

LESS IS MORE

Better Off Not Knowing

Improving Clinical Care by Limiting Physician Access to Unsolicited Diagnostic Information

A 70-YEAR-OLD WOMAN with back pain unresponsive to conservative measures underwent magnetic resonance imaging of the spine, which incidentally revealed a complex cyst in the kidney. Her physician felt obligated to investigate, but the cyst was beyond the reach of the radiologist for biopsy. Several anxious weeks later, the patient lay in a hospital recovering from a total nephrectomy. Final diagnosis: benign renal cyst.

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Most clinicians recognize a variant of this story from their clinical practice. A test is ordered for appropriate indications but provides information about an unrelated condition, leaving the physician and patient to contend with information they had not sought but which, nevertheless, they find impossible to ignore. We contend that patients would be better served if the medical profession adopted simple interventions to limit physicians' access to unsolicited diagnostic information. We discuss herein how this information can end up harming patients and suggest steps the health system could take to reduce the availability of such information.

TOO MUCH INFORMATION

Unsolicited diagnostic information is becoming common in many areas of medicine. Take for example a diabetic patient with proteinuria, whose physician wishes to determine their renal function and serum albumin level. Although these tests can be performed individually, combination panels are less expensive and encouraged by most laboratories. Conse-

quently, the physician orders a metabolic panel that identifies a mildly elevated alanine aminotransferase level. In cases like these, physicians seek specific information only to find themselves in possession of a wholly unrelated set of facts—"incidental-omas" that, more often than not, would have been best left undiscovered but cannot easily be ignored.

In another example, physicians are increasingly ordering computed tomographic scans to screen for colon cancer, inevitably leading to additional findings outside the colon. In one study, extracolonic findings generated additional workups in 7% of patients, many of whom experienced invasive testing or further radiation exposure.¹ These workups occurred even though the extracolonic portion of the computed tomographic scan is essentially an average-risk screening for intra-abdominal disease, which is not recommended by any group of experts.

Harmful unsolicited information is not limited to incidental findings but also occurs when testing is performed by protocol, such as in neonatal screening. For some disorders such as phenylketonuria, screening is clearly beneficial—the testing is accurate and the disease is easily treatable. However, with the advent of tandem mass spectrometry, neonatal screens now provide information about a myriad of congenital disorders, many of which are extremely rare and currently untreatable. Because of the low prevalence of conditions being tested and the inaccuracy of the tests, there are 50 false-positive results for every true-positive test, leading to more than 25 000 false-positive test results each year in the United States

alone.^{2,3} These false-positive results have adverse sequelae even after subsequent testing confirms that the infant is normal: anxiety triggered by the test result frequently creates broader parental concern about their child's health, with subsequent damage to parenting relationships and increased hospitalizations for unrelated illnesses.⁴

BETTER OFF NOT KNOWING

At first glance, it will strike many patients and clinicians as odd to think that medical information can be harmful. Rationally speaking, information on its own should neither harm nor benefit patients. If physicians could recognize the low pretest probability of serious conditions and the inaccuracy of most tests and simply ignore "incidental-omas," and patients could calmly accept physicians' reassurances about these findings, then no harm would be caused. But it is not easy for people to let information sit. To begin with, multiple physician incentives favor further testing, including increased reimbursement owing to the complexity of the visit and fear of lawsuits. Furthermore, patients rarely complain about further investigation. Most patients have limited financial disincentives to testing, are not comfortable with uncertainty, and assume that more information is better.⁵ Because most patients do not understand Bayes' theorem, they often perceive that they have benefitted from false-positive test results, incorrectly believing that the testing and follow-up procedures have improved their health. For most people (both patients and physicians), the benefits of testing appear obvious, while the harms are less apparent.

LIMITING HARM

How, then, can we limit the harm caused by this unsolicited diagnostic information? One approach would be to gather the information without transmitting it to the clinician or patient. Take for example bundled tests such as the metabolic panel. If a physician only wanted to know about a patient's serum creatinine and albumin levels, a laboratory could still run the less expensive bundled panel, while programming the computer to report only the requested results. The programming could be more sophisticated if that makes clinical sense, for example, reporting any "critical value" higher than some predetermined threshold.

A second approach would be to obscure data before it turns into information. For example, when conducting diagnostic imaging, areas of the body other than the parts under investigation could be blacked out. A screening test for colon cancer could limit itself to the colon, with computed tomographic scanners programmed to obscure other parts of the abdomen. The same could be done for magnetic resonance imaging of the spine.

A third approach would be to reclassify information in ways that reduce the strength with which patients and clinicians respond to the information. For instance, for screening tests with high rates of false-positive results, such as neonatal testing for inborn disorders, the initial report could indicate "positive preliminary screen result" rather than a specific diagnosis. This would

allow the physician to explain why further testing needs to be done, while emphasizing the preliminary nature of the findings. Not providing a specific diagnosis until confirmatory testing is performed may reduce unnecessary anxiety and curb the impulses to perform extensive additional workup.

All of these changes would be relatively simple to implement and could reduce the harms associated with incidental findings. Of course, these suggestions would do nothing to address the larger and growing issue of overuse of unnecessary testing.⁶ However, there are many instances when physicians are saddled with test results they did not intentionally seek. Given the difficulty of ignoring test results, we need to adopt policies and practices that shield us from distracting and unnecessary information. By doing so, the medical community will have found a way to acknowledge that more information is not always a good thing.

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