

Personal health records as portal to the electronic medical record

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Abstract This topic review discusses the evolving clinical challenges associated with the implementation of electronic personal health records (PHR) that are fully integrated with electronic medical records (EMR). The benefits of facilitating patient access to the EMR through web-based, PHR-portals may be substantial; foremost is the potential to enhance the flow of information between patient and healthcare practitioner. The benefits of improved communication and transparency of care are presumed to be a reduction in clinical errors, increased quality of care, better patient-management of disease, and better disease and symptom comprehension. Yet PHR databases allow patients open access to newly-acquired clinical data without the benefit of concurrent expert clinical interpretation, and therefore may create the potential for greater patient distress and uncertainty. With specific attention to neuro-oncology patients, this review focuses on the developing conflicts and consequences associated with the use of a PHR that parallels data acquisition of the EMR in real-time. We conclude with a discussion of recommendations for implementing fully-integrated PHR for neuro-oncology patients.

Keywords Electronic medical records · Patient access · Personal health records · Brain tumors

Introduction

Glioblastoma remains a devastating diagnosis, and is near-uniformly fatal regardless of treatment, with a median survival of less than 2 years [1]. Standard treatment is surgical resection followed by concurrent radiation and chemotherapy with the DNA-alkylating agent temozolomide, with 6–12 subsequent cycles of adjuvant temozolomide. While prospective randomized clinical trials have shown this combined regimen results in a statistically significant prolongation of life [2], treatment failure is expected and patients are therefore closely monitored for disease progression by serial MRI.

The stimulus for this topic review is a recent encounter with a 46-year-old, female with glioblastoma admitted for seizure. She had completed her initial therapy of radiation and adjuvant temozolomide and was currently being treated with temozolomide monotherapy. Upon entering her hospital room to discuss her most recent MRI scan, obtained just 8 h prior, she instantaneously announced that she already knew her tumor had been “cured” as she had independently accessed the MRI report from a web-based electronic medical record (EMR) portal with her laptop computer.

This episode was striking on several levels; first, while access to paper records is routine, presently it remains uncommon for hospitals to grant web-portal access to EMR via fully-integrated personal health records (PHR). Secondly, the patient’s lay interpretation of the dictated report was unfortunately distorted in this case, prompting an unnecessarily complex and upsetting explication of the

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actual MRI results, showing disease progression. Perhaps most importantly, however, the availability of this technology intruded on the patient experience by allowing an inpatient to receive critical health information that traditionally would be expected to be apportioned by the treating clinical team. While the potential of EMR-integrated PHR to improve efficient information exchange between the patient and practitioner is clear, early review of its use provides an important basis for critical evaluation and continuing discussion to better structure this benefit for neuro-oncology patients.

Background

Installation of the EMR into U.S. healthcare is relatively new and remains considerably limited. Despite widespread support for its implementation by policymakers and financial incentives through the American Recovery and Reinvestment Act of 2009, Jha et al. [3], found that only 1.5 % of non-Federal U.S. hospitals currently have a comprehensive EMR. A slightly greater proportion of U.S. hospitals (8–12 %) report having a more basic EMR that includes limited applications for clinical documentation such as medication and allergy lists, test and imaging results, and computerized order entry for medications [3]. Progress towards EMR implementation is hindered by the substantial cost and complexity of the technology and is well-described as presenting considerable ethical, legal and logistical challenges. Commentators within the wider literature have additionally expressed serious concern about storage and access to data, data ownership, and system security, especially with regard to patient privacy and confidentiality [4]. Certainly, these concerns will continue to provoke discussion and debate, however, the implementation of EMR is proceeding at a rapid pace. Here, we move beyond academic consideration of these initial apprehensions in order to begin an empirically-based and constructive dialog within the aftermath of its early implementation: how do we best extend access of the EMR to neuro-oncology patients?

