

Reporting radiology results to patients: keeping them calm versus keeping them under control

"The choice to try to improve systems of care delivery by such changes in access to test results is still a difficult one. These types of changes would be expected to bring with them substantive risks as well as potential improvements in quality of care. Will benefits outweigh risks?"

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In recent years, there has been evidence of increasing patient interest in easy, timely and complete access to all personal health information [1-4,101]. Breadth of interest has perhaps been increased by the recent American Recovery and Reinvestment Act of 2009 (ARRA) legislation which offers tangible incentives to providers who develop systems that offer patients access to electronic health records in order to maintain personal health records [5,102]. While the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 with ARRA outlines some specific required content for the patient-accessed medical records (e.g., allergies, medications and problem lists) in order for provider systems to qualify for financial incentives, inclusion of radiology reports has not been in early guidelines. However, there is evidence that patients specifically desire access to radiology results and so the question of how increased patient access to these test results might affect quality of care is raised [1,3,6-8].

The cons

A healthcare provider who is a regular consumer of radiology services, and the associated radiology reports, can probably fairly quickly create a list of some of the common arguments against an electronic system that would give patients the option of rapid access to written radiology reports of test results [3,6,9], for example:

- Patients will not understand the language of the reports, and so such access will not make them better informed about their health;
- Patients may become more anxious (i.e., relative to not having heard any results at all) after reading contents of typical radiology reports;

- Providers (both referring physicians and radiologists) will be inundated with telephone calls from anxious patients seeking urgent clarification of report contents and immediate advice regarding next steps in care;
- Radiologists are ill-equipped to discuss the implications of a test's results with a patient, since they are typically unfamiliar with the patient's medical context and have had limited or no personal contact with the patient;
- Referring physicians will receive calls from patients before the physicians have had time to review test results themselves and make preparations to provide the most appropriate guidance to patients;
- Current staffing limitations preclude easy development of a more efficient or accommodating system to review test results and provide more timely and thorough education to patients regarding the meaning of test results;
- It is preferable that the referring physician, as the patient's regular healthcare provider, serves as a 'filter' for radiology report contents – at times choosing to convey some, all or none of the report's contents to patients, as the physician deems appropriate.

The pros

On the other hand, a healthcare provider who has been a patient himself/herself can probably fairly quickly create a list of some of the common arguments in favor of a system that would give patients the option of rapid electronic access to written radiology reports [3,6,9], for example:



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- Patients want results as soon as possible, with many preferring results to be offered in detail and in writing – not a verbal, 'it was fine' a week or more later. (How many patients who work as healthcare providers find such notification acceptable?);
- Systems for direct patient access to radiology reports will decrease the incidence of radiology test results being overlooked or lost;
- Systems for direct access to radiology reports will help patients better prepare for their next doctor visit and educate themselves about their health;
- Systems for access to results that are linked to high-quality online educational materials may be very helpful to patients in educating themselves about their health;
- Direct electronic access to reports may facilitate patients' seeking useful social support for their condition and help empower them as partners with their physicians for decision-making;
- Direct electronic access to reports will decrease the time elapsed until patients can take the next appropriate step in their care;
- The wait for patients to hear results may be more stressful to them than direct and immediate access to even very serious and bad (i.e., cancer diagnosis) results;
- Patients should be able to choose their own preferred level of access on an individual basis, as in other highly technical services outside of medicine.

Perspectives: attempting more of a 30,000 foot view

In the spirit of attempting to consider the debate more impartially (if a physician can), or at least from a broad range of viewpoints, I find myself considering several additional points. Since radiologists' reporting directly to patients would be a substantial departure from the prevailing practice in most areas outside of mammography (at least in the USA), re-evaluation of the appropriate role of a radiologist seems fitting. Brenner has suggested that the duty of a radiologist involves the supervision of obtaining reasonable images, reasonable interpretation of those images and effective communication of that interpretation [10]. Is there an adequately compelling rationale for strictly limiting that effective communication to the referring physician, to the exclusion of the patient himself? Such restriction has been the traditional model for radiologists in the USA. But the patient would seem to be the ultimate human governor of his health and the one at greatest risk if communication failures occur at any point in the healthcare system. At a fundamental level, to whom do we as radiologists owe primary duty? Radiologists work primarily as consultants, often have very little direct contact with patients and historically have conveyed our expert opinions within information systems that are readily accessible only to other caregivers. Such traditional models of care may have developed for good reasons, but they may serve to make answering the duty question seem more difficult than it should be. The Hippocratic Oath is still pertinent: a radiologists' primary duty is to patients, not referring physicians. Some case law in recent years seems to reflect that courts may consider that radiologists have a primary duty to patients [11-13] and that communication of test results may be as important as the results themselves [14,15]. In one review of malpractice claims against radiologists, jurists' perspective on radiologists' responsibility to ensure communication to patients has been seen in tangible terms, with much larger indemnity payments when results are not conveyed to patients, whether or not the referring physicians were notified [16].

"At a fundamental level, to whom do we as radiologists owe primary duty?"

