Reporting test results directly to patients: Is there anything to lose?

Claire Kendall, Alan Forster,

The article by vanWalraven and colleagues today in Open Medicine highlights an important gap in patient care: who is responsible for monitoring and acting on test results when care is shared amongst different providers. While it is convenient to state that the accountability lies with the ordering physician or the patient’s family doctor, there are many points at which this approach can lead to ineffective and inadequate management. We suggest that one way to solve this problem might be to communicate the results directly to the patient.

The authors of this study found that almost one-third of patients who have an abdominal aortic aneurysm discovered incidentally on diagnostic imaging did not have any follow up imaging, and even when monitoring did occur, it was not performed with the frequency outlined in well known clinical practice guidelines. Incomplete monitoring was not associated with patient co-morbidity; in fact, the only findings related to lack of adequate follow up were advancing age and increased size of the aneurysm at detection.

These are fascinating findings that identify a serious problem in the continuity of patient care: not all patients with a potentially life threatening condition received adequate follow up. While this alone is important for aneurysms, it is likely these results apply to other conditions. How many solitary pulmonary nodules, abnormal iron studies, or other results are not followed appropriately? Furthermore, this study provides little guidance towards preventing this problem.

It’s a common clinical conundrum: defining who is responsible for incidental but important findings from diagnostic tests performed by physicians other than the family physician. Is it the family physician, the ordering physician, or both?

Family physicians frequently have patients who require treatment in the emergency department or hospital. Such patients often return to primary care without any documentation of the investigations conducted, let alone any abnormalities detected. In addition, most family physicians do not have access to hospital records, whether electronic or paper-based. On their end, hospital physicians might assume the family physician is following up abnormal results, especially those unrelated to their hospital stay or reason for referral. However, there is no feedback loop to let the hospitalist know that the correct information was conveyed, received, and acted upon.

If we rely on the family doctor to follow up on abnormal test results, we would require a foolproof way of ensuring that all patients actually have and identify with a provider, that the provider is accurately identified at the testing site, that the provider receives a copy of the report, and that the provider acts appropriately on the results. Our current health system does not include assurances that these processes will occur reliably (1, 2). Furthermore, our current processes are inefficient: physicians report spending over an hour per day following up on and communicating results (3,4) and self disclose that there often delays in doing so in a timely manner (3).

On the other hand, placing the responsibility on the ordering physician may make patients better off. He or she must receive the results and must take responsibility for acting on them. This would include identifying incidental findings unrelated to the patient’s presenting problem and arranging appropriate follow up. Challenges to this solution include the likelihood that hospital physicians work shifts, may be on clinical service for only a few weeks per year and therefore, they may not be available when the result is reported, leaving the results to be interpreted and managed by a covering colleague. Also, if they were originally seen in the emergency department or the hospital ward, there may not be an appropriate venue for the ordering physician to see the patient. Finally, the ordering physician is unlikely to have a clinical relationship with the patient, requiring this to be established for effective care. These issues leave several places for error to occur and likely contribute to the inadequate follow up seen in today’s article.

One possible approach to improve the likelihood that results are followed up is simply to provide test results to the patient directly. This would then transfer some responsibility for ensuring timely follow up to the patient. This might be a desirable shift given the increasing engagement by patients in their own health care decisions. As patients are the most affected by the results of any test, they will be unlikely to forget that a test was completed or that unexplained findings need to be monitored.

Patients themselves report that they feel they should be informed of *all* test results, regardless of whether further management is required, and are satisfied with receiving results via mail, telephone, or at an office visit (5). In a study of patients undergoing diagnostic imaging, the vast majority expressed the desire to hear the results directly from the radiologist, even if these results were abnormal, even, for example, that they suggested cancer (6). 40% indicated a preference for hearing the results from their primary care physician, but 94% indicated that if they felt entitled to hearing the results from the radiologist if they asked for them (6). Women undergoing screening mammography described that they, too, would rather have the results directly from the radiologist rather than waiting to see the ordering physician (7) although these findings conflict with earlier literature (8).

What are the risks to this approach? Although patients express the desire to know the results, it is possible that some may be distressed by the findings if they are unable to interpret the result or its meaning due to cognitive issues or the many complexities inherent to health care information. Second, knowing the results and being responsible for them are two different things: presenting the patient with results doesn’t mean they will be able to access the health care resources required to act on the information, such as to book a follow up abdominal ultrasound. Many patients in Canada remain without a family physician (1), and our current health care structure doesn’t allow for patients to navigate the referral system on their own. Another potential risk is the interpretation that providing the results to patients abdicates responsibility from the health care provider to the patient. This may be inappropriate, for example with patients who are not capable of making health care decisions, which would add the complexity of ensuring a surrogate decision maker is made aware of the results. In all cases, some physicians and patients alike may view this solution as an erosion of the physician-patient relationship.

However, many of these issues become less important in a responsive health care environment in which all patients have a primary care provider to help them navigate the system. It may even be paternalistic to NOT inform patients of their results directly, especially, as this study shows, because physicians often fail to act on important results. We would argue that our suggestion adjusts the physician-patient relationship in a positive by shifting the balance of power from the professional to the patient. However, having patients *receive* results doesn’t solve the problem of who is *responsible* for the results and our current system may not have the necessary ingredients to support patients in bearing this responsibility themselves.

In conclusion, the study by van Walraven and colleagues demonstrates there are often inadequate responses to important test results. This problem is structural and is related to our complex health system. While increasing use of electronic health records might help reduce the risk of this occurring, this solution does not address a fundamental gap in patient engagement. While there are some potential risks of enabling patients to be informed directly of their results, these are not fully understood. Health systems need to boldly innovate and assess these concerns from the patient’s perspective in order to ensure the timely, reliable and proactive follow up.

References

1. Ontario Health Quality Council 2010 Report on Ontario’s Health System pp22-23, 80-81 at http://www.ohqc.ca/en/yearlyreport.php accessed March 9, 2011.
2. van Walraven C, Weinberg AL. Quality assessment of a discharge summary system. CMAJ 1995; 152(9):1437-1442.
3. Poon EG, Gandhi TK, Sequist TD, Murff HJ, Karson AS, Bates DW. "I wish I had seen this test result earlier!": Dissatisfaction with test result management systems in primary care. Arch Intern Med. 2004;164(20):2223-2228.
4. Sung, S, Forman-Hoffman, V, Wilson MC, Cram, P. Direct Reporting of Laboratory Test Results to Patients by Mail to Enhance Patient Safety J Gen Intern Med 2006; 21:1075–1078.
5. Meza JP, Webster DS. Patient preferences for laboratory test results notification. Am J Manag Care. 2000;6(12):1297-1300
6. Schreiber MH, Leonard M,Jr, Rieniets CY. Disclosure of imaging findings to patients directly by radiologists: survey of patients' preferences. AJR Am J Roentgenol. 1995;165(2):467-469.
7. Levin KS, Braeuning MP, O'Malley MS, Pisano ED, Barrett ED, Earp JA. Communicating results of diagnostic mammography: what do patients think? AcadRadiol. 2000;7(12):1069-1076.
8. Lind SE, Kopans D, Good MJ. Patients' preferences for learning the results of mammographic examinations. Breast Cancer Res Treat. 1992;23(3):223-232.