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Better off Not Knowing: Improving Clinical Care by Limiting Physician Access to Unsolicited Diagnostic Information

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Abstract

A 70-year-old woman with back pain unresponsive to conservative measures went for an MRI 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.

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. In this article we discuss 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 cheaper and encouraged by most laboratories. Consequently, the physician orders a metabolic panel that identifies a mildly elevated alanine aminotransferase. 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 that cannot easily be ignored.

In another example, physicians are increasingly ordering CT scans to screen for colon cancer, inevitably leading to additional findings outside the colon. In one study, extra-colonic findings generated additional work-ups in 7% of patients, many of whom experienced invasive testing or further radiation exposure¹. These work-ups occurred even

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though the extra-colonic portion of the CT 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 >25,000 false-positive tests each year in the U.S. 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 illnesses⁴.

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 doctors could recognize the low pre-test 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 due to complexity of the visit, and the 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 better⁵. 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, a lab 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 CT scanners programmed to obscure other parts of the abdomen. The same could be done for an MRI 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” 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 testing⁶. However, as described above, 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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