



PROFESSION

Website offers Q&A on patients' ethical quandaries

Genetic testing and end-of-life care are among the issues covered in a patient-oriented bioethics initiative.

By **KEVIN B. O'REILLY**, *amednews staff*. *Posted April 16, 2012.*

Medical ethics is often the stuff of esoteric academic debates and journal articles littered with \$10 words. Now one of America's most venerable bioethics think tanks is expanding its reach with a public TV special and a patient-focused website that addresses the ethical challenges of emerging medical technologies.

Genetic testing, assisted reproduction, children's mental health and end-of-life care are among the issues addressed at the The Hastings Center's site, called "Help with Hard Questions." The website was launched in March to coincide with the airing of an episode of the PBS program "NOVA" that was co-produced by the center and focuses on the brave new world of genomics. The program can be viewed online.

"It is a shift," said Mary Crowley, the center's director of public affairs and communications. "Bioethics matters to people in their day-to-day lives, because it looks at issues how they're born, die and how they're affected by medical technology."

The user-friendly site lays out easily digestible primers on matters such as how genetic testing is done and why it matters, and explores some of the ethical dilemmas that arise. For example, should a mother who learns that she possesses the hereditary BRCA mutation that significantly raises the risk of breast and ovarian cancer tell her daughter about it?

Patients are invited to share their dilemmas and solicit input from the bioethicists at Hastings as well as from other registered users of the website.

"We're trying to allow people to have a broader conversation around issues where there isn't a yes-or-no answer," Crowley said. "We don't think there's a place to do that."

The site is intended as a supplement to, not a replacement for, discussions with physicians, genetic counselors and other specialists, officials at the center said.

"There are three things that the website intends to embody," said Thomas H. Murray, PhD, the center's president. "We want to pay attention to values, get the facts right and be respectful of differences. ... We're not an advocacy group. We're not promoting a particular point of view. We're not carrying water for any interest, commercial or otherwise. We're trying to promote sprightly, broad conversation with people who care about these issues. We'll see. It's an experiment."

The limits of genetic testing

One message of the "NOVA" program and the Hastings website is that whole-genome sequencing is so far yielding complicated probabilities, rather than iron-clad certainties, about whether individual patients will develop certain conditions.

"It's not 'Genes R Us' — it's genes are a part of us," Crowley said.

A study published online April 2 in *Science Translational Medicine* buttresses that point. Researchers analyzed data on thousands of identical twins to test the predictive value of whole-genome sequencing. They found that for 23 of 24 common diseases, the majority of individuals whose genomes are sequenced would get negative test results. But those results would be misleading, because the known populationwide risk of developing the conditions is at least 50%, the study said.

"We believe that genomic tests will not be substitutes for current disease prevention strategies," said Bert Vogelstein, MD, co-author of the study and professor of oncology and pathology at the Johns Hopkins Sidney Kimmel Comprehensive Cancer Center in Baltimore. "Prudent screening, early diagnosis and prevention strategies — such as not smoking and removing early cancers — will be the keys to cutting disease death rates."

The American Medical Association has policy recommending that genetic testing be carried out under the personal supervision of a qualified health care professional and encouraging the U.S. Federal Trade Commission to require that direct-to-consumer advertising for genetic testing be truthful and not misleading.

ADDITIONAL INFORMATION:

WEBLINK

The Hastings Center on ethical challenges of new medical technology (hastingshardquestions.org/)

"Cracking Your Genetic Code," episode of PBS' "NOVA" series, aired March 28 (www.pbs.org/wgbh/nova/body/cracking-your-genetic-code.html)

"A conversation with leaders in bioethics and genetics," The Hastings Center, March 19 (hastingshardquestions.org/conversation-leaders-bioethics-and-genetics)

"The Predictive Capacity of Personal Genome Sequencing," *Science Translational Medicine*, published online April 2 (www.ncbi.nlm.nih.gov/pubmed/22472521/)

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