Knowledge, Perception, and Behaviors of Relatives of People With Premature Heart Disease
A Systematic Literature Review

Thanh G.N. Ton, MPH, PhD; Thomas T. Fogg, MS, MPH; Chin-To Fong, MD; Collin John, MD, MPH; Shirley X.L. Li, BSc; Julie A. Marshall, PhD; Karen Peters, MPH, DrPH; William Neal, MD; Thomas A. Pearson, MD, MPH, PhD

Familial aggregation of coronary heart disease (CHD) is thought to account for 50% to 60% of total documented CHD before the age of 60 years. First-degree relatives of people with premature CHD (proband) exhibit a risk that is 2 to 12 times greater than that of the general population. The National Cholesterol Education Program’s Adult Treatment Panel recommends screening patients with a recognized family history of premature CHD, defined as heart disease in men <55 years and women <65 years. However, a number of recent surveys have demonstrated that these guidelines are not widely implemented.

Reasons for lack of screening based on family history are thought to exist at both the individual and provider levels. On the individual level, family members deny or are unaware of the familial aggregation of CHD and its risk factors. On the provider level, healthcare providers may not be engaged to identify high-risk families, conduct the screening, and intervene with relatives. To better understand the impact of a proband’s premature CHD on first-degree relatives, we conducted a literature review to assess relatives’ knowledge of CHD risk factors, risk perception, and implementation of and adherence to risk-reducing behaviors and their management by healthcare providers. The goal of this review is to identify gaps in the literature and provide recommendations for future research.

Methods and Results

The study design for this review was developed by a working group composed of individuals from 6 member institutions of the Centers for Disease Control and Prevention’s Cardiovascular Health Intervention Research and Translation Network. We conducted a systematic literature search within MEDLINE, PsychINFO, Embase, and the Cochrane Database. Syntaxes were constructed with the use of Medical Subject Headings for the following combination: (coronary heart disease AND [early onset or premature]) AND (mass screening OR risk OR family) AND (attitudes). Each search was limited to studies in humans, articles published in peer-reviewed journals, and presentation of original data. Commentaries, essays, consensus statements, guidelines, and editorials were excluded. Bibliographies of studies that met criteria for inclusion were reviewed for other relevant studies.

We defined a proband as an individual with premature CHD and included studies that defined the proband as having CHD before the age of 60 years. We included studies whose population was composed of first-degree relatives of probands and that were related to knowledge of CHD, risk perception, implementation of and adherence to risk-reducing behaviors, and management by healthcare providers. We excluded studies that assessed drugs to reduce biological levels of risk for CHD, addressed molecular or mechanistic factors related to CHD, assessed genetic associations or identified biomarkers, were related to CHD but not specifically to premature CHD, established family history as a risk factor for premature CHD, or established high prevalence of CHD risk factors among family members without addressing key topics.

We identified 504 studies. After we applied exclusion criteria, 37 studies were deemed relevant by the 2 reviewers (C.J., T.G.N.T.). A review of 650 total bibliographic citations identified 10 additional studies. Two independent reviewers abstracted the data on year of publication, type of study (qualitative or quantitative), design, objective, study population, inclusion and exclusion criteria, results, and conclusions. Cardiovascular Health Intervention Research and Translation Network members met to discuss the scientific quality of each article. Each article was given a quality score by the panel of 0, 1, or 2 to represent poor, good, and excellent scientific quality on the basis of study design, population selection, existence of bias, and generalizability of results. A score of poor quality excluded the study from the final analysis. Of 47 studies, 26 studies were further excluded by the panel for not meeting inclusion criteria, and an additional 4 were excluded because of poor scientific quality. The remaining 17 articles were included in the final analysis.

An organizational framework was developed to guide the discussion of the key topics for each article (Figure) and to help to identify potential gaps in the literature. We created evidence tables to summarize findings (Tables I and II in the online-only Data Supplement).

Characteristics of the studies are provided in Table 1. Study designs were cross-sectional (47%), followed by randomized trials (24%), case-control studies (18%), and prospective cohorts (12%). Nearly half provided data on knowledge of CHD risk factors, management by healthcare providers, and risk perception.
majority of studies provided information on implementation of risk-reducing behaviors (82%).