Electronic medical record access by patients

Patients' rights to access their clinical information and associated protections for the handling, exchange of and access to the medical record are indisputable, with a legal foundation contained within the Health Insurance Portability and Accountability Act of 1996, the Fair Health Information Practices Act of 1997, and additional legislation. PHR that are fully-integrated with a hospital EMR creates the possibility for real-time, unrestricted patient

access by mitigating the cumbersome and time-intensive functions of collection, compilation, storage, retrieval, and reproduction that exist with paper records. Reliable estimates of the number of US hospitals offering PHR are lacking; however, it is reasonable to note that existing systems are often highly limited, offering electronic communication with providers or access to basic laboratory test results and minor editing functions with allergy and medication lists. The literature strongly supports the notion that patients are universally in favor of access to their EMR [5]. Thus, with the evolution of EMR and perceived serviceability of the information contained, patient requests for parallel PHR implementation are likely to increase.

Potential consequences of increased data sharing

The concept of PHR is well-supported in the literature as a mechanism to promote patient participation in care [6, 7], increase healthcare access [8], achieve patient-centered care, and allow for prompt correction of inaccuracies in the medical record [9, 10]. The guiding hypothesis is that timely and consistent information can be fundamental to promote patient involvement in healthcare decision-making [10, 11]. Early findings of PHR use in primary care settings indicate the relative ease of use and straightforward benefits in this routine setting, including the opportunity to correct errors and add information, the capacity to schedule and manage appointments, and the potential to quickly access medical information [12]. Additionally, Groll et al. [13] made the provocative observation that in a group of more specialized-care patients (testicular cancer patients), the predominant motivation to access laboratory and radiology results via PHR was one of reassurance; the need to verify disease remission and objectively affirm treatment success. These psychosocial advantages of PHR are newly recognized as emergent clinical benefits from this technology, and similar benefits may be uncovered with continuing patient exposure.

Previous studies consistently document that routine medical record access results in improved communication and information exchange with clinicians and correlated to modest improvements in adherence, education, and empowerment for certain medical patients [5, 9, 14]. While PHR that allows immediate and comprehensive access to the EMR holds the potential for even greater benefits, its use in this context nevertheless remain understudied. Thus, concerns persist; physician apprehension to PHR cites patient confusion and distress over medical jargon [10, 11] and to a lesser extent, fear of increased work-load and concerns about the technology altering traditional patient-practitioner interaction [10]. As to the primary critique, that PHR confuses or upsets patients, evidence lends credence

to this concern within specific specialty-care patient populations. In their systematic review on the effects of patient access to paper medical records, Ross and Lin [14] found that most patients did not experience significant anxiety or concern; however, cancer patients, perhaps unsurprisingly, were more likely to report increased anxiety.

A second patient provides a prototypical example of this potential for anxiety, confusion, and uncertainty related to the provision of real-time test results. For neuro-oncology patients, neuroimaging with MRI is the most commonly ordered diagnostic test. MRI reports describing primary brain tumors are often complex and include descriptions of normal brain structures and abnormal findings, with additional comparison to previous images in order to report on tumor response or progression. Terms contained within these reports are not commonly used in the verbal communication of results to the patient. Additionally, standard therapy can confer transient tissue alterations, known as treatment effects, or “pseudoprogression”, which require further interpretation by the neuro-oncologist or additional imaging to better characterize changes seen on a single series of images.

Following a routine clinic visit, a 56-year-old man emailed to question extension of his treatment plan, which was derived from his clinical exam and a recent MRI scan with evidence of treatment effects. He had accessed the MRI report at home, which equivocated between tumor progression and pseudoprogression, underscoring the lack of specificity of some brain imaging changes. He was immediately concerned that the “progressions” mentioned in the report conflicted with his care-team’s interpretation of treatment response and was acutely concerned about prognosis.

