the pain, so I took a nitro and ended up on the floor. I had an angiogram right away that showed everything was fine. I don't have to take nitro pills any more.**

**Many of the women were younger at the time of the cardiac event, and had extensive commitments to family, friends, and career. One woman was working in health care, and, therefore, was required to work rotating shifts, as well as long hours, and often double shifts. Several of the women had teenage children, who were not yet independent, and still required "monitoring" and chauffeuring, which were both demanding obligations in terms of time and energy. Many of the women were socially active, and volunteered on several committees, which was rewarding, but tiring and time intensive. Although they enjoyed their role as grandmother, several of the women had diminished energy, and had to tell their adult children that they could no longer mind the grandchildren. Placing limits on these obligations was an often difficult, but necessary task in order to devote time to their own recovery. Being firm without**

**damaging relationships was the key. One of the women, in her early fifties, described her situation after her bypass surgery:**

**People don't realize what you have to do...I had to educate my friends that Monday, Wednesday and Friday, I don't go for lunch. So they all know now, "Ann" won't do that, she goes to Reh-Fit.**

**Cooperation and support was necessary if prescribed routines were to be maintained as a part of one's new lifestyle. Compliance with a regimen is often positive initially, and then gradually fades, eventually to return to old habits. Although "Ann" looked forward to her lunches with friends, she was committed to devoting that time to maintaining her exercise regimen. Once the women realized that "Ann" would be there Tuesdays and Thursdays, and she was not going to waver in her commitment, they accepted the limitations on her availability. She had managed to sustain this commitment for several years. Many of the women told of having to repeatedly make others aware of their redefined lifestyle. It was not that people were being unkind, they just forgot or did not understand the relevance of scheduled exercise to health and well-being.**

**Several of the older women in the study described having few difficulties recognizing their signs and symptoms, being diagnosed, receiving treatment, and coping adequately in the recovery phase of the illness. Because they had cared for husbands with cardiac disease, they knew what to expect, and were prepared to deal with their own illness. The remainder of the group, having had no contact with anyone who had experienced cardiac disease, felt ill prepared, at least initially, and had difficulty acting as their own advocates in an overwhelming and**

**complex health care delivery system:**

**It's a scary process...the thing is, you don't really have any questions to Ask because you don't know what questions you should be asking. You're not knowledgeable, so you just go in ...and you do what they tell You to do.**

**Several women, frustrated with delays, took matters into their own hands:**

**...I got myself into the system. I mean I admitted myself twice into the emergency.**

**That's the only way I got in was by going to emergency, which I really needed to do. It's a long process, you know.**

**The best example of finding one's voice was illustrated by a situation that occurred in an emergency department. It was a scenario that most people could relate to if they have ever been a patient. The woman telling the story had been repeatedly approached by a number of staff members asking essentially the same questions. She found this exhausting:**

**I don't know how many people came by and took my history and I finally said why don't you just put it on the computer and beat it.**

**Blunt, but she got her point across.**

### **Convincing the Gatekeepers**

**In gaining access to the health care system the women had a variety of stories to tell. Some were positive but there were an equal number that were disturbing. An eighty-eight year old experienced severe chest pain while shopping in downtown Winnipeg and made her way to a walk-in clinic where an EKG was done. It was recognized that she had changes indicative of infarction and she was sent to hospital in a cab. She was quite incensed when she**

described the experience, and rightly so:

I started feeling a little sorry for myself and I thought to myself...when are we going to get there. We had to stop for red lights and everything. I was feeling a little desperate, but we made it.

One of the younger woman told of her frustration with repeated trips to the emergency department of a rural hospital:

When I get the pain bad enough that I feel anxious, I go to the emergency. The last time they did an EKG, kept me in observation for three hours, and gave me nitro. It settled down so they sent me home. Two hours later, I had to go to St. Boniface. They called it unstable angina and did an angioplasty the next day.

Many of the women experienced no difficulty in receiving immediate emergency care on presenting to the hospital:

I didn't wait at all. I've been looked after right away.

I had squeezing and a dull ache in my left arm. I couldn't move. My husband took me to emergency and...I didn't have to wait a minute.

There were also reports of unexplained delays in undergoing surgical intervention, even with clear evidence of need:

I got into the hospital December 15th and I didn't have my surgery until April 23. I was on a waiting list, had my stress test and angiogram. I was just going downhill. They were taking me seriously but wanted to try medication instead of the angioplasty.

An especially distressed young woman told the following story:

The cardiologist thought I was having trouble with my esophagus, but I knew it wasn't my esophagus because I could swallow with no problem. Why would my esophagus act up as soon as I walk, you know. I was sent home from hospital after my angiogram and I couldn't walk the length of this room. I was 95% occluded and I just cried you know. I thought I'm gonna die. Eventually I was at home and not a day and a half later I had to call 911 because as soon as the nitro was wearing off every half hour, and I had to massively take a lot of nitro.

As this story was being told, the women in the group were visibly upset and were reacting with disbelief that someone this ill was sent home. There were gasps in the room when she reported calling 911. Difficulty being heard was also evident in this scenario:

I knew what the stress tests were like, so I went in and did it, and I got kind of dizzy, and all kinds of stuff and the lady said "you're fine". So I went to see my family doctor as I felt it wasn't well done. I said I don't think they are taking me very seriously. She rescheduled one with Dr. S. and when I went to see him, his first comment was did I have trouble vacuuming. I said yes and he said I think you are probably okay. Well, I went to hospital to take the stress test and Dr. S. was there. He shut it down and said you have problems. Somebody is finally taking me seriously.

and one of the participants told her story:

I was shopping....with my sister and got this pain. I went to the ladies washroom because my bra was too tight, and I undid the top. I felt not too bad but all of a sudden everything went blurry. The security guards took me to the walk in clinic and the doctor there said "oh, you'll be alright. Just go home and rest and you'll be fine". We went home and all of a sudden I really didn't feel fine. I thought I'd had the bin. My neighbour drove me to hospital and they took all these tests. The doctor said you've not had one heart attack, you had two. You had the second one when you were coming through the door.

Several women were shocked that being in hospital was not a guarantee of wellbeing:

My EKG was normal when I went into the hospital and then I had the heart attack there. I was no longer in ICU, but on the ward. The angiogram showed one vessel completely blocked and a little one narrowed. But I was told to go home and live right (eat right, lose weight and exercise) and I would be okay. Then the next day I had a cardiac arrest.

When I went into the hospital, my EKG was normal till I had my attack.

The majority of women who had undergone either PTCA or CABG

reported being extremely satisfied with the outcome of their surgical procedure:

Before I couldn't do anything. Life is absolutely marvellous. I can do so many more things. I look after my house now and I can do the gardening. The only thing I can't do is shovel snow but I'm better than I used to be.

It's just amazing the difference it makes in your life. Absolutely a big difference. My lips were blue, my skin was grey and it was just terrible.

They did a four way bypass and it was a new life completely. I enjoyed everything after that.

Interestingly, many of the women described how safe they felt once admitted to hospital:

I just felt happy. I was so content because I didn't have to think, I didn't have to worry. I mean, now, if you stick me in the hall there for a day, I would hate it, but I liked it. I just...it was secure.

The nurse told my daughter I looked lethargic, and I thought I wasn't lethargic, I was just so glad to be looked after. Well, this is wonderful, I am being cared for.

There is that feeling of now, I'm in expert hands. They can take care of me.

I felt high actually because I was well looked after...I loved all the attention I got because nobody pays attention to me. So suddenly people are asking are you all right and I'd say yes I am.

although one woman qualified that:

I think once you get in there, into the hospital, you're looked after. It is to get in!

A variety of experiences were noted with regard to diagnostic testing.

One woman, with a notable sense of humor, credited her speedy treatment to luck:

I think...there was someone waiting for an angiogram, because when I was rushed into the room, they were all scrubbed, standing with their

masks on...ready to go, almost scalpel in hand. The nurses all laughed and said, well, here's your patient, but not the one you're expecting. They were ready to work on somebody else. She's probably still in the linen closet.

Another woman was fascinated with the technology:

It was amazing...I watched the balloon blow up and it was marvellous...fascinating. I watched the whole thing.

Several women were not well informed and did not seem concerned with this state of affairs. They were quite content to place their faith in those who were caring for them, as illustrated by the following interaction:

I had something, I think it was called an angio-something. Angiogram?

They put a wire into my groin but they didn't have the balloon or anything.

So you never had an angioplasty.

No, I probably didn't.

This was supported by the following comments:

I don't think I had a lot of questions, in fact I know I didn't. I accepted the fact that this wasn't just a warning. This was it.

I was happy I didn't have a chance to ask a question, otherwise I'd have been scared. I had no chance, so I just, stupid, went through and didn't know nothing and I was happy about that, I didn't have any idea.

You just go in there and do what they tell you to do and you never think of the questions that you should be asking.

I don't want to hear it, just do it and get it over with.

One woman stated that she had received excellent teaching before surgery and throughout her recovery but she had one nagging question that she could not receive a satisfactory response to:

I want to know what they did with my heart when they opened me up and they took it out. I...picture my own heart sitting on a plate somewhere. A significant number of the women were dissatisfied with the lack of

testing done and delays in testing:

I had an EKG done and my family doctor thought there might be a little bit of a problem with my heart. He sent me to an internist who dismissed me as an 84 year old female who (he thought) couldn't walk well enough to take a stress test.

I had two heart attacks and I kept going to my doctor and I couldn't walk even around my yard. He gave me more medication, more medication until I passed out and came to hospital. The next day I had an angiogram and they stopped it and I headed straight to the operating room.

and one woman was not happy with the type of testing done:

I had my first attack when I was travelling in the car and passed out. They did all the tests on my head.

This same woman reported that a year and a half later, after repeatedly being prescribed more and more pills, an angiogram was done and she was sent straight to the operating room for a bypass.

In the conversations the women had, there was some evidence to support the existence of gender bias:

I don't think doctors are as concerned with women.

They push women off.

Well, they say, of course, it is because women, when they are having chest pain and whatnot, they don't complain so much about it. I mean, a man can't take pain, let's face it. And they do complain a lot more to their doctors.

I just feel that I wasn't taken as seriously.

It's hard to make doctors believe that women have heart attacks, or as serious as they are.

**I think women should prepare for resistance. The medical profession doesn't readily acknowledge heart disease if you are young. I presented classical heart pain but for a long time they thought it was gastric...I think women need to strongly advocate on their behalf or get someone to advocate on their behalf that says let's get to the bottom of this now.**

**but there was also evidence to refute the claim. The more recent experiences by the younger women were more positive, in dealing with physicians and staff who were, overall, more enlightened:**

**The doctors are more aware of women than they ever were.**

**They pay attention to women more, I think.**

**Well, I think the doctors are more aware. My doctor, the younger doctor, listens better.**

**When they were doing the testing they asked me my bra size. They need to know how much tissue is there so they are taking into consideration that I'm a woman.**

**The younger women did acknowledge that they were difficult to diagnose as they were not "typical" cardiac patients:**

**I just didn't fit in to any slots!**

### **Telling Others**

**Often women expressed that the topic under discussion, either positive or negative, was something they wished they had known. Much of the time, throughout the illness experience, the women did not know what to expect and found their lack of awareness and understanding of what was happening to them difficult. Having heart disease is a personal experience and even with supports, you travel alone, and it is a difficult journey. The experience is something that can only be understood by someone who has been there. All of the participants**

felt that knowledge and insight would have made the experience easier overall, and there was much that they wanted to pass along to other women.

One woman, after CABG found that she was changed, but friends and family expected her to recover and go back to being the way she was before:

People expect you just to have your surgery and go back to doing what you were doing and feel the same as you did before, but your life has changed. It frustrates me that people don't understand what you have been through. They don't understand how it changes your life.....Most people say you're feeling sorry for yourself. I am just frustrated that I can't do what I used to be able to do.

and others supported her dilemma:

I don't think even doctors realize how much it changes your life but after surgery there were so many things that I couldn't do...still can't do.

People don't understand what you're going through and it is very frustrating, and someone says something....and they don't realize that they've hurt you, but they have, you know.

The women wanted others who might be faced with cardiac disease to be more prepared than they were to deal with the lack of understanding that faced them, especially by those people who normally would be expected to be a source of support. A few spoke of the benefits of joining a support group:

They know how you feel and you're finally talking to somebody who knows. If you can get it off your chest, you feel better.

All but one of the women reported feeling very emotional after their surgery and found this very difficult to deal with, especially in light of the lack of understanding that was evident. Many did not know what was happening to them, and had they known that fatigue and depression were normal reactions after discharge, they would not have felt so abnormal and alone.

I felt like crying so much...everything frustrated me...they never explained any of that.

I cried a lot when I first came home. Any little thing would make me cry. I would be sitting there and bawl my head off. Now I don't.

and most reported at least some degree of depression:

I was really surprised that I was depressed. I knew I was not doing what I should be doing. I couldn't be bothered to get out of bed. I just sat there and read.

I could sit home for days. I just didn't want to do anything.

You don't want to admit to yourself that you're scared of your future.

I was a mess. My hair needed doing and I couldn't put my contacts in so I had great big glasses on. I went into a big slump after discharge for two days and I didn't notice I was doing it. You get up in the morning and don't bother getting dressed. You go lie down and have a sleep. Have your lunch and go lie down again and you're still not dressed. It can happen, especially if you're living alone. You're just walking around in a daze.

The one thing I did have when I was convalescing which surprised me because...I'm a very up person, I became quite depressed.

My husband didn't even notice until the house was getting really messy.

I wish someone had told me that I would feel depressed. I don't know why but it just seemed to be so classic after the heart attack or the bypass.

