THE CARDIOVASCULAR RISK PERCEPTION OF FIRST DEGREE RELATIVES OF INDIVIDUALS WITH PREMATURE CORONARY HEART DISEASE: DOES GENDER MATTER?

by

SUSANNE LEE BURNS

B.S.N., The University of British Columbia, 1997

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE STUDIES

(Nursing)

THE UNIVERSITY OF BRITISH COLUMBIA

April 2005

ABSTRACT

The presence of premature atherosclerosis or a clinical cardiac event in a first degree relative is a significant independent risk factor predisposing a person to the development of cardiovascular, peripheral vascular or cerebrovascular disease. First degree relatives (FDRs) of coronary heart disease patients have an increased risk of death from coronary disease compared to those without a family history. Appreciation or perception of one's personal risk for coronary heart disease may be integral to the adoption of a healthful lifestyle or the need for behaviour change. Knowledge of one's risk for heart disease does not always lead to the adoption of healthful lifestyle behaviour that may reduce one's risk. This may be due to a discrepancy between an individual's perception of his or her risk and the actual risk for developing disease. Inaccurate perceptions of personal risk, whether they are over or under-estimated, may reduce the likelihood of incorporating healthful lifestyle changes.

Applying a descriptive correlational design, 118 individuals participating in the Family Atherosclerosis Counseling and Testing Study, underwent a cardiovascular risk factor assessment including laboratory, anthropometric and behavioural measures. Participants also were asked to give their personal subjective risk estimates. Subjective risk perception estimates were then compared to an objective epidemiological risk estimate, the Framingham risk score, to determine the level of the participant's accuracy. Data analysis determined the relationship between level of accuracy (accurate, over-estimation, or under-estimation) and the influence of gender of the FDR (the participant), gender of the index patient, the kinship relationship to the index patient, and the variables of age and education. The results revealed that participants varied in their level of risk perception accuracy with 51.3% being accurate, 47.9% as over-estimating, and 0.9% under-estimating their risk. Education was not associated

with risk perception accuracy but age was significantly associated. The average age of those with accurate risk perceptions was 36.7 years (s.d. = 13.4) compared with over-estimators who were 43.9 years of age (s.d. = 12.4), on average (p = .003). The gender of the FDR and of the index patient was not associated with risk perception accuracy. The kinship relationship of the FDR to the index patient was significant: 63.3% of siblings over-estimated their risk compared to 31.5% of children (p = .001). Further study of the metabolic status and anthropometric markers suggested that over-estimators may indeed be accurate in their perception of their risk; the Framingham risk score may not be a sensitive measure of this population's risk.

TABLE OF CONTENTS

LIST OF TABLES

ACKNOWLEDGEMENTS

Success and accomplishment are not always immediate and come with support and encouragement from many different avenues. I wish to acknowledge first, my thesis supervisor, Dr. Pamela A. Ratner. Her unfailing direction, knowledge, and support have been invaluable throughout the development and completion of this project. Dr. Ratner provided immeasurable contributions to this thesis with her expertise in research and her ability as a teacher, guiding me smoothly through the many challenges. Her mentorship and capacity to expand my scholastic and professional goals are greatly valued. I am also very appreciative of the other members of my thesis supervisory committee, Dr. Joy L. Johnson and Dr. Carol Jillings, whose expert guidance, suggestions and thoughtfulness enhanced the quality of my work.

I would like to thank individuals within the Healthy Heart Program at St. Paul's Hospital beginning with Dr. Jiri J.Frohlich. Dr. Frohlich's exceptional mentorship, leadership, and knowledge of cardiovascular risk reduction have been invaluable in completing this thesis and in my professional development. I want to thank him for the many unique learning opportunities he has offered to me both as a student and a professional. With gratitude I acknowledge my working FACTS partners, Evelyn Wu and Dr. Rajashree Devaraconda whose support and laughter sustained me throughout this project.

I also wish to acknowledge the support given to me by the Heart and Stroke Foundation of Canada and the Canadian Institutes of Health Research, Institute of Gender and Health for a Nursing Research Fellowship Award.

Finally, I would like to acknowledge my friends and colleagues, Carol Galte and Shelly Greig, for their endless support, encouragement and laughter throughout the Masters program.

DEDICATION

This thesis is first dedicated to my husband Jeff, who has supported and encouraged me in every aspect of my life. Thank you for your endless love and patience, I could not have achieved this without you. This is dedicated to my sons, Nicholas and Mackenzie who always make me realize what is really important in life. Last, this work is dedicated to my parents, Jack and Peggy, who have provided me with lifelong support, and who always encourage me to follow my dreams.

CHAPTER 1: Introduction

The presence of premature atherosclerosis or a clinical cardiac event in a first degree relative is a significant independent risk factor predisposing the development of cardiovascular, peripheral vascular or cerebrovascular disease (De Backer et al., 2003). First degree relatives of coronary heart disease patients have an increased risk of death from coronary disease compared to those without a family history (De Backer et al., 2003; Sesso et al., 2001; Steeds & Channer, 1997). The prevalence rates of other significant risk factors, including those that are modifiable, in these family members, are also high (Allen & Blumenthal, 1998). Accordingly, the identification and reduction of risk factors in this high risk group is a key strategy for coronary heart disease prevention (De Backer et al., 2003; Fodor, Frohlich, Genest, & McPherson, 2000; Pearson et al., 2002).

Appreciation or perception of one's personal risk for coronary heart disease may be integral to the adoption of a healthful lifestyle or the need for behaviour change. Individuals with a family history of coronary heart disease may benefit by first understanding their personal risk for developing coronary heart disease and then by acting to reduce modifiable risks. However, it has been long established that knowledge of coronary heart disease risk does not always lead to the adoption of healthful lifestyle behaviour that may reduce one's risk. This may be due to a discrepancy between an individual's perception of his or her risk and the actual risk of developing disease. Inaccurate perceptions of personal risk, whether they are over or under-estimated, may reduce the likelihood of incorporating healthful lifestyle changes.

Specific to this thesis, the term coronary heart disease is used for a more specific focus than the general term, cardiovascular disease (see definition of terms). Atherosclerosis is the chosen term for the FACT study, from which this study is derived, and includes people with coronary heart disease, cerebral vascular disease, and peripheral vascular disease, although the majority of the FACT cohort is diagnosed with coronary heart disease. The terms gender and sex should also be distinguished for the purpose of this research. The term sex conveys differences between the male and female species, with emphasis on biophysical distinctiveness. The term gender conveys distinctions between men and women in a social context, especially in relation to their roles undertaken within that society (see definition of terms).

There is a paucity of literature available specific to gender and risk perception and further absence of literature related to the risk perception of first degree relatives of individuals with a history of coronary heart disease. Yet it seems reasonable to anticipate that there are differences in risk perception between men and women and that those differences have implications for the delivery of risk reduction interventions and education. Consequently, there is a need to identify the factors that influence the risk perception of first degree relatives of individuals with premature coronary heart disease and to determine whether there are gender differences in how individuals perceive their risk and in the factors that shape those perceptions.

Research Problem

Few researchers have examined risk perception in the context of coronary heart disease and even fewer have studied the first degree relatives of affected individuals. Understanding whether gender influences risk perception will benefit patients, nurses and other health-care providers in improving cardiovascular risk status through identification, education, and risk reducing strategies. First degree relatives have been substantially reported to be a high risk group (Fodor et al., 2000; Genest, Frohlich, Fodor, & McPherson, 2003; Pearson et al., 2002) and would greatly benefit from prevention efforts that begin with identification of, and education about, their cardiovascular risk factors. Nursing and health-care providers need to understand their patients' perceptions of risk and how they influence the likelihood of behaviour change that will result in the prevention or minimization of cardiovascular disease. To effectively treat individuals with a family history of premature cardiovascular disease, nursing and health-care providers will therefore, benefit from knowing what influences cardiovascular risk perception.

Risk Profiling

Risk factor profiling or risk factor identification aims to identify people at risk for coronary heart disease. Over recent decades, research has progressively advanced risk factor profiles for predicting coronary heart disease (Ulmer, Kelleher, Diem, & Concin, 2003). Early, accurate assessment of epidemiological risk is important because risk factors demonstrate a greater impact on the development of coronary heart disease over long periods of time (Grundy, 1998). To determine the absolute risk of coronary heart disease, the multi-faceted nature of all risk factors possessed by an individual must be considered. Several algorithms and global scoring systems have been developed to calculate risk of coronary heart disease based on long-term prospective epidemiological studies. Coronary risk charts may provide clinically useful reference guides to risk prevention but may suffer from lack of accuracy with particular risk factor constellations (Empana et al., 2003). Nonetheless, the Framingham Heart Study, a landmark study contributing vital scientific information, has enabled researchers to pioneer coronary risk profiling (prediction) algorithm development (National Heart, Lung, & Blood Institute, 2003).

Framingham Heart Study

Since 1948, the objective of the Framingham Heart Study (Anderson, Wilson, Odell, & Kannel, 1991) has been to identify the common factors or characteristics that contribute to coronary heart disease by following its development over a long period of time in a large group of participants who, at enrollment, had no obvious symptoms of coronary heart disease or had not suffered a heart attack or stroke. The original cohort (n = 5,209) consisted of men and women between the ages of 30 and 62 years from the town of Framingham in Massachusetts, United States. A second cohort, the offspring cohort (n = 5,124), were the original participants' adult children and their spouses, recruited in 1971. This second study, called the Framingham Offspring Study, also targeted the third generation, children of the offspring cohort, which is currently being recruited and examined. The study participants have been tracked through uniform biennial cardiovascular examinations, daily surveillance of hospital admissions, information from physicians and other sources outside the clinic, and death information (American Heart Association, 2003). The Framingham Heart Study's goal is to learn the circumstances under which cardiovascular diseases arise, evolve and end fatally in the general population. This information helps researchers determine, over a long period of time, the differences between those who develop cardiovascular diseases and those who do not.

Longitudinal observation of the Framingham Heart Study cohort has led to the identification of the major risk factors for coronary heart disease including high blood cholesterol, high blood pressure, smoking, obesity, diabetes, and physical inactivity. Other factors related to coronary heart disease risk have been identified, such as high density lipoprotein cholesterol and blood triglyceride levels, age, gender, and psychological issues. Other risk factors that contribute directly or indirectly to coronary heart disease include elevated Lipoprotein(a), a total cholesterol to HDL-C ratio, presence of left ventricular hypertrophy, abdominal obesity, elevated body mass index, a family history of coronary heart disease in any first degree relative (FDR), post-menopausal status, and ethnic background (Fodor et al., 2000; Wilson et al., 1998). Despite the Framingham group being almost all Caucasians, the identified risk factors apply universally to other ethnicities, although precision of risk estimation may be altered (Wilson et al., 1998). Differences in population risk levels may compromise the external validity of the risk algorithms developed from the Framingham data and may lead to overestimation of risk (Empana et al., 2003; Hense, Schulte, Lowel, Assman, & Keil, 2003). Empana et al. (2003) recently concluded that the Framingham and PROCAM (described below) risk functions overestimate the absolute risk of coronary heart disease in middle aged men from Belfast who were identified with moderate risk, and men from France who were identified with low risk. Limitations may include the attenuating risk factors not included in the algorithm such as obesity, metabolic coronary risk factors and family history of premature heart disease. However limited, the investigators were able to correctly rank order individuals according to absolute risk, which may be more clinically relevant (Hennekens & Agustino, 2003). Consideration of local guidelines in different populations for the management of patients with risk factors is typically advised (National Cholesterol Education Program, 2002).

The 1991 Framingham coronary risk prediction algorithm estimates total coronary heart disease risk (risk of developing one of the following: angina pectoris, myocardial infarction, or coronary disease death) over a period of 10 years (National Heart, Lung, & Blood Institute, 2003). It represents the summation of the contribution of each risk factor and is based on a multifactorial statistical model to determine global risk (Burke, 2003). These risk prediction algorithms have been adapted into straightforward scoring sheets allowing physicians, nurses, and other health-care providers to estimate multivariate coronary heart disease risk in middle-aged adults. Separate scoring sheets are used for men and women and include age, blood-pressure, blood cholesterol, HDL cholesterol, and cigarette smoking. The relative risk for coronary heart disease is estimated by comparison to low risk participants within the Framingham cohort.

Several caveats should, however, be recognized about the Framingham Heart Study risk algorithm. The risk estimating score sheets are only for use in people without known coronary heart disease and do not include other heart and vascular diseases, only coronary heart disease. With the cohort being almost all Caucasians, other populations may not "fit" the algorithm. Further, the number of events was very small in some of the sex-specific age groups and may therefore lack precision in risk estimation. The Framingham risk score is an estimation of short term risk of a 10-year period. This short duration may not sufficiently reflect the long-term or lifetime coronary heart disease risk of young adults, which is one in three for women and one in two for men. The 10-year hazards of coronary heart disease are, on average, higher in older persons, since age is a known determinant of coronary heart disease. Some candidates may therefore be over-identified for aggressive interventions and the relative risk estimates (risk in comparison with low risk individuals) may be more useful in the elderly than absolute risk estimates. A clinical examination should always be used in conjunction with the risk algorithm in determining a person's health status, which is necessary, in any case, to identify a family history of coronary heart disease, obesity or physical inactivity.

Prospective Cardiovascular Munster Study (PROCAM)

The Prospective Cardiovascular Munster Study (PROCAM) in Europe provides another scoring scheme to calculate an individual's global risk for coronary heart disease (International Task Force for Prevention of Coronary Heart Disease, 2003). The PROCAM Risk Score estimates the risk of developing a fatal or non-fatal myocardial infarction or sudden coronary death within 10 years (Assman, Cullen, & Schulte, 2002). The score was developed with data from 5389 middle-aged men from 35-65 years of age at recruitment into the PROCAM study in 1979 – 1985. They were followed for 10 years by questionnaire every 2 years and sustained a total of 325 major coronary events (Assman et al., 2002).

The PROCAM differs from the Framingham score by including information on family history of coronary heart disease, as well as LDL cholesterol and triglycerides. The PROCAM scoring scheme is based on a Cox proportional hazards model that uses 8 independent risk variables, ranked in order of importance: age, LDL cholesterol, smoking, HDL cholesterol, systolic blood pressure, family history of premature myocardial infarction, diabetes mellitus, and triglycerides (Assman et al., 2002). A preliminary 10-year follow-up analysis of women 45 to 65 years of age indicated a 4-fold lesser absolute risk of coronary events compared to men of the same age, whereas the Framingham score denotes a difference of only 2-fold between men and women (Assman et al., 2002). Validation of the PROCAM and Framingham scoring systems should however require application to a third independent data set for a true comparison between the Framingham and PROCAM scoring systems (Assman et al., 2002).

Despite the acknowledged limitations of these two key approaches to estimating risk profiles for coronary heart disease, there is great confidence that we can predict individual-level risk with precision and thus these tools are widely used in clinical and research settings. These tools also have been broadly utilized in public health.

Campaigns to educate the general public about known risk factors and to encourage appropriate lifestyle behaviour: reasonable amount of physical activity, abstinence from smoking, reduction in dietary fat intake, treatment of hypertension and diabetes, have had limited effect. Despite these efforts, it is not known how individuals with these risk factors estimate their own risk and whether they internalize these health messages.

Purpose of the Study

The purpose of this study was to examine the accuracy of the risk perceptions of first-degree relatives of patients with premature coronary heart disease. A further aim was to determine the influence of gender and kinship relationship on those risk perceptions. The study was formulated to answer the following questions:

1. What is the accuracy of the risk perceptions of first-degree relatives of patients with premature coronary heart disease when compared with objective epidemiological risk assessments?
2. What is the relationship between gender and the accuracy of the risk perceptions of first-degree relatives of patients with premature coronary heart disease?
3. Does the accuracy of the risk perceptions of first-degree relatives differ depending on whether their affected family member (index patient) is male or female?
4. Does the accuracy of the risk perceptions of first-degree relatives differ depending on their kinship relationship (e.g., father, mother, brother, sister) to the index patient?

Definition of Terms

The following definitions were used in this research study:

Accuracy: the careful, precise, and exact conformity with a truth or standard (Oxford at the Claredon Press, 1982).

First degree relative: an immediate, biological family member including a father, mother, brother, sister, daughter, son.

Gender: the parallel and socially unequal division into femininity and masculinity (Marshall, 1998).

Sex: the biological division into male and female with the grammatical classification as objects corresponding relatively to the two sexes (Oxford, 1982).

Cardiovascular Diseases: all diseases of the circulatory system including acute myocardial infarction, ischemic heart disease, valvular heart disease, peripheral vascular disease, arrhythmias, high blood pressure and stroke (Heart and Stroke Foundation of Canada, 2003).

Cardiovascular Disease Risk: the probability of an unfavourable cardiovascular event.

Coronary Heart Disease: an acute or chronic disease affecting the blood vessels of the heart, and involving an insufficient supply of oxygenated blood to the myocardium. This condition is most often a consequence of arterial narrowing, but can also be due to decreased oxygen transport known as ischemic heart disease (Lipid Health, 2003).

Objective risk: an estimated probability of a specific outcome based on objectively and empirically derived criteria.

Risk assessment: identification of an individual's risk for coronary heart disease.

Risk factor: an attribute associated with an increased probability of a disease. The generally accepted risk factors for coronary heart disease are smoking, high blood pressure, high cholesterol, family history of heart disease, diabetes, obesity, sedentary lifestyle, stress, age, excessive alcohol consumption and certain aspects of socio-economic status (Health Canada, 2003; Lipid Health, 2003).

Risk perception: the consciousness of one's own interpretation or understanding of the possibility or chance of threat or negative outcomes. Risk perceptions are subjective and are influenced by an individual's knowledge, beliefs and life experiences (Kingsbury, 2000). Risk perception comprises two key components: the likelihood of an adverse event and the perception of the seriousness of the event itself (Marteau, 1999).

CHAPTER 2: LITERATURE REVIEW

A comprehensive search of the literature related to cardiovascular disease risk and risk perception was performed, limited to scholarly work including both theoretical and empirically-based materials published between the years 1985 to 2003 (English language only). The focus was narrowed to studies that addressed the assessment of cardiovascular risk factors, screening of individuals for risk factor status, and gender related to risk perception for both primary and secondary prevention individuals. The literature search was conducted using the Cumulative Index of Nursing and Allied Health Literature (CINAHL), the standard medical literature analysis and retrieval system online (MEDLINE) and PUBMED databases. Search terms included "cardiovascular disease," "coronary artery disease," "coronary heart disease," "gender," "family history," "family members," "first degree relatives," "risk perception," "accuracy," and "risk assessment." All literature identified was not included within this review.

