



Introduction

Community education is an essential component of the Guilford Genomic Medicine Initiative (GGMI). The goal of GGMI is to develop a model to integrate genomic medicine services into a community health care system. A core component of this model is to collect and use family and personal medical history to stratify patients into groups based on their risk for three diseases; breast and ovarian cancer, colon cancer and thrombophilia. This information can then be used to improved health care management for those at increased risk.

To ascertain what the residents in Guilford County know about 1) family health history, 2) patterns of inheritance, 3) screening for common diseases, 4) genetic testing, and 5) the laws prohibiting genetic discrimination, we conducted a random-digit-dialing survey in the summer of 2006.

We focused on these topics for the following reasons:

- 1) Currently, family history is the best screening tool we have to identify people at increased risk for common diseases.^{1,2}
- 2) Social relationships, rather than genetic relationships, are a better predictor of whose health history a person will know, or think to collect.³
- 3) According to the Health Belief Model, behavior change only occurs if a person believes there is something they can do to modify their risk for disease.⁴ As behavior change is necessary for genomic medicine to succeed, we included questions about screening and genetic determinism.
- 4) Previous studies and our focus group findings suggest that many community members believe that genetic tests exist for most of the common chronic diseases.
- 5) The media often focuses on the potential for genetic discrimination.⁵ Fear of genetic discrimination is also thought to be a barrier to utilizing genetic information.

To determine what characteristics affect a person's knowledge of these topics, and to develop targeted educational messages we also collected demographic data.

The following is a summary of our survey results and education plan.

Methods

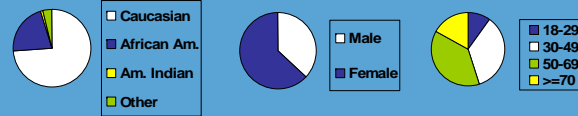
- We conducted a random-digit dialing telephone survey of residents in Guilford County, North Carolina in the summer of 2006.
- A list of randomly generated telephone numbers was obtained from Marketing Systems Group, Inc.
- The Troidahl and Carter table (1964) was used to identify the eligible adult in each household. The tables are based on the number of males, and individuals over the age of 18 in the home. Participants had to be English speaking residents of Guilford County.
- Each working number was called three times before it was removed from the list.
- A total of 1136 interviews were completed. Data was entered into a web-based database.
- An overall knowledge score was created by assigning one point for each correct answer. The highest possible score was 16.
- An experience score was created by assigning one point when a respondent said he/she 1) knew someone who had seen a geneticist or genetic counselor, 2) knew someone with a genetic disorder, or 3) knew about genetic testing for disorders that occur in adults. Zero points were given if their response to these questions was "no". Therefore, the experience score ranged from 0 to 3.
- Demographic information included year of birth, race, gender, education, and church attendance.
- Descriptive statistics were used to characterize respondents.
- Differences were measured by χ^2 tests for categorical data and ANOVA for group means.

Results

We reached 5195 households. A total of 1136 individuals completed the survey for a response rate of 22%.

Respondents were predominantly Caucasian (74%) females (63%), with a mean age of 52 years (sd = 16.386, range 18 – 95).

Demographic Data



Knowledge Questions

(References provided for questions taken or adapted from previous studies.)

- | Question | Percent Correct |
|---|-----------------|
| 1. Most health problems are caused by a combination of genes, the environment, and lifestyle. (T) | 92% |
| 2. Cancer screening is only recommended for people with a family history of cancer. (F) | 87% |
| 3. If you have a family history of a disease you are more likely to get the disease yourself. (T) | 84% |
| 4. Each of us has variations in our genes that make it more likely we will get certain diseases. (T) | 84% |
| 5. A person's race and ethnicity can affect how likely they are to get a disease. (T) | 84% |
| 6. It is important to know how old your relatives were when they got a disease. (T) | 79% |
| 7. You can only inherit breast cancer from your mother's side of the family. (F) | 74% |
| 8. If you have a variation in a gene that can cause cancer, there is nothing you can do to prevent getting cancer. (F) | 73% |
| 9. In North Carolina it is against the law for employers to treat one person differently than another based on the results of a genetic test. (T) | 71% |
| 10. It is possible to do a genetic test for most of the common diseases – such as heart disease, diabetes, high blood pressure and others. (F) | 58% |
| 11. Genes play a part in almost all diseases. (T) | 58% |
| 12. If a person has good health insurance through their employer it is legal for the insurance company to deny coverage based on the results of a genetic test. (F) | 52% |
| 13. Genetic tests can be done to find out how a person will react to certain drugs. (T) | 37% |
| 14. People are genetically more similar to their parents than to their brothers or sisters. (F) | 24% |
| 15. All women would benefit from getting a genetic test for breast cancer. (F) | 18% |
| 16. Everyone with a family history of a disease would benefit from getting a genetic test for that disease. (F) | 11% |

