Study finds health professionals, public unprepared for genomic medicine

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Although advances in genomic medicine for common adult chronic diseases such as heart disease, diabetes, and cancer hold promise for improved prevention, diagnosis and treatment, health professionals and the public are not prepared to effectively integrate these new tools into practice, according to a study released today by researchers from the Department of Veterans Affairs and the RAND Corporation.

Physicians and patients are optimistic about the health benefits that genetic testing might provide, but neither group is well informed about genetics and there are likely too few experts available to meet growing demands for genetic testing, according to the study in the March 19 edition of the *Journal of the American Medical Association*.

“Genetic testing increasingly will be available to aid in the diagnosis, prevention and treatment of common chronic diseases, not just rare genetic diseases,” said Dr. Maren Scheuner, lead author of the study and a natural scientist at RAND, a nonprofit research organization. “What requires attention now is how we will provide these services to an increasing number of patients.”

Researchers say the findings demonstrate a need for a large-scale effort to educate both health professionals and the public about genomic medicine, and to develop and evaluate new ways to deliver genetic services.

Researchers from RAND Health and the Department of Veterans

Affairs reviewed all studies published from January 2000 to February 2008 about the delivery of genomic medicine for common chronic diseases. The authors synthesized the findings from 68 relevant studies to develop a picture of the status of the delivery of genomic medicine in developed countries to diagnose, prevent and treat common chronic adult illnesses.

The studies consistently found that primary care physicians feel "woefully underprepared" to integrate genetics into their practice. This includes having neither the time nor the skill necessary to obtain and interpret family histories that might detect disease patterns that merit a referral for genetic testing or specialty consultation.

"Primary care clinicians are on the front lines of patient care and they are going to need to be prepared to incorporate genetics into their practices," Scheuner said. "Training and educating the healthcare workforce about the role of genetics in their clinical practice and increasing the size of the genetics specialty workforce are potential solutions to barriers we identified."

While consumers report having unclear notions about the value of genetic testing for common chronic diseases, they were interested in the prospect that the tests might help identify those people who are at greater risk for chronic illnesses that are preventable.

However, consumers are worried about the prospect of adverse consequences to genetic testing -- particularly loss of privacy and discrimination by health insurers or employers among those found to be predisposed to disease, according to the study. Despite this concern, researchers found there have been no well-documented cases of health insurers asking for or using presymptomatic genetic test results to define eligibility for coverage.

Researchers also found little research describing health outcomes associated with genetic testing for common chronic diseases. Most of the research to date has focused on patients' well-being after genetic testing, not on whether the testing prevented disease, changed treatment or extended lives. Well-designed studies that evaluate impacts on death and illness will be necessary to estimate the value that genetic tests add to health services delivery.

Researchers also found that scant research has been done to determine what might be the best system for providing genetic services for chronic adult illnesses.

Several studies in the United Kingdom found that using a nurse geneticist incorporated into a primary care practice resulted in high patient satisfaction and lower costs since fewer people required referral to a genetics specialist. But more research is needed about both the organization and the cost of systems to expand use of genetic medicine, according to researchers.

The study outlines several promising electronic tools that may offer benefits, including genetic consultation done via videoconference, disclosing genetic test results via telephone, and imbedding clinical support tools for physicians in electronic health records.

Researchers also found that most medical geneticists believe that there are too few trained specialists to adequately provide genetic services and that most directors of genetic laboratories support creation of more rigorous national standards for genetic tests to ensure quality of such testing.

Source: RAND Corporation