

Pediatric Palliative Care and eHealth Opportunities for Patient-Centered Care

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Background: Pediatric palliative care currently faces many challenges including unnecessary pain from insufficiently personalized treatment, doctor–patient communication breakdowns, and a paucity of usable patient-centric information. Recent advances in informatics for consumer health through eHealth initiatives have the potential to bridge known communication gaps, but overall these technologies remain under-utilized in practice.

Purpose: This paper seeks to identify effective uses of existing and developing health information technology (HIT) to improve communications and care within the clinical setting.

Methods: A needs analysis was conducted by surveying seven pediatric oncology patients and their extended support network at the Lombardi Pediatric Clinic at Georgetown University Medical Center in May and June of 2010. Needs were mapped onto an existing inventory of emerging HIT technologies to assess what existing informatics solutions could effectively bridge these gaps.

Results: Through the patient interviews, a number of communication challenges and needs in pediatric palliative cancer care were identified from the interconnected group perspective surrounding each patient. These gaps mapped well, in most cases, to existing or emerging cyberinfrastructure. However, adoption and adaptation of appropriate technologies could improve, including for patient–provider communication, behavioral support, pain assessment, and education, all through integration within existing work flows.

Conclusions: This study provides a blueprint for more optimal use of HIT technologies, effectively utilizing HIT standards-based technology solutions to improve communication. This research aims to further stimulate the development and adoption of interoperable, standardized technologies and delivery of context-sensitive information to substantially improve the quality of care patients receive within pediatric palliative care clinics and other settings.

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Introduction

Pediatric palliative care is a comprehensive treatment regimen designed to relieve suffering and to improve quality of life for children facing serious illnesses. This multidisciplinary field extends beyond merely pain alleviation, encompassing both management of symptoms and psychosocial support for the patient and their family.^{1,2} Given the potential number of post-

treatment years for survivors, true palliative care requires monitoring and remediation for both relapse and treatment-induced risks throughout the patient's life.³

Pediatric palliative care has distinct communication challenges, as care must be coordinated through various stakeholders including the child, family, healthcare professionals, chaplains, social workers, bereavement counselors, and school staff.⁴ The seamless flow of information among different parties involved is critical to enable personalized care for the child.^{5–7} This can be enabled through the strategic use of health information technology (HIT).⁸

The purpose of this study is to address the question of how current and emerging connective information technologies⁹ can be used to improve consumer health. The definition used here of HIT encompasses a very broad swath of applications ranging from the public-facing in-

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terfaces of eHealth (defined as health services and information services delivered or enhanced directly through the Internet^{10,11}) to the clinically oriented service environment enabled by a foundation of meaningful use for electronic medical records (EMRs).^{12,13} Also included in this sphere of analysis is the support afforded directly to patients through secure messaging systems,¹⁴ “tethered” personal health records (PHRs),^{15,16} and patient education portals.^{17–19}

At first blush, it may not be apparent how the “high touch” practice of pediatric palliative care may be benefited by an infrastructure of HIT. However, it is well established that pediatric palliative care places a premium on effective communication and a multidisciplinary approach to caring for the whole family throughout the entire care continuum.^{20,21} From diagnosis to survivorship, families face a plethora of communication challenges, underscoring the need for integration of care through effective and meaningful use of HIT to ensure compassionate, patient-centric care.²² It is within this area that the present study is conducted.

Methods

A prospective needs analysis was conducted using a contextual inquiry approach among seven pediatric oncology patients, their respective clinical care team (two to three staff members) and parents or caregivers within an existing clinical environment to observe firsthand all facets of their care. Interviews were conducted at the Lombardi Pediatric Clinic at Georgetown University Medical Center in May and June of 2010, with oncology patients aged 4–19 years. The selection criteria for patients involved: (1) broad enough age range to allow for varied exposures to technology; (2) sufficient time of engagement with the clinic—at least 6 months of engagement was necessary to assess communication challenges through diagnosis, treatment, and survivorship; and (3) a verbal consent to participate in the interviews. The semi-structured interviews for this observational study were conducted face-to-face and lasted approximately 20 minutes each. Interviews included key thematic questions to understand clinical condition, communication challenges with clinical staff, use of technology to manage care, coordination and communication. The characteristics of the patients interviewed can be seen in Table 1.