**Knowledge of Risk Factors**

We identified 8 studies with information on knowledge of risk factors among relatives of probands (Table I in the online-only Data Supplement). Three types of knowledge were reported: (1) awareness of the affected relative’s condition; (2) awareness of one’s own risk factors; and (3) general knowledge of CHD risk factors. In 1 study of 80 subjects without known coronary artery disease who were primary biological siblings of patients aged <60 years hospitalized with myocardial infarction, coronary artery bypass surgery, or unstable angina with angiographically documented CHD, 35% were aware of their affected relative’s hypertension, 30% of their relative’s angina, and only 2% of their relative’s high cholesterol.7 In a study of 172 asymptomatic biological siblings aged between 30 and 59 years, self-reported prevalence of hypertension and hyperlipidemia was lower than actual prevalence. In this study, 35% (13 of 37) of brothers and 53% (16 of 30) of sisters with hypertension were aware of their hypertensive states; 27% (9 of 24) of brothers and 25% (4 of 16) of sisters with hyperlipidemia were aware of their condition.2 In a larger study of 668 siblings, ~367 siblings qualified for dietary intervention under the Adult Treatment Panel II guidelines. Of these, 43% were aware of their hypercholesterolemia.6 In a study of 859 siblings, 380 were hypertensive; of these, 60% were aware of their hypertension.4 In this study, older siblings were slightly more likely to be aware of their hypertension than younger siblings.4 One study that employed a control group of 3802 hypertensives from the general population in Augsberg, Germany, found that hypertensive siblings of probands (n=524) were more aware of their hypertension than the general population of male hypertensives. Female siblings with hypertension did not differ in their degree of awareness from the general population of women with hypertension.10 Awareness was also documented among offspring of probands. Among 696 sons of probands, 35% with hypercholesterolemia were aware of their hypercholesterolemia, and 27% with hypertension knew of their hypertension.11 Inherent challenges in comparisons across studies are differences in population characteristics, locations, and venues of recruitment. For example, probands who participated in clinical trials8,10 may differ from those recruited from hospitals in their motivation to be healthy, which may subsequently affect their relatives’ awareness of risk factors. Studies conducted in the United States reported an equivalent or higher rate of awareness of hypertensive and hypercholesterolemic status among female siblings compared with male siblings, whereas a study in Germany conversely reported greater awareness among male siblings (64%) than among female siblings (55%).10 However, meaningful differences in awareness related to gender may be difficult to discern across studies of varying geographic locations, culture, and educational and healthcare systems. Few studies have control groups for internal comparisons.

Studies also documented general knowledge of risk factors among relatives. In a study of 80 siblings of probands, the majority commonly named stress, smoking, and diet as risk factors for CHD, but <25% cited age and sex.7 In a population of 87 healthy offspring with mothers with premature CHD, heredity was identified by only 28% as an important risk factor. Dietary factors, smoking, lack of...
died suddenly, siblings receiving the educational intervention arm (n=35) demonstrated higher perceived susceptibility to CHD than siblings in the control arm (n=23). For parents in the intervention arm, however, CHD risk was perceived to be less serious among them than among their control counterparts.16

Implementation and Adherence

Initiation of lifestyle changes among those with positive family history has been reported by several studies. A 2-year randomized intervention of care provided to 156 siblings by either a trained nurse or enhanced primary care demonstrated that siblings with high low-density lipoprotein levels were more effectively treated by a trained nurse than by primary care physicians in reaching the goal low-density lipoprotein levels.17 In a population of 571 sons of male probands, >90% reported seeing a family physician on a regular basis,11 and 30% to 60% attempted to stop smoking, adopted a low-fat diet, or exercised regularly and maintained body weight.11,13 In a study of 219 children of probands, the proportion of female offspring reporting dietary change within the preceding 2 years was greater (72%) than for male offspring (60%).13 Middle school–aged children of parent(s) with premature CHD with a history of premature CHD were physically more active if parents were active.18 One study reported a direct link between higher risk perception and implementation of risk-reducing behaviors. Among Canadian offspring of men and women with premature cardiac events, those who worried more about their personal CHD risk were significantly more likely to make dietary changes.13 Only 1 study compared differences in initiation of lifestyle changes across subgroups of relatives. This study randomized 19 families of probands (consisting of 58 first-degree relatives) to receive an educational intervention to collect their family history and increase their knowledge of risk factors. Overall, experimental families reduced their consumption of alcohol and high-fat meats, but siblings, in particular, perceived themselves to be more susceptible to cardiac events and perceived those events to be more serious relative to siblings in the control families.16

A number of studies described adherence to risk-reducing behaviors. In a study assessing lifestyle changes among 571 sons of parents with premature CHD, smoking cessation was successful in only 12% of those who attempted to quit, and regular exercise was maintained in only 25% of offspring who regularly exercised before the age of 20 years.11 In a study of an educational intervention to reduce risk among relatives of sudden cardiac death victims, younger age of death of the proband was correlated with greater adherence to blood pressure screening.16

Rates of treatment and control of hypercholesterolemia and hypertension were low. In an American population of siblings, 5.5% (n=5) of female siblings versus 2.3% (n=3) of male siblings who qualified for drug treatment for hypercholesterolemia were receiving medication at the time of screening. Of these 8 who were treated for hypercholesterolemia, only 2 had values under control.5 Studies that assessed treatment of hypertension estimated that 45% to 91% of siblings with hypertension were medically treated; however, the proportion under control was much lower, reportedly in the range of 16% to 30%.9,19 Another study noted that treatment targets among 510 healthy siblings were reached in only 31% with hypertension and 7% with hypercholesterolemia.19 Other studies report similarly low proportions of family members whose hypertension or hypercholesterolemia is controlled.19 To 8% and 14% of randomly selected children with hypertension and/or hypercholesterolemia were receiving treatment.19 One study that used a randomly selected sample of hypertensive individuals from the general population in Augsburg, Germany, as a comparison group reported that although hypertension is more often detected among male siblings of patients with myocardial infarction, the proportion of 143 male siblings under proper medical control is similar to that found among 971 individuals with hypertension from the general population (11.9% versus 8.9%, respectively).10 The authors of this study conclude that siblings of patients with myocardial infarction and/or treating physicians do not perceive the necessity to reinforce prevention measures in families with heart disease. Whether the rate of medical control can be attributed to nonadherence among patients or to the lack of successful medical management by healthcare providers, or both, is unclear.

