Health Family Trees: A Tool for Finding and Helping Young Family Members of Coronary and Cancer Prone Pedigrees in Texas and Utah

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Abstract: We report on the feasibility and utility of a new approach for identifying the small percentage of families in the general population with strong familial predisposition to early coronary heart disease, strokes, and common familial cancers (breast, colon, lung), using the "Health Family Tree," a medical family history. A total of 24,332 "trees" were completed by parents and students in 37 high schools in 14 urban and rural communities in Texas and Utah during the years 1980–86. Completed "trees" were obtained from 68 per cent of all enrolled students.

High-risk families, included 1,796 families with early coronary disease (7.5 per cent of all student families or 3.7 per cent of their parents' families), 870 stroke families (3.6 per cent), and 415 cancer prone families (1.7 per cent). Among these 3,081 high-risk families there were 8,245 family members already reported to have been diagnosed by a physician to have the familial disease of interest and 43,269 high risk unaffected siblings and offspring of these persons. The average cost per identified high-risk unaffected person was under $10. We conclude that the "Health Family Tree" is a feasible and cost-effective way to find high-risk families. (*Am J Public Health* 1988; 78:1283–1286.)

Introduction

About 5 per cent of families in the general population account for approximately 50 per cent of coronary deaths before age 55.[1–3] In these high-risk pedigrees, first-degree relatives of early coronary victims have a three-fold to ten-fold increased risk of developing early coronary events.[3] Some of them carry dominant genes that lead to heart attacks before age 45 in virtually all males in the current generations unless preventive measures are consistently followed for many years.[4]

Hypercholesterolemia, cigarette smoking, and hypertension are modifiable risk factors that play a major role in most of these coronary prone families.[1] Successful intervention probably yields greater dividends in these persons with strong familial predisposition than in the general population.[1,4,5]

While coronary heart disease is probably the most common chronic disease in which strong familial predisposition plays an important role, there are other families who have strong predispositions to strokes[6] which could be prevented through effective blood pressure screening and treatment. There are also rare but important families with strong family tendencies toward breast and colon cancer,[7] which are sometimes dominant inherited traits. Mammography, colonoscopy, and other proven screening tools can detect these cancers at an early curable stage.

Physicians dealing with high-risk families consistently find most high-risk persons in these disease prone pedigrees are *not* receiving the benefit of established risk reduction early enough to effectively prevent or delay serious disease consequences. There is a need for efficient, reliable, practical, and inexpensive methods for finding, educating, and helping high-risk families. In this report we describe the "Health Family Tree" project involving high school students, which can help meet these important needs.

We previously reported the validity and predictive value of coronary disease data from the "Health Family Tree" questionnaires.[3] When compared with independent medical data from a sample of 1,273 relatives enumerated in "tree" questionnaires, we found 79 per cent sensitivity, 91 per cent specificity, 67 per cent predictive value of a positive report, and 96 per cent predictive value of a negative report.[3] Young adults in these coronary prone families were found to have a six- to 10-fold increased risk of future coronary disease.[3] We now report the practical feasibility, utility and cost efficiency of using this approach to find high-risk families.

Methods

Recruitment and Data Collection

The "Health Family Tree" is a medical family history questionnaire that collects detailed disease and risk factor information of siblings, parents, aunts and uncles, and grandparents of high school students enrolled in required health education classes in selected school districts in Texas and Utah. Each "tree"questionnaire is a large fold-out chart, the size of a road map (two feet by three feet). A box of questions, as shown in Figure 1, is provided for each relative. Boxes are arranged on the questionnaire in the form of a pedigree diagram. The requested data are entered into a computer.

High schools are invited to use this questionnaire as part of the curriculum of the required health education course. It serves both as a tool for educating these high school students concerning disease risk in their own families and as a method for identifying high-risk families who can be encouraged to visit health professionals for evaluations and assistance in risk reduction. A suggested lesson plan is provided along with all of the materials necessary for completing this project (at no cost to the school districts).