Approval for this small-scale, qualitative study was obtained through the Georgetown IRB. As part of routine clinical care, the pediatric oncology clinic at Lombardi talks to families and children to obtain information on how they track information such as drug dosages, drug intervals, and symptom tracking. The study was integrated into routine care, and patients and parents were asked about their technology medium of choice (phone, Internet, hard copies) for receiving clinical information. No protected health information data were collected as part of this study. Within this setting, a wide range of communication needs were discussed with not only the patients, but also their support networks including parents, nurses, physi-

Table 1. Characteristics of patients interviewed in this study

Patient	Gender	Age (years)	Status at interview
GUI0001	Male	4	Post-treatment
GUI0002	Male	5	Post-treatment
GUI0003	Female	17	Post-treatment
GUI0004	Female	19	Post-treatment
GUI0005	Male	17	Pre-treatment
GUI0006	Male	14	Post-treatment
GUI0007	Female	6	In treatment

cians, chaplains, social workers, and other direct care providers (when available).

Patients represented a variety of stages within the cancer care continuum (Figure 1). In all cases, interviews began with a set of questions regarding diagnosis and treatment (age, type of cancer, date of diagnosis, types of treatment obtained) to establish rapport. Thereafter, participants were asked a series of leading questions regarding tools and techniques they used to communicate with the clinical care team, their parents, family and friends—especially as those communications pertained to the tracking of symptoms and treatments. They were also asked to identify any communication gaps that existed between themselves and their care team. Similar questions were posed to the parents and other available family members of these children. Members of the extended care team were also interviewed to ascertain their viewpoint on existing communication issues, and to confirm the responses of the patients.

Once the analyses of patient needs were completed, the technical members of the study team conducted a comprehensive systems analysis to determine the points of development needed to support optimal care in pediatric oncology. To do this, the team relied on an extensive search of research articles available through PubMed as well as technical policy documents obtained from the Office of the National Coordinator for Health Information Technology, the National Academies of Science, and the U.S. President’s Council of Advisors on Science and Technology. The goal was to identify the relevant technologies implicated by the stakeholders’ expressed needs, and to create a provisional blueprint for future development and implementation to meet these needs. In Table 2, a list of some of the primary examples of these technologies is offered along with an indication of the primary targeted user, the permissions generally granted to those users, key functions, and examples of products in place.

Results

Communication Needs Assessment

The survey results confirmed those seen in the existing literature documenting the critical communication priorities in this care setting and showing the multifaceted nature of pediatric palliative care communication (as illustrated in Figure 1).²³ It should be noted that not only is the information flow complex in content, but also there is

a need to circulate information to various entities in a timely manner. The arrows in Figure 1 represent information flow among the care team, patients, and their social network. Key themes highlighted in the interviews included facilitating continuity of care across practices (e.g., between oncologist and primary care pediatrician), symptom tracking and management (e.g., a child’s report of pain level to a nurse), access to the care team (e.g., a parent’s ability to reach the attending physician in a timely manner), efficient access to test results, and social and emotional support for the whole family. To facilitate description, the findings of communication and information needs have been generalized into three phases along the cancer continuum—diagnosis, treatment, and survivorship.

Diagnosis. In the interviews, date of diagnosis figured prominently. The description usually began with visiting a pediatrician regarding abnormal symptoms resulting in follow-ups with an oncologist. The diagnosis was delivered in person or via phone by a cancer center attending physician. Patients and families reported a wide range of communication patterns and preferences as they sought to make the initial treatment decisions. While most agreed that important news, such as a change in prognosis, should be delivered in person, discussions on other information needs showed a spectrum of preferences. Some parents reported relying