Coronary Heart Disease

The rationale for this research was based on the growing burden of coronary heart disease in Canada. Cardiovascular disease remains the leading cause of mortality and morbidity in North America and worldwide despite declines in mortality rates. The cardiovascular disease burden continues to grow in the Canadian population particularly among the aging, in young Canadians, native peoples and immigrants through the adoption of unhealthful lifestyles (Heart and Stroke Foundation of Canada, 2003). This trend in deteriorating lifestyle behaviour will continue to make cardiovascular disease the leading cause of death in Canada. Coronary heart disease deaths accounted for 36% of all deaths in Canada in 1999 (Heart and Stroke Foundation of Canada, 2003). Canada is faced with the same disease challenges as other industrialized countries, including the growing prevalence of obesity, diabetes, and an increasingly aging population. Paramount to the reduction and elimination of coronary heart disease risk factors is a focus on interventions at both the individual and population levels. Especially important is the targeting of higher risk populations, such as families with evidence of premature coronary heart disease, especially first-degree relatives (i.e., parents, sibling and children). The diagnosis of premature or early onset coronary heart disease is established before 55 years in males and 65 years in females. The evidence for a family history of early onset of coronary heart disease is considered an independent risk factor for the development of coronary heart disease among first-degree relatives (De Backer et al., 2003; Sesso et al., 2001).

Integral to nursing is the identification of, and education for, the reduction of coronary heart disease risk factors as important strategies in the prevention and minimization of coronary heart disease. The evidence that most coronary heart disease is preventable continues to grow. Long-term prospective studies consistently identify persons with low levels of risk factors having lower risk of heart disease and stroke (Pearson et al., 2002). Effective prevention and treatment strategies for coronary heart disease begin with general lifestyle changes (i.e., smoking cessation, maintenance of an optimal weight, a healthful diet, sufficient physical activity, moderate or no alcohol consumption, and treatment of diabetes mellitus, high blood pressure, and dyslipidemias) (Fodor et al., 2000). Communication between the health-care provider and the patient requires discussion of both individual risk factors and subjective risk perception to effectively influence coronary disease risk reduction and healthful behaviour change.

Risk Factors for Coronary Heart Disease

A broad variety of factors are associated with an increased risk of coronary heart disease, ranging from lifestyle behaviour to metabolic and biochemical factors such as smoking, diabetes, being overweight, physical inactivity, and high blood pressure (Heart and Stroke Foundation of Canada, 2003). Canadians run a high risk of developing coronary heart disease, with eight out of ten individuals having at least one risk factor and one in ten having three or more risk factors

(Heart and Stroke Foundation of Canada, 2003). Obesity, primarily abdominal adiposity, is associated with an increased prevalence of diabetes, hypertension, and markers of the metabolic syndrome including insulin resistance, low HDL-C, hypertriglyceridemia, elevated clotting and pro-inflammatory markers (Genest et al., 2003). Unhealthful lifestyle behaviour therefore greatly compounds underlying genetic predispositions for coronary heart disease, dramatically elevating cardiovascular risk.

Coronary heart disease risk factors are classified as non-modifiable or modifiable. Non-modifiable risk factors are fixed and not amenable to intervention including gender (male or post menopausal female), age (men > 45 years, women > 55 years or postmenopausal), personal history of coronary heart disease, and family history of coronary heart disease in a first-degree relative (males < 55 years or females < 65 years). A family history is defined by the National Cholesterol Education Program as having a close blood relative with a myocardial infarction younger than 55 years (father or brother) or younger than 65 years old (mother or sister) (National Cholesterol Education Program, 1994, 2002).

Modifiable coronary heart disease risk factors are factors that can be targeted for intervention to reduce overall risk. These include smoking, physical inactivity, hypertension, diabetes, dyslipidemia and obesity. Risk reduction is achieved by altering any of these variables through lifestyle changes and if necessary, the use of pharmacotherapy. Lifestyle changes include smoking cessation, initiation and maintenance of an exercise program, and weight reduction through dietary changes. Pharmacotherapy interventions may include medications for smoking cessation, anti-hypertensive and hypoglycemic agents, and cholesterol-lowering medications. Recently, medications for blood glucose reduction and weight loss are being utilized as cardiovascular disease risk reduction strategies.

Family History of Coronary Heart Disease

It has been well documented that family members of individuals with coronary heart disease have a higher prevalence of coronary risk factors (Andresdottier, Sigurdsson, Sigvaldason, & Gudnason, 2002; De Sutter et al., 2003; Kip, McCreath, Roseman, Hully, & Schreiner, 2002; Williams et al., 2001). Premature heart disease, in particular, is a powerful and independent indicator of a person's risk. Several prospective studies (National Cholesterol Education Program, 2002) have confirmed a family history of premature coronary heart disease as an independent risk factor. Many studies also identify clustering of cases of coronary heart disease within families (Allen & Blumenthal, 1998; Steeds & Channer, 1997). Allen and Blumenthal (1998) described the growing body of research identifying premature coronary heart disease in families as potentially mediated by familial clustering of elevated levels of coronary risk factors. Lifestyle behaviour and disease processes that aggregate in families with coronary heart disease include hypertension, dyslipidemia, tobacco dependence, diabetes, absence of exercise, alcohol abuse, unhealthful diets, obesity, and often, similar economic status (Burke, 2003; Higgens, 2000). Besides a family history of coronary heart disease, a family history of premature atherosclerosis including cerebral and peripheral vascular disease is also recognized as a risk factor for coronary heart disease (Valentine, Verstraete, Clagett, & Cohen, 2000).

The implicated behaviour, however, does not explain the entire problem. In research, a positive family history continues to have considerable predictive value even after correction for measured familial risk factors such as hypertension, hypercholesterolemia, obesity, and diabetes (Williams et al., 2001). Relatives in a family may share risk factors derived from the integration of both genetic and environmental factors, culminating in premature disease (Williams et al., 2001). A recent study in Reykjavik (Andresdottier et al., 2002) examined the relationship between a history of myocardial infarction in first degree relatives and the risk of developing coronary heart disease (myocardial infarction or coronary revascularization) in approximately 20,000 individuals in a randomly selected prospective cohort study and identified that approximately 15% of all myocardial infarctions can be attributed to familial factors or to factors that remain to be clarified. They attributed this increased risk of developing coronary heart disease in both men and women to having a family history of myocardial infarction and largely independent of other classical risk factors (Andresdottier et al., 2002).

Genetic and environmental interactions have not been clearly described and must both be considered for a comprehensive evaluation of cardiovascular risk. Mediation of the key mechanisms of atherosclerosis and coronary heart disease such as lipid metabolism, hypertension, insulin resistance, glucose and insulin metabolism, coagulation factors, smooth muscle proliferation and vascular growth, and the phenomenon of intra-arterial inflammation, may influence an individual's susceptibility to atherosclerosis (Clarkson et al., 1997; Sesso et al., 2001; Winkelmann et al., 2000). In addition to the physiological mechanisms contributing to coronary heart disease, psychological, socio-cultural and environmental influences should be included in the cardiovascular risk assessment.

Psychological factors such as acute stress, depression and anxiety have been investigated and associated with coronary heart disease (Rozanki, Blumenthal, & Kaplan, 1999). As well, hostility has been found to be a strong risk factor among patients with a genetic predisposition (Gidron, Berger, Lugasi, & Reuban, 2002). These findings validate the importance of screening psychological status, socio-cultural influences, as well as physiological risk factors to fully target and intervene with affected family members.

When a genetic risk of coronary heart disease is determined, the risk for first-degree relatives is elevated by a relative risk ratio of 1.7 to 2.0 (Genest et al., 2003) and has been reported up to an excess risk of 12 times the relative risk of that of the general population

(Becker, Yook, Moy, Blumenthal, & Becker, 1998; National Cholesterol Education Program, 2002). DeSutter et al. (2003) concurred that the magnitude of risk is generally about 2-fold with first degree relatives, with early onset of disease increasing this estimate. The number of relatives with a history of myocardial infarction and their affected relative's age also influence the strength of the association and the predictive value of family history (Kip et al., 2002; Schildkraut, Myers, Cupples, Kiely, & Kannel, 1989). Siblings of affected family members appear to have the highest relative risk, not only from their shared genetics, but from the effects of shared social, cultural, and environmental influences (National Cholesterol Education Program, 2002). The risk profiles of 580 siblings were analyzed from the Augsburg MONICA (Monitoring of Trends and Determinants in Cardiovascular Disease) myocardial infarction registry, wherein investigators found multiple risk factors present in 510 of the asymptomatic siblings; almost 30% were estimated to be at high risk for a cardiovascular event in the next 10 years (Hengstenberg et al., 2001). This population-based study also discovered that in Western Europe, preventive interventions continue to be insufficiently and poorly implemented in this easily identifiable and higher risk group (Hengstenberg et al., 2001). Similarly, family history as a risk factor for coronary heart disease was studied in the first-degree relatives of 707 (121 women, 586 men) survivors of acute myocardial infarction, sisters of the female patients were found to have a cumulative risk of coronary heart disease by age 65 almost twice that of sisters of the male patients. The risk for the brothers of female patients was not elevated (Pohola-Sintonen, Rissanen, Liskola, & Luomanmaki, 1998).

Sesso et al. (2001), studying the differences in paternal and maternal history in relation to age at time of myocardial infarction, found that a parental history of myocardial infarction past the age of 60 continued to predict the risk of coronary heart disease. Women rarely have myocardial infarctions before age 60, thus maternal history may be more important than paternal history, regardless of age at event (Sesso et al., 2001).

De Sutter et al. (2003) highlighted the significance of this empirical evidence by reporting that health-care providers rarely screen patients with a positive family history for coronary risk factors. Only 11.1% of siblings were screened and less than 50% of siblings were given general lifestyle advice on reducing their coronary risk factors. The importance of a positive family history should be underscored by nursing and health practitioners and established as a vital function in comprehensive coronary heart disease risk assessment.

Familial hypercholesterolemia (FH) is a genetic risk factor for coronary heart disease and related to premature coronary heart disease (Gotto & Pownall, 2003). Van Maarle, Stouthard, and Bonsel (2003) found that 556 respondents underestimated their numeric risk of having FH and having a myocardial infarction. Screening done at baseline, and follow-up at three days and seven months, indicated however that the FH-positive individuals perceived a greater risk of myocardial infarction, used more medication, and opted for more frequent gene therapy than those who were FH negative, indicating accurate risk perception (van Maarle et al., 2003). Van Maarle et al. (2003) acknowledged that their findings are concordant with other studies indicating unrealistic optimism. Respondents with a first-degree relative with premature coronary heart disease rated their chance of having FH higher than negative family history individuals (van Maarle et al., 2003).

Genetic screening in this high risk population is a significant, available intervention. The major goal of genetic risk screening is to increase awareness, which would hopefully lead to healthful behaviour change (van Maarle et al., 2003). However, there is currently no evidence that providing genetic risk information to people will increase their motivation to change their lifestyle compared to giving non-genetic based risk information (van Maarle et al., 2003). In fact, Marteau and Lerman (2001) reported that giving genetic information to change health behaviour may actually reduce motivation for engaging in behaviour change by making people believe that the condition is not controllable or preventable. Despite the uncertainty in having this knowledge, people are entitled to obtain their personal cardiovascular risk data and may require this information as part of the motivation process. Risk perception is affected by the information an individual receives and how they process threatening or problematic information. This in turn, influences their decisions about whether to undergo risk assessment and engage in risk reducing behaviour (Marteau, 1999). Further research is needed in the area of genetic counseling and its impact on coronary heart disease reduction.

Coronary Heart Disease and Gender

In Canada, coronary heart diseases remain the leading cause of death in both men and women with nearly 80,000 Canadians dying of coronary heart disease in 1999 (39,808 deaths in men and 39,134 deaths in women) (Heart and Stroke Foundation of Canada, 2003). Despite this fact, most women are unaware of their risk for heart disease. Many women believe that they have a higher risk for developing breast cancer than heart disease (Mosca et al., 2000; Pilote & Hlatky, 1995; Wilcox & Stefanick, 1999) and have been identified as having limited knowledge of heart disease (King et al., 2002). Regardless of heart disease being the leading cause of death in developed countries, and although mortality rates are improving, women have been historically underrepresented as participants in the cardiovascular research arena. Moreover, women have less discussion with their general practitioners (King et al., 2002) regarding their risk factor status, and are referred less frequently for early angiography, thrombolytic therapy, open heart surgery, and even cardiac rehabilitation (Berra, 2000; Jairath, 2001; Sparks & Frazier, 2002). Disparities in assessment, intervention and treatment in women for cardiovascular disease amplify their risk associated with a family history of premature coronary heart disease.

Sex- and gender-based differences exist in the prevalence, clinical presentation, and treatment outcomes of coronary heart disease. Sex-based differences include a later age at onset of coronary heart disease for women than men, differences in the presentation of symptoms, differences in the prevalence of depression, type 2 diabetes, and thyroid problems, and a higher fatality rate post myocardial infarction (Berra, 2000; Jairath, 2001; Sparks & Frazier, 2002). There is a noticeable difference in coronary heart disease risk between the sexes, with prevalence being two to five times more frequent in men than women, which markedly increases with age for both sexes but appears to have a sharper increase for women (Jousilahti, Vartiainen, Tuomilehto, & Puska, 1999). Despite the fact that women generally have a longer life expectancy than men, women have a poorer prognosis, both short- and long-term, after an acute cardiac event and die more often than men after a heart attack or bypass surgery (Ladwig et al., 2000; Mosca et al., 1997).

While the term sex refers more to physical differences, gender is influenced and developed by mostly societal and cultural influences, individual experiences, and values which are eventually developed from this exposure (King, 2003). The importance of gender-specific differences should, therefore, be considered and individualized in coronary heart disease risk reduction and prevention interventions.

Gender-based differences arise from social factors such as lower socioeconomic status for women including income, education, and occupational status, and other social factors of marital status and parenthood, which thereby influence the multiple social roles women carry (King, 2003). The socio-economic status of women in North America compared to men differs; women of all age groups earn less money, have lower status occupations (including homemaking), and have less formal education. King (2003) acknowledged that this is particularly evident for women who are the single heads or lone-parents of families. Fewer benefits related to health care especially, are therefore available to these women, compounding stress and time management challenges experienced while working in low status positions. Cardiovascular disease mortality rates differ by race and ethnicity and also reflect differences in socioeconomic status and acculturation. Those with lower socioeconomic status, measured by income, occupation, and education, have much higher heart disease and stroke rates (Malarcher et al., 2001). Women as well as men, with these less favourable conditions, tend to have a cluster of multiple risk factors which is further amplified by familial risk of premature heart disease (Laramee, 2000a) and further increases the need for aggressive risk reduction.

King (2003) acknowledged another significant gender-based difference regarding the social roles of women: women focus on others before concentrating on themselves, meaning they value the wellbeing and health of other family members first. These social factors culminate to influence women's understanding and motivation in their ability to initiate and participate in lifestyle behaviour change in both primary and secondary prevention of coronary heart disease. Consideration of an individual's socio-cultural background may increase health care providers' understanding of how individuals frame everyday experiences and how this influences healthful lifestyle behaviour change.

The multiple roles women carry and their socio-cultural environments influence risk perception (Krummel et al., 2001) and their capacity to engage in positive behaviour change (King, 2003). It is important that nurses and other health-care professionals consider and assess gender to understand the socio-cultural influences and implications for intervention. It is also prudent to consider that some men and women of lower economic status may consider issues of housing, food and safety needs of their family more of an immediate priority than some recommended risk reduction strategies.

Additionally, coronary heart disease risk perception of men and women is valuable and increasingly necessary knowledge with the growth in the self-management trend to increase patient participation in health care. This is valuable in chronic disease management where the patient is considered part of the patient care team and receives appropriate clinical and self-management support services (Wagner, 2000). A family history of premature coronary heart disease is a threat to both the affected individual and his or her family members. Nursing plays a unique role in facilitating self-management of healthful lifestyle activities in the prevention of coronary heart disease. Nurses as educators and front-line health-care providers can assist family members of individuals with coronary heart disease to recognize their genetic or familial predisposition as a significant health risk to enhance the adoption of preventive behaviour such as regular exercise and healthful eating patterns.

It has been established that those with a positive family history of coronary heart disease are a high risk group that is under treated and if treated, not treated to the fullest benefit. Nurses and other health-care practitioners must give careful consideration to sex and gender differences such as individuals' knowledge of cardiovascular risk status, to effectively target the prevention and reduction of coronary heart disease. Consequently, a key strategy in the primary prevention of heart disease for first-degree relatives of affected persons is a comprehensive risk assessment of all cardiovascular risk factors permitting the accurate determination and intensity of therapeutic interventions for both men and women (Burke, 2003).

Risk Perception

Much of the literature on risk perception involves studies of healthy individuals that have been completed in the form of surveys. A small number of studies were found that examined coronary heart disease risk perception and very few studies were found that focused on the risk perception of first degree relatives of individuals with premature heart disease. Risk perception literature specific to gender was even scarcer.

Knowledge and Coronary Heart Disease

The literature identifies several factors related to a perception of increased risk including awareness of risk factors for certain diseases, awareness of previous acute myocardial infarction, awareness of one's health, knowledge of general disease risk, and demographic variables, such as age, education and gender (Meischke et al., 2000). Self-perceived risk for coronary heart disease has been related to actual behaviour change and risk-reducing behaviour. Perception of risk therefore influences both a person's assessment of a situation and the response of intervention seeking behaviour. Knowledge about heart disease plays a significant role in influencing the risk perceptions of both men and women. Lack of awareness for coronary heart disease risks may impede primary prevention strategies and inhibit people endeavouring to make healthful lifestyle changes (Mosca et al., 2000). Inadequate education may also result in underestimation of personal risk. A telephone survey of 1,000 women in the United States identified that women do not perceive heart disease as a significant health risk, that they are not well informed about their personal risk, and feel the need to be better informed by their physicians (Mosca et al., 2000).

