



Introduction

The Guilford Genomic Medicine Initiative (GGMI) is a demonstration project. The goal is to create a genomic medicine practice model that works in the community health care setting in Guilford County. As part of this project, GGMI staff is developing a computer-based tool to collect and analyze family and personal health history information. Staff is working on the development of the clinical practice model and creating the infrastructure necessary to support the primary care practices involved in this project. We are also developing community and professional education programs.

In an effort to develop educational resources for primary health care providers in Guilford County, GGMI staff reviewed the available literature and existing education modules.¹ We also conducted key-informant interviews. Based on this information we developed four on-line, case-based educational modules. The topics covered include taking and assessing a family health history, breast and ovarian cancer, colon cancer, and thrombophilia. We also conducted focus groups with primary care providers in Guilford County.

Our focus group goals were to ascertain:

1. What resources primary care providers need to offer genomic medicine services to their patients.
2. How best to communicate this information.

Background

It has been suggested that genomic medicine will revolutionize medicine.^{2,3} However, this will require a shift in the medical model from the reactive treatment of disease to proactive healthcare.^{4,5} It will also result in the alteration of the roles of both healthcare providers and patients.⁵

In this new system that focuses on screening, early treatment, and prevention, primary care providers will require a core set of skills and knowledge to evaluate family history, recognize clinical findings that indicate genetic risk, and develop individualized health plans.^{6,7} Patients will have to assume a leadership role in the implementation of their own health plan, which may include increased disease surveillance, lifestyle or behavioral modifications, and pharmacological/surgical preventive options.⁵

However, barriers exist to the integration of genomic medicine services into primary care. Taking a family history and assessing a patient's risk takes time.⁸ The necessary infrastructure within the healthcare system does not exist.⁹ There are no practice models, delivery systems, or appropriate reimbursement mechanisms,⁵ and the genetic literacy of both healthcare providers and patients must improve if they are to collaborate as partners in health promotion and disease prevention.^{2, 10,11,12}

Methods

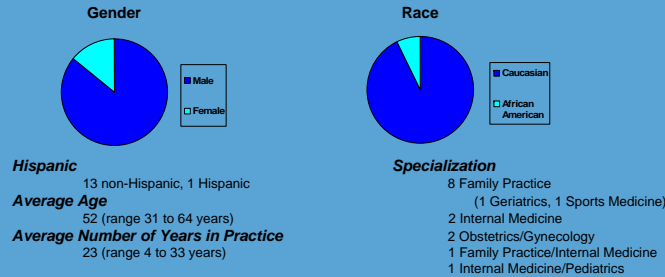
Letters were sent to a total of 353 primary care providers in and around Guilford County, North Carolina who had referred a patient to the Regional Cancer Center within the past 12 months.

- The letter instructed providers to contact the project coordinator if they wanted to participate in a focus group.
- Follow-up phone calls were made and faxes were sent to each office to increase participation.
- A total of 21 health care providers signed up and 16 participated in one of three focus groups.
- The focus groups were conducted following a hosted dinner. They lasted approximately 90 minutes.
- A standardized semi-structured script was produced which included 9 questions.
- During the course of the focus groups, participants were shown mock physician and patient reports that will be generated by the family history tool, and they were asked to comment on the content and format.
- Each focus group was audio taped and transcribed.
- Content analysis was done to identify common ideas, categories and themes.
- The appropriate institutional review boards approved this study.

Demographics

Fourteen physicians and two mid-level health care providers representing 9 practices in Guilford County participated in one of three physician focus groups.

The following data is specific to the 14 physicians who participated in the focus groups:



Results

The following are some of the underlying themes that emerged from the three focus groups.

Primary care providers recognize the need for education regarding genomic medicine.

"I mean, to me there's a huge educational process that has to happen for primary care physicians surrounding genetic testing and genetics, you know recommendations of how do you use our new genetic information in terms of managing risk and diagnosing new cases of disease."

"I'd like to have one of the side benefits of the project being here in Greensboro be enhanced education of the local physician population on genetic issues..."

Primary care providers will need to be able to consult with a geneticist or genetic counselor if they are going to integrate genomic medicine into their practices.

"Having an e-mail contact with someone who has the up-to-date resources"

"...to have someone that we can ask smaller questions of."

Primary care providers need access to up-to-date practice guidelines and recommendations.

"...recommendations that people can download onto their Palm Pilots"

"...a laminated card saying these are the most common issues, and these are some of the current recommendations for these particular issues. If you want information, here's where you can get it."

"...either recommendations from specialty groups or practice guidelines related to some of these issues. I'd love to have those resources, even if it's just a link as to how to get to them on the Web."

Access to genetic counseling services will be required for the successful integration of genomic medicine into primary care.

"...we need to streamline the system for accessibility to genetic counseling, through our oncology service here in Greensboro and getting that feedback information back to the patient."

"...having someone to who we can refer [patients to] for the full conversation."

"Are there enough resources in town for genetic counseling ...?"

Primary care providers want simple reports with specific recommendations when they refer patients for genetic counseling.

"I think often times written reports are essential because we have the opportunity to reinforce whatever recommendations are made.... So, we very much want to have something written that we can refer to and make a part of our check list for the things that we need to ask about when we see the patient again."

A report "... that gave you a little roadmap of what they thought needed to be done, ... if it was very, very simple, outline form, that you could go down point by point and talk with the patient about. Certainly, I don't need five pages of stuff..."

"What would be great is to get a paragraph explaining the value and – what needs to be done. It's educational for us, to take us another level." "Because that's how we learn, really. Besides reading books and going to conferences ..."

Strategies to disseminate information to patients' at-risk family members are necessary for genomic medicine to succeed.

"They would like a geneticist/genetic counselor to "...try to identify a family member who will get the info to other members of the family and --- [give them] something that would, you know, they [family members] could carry into their doctor...[with] a number on there where you could call..."

Conclusions

If primary care providers in Guilford County are to integrate genomic medicine services into their practices they need access to:

- Educational resources
- Geneticists and/or genetic counselors who can respond promptly to their questions and/or direct them to appropriate resources.
- Reliable websites with up-to-date evidence-based assessment and screening guidelines.
- Streamlined genetic services so that it is easy to get patients seen and reports back in a timely manner which include specific recommendations.
- Assistance disseminating information to the relatives of individuals at increased risk for common chronic diseases.
- Develop multiple educational resources and learning opportunities including on-line courses, grand rounds, conferences, web-based resources and informal discussions.
- Establish a consultation service to respond to phone calls and e-mail requests from health care providers in the community.
- Create a companion web-site to the on-line courses with a brief summary of the information covered in each course and handouts that can be printed out or downloaded to a Palm Pilot.
- Provide genetic counseling services to patients in the primary care practices that are participating in the development of the clinical practice model, and assess the need for additional genetic services. If necessary, create the infrastructure required to support these additional services.
- Explore various strategies to disseminate information to the relatives of at risk individuals and develop a plan to assess the effectiveness of each strategy.

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