I was depressed for a short period of time and I wish someone had told me to expect that as well. One of the nurses here said women will all experience it and I thought, "oh good".

Two of the women sought counselling for their depression, with opposite effects:

We are digging back to all the old things in the past so I'm becoming really depressed. Perhaps I should just go to a movie and forget about it instead. I'm not sure if seeing a psychologist is benefitting me or if it's just bringing on more stress. I went there with a positive attitude and I know he means well, but I'm not sure we're getting anywhere....I come out of

there really upset and I want to eat a lot and I'm not sure if it's really helping me.

I find it helpful. I know it's very hard work - I always come out feeling really tired but I feel really lighter. I feel really terrific for about an hour and a half and then it's like wham, I'm exhausted.

Many of the women felt that attitude is what got them through the experience:

I always figured it was my life, if I wanted it to change, I had to do something about it.

Life just goes on. Whatever will be, will be.

Several cautioned women to access health care early and to actively seek answers to their questions:

See your doctor as soon as you suspect anything because the sooner you see your doctor, the sooner your problem is addressed.

Make sure your doctor has explained everything that is involved, both physically and emotionally.

One of the women, 88 years old and unsatisfied with her doctor's explanation of the side effects of her medication, "surfing the Internet" with her son's 85 year old mother-in-law, as "younger people are better with this new technology". She felt that "if you're not getting satisfaction, look for your own answers". Her advice is that "you just have to get the knowledge". Many of the women also cautioned that if you think something is wrong, seek medical help immediately:

You do not wait.....you don't wait.

Some women wait because they are scared, scared because they don't know what is happening, or scared that they are going to die. You are gonna die anyways, so you got to know the truth.

Knowing what they had experienced and were still experiencing, many of

the women feared for their children, especially their daughters and advocated prevention rather than intervention in the future:

**This is happening to me and I know it happened to my mother. What about you girls?....so I said, well, start looking after yourself now.**

### **Helps and Hindrances**

Helps and Hindrances, the second main theme, contained two categories: Health Care System and Spouse, Family and Friends. This theme encompassed any aspects of the experience that were seen as being helpful, as well as those that were not of benefit.

#### **Health Care System**

The majority of the women, whether their experience was recent or in the past, had only praise for the care that they received in the emergency department, while undergoing diagnostic testing and while recuperating from surgical interventions.

In discussing many of the aspects of the experiences throughout the illness trajectory, it was apparent that the majority of the women had received excellent teaching from a variety of sources. They had an understanding of their cardiac anatomy and physiology, were knowledgeable about diagnostic testing and surgical procedures, were aware of dietary restrictions and lab values and many were able to assess their own pulse rates and blood pressures at home:

**I have my own blood pressure monitor...the top part of it was pretty high...so he gave me extra pills. Now my heart beat is fast and I phoned the emergency one day...to find out what the normal heart beat was and they said between 50 and 100. Well mine is 72, 75 sometimes.**

Sometimes I do housework...go outside and shake rugs or something and I come back in and then I take my blood pressure. I want to see how it works. Sometimes it's up.

Most times, the conversation indicated that the women in the focus groups had a good basic understanding of what was happening to them, but one woman described how she watched the EKG monitor after her surgery:

When I woke up, the first thing I can remember is looking at the monitor. You look to see if you're alive. And when he pulled that wire (lead) off my chest, I looked at the monitor and it went "zinc", just plain. My heart must have stopped or something.

There was much discussion about how busy staff were in the hospital, but most of the women felt that they had received the best care possible:

The nurses were very, very busy and yet, when you called for help, something to ease your pain, they were there. And you didn't sit waiting and waiting and waiting. They just came right away.

Fear of the unknown, when facing any procedure, was alleviated when adequate explanations were forthcoming:

...the nurses were great, the technicians were great. They would... tell you exactly what they're going to do.

They explained everything. So they didn't come at you with any procedure but tell you what they were going to do and what will happen afterwards.

Not only did staff provide information, they provided personalized care:

The dietician, the nurses, in the class I took (at Reh-Fit), it was sort of the support. I learned to laugh again. And I just, I find that in every way, they are very supportive.

I thought the staff were so considerate and so concerned. They apologized, I'm sorry we have to do this but they were forever apologizing.

The other thing I found wonderful was the doctors. Even in Emergency,

the doctor said you've had a heart attack. And I said, yes, I know. It wasn't going to take a brain surgeon to tell you this. But they were so thoughtful, and they said you're going to be fine.

There was communication at (the hospital) both with the medical staff and the nursing staff. And even the orderlies that trucked you up and down, you know it was good. We're just going down here, it will take you this much time and you've already been told that by your nurse, and by your doctor. I found that they were excellent.

The doctor was good. You want to rely on someone, because I like the doctors. If you trust them it helps. He just comes in and talks to you and makes you, I don't know, he just explains the whole thing to you.

I don't feel that they could have been any more attentive. They all seemed to know what they were doing and they worked as a team...it was very precision-like. At the same time, they were very aware that I was a person.

I certainly felt that they cared about me, in spite of everything. I was a real person.

To ensure patient compliance with medication regimes, the patient must receive adequate information related to the rationale for being prescribed the medication, side effects to observe for and how to properly take the medication. Many of the women had received verbal instructions, regarding their medications, from the nurse prior to discharge. Most also received printouts of information with prescribed medications, and this had been reviewed with them by the pharmacist. This overlap was viewed as most beneficial in reinforcing information:

Now they give you information...a print out...and the pharmacist is there to tell you. It is emotionally better. You feel more relaxed and you can look at the sheet.

The doctors don't tell you (side effects), at the pharmacy, they'll give you one-on-one to talk about it, which is better, especially if it is a new

medication.

**Pharmacists are just fantastic. I take 10 pills a day so I have to make sure they are not going to react with anything.**

**All of the women agreed that they liked to have someone sit and talk to them in person when they were imparting information, but also found going home with printed material very beneficial.**

**Although not a negative comment, one woman voiced her preference when receiving education:**

**I found the doctors excellent, they were really good but the nurses are able, I was able to talk to them a little easier. The doctors are all men and they had a different way of approaching things.**

**A final comment that related to education was supported by several of the participants:**

**There were so many people coming in and out ...there to help you and they were so nice. If you really wanted to help yourself, take the opportunity that everybody was bringing to you, everything was there for you if you wanted it. And if you didn't take it, you were crazy.**

**Some women had negative experiences and felt that this was an appropriate venue for passing along suggestions for improving the approach to patient care. One woman told of a nurse who refused to help her with her morning care, even though she had intravenous lines in both hands:**

**She was just awful. I told her I was very independent and I don't ask for help if I don't need it and she didn't help.**

**Another woman was escorted by a nurse to another health care facility for diagnostic testing:**

**...so they called in somebody who didn't stay with me. She went and**

visited with her friends there.

In one case, a young participant, "Sue", verbalized that her sole purpose in attending the focus group was to have her story heard. She had a terrible experience while undergoing a coronary angiogram and felt totally abandoned by the health care system. In receiving her pre-teaching, she was reminded that someone had to look after her the night of the procedure, after she was discharged. This presented a major problem as she was divorced, her children lived in another province, her elderly mother was too afraid to care for her as "Sue" was extremely ill. Friends were unable to care for her because of prior commitments, or because they also realized how sick she was and were unwilling to accept responsibility for her care:

Nobody wants to have the lady down the street who is clutching her chest and popping nitros to stay over at their house.

She described the situation, in hospital, immediately before the angiogram:

Everybody was scared of me croaking on them, I was scared I was going to croak, you know. So I was there before the angiogram and I still hadn't found anyone to babysit me that night and I felt like a piece of garbage.

"Sue" tried to reason with the staff after the procedure:

The expectation was very clear that we just keep people who are from out of town, and I wasn't from out of town.

and even tried to take responsibility for her own care after discharge:

But they said everyone has someone and we trust you do and I had no one and it was just so awful. Finally I found someone who I could impose upon. The nurses waved me off, glad to see me go and I started out.

The situation got worse for "Sue" as being unfamiliar with the hospital, and

unable to walk great distances, she managed to get lost and found herself at the wrong entrance, some distance where she was to be picked up, with no energy left:

I ended up collapsing by a garbage can. I was so embarrassed, but I just couldn't move. My body told me that if you push yourself any more then you will die. And I kept thinking I have two daughters, their father is an alcoholic, I can't afford to die.

She stayed by the garbage can for about 45 minutes, with people passing by:

...I was too weak and people would look at me and they must have thought I was a drug addict. And I was thinking God I hope none of my students and their parents pass by. There's the teacher collapsed on (the street) by the garbage can. There was a security car that made rounds and I thought if I could wave at it, I could make them stop.

"Sue's" description of the situation only got worse, as staff from the department that had done the angiogram came outside for lunch, and passed by her:

They hadn't offered to help, but at least they knew where I was. So when the lady who was picking me up phoned they said she might be on (the street) and sure enough, there I was.

By this time, "Sue" was too weak to walk and needed to be helped into the car.

When relating the story, "Sue" was still visibly shaken, and although she was able to tell the story with some humor, she had tears in her eyes. The rest of the group was totally silent, and also teared up thinking of this poor woman, abandoned.

Her overview of the situation follows:

I think it is very cruel for those planning this to assume you will have someone to look after you. I felt it was the most difficult experience, far more difficult than the surgery. It meant I had to rely on resources that I didn't have. But to be forced to rely on someone when you have no one, it just crushed me. That's why I'm here.

**A need for guidelines in decision making was expressed in one situation:**

**I'm a novice at this - when I was in hospital, the doctor came and said well if you want to have a shower, you can have a shower. I had been in bed for 5 days and this was my first time up. I went and had my shower and afterwards, I thought, hey, maybe you should have told somebody you were in the shower. I knew better after that.**

**and one woman felt that not only did physicians exclude patients from decision making related to their care, they did not attempt to prepare the patient for the tests:**

**They just said, this is what we're going to send you for, just the different tests that they were going to do but they don't tell you what to expect.**

**The hospital stay was found to be extremely short, especially for one elderly woman:**

**When you're younger, you recuperate faster, but as you get older, they shouldn't throw people out of the hospital four days after heart surgery. It takes longer to recuperate and if you have nobody at home, what are you supposed to do?**

**Another affirmed her position, stating:**

**My open heart was on Thursday and I went home Tuesday. That's too fast for an older person...I was wondering, why are they throwing me out so soon.**

**In spite of praising the care received in hospital, the women did discuss how the health care system has changed in recent years. Staffing levels have been dramatically reduced, roles have changed, and this was reflected in the basic care received at times, and in the "little things" that were not done in hospital. Resources were available, but often patients had to make their own arrangements. One woman's advice to others was to arrange to have a**

**hairdresser come to the ward:**

**I kept getting my hair done twice a week when I was in hospital. I was too sick to wash my hair when I went in and it really lifted my spirits. I would recommend it to any woman going in there. It was worth the little bit of cost.**

**and health care aides, or unit assistants:**

**I valued the human aspects of the health care aides at the St. B. They made me laugh and I wanted to cry. They brought me a face cloth.**

**They were human beings that I could relate to.**

**Volunteers were also seen as a source of support:**

**I tapped into that as much as I could because I didn't have family around so the volunteers made a big difference.**

**A problem that was identified by some of the women was identification of staff:**

**You can't tell who is a unit assistant or who is a nurse. They are all wearing jeans and t-shirts. The dress code doesn't exist.**

**Several of the women did have home care in place after discharge and few were pleased with the services provided. One woman was especially unhappy and describes the situation:**

**She came for fifteen minutes, stood at the door and said to me, I don't do bathrooms, I don't cook, and I don't wash floors. I was in the hospital for over two months...and your stuff gets dusty. I wanted her to vacuum and do the bathtub, because I took a quick bath before I went (to hospital). She says she doesn't do that and she wanted a cigarette badly and asked me if she could have a cup of coffee. I was sicker than a dog. I couldn't even walk. I phoned and told them I didn't want her.**

**The women unanimously agreed that there was one area of education that was sorely lacking and had the most relevance:**

**I think they should have a little instruction book or suggestion book for the husbands!!**

### Spouse, Family and Friends

In spite of any difficulties with the relationships that were discussed by the women, they did verbalize a foundation of connectedness with their families. One woman, in introducing herself at the beginning of the group, broke down as she stated "I love my family". This triggered a multitude of emotions in the rest of the group, and in spite of the fact that we hardly knew each other, we all became teary and then started laughing at ourselves.

Several of the women described their spouses as being a source of support, but only one woman described her husband as being the best source of support. She described how he was not only psychologically and emotionally supportive, but he vacuumed, did laundry, shopped, and continued to do the cooking. The following comments indicate that some of the relationships were strengthened as a result of the threat of illness:

We get along better now than we ever did before.

I was very independent and we do our own thing, but he was my mainstay. He was my main support. He was the one I wanted so I guess there is good out of it.

I think he was absolutely stunned that anything could happen to me. He reacted interestingly, incredibly well. So attentive.

He has been just fantastic. When I do go to things in the evening, and I get tired, he knows. And if I say, I think we're going now, boom, we're out of there. He also says to me during the day, what are you doing today. He'll say, you're doing too much. So he's training me to do less.

Many women had stories to tell that did not portray their husbands as being especially supportive. As these stories unfolded, the women nodded in

agreement, having experienced similar situations. "They were just being men".

Several examples follow:

I really didn't feel well and my husband drove me to the doctor's office. The nurse said get to the hospital right now. My husband says to me, would you like to go for a coffee first?

Another woman added:

Oh forget it. He can't stand to see me sick. He gets scared. He runs.

and her statement was clarified by another participant:

I think all men are like that. I think they're scared.