Such professional duty includes dedication to minimizing error. Medical errors - especially those related to communication failures within typical complex systems of care delivery - have been a focus of the popular press and of discussions about healthcare costs and tort reform. The issue of what effect patients' direct access to radiology reports would have on safety rises to the forefront. It seems logical that test results that are made available to both referring physicians and patients would be less likely to be lost, overlooked or ignored than those made available to referring physicians only. In fact, the Institute of Medicine has chosen the failure of communication of abnormal radiology test results as a model for how medical care systems fail in terms of safety, effectiveness and timeliness of care [17]. The final report of the Committee on the Quality of Health Care in America of the Institute of Medicine included a recommendation to all healthcare providers to reorganize healthcare processes so that "Patients should have unfettered access to their own medical information and to clinical knowledge" [18].

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Yet the ethical waters may appear muddled by reasonable questions as to what harm might potentially result from such changes in patient access to test results, namely harm related to increased patient anxiety. Would providers be benefiting patients by facilitating their prompt direct access to written radiology reports? The desire for beneficence likely motivates many physicians to filter information flow to patients, in order to avoid contributing to unnecessary patient anxiety. Traditional physician values include weighing the risks and benefits of all aspects of healthcare delivery, including consideration of the very different perspectives of those with widely varying medical knowledge bases (i.e., providers vs patients). The desire to avoid unnecessary anxiety or pain for patients is noble. Keeping patients calm seems better for patients. But determining how much information to reveal to an individual patient is a difficult task. It is perhaps inappropriate for providers to assume sole responsibility in making such determinations. One could reasonably argue that the individual patient should at least share in these types of decisions regarding his/her own healthcare. Putting the shoe on the other foot, how many providers, as patients themselves, prefer that someone else make all decisions about how much access they have to their own personal health information?

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"In this information age ... it is striking that healthcare providers still expect an outpatient to be satisfied waiting a week or two to hear a verbal summary of the results of his/her MRI."

Perhaps closely linked to the noble desire to avoid patient anxiety is the desire to avoid the anticipated negative effects of such anxiety on caregivers, in particular, potential effects on provider workflow and staffing needs (e.g., a greater number of urgent patient phone calls, more patient confusion and more questions directed to providers). For many providers, workflow pressures are arguably already nearly at a crisis point, with less time spent with each patient and more patients seen per day, oftentimes with decreased staff assistance. Something that would further increase these workflow pressures is not likely to be regarded by providers as desirable or good for healthcare in general. If giving patients more information more quickly would substantially adversely affect provider workflow - especially for nonemergent conditions - it may be viewed as creating more problems than it resolves and

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as an unacceptable option for providers. In a system with real constraints on provider time and need for efficiency in care delivery, keeping patients under control may seem better for everyone involved.

It is possible that provider workflow in typical current practice environments has become such that concerns about workflow are at least as compelling as fear of patient anxiety as a motivating factor for limiting patient access to radiology results. What counter points might be compelling enough to outweigh such pressing workflow limitations? Again the role of the person considering this question is likely quite relevant in anticipating the answer. The perspective of a patient may be very different from that of a provider. In this information age - when an individual with internet access can instantly read today's news report from Baghdad, review his/her financial portfolio and hourly updates on the NASDAQ, see live video feed of the BP Gulf of Mexico oil spill of 2010 or find an aerial photo and last week's purchase price of a house down his/her street - it is striking that healthcare providers still expect an outpatient to be satisfied waiting a week or two to hear a verbal summary of the results of his/her MRI. For the provider, much more detail is usually available, often within hours of the MRI scan. Is the typical notification system for patients (i.e., verbal summary at a time convenient for providers) primarily a way of minimizing patient anxiety, or is it perhaps as much a way of controlling patient response to test results? It may seem (at least in western cultures) that, in a context outside of medicine, an individual with a problem is not usually advised to best respond to that problem by maintaining a state of ignorance about it. One could imagine that systematically failing to facilitate that individual's detailed knowledge about his problem would be seen as very odd and counter-productive guidance in many settings. Medicine may be a unique context, however, and the argument is made that a patient's medical knowledge base is inadequate to the task. There has been, and may always be, a knowledge base disparity between providers and patients, but the degree of disparity would seem to vary widely by individual patient (and provider). Providing high-quality care arguably includes working to fully educate patients and facilitate their indepth understanding of specific personal health related issues. Unfortunately, even if providers support this idea conceptually, they may lack the resources to make this type of patient education a practical reality in a clinical setting.

Patient satisfaction can be another driver for changes in patient access to radiology results. As those practicing medicine in a competitive marketplace, should providers facilitate easy, complete patient access namely because some patients desire it? It would seem reasonable that some patients, in order to better understand their health, and most appropriately manage it, would desire detailed, written and prompt results of all of their diagnostic tests. One might wonder whether there are perhaps very few physicians or nurses who, as patients, do not circumvent typical notification channels so as to obtain more rapid and complete results of personal medical tests. If so, why should there be any less interest on the part of a patient who happens to work in a field other than medicine? With the technological developments of the past few decades, motivated and competent patients are probably able to educate themselves to a substantive degree with regards to a specific disease process; in some cases, knowledge disparities can be almost eliminated.