Perceptions of personal risk for a disease appear to be an important factor in disease prevention behaviour (Meischke et al., 2000). Specific to coronary heart disease, perceived risk has been positively related to increased motivation and risk reducing behaviour change (Meischke et al., 2000). Behavioural models suggest that understanding the threat of a disease depends on people's perceptions of its seriousness and their own vulnerability. Knowledge of disease risk therefore, appears to play a significant role in how people understand health risks and the likelihood that they will personally be affected by a particular disease. Preventive medicine focuses on an individual's behaviour that would alter the course of disease or health.

For many years, researchers have explored individual meaning of health and illness in behaviour. This had led to the development of the well-known social cognition model, the Health Belief Model. The Health Belief Model provides a framework for understanding an individual's perceived susceptibility and severity of a threatening illness, and the benefits and barriers of the treatment or behaviour change needed to avoid the threat (Jairath, 1999). The Health Belief Model hypothesizes that there are three groups of factors that simultaneously influence healthful behaviour change: susceptibility or a perceived threat, belief that the health recommendation is beneficial in reducing the threat and is acceptable to the patient, and existence of adequate motivation to make health issues salient. Specific to coronary heart disease, the Health Belief Model identifies individuals as being more likely to engage in risk-reducing behaviour if they believe that they are at high risk for heart disease, that they will suffer serious consequences, and that their actions will decrease the severity of the consequences. The drawback of this particular model, however, is that it does not provide any guidelines or information on gender specific interactions.

The British Family Heart Study (Marteau, Kinmonth, Pyke, & Thompson, 1995), a large randomized controlled study involving both primary and secondary coronary heart disease patients, offered nurse-led screening for risk of coronary heart disease. They found that the self-assessments of coronary heart disease risk, prior to clinic screening, in 3,725 individuals, were somewhat realistic; the self-assessments were found to be especially related to individual and family medical history and to body mass index. The majority of these people indicated that their risk of having a heart attack in the next 15 years was average or lower than average, indicating a greater degree of optimistic bias (37%) compared to pessimistic bias (21%) (Marteau et al., 1995). Although this large study showed general agreement between self-rated risk and epidemiological risk, optimistic realism did exist. The inclusion of both subjects with and without cardiac disease may have influenced these findings since secondary prevention subjects may perceive their risk more accurately or pessimistically depending on their knowledge and degree of heart disease experience. Marteau et al. (1995) suggested that risk ratings may result not only from optimism but by weighting different risk factors by their familiarity and prevalence; some people may be able to rate themselves more accurately than a risk score. Smoking and family history of coronary heart disease were given more weight by the respondent than by the epidemiological risk ratings. These are considered "visible" risk factors, and again, risk perception in heart disease may be influenced by the weighting of different factors as well as previous education or exposure to information on a particular risk factor. Smoking is a good example of a cardiovascular risk factor that has been targeted by public education campaigns, and therefore identified and given more weight by individuals.

In a similar study assessing accuracy of perceived risk of heart attack, 732 healthy respondents without heart disease reported being influenced by established risk factors in estimating their overall risk, but were still found to be optimistically biased when compared to objective risk measures (Avis, Smith, & McKinlay, 1989). Avis et al. (1989) administered a health-risk appraisal instrument to assess risk factor prevalence and risk perception at baseline and at 2 months follow-up which did not show any changes in perception even in light of the provision of personal risk factor status. This study showed that people allowed epidemiologically established risk factors (especially exercise and cholesterol) to influence their perceived risk. Previous research has identified the underestimation of personal risk for developing certain diseases, which is consistent with Avis et al.'s (1989) findings that younger age and lower education are associated with optimistic bias. Family history of heart disease is associated with an overestimation or pessimistic bias (Marteau et al., 1995). For these reasons, determination of a person's subjective risk perception gives the practitioner the opportunity to identify actual or objective risk, and to communicate any differences to facilitate improved accuracy in risk perception. Nurse clinicians and health-care professionals can communicate and clarify any discrepancies in cardiovascular risk perception and knowledge about heart disease to improve healthful lifestyle behaviour.

The REACT study (Rapid Early Action for Coronary Treatment; Erhardt & Hobbs, 2002) is a large survey involving five European countries to assess general public perception of cardiovascular risk. Erhardt and Hobbs (2002) identified that most of the public participating (n = 5,104) in the study believed themselves to be at average or below average risk of developing coronary heart disease. In those who were rated as high risk, nine out of ten underestimated their personal level of risk and only 45% of these participants identified coronary heart disease as the leading cause of death in their country. Similar to both Marteau et al. (1995) and Avis et al.'s (1989) research, the REACT study participants underestimated their risk for coronary heart disease and were ignorant of the leading causes of heart disease, especially dyslipidemia (Erhardt & Hobbs, 2002). The REACT study participants with actual coronary heart disease or with risk factors did not differ in risk perception compared to those individuals who had no disease. A similar European survey was conducted of individuals with primary and secondary coronary heart disease (n = 5013) by the HELP Study Group (Shepherd et al., 1997). Respondents included members of the general public (n = 5,013), individuals at high risk for coronary heart disease (n = 2,500), individuals who had suffered a heart attack (n = 1,256) and members of their families (n = 1,249) who completed a survey to assess their awareness and attitudes to coronary heart disease and health behaviour practices. Like the REACT survey, the mean levels of worry that the respondent may suffer a heart attack were low for both the general public group (4.2 ± 0.04) and the high risk group (4.1 ± 0.05) on a scale from 1 (not worried at all) to 10 (extremely worried) (Shepherd et al., 1997). Despite direct experience with myocardial infarction, patients' and family groups' concerns were not high; the mean scores were 5.1 ± 0.08 and 4.5 ± 0.08, respectively.

A comparison of perceived versus objective risk of heart attack and stroke in a randomly selected sample from two surveys in New England (n = 4171) also revealed an underestimation of cardiovascular risk (Niknian, McKinlay, Rakowski, & Carleton, 1989). The investigators found that higher levels of agreement between objective and perceived risk were associated with younger age, female gender, higher education, non-smoking status, using hypertensive medication, or having a lower body mass index (Niknian et al., 1989).

Effective communication of risk for the prevention and treatment of chronic disease may need new strategies for measuring and conceptualizing risk perception. Although comparative risk judgments about environmental hazards and diseases provide a broader context for individuals to understand their personal risk (Walker, 2003), communication between experts and lay individuals may act as a barrier to risk communication. Health-care professionals can communicate and clarify any discrepancies in the level of cardiovascular risk and knowledge about heart disease to improve healthful lifestyle behaviour.

Pessimistic Versus Optimistic Bias in Risk Perception

Several studies have found that people frequently underestimate their general health risk (van Maarle et al., 2003; Walker, Mertz, Kalten, & Flynn, 2003; Weinstein, 1980, 1983) and underestimate their risk for coronary heart disease (Avis, McKinlay, & Smith, 1990; Avis et al., 1989; Becker & Levine, 1987; Bjerrum, Hamm, Toft, Munck, & Kraqstrup, 2002; Erhardt & Hobbs, 2002; Green, Grant, Hill, Brizzolara, & Belmont, 2003; Kreuter & Stretcher, 1995; Ladwig et al., 2000; Marteau et al., 1995; Meischke et al., 2000; Niknian et al., 1989; Ponder, Lee, Green, & Richards, 1996; Shepherd et al., 1998; Stretcher, Kreuter, & Korbin, 1995; van

Teil, van Vliet, & Moerman, 1998; Zerwic, King, & Wlasowicz, 1997). Weinstein (1980) found that health-protective behaviour is predicted partly by an individual's perceived susceptibility and illness beliefs of one's own vulnerability to becoming ill. Optimistic bias is regarded as an unrealistic assessment of risk status by individuals who are actually characterized as being at high risk for developing a specific disease. Individuals who describe an overestimation of personal risk have a pessimistic bias (Stretcher et al., 1995).

Several influences may shape an individual's formulation of an optimistic bias. Cognitive errors such as lack of information and lack of experience or motivational needs like self-esteem and denial influence optimistic bias (Avis et al., 1989). Individuals who underestimate their risk or who are optimistic may be less inclined to initiate behaviour change. Over estimation or pessimistic bias in individuals, may not result in behaviour change because of a sense that nothing (including behaviour change) will make a difference (Stretcher et al., 1995). Unrealistic bias stems from a lack of information, selective recall, or egocentrism affecting the process of risk assessment (Weinstein, 1983, 1984). Weinstein and Klein (1995) acknowledged that people are reluctant to believe anything other than the point that their risk is below average. Weinstein (1984) acknowledged that when people make comparative risk judgments they are frequently optimistically biased in that they believe their own chances are less than the chances of their peers encountering any health problems. Interestingly, a group of 535 practicing physicians who were assessed for their personal risk perception for developing diabetes were found to have an optimistic bias (Walker et al., 2003). It is noteworthy that risk perception biases vary from one risk to another and are not stable traits (Kreuter et al., 1995).

Multiple interpretations contribute to perceptions of risk (Walker et al., 2003) and require effective communication to deliver clear messages about personal risks to motivate healthful behaviour. Offering only objective risk assessment information to individuals and not considering their perceived risk, could influence misinterpretation of risk and deter behaviour change. Risk message interpretations may be skewed further by health-care professionals using complex terminology, thereby increasing cognitive errors (Walker et al., 2003). General knowledge of coronary heart disease does not necessarily translate into accurate risk perception and risk reducing behaviour and may lead to misconceptions of personal risk (Avis et al., 1990). Individuals with known risk factors continue to be largely ignorant of their personal risks and for people with existing coronary heart disease, ignorant to the course of their illness (Zerwic et al., 1997). Ignorance of disease risks as well as the presence of an optimistic bias magnify the need for the individualized assessment of a person's understanding of his or her risk for coronary heart disease.

Gender and Risk Perception

The literature reviewed for this research revealed a paucity of information relevant to risk perception and gender differences related to coronary heart disease, and an absence of specific literature on the subjective risk perceptions of first degree family members and the role that kinship relationship plays (e.g., does it matter if the affected relative is a parent, sibling or child?). Some researchers have found that gender is related to specific risk factors (Kreuter & Stretcher, 1995; Ladwig et al., 2000; Meischke et al., 2000; Stretcher et al., 1995) however, most do not make reference to gender. The few studies that addressed the influence of gender on perception of coronary heart disease risk tended to examine optimistic bias or underestimation of personal risk (Kreuter & Stretcher, 1995; Ladwig et al., 2000; Meischke et al., 2000; van Teil et al., 1998).

The REACT study group (Meischke et al., 2000) assessed the perceived risk of acute myocardial infarction in 1294 respondents (57% female) and reported that women who incorrectly believed that heart disease is not the most common cause of death for women in the United States also reported significantly lower risk perceptions (underestimation of risk) than those who answered correctly. Overall, subjects who reported poor general health had a higher perceived risk of acute myocardial infarction. Age increased perceived risk but gender, education level and race/ethnicity were not significant.

Meisckhe et al. (2000) found an inverse relationship between the number of reported risk factors and general health. However, over 50% of the subjects who reported good or excellent health indicated having one or more risk factors, indicating an optimistic bias. They did not distinguish any gender differences in this particular analysis. Another large survey examining the correspondence between subjective and objective risk of heart attack and stroke in a randomized sample (n = 4171) of adults in New England identified an underestimation of disease risk (Niknian et al., 1989). Agreement between perceived and objective risk showed that accuracy was associated with being female, being a non-smoker, taking anti-hypertensive medication, having a lower body mass index, and being more educated. Kreuter and Stretcher (1995) found somewhat conflicting results for people in a primary care setting participating in a pre- and post-test randomized survey (n = 1317, 65% female) using a computerized health risk appraisal feedback tool. Women, subjects with fewer years of education, African Americans, and those of younger age were optimistic about the risk of heart attack and stroke.

The health perception of 317 post angioplasty (stent implantation) patients (24.6% female) six months after their intervention, indicated that women exhibited a trend towards an impaired or negative health perception (Ladwig et al., 2000), but after adjusting for confounding factors, the gender differences disappeared. Ladwig et al. (2000) reported that women in their study had a preponderance of sleeping disorders, anxiety, and depression, which may have affected their illness perception and specific areas of adaptation following a coronary event. A sample of 101 healthy middle-aged women were surveyed about their perceived future health risks of coronary heart disease, osteoporosis, and breast cancer and their uptake of preventive strategies and hormone replacement therapy (Hunter & O'Dea, 1999). The women appeared to have reasonably accurate perceptions of their future risk of developing coronary heart disease; however, those who rated themselves in poorer health, as non-exercisers, and on regular medication, rated themselves at relatively higher risk.

Ponder et al. (1996) examined young people (n = 58) who had completed a science course including human genetics, and their parents (n = 54), on the impact of family health history and susceptibility to different diseases. Both the childrens' and parents' groups believed that they had an increased likelihood of developing cancer because of an affected relative. Particularly, more women than men, of both generations, believed that they were more likely to develop cancer because they had an affected relative. This over-estimation of risk, however, was not significantly different between the sexes for either heart disease or diabetes risk.

Risk perception may be influenced by the multiple role responsibilities of women within a family. Some women may not react favourably to combining the responsibilities of both work and family and respond inappropriately to increased time pressures and demands that may cause greater risk of fatigue, anxiety, depression, and poorer physical health (Fleury, Keller, & Murdaugh, 2000). Fleury et al. (2000) also made reference to the well-known Framingham Study findings that elevated risk factors and development of coronary heart disease in women were heightened by this element of "conflicting roles". Chronic life stress, less favourable living conditions, less opportunity to affect positive health behaviour and outcomes are intertwined with women's multiple roles.

Risk Perception and Family History of Coronary Heart Disease

The literature mainly describes studies that examined the risk perceptions of healthy individuals. Risk perception may, however, differ between this group and people with known cardiac disease in their family. There have been mixed results in the study of perception of risk and family history of coronary heart disease. Becker and Levine (1987) reported that siblings (n = 80) of persons hospitalized with symptoms of coronary heart disease did not estimate their personal risk to be high despite having moderate knowledge of coronary heart disease. Other investigators have found increased perceived vulnerability in the presence of a family history of heart disease. Avis et al. (1989) reported that individuals with a family history of heart disease had more pessimistic perceptions in a group of 732 healthy individuals compared to individuals who did not have a family history of coronary heart disease. Similarly, Marteau et al. (1995) found that pessimistic biases were twice as likely to occur in respondents who had a first degree relative with premature coronary heart disease or a parent who had died from coronary heart disease, and were more likely to be smokers and to be overweight.

In the European REACT survey (n = 5104) (Erhardt & Hobbs, 2002), nearly one fifth of the respondents (17%) reported an immediate family member having had a premature heart attack. Only 35% of the total sample were aware of the increased risk for heart disease when a positive family history of premature heart attack was present, with even fewer (17%) aware that diabetes increased coronary heart disease risk. Similar in findings, the HELP Study group (Shepherd et al., 1997) identified that post–myocardial infarction patients' and their families' concerns for developing coronary heart disease to be average to under-estimations, representing an optimistic bias; more than 50% of the high risk group were not willing to make any changes for a healthier lifestyle.

Family health history was the basis for a study of 58 healthy young people's and 54 of their parents' susceptibility to health risks (Ponder et al., 1996). When family health history was positive, respondents had a higher degree of perceived vulnerability to heart disease and diabetes than to cancer. Personal actions and behaviour were seen as important in influencing the chance of developing heart disease and cancer, but less so for diabetes. Despite this increased perception of vulnerability to heart disease, nearly one half (41%) of the respondents who reported heart disease in a family member did not perceive this to have any effect on their own personal susceptibility. Like other studies indicating underestimation of risk, those respondents reporting a family history of heart disease, did not perceive that they had an increased susceptibility indicating an optimistic or unrealistic risk perception (Ponder et al., 1996).

Very few studies have examined the risk perception of first degree relatives of family members with premature coronary heart disease. The study of gender influences on risk perception is also scarce in the literature. Knowledge of this information may contribute to improved education and accuracy of cardiovascular risk for this high risk group.

Summary

Coronary heart disease remains the leading cause of mortality and morbidity in both men and women in Canada. A family history of coronary heart disease is an independent risk factor and dramatically elevates risk. The number of relatives affected influences the strength of the association and impacts the predictive value of familial risk for premature coronary heart disease. Siblings are at an increased risk compared to other family members but when a sister is the affected family member with coronary heart disease, her relatives have been recognized to be at higher risk than when the affected family member is a brother.

Risk perception plays a key role in the education and delivery of health-care interventions targeting the reduction of heart disease. Health promotion is more effective when individual risk perceptions are explored and interventions are tailored to be sensitive to individual perceptions. Individuals with a positive family history of coronary heart disease frequently underestimate their personal risk, despite having exposure to a relative affected by heart disease. It therefore appears necessary to examine individuals' knowledge of risk factors and also their personal beliefs about their risk profile. Nurses and other health-care professionals may then better understand a person's responses to risk reduction interventions and provide more effective therapy.

CHAPTER 3: METHODS AND PROCEDURES

Summary of Research Project

This thesis project was designed to examine the risk perceptions of first-degree relatives of individuals with premature coronary heart disease and the influence of gender and kinship relationship on those perceptions. Self-perceived risk was compared to validated objective risk scores. This comparison determined the level of accuracy in individuals' perceptions of their risk for cardiovascular disease and permited the exploration of possible gender differences. The influence of the kinship relationship between the index patient and first-degree relative, and the influence of the gender of the index patient were explored.

Research Design

The research undertaken for this thesis was part of a larger clinical trial, the Family Atherosclerosis Counseling and Testing Study (FACTS). This thesis research was a descriptive correlational design and was conducted independently of the FACTS project. The setting for the study was St. Paul's Hospital, Healthy Heart Program. The next sections provide an overview of the FACTS research study followed by a detailed description of the thesis research project.

The Family Atherosclerosis Counseling and Testing Study (FACTS)

FACTS Purpose

The purpose of the ongoing FACTS project is to identify and phenotype young patients with evidence of premature atherosclerotic vascular disease (cardiovascular disease, peripheral vascular disease or cerebrovascular disease) and their first-degree relatives and spouses. The FACTS project is designed to test the hypothesis that these first-degree relatives will have more frequent and more severe risk factors for vascular disease than found in the general population. They may also have greater awareness of their risk profile and be more likely to adhere to lifestyle and treatment recommendations designed to reduce their risk. This study also will test the hypothesis that education about risk factors will result in differences in the family cohorts of the intervention group with respect to their risk factor profile one year following an educational intervention.