Many of the women described themselves in terms of being a grandmother and it was evident that this relationship was a source of comfort and pleasure. Again, the group teared up as one woman stated what she was most thankful for:

I didn't think for a long time that I'd ever see my grandchildren. I was so sick, especially with my last heart surgery, so I didn't know if I'd ever be around to see my grandchildren...it is a great joy for me.

One of the participants described a story that she found distressing, and illustrated how her six year old grandson processed what he had heard about grandma being ill. He had come home from school all upset because he thought he was having a heart attack. He told her it was because his heart was pounding so fast. She explained that that happens when you run around, but she was unable to talk him out of this notion:

That was very upsetting and later I sat and talked to him about it after I stopped being upset but just felt terrible that he thought that. I didn't look any different so it's interesting how he was playing out information he didn't understand.

A similar experience was described by another woman:

My grandkids, they keep looking at me, they say you don't look like somebody who has had a heart attack. They came over to see me right away, they're 10 and 14, and they couldn't believe I had a heart attack. They say you don't look any different. They're just being nice. They don't understand.

Perceptions of family support varied, and in some situations level of support was questionable:

My kids were more supportive than my husband. He's one of these guys who doesn't say much. If you are sitting and you can't get up to make him a coffee, he says don't worry about it, you don't have to. What I like is he doesn't yell or say something if you're not feeling good.

It's the house that really frustrates me, because my husband sits in his chair and watches television.

Mine retired and he sits in front of the TV from when he gets up in the morning and it's just really hard to work around that. Women don't get to retire.

I keep a lot of it to myself. My kids would probably listen to me but I don't think they'd understand. And my husband I know won't understand.

and in some cases was overwhelming:

My family was over supportive, they were a royal pain sometimes.

I was so scared, and then my two sisters had to come and see what was happening. You're lying there...tubes in both arms, monitors on, an oxygen mask on and I look at the two of them and they're both going green and crying. And I'm thinking, go home, leave me alone.

While I was waiting for surgery, the doctors wanted to try out medication to see if that would help me and my daughter was very emphatic. No don't want that. She's due for surgery and that's what we're going to wait to have.

Most of the women stated that they did not like to ask for help, but liked

the security of knowing that help was available if needed:

You know they're there and if you need them, they're there for you....I can't ask for anything more than that.

My family and friends were very supportive and they were anxious to know what they could do to help.

For the most part, women verbalized that even if understanding was not forthcoming, assistance was available:

I have lots of support from my daughters...sons...and my two sisters are wonderful. Even the children who live in Toronto, they kept phoning me to see how I was.

and many found that their daughters were vigilant in terms of ensuring compliance with the discharge instructions:

(my daughter) says you're not doing your exercises, are you? and she gave me such a talking to, she went and told my other daughter, who is the nurse. I had just the two of them on my back but I needed it. Well, you know, after she left, I thought I'd better get up and get dressed or somebody is going to catch me.

My daughter (would) say get dressed and go have your shower. Then she'd tidy up the house and say go sit in your chair and do your exercises. And I'd be having a rest and she'd say I can't hear you...She's a great support. Oh, God, she just drove me insane, but I mean, it helped.

Some of the women chose to be selective in what they told their children, because they did not want to bother or worry them:

I didn't tell my daughters what I told you. I didn't vent with them. I told them it was bypass surgery and it's really nice in here and it's no big deal...I didn't want them to worry. I kept telling them the doctors and orderlies are so nice and so cute, so one of my daughters mailed me some condoms and said to enjoy my stay in hospital. They phoned me and I really appreciated the contact with them, but I didn't want to interfere with their lives.

Friends were a good source of support:

**You need somebody to get you going!**

**I have a whole host of friends who have been most attentive. They were all showing up and bringing me food and they are still all helping. It was funny, as initially they all hovered, talking in hushed tones.**

**I have a friend, "Cathy" who is like a mother to me. She did everything. She looked after me.**

**although in some cases more forceful than family members would have been.**

**One woman was suffering tremendous back pain, and feeling very unwell when a friend phoned to confirm their dinner plans for the following day. As soon as the friend heard what she was experiencing, she said:**

**My God, you're having a heart attack. I'm phoning an ambulance.**

**One woman's husband phoned her friend on the coast as his wife was not herself and he was unsure of what to do. The friend phoned and said "What the hell are you trying to prove? I'll be there tomorrow". Once she arrived she took over:**

**And that's all it took. I didn't want to go out and she said you're going out. You need new clothes, you've lost a lot of weight, now come on, smarten up. In three days, she left and I was just fine. I don't know what that was all about but it definitely was connected.**

**One woman did report that her father-in-law's response was "it wasn't my fault that you had a heart attack". She did not clarify what the relationship had been like previously.**

**Half of the women in the study lived alone and felt that even though they were doing their best to retain their independence, and might not believe that they needed to be watched over at the time, some type of mechanism or follow-**

up needed to be in place to ensure their well-being:

There wasn't anybody really there but I had a friend who would call every half hour or every hour to see if I was okay, but you know that's a long time, so, I don't know. I'm finally realizing what people say when they are alone they carry a little beeper with them

or....

I make sure I have the phone right beside my bed.

Thank God for 911!

Another woman felt that personal contact was essential:

They should have someone come and, over to the house, not by telephone, but over to the house and see how they are doing periodically. Even if it is just a neighbour.

#### Validation

The third main theme, validation, was also threaded throughout the discussion as the women compared and contrasted their experiences. They often asked "Did you feel the same way?" or "Were you treated the same way?" This was an attempt to normalize their experience, as well as an information seeking and information sharing exercise. Great comfort was derived from knowing that others had shared the same journey.

The topic of death was broached by one woman who initially bemoaned recently having to pay to replace her hot water heater but clarified:

...it comes with the territory. I'm glad to be around to be able to do it. For a while there, it was just...

The group had previously been laughing about a shared joke and became silent and introspective at this comment, nodding, and looking down at the table in

front of them. This brush with mortality was a shared experience that was too real. Many of the women had clearly thought about the possibility of death, as discussed in the following conversation:

You start thinking about the future, well, maybe I better wind up things and get things organized. I know I've been thinking a lot about having a will, you know. I don't want to be around to suffer.

Oh, do you have a will?

A living will?

Yes, I have one, too.

That's what happens, it doesn't work all the time. I told my children what I want them to do and I guess that's not the smartest thing in the world. I guess what you really have to do is write it down on paper but hopefully there won't be a problem.

I think a lot about living, mostly living, but I always think of death. It's got to come.

When I had my last surgery the doctor...almost lost me twice and ever since then I think so much dying, you know.

You're just scared to die.

During this exchange, the group was very subdued, and kept nodding, indicating that they shared the same feelings. One group of women, in particular, expressed more concern about dying alone:

I don't like being by myself. I'm anxious if I'm alone in the house. This may sound stupid but when I pass away, I don't want to be alone. That's right. When I had my cardiac arrest, I asked my husband to take time off work and my daughter had just gone back to Vancouver and she turned around and came right back. And I said, I don't want to die alone. They stayed with me for two days, all night and all day.

The expressions on the women's faces changed dramatically during this

conversation. It appeared that having other women verbalize these same fears took a great weight off, as the feeling was now considered normal. One of the women described how she actually phoned the ambulance service and asked "How do you get into people's houses if the door is locked and they are upstairs?" She was told to leave a key with a neighbour, but her solution was to have an alarm system installed and she leaves the door unlocked with the alarm system activated. This story prompted other women to admit that they had a similar solution to the same dilemma:

Did you do that, too?

I like to leave the back door open.

So it's not just me?

No, it's not just you. I still feel that way.

I don't feel anxious at all, now that we have the alarm system.

Many women had a fatalistic attitude towards death:

...and now I figure, well, if I'm going to go, I'm going to go but I'm going to enjoy myself while I can.

God ain't finished with me yet.

People keep saying I look good, but I don't feel good. I guess it's still better than the alternative.

Life just goes on. Whatever will be, will be.

Use of medication was another area that women needed to share and

affirm:

Of course I forgot to put my nitro patch on today so...

**You have the nitro spray?**

**I've got the nitro spray.**

**So do I.**

**Are you having chest pain now?**

**While this conversation was circling around the group, each of the women dug into her purse and brought out their particular form of nitroglycerin.**

**Comparison of side effects is illustrated in the following conversation related to nitroglycerin:**

**I had the patch and it just drove me crazy.**

**Did it give you headaches?**

**Headaches? I've never had them so bad in my life**

**I know, it just felt like your head was going to explode.**

**I was just the meanest creature in the world, I couldn't live with myself.**

**One of the other groups had a similar discussion:**

**Oh, I know, I still get it when I use my patch.**

**You do? Do you get it when you use the nitro spray?**

**Sometimes, if I do I get it really bad, right here.**

**Where was yours, here?**

**I used to get it right here, I used to feel like right here, really...cause it opens the blood vessels.**

**Lack of education was also a topic of conversation, as the women sought validation in feeling they should have been informed about the use and side effects of nitroglycerin:**

**They are so negligent. They didn't tell me I could get these headaches, but I did complain.**

**They gave me the nitro spray and they didn't say anything about that....**

**I had chest pain and I did have the spray but I didn't know more or less what to do with it.**

**...well he said try this next time you have a pain in the chest.**

**Aspirin use was one topic that the women clearly wanted to validate, and there was an assortment of information that was shared:**

**If you have to take baby aspirin, you can get it at Walgreen's in the States, enteric coated baby aspirin or they also call it adult low dose...it costs \$8.00 for 250 and here it is about \$6.00 for 24.**

**Why baby aspirin?**

**It's a lower dose.**

**The value of aspirin was unclear as a result of vague information given by the physician:**

**They took away the coated aspirin. They said it would thin my blood, but then they took me off it. He said you don't need it.**

**A question that arose in one group was whether aspirin should be taken when one was also on nitroglycerin. One group had been told to keep aspirin with them and take it on experiencing chest pain, although they were not all on consistent dosing on a daily basis.**

**Education was another area that prompted discussion and comparison. Even though many were confident in the information that they had received, they were continually validating, and looking for new or varied information on an array of subjects. Organization was a shared trait as one woman brought out a file**

folder which contained every piece of information she had received. This prompted the rest of the women to bring out and compare their folders, containing health histories, discharge sheets, photocopies of hospital charts, and educational books from many rehabilitation programs in the city. This information was obviously well-read and areas important to each of the women were highlighted or marked in some way.

Many of the women found that they had received more than adequate information and were happy with their level of knowledge. Information sharing and validation of choice of stores is evident in the following conversation:

I get information from Shoppers and Safeway. It is very good. They tell you what to expect.

I was going to call Superstore because it is so much cheaper but after I had my heart attack and I was on so many medications, I went back to Shoppers even though it is a lot more money.

Yes, that is the drugstore we go to all the time.

Well, my doctor told me she didn't like Superstore.

Even at the hospital pharmacy, they gave me fact sheets on my medication.

Extreme fatigue was reported by each of the women in the study. This was a source of frustration that required validation:  
I sleep all the time. That's one of the main things. You're more tired.

Oh, yes.

I'm tired all the time.

You don't have the energy.

You too?

Similar exchanges occurred in every focus group. In seeking validation, group support was evident as the women listened intently while each story was told, nodding to indicate empathy, if not sympathy.

### **Living for the New Me**

In this last main theme, Living for the New Me, wherein the women discussed the process of coming to terms with having CHD, two categories emerged: Roles and Responsibilities and Lifestyle Change. It is at this point that a choice was made about how one chose to respond, based on individual values.

#### **Roles and Responsibilities**

The women in the study reported many changes in their lives after a cardiac event. The most difficult one was the change in focus from looking after other people to looking after oneself:

**You start taking care of yourself after something like this happens. Before you looked after everybody else.**

**First of all my health comes first and the rest comes after.**

**I would just take care of everybody else...now I stop and think and pull back and say, have I enough energy. You can't run around like that forever.**

**I am first, my health.**

**I think the same way, too. I'm first, if I don't feel like going somewhere or doing something, I don't do it. You know, I can't force myself, I don't force myself to do anything physical that I don't feel that I want to do.**

**You need to put yourself ahead of everybody, if you're having chest pain or if you're not feeling right.**

Even though they were verbally forceful when making these statements, there was an apologetic tone in their voices, and it felt as if they were waiting for some sort of retribution for being "selfish".

Diminished energy level was a source of frustration for all of the women and required planning to effectively carry out activities of daily living. One woman described how making her bed took her almost an hour:

You get the stuff off and you have to sit...and wait until my arms get feeling better. Then you can go back and do another bit, tuck them in, maybe put the bottom sheet on. For two years it took longer than that and then I'd be finished for the rest of the day until I got my energy back. And when I was able to finally do it in one bunch ended up taking an hour.

Others describe their experience with fatigue:

It runs out - I wake up with energy but it goes really fast.

A lot of times, I just sit back in my chair and snooze, even if it is 10, 15 minutes, you need it. You just can't stay up.

I do find that I go to bed earlier..I'm just bushed and I have a sleep every day after lunch.

I just get tired, really tired. I start doing something and I have to stop because I'm just tired. I get to bed early but I can't sleep so I read and listen to music.

Your body tells you when you're tired.

You become more in tune with your body. I know my body. There are things I can't do and just soon as I start, I know I have to back off.

Yes, I certainly know when I have done enough. There is a curtain that comes down that says okay, go to bed.

I'm so tired. I have been reading that women will be tired. I've been noticing that when I'm really, really tired, that's when I probably have to use the nitro. That's almost a given.

I worry about getting too tired because that's when I had my cardiac arrest. I've never felt that tired in my life.