Table 1. Characteristics of 17 Studies Included in Analysis

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total, n (%)</th>
<th>Publication date, median (IQR)</th>
<th>Type of study, n (%)</th>
<th>Geographic location, n (%)</th>
<th>Topic related to</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cross-sectional 8 (47.1)</td>
<td>United States 9 (52.9)</td>
<td>Risk perception</td>
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<td></td>
<td></td>
<td></td>
<td>Case-control 3 (17.7)</td>
<td>Canada 2 (11.8)</td>
<td>Implementation of risk-reducing behavior</td>
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<td></td>
<td></td>
<td></td>
<td>Prospective 2 (11.8)</td>
<td>Europe 6 (35.3)</td>
<td>Adherence to risk-reducing behavior</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Randomized trial 4 (23.5)</td>
<td>Belgium 2 (33.3)</td>
<td>Management by healthcare providers</td>
</tr>
</tbody>
</table>

IQR indicates interquartile range.

*Each article may contain data on multiple key topics.

Exercise, and stress were commonly cited as risk factors among offspring of probands.12,13 In a group of 219 Canadian offspring aged ≥16 years, 13% identified heredity as an important risk factor.13 These results are similar to responses from a nationally representative sample of American women in which an overwhelmingly large majority recognized that maintaining healthy cholesterol levels, exercising, quitting smoking, and reducing dietary cholesterol and salt intake were important in preventing heart disease.14 The report did not present data on knowledge of heredity as a risk factor.

In summary, studies demonstrate that level of awareness is low across these dimensions. Family members recognized stress, smoking, and diet as important risk factors but did not necessarily recognize age, sex, and heredity.

Perception of Risk

Descriptions of risk perception varied across studies. In a predominantly white population of 80 siblings, the majority (67%) believed their personal CHD risk to be the “same as or less than other people in the general population.” Among 87 offspring of female probands, 47% perceived their risk for future heart attack as less than or equal to others their age, and 58% described their concern as an average or below average level of concern.12 In a study of 571 sons of male probands, only half reported that they were highly concerned about their heart health.11 These results suggest that family members appear to underestimate their own risk of CHD to be similar or less than the population, but more studies comparing perception between family members with and without family history of premature CHD are needed. One study that directly compared perception of subjects with and without a family history of premature myocardial infarction found that those with a positive family history perceived their own risk of heart attacks to be greater than those without a family history.15

Levels of risk perception may differ across different subgroups of relatives. In a study assessing the effectiveness of an intervention promoting risk-reducing behaviors among relatives of probands who...
In general, family members successfully implement risk-reducing behaviors in response to interventions; however, successful adherence to lifestyle changes appeared particularly difficult for smoking cessation, exercise, and achievement of treatment goals.

Screening and Medical Management by Healthcare Providers

Eight studies presented data on how family members are screened or medically managed by their healthcare providers (Table II in the online-only Data Supplement). In Belgium, only 18.6% of 321 first-degree relatives (24% of siblings; 9% of offspring) recruited from 4 hospitals ever had an examination because of heart disease of their family member.20 Rates for general screening of family members specifically due to a family history ranged from 5.6% to 9.3% in children, 10.5% to 18.6% in siblings, and 15% to 22% of first-degree relatives as reported in 3 European studies.21-23 In a Norwegian study of 566 patients with premature CHD, characteristics of probands that predicted successful screening in their children were female, nonimmigrant status, low education, and nonsmoking status. Sisters were more likely to complete screening than brothers, and daughters were more likely to complete screening than sons.23

Data regarding the physician’s role in managing family members were presented in a number of studies. In a study of 5553 patients with premature CHD admitted to 53 hospitals throughout the United States, advice to screen family members appeared in the discharge plan in <1% of probands.6 When such advice was given, it commonly occurred after an acute event in the proband rather than during admission or preventatively before the event. European studies of screening report that advice on healthier lifestyle was provided to 30% to 50% of siblings and 15% to 25% of children.20,21 Among 571 sons of male probands, only 60% were provided nutritional counseling.11 Of sons with lipid measurements, only 10% were made aware of their results, 11% were given advice on a low-fat diet, and 18% were advised to exercise.11 In summary, rates of screening among family members for CHD risk factors were extremely low, ranging from ~6% to 67% across studies depending on the type of relationship to the proband and risk factor being screened. Studies also documented that physicians seldom advise family members to adopt healthier lifestyles.