In glioblastoma patients, pseudoprogression is reported to occur in ~20 % of patients on the first follow-up imaging with MRI after treatment with concurrent temozolomide and radiation [15]. The radiological findings are often indistinguishable from tumor recurrence and can include increased size of the enhancing lesion and edema [15]. Often, patients may demonstrate clinical worsening, which is also, but not exclusively, seen with true tumor progression, further complicating the operational scan interpretation by the neuro-oncologist. Ultimately, the final clinical interpretation of isolated radiological findings rely on cumulative evidence gathered from careful assessment of the patient, review and comparison of previous scans, and serial observations [15]. In many instances, clinical judgment and previous experience weigh heavily in determining the preponderance of data in favor of pseudoprogression versus true disease progression. Not an infrequently encountered concern, misinterpretation and failure to appreciate these nuances of radiology reports, can spark anxiety and make it difficult for patients to consider

all relevant aspects of the clinical scenario. This may be additionally complicated by the technical language of the report; oftentimes, the readability of these documents is not altered before being released through the PHR.

Scope and content of the information contained within PHR

The demand for unfettered access to clinical data challenges health information systems to keep up with the effusive output of clinical data acquisition. As the push for PHR continues, the onus on system architects is in developing filters and user-friendly applications to render patient-advantageous information and to prevent information overload. At the most basic level, a key consideration when implementing PHR is what information patients should have immediate access to, what information should have “delayed” access, and which information, if any, should never be offered or significantly modified in PHR-format. Basic data regarding how patient-accessible EMR technology is viewed, accepted and eventually capitalized by neuro-oncology patients is fundamentally lacking and would help inform some of these decisions.

For most oncology populations, appreciating and defining appropriate time limits to the release of potentially distressing or highly technical information such as radiology reports, is a fundamental first task that must be coordinated before PHR implementation. As another patient recently illustrated, a delay on the release of pathology results is also reasonable. This would help avoid situations where patients are left on their own, for even a small period of time, to make premature assessments and predictions regarding their disease and treatment status. In this case, the patient had an established grade II oligodendroglioma. In these tumors, allelic losses of chromosome 1p and 19q correlate with higher chemosensitivity as well as better prognosis [16, 17].

At radiologic progression, the patient underwent lesion biopsy. After discharge but prior to his follow-up appointment, the patient accessed his pathology report through the PHR, detailing a grade 3 mixed oligoastrocytoma. However, the pending ancillary molecular marker data of critical importance in this case, the 1p/19q status of the tumor, was not yet available. Not unexpectedly, the patient was solely focused on the advancement of grade. He reported urgently to clinic in advance of his scheduled appointment, visibly distressed and having spent the interim time immersed in an internet search. A discussion of treatment options was at best, speculative, since the molecular data was still pending. This case highlights the importance of delay in report transmittal to the PHR until all related components are available or the prearrangement

of medical review and interpretation prior to the release of diagnostic results to the PHR.

Patient preferences to receive their clinical information

The manner in which physicians communicate deleterious information to cancer patients can influence their distress response [18, 19]. Yet little data exists regarding patients' preferences to receive clinical information and none specific to neuro-oncology were identified. Care of the brain tumor patient requires a comprehensive approach utilizing diverse specialists within neuro-oncology, neurosurgery, radiation oncology, and others. In a systematic review on communication, information and support for patients with malignant glioma, Davies and Higginson [20] found that up to one-third of patients report conflicting or inconsistent information across care disciplines. Here, the potential of the PHR to improve information consistency seems apparent.

More problematic is determination of what clinical data confers the most benefit and when. Previous research supports that most cancer patients desire detailed health information but that information needs vary patient to patient and within-patient as disease remits, stabilizes or progresses [13, 21]. Most recommendations call for a highly individualized approach, that elicits patient information preferences through continuous assessment, and when desired, that information be plainly presented, incorporating strategies to support comprehension [20, 22]. Much of the data regarding cancer patients' preferences to receive information is specific to the disclosure of "bad news" [21–23]. Importantly, far less is known about how best to specifically delineate the details of prognosis and the associated staging or surveillance scans, as well as other test results, and the psychosocial implications that parallel the various methods of disclosure. The patient's input into these decisions is of critical importance.