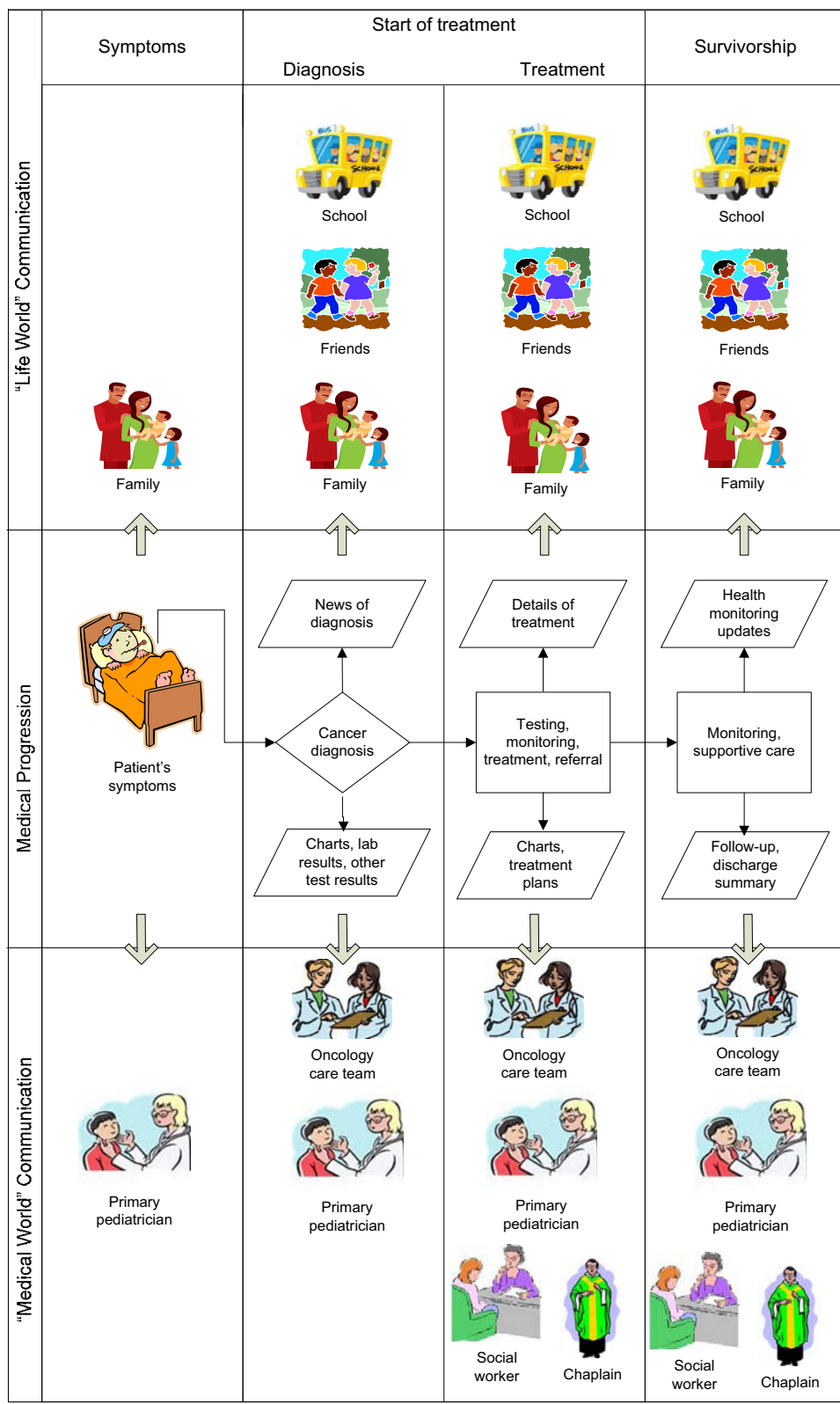


Figure 1. Information flow within the cancer care continuum

almost exclusively on information delivered directly from the care team. Others described gathering information from outside sources (e.g., the Internet).