Discussion

Differences in results across studies may be due to demographic variations in study population, participant selection criteria, differences in practice and culture between countries, recruitment strategies, and other characteristics. Results regarding knowledge and awareness, in particular, are likely to be affected by the current medical condition of subjects. Whereas certain studies recruited relatives without apparent symptoms of CHD, others did not exclude those with underlying conditions. Despite this, general patterns emerged. In regard to general knowledge, relatives reported varying levels of knowledge and awareness. Relatives appear to understand that risk of CHD increases with poor diet, lack of exercise, and smoking, which are the same risk factors recognized by the majority of the general population of women in the United States.14 However, heredity was not commonly regarded as a risk factor, even though this population bears 50% to 60% of the total burden of premature CHD. Awareness of one’s own risk factors appears limited. Although estimates varied across studies, a significant proportion of relatives reported not knowing about their own hypertensive and hypercholesterolemic conditions. The highest level of awareness of one’s own hypertension reported in the studies we reviewed was only 64%.

These results suggest that limited general knowledge and a low level of personal awareness represent barriers to risk-reducing behaviors. Evidently, much improvement is desirable regarding general knowledge of CHD risk factors, particularly in the recognition of heredity as a risk factor. Why heredity, age, and sex were not generally recognized by this population as important risk factors is unclear. Possibly, the understanding of risk factors among this population may be limited to those that are modifiable. Raising awareness of the importance of non-modifiable risk factors may help to increase perception of risk to levels that are more appropriate for this population. The recognition of a positive family history, however, is a complex process explored by Hunt and colleagues.24 Family history is open to many interpretations and is dependent on the number and age of relatives affected and the relationship to the proband. Hunt and colleagues suggest that even people with a large number of relatives affected by heart disease are not likely to recognize a positive family history and that the level of recognition can depend on the proband’s sex, social class, and age at death. On the other hand, even if individuals acknowledge the theoretical importance of family history, a personal family history may still not be recognized because of incomplete knowledge of the relative’s health. A national survey of US residents aged ≥18 years found that although 96% of respondents believed that family history is important, <30% actively collected health information from their relatives.25

Demonstration projects to increase awareness of the importance of family history and to educate both the general and healthcare communities on how to collect family history information are currently under way. The US Surgeon General’s Family History Initiative is under evaluation as a way to facilitate the collection of family history information.26 The Family History Initiative encourages conversations about health among families on National Family History Day (the American Thanksgiving Day holiday) and provides a Web-based tool to facilitate the collection of family history information. One recently completed demonstration project among women in urban Appalachian communities showed that two thirds of participants could successfully find the Web-based tool after training and that almost one half could teach a relative to find the tool. However, obstacles to access were also reported.27

Relatives of probands appear to underestimate their own risk. Reports suggest that the majority of family members do not perceive themselves to be at risk. Siblings may represent a unique subpopulation of family members who do not generally perceive their own relative risk7,12 but in whom risk perception can be effectively altered by intervention.16 In contrast, parents did not appear to alter their risk perception after the same intervention.16 Hunt and colleagues24 hypothesize that risk perception may not be static and may be modified by events.

Risk perception is a complex process that has been studied in relation to an individual’s adherence to health behaviors. According to the Health Belief model, individuals who recognize their risk for disease will not take action unless they perceive the illness to have serious consequences. Evidence from studies testing the model suggests that perceived susceptibility significantly contributes to preventive health behaviors.28 An individual’s personal sense of vulnerability, however, is thought to be developed through a sense of salience and a personalizing process.29 Salience is determined by acknowledging a family
Relatives do not recognize heredity, age, or sex as risk factors.

Relatives are not often aware of the health of probands. They do not always recognize or collect information on their own family history.

Relatives deny their family history or do not perceive their risk as higher than that of the general population. Relatives tend to stress differences between themselves and the proband or offer counterexamples. Risk perception appears to be a dynamic and variable process.

Risk-reducing behaviors vary according to personal and proband characteristics. Screening remains low across all subpopulations and geographic locations. Smoking is a barrier to screening and other risk-reducing behaviors.

Relatives under treatment are commonly not treated adequately. Risk-reducing behaviors for smoking cessation, weight control, and diet are difficult to sustain.

Healthcare providers infrequently offer screening or advice on healthy lifestyles to family members.

It is unclear why family members do not recognize age, sex, or heredity.

It is unclear how to motivate individuals to collect family health history.

Whether subpopulations of family members, such as siblings or offspring, are more likely to deny their risk is unclear.

It is unclear why healthcare providers do not more frequently offer advice to patients to screen their relatives. Potential barriers may include poor communication between physicians and between physicians and their patients.

It is unknown whether poor medical treatment of risk factors is attributable to the individual's lack of adherence or the physician's failure to manage their patient's condition, or both.

A clear understanding of why healthcare providers do not implement current guidelines is lacking.

A clear understanding of factors that lead to inadequate control of risk factors is warranted. Evaluation of long-term effectiveness of interventions that involve entire families should be performed.

A more in-depth understanding should be explored among healthcare providers regarding the barriers they face in implementing current guidelines. Systems changes that promote guideline compliance should be explored.