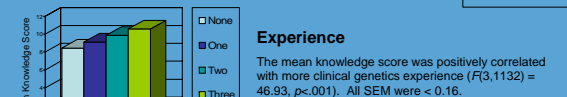
Percent Correct

Mean Knowledge Score

The overall mean knowledge score was 9.44 (sd=2.109, range 2 – 16).

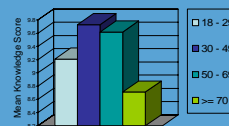
Education

The mean knowledge score was positively correlated with education ($F(3,1122) = 54.31, p < .001$). All standard errors of the mean (SEM) were < 0.5.



Experience

The mean knowledge score was positively correlated with more clinical genetics experience ($F(3,1132) = 46.93, p < .001$). All SEM were < 0.16.



Age

The mean knowledge score for individuals age 70 and above was significantly lower than for individuals between the ages of 30 and 69 ($F(3,1104) = 11.71, p < .001$). All SEM were < 0.6.

Race

While the actual difference is small, the mean knowledge score for Caucasian respondents ($m = 9.60, sd 2.1, range 2 - 15$) was higher ($p = .001$) than the mean knowledge score for African American respondents ($m = 9.07, sd 2.1, range 2 - 16$). All SEM were < 0.14.

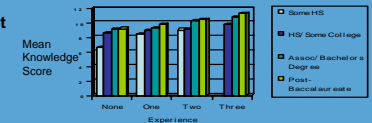
Gender

There was no statistically significant difference between the mean knowledge scores for males ($m = 9.53, sd = 2.101, range 2-16$) and females ($m = 9.39, sd = 2.082, range 2-15$).

Demographic Data & Church Attendance

Approximately 49% of African American respondents attend church weekly compared to 36% of Caucasian respondents ($\chi^2, p < .001$). More women (71%) than men in our sample population attend church weekly, and 65% of weekly church goers were 50 years of age or older.

Experience & Education



A 4 X 4 between-subjects factorial ANOVA was calculated comparing mean knowledge scores for subjects based on their educational background and experience. The correlation between education and experience as they relate to the mean knowledge score was significant ($F(8,1111) = 2.12, p < .05$).

Conclusions

The majority of residents in Guilford County, NC know that susceptibility to disease is based on family history, race, lifestyle, the environment, variations in genes and the age at which a disease was diagnosed. Most are also aware that everyone should be screened for cancer. This suggests that past education efforts have been successful in communicating these concepts.

However, residents appear to be less sure about patterns of inheritance and which family members they need to talk to regarding their health history. Over 25% appear to believe in genetic determinism. Many respondents perceive that genetic tests are already available for most diseases, and just over half know about genetic discrimination laws. These topics will be addressed in our educational programs.

The other information we found helpful in developing our approach to community education included the fact that knowledge scores were positively correlated with education, experience and age. However, it is not possible to say whether this represents a cause and effect relationship.

Education Plan

1. Build on people's knowledge that diseases "run in families".
2. Develop experiential learning opportunities such as having participants record their own family health history.
3. Work with parish nurses, especially in African American churches to provide resources and presentations to the members of their congregations.
4. Communicate the limitations of genetic testing and the fact that most existing tests are only appropriate for a subset of people.
5. Reinforce the idea that there are things people can do to reduce their risk for disease even if they have a genetic predisposition.
6. Include information about the existence of state and federal legislation to prevent genetic discrimination.

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