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Patients see benefits and risks to direct-to-consumer genetics tests

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Patients see potential benefits from direct-to-consumer genetic testing, but are also concerned about how test results will be used, and generally are unwilling to pay more than $10 or $20 for them, according to focus groups conducted by researchers at Loyola University Chicago Stritch School of Medicine.

Findings by first author Katherine Wasson, PhD, MPH, and colleagues are published in the *American Journal of Bioethics* Primary Research. Wasson, an assistant professor in Loyola's Neiswanger Institute for Bioethics and Health Policy, is an expert on the ethics of direct-to-consumer genetics tests.

More than a dozen companies, including 23andMe, deCODE Genetics and Navigenics, test consumers' genomes for single-gene disorders such as cystic fibrosis; for risks of developing complex disorders involving multiple genes, such as cancer, heart disease and diabetes; for sensitivities to drugs such as Coumadin; and for traits such as hair color, eye color and baldness. Costs range from roughly $100 to $1,500. Consumers can order these tests directly and receive results without the involvement of a qualified health-care professional, such as a geneticist or genetic counselor.

Wasson and colleagues conducted four focus groups with a total of 29 adult primary-care patients recruited from the waiting rooms of Loyola University Medical Center. After hearing an overview of direct-to-consumer genetic testing, participants were asked their thoughts and

opinions. Each focus group lasted 1½ to 2 hours. Sessions were recorded and transcribed verbatim. Researchers read and analyzed the transcripts line-by-line and word-by-word for themes that emerged from the data.

Direct-to-consumer genetic tests are not covered by insurance companies. Many participants were willing to pay in the $10 to $20 range (the equivalent of a co-pay). A few were willing to pay $100 to $400. "This situation could exacerbate inequalities in the health-care system, with those having greater financial resources being able to access this elective health-related information while those with fewer resources are unable to pay for it," researchers wrote.

Participants generally expressed willingness to test their children, including adopted and foster children. They said testing for disease risks would provide helpful information for the future. But these views are contrary to professional and ethical guidelines, which recommend testing children only if there is an effective intervention for the disease that's being tested. Otherwise, the children should wait until adulthood and decide for themselves.

"Children could be tested without understanding its implications, and parents might take actions that are inappropriate and potentially harmful, based on results without consulting a qualified health professional," researchers wrote.

Participants gave four main reasons why they might want to get direct-to-consumer genetic tests: to gain information, seek prevention, seek interventions or help others. One participant said: "I do have a strong family history of cancer, diabetes and my own personal history of cancer, so just to know down the line if it can come back or if something else could occur or if I could pass it on to my kids, I would like to know that."

Participants also had four main concerns about genetic testing: Are the tests accurate? Who will interpret them? Should results be shared with consumers' physicians and entered in medical records? And do the tests raise ethical issues such as risks to privacy and confidentiality?

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