Summary of Evidence, Gaps in Literature, and Recommendations for Future Research

<table>
<thead>
<tr>
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<th>Gaps in Literature</th>
<th>Recommendations for Future Research</th>
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<tbody>
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<td>- Relatives do not recognize heredity, age, or sex as risk factors.</td>
<td>- It is unclear why family members do not recognize age, sex, or heredity.</td>
<td>- Research regarding approaches to communicating an appropriate perception, especially for heredity and family history, would be useful.</td>
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<td>- Relatives are not often aware of the health of probands. They do not always recognize or collect information on their own family history.</td>
<td>- It is unclear how to motivate individuals to collect family health history.</td>
<td>- Campaigns such as the US Surgeon General's Family Health Initiative should be evaluated for its effectiveness in facilitating collection of family history information.</td>
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<td>- Relatives deny their family history or do not perceive their risk as higher than that of the general population. Relatives tend to stress differences between themselves and the proband or offer counterexamples. Risk perception appears to be a dynamic and variable process.</td>
<td>- Whether subpopulations of family members, such as siblings or offspring, are more likely to deny their risk is unclear.</td>
<td>- Identification and evaluation of methods to increase risk perception to appropriate levels are warranted. Identifying subpopulations of family members who are more prone to downplaying their risk perception may help to guide interventions.</td>
</tr>
<tr>
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<td>- It is unclear why healthcare providers do not more frequently offer advice to patients to screen their relatives. Potential barriers may include poor communication between physicians and between physicians and their patients.</td>
<td>- Methods to support healthcare providers to increase the rate of screening among relatives of probands should be explored. Research could include how electronic personal health records and reminders can improve communication between physicians and between physicians and their patients.</td>
</tr>
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<td>- Relatives under treatment are commonly not treated adequately. Risk-reducing behaviors for smoking cessation, weight control, and diet are difficult to sustain.</td>
<td>- It is unknown whether poor medical treatment of risk factors is attributable to the individual's lack of adherence or the physician's failure to manage their patient's condition, or both.</td>
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physicians to monitor the condition over time, or both, rather than lack of healthcare access or utilization. In the general US population, rates of control for hypertension in 2005 were only slightly higher than those reported by studies in relatives of probands: 46% for non-Hispanic whites and non-Hispanic blacks and 35% for Mexican Americans. Other national data showed that of those aged ≥20 years with hypertension, 45% of those treated were medically controlled. Evidently, treatment goals among family members are not more commonly reached than in the general population.

Changes in lifestyle such as regular exercise, adoption of a low-fat diet, and cessation of smoking have been implemented successfully by relatives of probands. Not surprisingly, however, certain changes were more difficult than others to sustain, including smoking cessation, regular exercise, and attainment of desired body weight and body mass index. Smoking, in particular, has been reported as a barrier to screening and other risk-reducing behaviors in numerous studies. However, interventions that involve entire families, rather than just individuals with a family history, appear promising in their ability to improve diet, increase physical activity, prevent excessive weight gain, and prevent smoking.

Limitations
Several limitations exist in our study. First, because our search syntax focused on family members, it did not identify studies whose populations are composed of healthcare providers to help provide insight into their knowledge, perception, and management of family members. We attempted to glean available data regarding family members’ interaction with their physicians from studies whose population were composed of family members. A thorough understanding of the perspective healthcare providers will require a different and specific literature search. Second, although a synthesis of current literature provides an important perspective, the majority of studies summarized here lack internal comparison groups. Therefore, comparisons across studies should be made with caution given differences in study design or population characteristics that may affect results.

Conclusions
We have summarized barriers related to key topics that may impede first-degree relatives from engaging in risk-reducing behaviors (Table 1). Such barriers include the following: (1) failure to understand the importance of heredity as a risk factor for heart disease; (2) denial of a family history of premature CHD; (3) inappropriate risk perception or underestimation of one’s own sense of vulnerability; (4) failure of physicians to screen and provide advice; (5) inability to sustain risk-reducing behaviors after implementation; and (6) lack of medical control among those in treatment. Finally, we present recommendations for future research to help further our understanding of how to reduce these barriers such that the burden of heart disease may be reduced among people with a family history of premature CHD (Table 2) and therefore within the community.

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References


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Data Supplement (unedited) at:
http://circ.ahajournals.org/content/suppl/2011/08/18/124.8.958.DC1
Appendix Table 1. Evidence table of studies of relatives regarding their knowledge of risk factors, perception of risk, and implementation of or adherence to risk-reducing behaviors

