
EDITORIAL

When 4 does not mean 4: A patient portal lesson

Last year I received a panicked call from one of my colleagues late one Friday afternoon. One of his long standing patients had received a copy of a CT report ordered by her primary care physician. The study was to evaluate abdominal pain and she asked to be copied on the results. She called this colleague to tell him that she had been diagnosed with stage 4 kidney cancer and was quite distraught as would be expected. He asked if I would call her. After calming her enough to get some details, she had not yet spoken to her primary care physician. She directly called her specialty physician who she had a 20 year relationship with. It seems that she had misinterpreted the report. The radiologist report stated that there was a small (< 4 cm) Bosniak 4 renal cyst. Rushing to the Internet she associated the number 4 with stage 4 renal cell carcinoma. To make a long story short, she underwent a laparoscopic radical nephrectomy with organ confined disease (stage T1a) renal cell carcinoma with an excellent long term prognosis.

While this is not really a story about a patient portal it is illustrative of the potential downside of direct patient access to their medical testing results without the benefit of face to face provider interpretation. According to HealthIT.gov "a patient portal is a secure online website that gives patients convenient 24 hour access to personal health information from anywhere with an Internet connection" allowing access to health information such as: recent doctor visits, discharge summaries, medications, immunizations, allergies and lab results. The government site promotes many benefits of the patient portal: "enhance patient-provider communication, empower patients, support care between visits and most importantly, improve patient outcomes".

Patient portals typically involve a personal health record, or PHR, an electronic application used by patients to maintain and manage their own health information. A PHR differs from an EHR in that patients themselves usually set up and access the PHR. Patients can use a PHR to keep track of information from doctor visits, record other health-related information, and link to health-related resources.

Patient portals are now part of "Meaningful Use", the governmental monitoring program that sets specific objectives that eligible providers and hospitals must achieve to qualify for Centers for Medicare & Medicaid Services (CMS) Incentive Programs. In 2009, President Obama signed the American Recovery and Reinvestment Act (ARRA) with a section called the Health Information Technology for Economic and Clinical Health Act (HITECH) allocating \$19.2 billion to develop healthcare information technology. At phase 2 of "Meaningful Use" providers are now mandated that 50% of patients must have access to an electronic copy of their health information and 5% of patients must have used the capability to access and download their information. Failure to comply can quickly change incentives from the government into provider penalties.

The impact of these programs has never been formally studied on a large scale with only a few published outcome studies in a very limited number of disease and practice settings. The patient portal is a potentially beneficial addition to enhance patient care, particularly for the management of more chronic conditions. The lesson here is that unbridled access to patient testing data must be more carefully controlled. Access to major diagnostic findings by the patient before they have the opportunity to have the information reviewed and discussed with the provider is a concern. The rush to have providers develop and implement portals to meet government mandated meaningful use without more strict access guidelines may result in more confusion and anxiety for some patients.

Health care is not as simple as going to the Internet and self-diagnosing. Empowering patients is a laudable goal but cannot trump interpretation and a discussion with providers who have more extensive medical knowledge that the average patient can glean from the Internet.

A well respected medical on line editor and advocate for patient medical record access recently noted that "For centuries, the medical community believed that patients could not handle seeing their own information for fear that it would induce major anxiety. They also believed that the information wouldn't be understood; medical jargon is much too complicated for a layperson". In the world of "medical jargon" sometimes the number 4 is not really the number 4.

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