Much discussion particularly centered around the inability to resume a typical woman's role, that of housework and taking care of the family. Sometimes this was because of physical difficulty as a result of cardiac disease, and sometimes it was related solely to fatigue. Whenever this topic was discussed in each of the groups, the women were in agreement that they felt a particular need to be in charge of this domain. Even the younger women had been socialized to focus on this responsibility. Those women who were married reported that the husband's response was usually "don't worry about it". It was unusual for the husband to either take over housework or make arrangements for it to be done. Some of the women's comments are outlined:

**It just frustrates me because I can't do the cleaning.**

**I'm not Mrs. Clean...but just when you can't do it, you get really frustrated and annoyed.**

**I don't vacuum because of pushing and pulling, stretching.**

**When I'm tired, I sit down and rest and if I'm really busy in the house, cause once you get tired, you just can't. Everything is a really big chore. So if you have a rest for 15 minutes, then you can get up and carry on with some enthusiasm.**

**Most of these women reported being active and involved in a number of activities previously and were frustrated at their current inability to do as much as they could before, as discussed in one group:**

**I still feel like I should be doing more than I do.**

**It really frustrates me because I can't do the things that I want to do.**

**It's hard to deal with, to say no.**

**When asked whether this frustration was a result of family pressure,**

women in the following conversation agreed that the pressure was self-induced:

We do it. My family is really supportive, but we just can't stand that.

You know, we may be trying to prove something to ourselves.

I think that you kind of want to get back into your normal life.

We're just proving that this is something that is just never going to happen again. You go on with your life.

That's right, yes.

### Lifestyle Change

Although many of the women did experience some change in lifestyle as a result of cardiac disease, two women found that their lives changed completely:

I don't work and I just have time to do what I like to do. I go three times a week to the Reh-Fit. I do lots of things but I have to pace myself. If I don't rest one day then I won't be able to do my things the next day and I have trouble sleeping.

I was working in a job that had high expectations in terms of putting in the time, so I quit my job. I made a lot of changes. I re-evaluated why I was doing this, running someone else's business instead of doing things that you want to do so it made me stop and look at my life. Now I do things I want to do for a change.

Overwhelming fatigue was a major factor influencing lifestyle and this was experienced by all of the women. This was, in part, due to their inability to sleep:

About 9:30 at night I'm ready to go to bed. I don't sleep when I go to bed, but I read and at least I'm laying down and relaxing.

I don't sleep at night and I can't get up early in the morning. Right now I'm tired.

I'm tired from doing nothing but I can't sleep.

My doctor told me that when you get older you don't need as much sleep as you do when you are younger. If I get two hours of sleep, that's about

all I get.

Some of the women dreaded the approach of nightfall because of their inability to sleep:

I make myself worry and I get so worked up at night. I worry. I try to think of everything else but nothing will come into my mind. So I get up and go make myself a snack.

I just dread when night comes.

I do too. I think I'm sick worrying about worrying before I go to bed. But what am I going to do? Knock my brain out?

One woman reported fearing nighttime because going to bed signalled the return of leg pain:

I know it's coming. It's good when I first lie down and then all of a sudden I can feel that burning pain start. It doesn't happen in the day time.

I dread the night

while others reported sleeping better than ever:

I'm out cold.

Even the women who slept well, still reported difficulties with fatigue.

Activities need to be paced and reorganized to accommodate fatigue:

I try and do most of my things in the morning or just shortly after because I have a bit of a nap. I can't make it, well, I could, I guess, but I feel better if I lie down in the afternoon and rest.

Most of the women in the study had participated in some type of cardiac rehabilitation program and many were still engaged in some type of regular exercise. Some maintained memberships in organizations such as Reh-Fit or the Wellness Centre, and some had a more informal program that they carried out on their own. The general consensus is that "you look after yourself a lot

**better now":**

**I would advise definitely that (women) get in contact with a place like Reh-Fit. I know I'm biased because I like the Reh-Fit, but any exercise program which has been planned for you by a professional who knows what you need, given your health. I believe that's the biggest change I've made. Even if sometimes I feel I don't want to come, I'm glad that I do.**

**One woman reported:**

**Several years ago, I asked my doctor if I should take an exercise program and he said, no, you don't need to. He also told me my cholesterol was fine. But I thought I'd come to the Reh-Fit anyway. Nobody exercised years ago, and nowadays they'll tell you, it doesn't matter whether you are healthy or not, exercise will improve your health.**

**Several of the women spoke of financial concerns or time constraints**

**influencing their decisions to remain in a rehabilitation program:**

**I'm a school teacher and this year I'm working .75 instead of full time because I needed to have time and energy to commit to coming in here (Reh-Fit).**

**I've always got lots to do and coming here three days a week, I sort of quibbled with that, but I realized that I had to look after myself. For about two weeks I stewed. Who wants to pay \$400.00? Then I said, be good to yourself. And I enjoy coming here.**

**but many agreed with one woman who succinctly and forcefully stated "I realized I had to look after myself".**

**Choice of recreational activities changed for some women depending on what they were able to tolerate. Many women previously curled, but found that they could no longer tolerate the cold and sweeping was difficult. They took up golf, and use a cart if they are unable to walk. One woman found that her motivation was canine:**

**I had my dog and that got the walking going.**

Insecurity was a problem, and many wondered about the future:

**I always wonder, is there something wrong with me?**

**My biggest question is am I ever going to feel a big improvement in the way I feel. Since I've had my surgery, I just feel like I'm just not whole. I can't do the things I want to do and it is frustrating.**

**I hope everything is okay with me, but you do worry a little bit. I do sometimes you know.**

**The toughest thing about a heart attack, for me anyway, is the fear that goes along after. It is one thing to break your arm and watch it heal; it's another thing for a good year to live with having had a heart attack because...anytime I felt even a little uneasy, I would think oh, is this...? That's the hard part. You really don't know what's going on inside you.**

**I look back on things I did in the past and I thought, will I ever be able to do that again. Some of it I won't do.**

**There was a real sense of loss as women outlined the things that they could no longer do:**

**You can't brush the dogs. I can't take my dog for a walk because she's a big dog and she's got a lot of power in her.**

**I can't lift up the grandchildren. The littlest one I can because he only weighs about 25 pounds, but he has to jump to help me pick him up. You hold him for about two minutes or a minute and then it's okay, down you go.**

**I had no patience for the grandchildren. I wished my daughter would come alone.**

**I had to change some things with the grandchildren. Not lifting them and not, you know, grandma just couldn't come and take over so they could go away. My oldest daughter was the best, but the other two. Oh mom, could you come do this with the kids. Even just to get them into the crib!**

**I can't go and dance, I used to love going to dances.**

**Concern about body image was only addressed by one woman, who was**

**the youngest participant:**

**If I wanted to wear a scooped-neck dress, I can't because now I've got that scar. I guess as we all get older, it won't matter. I mean a scar is kind of normal.**

**Many wondered if they would ever be able to drive the car again. One woman who travelled extensively did not know if she would be able to travel again, especially by herself. She also doubted that she would ever go to a Third World country again as she would not want to take the chance of getting sick there.**

**Excess weight was a problem for some of the women, and, it seems, a constant battle:**

**Everybody says, well, if you'd lose weight, you'd feel better. If you've got a heart problem, how easy is it to go out and do a lot of exercise.**

**Women who lived in rural areas found this a particular problem, as they did not have access to the same types of rehabilitation programs that existed in the city. Walking outdoors posed a problem because many of the roads were isolated and in the winter time the roads were very icy. One woman described:**

**I've got a circular driveway. I could walk around but I go around once and that's it. I'm finished.**

**Change in diet also accompanied CHD and the women were knowledgeable about dietary restrictions. They were able to verbalize changes that had been implemented:**

**We have not to have anything to eat that has cholesterol for one thing...No good food! I have a book that tells me what to eat and what not to eat.**

**Because I'm on blood thinners, there are certain foods that I can't eat.....because they have Vitamin K in them. Vitamin K thickens your blood.**

**That's the biggest change I've made - watching the food I put in my mouth, to maintain a healthy diet.**

**but they also indicated that sometimes this was difficult:**

**...women should really look after themselves and eat proper food because, so many times, women are always on the run, looking after their families or going to work. And they just grab a bite to eat and most of the time it is not nutritious.**

**If I want to have specific things or a low calorie meal I have to fix that just for me because he (husband) won't change.**

**One woman's response to the dilemma of cooking one meal for the family and one for herself was:**

**Oh, phooey on that. That would be the frosty Friday!**

**Some of the women reported having to be very careful in their daily activities because of an increased incidence of bruising as a result of being on anticoagulants:**

**I bruise very easy. Somebody can just pinch me and I have a bruise.**

**I've always got bruises.**

**I don't even know where I get them from.**

**Just bump against me and I get bruises. So you have to be careful.**

**Many of the women had to learn new skills, including how to take a blood pressure and finding their own pulse, and described no difficulties in acquiring this expertise.**

**The majority of women in the study reported that the changes in their lives**

were for the better in most cases:

Before my surgery, I was taking 42 pills a day as well as about 14 nitros. I couldn't walk from here to that door.

After my heart attack I came to Reh-Fit for the six months that they give you on your Blue Cross. My own doctor said to follow it through, which I did. I was initially amazed that I could even manage 1/4 of the track, and at the end of six months, I was roaring around the track.

I've lost 30 pounds.

and an added bonus was that some family members, especially husbands, reaping the benefits of eating a healthier diet and exercising as they participated in activities:

He's probably eating more healthfully now because that's the way I cook. I don't use salt any more, things like that.

Stress was not a major topic of discussion, but was acknowledged as a part of our every day lives. Many of the women noticed a decrease in stress that came with leaving their jobs due to illness:

For women who are still in a work situation I find that it is getting more and more stressful, dealing with people, dealing with the public, dealing with co-workers.

I changed my profession.

Stress was managed in a variety of ways:

I think we are more aware of stress. We're more conscious of it now. I know I try to back up, but that's because I'm more aware of the damage that it can do to people in their lives. You're much happier if you can cool it.

I only come to Reh-Fit at the times when the big traffic is gone.

Throughout the study, women verbalized how they had implemented and

coped with the changes that were dictated by their health status. The biggest challenge and a source of continued frustration was the discrepancy between their mental will to be active and their physical inability to respond, whether due to fatigue, or medical and physiological restrictions. Although the women knew this was unrealistic, in their hearts, they all harbored the same wish:

I want to be able to do everything like I used to do.

#### 4.3 Chapter Summary

Utilizing focus groups, women with a common diagnosis (CHD) were brought together and encouraged to tell their stories and discuss their personal experiences in a supportive, understanding environment. Thematic analysis was utilized to develop the four themes that emerged from the categories evident in the focus group transcripts.

The first theme of Being Heard encompassed four categories. Three represented the women's ongoing struggle to have their pleas for help heard (Finding Your Own Voice) and gain access to the health care system (Convincing the Gatekeepers) once they came to the realization (Heeding Your Body) that something was very wrong with their bodies. The fourth category, Telling Others, was the passing on of insights that would hopefully make the journey easier for other women.

The second theme, Helps and Hindrances, contained two categories, The Health Care System and Spouse, Family and Friends. This theme outlined the behaviors and interventions that were considered supportive throughout the

journey as well as those that were not helpful. By being clear and honest in identifying one's needs, those who were willing to be of assistance, could more effectively intervene.

Validation, the third theme, allowed women to discuss and normalize their experience, by comparing their perspective with others who had shared a similar experience.

The final theme, Living for the New Me, outlined the Lifestyle Changes the women had to accommodate as dictated by their conditions, including diet, exercise, and medications. The category of Roles and Responsibilities outlined the more personal changes that were experienced. Losses were discussed, and adaptations necessary to accommodate their changed physical needs, especially in terms of fatigue, were shared. This is where the true meaning of the experience of living with CHD and individual methods of coping were revealed.

## CHAPTER FIVE

### DISCUSSION OF THE FINDINGS

#### 5.0 Introduction

This study explored the experience of women living with CHD and their struggle to overcome barriers to care. A background to the study will be provided, along with an overview of the research question and study design, discussion of methodological issues, the findings as they relate to the literature and finally, suggestions for nursing practice, education and further research.

#### 5.1 Background to the Study

Historically, heart disease was considered a normal process to be expected in old age (King & Paul, 1996). It was not an important health issue, unless it occurred in younger men, interfering in their productive years, thus this population became the focus of interest in the early 1900s. Heart disease in women was perceived as "a hindrance to the ability to fulfill the roles of childbearer and homemaker" (King & Paul, 1996, p. 89). The notion of feminism, that which is "woman-centered" (Hamilton, 1993), emerged in the 1960s, and helped to direct attention to women's unique health needs apart from their reproductive role. Boogard's (1984) article on women recovering from myocardial infarction is credited with being instrumental in gaining the attention of contemporary nurse researchers and stimulating the interest in exploring women's experience with cardiac disease (King & Paul, 1996).

Healthier lifestyles and advances in medical and surgical treatment have

contributed to the steady decline in death rates for CHD since the 1950s (Fields, Savard, & Epstein, 1993), although the decline has not been as rapid for women.

Cardiovascular disease remains the leading cause of death in North America, claiming 40,000 women annually, and almost as many men (Heart and Stroke Foundation of Canada, 1999). CHD has traditionally been viewed as a disease of middle-aged men (Wingate, 1991). In Canada, the Heart and Stroke Foundation (1999) reported that 86% of women were unaware that the most serious threat to their health was heart disease and stroke and physicians were equally unenlightened (Libov, cited in Women's Connection Online, 1997).

Typically, men experience heart disease in their 40s or 50s, and women about 10 years later, coinciding with menopause. When naturally occurring estrogen is no longer produced by the ovaries, women lose their gender-based cardiac protection. Women live longer than men do, and the likelihood of a woman developing heart disease increases with age. It is predicted that by the year 2015, almost half of Canadian females will be 45 years or older, making this a significant population.