<table>
<thead>
<tr>
<th>First Author (Year, Setting)</th>
<th>Study Description</th>
<th>Definition of Premature CHD in Proband</th>
<th>Study Description</th>
<th>Definition of Premature CHD in Proband</th>
<th>Study Description</th>
<th>Definition of Premature CHD in Proband</th>
<th>Implementation of and/or Adherence to Risk-Reducing Behaviors</th>
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<tbody>
<tr>
<td>Allen (1996, US)</td>
<td>Examine the prevalence of hypercholesterolemia</td>
<td>Siblings, n=668, asymptomatic, 15% African American, mean age=45</td>
<td>Age &lt; 60 with acute MI, bypass surgery, angioplasty, angina symptoms with ≥1 stenosis of 50% or more, identified during hospitalization</td>
<td>Of those qualifying for dietary treatment (367 of 668), % aware of own: • High cholesterol: 43% • High blood pressure: 52% of sisters, 39% of brothers (p=0.01)</td>
<td>Of those meeting drug treatment criteria (220 of 668), % receiving medication: • 5.5% of sisters • 2.3% of brothers</td>
<td>Or those receiving drug treatment (n=8), only 2 were under control.</td>
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<tr>
<td>Allen (1998, US)</td>
<td>Determine risk factors, and knowledge, attitude and beliefs of CHD risk</td>
<td>Offspring, n=87, 72% White, 36% male, mean age=37</td>
<td>Mothers age &lt;60 with coronary bypass graft surgery or documented history of MI, identified from clinical trial</td>
<td>% identified risk factors for CHD: • Diet: 76% • Smoking: 47% • Lack of exercise: 34% • Stress: 34% • Heredity: 28% • High cholesterol: 25% Unsere what causes high cholesterol: 17% Recognized heredity as risk factor for high blood cholesterol: 11%</td>
<td>Perceived risk for MI as lower than others: 67% Less than average concern for future heart attack: 58% Age of mother’s cardiac events not associated with risk perception.</td>
<td>% offspring who had: • Regular source of care: 80% • Exam, past 2 years: 69% • Blood pressured checked: 94% • Cholesterol checked, past year: 34% • Never checked cholesterol: 30%.</td>
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<td>Becker (1987, US)</td>
<td>Examine perceptions of CHD risk and lifestyle changes</td>
<td>Siblings, n=80, 45% male, mean age=46,</td>
<td>Age &lt;60 and hospitalized with MI, bypass surgery or angiographically documented unstable angina, identified during hospitalization</td>
<td>Knowledge scores associated with higher education. % aware of condition in proband: • Surgery: 100% • Smoking: 94% • Hypertension: 35% • Angina: 30% • High cholesterol: 2%</td>
<td>Perceived risk as lower than others: 67% Perceived risk not associated with knowledge, age, years of education, index case diagnosis, or number of prior events in the family.</td>
<td>No statistically or clinically significant differences in smoking, body weight, exercise, salt/fat intake, stress level or composite lifestyle scores after four months of event in proband.</td>
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<tr>
<td>Becker (1988, US)</td>
<td>Determine prevalence and awareness of CHD risk factors</td>
<td>Siblings, n=172, asymptomatic, 99% White, 51% male, mean age=45</td>
<td>Patients with documented coronary heart disease &lt;60 years of age, identified during hospitalization</td>
<td>% aware of own hypertension: • 35% of brothers • 53% of sisters</td>
<td>% aware of own hyperlipidemia: • 27% of brothers • 25% of sisters</td>
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Determine nurse management (NURS) or enhanced primary care (EPC) can improve proportion reaching treatment target.

Siblings n=267, without known CHD or life-threatening conditions, demographic balanced between arms

Age < 60 with acute MI and pathological Q waves and elevation of creatinine kinase twice above normal levels, or revascularization (angioplasty or bypass), or angina with 50% stenosis, identified during hospitalization

Adjusted OR of achieving LDL-C goals in the NURS: 4.1 (95% CI: 1.6, 10.9)
Dietary profile improved in the NURS.
No changes in BMI, body weight or physical activity in either group. % subjects started on treatment:
• NURS: 45.2%
• EPC: 16.7%
Only drug treatment accounted for achieving lower LDL-C levels.

To test an educational intervention to promote screening of first degree relatives of patients with premature CHD

First-degree relatives, n=64, 71% male, mean age =50

Men < 55 years and women < 65 years with acute coronary surgery, acute MI, dilation of coronary artery, bypass, identified after hospitalization

% “had an exam because of family history”:
• Siblings: 24%
• Children: 9%
% “thought about” getting an exam:
• Siblings: 15%
• Children: 33%
% “spoke about” getting an exam:
• Siblings: 7%
• Children: 15%
% advised to get exam but did not:
• Siblings: 3%
• Children: 12%

Determine whether youth characteristic s, peer, family, and community are related to physical activity of young adolescents

Children recruited from elementary schools, n=113, 53% male, mean age=12

Fathers < 55 years and mothers < 65 years with angina, angioplasty, MI, or bypass, screened through children recruited in elementary school

Geographical region and father’s physical activity significantly predicted child’s physical activity.
Children living in the coastal region were less likely active than other children. Children were more active when they had active peers only when the youth were midpubertal or when they were in the coastal region.