The FACTS study research questions include the following:

1. What are the differences in Framingham risk scores, anthropometric and biochemical measures in the family cohorts assigned to receive intervention and usual care?
2. What are the changes observed in lifestyle between baseline and 12 months?
3. What are the changes in compliance to prescribed regimens?
4. What is the DNA profile and phenotyping for gene environment interaction?
5. What is the prevalence of shared risk factors and mode of inheritance in families?
6. What is the difference between maternal and paternal risk factors?
7. What is the difference in risk perception (objective versus subjective risk)?
8. What is the perception of survival of the index patient?

FACTS Research Design

The FACTS project is a prospective randomized control follow up study that was begun in May 2003. The randomization method is block randomization using a block of 4 (restricted randomization). The usual care or intervention group allocation is randomly chosen within a block of 4. This is done to help with balancing the group size and reducing the unpredictability of the study.

FACTS Study Protocol

Two research assistants were hired and trained by the FACTS project coordinator to recruit subjects, administer the questionnaire and complete the data collection in a systematic approach. The recruitment of eligible participants occurred at St. Paul's Hospital, Vancouver, British Columbia from the interventional catheterization laboratories, the Lipid Clinic and Cardiovascular Risk Reduction and Prevention Clinic within the Healthy Heart Program, the Heart Function Clinic, and the cardiac inpatient wards (5A and 5B). Study participants were also recruited from the outpatient Cardiac Rehabilitation and Prevention Program at Vancouver Hospital and cardiologists' offices within the Greater Vancouver area.

From Monday to Friday the research assistants screened for eligible patients attending the clinics or out-patient catheterization laboratories. Index patients in the out-patient clinic settings were first approached by either their nurse or doctor to assess their interest for participation in the study. If the patient wished to participate in the study or enquired about more information, the research assistant saw the patient, explained the study, obtained the consent, and then, if agreeable, collected the required data and blood specimens. Patients in the Cardiac Interventional Unit (CIU), were seen post-catheterization, and only approached after their procedure and when they were no longer sedated. The research assistant approached them at the bedside to obtain consent and to administer the data collection tool. Patients recruited in the out-patient clinic setting were approached after their scheduled clinic appointment. All participants were interviewed face-to-face in the clinic settings, at the bedside in the CIU, or the cardiologists' offices.

After the index patient had been recruited, their first degree relatives were mailed a letter asking them to participate in the study. This was followed 4-5 days later by 1 or 2 telephone calls. Once telephone contact had been made with the first degree relative, and they had agreed to participate in the study, an initial appointment for assessment was booked. The study was explained, consent obtained, and data collection proceeded. All of the first degree relatives were given the results of their Framingham risk assessment and a letter was sent to their general practitioner describing their cardiovascular risk and recommendations for treatment.

Following the data collection, the family cohorts (the index patient and their first degree relatives) were randomly assigned to a usual care or intervention group. The usual care group received an assessment at baseline and at 12 months. The intervention group had, or will have, assessments at baseline, 4 months, 8 months, and 12 months, combined with individual cardiovascular risk reduction counseling, telephone and group support.

FACTS Sample

The target population for the FACTS Study were the first degree relatives and their spouses of individuals with premature atherosclerosis, including men and women. Recruitment criteria for the index patients included males aged 50 years or less and females aged 60 years or less at the time of an adverse event with clinical evidence of atherosclerotic disease. They must have had at least two first degree relatives who lived in the Lower Mainland. Only the index patients, not their first-degree relatives, were required to have clinical evidence of atherosclerotic vascular disease to be eligible for enrolment into the study. Exclusion criteria for the index patients included lack of English comprehension, negative screen for coronary artery disease, coronary artery disease cause proven to be a secondary cause (i.e., polycythemia, HIV positive with HIV medications, dyslipidemia, vascular diseases, rare autosomal recessive disorders), failure to consent, unwillingness to contact the first degree relatives and geographic distance to St. Paul's Hospital.

First degree relatives, including siblings, adult children or parents of index patients and their spouses living in the Greater Vancouver area, were asked to participate. Criteria for enrollment of first degree relatives included their being beyond puberty, over 18 years old, and willing to provide information about their cardiovascular risk factor profile. The first degree relative's geographic proximity to St. Paul's Hospital was considered in the recruitment because they were required to travel to the hospital. Exclusion criteria for the first degree relatives included lack of English comprehension, indicated coronary artery disease cause was proven by a secondary cause (i.e., polycythemia, HIV positive with HIV medications, dyslipidemia, vascular diseases, rare autosomal recessive disorders), failure to consent, and unwillingness to participate in the intervention group if randomized to it.

Before commencement of the study, hospital admissions for patients with premature atherosclerosis were explored. It was determined that a targeted sample of 250 index patients and 600 first degree relatives and their spouses (approximately 2 to 3 first degree relatives per index patient) was feasible. The recruitment of study participants was conducted between May 2003 and March 2005. In consultation with a statistician, estimated statistical power was calculated a priori based on the LDL-C variable. Power was estimated to be sufficient to find a difference of 10% in LDL-C between the intervention and control groups at the end of one year in this sample. The planned analysis included case versus control, segregational analysis and stratified analysis based on family size.

Data Collection

A comprehensive questionnaire for the FACTS project was developed by experts in the field of cardiovascular risk reduction (see Appendix A). It included sociodemographic information, medical history, subjective risk perception, absolute risk perception, menopausal history if female, and a cardiovascular risk factor profile (smoking, hypertension, dyslipidemia, diabetes, sedentary lifestyle, obesity). Anthropometric measures (i.e., height, weight, and waist circumference), blood pressure, heart rate, biochemistry and lipidemic markers were also obtained. Established instruments were used to objectively estimate exercise frequency and dietary habits, and to estimate 10-year risk of coronary heart disease. Information of family history was constructed as a genogram obtained from the index patient.

During the initial appointment, the interviewer first read the question to the respondent and then entered the respondent's answer. This process allowed for simultaneous data collection and capture, to ensure that the interviewer recorded an accurate response. The data were entered into the study's computerized database. The participant was mailed the dietary and exercise questionnaires to complete independently prior to the first appointment. Clarification was given at the subject's request for the independently completed nutrition and exercise questionnaires. Data collection therefore entailed both objective and subjective information from the study participants.

Measurement

Sociodemographic Variables

The socioedemographic variables were developed with comprehensive survey questions, replicated from a larger research study within St.Paul's Hospital. The items included were name (1d), date of birth (1e), sex (1f), ethnicity of participant's mother, father, grandmother, and grandfather (1g), and personal history of education (2a).

Exercise

The FACTS questionnaire asked general questions on frequency, intensity, timing, and type of exercise (2b) according to the FITT identification, which is a well known method to assess exercise behaviour. To increase the accuracy of the evaluation of exercise, the Modifiable Activity Questionnaire (MAQ) (Krista et al., 1988) was also used (See Appendix C). This is a comprehensive tool evaluating an adult's past week and past year of participation in leisure-time physical activity, sports, and occupational activities.

Diet and Alcohol

A comprehensive assessment of nutritional status was obtained via the Brief Food Questionnaire developed by Block (2000) from the Berkley Nutrition Services. This is a validated questionnaire used extensively to provide essential nutrient data for research on the role of diet in health and disease (Berkeley Nutrition Services, 2003). Alcohol consumption questions were listed in both the general questionnaire (2e) and in the Brief Food Questionnaire.

Smoking History

Items pertaining to tobacco use (2d) were taken from Health Canada's Summary Report of the Workshop for Monitoring Tobacco Use (Mills, Stephens, & Wilkens, 1994).

Menopausal Status

Women completed five items related to menopausal history (2f) and use of hormone replacement therapy.

Family History

The participant's family history was obtained by both questions and a genogram. Data were collected on the participant's family history of coronary artery disease, peripheral artery disease, cardiovascular disease or evidence of diabetes, hypertension or dyslipidemia (5). A genogram was obtained from the index patient and was copied for the first-degree relative's records. This provided the marital status of both the index patient and the first-degree relative. A genogram identified the relationship of each family member (e.g., mother, father, brother, sister, or child).

Cardiovascular Risk Factors

Many questions were asked relating to personal cardiovascular risk status. Questions were asked about personal history of cardiovascular risk factors or disease (7a), related interventions (7d-f) and use of any medications (6). Information was also collected on current diagnosis, if relevant (10). The cardiovascular diagnosis was self-reported and was confirmed by retrieval of the participant's medical reports. Recent history of any change in exercise, eating, smoking, alcohol intake and weight was determined by rating it as decreased, the same or increased (3).

Finally, data pertaining to the participant's physical examination (8) and laboratory results (11) were obtained. The data collected from the physical examination allowed for the calculation of epidemiological cardiovascular risk status. Epidemiologically-assessed risk was calculated from the well validated cardiovascular risk assessment tool, the Framingham Risk Score (Kannel, Feinleib, McNamara, Garrison, & Castelli, 1979) and the PROCAM risk score (Assman et al., 2002). The Framingham coronary prediction algorithm provides estimates of total coronary heart disease risk (risk of developing one of the following: angina pectoris, myocardial infarction, or coronary disease death) over the course of 10 years (see Appendix 3).

Research Methods

This thesis research was a component of the larger FACTS project. The following information is specific to this thesis; it identifies the main differences between the larger study and the thesis. To review, the purpose of this thesis research was to examine the accuracy of the risk perceptions of first-degree relatives of patients with premature atherosclerosis. A further aim was to determine the influence of gender and familial relationship on those risk perceptions.

Research Protocol

The study protocol followed the previously outlined FACTS project protocol.

Sample

For the purpose of this thesis research, the sample was limited to the first-degree relatives, all of whom were recruited from the larger study. The index patients and spouses of the first-degree relatives were not included. The participants were recruited by the research coordinator and one research assistant. (See page 39, FACT Sample, for full description of the sample cohort). The descriptive correlational design of this study permitted the examination of the relationships that exist between first-degree relatives' level of accuracy in risk perception and their gender and kinship relationships.

Data Collection

Data collection occurred as outlined for the FACTS project protocol.

Measurement

This thesis research was planned independently and prior to the development of the FACTS project. I was therefore able to participate in the design of the FACTS project and consider, a priori, the appropriate data necessary for this thesis research. The FACTS study captured data on the respondents' cardiovascular risk factors including exercise, diet, smoking, hypertension, family history, weight and dyslipidemia. The respondents' sociodemographic variables, medical history, medication use, estimated 10-year risk of cardiovascular disease were also obtained. Important to this thesis was the measurement of the respondents' perception of cardiovascular risk in relation to their prevalence of cardiovascular risk factors. This was attempted by adding a subjective and absolute risk question and another risk prediction measurement, the PROCAM table, to the baseline FACTS questions.

Cardiovascular Risk Factors

For the purpose of this thesis research, cardiovascular risk factors described for the FACTS project remained the same.

Risk Perception

Self-assessed risk of cardiovascular disease was assessed by asking the following question: "What do you think is your risk of having a heart attack in the next 10 years, compared with other people of your age and sex: high, medium, or low?" This question was obtained from the large primary prevention study, the British Family Heart Study (Marteau et al., 1995). The ratings were changed to concur with the epidemiological cardiovascular risk assessment tool used in this study. Absolute risk was assessed by asking the question, "What do you think is your risk of having a heart attack in the next 10 years?" and the subject was asked to give a percentage ranging between 0% and 100%.

Accuracy of Perceived Risk of Cardiovascular Disease

Both subjective and objective questions were obtained to assess the accuracy of risk perception. As stated earlier, participants were asked what they believed to be their risk of having a heart attack in the next ten years compared to someone of their own age and sex by rating it high, moderate, or low. Subjective risk was also obtained by asking what they thought their risk of having a heart attack was in the next ten years and giving a percentage answer from 0% to 100%. This percentage scale allowed the participant to give a rating from "absolutely no chance" (0%) to "absolute conviction" (100%) that they would have a heart attack. To evaluate risk perception accuracy, the subjective ratings were compared with the epidemiological objective risk scores of the Framingham and PROCAM risk scores. The accuracy of risk perception results were then described as accurate, under-estimated, or over-estimated.

Gender

Little is known about gender differences in cardiovascular risk perception. To determine whether there are gender differences in how first-degree relatives perceive their risk and in the factors that shape those perceptions, the risk perceptions of men and women were compared. Also, the gender of the index patient was explored to determine whether it accounted for differences in risk perception.

Kinship Relationships

The kinship relationship between the index patient and the family member was determined by identifying if the index patient was a mother, father (parent), brother, sister (sibling), son, or daughter (child) of the participant. Accuracy of risk perception was compared among these groups.

Reliability and Validity

Reliability of Data Collection

The FACTS research team undertook all actions necessary to avoid potential sources of systematic or random error. Random error was kept to a minimum by having well trained interviewers who had previous knowledge of research procedures. As well, each interviewer was very familiar with the questionnaire content and had been involved since the inception of the FACTS study. The research assistants were monitored throughout the study for appropriateness of conduct and procedure adherence. The research coordinator randomly reviewed collected data and also listened to selected interviews to ensure proper study protocols were being adhered to.

Reliability of the Questionnaire

Experts in cardiovascular risk reduction gave careful consideration to the questions for the development of the FACTS project questionnaire. Questions were chosen to correctly measure the variables to reduce the occurrence of systematic error. Both the subjective and absolute risk assessment questions were situated at the beginning of the questionnaire after the demographic section, to avoid sensitization of the participants' risk perception. The potential for subjects to score higher on their self-assessed cardiovascular risk may have occurred if specific questions were asked prior to the subjective risk assessment questions.

First-degree relatives of individuals with premature atherosclerosis were offered the opportunity to assess their own risk for cardiovascular disease. Personal risk perception may not have been considered previously or not until the occurrence of their family member's diagnosis with cardiovascular disease.

Content Validity of the Questionnaire

The investigators who developed the questionnaire were physicians and nurses engaged in clinical practice, and who are independent and university-based researchers specializing in the area of cardiovascular disease prevention and reduction. The Framingham risk algorithm has been established as a well-validated risk stratification tool, as has the PROCAM risk score.

Generalizability

The study sample for the FACTS study represents all first-degree relatives of patients with premature atherosclerosis living within the Greater Vancouver area. The index patients and their FDRs were sought from a variety of settings from outpatient clinical settings to interventional catheterization laboratories and cardiologists' offices. These settings are comparable to other metropolitan areas and therefore, the findings of this research should be generalizable to other similar metropolitan areas in Canada.

Data Analysis

The statistical analysis of the data proceeded as follows. In the pre-analysis phase, the data forms were reviewed for completeness and legibility. Missing data were retrieved by contacting the participant or by locating the correct information. The data were then coded for input into a computer file. Once the data were entered into a computer file they were verified.

The data were entered twice and verification occurred by comparing the two sets of data records visually. After the records were verified, data cleaning checked for outliers and wild codes and internal data consistency checks were performed. Inspecting frequency distributions for the lowest and highest values addressed any outliers. An analysis file was created with the generation of a codebook.

A preliminary assessment of the data was performed to identify any missing values. The extent of the distribution and patterning of the missing data was determined. Steps were taken to assess data quality. The next step in the preliminary analysis phase included the assessment of the direction and extent of any biases if apparent. Assessment of assumptions for statistical tests were reviewed for any violations.

Research Question 1

What is the accuracy of the risk perceptions of first-degree relatives of patients with premature coronary heart disease when compared with objective epidemiological risk assessments?

Objective Epidemiological Risk Assessment

The objective risk assessment was characterized by the Framingham risk score, which is estimated in percentages that are then categorized: low risk = 0% - 9%, moderate risk = 10% - 19%, and high risk ≥ 20%. Frequency distributions tables were constructed of the Framingham percentage scores and categories. The PROCAM score, the additional objective risk assessment, was also described for the entire sample, and both genders. The results of both assessments were reviewed for normality.

To examine the relationship between the Framingham risk score (percentage) and the PROCAM risk score, a bivariate correlation using Pearson's product moment correlation was calculated. Scatter diagrams were viewed to test the assumptions of linearity and equal variance.

Subjective Risk Perception

Frequency distributions tables for the sample and gender-specific responses to each of the subjective risk questions are provided. The distributions were reviewed for symmetry and normality.

Accuracy of Risk Perception

To determine the accuracy of the respondents' risk perceptions, a contingency table was created of the categorical Framingham risk scores (low, medium, high) and the categorical subjective risk perceptions (low, medium, high). A new variable was created such that the respondents with agreement in their objective and subjective assessments (the diagonal cells) were coded as "accurate." Those who reported that their risk was "low" and who were "medium" or "high" on the Framingham risk assessment, and those who reported "medium" risk and who were "high" on the Framingham risk assessment were coded as "under-estimators". Conversely, those who reported that they were at "high" risk and had "low" or "medium" Framingham risk assessments were coded as "over-estimators," as were those who reported "medium" risk and had "low" Framingham scores.

Research Questions 2, 3 and 4

What is the relationship between gender and the accuracy of risk perceptions of first-degree relatives of patients with premature coronary heart disease?

Does the accuracy of the risk perceptions of first-degree relatives differ depending on whether their affected family member (index patient) is male or female?

Do the risk perceptions of first-degree relatives differ depending on their kinship relationship (e.g., parent, sibling, child) with the index patient?

Research questions 2-4 were addressed with the chi-square test for independence to test whether there were associations between the accuracy of the respondents' risk assessments and their gender, the gender of their first-degree relative (i.e., the index patient), and their kinship relationship with the index patient (i.e., parent, sibling, child).

Ethical Considerations

This study consisted of analysis of data from the FACTS study. The FACTS study team received ethical approval from the St. Paul's Hospital Research Ethics Board (ethics certificate approved). Patient protection was of high priority in the development of the FACTS study. Participants (index patients) were approached in a friendly manner and were informed of the purpose and obligations of participating in this study. Anonymity of the participant was maintained with coding and securing all study information in a locked file cabinet. If the study participants had questions regarding the study or their personal health status, the interviewers answered to the best of their knowledge or made recommendations to obtain the requested information.

CHAPTER IV: ANALYSIS AND RESULTS

In the original design of the study, patients were to be recruited from only one hospital site at St. Paul's Hospital, Vancouver, British Columbia (from the interventional catheterization laboratories, the Lipid Clinic and Cardiovascular Risk Reduction and Prevention Clinic within the Healthy Heart Program, the Heart Function Clinic, and two cardiac inpatient wards) and as well, from seven cardiologists' offices within the Greater Vancouver area. Commencement of recruitment began in May 2002 until present for index patients and May 2003 for first degree relatives. Due to difficulty of recruitment and the small number of participants recruited by September 2003, it was decided to expand recruitment to the outpatient Cardiac Rehabilitation and Prevention Program at Vancouver Hospital, Vancouver, British Columbia. This is a program that is comparable to the Healthy Heart Program at St. Paul's Hospital. Ethical approval was granted from both the University of British Columbia and Vancouver Hospital Research Ethics Boards. Another somewhat haphazard form of recruitment occurred by way of a television program aired on the Canadian Broadcasting Corporation in October 2004, which described the FACTS research study. This program resulted in many people calling to see whether they could be recruited into the study. Five subjects included in this thesis research were recruited in this manner.