Students are invited to participate regardless of whether they live with natural, adoptive, or step-parents. The "tree" questionnaire reports whether or not the student is a blood relative of each parent and also if aunts, uncles, and grandparents are blood relatives of the listed mother and father. Genetic risk is assessed separately for each listed parent and may help index high-risk parental pedigrees even if the

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MOTHER OR GUARDIAN

Blood relative of person #1 Yes ☐ No ☐ Male ☐
In-state resident? Yes ☐ No ☐ Female ☐
Living? Yes ☐ No ☐
Year of birth _____ Age (now or at death) ____

Causes of death _____

_____

Number of natural children of this person _____
Has he/she ever been told BY A DOCTOR that he/she suffers from any of the following health problems?

YES	NO	DON'T KNOW	AGE AT FIRST DIAGNOSIS
☐	☐	☐	_____Heart attack
☐	☐	☐	_____Angina pectoris
☐	☐	☐	_____Coronary bypass surgery
☐	☐	☐	_____Stroke
☐	☐	☐	_____Breast cancer
☐	☐	☐	_____Lung cancer
☐	☐	☐	_____Colon cancer
☐	☐	☐	_____Other cancer (Excluding skin cancer):
☐	☐	☐	_____High blood pressure
☐	☐	☐	_____High blood cholesterol
☐	☐	☐	_____Diabetes

CIGARETTE SMOKING

☐ Smoker: Has smoked cigarettes regularly for at least 1 year
☐ Ex-smoker: Stopped for at least 1 year after smoking regularly
☐ Non-smoker: Never smoked cigarettes regularly
☐ Don't know

IF SMOKER OR EX-SMOKER mark average amount smoked
☐ Less than 1 pack a day
☐ About 1 pack a day
☐ More than 1 pack a day

USUAL WEIGHT	(MARK BOTH COLUMNS)	GREATEST WEIGHT
☐	Slender or average	☐
☐	10 - 49 lbs. overweight	☐
☐	50 - 99 lbs. overweight	☐
☐	Over 100 lbs. overweight	☐
☐	Don't know	☐

Alcoholic beverages (beer, wine, cocktails)? ☐ Regularly ☐ Sometimes ☐ Never ☐ Don't know

Vigorous routine exercise at least 3 times per week ?
☐ Yes ☐ No ☐ Don't know

FIGURE 1—Sample Health Questionnaire Box Filled Out for Each Family Member (student, parents, siblings, aunts, uncles, grandparents)
SOURCE: Hunt SC, *et al.* Ref. 3. (Reprinted with permission of authors and publisher.)

student is adopted and does not share their genetic risk. If they wish, students may fill out extra "trees" to list information on biological and non-biological parents when both are known.

In Utah high schools, the Health Family Tree has been administered as the central focus of four or five class periods. In Texas high schools, health classes have used the Health Family Tree as a part of a 15-lesson curriculum unit on heart diseases.[8,9] Subsequent cognitive reinforcement is also provided in other classes in Texas.[10,11] In both states, high school teachers explain the basic vocabulary and concepts regarding heart attacks, strokes, risk factors, and heredity. Students take home the questionnaire and a consent form that must be signed by their parents. Teachers provide alternative assignments for students whose parents decline to participate.

Many students do not know much of the information requested on this form, but learn it from their parents. The family is given approximately one week to complete this information and is encouraged to contact relatives by telephone when necessary to obtain accurate information.

In class, students transcribe the information from the detailed questionnaire onto optical scanner forms and fill out a demographic questionnaire to indicate their race, current knowledge about familial disease risk, type of parent (natural, adoptive, step, or guardian), and educational status of each parent.

Computer and Statistical Methods for Identifying High-Risk Families

Optical scanner forms are analyzed at the University of Utah Cardiovascular Genetics Research Clinic; data are scored for each major disease and risk factor to indicate significant familial aggregation.

As previously described,[3] the family history score (FHS) compares the observed (O) to expected (E) number of family members with the disease, using the formula:

$$FHS = \frac{(|O-E| - 1/2)}{\sqrt{E}} \frac{|O-E|}{O-E}. \text{ If } |O-E| \leq 1/2 \text{ then}$$

$$FHS = 0.$$

The number of expected relatives is calculated by applying age-sex specific disease incidence rates from the general population of all persons in Health Family Tree data to the age and sex distribution of relatives enumerated separately for paternal and maternal sides of each student's family. Even one semester of "tree" data has provided stable coronary incidence rates (data available on request to author).