Our knowledge of cardiovascular disease is based on research in which the white, middle-class male perspective was central (Duffy, 1985; Sigsworth, 1995; Wuest, 1993). The FDA only reversed its policy on excluding most women from early phases of clinical trials in the early 1990s (Bennett, 1993). As attention turned to women and CHD, researchers identified unique female attributes for risk factors (Giardina, 1998), gender based therapeutics (Woosley,

1998), physiology (Romeo, 1995; Wingate, 1997) perception of risk (Liebert, 1997), attention to symptoms (Dempsey, Dracup, & Moser, 1995), self care actions (Hartweg, 1993), and recovery rates following CABG surgery (Sauve & Fortin, 1996).

In spite of advances in recognition of the differences between men and women, with respect to CHD, gender bias does still exist. Schwartz et al. (1997) found that even those women who were properly diagnosed, were not treated as aggressively as men, were less likely to be prescribed prophylactic medication, such as aspirin, and were not prescribed standard diagnostic procedures as often as men. Mosca et al. (1997) suggested that this might be due to difficulties encountered when treating women as a result of gender differences in presentation, varying accuracy of diagnostic tests and atypical symptoms. Even when women gained entry into the health care system, they were less likely to be slated for angiography (Ayanian & Epstein, 1991) or revascularization (Amsterdam & Legato, 1993; Wenger, 1992).

## **5.2 Research Question and Study Design**

The research question was "What is the experience of women living with coronary heart disease?" Sigsworth (1995) advocated that feminist research is based on women's experiences and the validity of women's perceptions as their "truth" is recognized. The decision to undertake this study arose from the need to address continuing gender bias in the treatment of women with CHD.

Feminist theory formed the basis of the study, acknowledging three principles

that Hall and Stevens (1991) identified as inherent in feminist inquiry:

- 1) a valuing of women
- 2) a validation of women's experiences, ideas and needs
- 3) acknowledgement of conditions that oppress women and a desire to bring about social change.

In taking a feminist perspective, the researcher is joined in a reciprocal relationship with the participants and attempts to understand the world from their perspective (Hall & Stevens, 1991). As a woman, and one with a strong family history of heart disease, I truly took a personal interest in the stories the women had to tell. This sincerity allowed me to quickly develop a rapport with the participants and they were willing to confide their stories in a safe, supportive environment. I could see how difficult their world became on feeling that first cardiac twinge, whether vague or classic in nature.

The Human Response to Illness Model (Mitchell, Gallucci, & Fought, 1991) views an individual's response to states of illness and to situational or developmental transitions or crises. This is accomplished from four perspectives; normal physiologic regulatory, pathophysiologic, experiential and behavioral. The latter two perspectives guided data gathering. From the experiential perspective, information about the personal experience was generated by self-report and captured on audiotape. Behavioral responses, motor and verbal, were observed and captured in field notes.

### **5.3 Methodological Issues**

Gulanick and Keough (1997) described the strength of the focus group as "the ability to uncover emotions and feelings that other methods often fail to reveal, and to provide qualitative insights into the personal experiences of individuals" (p. 24). It was this attribute that led to the decision to use focus group methodology to elicit the responses that would answer the research question.

A total of 28 women participated in the study. Six focus groups of between four and six women were conducted. The participants were assured of confidentiality and encouraged to be open in their discussion. The study received ethical approval from the Ethics Committee at the Faculty of Nursing at the University of Manitoba and access approval from the Health Sciences Centre Research Committee.

The length of time from the cardiac event ranged from 6 months to 31 years. The women were provided with a Discussion Guide (Appendix K) prior to the focus group session, to give them an idea of the content to be discussed and to help them organize their thoughts. This possibly assisted with recall, as even those women who had experienced their cardiac event in the past had no difficulty in recollection of details of the experience.

In spite of differing backgrounds and a range of ages of participants (47 to 88 years), the focus groups were cohesive and the discussions were productive.

I began each focus group by having the women talk about their hobbies, and

what they liked to do in their spare time. This was effective in facilitating initial conversation on a non-threatening topic, as women began to talk about common interests. I was pleasantly surprised at how quickly the women became comfortable with each other and at how openly the participants discussed their experiences. I did wonder, in two of the groups, if taping was going to be a deterrent to conversation, as some of the members seemed to focus on the tape recorder, when I turned it on initially. Fortunately, they very quickly became at ease, and this was not a problem.

Each focus group was scheduled to last no more than one hour, but four of them lasted up to 90 minutes, and all of the discussions continued long after the tape recorder was shut off. This suggested that the women who did choose to participate had a need to tell their stories. The groups did verbalize a wish that a discussion group such as this could continue, as they had found it helpful to share stories with a group of women who had been through a similar experience. It was apparent by the nature of their discussions that the women had received adequate education, either in hospital or in cardiac rehabilitation, with regard to medications, testing, lab results, and healthy lifestyle. The nature of their questions, that surfaced after the tape recorder shut off, were more personal, and to them, silly, but important. One woman wanted to know exactly what they had done with her heart in the operating room as she had a picture of it sitting somewhere on a plate. Several women wanted to know what cabbages had to do with your heart.

The tapes and field notes were reviewed after each of the groups was held. Effectiveness of the questions, responses elicited, as well as role of the moderator were evaluated and strategies for change were considered prior to the next session. The only major change instituted was being less directive. I was fairly controlling in the first group, which did not appear to adversely affect the discussion or the quality of the data, but I found that once the women started interacting, the groups generally took themselves through the same range of topics without my assistance. I kept track of the nature of the discussion, and if content was missed, I used a lull in the conversation to elicit a response.

The only real difficulty I encountered in conducting the focus groups was recruitment and I can only speculate on why women were unwilling to participate. Because of the number of women who attend the clinic, I initially was only soliciting participants from the Cardiology Clinic at Health Sciences Centre. Staff reassured me that I would have my quota of clients in no time, but unfortunately this did not happen. Staff were informing patients about the study, pamphlets were taken from the displays in the clinic, and the women I approached while they waited for appointments seemed interested in the study. Because I had no way of identifying these women, I did not have the opportunity to follow up and investigate why they had chosen to not participate. Possibly, because Health Sciences Centre is a large teaching hospital, the clients had been subjected to too many students seeking participants in research studies. Staff, overwhelmed in a busy clinic setting, might not have had the time to promote the study, other

than passing on pamphlets. Another option was that the women just felt too unwell to participate. As a result, I expanded to other sources.

The best response was from the clients at the Reh-Fit Centre. I was again expecting a mild response at best, because this recruitment was occurring over the summer time. Staff were extremely helpful, and clients also actively passed along information to those who might be interested in participating. The female clients at Reh-Fit were clearly interested in promoting and maintaining their health, and were willing to be vocal in letting others know about their experience. The other factor that positively affected recruitment was my ability to interact with the women directly. I was very visible, participating in the classes, exercise groups, walking on the track, and quickly became known to the clients.

Recruitment in the Interlake Region was diminished, possibly because I was unknown to the members at the Gordon Howard Seniors Centre. As well, there was a local campaign, at the time, by the RCMP, directed at seniors, cautioning them about interacting with strangers.

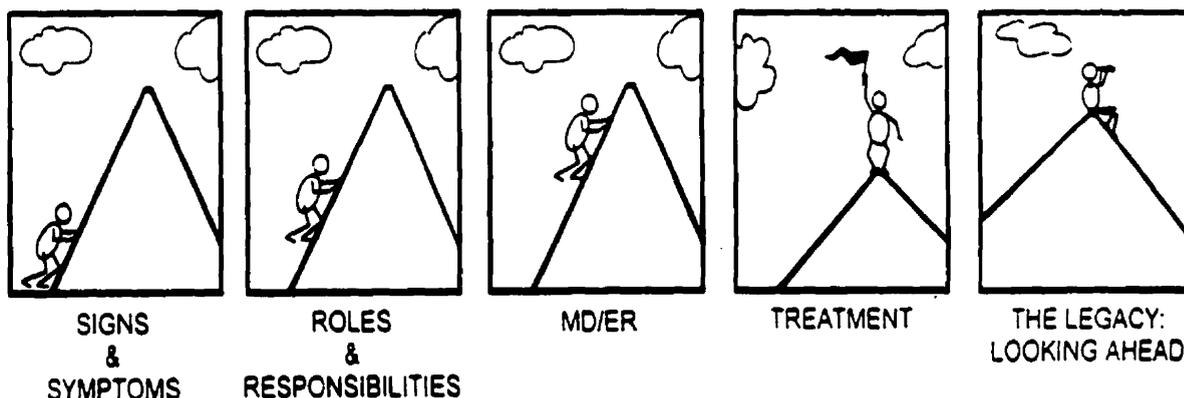
The women who did participate contributed valuable information to the study. Women had their own personal reasons for choosing whether or not to participate. Although I remain curious as to the actual rationale, I remain grateful to the women who did choose to be a part of the study. I was able to recruit enough participants to reach data saturation, which occurs when no new information is forthcoming (Carey, 1995), with more emphasis on the richness of the data, rather than the amount collected.

#### 5.4 The Findings as They Relate to the Literature

Of recent, it has been identified that coronary heart disease is more significant in women than previously acknowledged. The differences between men and women, and issues specific to women, are receiving increased attention in current research. Although there is little research currently devoted to the experience of women living with coronary heart disease, this study did support the findings of those studies, which have been conducted (Angus, 1996; Benson, Arthur, & Rideout, 1997; Boogard, 1984; Hawthorne, 1993; Hawthorne, 1994; Helpard & Meagher-Stewart, 1998; LaCharity, 1997).

In analyzing the transcripts, and organizing the data into the categories and then themes, it was necessary to read the information over repeatedly. It became apparent that what was evolving was evidence of continued gender bias, producing barriers to accessing care, not only by the health care system, but by the women themselves. What they were experiencing was an ongoing struggle, an uphill battle, to attain legitimacy. This struggle is depicted in the following schematic overview:

### **BARRIERS TO CARE**



The categories and themes that evolved from the process of data reduction are intertwined in this depiction. One, or several, may take precedence at different times along the illness trajectory, depending on the barrier. The initial barrier was the recognition and acknowledgement of signs and symptoms, then overcoming roles and responsibilities in deciding to seek care, breaking past the gatekeepers to access treatment and finally, living with the legacy, positive or negative.

### Signs and Symptoms

The struggle originated with the women themselves, and their knowledge, recognition or acknowledgement of signs and symptoms. Possibly because women developed symptoms of CHD later in life, there was less concern directed to the issue, both by women and physicians (Halm & Penque, 1999). Gender bias was widespread in believing that heart disease was a "man's disease". "Women are less likely than men to have a myocardial infarction as the initial presentation of coronary artery disease" (Hendel, 1990, p.44), but if they do, it is more likely to be fatal (Rimmer, 1993). Wenger (1990) found that women were more likely to experience angina as a first indicator of coronary artery disease.

Halm and Penque (1999) describe "classic" chest pain as crushing or stabbing, with fullness or squeezing in the center of the chest, or an uncomfortable pressure. These were usually triggered by exertion and relieved by rest. Pedwell (1995) added that the signs of a "man's heart attack" were

dramatic and included pain shooting down the left arm. "There's no doubt in anyone's mind that he should be whisked off to the emergency department with red lights flashing" (Pedwell, 1995, p. 68). Some of the women in my study, having cared for husbands with cardiac problems, recognized their own signs and symptoms as indicative of cardiac distress. They sought help immediately and gained entry into the health care system, being treated with the same urgency as male patients with a similar presentation. Diagnostic tests were carried out, appropriate treatment was prescribed and they were discharged home with instructions for subsequent care.

The remaining women in the study experienced vague and unusual signs and symptoms. Some described feeling sweaty, nauseous and dizzy, or reported overwhelming and unexplained fatigue. Heartburn was a common symptom (Moser, 1997), that was treated at home, and not viewed with much significance. Even after being diagnosed, many of the women were surprised that their symptoms were not triggered by exertion and were not relieved by rest. Many of the women were sitting watching TV, or reading the newspaper, after having completed their exercise regime for the day, when they became ill.

Rimmer (1993) suggested that women do not take chest pain seriously, relating it to indigestion or muscle strain, and thus delay in seeking treatment. One of the women was actually exercising at Reh-Fit and had "this huge pain in my right arm, massive pain, heavy and I thought...I must have been lugging too many groceries". She stopped exercising and went home, not seeking

assistance in spite of the many supports available at the Reh-Fit Centre.

Women were more likely to report arm or shoulder pain, jaw, neck or throat pain, and back pain was twice as common in women as in men (Halm & Penque, 1999). Many of the women in my study reported experiencing severe and sometimes debilitating back pain that was not investigated further. They were given muscle relaxants and told to rest. Mosca et al. (1997) warned that chest pain and possible atypical symptoms of angina should be pursued in women.

Women in my study were angry at themselves in retrospect, when they could more objectively look at their actions and rationale for not immediately seeking health care. Hackett and Cassem (1969) reported that denial was a conscious or unconscious defence mechanism to allay fear or anxiety. One of the women admitted that she had "a tightness in my chest and I felt quite strange. I kept thinking it was the hiatus hernia, though in the back of my mind I had heart".

Some of the women did not connect what they were feeling with evidence of CHD. They recognized that something was different in their bodies but they were unsure of the source (Dempsey, Dracup & Moser, 1995). They felt that they would recognize classic signs and symptoms, but "I had different symptoms all the time, pressure in my chest and a feeling of anxiety. I thought I pulled a muscle or something". One woman described "It feels like your bra is too tight, like somebody's got their hands squishing you all around your bust. You feel like

if you take your clothes off, you feel better. It wouldn't hurt so much".