Efficiency of Sampling

The total number of index patients contacted for recruitment between May 2002 and December 2004 is presented in Table 4.1.

Table 4.1

Recruitment of Index Subjects

	Frequency (%)
Potential subjects	12400
Women	3874 (31.2)
Men	8526 (68.8)
Ineligible	
Women > 60 years old	2017 (16.3)
Men > 50 years old	5240 (42.3)
Enrolled	238 (1.9)
Not Enrolled	4905 (39.6)

It was difficult to recruit young index subjects (men less than 50 years of age and women less than 60 years of age) having the diagnosis of premature CVD. This is evident in the very large number of people screened (> 12,000 people) with only a 1.9% enrollment rate. There were a total of 7257 ineligible subjects (females > 60 years old and males > 50 years old) due to the restrictive age requirements. The total number of index patients recruited was 238 (4.6% of eligible index patients). Only age restrictions were recorded and other reasons for ineligibility were not recorded by the research assistants.

The total number of first degree relatives contacted for recruitment is shown in Table 4.2. A total of 450 first degree relatives were invited to participate in the FACTS project. There were 118 eligible first degree relatives, not including spouses, enrolled by December 2004 for this thesis research. The reasons for participant ineligibility and recruitment were not recorded by research assistants and therefore are unknown.

Table 4.2

Recruitment and Enrollment of First Degree Relative Subjects

	N (%)
Potential subjects	450*+
Enrolled	118 (26.2)
Not Enrolled	332 (73.8)

* Potential subjects were mailed two letters of invitation to participate in the study.
+ A minimum of two telephone calls and up to four telephone contacts were made.

Characteristics of the Participants

This relatively young cohort of individuals had an average age of 40.5 years (SD = 13.6, range 16 - 76 years). Other demographic information including sex of the participant, sex of the index patient, and the participant's kinship status to the index patient is included in Table 4.3. There were more male (n = 83) than female (n = 30, unknown n = 5) index patients with premature coronary heart disease, which is consistent with the prevalence of the disease. This was a highly educated sample with 36.4% of the subjects having a university-level education (see Table 4.4).

The maternal and paternal ethnicity of each subject was identified; 89 (75.4%) subjects described their background as 'Caucasian'. This is somewhat unrepresentative of the local population, because the Lower Mainland of BC represents a broad and diverse range of ethnic populations and a large population of East and South Asian people. The ethnic backgrounds of the participants are represented in Table 4.5.

Table 4.3

Demographic Variables of First Degree Relatives (Participants)

Characteristic	Frequency (%) N = 118
Sex of participant	
Female	66 (55.9)
Male	52 (44.1)
Kinship relationship with index patient	
Mother	2 (1.7)
Father	2 (1.7)
Sister	38 (32.2)
Brother	22 (18.6)
Daughter	25 (21.2)
Son	29 (24.6)
Sex of the index patient	
Female	30 (25.4)
Male	83 (70.3)
Unknown	5 (4.2)

Table 4.4

Educational Attainment of Participants

Education Level	Frequency (%) N = 118
High school completed	29 (24.6)
Some trade / technical / vocational business	20 (16.9)
Diploma / certificate in trade / technical / vocational / business	25 (21.2)
Bachelor's degree (BA, BSc, LLB, etc.)	38 (32.2)
Master's degree (MA, MSc, MBA, etc.); Degree in Medicine / Veterinary / Optometry (MD, DDS, DMD, DVM, OD)	5 (4.2)
Unknown	1 (0.8)

Table 4.5

Family Ethnicity of Participant

Parent	Frequency (%) N = 118
Mother	
Caucasian	89 (75.4)
Black	1 (0.8)
Mid – Eastern	6 (5.1)
Aboriginal	1 (0.8)
Asian	9 (7.6)
South Asian	11 (9.3)
Unknown	1 (0.8)
Father	
Caucasian	89 (75.4)
Black	1 (0.8)
Mid – Eastern	6 (5.1)
Aboriginal	0
Asian	9 (7.6)
South Asian	11 (9.3)
Unknown	2 (1.7)

Cardiovascular Risk Profile

Risk perception may be influenced by the presence or absence of other risk factors besides premature coronary disease in a first degree family member. Of particular interest is the prevalence of other predisposing characteristics (such as increased weight) and how this may influence risk perception accuracy. Anthropometric measurements of weight, waist circumference and body mass index (BMI) were collected, as well as systolic and diastolic blood pressure (see Table 4.6). The sample had anthropometric measurements that, on average, placed them at risk: the waist circumference measures of the women were borderline with a mean of 87.9 cm; their mean weight was 71.5 kg and their BMI was elevated (mean 26.8 kg/m^2). The men's BMI was also elevated (mean 27.0 kg/m^2).

The laboratory data for the participants are presented in Table 4.7 (i.e., lipid profile and other metabolic markers of glucose, homocysteine, apolipoprotein B, apolipoprotein AI, and high density C-reactive protein). As expected for this young cohort, the lipid profiles were within normal limits. Interesting, however, are the higher levels of the newer metabolic markers such as elevated homocysteine (mean of 9.8 umol/L), C-reactive protein (mean 2.1 mg/L), and elevated apolipoprotein AI (mean 1.5 g/L). The participants' smoking history was self-reported: never smoked (66.9%), current smoker (13.6%), and ex-smoker (19.5%). One third of the cohort had direct exposure to cigarette smoking (see Table 4.9).

Table 4.6

Physical Characteristics Related to Cardiovascular Risk Factors

Variable	M	SD	n[1]
Age	40.5	13.5	117
Anthropometric measurements			
Weight (kg.)	76.7	17.7	117
Females	71.5	17.3	65
Males	83.1	16.0	52
Waist circumference (cm)	90.9	14.3	114
Females	87.9	14.4	65
Males	94.7	13.4	49
Body mass index (kg/m2)	26.9	5.4	117
Females	26.8	5.8	65
Males	27.0	4.9	52
Cardiovascular measurements			
Systolic blood pressure (mmHg)	119.3	18.0	117
Females	115.5	18.4	65
Males	124.0	16.7	52
Diastolic blood pressure (mmHg)	75.0	12.7	117
Females	71.2	11.4	65
Males	78.9	13.3	52

[1]Some cases had missing data.

Table 4.7

Laboratory Values of First Degree Relatives

Variable	M*	SD**	MD***	n
Total cholesterol (TC) (mmol/L)	5.1	1.1		118
Low density lipoprotein cholesterol (LDL-C) (mmol/L)	3.1	0.9		116
High density lipoprotein cholesterol (HDL-C) (mmol/L)	1.4	0.4		118
Triglyceride (mmol/L)	1.3	0.8		118
Total cholesterol: HDL-C ratio (mmol/L)	3.9	1.2		118
Fasting glucose (mmol/L)	5.0	1.1		118
Apolipoprotein B (g/L)	0.96	0.26		118
Females	0.95	0.25		66
Males	0.98	0.28		52
Apolipoprotein AI (g/L)	1.5	0.33		118
Females	1.6	0.33		66
Males	1.3	0.25		52
Lipoprotein(a) (mg/L)	255	294	129	112
High-sensitivity C-reactive protein (mg/dL)	2.1	2.5		118
Homocysteine (umol/L)	9.8	3.6	9.4	117
Females	8.8	2.8		66
Males	10.0	4.4		51

*M = Mean
**SD = Standard Deviation
***MD = Median

Independent sample *t* tests were used to analyze differences in each cardiovascular risk factor by gender (see Table 4.8). There were significant differences in every variable except apolipoprotein B and BMI. The assumption of equal variances was tested and found to be met. The assumption of random subsets was not met.

Table 4.8

Mean Differences in Cardiovascular Risk Factors by Gender

	Females	Males		
Variable	M (SD)	M (SD)	t (*df*)	*p* value
Systolic BP	115.5 (18.4)	124.0 (16.7)	-2.6 (115)	.01*
Diastolic BP	71.8 (11.4)	78.9 (13.3)	-3.1 (115)	.002*
Body mass index	26.8 (5.8)	27.0 (4.9)	-2.3 (115)	.82
Waist circumference	87.9 (14.4)	94.7 (13.4)	-2.6 (112)	.01*
Weight	71.5 (17.3)	83.1 (16.0)	-3.7 (115)	.000**
Apolipoprotein B	.95 (.25)	.98 (.27)	-.71 (116)	.47
Apolipoprotein AI	1.6 (.33)	1.3 (.27)	5.1 (116)	.000**

* $p < .01$
** $p < .001$

Objective Epidemiological Risk Assessment

To compare the participants' subjective risk perception to their objective risk assessment, the Framingham risk score was used. The first research question (What is the accuracy of risk perception of first-degree relatives of patients with premature coronary heart disease when compared with objective epidemiological risk assessments?) was answered by first calculating the frequency distributions for the Framingham risk scores. We expected that the majority of participants would be within the low risk category because of their young age; 94.1% were rated to be at low risk, 5.1% were at moderate risk, and only 0.8% were rated to be at high risk (see Table 4.9).

The cardiovascular risk assessment of ten-year risk computed by the Framingham risk stratification score does not include information about an individual's family history. Clinicians often increase the score by a factor of 2.0 when a first degree relative has premature coronary artery disease (Genest et al., 2003). This doubling of scores changed the risk category of 13 (11.0%) participants who were reclassified from being at low risk to moderate risk and 6 (5.1%) participants who were reclassified from being at moderate risk to high risk (see Table 4.9).

Table 4.9

Cardiovascular Risk Factor Information

Variable	Frequency (%) N = 118
Smoking	
Never	79 (66.9)
Current	16 (13.6)
Ex-smoker	23 (19.5)
Framingham risk score	
Low	111 (94.1)
Moderate	6 (5.1)
High	1 (0.8)
Doubled Framingham risk score	
Low	98 (83.1)
Moderate	13 (11.0)
High	7 (5.9)

Risk Perception

Subjective Risk Perception

Important to this study is the accuracy of the individuals' risk perceptions when they knowingly have a first degree relative with premature coronary artery disease. The participants estimated their risk for coronary heart disease as low, moderate, or high: almost one half (46.6%) of the sample indicated their risk to be low, 35.6% rated themselves to be at moderate risk, and only 16.9% reported their risk to be high. One participant refused to answer this question and the subsequent absolute risk estimation question. The subjective ratings by gender are presented in Table 4.10.

Table 4.10

Subjective Risk Perception

Variable	Females N (%)	Males N (%)	Frequency (%) Total N = 118
Subjective risk estimate of coronary heart disease in next 10 years			
Low	32 (48.5)	23 (44.2)	55 (46.6)
Moderate	22 (33.3)	20 (38.5)	42 (35.6)
High	11 (16.7)	9 (17.3)	20 (16.9)
Unknown			1 (0.8)

Noteworthy is the relationship between subjective risk and the total cholesterol and high density lipoprotein ratio (TC: HDL-C). The higher the subjective risk rating, the higher the TC: HDL-C ratio (see Table 4.11).

Table 4.11

Analysis of Variance for Subjective Risk Perception and TC: HDL-C

Subjective Risk Perception	M (SD)	n	*df*	F	*p* value
Low	3.6 (1.2)	55	3	2.62	.05
Moderate	4.1 (1.3)	42			
High	4.5 (1.5)	20			

Absolute Risk Perception Estimates

The respondents gave a second estimate of their coronary heart disease risk by comparing it to someone of their same age and sex by providing a value ranging between 0% (meaning there was absolutely no chance) to 100% (meaning there is absolute certainty) (see Table 4.12). The absolute risk estimates were grouped to minimize the influence of response determination (see Table 4.13). Chi-square testing did not reveal any significant differences between the gender's absolute risk estimates ($\chi^2 = 2.79$, $df = 3$, $p = .42$). The assumption of expected frequencies was not met with one cell not meeting the minimum expected frequency requirement.

One-way analysis of variance was used to determine whether the participants who were grouped into the low, moderate, or high risk groups on the basis of their subjective risk assessments differed in terms of their mean absolute (percentages) risk assessments. For this analysis, the independent variable was the subjective estimate of low, moderate, or high, and the dependent variable was the absolute percentage estimate. The groups reported mean absolute estimates of: "low = 14.5%; "moderate" = 43.9%; and "high" = 56.3% (see Table 4.14).

Table 4.12

Absolute Risk Perception Estimate

Estimate	Frequency (%) N = 118
Subjective absolute risk estimate of coronary heart disease in next 10 years	
0 – 10%	34 (28.8)
11 - 20%	20 (16.9)
21 – 30%	11 (16.9)
31 – 40%	8 (6.8)
41 – 50%	22 (18.6)
51 – 60%	11 (9.3)
61 – 70%	5 (4.2)
71 – 80%	5 (4.2)
81 – 90%	1 (0.8)
91 – 100%	0 (0.0)
Unknown	1 (0.8)

Table 4.13

Absolute Risk Estimates Grouped

Group	Female (%)	Male (%)	Frequency (%) N = 117
0 – 20%	31 (57.4)	23 (24)	54 (45.8)
21 – 40%	8 (10.6)	11 (8.4)	19 (16.1)
41 – 60%	18 (18.3)	15 (14.7)	33 (28.0)
61 – 100%	8 (6.1)	3 (4.9)	11 (9.3)
Unknown			1 (0.8)

Table 4.14

Mean Levels of Subjective Risk Perception Estimates with Absolute Percentage Estimates

	Absolute Estimate	
	Mean	(SD
Subjective Estimate		
Low risk (n = 55)	14.52	11.24
Moderate risk (n = 42)	43.86	18.68
High risk (n = 20)	56.37	19.15

	Sum of Squares	*df*	Mean Square	F	Significance
Between Groups	34591.515	2	17295.76	0.18	.000
Error	28095.562	114	246.45		

Risk Perception Accuracy

The Accuracy of Subjective Risk Estimates

1. What is the accuracy of risk perception of first-degree relatives of patients with premature coronary heart disease when compared with an objective epidemiological risk assessment?

There were 55 subjects who were accurate in the "low" estimate group, 36 subjects who over-estimated subjectively as "moderate" but rated objectively as "low", 5 subjects who were accurate in the "moderate" estimate group, 1 subject under-estimating as "moderate" but rated objectively as "high", 19 subjects estimated themselves as "high" but were "low" per Framingham assessment, and only one subject rated him or herself as "high" but was "low" on the objective risk assessment [Pearson $\chi^2(4, n = 117) = 8.89$, $p = .064$]. See Table 4.16 for the subjective and objective cross-tabulation comparisons.

Table 4.15

Subjective and Objective Risk Perception Estimates

Variable	Objective risk estimate Frequency (%) Low	Moderate	High	Total N = 117
Subjective risk estimate				
Low	55 (100)	0	0	55
Moderate	36 (85.7)	5 (11.9)	1 (2.4)	42
High	19 (95)	1 (5.0)	0	20
Total	110 (94)	6 (5.1)	1 (0.9)	117

To determine the accuracy of self-perceived cardiovascular risk by contrasting it with the participant's actual clinical or objective risk, we grouped the respondents' risk assessments as under-estimates, accurate, and over-estimates by cross-tabulating subjective risk by the objective risk estimates according to their corresponding categories of low, moderate and high. Table 4.16 displays the distribution of this grouping.

Table 4.16

Degree of Accuracy of Subjective Risk Perception with Framingham Risk Score

Variable	Frequency (%) N = 118
Under-estimate	1 (0.8)
Accurate	60 (50.8)
Over-estimate	56 (47.5)
Unknown	1 (0.8)

Over 50% of the subjects were accurate, just under one half (47.5%) over-estimated their risk, and only one subject under-estimated their risk for cardiovascular disease according to the Framingham risk estimates. In further analyses, we omitted the one participant who had under-estimated her/his rating.

After adjusting the Framingham risk score by doubling the scores, chi-square analysis was used to identify any differences between subjective risk estimates and the doubled Framingham risk scores. Although significant, the assumption for expected cell frequency was not met because of the small sample size, $\chi^2(4, n = 117) = 20.06, p = .000$. Doubling the objective risk scores resulted in different accuracy ratings, notably, the accurate and under-estimated groups, were increased, with over-estimations decreasing from 47.5% to 39.3% (see

Table 4.17). A significant relationship was found in accuracy levels between the original and doubled Framingham risk scores (χ^2 (2, n = 116) = 82.21, p = .000). The assumption for minimum expected frequency size was not met in two cells.

Table 4.17

Degree of Accuracy with Original and Doubled Framingham Risk Scores

	Frequency (%) N = 117 Type of Score	
	Original	Doubled
Risk Estimate		
Under-estimate	1 (0.8)	7 (6.0)
Accurate	60 (50.8)	64 (54.7)
Over-estimate	56 (47.5)	46 (39.3)

Demographic Variables and Accuracy

No relationship was found between degree of risk assessment accuracy and level of education, χ^2 (4, n = 115) = 3.8, p = .44. There was a significant relationship between age and accuracy (see Table 4.18). Over-estimators were older, on average, than those who accurately reported their level of risk.

Gender and the Accuracy of Risk Perceptions

2. *What is the relationship between gender and the accuracy of risk perceptions of first-degree relatives of patients with premature coronary heart disease?*

To determine whether there was a relationship between the gender of the participants and the accuracy of their risk perceptions, a chi-square test was conducted, which yielded a non-significant result, $\chi^2(1, N = 116) = .002, p = .96$. Again, however, this analysis did not meet the assumption of the minimum expectation of frequency size (see Table 4.18). Perhaps noteworthy, albeit statistically non-significant, was that 49% (n = 32) of females and 47% (n = 24) of males over-estimated their risk (see Table 4.18).

Gender of the Index Patient and Accuracy of FDR's Risk Perceptions

3. *Does the accuracy of the risk perceptions of first-degree relatives differ depending on whether their affected family member (index patient) is male or female?*

Chi-square tests were used to establish whether the gender of the index patient was associated with the respondents' degree of accuracy in assessing their own risk (see Table 4.18). The assumption of expected frequencies was met; the relationship was not statistically significant, $\chi^2(1, N = 111) = .006, p = .94$.