Table 2. Existing and emerging technology options within the HIT portfolio

Type of HIT	Primary user(s)	Permissions	Key functions	Example of commercial and organizational solutions
Clinical information exchange				
EHR	Clinical team	Full read/write	Storage of demographics, history, and test results to be used for patient care	Epic, GE Centricity, Allscripts
Patient portal (off EHR)	Patient	Read + supported interactions	Ability for the patient to remotely access subsets of data from an HER (ex lab results), request appointment, or submit intake forms	Medical Web Experts Patient Portal, GE Centricity, Patient Online
PHR	Patient	Full read/write	Patient-controlled record where information is imported from other types of records or entered by the patient	Google Health program, SmartPHR
Tethered PHR	Patient Clinical team	Read + supported interactions Full read/write	Typically sponsored by an employer, healthcare payer, or insurer. Allows patients to enter their own information but also receives information from different sources like doctor's office, a lab, or a hospital that they were in.	Veteran's Health Administration's My HealtheVet
Social support				
Information-sharing portals	Patient or immediate family	Read/write	Ability to share news of treatment with many by entering data only once	www.caringbridge.org
Online peer-to-peer support groups	Patient or family or physician	Read/write	Provides a medium for those invested in cancer to support one another via online communication	www.candlelighters.org

EHR, electronic health record; HIT, health information technology; PHR, personal health record

Treatment. When discussing treatment, families often described spending countless hours in hospitals. Time spent in the hospital placed stress on the whole family, as parents and siblings frequently wait with the patient, and the hospital setting often produces both physical and social isolation. A commonly cited reason for time spent in the hospital was waiting for lab results. Multiple parents mentioned a desire to return home and receive test

results through another medium such as e-mail, especially as routine tests at later stages of treatment often showed no changes.

Tracking symptoms, drug dosages, and adverse events was a challenging endeavor for parents during the treatment phase. Visiting different doctors required a complete list of current medications and previous treatments. Parents expressed interest in having such information

readily available for the referred physician. Some parents reported that hand-delivery of records was, in cases, substantially quicker than exchange through standard clinical channels.

The methods by which parents attempted to recall recent symptoms varied considerably. Some maintained calendars and journals; others used computer-based technologies to assist the recording and maintaining of records; and others simply relied on memory. While many such methods appeared to function to a degree, it was evident that an easy-to-use technology solution that standardizes information capture would be preferable.

Parents commented on their preference for receiving crucial diagnoses electronically and the importance of communicating with the attending physicians in person or by phone at the point of receiving a diagnosis. When in-person delivery is not an available option, any electronic delivery of diagnostic news must be accompanied by a functional support structure to assist clinical decision making. Ameliorative process changes might include providing more patient education up-front about risks or adverse outcomes, and ensuring availability by psychosocial support teams prior to and during delivery.

Survivorship. After treatment, patients return to their pediatricians while being monitored by their oncologists. Patients spend substantially less time in the hospital, although many still reported notable logistic issues. Treatment history and symptoms need to be communicated to the primary care pediatrician for effective care to be rendered (e.g., a higher dosage of opioids when needed and tolerated). Lines of communication need to remain open as the patient encounters new symptoms, signs of recurrence, or is simply struggling to cope with the psychosocial impact of a serious illness.

Systems Analysis

In light of the communications needs assessment, and a review of existing technologies, the following section offers a set of observations and recommendations to help spur the use of HIT applications in the development of a more-effective system for patient-centered pediatric palliative care. In general terms, HIT has the potential to improve care by making patient records readily accessible to patients, families, and healthcare teams. In addition, HIT contributes to patient-centered care by facilitating direct communication among members of the care team (including patients and caregivers), supporting proactive health behaviors through reminder systems and decision supports, improving the quality of care through patient-reported outcomes, and finally, supporting general educational and psychosocial needs.

In this analysis, four specific issues were identified in the use of HIT and cyberinfrastructure to support pediatric palliative care: (1) extending the flexibility of supported interactions; (2) building a foundation for standards-based information dissemination; (3) addressing issues of universality in information representation; and (4) advancing patient care within the context of a fully realized cyberinfrastructure.