"The concept of free sharing of information ... has face value as a means to promote better quality care and potentially healthier, more satisfied patients."

Patients who desire to know more about their healthcare and take more responsibility for their own health are often demonstrating a desire to act more autonomously with regard to personal health. Offering direct patient access to radiology results as an option might help to promote such patient autonomy. Direct reporting of results would be expected to facilitate getting results to patients more quickly and reliably, possibly reducing delays and opportunities for results to be lost or overlooked. Direct reporting of results could support patient autonomy by affording choice, offering more information and encouraging patient self-initiation [19-21]. Increased patient autonomy has been seen in multiple studies to lead to better health outcomes [20,22-25], and there is evidence that patients desire greater autonomy in healthcare [26-28].

Discussion

Beneficence, even in the focused area of reporting of radiology test results, seems not to be a simple issue for healthcare providers. The desire to avoid contributing to unnecessary patient anxiety is noble and likely a motivator for the typical system, whereby referring physicians provide verbal summaries of radiology test results to patients within a time deemed reasonable by the physician. Most patients do not have the same medical knowledge base as physicians and so the rationale for current notification methods is that patients cannot handle full transparency with regard to complex test results. From the perspective of the providers, keeping patients calm seems a good goal for everyone involved. But patient medical knowledge base is variable on an individual basis and is likely subject to rapid change, at least in some patients, by means of focused education. It is possible that at least some patients could very well cope with - and would prefer - full transparency of test results rather than the more common current methods of reporting by means of verbal summaries from referring physicians.

Delayed and verbal notification could remain commonplace because provider workflow concerns may be an effective motivator for limiting patient access to written radiology reports. Patients may not be immediately informed of detailed results in writing because of providers' need to triage work to manage work environments effectively as well as providers' preference for providers (not patients) primarily directing the management of their patients' healthcare. Since patients typically do not have the medical knowledge base of providers, some may reason that patients cannot be full partners with regard to healthcare decision-making. From the providers' perspective, keeping patients under control may seem necessary for the best chance of appropriate care and especially for achieving expected levels of efficiency in care delivery.

Does the system really need to be so substantively changed to offer patients prompt, full access to all radiology reports? Disparities in knowledge base appear to be the underpinning of arguments against change; such disparities are an expected feature of patientphysician relationships. How do these disparities affect efforts to promote patient autonomy in healthcare (i.e., something which has been associated with better outcomes)? One definition of autonomy suggests that it is related to acts that are endorsed by a person - after consideration – because that person considers those acts to be useful or important in achieving that person's goals [29,30]. A person without adequate knowledge to reflect on a personal healthcare decision, therefore, would not be capable of acting autonomously with regard to that decision and could be considered vulnerable in this arena [31]. For caregivers to respect the social dignity of a patient as a person would seem likely to require that the provider pay specific attention

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to this vulnerability, namely to respecting the individual's choice to act autonomously by helping to enable that autonomy [32]. Towards one end of the autonomy spectrum, a patient may reasonably choose to defer his healthcare decisions to his provider [31,33,34]. This choice may potentially eliminate the patient's need for a greater knowledge base. Towards the other end of the spectrum, a patient may choose to act more autonomously in making his/her own healthcare decisions in partnership with his/her physicians. This choice would likely highlight the patient's need for (and vulnerability without) an enhanced knowledge base. Working to minimize relevant disparities in knowledge about a specific personal healthcare issue, providers can protect patients against a specific vulnerability and more fully respect a patient's social dignity.

Knowledge is probably necessary for autonomy (at least as the term is defined above). But also, "knowledge is power" (SF Bacon, Religious Meditations, Of Heresies, 1597). Regardless of true motivation, providers who fail to facilitate complete patient access to test results may be perceived by patients as practicing in a way to systematically limit patient knowledge for purposes of maintaining physician control in the relationship. Keeping patients under control may be very negatively viewed by some patients, and in this information age it may subvert efforts to build trusting and effective patient-physician relationships. The concept of free sharing of information - even with the anticipated need for increased provider time and effort for education to facilitate a patient's desired level of autonomy – has face value as a means to promote better quality care and potentially healthier, more satisfied patients. Physicians

often seem to highly value information and autonomy and recognize the power they afford; we should respect the fact that a patient may value information and autonomy just as much.

The choice to try to improve systems of care delivery by such changes in access to test results is still a difficult one. These types of changes would be expected to bring with them substantive risks as well as potential improvements in quality of care. Will benefits outweigh risks? What considerations should be paramount in deciding the course of change, if any? I suggest that the chosen perspective for decision-making should probably focus on the more vulnerable position, that of the patient, and indirectly also take advantage of the clinical experience of providers. The most relevant question may be - how do we caregivers want to be treated when we are patients? Thoughtful answers vary by situation and do not seem simple. Systems and processes probably need to be carefully designed and tested. But in the end, the most helpful mentality for providers in determining the best next step in reporting-related quality improvement may not reflect the easiest path but instead the most noble: "So in everything, do to others what you would have them do to you" (Matthew 7:12 New International Version).

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