Table 4.18

Demographic Variables and Risk Perception Accuracy

Variable	Accurate N = 60 (%)	Over-estimate N = 56 (%)	$\chi^2(df)$	*p* value
Sex of participant				
Male	52.9	47.1	.00[1](1)	.96
Female	50.8	49.2		
Sex of the index patient				
Male	53.1	46.9	.01[1](1)	.94
Female	50.0	50.0		
Relationship				
Sibling	36.7	63.3	10.31[1](1)	.001[2]
Child	68.5	31.5		
Education				
High school	37.9	62.1	3.76(4)	.44
Some trade school	50.0	50.0		
Diploma/certificate	60.0	40.0		
Bachelor's degree	57.9	42.1		
Professional/master's	40.0	60.0		
	Mean (SD)		t (df)	
Age	36.7 (13.4)	43.9 (12.4)	-3.09(113)	.003[3]

[1] Continuity correction.
[2] $p < .001$
[3] $p < .01$

Kinship Relationship with the Index Patient and Accuracy of FDR's Risk Perceptions

4. *Do the risk perceptions of first-degree relatives differ depending on their relationship (e.g., parent, sibling, and child) with the index patient?*

Statistical analysis was conducted to determine if the kinship relationship that the participant had with the index patient was associated with the accuracy of their risk perceptions (see Table 4.18). When the participants were grouped by their kinship relationship with the index patient as a sibling or child (i.e., the few parents were deleted), siblings were found to over-estimate their risk (63.3%) compared to children (31.5%) [$\chi^2(1, N = 114) = 10.31, p = .001$]. The influence of kinship relationship was strong. Siblings were one fourth as likely to be accurate in their risk perception than were children of the index patients (OR = .27; 95% CI: .12 - .58).

Risk Perceptions and CVD Risk Factors

Independent sample *t* tests were used to analyze differences in levels of accuracy among each of the physical characteristics: systolic and diastolic blood pressure, body mass index, waist circumference, and weight (see Table 4.19). All of the data were inspected for normality before conducting the parametric analyses. Levine's tests and t-tests for equality of means were performed to test for homogeneity of variance. Equal variance was assumed for all variables except the variable of weight. It is noteworthy that the participants who were classified to have over-estimated their risk had significantly greater diastolic BP's, BMI's and waist circumference measurements than those who were considered to be accurate relative to the Framingham score.

Table 4.19

Mean Differences in Cardiovascular Risk Factors and Accuracy of Risk Perceptions

Variable	Accurate Risk Perception N = 60 M (SD)	Over-estimated Risk Perception N = 56 M (SD)	t (df)	*p* value
Systolic BP	116.0 (17.0)	121.8 (18.4)	-1.8 (114)	.08
Diastolic BP	72.4 (11.0)	77.5 (13.8)	-2.2 (114)	.03*
Body mass index	25.9 (4.9)	28.0 (5.7)	-2.1 (113)	.04*
Waist circumference	87.9 (12.6)	94.1 (15.6)	-2.3** (102.2)	.02*
Weight	74.5 (15.2)	79.3 (19.9)	-1.4** (102.9)	.15

* $p < .05$
** Equal variances not assumed

Summary

The findings indicate several significant features associated with the accuracy of risk perceptions of first degree relatives of individuals with premature coronary heart disease. There were no significant relationships between the genders of the participants or of the index patients and the FDRs' accuracy of their risk perceptions. Kinship relationship status was significantly associated with their accuracy; siblings tended to over-estimate their risk compared to children of the index patients. The only other variable associated with accuracy was age. The cardiovascular risk factors associated with degree of accuracy were the variables, diastolic blood pressure, body mass index, and waist circumference.

CHAPTER V: DISCUSSION

This final chapter provides a discussion of some of the key findings of this research. It addresses the focus population of first degree relatives who are a high risk group, not only because of their genetic and familial history, but because of the prevalence of other cardiac risk factors observed in the group. The accuracy of their risk perceptions for coronary heart disease, relative to the epidemiological Framingham risk score, and its association with gender (both their own and that of the index patient) and kinship relationship with the affected family member are discussed. As well, the findings of other demographic and cardiovascular variables associated with risk perceptions are addressed. An examination of the limitations of this study and the implications these findings have for both clinical care and future research is included.

Cardiovascular Risk Factor Prevalence

A family history of coronary heart disease in a first degree relative may be primarily genetic, it may reflect genetic predisposition to cardiovascular risk factors, or it may be contributed from a shared household effect. To understand personal risk for coronary heart disease, individuals must have knowledge of risk factors and therefore reasons to adopt healthful lifestyles. To identify factors that may influence the accuracy of individuals' risk perceptions, we examined both demographic and cardiovascular risk factors.

Demographic Variables

This sample of first degree relatives of patients with premature coronary heart disease was well educated and young. The average age was 40.5 years, with 78% of the sample having a postsecondary diploma or higher level of educational achievement. Of this group, 36% were educated with a university degree or higher. Three quarters of the sample (75%) described themselves as 'Caucasian,' which is not representative of the local multiethnic population.

Cardiovascular Risk Factors

Participants' lipid profiles and anthropometric measurements are important in determining their risk profiles for coronary heart disease. The lipid profiles and glucose levels of this sample were within normal range. Their blood pressures also were found to be within normal range: mean systolic pressure = 119 mmHg and mean diastolic pressure = 75 mmHg. Waist circumference was borderline for women at 87.9 cm, and body mass index was elevated in both the men (mean = 27 kg/m^2) and the women (mean 26.8 kg/m^2). Both of these variables contribute to the clustering of risk factors that lead to the development of metabolic syndrome, an emerging concern in North America. Abdominal adiposity, insulin resistance, elevated triglycerides, low HDL-C and hypertension quantitatively define the metabolic syndrome and signify increased risk for the development of coronary heart disease (Miller, 2003).

Screening for the newer metabolic markers identified increased levels of homocysteine, and high-sensitivity C-reactive protein in this sample. Homocysteine is another metabolic marker that is associated with atherosclerosis. The participants, on average, were found to have borderline to high levels in this sample (total cohort median = 9.4 umol/L; females median 8.75 umol/L, males median 10.0 umol/L). Normal plasma homocysteine levels range between 5 and 15 umol/L, however, even mildly elevated levels are associated with an increased risk of cardiovascular disease in epidemiological studies (Genest et al., 2003). An increased risk of stroke, cardiovascular disease, and deep vein thrombosis are associated with plasma homocystiene levels above the 90^{th} to 95^{th} percentile (Genest et al., 2003). Apolipoprotein B was at borderline levels in the sample with a mean of .96 g/L (SD = .26). The elevated levels of C-reactive protein (mean = 2.1, SD = 2.5) are an objective marker of inflammation and increases an objective marker of inflammation and increases risk for coronary heart disease. C-reactive protein is also associated with abdominal obesity. C-reactive protein has been recognized to add diagnostic value to the Framingham risk prediction scores (Ridker, Rifai, Buring, & Cook, 2002). The smoking histories of the participants indicated that one third had direct exposure to cigarette smoking with 14% currently smoking and 20% being past smokers.

In evaluating these selected cardiovascular risk factors by gender, there were mean differences found in the systolic and diastolic blood pressures, waist circumference, weight, and homocysteine levels. Women had higher mean levels of homocysteine than men. Women were borderline for waist circumference and had elevated body mass index, as did the male participants. The prevalence of these elevated metabolic and anthropometric markers establishes further the increased cardiovascular risk of this cohort and the need for thorough risk assessments of family members of individuals with premature coronary heart disease.

Subjective Risk Perception

The respondents were asked to rate their perceived risk of heart disease in the next ten years as low, moderate, or high, compared to individuals of their same age and sex. These subjective risk perception estimates resulted in almost one half of the respondents rating their risk as "low", 35.6% as "moderate", and only 16.9% as "high" risk. Gender-specific ratings were similar in nature.

To further explore the subjective risk estimates, the respondents were asked a second question to rate their risk of heart disease in the next ten years compared to individuals of their same age and sex by indicating a percentage between 0% and 100%. The means for the three self-identified groups were ranked appropriately: those who reported their risk as 'low' had a mean of 14.5%, the 'moderate' risk group provide a mean risk estimate of 43.9% and the 'high' risk group offered a mean of 56.3%. There was no significant difference between the men's and women's absolute risk ratings.

Objective Risk Estimation

The gold standard for clinical risk stratification for cardiovascular disease has been based upon the Framingham Study. This epidemiological risk equation estimates the 10-year risk of "hard cardiac end-points" including nonfatal myocardial infarction and death from coronary heart disease. It is used for individuals past the age of 20 years. Perhaps not surprising, in this research, a full 111 of the 118 respondents (94.1%) were estimated to be at low risk for CHD by the Framingham score, despite having a positive family history. Clinical risk stratification must also include an assessment of factors not incorporated into the Framingham score, such as weight, waist circumference, body mass index and the newer metabolic risk markers. This finding is indicative of the caveats of the Framingham risk stratification tool that have been acknowledged by researchers who have studied populations in countries outside North America and of diverse ethnic backgrounds (Wilson et al., 1998). Doubling the Framingham scores for first degree family members of individuals with a history of premature coronary heart disease, as recommended by the Canadian dyslipidemia guidelines, adjusts somewhat for this discrepancy and incorporates genetics into the stratification score. In this study, such adjustment reclassified 13 participants (11%) who were originally found to be at low risk as at moderate risk, and 6 participants (5.1%) increased from the moderate to the high risk category.

The tendency of the Framingham algorithm to possibly underestimate the risk of persons with positive family histories has clinical implications for treatment decision making. Individuals who are classified as low risk by the Framingham 'gold' standard may warrant treatment of identifiable risk factors. The current "gold standard" for the estimation of short-term cardiovascular risk (10-year period) may not sufficiently reflect the long-term or lifetime coronary heart disease risk of young adults. This finding further solidifies the importance of the clinical examination, which should always be used in conjunction with the risk algorithm in determining a person's health status. This is necessary, in any case, to identify a family history of coronary heart disease, obesity or physical inactivity.

Another important implication from this work is the consideration of the efficacy of the Framingham risk stratification tool used to predict the short-term risk of coronary heart disease. The 111 subjects who were rated to be at low risk were actually at an increased risk not only because of their family history but because they had elevated metabolic and anthropometric risk factors. Clinicians need to be astute in their interpretation of objective risk assessments and how they may influence their decision making regarding the education and treatment of first degree relatives of persons with premature coronary heart disease. Selective recall by patients may complicate the situation if they are told that they are at "low risk" according to an objective risk estimator; such information may skew their understanding of their actual risk factors and affect their potential for positive behaviour change.The PROCAM risk estimation tool, described in the literature review, may be a better indicator of risk in this population particularly because it incorporates family history. Although it may have proven to have utility in establishing accurate cardiovascular risk estimates, it was not used in this study because many of the participants were less than 40 years of age. The PROCAM score was originally developed with data from middle-aged men aged 35-65 years (Assman et al., 2002).

The Accuracy of FDRs' Risk Perceptions

Demographic Variables and the Accuracy of FDRs' Risk Perceptions

The demographic variables of age, education, and kinship relationship with the index patient were analysed in relation to risk perception accuracy to identify other correlates of accuracy. No relationship was found between education and the accuracy of the participants' risk estimates, which is consistent with the findings of Meichke et al. (2000). Niknian et al. (1989), however, found higher levels of accurate risk perceptions in those with relatively higher levels of education. Lack of knowledge about cardiovascular risk factors appears to show an optimistic bias in healthy individuals (Avis et al., 1990; Erhardt & Hobbs, 2002; Weinstein, 1984). Because this study's sample was highly educated and still continued to over-estimate their risk, the findings solidify the notion that general knowledge doesn't necessarily translate into accuracy (Avis et al., 1990).

Healthcare practitioners have observed that knowledge of cardiovascular risk factors and individual understanding of personal risk does not always result in behaviour change. This may result from the belief that nothing will make a difference, which has been related to a pessimistic bias (Stretcher et al., 19995). Not captured in this study was the participants' knowledge of cardiovascular disease risk factors and where they may have learned such information. This young cohort could have been exposed to public health campaigns about heart disease and its emphasis as the number one killer of Canadians. They may have received risk information from schools, the media, and the health professionals with whom they come into contact. It is well known that individuals interpret information in different ways and that multiple interpretations may contribute to perceptions of risk (Walker et al., 2003).

Age was found to have a bivariate relationship with the accuracy of risk perceptions. Younger people may have a better understanding of cardiovascular disease risk factors or may have better communication with their health care practitioners.

Subjective and Objective Risk Estimates

Comparison of the first degree relative's subjective ten-year risk estimates of coronary heart disease with the Framingham risk estimates risk resulted in 50.8% of the participants being considered 'accurate;' 47.5% over-estimated their risk and only 0.8% participant under-estimated their risk. The participants' tendency to over-estimate their risk is consistent with Marteau et al.'s (1995) work that found that individuals with a family history of heart disease over-estimated their risk or had a "pessimistic" bias. Shepherd et al. (1997) found the opposite results; both the individuals with heart disease and their family members that were included in their study had low levels of worry or concern about developing heart disease – they had an optimistic bias. The current study's findings of the predominance of over-estimation are not concordant with the majority of other researchers' work that reports under-estimation or "optimistic" biases as the major risk perception for coronary heart disease. These results of over-estimation may have occurred as the result of sampling bias; we may have attracted people into the study who were overly concerned about their current and future health in the face of having a family relative with premature heart disease.

Gender and the Accuracy of FDRs' Risk Perceptions

There was no significant relationship found between gender and the accuracy of first degree relatives' perceived risk, whether we examined the gender of the participant or their relative affected by premature coronary heart disease. Not withstanding this result, it is noteworthy that 49% of the women and 47% of the males over-estimated their risk. Niknian et al. (1989) and Hunter O' Dea et al. (1999) found that female gender corresponded with higher levels of agreement in risk perception. Two other studies have found that women tend to have an optimistic bias in their cardiovascular risk perceptions (Kruiter & Stretcher, 1995; Meichke et al., 2000). This study may be different in that the target population was first-degree relatives of individuals who had recently been diagnosed with premature heart disease. Having been confronted with such pertinent information that has a direct relationship to the first-degree relatives' health, may have in turn, influenced risk perception.

Kinship Relationship with Index Patient and Accuracy of Risk Perception

The accuracy of the risk perceptions of the participants was related to the kinship relationship they had with the index patient. Over-estimation of risk was noted in 63% of siblings compared to 32% of children; that is, brothers and sisters of affected patients were more likely to over-estimate their risk than were the children of affected patients.

Kinship relationship does appear to be associated with cardiovascular risk; in the literature, siblings have been noted to over-estimate their risk. Importantly, the literature also acknowledges that sisters of persons with coronary heart disease have been shown to be at higher clinical risk than brothers. The National Cholesterol Education Program (2002) reported that siblings of affected family members have the highest relative risk. It is believed that this elevated risk arises not only from shared genetics, but from the effects of shared social, cultural, and environmental influences. The clustering of risk factors reported amongst families is similar to this study's findings of multiple risk factors observed amongst the participants. This is consistent with a recent study that reported that sibling history is more strongly associated with subclinical atherosclerosis than parental history of premature coronary heart disease (Nasir et al., 2004). This may be relevant to this study wherein the participant's had a mean age of 40.5 years and almost 60% of them rated their risk accurately relative to their objective risk estimates.

What is most noteworthy in these findings is the possibility that persons who were classified to have over-estimated their risk, relative to their Framingham scores, may well indeed have an accurate perception about their degree of risk (i.e., the Framingham score may have underestimated their risk). These first degree relatives all had positive family histories, had some biomarkers of risk, and tended to be siblings, which placed them at greater risk. Is this over-estimation of risk perception actually accurate in light of this evidence? The answer to this question cannot be determined here; however, it may alert clinicians to be more astute in capturing an accurate family history followed by a thorough assessment of all risk factors in order to appropriately target this higher risk group.

Cardiovascular Risk Factors and Accuracy of Risk Perception

Selected cardiovascular risk factor variables were analysed in relation to the FDRs' accuracy levels: associations were found between diastolic blood pressure, body mass index, and waist circumference and degree of accuracy. No relationships were found between systolic blood pressure, weight and accuracy.

Limitations of the Study

There are several limitations that should be considered when interpreting the results of this study. The first limitation of this study was recognized through the literature review process. There was very limited information found about the risk perceptions of first degree relatives of individuals with premature coronary heart disease. Indeed, there was limited information available about the risk perceptions of disease-burdened individuals, in general, and of healthy individuals. Much of the available literature focuses on the knowledge of cardiovascular disease that people possess, rather than on their risk perceptions, *per se*.

The subjective risk question used in this study was taken from a larger clinical trial with similar objectives (Marteau et al., 1995). The absolute risk question that was also used requested an estimation between 0% and 100%. It is not clear how respondents determine their response to this question and what their frame of reference might be.

Although many of the other physical variables were measured in the initial interview by the research assistant, some were not. This could contribute to recall bias and lead to inaccurate information provided by the respondent. Self report and recall bias may contribute to underestimation of cardiovascular risk factors and ultimately affect the findings of this.

Another important limitation of these findings is the sample. There were many difficulties in the recruitment of the affected family members (index patients) diagnosed with premature disease, as well as the recruitment of the focus sample, the first degree relatives. Because of the slower than anticipated recruitment of participants, the sample size, in this study, was limited to 118 subjects. This had many implications for the planned statistical analyses and meant that some assumptions of the statistical tests were not met, especially the minimum expected frequencies required for the Chi-squared analyses. The small sample likely contributed to an inflated Type II error rate.

Also of concern is the possibility that the sample was biased because of the relatively high level of education possessed by the participants. What cannot be determined is whether the lack of association is related to the limited variability in the educational backgrounds of the participants, insufficient statistical power associated with the small sample size, or a finding that will be supported in future research.

This sample was also most likely biased because 89% of the participants described themselves as "Caucasian." They were undoubtedly unrepresentative of the local population, which has a large Asian and South Asian community.

Another limitation of this study was not having available modifiable risk factor information about lifestyle behaviour such as diet and physical activity behaviour. These two lifestyle behaviours may have been valuable in explaining the differences in the participants' understanding of their risk. Other factors not studied that may be worthy of investigation in future studies include psychosocial variables such as depression and perceived stress levels. These factors could have a large effect on first degree relatives' perceptions of their risk and may be useful in the planning of clinical interventions by nurses and other healthcare professionals.