Recommendations and closing

There remain a number of ethical, legal, and other obstacles hindering patient information access in clinical settings (Table 1). While much attention has been given to EMR, PHR requires additional consideration. Here, it was demonstrated how the direct conduit of a practitioner-centric EMR into a patient-accessible PHR has led to interference in care provision and threatened support for positive psychosocial outcomes for brain tumor patients. The current rationale for pursuit of EMR-integrated PHR posits that transparency of care and better communication flow will result in higher quality patient care. Indeed, the

Table 1 Summary of obstacles to EMR-integrated PHR

EMR-derived aspects	PHR-derived aspects
Substantial cost and complexity of implementing and managing these new technologies	Paucity of data regarding patient experience and preferences with PHR
Limited customization of commercial systems to suit institutional and patient-specific preferences	Debate about the types of data that should be available to patients via PHR
Concerns for data ownership, access, and storage	Debate about the timing of clinical data release to PHR
Resistance from clinicians to transition and adapt to new technologies	Complexities of customizing technology to individual patient preferences
Incompatibility of home-grown and commercial technologies across institutions	Concerns over patient reactions to unedited medical and technical jargon
	Concerns regarding how best to manage PHR-enabled email communications from patients
	How to address demand for real-time access to clinical data by others, including outside clinicians and caregivers
	How to minimize technical issues with accessing the system

need to ensure that clinical information is delivered to patients in a systematic, accurate and reliable way is incontrovertible in policy and practice guidelines. Yet, there currently exists a real tension in deciding a standard requirement for the types of information to be available through PHR.

With limited formal data concerning patient experiences with PHR, we recommend that clinicians should fully comprehend and educate their patients as to what clinical information will appear in the PHR, so that patients can proactively determine which data points to review and when to review them. In our evolving experience, many of our patients now avoid reading new MRI surveillance reports until they present to clinic, so that results are first reviewed in concert with the neuro-oncologist. Those patients that wish to review results in their PHR prior to their appointment are encouraged to refrain from emailing questions ahead of time, to allow for a face-to-face discussion of their results after they are reviewed in full. In the future, with the availability of these technologies, we recommend that patients should be able to individualize upfront within a PHR what types of information they want immediate or delayed access to, and the ability to offer extension of PHR access to caregivers, family members and friends.

Ideally, as EMR-integrated PHR becomes more commonplace, prospective analyses will best inform the design and implementation of health information technologies,

taking into account the needs of specialized clinical populations, such as neuro-oncology patients, technical aptitude of system users, and clinical concerns of practitioners. In the absence of such data, we suggest active input from clinicians and ongoing evaluation from users to drive formative assessments and appropriate system revisions. Modifications and adjustments should proceed in concert with clinical staff, based on their observations of patient-caregiver experiences.

PHR that is fully integrated and in real-time with our institutional EMR has shown immense potential to serve clinicians and patients alike; but may also create a different set of hazards, previously unanticipated, that must be identified and managed. Uncoordinated access to clinical imaging, laboratory and pathology results, and specialty reports such as surgical procedure narratives, can induce distress and anxiety for neuro-oncology patients and transform the clinical encounter; not because of a lack of clinical information, but because patients may be overwhelmed by the language, content, or complexity of its meaning.

In closing, it remains an enduring point that the neuro-oncology care team is best prepared to actualize good outcomes and promote patient participation in care by assessing individual needs and preferences for information. Members of the neuro-oncology team are well-appointed to evaluate patients' and caregivers' capacities to receive information and to make adjustments on the dissemination means based on the patient's understanding and stated preferences. The neuro-oncology team's comprehensive expertise and experience with a spectrum of related cases generally provides an important infrastructure for plausible expectations about the disease that cannot be adequately delineated to the patient in radiology, pathology, and other clinical reports. The highly-technical clinical data contained within the PHR by itself is insufficient in establishing and cultivating an information conduit for the patient and can never replace communication of critical health-information by the practitioner. Instead, the contribution of PHR to the clinical care of the patient must be as a complement to the patient's existing health and psychosocial support frameworks [10]. The concerns of clinicians that early versions of these healthcare technologies may inadvertently compromise patient's best interests is legitimate. While debates concerning conflicts with these fundamental principles tend to have a high degree of subjective and emotional input, we advocate for a pragmatic and data-driven focus on the improvement of these tools to better serve our patients.

Conflict of interest The authors declare that they have no conflict of interest.

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