High-risk families were selected as those with FHS ≥ 1.0 that also had at least two relatives with the disease. For coronary disease, high-risk families also had to have at least one *early* disease case (diagnosis before age 55).

A computer report mailed directly to each student family gives feedback and advice tailored specifically to disease and risk factor data reported on the "Health Family Tree" questionnaire. Reported high-risk families are strongly encouraged to take the family history analysis to their physicians to discuss their apparent positive family history.

A special roster of high risk-families is also prepared and used in additional programs being piloted to help high-risk individuals. In Texas, special educational intervention and behavior change programs have been convened in the evenings by Baylor College of Medicine at local schools for parents and students. In Utah, public health nurses from the state and local health departments visit the homes of high-risk families to explain their high family risk and the potential benefits of further screening and risk evaluation with the help of their personal physicians. Some of these families are invited to attend the Cardiovascular Genetics Research Clinic at the University of Utah to study their familial disease mechanisms.

TABLE 1—"Health Family Tree" Summary Data

	Texas		Utah		Total	
Years of Participation	1980–86		1983–86		1980–86	
Communities	4		10		14	
School Districts	5		9		14	
Schools	7		30		37	
Students Enrolled in Health Education	14,071		21,911		35,982	
"Trees" Collected	9,287		15,045		24,332	
Response Rate (%)	66		69		68	
High-Risk-Families	N	(%)	N	(%)	N	(%)
Coronary	789	(8.5)	1,007	(6.8)	1,796	(7.5)***
Stroke	399	(4.3)	471	(3.2)	870	(3.6)
All Atherosclerosis	1,188	(12.8)	1,478	(10.0)	2,666	(11.1)
Breast Cancer	56	(0.6)	115	(0.8)	171	(0.7)
Colon Cancer	18	(0.2)	62	(0.4)	80	(0.3)
Lung Cancer	65	(0.7)	99	(0.7)	104	(0.7)
All Cancer	139	(1.5)	276	(1.9)	415	(1.7)
Total High-Risk Families	1,327	(14.3)	1,754	(11.9)	3,081	(12.7)
Affected Family Members*	3,559		4,686		8,245	
High-Risk 1° Relatives**	16,661		26,608		43,269	
Total Relatives Surveyed	126,675		229,057		355,732	

*Persons in high-risk families who already have the disease.

**Persons in high-risk families with a strong positive family history who do not have the disease but have a 3- to 10-fold increased risk of developing it in the future.

***Per cent of all *trees* are listed in parentheses. Family history information is evaluated separately for the families of the student's father and mother. Thus the per cent of all adult nuclear *families* would be about half the per cent listed.

Results

Summary descriptive data are presented in Table 1. Broad experience was gained in collecting "trees" from 37 high schools in 14 communities. A response rate of about two-thirds of enrolled students was consistently obtained in both Utah and Texas. This represents family history data collected with sufficient completeness to provide meaningful information. Those counted as nonrespondents either elected not to participate in the project or provided data inadequate for analysis and evaluation.

Response rates were slightly higher in students whose parents attended college (72 per cent in Utah and 71 per cent in Texas) when compared to students whose parents had not obtained a high school diploma (67 per cent in Utah, 61 per cent in Texas). Students living with natural biological parents had somewhat higher response rates (Utah 71 per cent, Texas 69 per cent) when compared to students who lived with adoptive parents (Utah 67 per cent, Texas 68 per cent) or step-parents (Utah 65 per cent, Texas 66 per cent). Students living with a guardian had the lowest rates (Utah 55 per cent, Texas 51 per cent). In Texas, where approximately one-half of the students were White and one-fourth each were Black or Mexican American, the response rate by race was 73 per cent for White, 59 per cent for Black, and 57 per cent for Mexican American.

As shown in Table 1, 2,666 families were reported showing significant aggregations of early coronary disease or stroke; 415 families were reported with high risk for cancer of the breast, colon, or lungs. The percentage of all students having families with increased risk of these diseases was very similar between Utah and Texas. While a small percentage of total families was found to be at high risk of these diseases, once found, each high-risk family had an average of 2.7 affected members who already had the disease and 14 currently unaffected high-risk first-degree relatives. A total of 43,269 high-risk persons were identified. Most of these were youth including the high school students, their siblings, and their first cousins (offspring of affected aunts and uncles enumerated on the "tree").

