The Information Age, Cyberspace, and Cancer

By Edward P. Ambinder, MD | April 17, 2012

Department of Medicine and the Tisch Cancer Institute, Mount Sinai School of Medicine, New York, New York

We are living in unprecedented times, in which oncologists and their patients are facing disruptive changes in healthcare, research, education, governmental politics, business, communication, and finance—changes brought on by the individual growth and merging of the fields of information technology, biology, and physics. This dramatic increase in the quantity, quality, and ease of finding information—and the effortlessness of connecting everyone and everything—all of which has been brought about by the Internet, has changed our lives forever. However, many of us remain frustrated with our inability to control this information overload in a time-limited living situation.

Our medical profession is under constant disruption as we practice in large, multi-discipline, accountable care organizations rather than in small silos; document our patient care using electronic media rather than paper; and see the doctor-patient relationship become more patient-centric. We are increasingly communicating electronically with all health care stakeholders, including our patients.

Clayton Christensen presciently warned us about the disruptive effects of this transformation in 1997[1] and he warned us specifically about its effects on healthcare in 2008.[2] Indeed, for the first time, this new, disruptive digital world is increasingly defined by information’s becoming electronically mobile, cheap, available to all, and consumer-oriented to such an extent that almost all recent information technology advances in hardware and software begin with the consumer rather than the computer professional or big business. Cancer doctors and their patients must begin to understand where we are headed to better prepare for this new world.

For most of the Information Age, chemotherapy drugs, along with surgery and radiation therapy, have been our major cancer treatments. We are frustrated with chemotherapy’s ineffectiveness because “one size” does not fit all patients—and because in our practices we lack interoperability (ability to send data from one computer to another with true understanding of the data content’s meaning); standardized labeling and descriptors of cancer data; and inexpensive, user-friendly electronic oncology tools. With one notable exception—the gene sequencing technologies that are enabling oncologists to begin to molecularly stage patients and thus make more precise diagnoses and prognoses and choose more effective therapies—medicine, compared to almost all other professions, has been a laggard when it comes to adopting and adapting to technology’s transformative effects.

Cancer doctors in the past have been strongly reproached by the Institute of Medicine for not using health information technology effectively and for not providing cancer patients with helpful information.[3] Specifically, the criticism centered on our not giving cancer patients adequate guidance about their proposed cancer treatment and guidance for the period that followed completion of their therapy and return to their primary care physician. In response, the American Society of Clinical Oncology (ASCO) has developed a patient and referring physician report that defines a Cancer Treatment Plan and a Cancer Patient Survivorship Plan, and these reports have been incorporated into many oncology electronic health records (EHRs).[4] Unfortunately, too few of us are using them effectively.[5]

The Three Chief Elements of Health Information Technology

There are three major standardized features of health information technology. First is the common data element that defines the data to be collected in the medical record and the specific identifying label of each data field. It includes the clinical vocabularies used to describe the clinical encounter (eg, SNOMED-CT) and the laboratory data (eg, LOINC), terms describing basic and clinical research activities (eg, cancer Biomedical Informatics Grid [caBIG]), and elements and codes that define specific disease classifications used for mostly billing and registry purposes (eg, ICD-9 and ICD-10 codes). Next are the software functionalities that refer to what tools and capabilities a software program should have. Finally, there is interoperability, which defines how the data created in one EHR can be sent to another EHR with full understanding of their meaning so that they will be placed in the appropriate data fields of the receiving program. ASCO, through its Health Information Technology Working Group, of which I am a member, and the National Cancer Institute's caBIG and Community Cancer Center Program created the Clinical Oncology Requirements for the EHR (CORE) that delineated the core common data elements, functionalities, and interoperability standards that have helped define oncology EHR certification criteria used by the Certification Commission for Healthcare Information Technology (CCHIT) and that will guide future software design for the oncology community.[6]

The Move From “Old to “New” Technologies: the Influence of Consumers and Mobile Devices