Analyze risk profile and utilization of preventive strategies

Siblings, n=580, 47% male, mean age=55

First MI < age 60 among residents of Augsberg, Germany

% hypertensives receiving treatment: 92%
% treated reaching target for:
• Hypertension: 31%
• Hypercholesterolemia: 7%

Estimate, physicians’ Male Offspring,

Men age ≤ 55 with MI or bypass,

% aware of:
• Hypertension: 7.6%
Half was highly concerned about their

At baseline, 1/3 to 1/2 attempted to stop smoking, adopted low-fat diet, exercised,
<table>
<thead>
<tr>
<th>Country</th>
<th>Description</th>
<th>Sample Details</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Canada     | Promotion of healthy lifestyle and counseling and assess personal health initiatives by offspring | n=571, 100% men, mean age=32 recruited from cardiac rehabilitation program                      | • High cholesterol: 10.8%  
• High triglycerides: 5.8%  
After 2 years, 79.2% indicated that their health awareness had been enhanced by their initial visit.  
Heart health, even  
maintained body weight.  
• % remained smokers: 23%  
• % continued to exercise: 25%  
• % see doctor regularly: 91%  
• % had lipids checked: 53%  
After educational program, higher proportion exercised regularly and had suitable body weight. |
| Langer (1994, Canada) | Assess awareness and management of risk factors | Offspring, n=219, 44% male, median age=20 Men age < 50 or women age < 60 with MI or at least 50% diameter stenosis | % listed as risk factors:  
• Diet: 99%  
• Smoking: 58%  
• Stress: 57%  
• Lack of exercise: 21%  
• Heredity: 13%  
• Hypertension: 9%  
Level of worry significantly related to only dietary change.  
% who worried less changed diet: 52%  
% who worried more changed diet: 76%  
% measured cholesterol past 3 years: 44%  
% changed diet in past 2 years: 67%  
% measured blood pressure in past year:  
• Men: 57%  
• Women: 80%  
Smokers less likely to improve their health in the preceding years. |
| Metzger (2002, Germany) | Determine management of hypertension among hypertensive siblings compared to hypertensives from general population | Siblings, n=524, 46% male, without history of MI, mean age=55 MI at age < 60, resident of Augsburg, Germany and 3802 hypertensives from general population | % Male hypertensive siblings aware of own hypertension: 63.6% compared to 55.3% of hypertensive individuals from general population  
% of women aware of own hypertension did not differ between siblings and general population |
| McCance (1985, US) | Test nursing intervention’s ability to reduce CHD risk | First-degree relatives, n=58, demographic balanced between experimental and control groups | Experimental siblings demonstrated greater susceptibility and seriousness compared to controls.  
Control siblings showed undesired direction for all health beliefs.  
% perceiving lifetime risk of MI to be equal or more than the average:  
• Women with FHMI: 60%  
• Women with no FHMI: 47%  
• Men with FHMI: 75%  
• Men with no FHMI: 48%  
Experimental subjects reduced consumption of alcohol and high-fat meats compared to control group.  
Younger age of death correlated with greater adherence to blood pressure screening.  
Parents who believed CHD is more serious were more likely to obtain serum cholesterol measurements.  
Smokers less compliant to blood pressure screening. |
| Patel (2007, US) | Assess association between family history of premature MI and CVD risk factor burden, risk | First-degree relatives recruited from Dallas Heart Study with self-report of family  
Men age <50 and women <55 with MI | % of women with FHMI were more likely to smoke than those without FHMI, an association not seen in men.  
Men with FHMI were less likely to be sedentary than men without FHMI, an association not seen in women. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Tonstad (2002, Norway) | Determine the feasibility of family screening and proband characteristics of associated with screening of children or siblings. | History of MI, n=2402, 50% African American, 45% male, mean age=40 | Half of sample believed heredity was important for their CHD. Greater % of men than women believed that lifestyle was important for CHD. | Proband characteristics predicting screening of children:  
- Female  
- Nonimmigrant status  
- Low educational  
Proband characteristics predicting screening of siblings:  
- Age  
- Female  
- Nonimmigrants  
- Nonsmokers  
<½ of brothers and sons completed the screening. Sisters and daughters more likely to complete screening than were brothers and sons. |
| Yanek (1998, US) | To examine deviations in prevalence of hypertension and associated coronary risk factors in healthy siblings of persons with documented CHD along with their levels of awareness, treatment, and control of the risk factor from national reference norms. | Siblings, n=856, 49% male, 19% African American, mean age=46 | % of 380 hypertensive siblings aware of own hypertension: 60%  
Hypertensive sibling women were slightly but not significantly more likely to be aware than men.  
African Americans were slightly but not significantly more likely to be aware of white siblings.  
Older siblings were somewhat more likely to be aware of their hypertension.  
% of 380 hypertensive siblings treated with medication: 45%  
% treated under control: 16%  
Hypertensive sibling women were significantly more likely to be treated and under control.  
African Americans not significantly more likely to be receiving treatment than white siblings.  
Older siblings (45-59) were significantly more likely to be treated and controlled.  
Education level did not influence rates of treatment, or control.  
Few hypertensive siblings reported lifestyle efforts to treat high BP. |
### Appendix Table 2. Evidence table of studies regarding management of relatives of probands by healthcare providers