Extending the flexibility of supported interactions. A number of new technologies are being developed to extend the flexibility of information systems to support crucial interactions. For example, a secure patient portal has been used with some success to allow patients to review components of their own EMR remotely²⁴ with an interface similar to secure online banking sites. A patient portal could reduce the time spent waiting in a clinic for test results by making them accessible online, thus reducing the logistic challenges faced by these patients and their caregivers.

The lines between different types of technology become blurred as vendors strive to improve support for crucial health interactions. For example, some tethered PHR systems allow users to enter data that can then be imported into their EMR pending confirmation from both the patient and the clinician.²⁵ This method of obtaining patient-reported data can facilitate the capturing and sharing of at-home symptom monitoring such as subjective reports of pain level or physiologically recorded vital signs, hence improving family–clinician communication. Such patient-generated data have been validated as high quality²⁶ and could lead to better care management and decision making. These reports might be collected from patients through mobile devices (e.g., iPod, smartphone, iPad), an approach that could take full advantage of existing consumer electronics.

Building a foundation for standards-based information dissemination. In a report to the U.S. President and Congress, the President's Council of Advisors on Science and Technology (PCAST) emphasized the role of data standards to improve the transmission of data among health information systems. Standards in electronic data interchange would allow the private sector to innovate, while guaranteeing that information passes among systems seamlessly and transparently. Moreover, the development of standard meta-data to record the results of privacy and consent decisions would further ease the burden on transmitting data for research and practice while honoring patients' disclosure decisions. Just as the development of standards for hypertext markup language (html) helped the web flourish organically, development of standard practices for exchanging health data—the PCAST argued—would help spawn

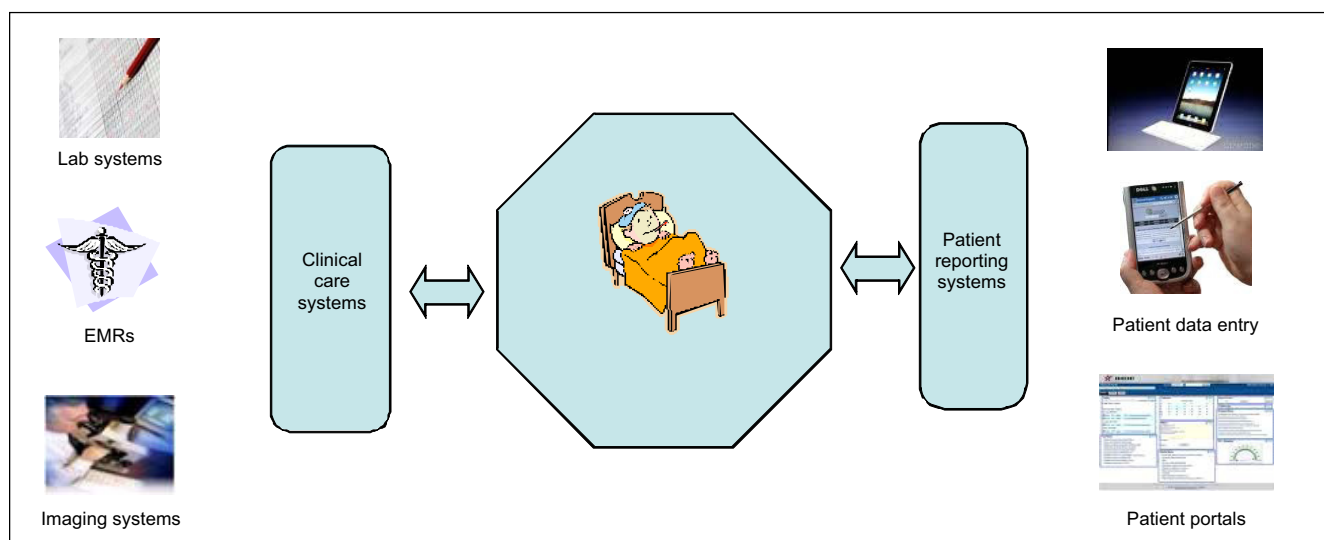


Figure 2. Clinical care and patient reporting systems
EMR, electronic medical record

innovation within HIT ecosystem while also serving to protect the privacy concerns of consumers.²⁷