Implications

Imperative to nursing and other health-care practitioners is the ability to accurately promote optimal health for individuals regardless of disease prevalence. This study has contributed to the limited knowledge on first degree relatives of family members affected by premature coronary heart disease. Nurses and other health-care practitioners must recognize the need to establish a comprehensive family history to correctly establish individuals' risk for coronary heart disease. The identification of individuals with a positive family history should lead to further assessment and risk factor screening of all family members. Extended screening of family members, if completed, could result in global risk screening and the prevention of cardiovascular disease. By targeting families, multigenerational screening could occur and influence the lifestyle choices of extended family members, and possibly decrease the incidence of the clustering of risk factors found within families.

This study adds to the limited body of knowledge about risk perceptions, particularly the risk perceptions of first degree relatives of family members with premature coronary heart disease. The finding that siblings tend to over-estimate their risk of disease may inform the delivery of health-care interventions. It is difficult for nurses and other health-care providers to inform patients that, despite having multiple risk factors and a family history of disease, they are still estimated to be at "low" risk by epidemiological risk stratification tools. Recognition of over-estimation of risk by siblings may allow practitioners to open a door to a discussion of why the individual may actually be correct in his or her estimation of disease when considering other risk factors not captured by the objective risk tools. It is also important to acknowledge the importance of individualizing health education and interventions and the necessity of ensuring that individuals comprehend what is being communicated.

Another important question that arises from this work is the efficacy of the Framingham risk stratification tool for this particular population. Clinicians need to be astute in their interpretation of objective risk assessments and how their interpretations may influence their decision making regarding the health education and treatment of first degree relatives.

These findings add to the limited knowledge about gender differences within this higher risk group. The accuracy of the FDRs' risk perceptions was not influenced by gender (their own or that of the index patient) although the observed gender differences noted in the clinical findings (the risk factors of systolic and diastolic blood pressure, and waist circumference having significant differences) are noteworthy. Also of importance, are the elevated levels of the newer metabolic risk markers (C-reactive protein and homocysteine) for the entire cohort. The variable of C-reactive protein is also related to increased waist circumference and BMI, which are identified contributors to the development of metabolic syndrome, which as well, increases risk for cardiovascular disease.

The findings reported here warrant further research of the variables that may influence the accuracy of the risk perceptions of first degree relatives of individuals with premature coronary heart disease. The use of a larger sample size would certainly add to the depth and reliability of the findings. Further study of risk perceptions and the factors that affect the degree of accuracy may add to the body of knowledge of what influences healthful lifestyle behaviour and more importantly, how nurses and other health-care practitioners can provide effective and comprehensive care.

References

Abbey, S. E., & Stewart, D. E. (2000). Gender and psychosomatic aspects of ischemic heart disease. *Journal of Psychosomatic Research, 48,* 417-423.

Allen, J. K., & Blumenthal, R. S. (1998). Risk factors in the offspring of women with premature coronary heart disease. *American Heart Journal, 135,* 428-434.

American Heart Association. (2003, June). Framingham Heart Study. [On-line], Available: http://www.americanheart.org/presenter.jhtml?identifier=4666.

Anderson, K. M., Wilson, P. W., Odell, P. M., & Kannel, W. B. (1991). An updated coronary risk profile: A statement for health professionals. *Circulation, 83,* 356-362.

Andresdottir, M. B., Sigurdsson, G., Sigvaldason, H., & Gudnason, V. (2002). Fifteen percent of myocardial infarctions and coronary revascularizations explained by family history unrelated to conventional risk factors. The Reykjavik Cohort Study. *European Heart Journal,* 23, 1655-1663.

Assman, G., Cullen, P., & Schulte, H. (2002). Simple scoring scheme for calculating the risk of acute coronary events based on the 10-year follow-up of the Prospective Cardiovascular Munster (PROCAM) Study. *Circulation, 105,* 310-315.

Avis, N. E., McKinlay, J. B, & Smith, K. W. (1990). Is cardiovascular risk factor knowledge sufficient to influence behavior? *American Journal of Preventive Medicine, 6,* 137-144.

Avis, N. E., Smith, K. W., & McKinlay, J. B. (1989). Accuracy of perceptions of heart attack risk: What influences perceptions and can they be changed? *American Journal of Public Health, 79*, 1608-1612.

Becker, D. M., & Levine, D. M. (1987). Risk perception, knowledge, and lifestyles in siblings of people with premature coronary disease. *American Journal of Preventive Medicine, 3*, 45-50.

Becker, D. M., Yook, R. M., Moy, T.. F., Blumenthal, R. S., & Becker, L. C. (1998). Markedly high prevalence of coronary risk factors in apparently healthy African –American and white siblings of persons with premature coronary heart disease. *American Journal of Cardiology, 82,* 1046-1051.

Bjerrum, L., Hamm, L., Toft, B., Munck, A., & Kragstrup, J. (2002). Do general practitioner and patient agree about the risk factors for ischemic heart disease? *Scandinavian Journal of Primary Health Care, 20,* 16-21.

Berkeley Nutrition Services (2003). *Brief food questionnaire.* Retrieved November 5, 2003, from University of California – Berkeley, Berkeley Nutrition Services Web site: htpp://www.nutritionquest.com/faq.html#B98differences

Berra, K. (2000). Women, coronary heart disease, and dyslipidemia: Does gender alter detection, evaluation, or therapy? *Journal of Cardiovascular Nursing, 14*(2), 59-78.

Block, G. (2000). *Brief food questionnaire.* Retrieved November 5, 2003 from University of California – Berkeley, Berkeley Nutrition Services Web site: htpp://www.nutritionquest.com/

Burke, L.E. (2003). Primary prevention in patients with a strong family history of coronary heart disease. *Journal of Cardiovascular Disease, 18*, 139-143.

Clarkson, P., Celemajer, D. S., Powe, A. J., Donald, A. E., Henry, R. M. A., & Deanfield, J. E. (1997). Endothelium-dependent dilatation is impaired in young healthy subjects with a family history of premature coronary disease. *Circulation, 96*, 3378-3383.

De Backer, G., Amborsioni, E., Borch-Johnsen, K., Brotons, C., Cifkova, R., Dallongeville, J., et al. (2003). European guidelines on cardiovascular disease prevention in clinical practice. Third Joint Task Force of European and Other Societies on Cardiovascular Disease Prevention in Clinical Practice. *European Heart Journal, 24,* 1601-1610.

De Sutter, J., De Backer, D., Kotseva, K., Sans, S., Pyorala, K., Wook, D., et al. (2003). Screening of family members of patients with premature coronary heart disease. Results from the EUROASPIRE II Family Survey. *European Heart Journal, 24,* 249-257.

Durington, P., & Sniderman, A. (2000). *Hyperlipidemia. Fast facts Indispensable guide to clinical practice.* Oxford, UK: Health Press.

Empana, J. P., Ducimetiere, P., Arveiler, D., Ferrieres, J., Evans, A., Ruidavets, J. B., et al. (2003). Are the Framingham and PROCAM risk functions applicable to different European populations? The PRIME Study. *European Heart Journal, 24*, 1901-1911

Erhardt, L., & Hobbs, F. D. (2002). Public perceptions of cardiovascular risk in five European countries: The REACT survey. *International Journal of Clinical Practice, 56*, 638-644.

Fleury, J., Keller, C., & Murdaugh, C. (2000). Social and contextual etiology of coronary heart disease in women. *Journal of Women's Health & Gender-based Medicine, 9*, 967-978.

Fodor, J. G., Frohlich, J. J., Genest, J. J., & McPherson, P. R. (2000). Recommendations for the management and treatment of dyslipidemia. *Canadian Medical Association Journal, 162,* 1441-1447.

Genest, J. J., Frohlich, J. J., Fodor, J. G., & McPherson, P. R. (2003). Recommendations for the management of dyslipidemia and prevention of cardiovascular disease: Summary of the 2004 update. *Canadian Medical Association Journal, 169*, 921-922.

Gidron, Y., Berger, R., Lugasi, B., & Reuban, L. (2002). Interactions of psychological factors and family history in relation to coronary artery disease. *Coronary Artery Disease, 13,* 205-208.

Gotto, A., & Pownall, H. (2003). *Manual of lipid disorders. Reducing the risk for coronary heart disease.* Philadelphia: Lippincott Williams & Wilkens.

Green, J. S., Grant, M., Hill, K. L., Brizzolara, J., & Belmont, B. (2003). Heart disease risk perception in college men and women. *Journal of American College of Health, 51*, 207-211.

Greenlund, K., Zheng, Z., Keenan N., Giles W., Casper M., Mensah G., et al. (2004). Trends in self-reported multiple cardiovascular disease risk factors among adults in the United States, 1991-1992. *Archives of Internal Medicine, 164*, 181-188.

Grundy, S. (1998). Hypertriglyceridemia, atherogenic dyslipidemia and metabolic syndrome. *American Journal of Cardiology, 81,* 18B-25B.

Health Canada. (2003, June). *Cardiovascular disease surveillance.* [On-line]. Available: http://www.dsol-smed.hc-sc.gc.ca/dsol-smed/cvd/glossa_e.html.

Heart and Stroke Foundation of Canada. (2003). *The growing burden of heart disease and stroke in Canada 2003.* Ottawa, ON: Author.

Hengstenberg, C., Holmer, S. R., Mayer, B., Engel, S., Schneider, A., Lowel, H., et al. (2001). Siblings of myocardial infarction patients are overlooked in primary prevention of cardiovascular disease. *European Heart Journal, 22*, 926-933.

Hennekens, C. H. (2003). Screening individuals and families with premature coronary heart disease: A clinical and public health challenge. *European Heart Journal, 24*, 212-213.

Hennekens, C. H. & D'Agostino, R. B. (2003). Global risk assessment for cardiovascular disease and astute clinical judgement. *European Heart Journal,* 24, 1899-1900.

Hense, H. W., Schulte, H., Lowel, H., Assman, G., & Keil, U. (2003). Framingham risk function overestimates risk of coronary heart disease in men and women from Germany-results from the MONICA Augsberg and PROCAM cohorts. *European Heart Journal, 24,* 937-945.

Higgens, M. (2000). Epidemiology and prevention of coronary heart disease in families. *American Journal of Medicine, 108*, 387-395.

Huck, S. W. (2000). *Reading statistics and research.* New York: Addison Wesley Longman.

Hunter, M. S., & O'Dea, I. (1999). Perception of future health risks in mid-aged women: Estimates with and without behavioral changes and hormone replacement therapy. *Maturitas: The European Menopause Journal, 33*, 37-43.

International Task Force for Prevention of Coronary Heart Disease: Carmena, R., Fruchart, J. C., Olsson, A., Paoletti, R., Riesen, W., Tikkanen, M., et al. (2003). *Pocket guide to the prevention of coronary heart disease.* [On-line]. Available: http://www.chd-taskforce.com.

Jairath, N. (1999). *Coronary heart disease and risk factor management: A nursing perspective.* Philadelphia: WB Saunders.

Jairath, N. (2001). Implications of gender differences on coronary artery disease risk reduction in women. *American Association of Cardiovascular Nurses Clinical Issue, 12*(1), 17-28.

Jenner, J., Ordovas, J., Lavon-Fava, S., Schaefer, M. M., Wilson, P.W., & Castelli, W. P., et al. (1993). Effects of age, sex, and menopausal status on plasma lipoprotein(a) levels. The Framingham Offspring Study. *Circulation, 87*, 1135-1141.

Jousilahti, P., Vartianinen, E., Tuomilehto, J., & Puska, P. (1999). Sex, age, cardiovascular risk factors, and coronary heart disease. A prospective follow-up study of 14,786 middle-aged men and women in Finland. *Circulation, 99*, 1165-1172.

Kannel, W. B., Feinleib, M., McNamara, P. M., Garrison, R. J., & Castelli, W. P. (1979). An investigation of coronary heart disease in families: The Framingham Offspring Study. *American Journal of Epidemiology, 110,* 281-290.

King, K. (2003). Coronary heart disease prevention. Views on women's gender-based perceptions and meanings. *Journal of Cardiovascular Nursing, 18*, 274-281.

King, K. B., Quinn, J. R., Delhanty, J. M., Rizzo, S., Eldredge, D. H., Caulfield, L., et al. (2002). Perception of risk for coronary heart disease in women undergoing coronary angiography. *Heart & Lung, 31,* 246-252.

Kingsbury, K. J. (2000).The correlations of coronary angioplasty patient perceptions of their risk for cardiovascular disease progression and death (Master's thesis, University of British Columbia, 2000).

Kip, K .E., McCreath, H. E., Roseman, J. M., Hulley, S. B., & Schreiner, P. J. (2002). Absence of risk factor change in young adults after family heart attack or stroke. The CARDIA Study. *American Journal of Medicine, 22*, 258-266.

Krista, A. M., Sandler, A. M., Cauley, J. A., La Port, R. E., Hom, D. L., & Pambianco, G. (1988). The assessment of historical physical activity and its relation to adult bone parameters. *American Journal of Epidemiology, 127*, 1053-1063.

Kreuter, M. W., & Stretcher, V. J. (1995). Changing inaccurate perceptions of health risk: Results from a randomized trial. *Health Psychology, 14*, 56-63.

Krummel, D. A., Koffman, D. M., & Bronner, Y. (2001). Cardiovascular health interventions in women: What works? *Journal of Women's Health & Gender Based Medicine, 10,* 117-136.

Ladwig, K. H., Muhlberger, N., Walter, H., Schumacher, K., Popp, K., Holle, R., et al. (2000). Gender differences in emotional disability and negative health perception in cardiac patients 6 months after stent implantation. *Journal of Psychosomatic Research, 48,* 501-508.

Laramee, L. A. (2000a). Coronary disease: A women's killer part I. *Canadian Journal of Diagnosis,* September, 67-74.

Laramee, L. A. (2000b). Coronary disease: A women's killer part II. *Canadian Journal of Diagnosis,* November, 73-81.

Lipid Health. (2003, June). Lipid health: An online resource for healthcare providers. [Online]. Available: http://www.lipidhelath.org/content/glossery.asp.

Malarcher, A. M., Casper, M. L., Matson Koffman, D. M., Brownstein, J. N., Croft, J., & Mensah, G.A. (2001). Women and cardiovascular disease: Addressing disparities through prevention research and a national comprehensive state-based program. *Journal of Women's Health & Gender Based Medicine, 10,* 717-724.

Marshall, G. E. (1998). A dictionary of sociology. Retrieved December 2, 2003 from Oxford Reference Online. http://www.oxfordreference.com/views/ENTRY.html?

Marteau, T. M. (1999). Communicating genetic information. *British Medical Journal, 55,* 414-428.

Marteau, T. M., Kinmonth, A. L., Pyke, S., Thompson, S. G., & The Family Heart Study Group. (1995). Readiness for lifestyle advice: Self-assessments of coronary risk prior to screening in the British Family Heart Study. *British Journal of General Practice, 45,* 5-8.

Marteau, T. M., & Lerman, C. (2001). Genetic risk and behavioral change. *British Medical Journal, 322,* 1056-1059.

Meischke, H., Sellers, D. E., Robbins, M. L., Goff, D. C., Daya, M R., Meshack, A., et al. (2000). Factors that influence personal perceptions of the risk of an acute myocardial infarction. *Behavioral Medicine, 26*, 4-14.

Miller, N. (2003) Aggressive blood pressure management. *Journal of Cardiovascular Nursing, 18*, 108-115.

Mills, C., Stephens, T., & Wilkens, K. (1994). Summary report of the workshop on data for monitoring tobacco use. *Chronic Diseases in Canada, 15*, 105-110.

Mosca, L., Jones, W. K., King, K. B., Ouyang, P., Redberg, R. F., & Hill, M. N. (2000). Awareness, perception, and knowledge of heart disease risk and prevention among American women. *Archives of Family Medicine, 9,* 506-515.

Mosca, L., Manson, J. E., Sutherland, S. E., Langer, R. D., Manolio, T., & Barrett-Connor, E. (1997). Cardiovascular disease in women: A statement for healthcare professionals from the American Heart Association. *Circulation, 96,* 2468-2482.

Nasir, K., Michos, E., Rumberger. J., Braunstein, J., Post, W., Budoff, M., et al. (2004). Coronary artery calcification and family history of premature coronary heart disease. Sibling history is more strongly associated than parental history. *Circulation, 110,* 2150-2156.

National Cholesterol Education Program. (1994). Second report of the expert panel on detection, evaluation, and treatment of high blood cholesterol in adults (Adult Treatment Panel). *Circulation, 89,* 1333-1445.

National Cholesterol Education Program. (2002). Third report of the national cholesterol education program (NECP). Expert panel on detection, evaluation, and treatment of high blood cholesterol in adults (Adult Treatment Panel 111). Final report. *Circulation, 106,* 3143-3421.

National Heart, Lung, and Blood Institute. (2003). *The Framingham Heart Study, celebrating over 50 years of research success.* [On-line], Available: http://www.nhlbi.nih.gov/about/framingham/index.html.

Niknian, M., McKinlay, A. M., Rakowski, W., & Carleton, R. A. (1989). A comparison of perceived and objective CVD risk in a general population. *American Journal of Public Health, 79,* 1653-1654.

Oxford at the Claredon Press. (1982). *The concise Oxford dictionary (7th ed.).* New York: Oxford University Press.

Pearson, T. A., Blair, S. N., Daniels, S. R., Eckel, R. H., Fair, J. M., Fortman, S. P., et al. (2002). AHA guidelines for primary prevention of cardiovascular disease and stroke: 2002 update. Consensus panel guide to comprehensive risk reduction for adult patients without coronary or other atherosclerotic vascular diseases. *Circulation, 106,* 388-391.

Pilote, L., & Hlatky, M. A. (1995). Attitudes of women toward hormone therapy and prevention of heart disease. *American Heart Journal, 129,* 1237-1238.

Pohola-Sintonen, S., Rissanen, A., Liskola, P., & Luomanmaki, K. (1998). Family history of coronary heart disease in patients under 60 years of age. *European Heart Journal, 19,* 235-239.

Ponder, M., Lee, J., Green, J., & Richards, M. (1996). Family history and perceived vulnerability to some common diseases: A study of young people and their parents. *Journal of Medical Genetics*, *33,* 485-492.