Once it became evident that "something was going on", the next step in the quest to access health care was dealing with barriers established by roles and responsibilities.

### Roles and Responsibilities

Caves (1998) found that concern for others lead to delays in women seeking treatment. Abbey (cited in Heart Stroke Foundation, 1996) stated that women tend to define success in terms of relationships and thus put everyone's needs ahead of their own. Several women in my study identified that they did not want to be a bother, even though they were experiencing extreme discomfort. "I sat up all night at home in misery because I didn't want to wake my husband up" and "I told the kids I am going to lay down. I'm not feeling well. Don't tell your dad. That's what I always say, don't tell your dad." It is hard to imagine being in a relationship that is so fragile and unsupportive that one would prefer to suffer in silence than seek assistance from a significant other.

Braiker (cited in Heart & Stroke Foundation, 1996) described a Type E personality, typical of the role of a woman "Everything to Everybody". "I was making coffee, all alone in the kitchen and I had this huge pain in my chest and I was gasping. I thought, I don't have time for a heart attack. So I stopped, stood very still, and it passed". Even though we jokingly asked this woman who would make the coffee if she died, it was apparent that she was so focused on the task at hand, her responsibility, that she was not aware that she was placing herself

in danger.

Arnold (1997) described women as being more comfortable as caregivers than care receivers, again putting the needs of others first. One woman, who lived on an isolated farm, described how she was experiencing excruciating pain in the middle of the night and finally phoned the hospital. When they told her they would send out an ambulance, she did not want to bother them, as the driveway and farm yard were snow packed. They let her drive herself in, and en route, she got stuck and had to extricate her car from a snow bank. Needless to say, when she did arrive at hospital, they confirmed that she had experienced a heart attack. The first two barriers, Signs and Symptoms and Roles and Responsibilities were impacted by the theme of Being Heard. Women, even if they were not aware of the significance of what they were experiencing, were not listening to what their body was trying to tell them. Something was wrong and they were not responding. Indecision, or focusing on other tasks, was further complicated by women being socialized to dependency, letting males be the decision makers (Collier, 1982). As half of the women in the study were widows, there was not a male present to make the decision to seek care.

#### **Convincing the Gatekeepers**

Once the women recognized the signs and symptoms and overcame their commitment to everyone's needs but their own, the next hurdle was convincing a physician of the problem and accessing treatment. Communication with a physician was a problem that many women experienced (Allen, Gilchrist,

Levinson & Roter, 1993) and an impediment to treatment. Pedwell (1995) cited the Canadian Women's Health Test that reported the average physician visit lasted nine minutes and women were typically interrupted within the first 18 seconds. Physicians need quality time with the patient and in that time, they need to listen. Many women in my study reported feeling overwhelmed by the thought of accessing the health care system at any point. One of the women reported "It's a scary process...the thing is, you don't really have any questions to ask because you don't know what questions you should be asking. You're not knowledgeable, so you just go in and you do what they tell you to do."

Another described her difficulty in being heard by her physician when experiencing an adverse reaction to a medication. "The doctor couldn't tell what was the cause of my chest pain and he put me on nitro pills..I kept telling him I just pass out when I take those...pills. I don't think he believed me. I was in his office one day and...got the pain, so I took a nitro and ended up on the floor. I had an angiogram right away that showed everything was fine. I don't have to take those nitro pills any more".

The Framingham Heart Study identified that angina was the "predominant initial clinical presentation of CHD among women" (Wenger, 1990) but because this was not complicated by infarction in 86% of the women, possibly this fostered the misconception that angina was a benign problem in women. The dilemma of chest pain in women was reinforced by studies such as the Coronary Artery Surgery Study (CASS) Registry, which documented the discrepancy

between "chest pain" and "angina pectoris". Half of the women with chest pain had little or no coronary artery pathology. Whereas men tended to experience anginal symptoms with physical exertion, women were more likely to be at rest (Moser, 1997). Mosca et al. (1997) assigned little prognostic value to chest pain in women.

Armitage, Schneiderman, and Bass (1979) cited the historical perspective that regards men as typically stoic and females as typically hypochondriacal. Davidson (1996) warned that women would be misdiagnosed if physicians follow the classic male model for recognizing heart disease. Douglas and Ginsberg (1996) stated that evaluation of chest pain was a critical step in the treatment of women with heart disease and the point at which women were likely to be treated differently from men. They warn physicians to be aware of their own bias in treating women with chest pain. Legato and Colman (1991) reported that cardiologists were three times more likely to diagnose a woman's chest pain as being "in her head" as they were a man's.

This bias was supported by several anecdotes provided by participants in the study. "The cardiologist thought I was having trouble with my esophagus but I knew it wasn't my esophagus because I could swallow with no problem. Why would my esophagus act up as soon as I walk?". Women generally felt that doctors did not take them as seriously and were not as concerned with women. "Women should prepare for resistance. The medical profession doesn't readily acknowledge heart disease if you are young. I presented classic heart pain but

for a long time they thought it was gastric". Actually making it as far as the emergency room was seen as a great success, but many women reported being sent home and having to return, often several times, before being admitted to hospital. Women in my study found that going to the physician's office was not a good strategy. One woman did manage to have an EKG done and when it showed she was having a myocardial infarction, she was sent to hospital by taxi.

Many women felt insecure and vulnerable away from the "safe" hospital environment (Pinneo, 1984). This was supported in my study, and even though some of the women were describing their feelings long after the experience, the relief could still be heard in their voices as they recalled their stories. "I just felt happy. I was so content because I didn't have to think. I didn't have to worry...it was secure". Another woman stated "There is that feeling of, now I'm in expert hands. They can take care of me". The feeling was that once they got into hospital, they were looked after. The problem was overcoming the barriers to get into the health care system.

The theme of Being Heard was again evident in surmounting this barrier. The women had to overcome their "silence" and become assertive, and in some cases, aggressive, in convincing the gatekeepers that they did have a problem and required care.

### Accessing Treatment

Female patients were more likely to have their symptoms attributed to psychosomatic causes and ultimately were less likely to be referred for invasive

testing (Armitage, Schneiderman, & Bass, 1979; Clancy & Massion, 1992; Legato, Padus, & Slaughter, 1997). Once the women were in the health care system, they were still less likely than men to receive thrombolytic therapy for acute management of myocardial infarction, less likely to undergo coronary angiography and less likely to undergo any form of myocardial revascularization (Wenger, 1992). This, in spite of the fact that once a woman has evidence of cardiac disease, she is at increased risk for reinfarction.

This is clearly due to gender bias, but women complicated the process by their tendency to delay seeking help as the effectiveness of thrombolytic therapy is time limited (Dracup & Moser, 1995). Moser (1997) reported that half of all deaths from MI occurred within two hours of onset of symptoms, and typically women delayed two to four hours before seeking treatment. Circumstances that contributed to the delay varied. Moser (1997) stated that women who consulted with an acquaintance had shorter delay times than those who consulted with a spouse or other family member. Because of age, many women were likely to be retired at the time they experienced cardiac signs and symptoms, and not in a position to confer with others. Many of the women were widowed, and likely to be living alone, therefore lacked the influence of a significant other to seek care.

Legato and Colman (1991) stated that men with CHD were ten times more likely to be referred for further testing to identify if surgical intervention was needed. Dr. Loretta Daniel (cited in Rogers, 1998) stated that in Ontario, half as many female patients are referred for angiography, angioplasty and bypass

surgery. The reason was that many doctors were still convinced that heart disease was a man's problem (Reich-Atkins, 1992). Methods for performing many of the tests have been developed using men and interpretation of results was established based on data obtained from males (Beery, 1995; Belgrave, 1993; Kwok, Kim, Grady, Segal, & Redberg, 1999). As a result, non-invasive tests have less predictive accuracy in women, including a high percentage of false positives in both the treadmill test and Thallium scans. This was experienced by many of the women in the study.

Rogers (1998) reported that when women do come to hospital, they are usually older, sicker, and advanced disease may preclude them from surgery. Those who do undergo revascularization procedures such as CABG or PTCA have higher risk for morbidity and mortality because of advanced age, unstable symptoms and co-morbidities (Moser, 1997). Interestingly, Beery (1995) speculated that it only appeared that women were undertreated, because men were referred too often and possibly overtreated.

#### The Legacy: Looking Ahead

MacKenzie (1993) discovered that after discharge, women identified a new role, that of Heart Patient, which became a priority. Women became necessarily "selfish" in focusing on their own needs, which was critical to their survival (Toobert, Stryker, & Glasgow, 1998). This was acknowledged by the women, although their tone of voice suggested that this was a real struggle for them. One of the women stated "You need to put yourself ahead of everybody,

if you're having chest pain or if you're not feeling right". Another confirmed "You start taking care of yourself after something like this happens. Before you looked after everyone else". Many of the women reported a strong focus on household chores, which they were reluctant to delegate, as no one else could perform these tasks to suit them. They returned too quickly to these responsibilities instead of focusing on recovery. The difference between men and women is that men recover away from their workplace while women recover in the workplace. Rankin (1993) suggested that women not remove their bathrobe until recovered, as this appeared to authorize neglect of household chores.

Carhart and Ades (1998) promoted the utility of participation in a cardiac rehabilitation program because of demonstrated reduction in mortality and to enhance general wellbeing. There is limited information relating to women and exercise, because research has been done on middle aged men, but those women who have been studied do show the same benefits. Sallis et al. (cited in Moore, Ruland, Pashkow, & Blackburn, 1998) found that healthy older women were less likely than men to begin an exercise program and more likely to stop over time. Physicians were less likely to refer women to programs (Carhart & Ades, 1998), and women with coronary heart disease were generally older with comorbidities that prevented participation in exercise. Women were also limited by lack of access to transportation, having a dependent spouse at home, lack of finances, and time constraints because of obligation to housework. Many of the women in this study were recruited from a rehabilitation facility and several of

these women had been members prior to receiving their diagnosis, so there was evidence of a willingness to participate. Even so, they did discuss difficulties getting to the facility, having to deal with taxis, buses or handivans for those who did not drive. Several of the women admitted that the cost and time required were factors that made them rethink their decision to participate, but enjoyment, social contact and perceived health benefits won them over. For those who did not participate, reasons included not being referred, and physical constraints because of comorbidities. One woman was told by her physician that it was not necessary. For the women from rural regions, the reason was purely lack of access to a program.

Hildingh, Fridlund and the Miss-W Study Group (1997) identified children, parents or siblings as providing the most support, spouse and intimate friends secondarily. This was supported by the conversations in the focus groups. One woman reported that she really did not feel well and had been driven to the physician's office by her husband. The nurse told them to get to the hospital right away, and the husband's response was "would you like to go for a coffee first?" Only one woman identified her husband as being the best source of support, psychologically, emotionally and physically. She felt that he was afraid when faced with the reality that he could lose her, and this only served to strengthen an already solid relationship. A study by Helpard and Meagher-Stewart (1998) reaffirmed that marital status did not ensure support and women were more likely to receive more support from significant others. They also

found that women did not share their emotions, as they did not want to burden anyone. Many participants in my study shared their frustration at the lack of understanding. They felt that people just did not understand what they were experiencing and thus could not truly be supportive.

The other commonality discussed by every participant was the overwhelming fatigue and depression that they experienced after discharge from hospital. This was reported in the literature by Pinneo (1984), but the women verbalized that they were not warned to expect this, and it made recovery very difficult. They described waking up with energy, but finding that it dissipated very quickly. Many of the women were tired from doing nothing, but could not sleep at night, and dreaded nightfall, because they were wide awake, with their minds racing. Several of the women were totally taken aback by the depression and being overly emotional. Some recognized it in themselves, and others were totally unaware of their behavior until it was pointed out by a support person. One woman described "I felt like crying so much, everything frustrated me. They never explained that". Another said that she could sit home for days and just did not want to do anything, which was very out of character.

Artinian and Duggan (1995) pointed out how important it is to include families in education and provide phone follow-up after discharge. The women did express a wish that phone follow-up or a home visit could have occurred, as this would have been a very helpful intervention. Most of the women unanimously agreed that there was one area of education sorely lacking "they

should have a little instruction book or suggestion book for the husbands!" In spite of any of the difficulties experienced with family relationships, the women verbalized a foundation of connectedness with their families, and especially in terms of their role as grandmother.

Many of the women admitted to thoughts about death, feeling the need to make a will and get things in order, and became teary when they talked about possibly not seeing the grandchildren grow up. Their greatest fear, however, was not of death, but of dying alone. This was not reported in the literature, but it was expressed by the majority of participants in the study. This fear was so great that several of the women had phoned the ambulance service to find out how the attendants gained access to a home if someone dialed 911 and then collapsed with the doors to their home locked. Several of the women expressed their fears of dying alone to their families, who set up around the clock vigilance. Others had alarm systems installed in their homes, and left their doors unlocked, relying on the alarm to notify them of intruders.

The theme of Helps and Hindrances was threaded throughout the range of Barriers to Care. The theme of Living for the New Me focused on how each woman dealt with The Legacy, or how life changed after experiencing the diagnosis of coronary heart disease. Validation was also apparent in every topic of conversation, as the women wanted to ensure that what they had been told was correct, and that they had been told everything that they needed to know. There was constant comparison of signs and symptoms, responses of families,

lab results, methods of performing the diagnostic tests, and acknowledgement that others had also experienced fatigue and depression. Not only were they normalizing and comparing their own experience, they constantly offered support to each other as well as helpful tips that they had utilized in coping. The overall atmosphere was one of women helping women.

In closing each focus group, the women were asked if there was anything else that they would like to pass on to other women who were experiencing, or who had the potential to develop, coronary heart disease. The first advice they had was that prevention was the key, and get started young. Many of the women had discussed this in detail with their daughters, and warned them of their risks. The second was that you need to look out for yourself, and be vocal if you are not getting the attention you require. The last was know your body and pay attention to what it is telling you.