Based on questionnaires completed at the same time as the "Health Family Tree," only 28 per cent of high school students and parents who were members of high-risk pedigrees reported that they were already getting help from physicians to try to reduce their markedly elevated risk.

In 1987, the direct costs for the project in Utah collecting 10,000 "trees" was $83,000 or about $8.30 per tree. Costs included $15,900 for printing one tree and 11 scanner forms per student, $7,700 for optical scanning to enter data into the computer, $5,600 for computer costs to analyze 10,000 family histories and print tailored reports for each family, $2,200 for postage to mail reports to families, and $51,600 personnel salaries and benefits (full-time public health nurse and part-time secretaries and computer personnel).

For 1,190 high-risk families, the cost is $70 per family identified. For 18,088 first degree relatives of affected persons in high-risk families, the cost is $4.60 per relative. If half of them actually have the disease prone gene (e.g., heterozygotes for familial hypercholesterolemia), the cost per asymptomatic person with very high disease risk is $9.21.

Discussion

We have demonstrated the feasibility of collecting "Health Family Trees" in a large sample of public high school students including high and low socioeconomic strata, urban and rural communities, and minority races. The enthusiasm and interest of the teacher appeared to be the major determinant of participation rates. Some teachers consistent-

ly involved 95 per cent of enrolled students and others consistently less than 40 per cent.

As reported earlier, the data can be used as a screening tool. About 33 per cent of reported "heart attacks" are not confirmed as coronary artery disease.[3] They were usually other heart problems such as valvular heart disease and can usually be detected by mail or phone. Once a high-risk family is confirmed, it contains about 14 asymptomatic high-risk persons who are first degree relatives of multiple disease cases. Most of them are children and young adult offspring of persons with early coronary disease. Instituting screening and preventive measures in this timely age group should help prevent or delay coronary disease manifestations.

Validation studies have not been completed for reported familial aggregations of cancer from the "Health Family Tree." Verified high-risk cancer families could also benefit from preventive measures (smoking avoidance) or screening programs (mammography, colonoscopy, etc.).

The cost per identified high-risk person was less than $10. The major factors in cost savings were free labor (students, parents, teachers, volunteer helpers) and automated data entry (optical scanner forms) and automated reporting (computer generated reports tailored to family history scoring results).

We also have administered the same questionnaire to research clinic patients and entered them into a computer using keyboard entry. The costs for data input and secretarial labor alone exceed $25 per "Health Family Tree" using this approach. This level of cost would be reasonable and justified in a diagnostic clinic setting evaluating patients with early coronary disease who might have a positive family history. This could open avenues for helping unaffected high-risk family members. A revised version of "Health Family Tree" materials designed for use with individual patients encountered in normal inpatient and outpatient settings will soon be available.

The educational benefit to students and their families is difficult to quantify but should not be overlooked. Teachers, students and parents predominately gave very positive reactions to the exercise. Several hours of discussion of disease and risk factors in close relatives should reinforce major concepts for students better than textbooks and abstract classroom activities.

The ultimate success of any screening project depends on the effectiveness of follow-up. Will high-risk student families seek the help of their own physicians as emphatically directed by their"Health Family Tree" analysis report? If they do see their physicians, will they begin and maintain effective risk-reduction measures? Will serious familial diseases really be prevented or delayed? The answers to these questions are not yet known. We suspect that much remains to be accomplished before effective follow-up and risk reduction become the rule rather than the exception. As a large number of high-risk families are identified and encouraged to seek this help, physicians and other health professionals should be motivated to become more involved in risk reduction for high-risk families. At Baylor College of Medicine, the University of Utah Medical School, and the Utah Department of Health (Family High Risk Program), videotapes, brochures, and other educational materials have been developed to begin meeting these important needs.

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Requests for Materials

The Health Family Tree forms are protected by copyright. Individual copies may be obtained from either Texas or Utah co-authors by sending a check for $5.00 (to cover materials, postage, and handling). Upon request, prices can be quoted for large quantities that could be used for full implementation of this approach in other locations.

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