Ridker, P. M., Rifai, N. F., Buring, J. E., & Cook, N. R. (2002). Comparison of C-reactive protein and low-density lipoprotein cholesterol levels in the prediction of first cardiovascular events. *New England Journal of Medicine, 347*, 1557-1565.

Rozanki, A., Blumenthal, J. A., & Kaplan, J. (1999). Impact of psychological factors on the pathogenesis of cardiovascular disease and implications for therapy. *Circulation, 99,* 2192-2217.

Schildkraut, J. M., Myers, R. H., Cupples, L. A., Kiely, D. K., & Kannel, W. B. (1989). Coronary risk associated with age and sex of parental heart disease in the Framingham Study. *American Journal of Cardiology, 64*, 555-559.

Sesso, H. D., Lee, I. M., Gaziano, J. M., Rexrode, K. M., Glynn, R. J., & Buring, J. E. (2001). Maternal and paternal history of myocardial infarction and risk of cardiovascular disease in men and women. *Circulation, 104,* 393-398.

Shepherd, J., Alcade, V., Befort, P. A., Gutzwiller, F., Boucher, B., Erdmann, E., et al. (1997). International comparison of awareness and attitudes towards coronary risk factor reduction: The HELP study. *Journal of Cardiovascular Risk, 4,* 373-384.

Shepherd, J., & HELP Study Group. (1998). International comparison of awareness and attitudes towards coronary risk factor reduction: The HELP study. *Atherosclerosis, 137* (Suppl.), S117-S123.

Sparks, E. A., & Frazier, L. Q. (2002). Heritable cardiovascular disease. *Journal of Obstetrics, Gynecologic, & Neonatal Nursing, 31,* 217-228.

Steeds, R. P.,& Channer, K. S. (1997). How important is family history in ischemic heart disease? *Quarterly Journal of Medicine, 90,* 427-430.

Stretcher, V. J., Kreuter, M. W., & Korbin, S. C. (1995). Do cigarette smokers have unrealistic perceptions of their heart attack, cancer, and stroke risks? *Journal of Behavioral Medicine, 18*(1), 45-54.

Ulmer, H., Kelleher, C., Diem, G., & Concin, H. (2003). Long-term tracking of cardiovascular risk factors among men and women in a large population-based health system. The Vorarlberg Health Monitoring & Promotion Programme. *European Heart Journal, 24,* 1004-1013.

Valentine, R. J., Verstraete, R., Clagett, G. P., & Cohen, J. C. (2000). Premature cardiovascular disease is common in relatives of patients with premature peripheral atherosclerosis. *Archives of Internal Medicine, 160,* 1343-1348.

Van Maarle, M. C., Stouthard, M. E., & Bonsel, G. J. (2003). Risk perception of participants in a family-based genetic screening program on familial hypercholesterolemia. *American Journal of Medical Genetics, 116A,* 136-143.

Van Tiel, D., Van Vliet, K. P., & Moerman, C. J. (1998). Sex differences in illness beliefs and illness behaviour in patients with suspected coronary artery disease. *Patient Education and Counseling, 33,* 143-147.

Wagner, E. H. (2000). The role of the patient care teams in chronic disease management. *British Medical Journal, 320,* 569-572.

Walker, E. A., Mertz, C. K., Kalten, M. R., & Flynn, J. (2003). Risk perception for developing diabetes: Comparative risk judgments of physicians. *Diabetes Care, 26*, 2543-2548.

Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology, 39,* 806-820.

Weinstein, N. D. (1983). Reducing unrealistic optimism about illness susceptibility. *Health Psychology, 2,* 11-20.

Weinstein, N. D. (1984). Why it won't happen to me: perceptions of risk factors and susceptibility. *Health Psychology, 3,* 431-457.

Weinstein, N. D., & Klein, W. M. (1995). Resistance of personal risk perceptions to debiasing interventions. *Health Psychology, 14,* 132-140.

Wilcox, S., & Stefanick, M. L. (1999). Knowledge and perceived risk of major diseases in middle-aged and older women. *Health Psychology, 18*, 346-353.

Williams, R. R., Hunt, S. C., Heiss, G., Province, M. A., Bensen, J. T., Higgens, M., et al. (2001). Usefulness of cardiovascular family history data for population-based preventive medicine and medical research (the Health Family Tree Study and the NHLBI Family Heart Study). *American Journal of Cardiology, 87,* 129-135.

Wilson, P. W. F., D'Agostino, R. B., Levy, D., Belanger, A. M., Silbershatz, H., & Kannel, W. B. (1998). Prediction of coronary heart disease using risk factor categories. *Circulation, 97,* 1837-1847.

Winkelmann, B. R., Hager, J., Kraus, W. E., Merlini, P., Keavney, B., Grant, P. J., et al. (2000). Genetics of coronary heart disease: Current knowledge and research principles. *American Heart Journal, 108*, 387-395.

Zerwic, J., King, K. B., & Wlasowicz, G. S. (1997). Perceptions of patients with cardiovascular disease about the causes of coronary artery disease. *Heart & Lung, 26*, 92-98.

APPENNDIX A

Atherosclerosis cohort of gene environment Study questionnaire (v2)

1. Personal data:

(a) PHN #

(b) Patient ID

(c) Visit Date

(d) Name:

First

Last

(e) Date of Birth:

(f) Sex: Male **- 0** Female **1**

(g) Subjective risk:

What do you think **is** your risk of having a heart attack in the next 10 years, compared with other people of your age and sex:

☐ **1-** Low
☐ **2-** Moderate
☐ **3-** High

(h) Absolute risk:

What do you think **is** your risk of having a heart attack in the next 10 years:

Percentage:

2. Personal history:

a. Education:

☐ **0**-High school not completed
☐ **1**-High school completed
☐ **2**-Some trade/ technical/ vocational /business
☐ **3**-Diploma/certificate in trade/technical/vocational/business
☐ **4**-Bachelor's degree (BA, B.Sc., LLB etc.)
☐ **5**-Master's degree (MA, M.Sc., MBA etc.)
☐ **6**-Degree in Medicine/veterinary/Optometry (MD, DDS, DMD, DVM, OD)
☐ **7**-Doctorate (Ph.D., D.Sc., D.Ed)

b. **Exercise:**
Please see "Modifiable Activity Questionnaire (MAQ)"

(c) Diet:
Please see "Willett" Questionnaire

(d) Smoking:

Start Age	**Stop Age**	**Type** (cig, pipe, cigar, marijuana)	**#/day**	**Exposure (1° or 2°)**

Utero: Yes ☐ No ☐

(e) Alcohol:

What category best describes your drinking habits?

☐ **0**-Never
☐ **1**-Occasional (less than 2-3 drink /wk)
☐ **2**-moderate (7-14 drinks /wk or 1-2 drink a day)
☐ **3**-Heavy (>14 drinks/wk or >2-3 drinks a day)

(f) <u>For women only</u>:

Have you had any menstrual period during the past 2 years? Ye☐ No☐ If No,

(i) Have you reached menopause? **1**-Yes ☐ If yes, what age? ----- Years
2-No ☐
3-In menopause ☐
4-Showing symptoms ☐

(ii) If reached menopause, was it due to **1**-Natural ☐
2-Surgery ☐
3-Radiation ☐
4-Unsure ☐

(iii) If reached menopause, are you on hormone replacement therapy?
1-Yes ☐ If yes, since when?___Years
☐
2-No
3-Unknown ☐

(iv) Have you ever taken birth control pills?
1.Yes ☐ If yes, How long? ____Years
2-No ☐
3-Menstrual cycle medication☐

3. Recent history:

In the past six months the following have changed:

(a) Exercising	**0**-Decreased ☐	**1**-Same ☐	**3**-Increased ☐
(b) Eating	**0**-Decreased ☐	**1**-Same ☐	**3**-Increased ☐
(c) Smoking	**0**-Decreased ☐	**1**-Same ☐	**3**-Increased ☐
(d) Drinking Alcohol	**0**-Decreased ☐	**1**-Same ☐	**3**-Increased ☐
(e) Weight	**0**-Decreased ☐	**1**-Same ☐	**3**-Increased ☐

4. Medical history:

	1-Yes	2-No	3-Symtoms
(a) CAD:	☐	☐	☐
(b) PVD	☐	☐	☐
(c) CVD(Stroke, TIA's)	☐	☐	☐
(d) Diabetes mellitus	☐	☐	☐
(e) Renal insufficiency	☐	☐	☐
(f) Hypertension	☐	☐	☐
(g) Obesity	☐	☐	
(h) Frequent Chronic infection	☐	☐	

Specify____

5. Family History: (from the pedigree)

	1-Yes	2-No	3-Symptoms	How many relatives?
(a) CAD:	☐	☐	☐	☐
(b) PVD	☐	☐	☐	☐
(c) CVD(Stroke, TIA's)	☐	☐	☐	☐
(d) Diabetes mellitus	☐	☐	☐	☐
(e) Hypertension	☐	☐	☐	☐
(f) High blood cholesterol	☐	☐	☐	☐

A pedigree will be drawn for family members with and without the above illnesses. Age and cause of death will also be included if applicable.

6. Current Medications: (from the chart)

Medication	Yes	No	Name of Medication	Dosage	Frequency	**Concentration**
1) ASA						
2) ACE inhibitors						
3) Beta blockers						

4) Calcium Channel blockers						
5) Antioxidants						
6) Lipid lowering drugs						
7) Insulin sensitizers						
8) Other						

7. Awareness of disease and coronary heart risk factors perception:

(a) Have you ever been diagnosed or treated for any of the following? (Interview)

Risk factors	**Yes**	**No**	**Currently Evaluating**	
(i) High blood pressure				
	Yes	**No**	**Tested**	
(ii) High blood cholesterol				
(iii) High blood sugar				
	Yes	**No**	**Symptoms**	**Unsure**
(iv) MI before age 55				
(v) Did you have an MI				
	Yes	**No**	**TIA Positive**	
(vi) Stroke before age 65				
	Yes	**No**	**Symptoms**	
(vii) Heart failure				
(viii) Decreased blood flow to the legs				

If answered yes for (i) and (ii),

Risk factors	Value	Date of first diagnosis
Highest blood pressure	/	
Highest cholesterol		

(c) Have you ever had heart or vascular surgery?

Yes -1 ☐ No -2 ☐

(d) If yes, which of the following procedures have been done to you?

		1-Yes	2-No	3-Unknown	Positive	Negative
(i)	Angiography	☐	☐	☐	☐	☐
(ii)	Coronary Angioplasty	☐	☐	☐		
(iii)	Peripheral Vessel Angioplasty	☐	☐	☐		
(iv)	Bypass surgery	☐	☐	☐		
(v)	Peripheral Vascular Surgery	☐	☐	☐		

Procedure	Date	Results

(e) Are you on any of the following medications?

		1-Yes	2-No	3-Unknown
(i)	High blood pressure	☐	☐	☐
(ii)	High blood lipids	☐	☐	☐
(iii)	Angina or chest pain	☐	☐	☐
(iv)	Blood thinning	☐	☐	☐
(v)	Diabetes or high blood sugar	☐	☐	☐
(vi)	Aspirin	☐	☐	☐

8. Physical examination:

Weight ☐ Kgs Height ☐ Cms

Waist circumference ☐ **Cms** **Heart rate (HR)** ☐ **/min**

Blood pressure (sitting R arm) ☐ **mmHg**

Xanthelesma ☐ **Arcus** ☐ **Tendon xanthomas** ☐ **Palmar** ☐

9. Current Angiography result:

(a) How many vessels affected? None ☐ 1 ☐ 2 ☐ 3 ☐

(b) % of obstruction <50% ☐ >50% ☐

10. Current Diagnosis:

- ☐ **0-** Angina
- ☐ **1-**Coronary artery disease
- ☐ **2-** Acute coronary syndrome
- ☐ **3-** Myocardial infarction
- ☐ **4-**Congestive heart failure
- ☐ **5-**Cardiomyopathy
- ☐ **6-**Valvular disease
- ☐ **7-**Cerebrovascular disease
- ☐ **8-**Peripheral vascular disease
- ☐ **9-**Hypertension
- ☐ **10-**Diabetes mellitus
- ☐ **11-**Metabolic syndrome
- ☐ **12-**Liver disease
- ☐ **13-**Renal disease
- ☐ **14-**Lung disease

Other ____________________

11. Lab Data:

TC ____________
TG ____________
FC ____________
LP A1 ____________
HDL TC ____________

Apo B ____________
Apo A1 ____________
FER $_{HDL}$ ____________
MER $_{HDL}$ ____________
HDL TG ____________

LDL ____________
Fasting glucose ____________

CRP ____________
Homocystine ____________

APPENDIX B

NATIONAL CHOLESTEROL EDUCATION PROGRAM
Third Report of the Expert Panel on
Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III)

Risk Assessment Tool for Estimating 10-year Risk of Developing Hard CHD (Myocardial Infarction and Coronary Death)

The risk assessment tool below uses recent data from the Framingham Heart Study to estimate 10-year risk for "hard" coronary heart disease outcomes (myocardial infarction and coronary death). This tool is designed to estimate risk in adults aged 20 and older who do not have heart disease or diabetes. Use the calculator below to estimate 10-year risk.

Age:	[ ] years
Gender:	○ Female ○ Male
Total Cholesterol:	[ ] mg/dL
HDL Cholesterol:	[ ] mg/dL
Smoker:	○ No ○ Yes
Systolic Blood Pressure:	[ ] mm/Hg
Currently on any medication to treat high blood pressure.	○ No ○ Yes

Calculate 10-Year Risk

TOP **Total cholesterol** - Total cholesterol values should be the average of at least two measurements obtained from lipoprotein analysis.

TOP **HDL cholesterol** - HDL cholesterol values should be the average of at least two measurements obtained from lipoprotein analysis.

TOP **Smoker** - The designation "smoker" means any cigarette smoking in the past month.

TOP **Systolic blood pressure** - The blood pressure value used is that obtained at the time of assessment, regardless of whether the person is on antihypertensive therapy (treated hypertension carries residual risk).

TOP **More Information** - Determining 10-year (short term) risk for developing CHD is carried out using Framingham risk scoring. The risk factors included in the Framingham calculation are age, total cholesterol, HDL cholesterol, systolic blood pressure, treatment for hypertension, and cigarette smoking. Because of a larger database, Framingham estimates are more robust for total cholesterol than for LDL cholesterol. Note, however, that LDL cholesterol remains the primary target of therapy. The Framingham risk score gives estimates for "hard CHD" which includes myocardial infarction and coronary death.

ATP III Home | NCEP Home | NHLBI Home | NIH Home

APPENDIX C

MODIFIABLE ACTIVITY QUESTIONNAIRE (MAQ)

1. Please circle all activities listed below that you have done more than 10 times in the past year:

Jogging (outdoor, treadmill)	1	Gardening or Yardwork	22
Swimming (laps, snorkeling)	2	Badminton	23
Bicycling (indoor, outdoor)	3	Strength/Weight training	24
Softball/Baseball	4	Rock climbing	25
Volleyball	5	Scuba Diving	26
Bowling	6	Stair Master	27
Basketball	7	Fencing	28
Skating (roller, ice, blading)	8	Hiking	29
Martial Arts (karate, judo)	9	Tennis	30
Tai Chi	10	Golf	31
Calisthenics/Toning exercises	11	Canoeing/Rowing/Kayaking	32
Wood Chopping	12	Water skiing	33
Water/coal hauling	13	Jumping rope	34
Football/Soccer	14	Snow skiing (X country/Nordic track)	35
Racquetball/Handball/Squash	15	(downhill)	36
Horseback riding	16	Snow shoeing	37
Hunting	17	Yoga	38
Fishing	18	Other	39
Aerobic Dance/Step Aerobic	19	Walking for exercise (outdoor, indoor at mall or fitness center, treadmill)	40
Water Aerobics	20		
Dancing (Square, Line, Ballroom)	21		

Activity	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	Average # of Times Per Month	Average # of Minutes Each Time

2. In general, how many HOURS per DAY do you usually spend watching television?______hrs

3. Over this past year, have you spent more than one week confined to a bed or chair as a result of an injury, illness or surgery? ______yes _____no

   If yes, how many weeks over this past year were you confined to a bed or chair? ______weeks

4. Do you have difficulty doing any of the following activities?

   a. getting in or out of a bed or chair? Yes _______ No _______

   b. walking across a small room without resting? Yes _______ No _______

   c. walking for 10 minutes without resting? Yes _______ No _______

5. Did you ever compete in an individual or team sport (not including any time spent in sports performed during school physical education classes)?
   If yes, how many total years did you participate in competitive sports? __________

6. Have you had a job for more than one month over this past year, from last _________ to this _________? Yes _______ No _______

List all JOBS that you have held over the past year for more than one month. Account for all 12 months of the past year. If unemployed/disabled/retired/homemaker/student during all or part of the past year, list as such and probe for job activities of a normal 8 hour day, 5 day week.

Job name	Job code	Walk or bicycle to/from work Min/Day	AVERAGE JOB SCHEDULE			Out of the total # of "Hrs/Day" the individual reported working at this "job", how much of this time was usually spent sitting? Enter this # in "Hrs Sitting" column, then place a check "√" in the category which best describes their job activities when they were not sitting.			
			Mos/Yr	Day/Wk	Hrs/Day	Hrs spent sitting at work	Check the category that best describes job activities when not sitting		
						Hrs sitting	A	B	C
Eg. Painter	*8*	*30*	*4*	*5*	*9*	*0*		√	

Category A

(includes all sitting activities)

Sitting
Standing still w/o heavy lifting
Light cleaning – ironing, cooking, washing, dusting
Driving a bus, taxi, tractor
Jewelry making/weaving
General office work
Occasional/short distance walking

Category B

(includes most indoor activities)

Carrying light loads
Continuous walking
Heavy cleaning – mopping, sweeping, scrubbing, vacuuming
Gardening – planting, weeding
Painting/Plastering
Plumbing/Welding
Electrical work
Sheep herding

Category C

(heavy industrial work, outdoor construction, farming)

Carrying moderate to heavy loads
Heavy construction
Farming – hoeing, digging, mowing, raking
Digging ditches, shoveling
Chopping (ax), sawing wood
Tree/pole climbing
Water/coal/wood hauling

JOB CODES

<u>Not employed outside of the home:</u>

1. Student
2. Home Maker
3. Retired
4. Disabled
5. Unemployed

<u>Employed (or volunteer):</u>

6. Armed Services
7. Office worker
8. Non-office Worker