### **5.5 Implications for Practice and Education**

Many helpful insights for those working in care settings emerged from the discussions with women who had first-hand knowledge of what it was like to live with coronary heart disease. As a health care provider, it was not reassuring to learn of the many barriers that had to be surmounted before care could be accessed.

Myths about women and heart disease need to be dispelled to ensure that women receive the attention they require when presenting in a clinical area. There must be a move away from care based on the classic male model to a

focus on gender-specific needs. Development of women's health specialties, or inclusion of threads throughout the educational content, in both nursing and medicine are required to address woman-centered practice. We need to promote an awareness of the differences that exist in caring for a woman, including knowledge of recently identified anatomical and physiological differences, as well as gender bias in diagnostic testing. As with all patients, we need to listen.

In providing education, topics should be individualized as much as possible, considering each client's background knowledge and level of understanding. Some patients might require extensive information-giving as they might not even know what to ask. We sometimes assume that silence is knowledge. A relevant consideration, as well, is that patients in hospital night have a decreased attention span, influenced by medications and/or pain, as well as being overwhelmed by the situation. Staff also have time constraints because of the nature of the clinical area and rapid turnover of patients in today's health care setting. This disparity must be resolved. Presently, education might not be as effective as we think it is, given the hectic pace in hospitals. Patients receive pre-operative information in the fast-paced pre-admission clinic and instructions while on the unit, often given by a nurse on the run. Follow-up appointments are scheduled in the ambulatory clinic, where there is competition for time due to the volume of patients scheduled. Ideally, patients need a community setting where they could access information at their own pace, either before or after surgery. Discussion groups where women could just come to talk with cohorts would be

beneficial, as would a telephone hot-line, to facilitate easy access to information.

Dependable physical and psychological support at home is essential, especially in the immediate period after discharge. Improved access to rehabilitation programs would help to address some of the educational gaps and serve to introduce the clients to lifestyle change in a supportive environment.

Unfortunately, staffing and cost are issues with all of these interventions that are not easily resolved.

Expanding the focus on prevention, especially targeting young women and educating them about risk factors is essential. Participation on their part is an issue, as many of these women are at a stage of their growth and development when they are unreceptive to such information, as they are unable to visualize themselves as at risk. Peer pressure is an obstacle when such things as smoking are discussed.

Women identified that no one understood what they were experiencing. Possibly this could be improved by ensuring that families are included in teaching and counselling sessions. Establishing a community family resource centre could be beneficial and the idea of setting up a pamphlet for husbands is not a bad idea. This is a significant group that would most likely benefit from direct attention in preparing them for what to expect and letting know what their role is in providing support. It was very evident when attending the classes at the Reh-Fit Centre that men were most often accompanied by a wife who organized her mate, telling him where to sit, finding his booklet, getting a pen and writing

down information that was seen as pertinent. Not one woman received such support.

Another topic of relevance for staff is the rapid expansion, especially in the past two years, of information related to women and coronary heart disease.

The challenge is to keep abreast of developments and impart the most relevant and current information to clients. We also need to bear in mind that, considering the demographic profile, and population statistics, we will soon be dealing with a large population of older women, with CHD, who will most likely present with a varied array of co-morbidities. We must be prepared to effectively meet this challenge.

#### **5.6 Suggestions for Further Research**

In reviewing the information discussed in the focus groups, four topics of interest emerged:

- 1) **The urban vs the rural experience of women with coronary heart disease.**  
The majority of women in the study were from the urban area, but several relevant differences were identified. Even if referred, women in rural areas presently do not have access to cardiac rehabilitation programs. They also do not have facilities that would promote exercise in a safe environment, such as the mall walking programs within the city.
- 2) **The experience of the male as caregiver following cardiac surgery.**  
The experience of living with coronary heart disease was explored from the woman's perspective, and many barriers, as well as helps and hindrances were

identified. It would be interesting to hear the male perspective of the same experience. What was it like to be a man, caring for a woman with CHD?

- 3) Identification of the educational needs of the client with CHD as described by men, women and health care professions.

This would affirm that we truly were providing the most relevant and useful information to the clients. The study would identify any disparities that do exist and allow these to be addressed.

- 4) Telephone follow-up after cardiac surgery to assess level of satisfaction with discharge preparation.

Although the nature of this intervention is quality assurance, it could also serve to identify those questions that patients still have after discharge. This information could impact on the content of the plan for discharge preparation.

## 5.7 Chapter Summary

This chapter provided an overview of the study, and discussed the findings as they related to the literature review, either supporting or refuting the findings of other authors. Suggestions for practice, education and further research were provided.

### **Conclusion**

Utilization of the focus group method for exploring the experience of women with coronary heart disease effectively identified that women are dealing with a series of barriers to care. Gender bias does still exist and women face a lonely struggle in accessing treatment. They want to be heard, believed, and receive the care and support to which they are entitled.

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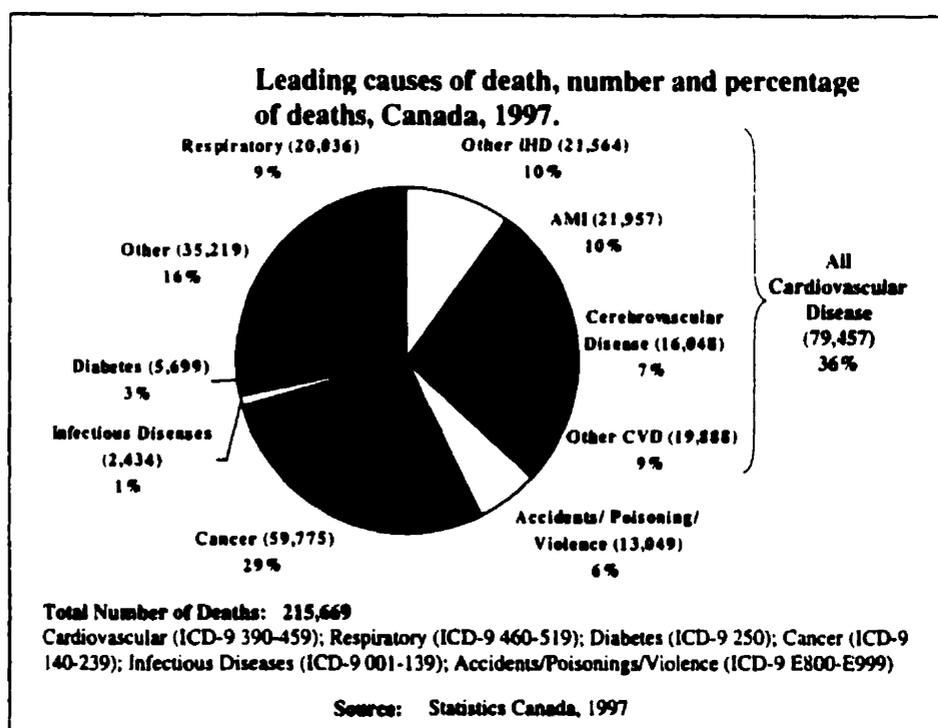
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## APPENDIX A

## Leading causes of death, number and percentage of deaths

Canada, 1997



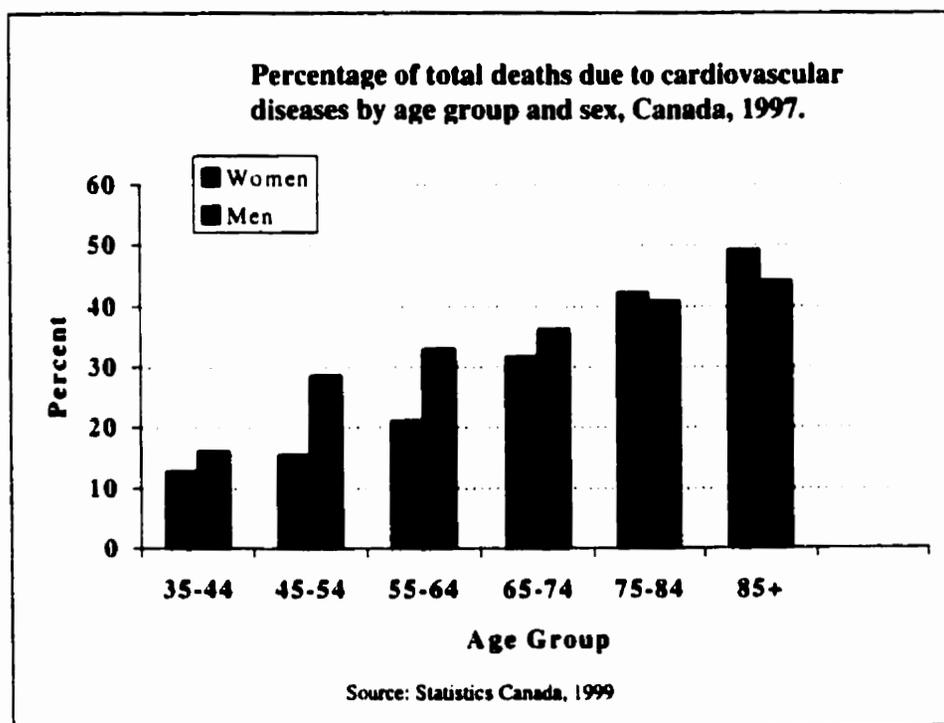
(Heart and Stroke Foundation of Canada, 1999, p. 68)

## APPENDIX B

## Percentage of total deaths due to cardiovascular diseases

by age group and sex

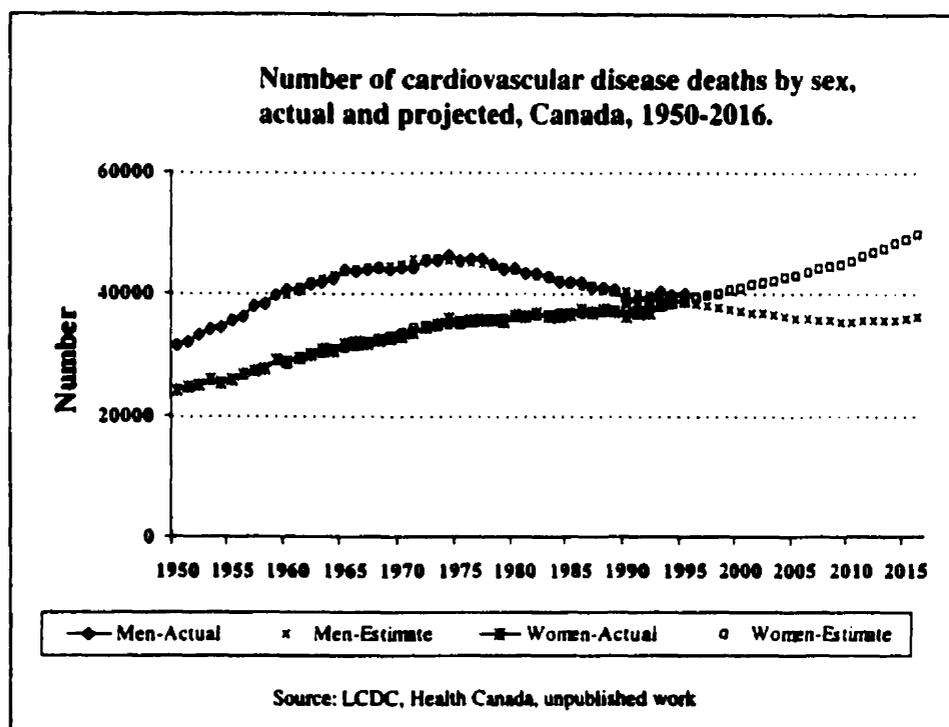
Canada, 1997



(Heart and Stroke Foundation of Canada, 1999, p. 68)

## APPENDIX C

Number of cardiovascular disease deaths by sex,  
actual and projected  
Canada, 1950 - 2016

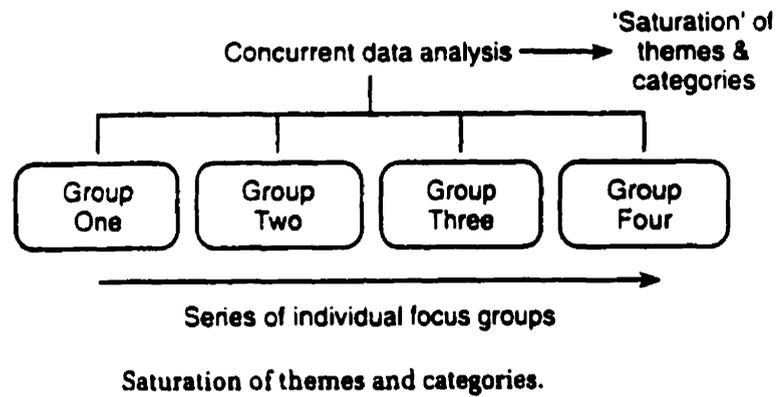


(Heart and Stroke Foundation of Canada, 1999, p. 71)

**APPENDIX D****American Heart Association Checkup Checklist for Women****Items to Discuss with a Doctor**

- Age**
- Race**
- Family history of heart disease, diabetes, cancer, other diseases**
- Blood pressure**
- Blood cholesterol, plus HDL and LDL cholesterol if appropriate**
- Blood triglycerides**
- Glucose tolerance (for people concerned about diabetes)**
- Ideal weight for age, height, and body type**
- Smoking behavior**
- Alcohol consumption**
- Response to stressful situations**
- Satisfaction with work and family life**
- Oral contraceptives**
- Estrogen replacement therapy (for postmenopausal women)**
- Dietary changes**
- Exercise routines**

(in Zaret, Moser, & Cohen, 1992, p. 238)

**APPENDIX E****Saturation of themes and categories**

(Sim, 1998, p. 349)

## APPENDIX F

### Informational Poster

#### **Are you a Woman with Coronary Heart Disease??**

If so, please read this poster!! If you are a woman, over 18 years of age, able to communicate in English, and interested in participating in a research study, I am interested in talking to you.