<table>
<thead>
<tr>
<th>First Author (Year, Setting)</th>
<th>Objectives</th>
<th>Relation</th>
<th>Proband Definition</th>
<th>Selected Findings</th>
</tr>
</thead>
</table>
| Becker (1998, US)            | Determine nurse management (NURS) or enhanced primary care (EPC) can improve proportion reaching treatment target. | Siblings       | Age < 60 with acute MI and pathological Q waves and elevation of creatinine kinase twice above normal levels, or revascularization (angioplasty or bypass), or angina with 50% stenosis, identified during hospitalization | Adjusted OR of achieving LDL-C goals in the NURS: 4.1 (95% CI: 1.6, 10.9)  
Dietary profile improved in the NURS.  
No changes in BMI, body weight or physical activity in either group.  
% subjects started on treatment:  
- NURS: 45.2%  
- EPC: 16.7%  
Only drug treatment accounted for achieving lower LDL-C levels. |
| De Sutter (2003, Europe)     | Determine whether guidelines for screening of relatives are followed, and if so, how effectively relatives are being managed. | First-degree relatives, n=3322, 47% male, mean age of siblings=51, mean age of children=29 | Men age <55 and women age <65 with bypass, angioplasty without bypass, acute MI or ischemia without bypass or angioplasty, identified through medical records |  
% screened for CHD risk factors:  
- Siblings: 46%  
- Children: 29%  
% screened due to CHD in family:  
- Siblings: 11%  
- Children: 7%  
% had cholesterol measured:  
- Siblings: 69%  
- Children: 37%  
% given lifestyle advice:  
- Siblings: < 50%  
- Children: < 25%  
Advice on healthier lifestyle was given more frequently in siblings than in children. |
| Study Authors (Year, Location) | Determine an educational program's ability to increase screening among relatives | First-degree relatives, n=174, intervention group (71% male, mean age=50); usual care (64% male, mean age=51) | Men age <55 and women age <65 with bypass, angioplasty, acute MI or ischemia, identified during hospitalization | % screened at baseline:  
• Siblings: 25% in usual care; 23% in intervention  
• Offspring: 17% in usual care; 4% in intervention  
% screened during study period:  
• Siblings: 29% in usual care; 73% in intervention  
• Offspring: 15% in usual care; 52% in intervention |
|---|---|---|---|---|
| Debruyne (2004, Belgium) | To test an educational intervention to promote screening of first degree relatives of patients with premature CHD | First-degree relatives, n=197, mean age of siblings=50; mean age of children=27 | Men < 55 years and women < 65 years with acute coronary surgery, acute MI, dilation of coronary artery, bypass. identified through cardiologist | % “had an exam because of family history”:  
• Siblings: 24%  
• Children: 9%  
% “thought about” getting an exam:  
• Siblings: 15%  
• Children: 33%  
% “spoke about” getting an exam:  
• Siblings: 7%  
• Children: 15%  
% advised to get exam but did not:  
• Siblings: 3%  
• Children: 12%  
% given advice regarding lifestyle changes:  
• Siblings: 30%  
• Children: 15% |
| Debruyne, (2006, Belgium) | Determine an educational program’s ability to increase screening among relatives | First-degree relatives, n=174, intervention group (71% male, mean age=50); usual care (64% male, mean age=51) | Men age <55 and women age <65 with bypass, angioplasty, acute MI or ischemia, identified during hospitalization | % screened at baseline:  
• Siblings: 25% in usual care; 23% in intervention  
• Offspring: 17% in usual care; 4% in intervention  
% screened during study period:  
• Siblings: 29% in usual care; 73% in intervention  
• Offspring: 15% in usual care; 52% in intervention |
| Hengstenberg (2001, Germany) | Analyze risk profile and utilization of preventive strategies | Siblings n=580, 47% male, mean age=55 | First MI < age 60 among residents of Augsburg, Germany | % hypertensives receiving treatment: 92%  
% treated reaching target for:  
• Hypertension: 31%  
• Hypercholesterolemia: 7% |
| Kavanagh (2000, Canada) | Estimate, physicians’ promotion of healthy lifestyle and counseling and assess personal health initiatives by offspring | Male Offspring n=571, 100% men, mean age=32 | Men age ≤ 55 with MI or bypass, recruited from cardiac rehabilitation program | % see doctor regularly: 90.5%  
% who see doctor regularly and:  
• Had lipid measurements: 53%  
• Advised of results: 9.5%  
• Advised on low-fat diet: 11%  
• Recommended exercise: 18%  
% with hypercholesterolemia and  
• Received nutritional counseling: 60%  
• Blood pressure screening: 76%  
• Provided results: 12% |
Metzger (2002, Germany)

Determine management of hypertension

<table>
<thead>
<tr>
<th>Siblings</th>
<th>MI at age &lt; 60, resident of Augsberg, Germany</th>
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<tbody>
<tr>
<td>n=524, 46% male, without history of MI, mean age=55 and 3802 hypertensives from general population as controls</td>
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</tbody>
</table>

% hypertensive subjects treated and under control:
- Siblings: 9% males; 13% females
- General population: 13% males; 14% females

Physicians detected hypertension more often in male siblings of MI patients than in general hypertensive population. But percentage under controlled treatment similar among siblings as among general population. In families with heart disease, reinforcement of medical control was no greater than in general population.