Today, general-purpose Windows and Mac OS X computers are the machines most commonly used for EHRs. These computers can do hundreds of thousands of different things, sometimes all at the same time, although users of non-Mac computers pay for this capability with instability, perfor-
mance degradation, viruses, and steep learning curves. These computers can do pretty much anything, but they carry the burden of 30 years of rapid, unplanned change. Many physicians are frustrated with a lot of the existing EHR software choices that rely on the existing PC and Mac paradigm that uses windows, icons, menus, and pointers (WIMP) for human-computer interaction. This older technology requires huge initial costs ($88,000 to $100,000 per physician for EHR startup expenses), is difficult to navigate (through the different parts of the program), and lacks interoperability. It requires indeterminate training periods, impedes office workflows, is frequently abandoned (20% or higher abandonment rates), and has poor learning recall without constant use. Since most programs are proprietary, a practice is locked into the tool sets of the purchased program and is unable to substitute an easier and better software tool when it comes along. Customization is cumbersome, and huge expenses are incurred if one wants to interface the EHR with other medical software. In addition, existing EHRs do a poor job of providing meaningful and sophisticated decision support tools, electronic guidelines and technology assessment tools, authoring and customization tools, easily customized report writers, point-of-service links to educational resources for physicians or patients, seamless communication and messaging services between health care stake holders, and coordination of care capabilities.

Patients also are frustrated with the older technology. As they rapidly adopt smartphones and tablets that provide instant-on, instant-off, multi-touch, multi-sensor, and multi-communicator cloud-based computing; new voice interfaces, such as Siri on the iPhone; and the app model of purchasing software for simple “plug and play,” consumers are witnessing the future of integrated computer hardware and software, coordinated through the cloud, in which inexpensive devices and their software become more humanly natural in operation.

Medicine is also following this trend, as some EHR vendors are beginning to provide access to their programs via iPhones, iPads, and Android devices, and others are calling for an Apple-like app platform for EHRs.[7]

As a long-time observer of health information technology and an oncologist who has used both the old and new interfaces created by the same company for identical functionality, I am a convert to the new system. Now, I just pick up any of my devices, turn it on, and instantly use the software with a smile on my face—without reading help manuals or attending interminable classroom lectures. I easily navigate to the appropriate places in the program from almost any location in the world, confident that the program is backed up in the cloud and easily updated so that I always have the latest version of the software on any of my devices.

**EHRs and PHRs**

Patients will continue to take a more responsive role in health care as they pay a larger share of its cost, make known their values and wishes, and help make key decisions. With the unlimited educational resources of the Internet, our patients have access to the same medical literature and textbooks that we have. With meaningful use requirements for providing electronic patient reports to the patient, with the Centers for Medicare and Medicaid Services (CMS) proposing that patients have access to their laboratory test results, with emailing between patients and oncologists becoming commonplace (and reimbursable with some payers), and with most medical reports becoming available in digitized form, patients will be in control of their medical record. A pilot project that makes almost the entire medical record electronically available to patients has been successfully implemented at the MD Anderson Cancer Center; the majority of patients are more than satisfied, and most doctors, many of whom were skeptical initially, have become converted proponents of “open access” care. In addition, the health care system has become more cost-effective and safer.[8]

As patient information becomes digitized and is sent electronically to them by hospitals and providers, patients will need to create a personalized electronic patient personal health record (PHR) to hold these data and their own patient-derived data. Patient portals, such as Microsoft’s HealthVault, have begun to provide functionalities to help the patient, but the record collection and collation process is still cumbersome, especially given that most medical data today still reside on paper.[9] Aegis Review, a virtual cancer second opinion and navigator company, has an efficient method of using a case manager and medical scribe to collect and organize a cancer patient’s record and to then create a secure and shareable electronic PHR.[10] Hopefully the future will see the seamless integration of the EHR with the PHR.

**Rapid Learning Systems**

As cancer patients increasingly have their medical records digitized, it becomes obvious that there is a treasure trove of clinical data in these records that have the potential to benefit society by opening up what happens to the 97% of cancer patients who do not go on clinical trials. By learning about the comparative benefits or harm of our new treatments and procedures in non–clinical trial patients after these therapies have been granted regulatory approval, we can apply findings and improve treatments on a continuous, ongoing basis.

The National Cancer Policy Forum of the Institute of Medicine workshop entitled “A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care”[11] examined the elements of a rapid learning system for cancer. It recommended that the elements of such a system include: registries and databases, emerging information technology, tools for patient-centered and patient-driven clinical decision support and patient engagement, ways of accommodating culture change, clinical practice guidelines, point-of-care needs in clinical oncology, and federal policy issues and implications. ASCO and others have begun to define a Rapid Learning System for Cancer.[12] It will use the tools of the Information Age to develop a more thorough understanding of cancer biology, defining a cancer based on a molecularly-driven diagnosis; it will also incorporate a therapeutic development system that uses oncology EHR registries to produce smarter and faster clinical trials. Because of its more seamless integration of clinical and translational research, it has the potential to ensure that every cancer patient’s experience can inform research and improve care and help us take full advantage of the wonders of the Information Age and cyberspace.[13]

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