Researchers find that not all patients will pay for genetic testing

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More than one-fifth of people who have received referrals to test for cancer-causing genes say they will only undergo testing if their insurance covers the cost—just as more insurers are instituting cost-sharing for medical services like genetic testing, according to new findings from Fox Chase Cancer Center in Philadelphia released at this year's 2012 Annual Meeting of the American Society of Clinical Oncology on Saturday, June 2.

Even though patients may pay thousands of dollars for some types of genetic testing, if they learn they carry mutations that put them at risk of other cancers in the future, that money will be well-spent, says study author Jennifer M. Matro, M.D., a medical oncology fellow at Fox Chase. Patients who are more at risk of certain cancers will know to schedule regular screening and check-ups so they can catch tumors at their earliest stages, when treatment is easier—and less expensive, she notes.

"Cancer care is becoming more personalized, but there are costs to that," says Matro. "The goal of genetic testing is to give patients the best opportunity to detect their cancers earlier, which can save costs in the long run."

But given how expensive genetic testing can be, Matro recommends that researchers learn more about which patients are most at risk and truly need testing, to spare those who may not carry enough compelling risk factors. "We need to discover more risk factors for genetic mutations, so

we can spare those patients who really don't need to pay for genetic testing."

"Genetic testing is now routinely integrated into cancer care," says Matro. If someone develops a colorectal cancer, for instance, a reflex preliminary screening test is done on the tumor to identify patients at risk for Lynch syndrome, which would put them at risk for other gastrointestinal cancers, endometrial, and renal cancers, among others. If the test is positive, the patient is then referred for additional testing to diagnose Lynch syndrome. If the screen is negative, no additional testing is done. This preliminary screen is generally covered by all insurers, but patients may be asked to pay some of the cost if additional testing is needed.

To determine whether these costs affect patients' decisions to obtain genetic testing, Matro and her colleagues at Fox Chase reviewed data collected from 406 people whose doctors suspected they may have cancer-causing mutations, based on their personal and/or family history.

The researchers found that 82 people—21.3%—said they would undergo genetic testing only if it was paid for by their insurance. Among those willing to pay some out of pocket costs, nearly 90% provided a limit for how much they would pay; most limited out of pocket costs to $500 or less.

Not surprisingly, people who were more worried about their risk of cancer and had more positive attitudes towards genetic testing were more willing to pay higher costs. Interestingly, women, people who were less educated, and those with more first-degree relatives who had cancer were less likely to agree to high co-pays for genetic testing.

It's likely in some cases that simple cost is the issue, Matro speculates, since people with less education may also make less money, and women

may not be the primary bread-winners in their household, so have less access to money. "It's counterintuitive that people with more relatives who had cancer would be willing to pay less for genetic testing," she concedes. "Perhaps they assume the test will be positive, so don't want to be saddled with a hefty co-pay. Alternatively, they may feel confident navigating the healthcare system after helping family members with cancer, and believe they can handle whatever diagnosis they eventually receive."

Provided by Fox Chase Cancer Center