I am a University of Manitoba nursing student, completing my degree in the Master of Nursing program. The research study I am doing is entitled "The Experience of Women with Coronary Heart Disease". We know that cardiovascular disease is a leading cause of death of women in Canada. Most of the research in this area has been done on men, and the results have been used in diagnosing and treating women. We know that women have their own special needs, and want to know what it is like to be a woman with heart disease.

Participation in the study is voluntary. If you are interested, and agree to participate, it will involve completing a questionnaire (about 15 minutes), reviewing 8 questions, and then participating in a discussion group. The discussion group will take no more than 90 minutes, and will consist of no more than 12 women, all with coronary heart disease. You will be given reimbursement for your travel or parking costs and refreshments will be provided. Several discussion groups will be held, so you can choose which time and date suits you best. There are no known physical risks involved in participation.

The information discussed will be tape recorded, and kept confidential - only my thesis Chair, Dr. Barbara Naimark, secretary, and I will see the raw data. You will not be identifiable when the data is analyzed, or reported, as only your first name will be used during the discussion. Any information discussed within the Focus Group will remain confidential. If you wish, you will be provided with a written summary of the results of the study once it is complete.

Thank you for reading this poster. Your participation will help us better understand what it is like to be a woman with coronary heart disease. If you would like to participate, or would just like more information, please feel free to call me at 787-1110 and leave me a message. I will return your call as soon as possible.

**Marilynne Hogg, RN, BN Master of Nursing Student, U of M**

**Appendix G**  
**Informational Pamphlet**



### **Information about the Research Study**

**My name is Marilynne Hogg and I am a University of Manitoba nursing student, completing my degree in the Master of Nursing program. The research study I am doing is entitled "The Experience of Women with Coronary Heart Disease". We know that cardiovascular disease is the leading cause of death of women in Canada. Most of the research in this area has been done on men, and the results have been used in diagnosing and treating women. We also know that women have their own special needs. In my study, I want to talk to women in small discussion groups and hope to find out what it is like to be a woman with heart disease. The discussion group will take no more than 90 minutes. PLEASE READ ON!!**

- To participate in the study, you must:**
- Be a woman with coronary heart disease (Have you had a heart attack?, Do you have chest pain?, Have you had a bypass?)
  - Be over 18 years of age
  - Read, write and speak English
  - Agree to having the discussion tape-recorded

**What will you need to do if you participate?**

- I will discuss the study with you in more detail
- You will let me know which session you are able to attend
- I will give you an outline of some of the questions we will discuss so that you can think about your answers ahead of time
- You will complete a questionnaire, at the beginning of the discussion group that describes you and your present situation (this should take about 15 minutes)

**Why should you participate?**

There has been little research done on the lived experience of women with coronary heart disease. I hope to be able to identify difficulties women encounter, needs they have, and areas that are not currently being addressed. This information can help members of the health care team to more adequately care for women with coronary heart disease. To do this, I need to talk to women

who are willing to share insights into their personal journey with coronary heart disease. I need to talk to the real experts. I need to talk to you.

You are under no obligation to participate in this research study. Your decision will not affect the care you receive at Health Sciences Centre. If you choose to participate, personal information and anything discussed in the groups will be kept confidential. As well, if you decide to participate and then change your mind, you are free to withdraw from the study at any time.

If you choose to participate, you will be given assistance with transportation or parking and refreshments will be provided at the beginning of the discussion group.

**Would you like to volunteer, or do you need more information? Please do not hesitate to call:**

**Marilynne at 787-1110**

**Thank you for taking the time to read this pamphlet.**

## APPENDIX H

### Disclaimer

**You are invited to participate in a group discussion that will help us to better understand what it is like to be a woman with coronary heart disease. My name is Marilynne Hogg, and I am a Graduate Student in the Faculty of Nursing at the University of Manitoba. I will be the group discussion leader. In the group, you will be discussing the questions in the Interview Guide, that I will give you beforehand, with approximately 11 other women who also have coronary heart disease. The discussion will last no more than 90 minutes. At the beginning of the discussion you will be asked to fill out a questionnaire, providing some information about yourself. This should take about 15 minutes.**

**Participation in the group discussion is voluntary and there is no obligation to participate. You may withdraw from the group discussion at any time. You will give your consent to participate by attending the group interview. The group discussion has been approved by the Ethical Review Committee of the Faculty of Nursing. I have also been granted permission to conduct this study by the Health Sciences Centre Access Committee.**

**You will be reimbursed for transportation or parking expenses, and refreshments will be provided at the beginning of the discussion. Several discussion groups will be held, so you can choose which time and date suits you best. There are no known physical risks involved in participation.**

**All of the information shared during the discussion will be confidential. Only my Thesis Chair, Dr. Barbara Naimark, secretary, and I will have access to the data gathered. The questionnaires will not contain your name. I will need to keep a record of the names, addresses and phone numbers of the participants while I plan the discussion groups, but I will be the only person with access to this information. The results of the group discussion will be used to complete my thesis requirements, and will be published or may be used for presentations. At no time will you be identified. If reference is made to a comment you provided, a false name will be used. Information discussed within the Focus Group will remain confidential. All information connected to the study will be kept in a locked file for seven to ten years, and will then be destroyed.**

**There may be no direct benefits to you personally, but participation in the group discussion will provide valuable information for health care practitioners who are caring for women with coronary heart disease. You may benefit from talking about your experiences with other women who share the same diagnosis.**

**Participant:**

**Date:**

**Address:**

**Phone:**

**Preferred Discussion Group:**

**Please send a copy of the research report to:**

**The researcher, Marilynne Hogg, can be reached at 787-1110.**

**The thesis chair is Dr. Barbara Naimark, and she can be reached at 474-7467.**

## APPENDIX I

### Discussion Guide

To help guide your discussion when you attend the Focus Group session, please consider the following questions. Feel free to add any other questions or content that you feel is important. I would like to remind you that during the discussion, only first names will be used. Also, please remember that everyone will need an opportunity to voice their opinions during the discussion.

1. What lead to your diagnosis? i.e. what signs and symptoms or difficulties were you having? how long did it take before you were diagnosed?
  
2. How would you describe the care that you received from:
  - doctors
  - nurses
  - technicians
  - other health care workers
  
3. Can you remember some of the questions you had?
  
4. Were your questions adequately answered?
  
5. What actions by family/friends/health care workers would you describe as supportive? non-supportive?
  
6. What do you wish people had done that they didn't do?
  
7. How have your roles and responsibilities or activities changed? What is different from before your diagnosis?

**8. Please complete the following:**

**I wish I had known.....**

**If I had any advice for a woman with a diagnosis of Coronary Heart Disease or thinking they have Coronary Heart Disease, it would be.....**

**I still need to know.....**

**APPENDIX J****Letter to Staff in the Cardiology Clinic**

**My name is Marilynne Hogg and I am a Graduate Student in the Faculty of Nursing at the University of Manitoba. To fulfill the requirements for my Master of Nursing thesis, I will be conducting Focus Groups with women who have a diagnosis of Coronary Heart Disease. We know that cardiovascular disease is a leading cause of death of women in Canada. Most of the research in this area has been done on men, and the results have been used in diagnosing and treating women. Women have their own special needs, and I want to give women the opportunity to tell their own stories. I would like you to know something about my study, as I am soliciting your participation and in case women approach you with any questions.**

**The purpose of the study is to explore the experience of women with coronary heart disease. I have placed a poster in the Cardiology Clinic and hope to recruit my subjects from the Cardiology Clinic. I will be asking you to approach female patients with coronary heart disease and give them a pamphlet that details what would be required of them if they choose to participate. I have attached a guideline (Appendix F) for how you might approach a patient. My study has received approval from the University of Manitoba Nursing Ethics Committee and I have access approval from Health Sciences Centre.**

**I will be conducting approximately 3 focus groups, with no more than 12 women in each group. The sessions will be held at Health Sciences Centre, at a time convenient for participants, and this will be negotiated on an individual basis. The groups will take approximately 90 minutes. Interested parties will be provided with a disclaimer, a discussion guide, and will complete a demographic questionnaire that should take approximately 15 minutes.**

**Participants have been reassured that anything they discuss will remain confidential. They may also withdraw from the study at any time without fear of repercussion. Information gathered will be used in my thesis, will be published, and will be utilized in presentations, but group members will not be identified.**

**If you would like more information about the study, or have any questions, please feel free to contact me at 787-1110.**

**Thank you for your assistance.**

## **Appendix K**

### **Guideline for Staff in Approaching Patients Regarding Research Study**

**Marilynne Hogg, a Master of Nursing student at the University of Manitoba, is seeking women with coronary heart disease to participate in a research study. This pamphlet contains the details of the study. If you would like to participate, or have questions, please call her at the number listed inside.**

**APPENDIX L**  
**The Experience of Women with Coronary Heart Disease**

**Demographics**

1. Age \_\_\_\_\_
  
2. Are you...?  

_____ Married	_____ Separated
_____ Single	_____ Divorced
_____ Widowed	
  
3. What is your cultural background?
  
4. What is your highest level of education?  

_____ Less than High School	_____ Technical Training
_____ High School Diploma	_____ University Degree
_____ Other (Please explain)	
  
5. Are you employed outside the home?  

_____ No
_____ Yes

If yes, please state your occupation
  
6. What is your approximate yearly income? \_\_\_\_\_
  
7. Do you.....?  

_____ Live alone
_____ Live with children
_____ Live with spouse/Significant Other
_____ Other (Please explain)

8. Describe your present housing...

- |                                                 |                                            |
|-------------------------------------------------|--------------------------------------------|
| <input type="checkbox"/> House                  | <input type="checkbox"/> Condominium       |
| <input type="checkbox"/> Duplex                 | <input type="checkbox"/> Granny Apartment  |
| <input type="checkbox"/> Apartment              | <input type="checkbox"/> Seniors Apartment |
| <input type="checkbox"/> Other (Please explain) |                                            |

6. What was your diagnosis?

- |                                                         |                                               |
|---------------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Chest pain                     | <input type="checkbox"/> Coronary angioplasty |
| <input type="checkbox"/> Heart attack                   | <input type="checkbox"/> Coronary bypass      |
| <input type="checkbox"/> Chronic ischemic heart disease |                                               |
| <input type="checkbox"/> Other (Please explain)         |                                               |

7. In what year did you receive your diagnosis? \_\_\_\_\_

8. Do you have a family history of Coronary Heart Disease?

- Yes  
 No

If yes, please explain and be as specific as possible.

9. Please check your present status:

- Pre-menopausal  
 Menopausal  
 Post menopausal

10. Do you smoke?

- Yes  
 No

**Table 1**  
**Demographic Data Summarized**

<b>AGE OF PARTICIPANTS (n=28)</b>		
<b>Range</b>	<b>Mean</b>	<b>Median</b>
<b>47 - 88 years</b>	<b>64.6 years</b>	

<b>MARITAL STATUS (n=28)</b>	
<b>Married</b>	<b>10 (35.7%)</b>
<b>Single</b>	<b>3 (10.7%)</b>
<b>Widowed</b>	<b>12 (42.8%)</b>
<b>Divorced</b>	<b>3 (10.7%)</b>

<b>LEVEL OF EDUCATION (n=28)</b>	
<b>Less than High School</b>	<b>7 (25%)</b>
<b>High School</b>	<b>10 (36%)</b>
<b>Technical Training</b>	<b>2 (7%)</b>
<b>RN Diploma</b>	<b>2 (7%)</b>
<b>Teaching Certificate</b>	<b>2 (7%)</b>
<b>University Degree</b>	<b>5 (18%)</b>

<b>YEARLY INCOME (n=14)</b>		
<b>Range</b>	<b>Mean</b>	<b>Median</b>
<b>\$5,000 - \$50,000</b>	<b>\$26,284.98</b>	<b>\$20,000.00</b>

LIVING ACCOMMODATION (n=28)	
Live Alone	14 (50%)
Live with a Daughter	1 (4%)
Live with Spouse or Significant Other	11 (39%)
Live with Siblings	2 (7%)

LENGTH OF TIME SINCE DIAGNOSIS/CORONARY EVENT (N=28)	
Range	Mean
6 months - 31 years	7 years

MENOPAUSAL STATUS (n=26)	
Pre-Menopausal	2
Post-Menopausal	24

USE OF HORMONE REPLACEMENT (n=9)	
Use of Hormone Replacement (present or past)	7
Currently Deciding	2

SMOKING STATUS (current) (n=28)	
Did not smoke	28

**Table 2**  
**Summary of Diagnoses**

<b>DIAGNOSES</b>	
<b>Chest Pain</b>	<b>6</b>
<b>Chest Pain with PTCA</b>	<b>2</b>
<b>Chest Pain with Heart Attack</b>	<b>1</b>
<b>CABG</b>	<b>6</b>
<b>PTCA</b>	<b>1</b>
<b>Heart Attack</b>	<b>5</b>
<b>Heart Attack with CABG</b>	<b>1</b>
<b>Heart Attack with PTCA</b>	<b>1</b>
<b>Chest Pain, Heart Attack and PTCA</b>	<b>2</b>
<b>Heart Attack with PTCA and CABG</b>	<b>1</b>
<b>Chest Pain with Heart Attack, Chronic Ischemic Heart Disease with CABG x 2</b>	<b>1</b>