According to the PCAST report, standardized rules for electronic data interchange are needed to ensure that a patient's health record can be transported across systems over the life span. This notion is especially important in pediatric oncology, where survivors may have their whole lives ahead of them. Interoperable data systems will allow support teams to help the cancer survivor keep close tabs on potential late-stage side effects, recurrences of the initial cancer, or to be primed for the occurrence of new secondary cancers. The data systems could also inform social service providers to ensure that the needs of the "whole patient"² are met; including the psychological needs of adults who had experienced some level of trauma in their earlier lives.

Addressing issues of universality in information representation. Pediatric palliative care is a team-based activity that includes the patient, the family, and the entire clinical care team (Figure 2). Given the variation in clinical knowledge within the team and the varying expertise in different aspects of care, it is vital that members achieve a shared understanding of the child's condition. Two different technology resources can facilitate this process: controlled terminology and user-targeted content.

Controlled terminologies, which would provide more precise descriptions than free text of a patient's condition, medications, and treatments prescribed, should be available from within EMRs. Use of a controlled terminology such as Systematized Nomenclature of Medicine—Clinical Terms (SNOMED CT®) allows for different levels of detail to be expressed in the user interfaces of

applications like the EMR or PHR to support the level of detail needed by different users.

This precise framework addresses specialists' need for detailed information, while patients and other care providers will appreciate more readily understandable vocabulary options.

User-targeted content refers to the availability of high-quality medical information targeted for specific audiences. A good deal of health content is already available on the open web, but the deluge of information is often confusing to patients. A solution is to target the content to patients as needed. For example, the Health Level (HL) 7 Context Aware Information Retrieval standard (known as "InfoButton") enables user-oriented content related to specialized clinical terms to be made readily accessible in user interfaces.²⁸ Data collected within the National Cancer Institute's Centers of Excellence in Cancer Communication Research suggest that targeting information to users' specific context can improve understanding, spur motivation, and reduce disparities.

Advancing patient care within the context of a fully realized cyberinfrastructure. Although efforts to this point have focused on making basic health information technologies **operable** within single-provider settings, future efforts will likely focus on making advanced applications **interoperable** within an evolving ecosystem of cyber-enabled care. Standardized mechanisms for electronic data transmission will allow patients to carry their records with them from provider to provider, even if that means sharing some part of their personal data with securely protected "cloud services" to transport information from wholly integrated care systems to single, outpatient providers. Advances in consumer electronics may

easily extend the functionality of data-enriched care systems into the home; or on the road, as when going off to school or when visiting family. Interconnected pharmaceutical systems could begin to document side effects and errors when they occur in close to real time, much in the same way that Internet-enabled software applications push error messages to vendors in the service of quality improvement.

In fact, future improvement of the PHR could focus even more on further integration with other systems; including helping patients contact specialists, providing relevant medical knowledge, and automatically renewing prescriptions. The information could prompt specific recommendations for care. Eventually, other factors such as the patient's location and logistic characteristics could also be integrated. Such functions of PHRs could help for simplifying the multifaceted care plan that is often needed to guide palliative care in pediatric oncology.

Discussion

This report discusses the means by which an array of existing and emerging HIT options can be marshaled to improve the care of individual patients; to improve health outcomes when at all possible and to improve quality of life even when improved health outcomes are not possible. The true contributions from cyber-enabled health care are likely to play out “behind the scenes,” as when the data collected through EMRs can help inform quality improvement⁶ in a true “learning healthcare organization”^{29–31} or when patients and their loved ones turn directly to the social sphere of the Internet to seek solace, answer questions, and offer their own contributions back to their communities.^{32,33}

This less-prominent role of HIT in no way minimizes the overall value to the healthcare system that these systems will provide. When properly deployed, a health-related cyberinfrastructure can be used to trigger reminders for important medical events³⁴ (e.g., an age-triggered reminder for a mammography test); offer cognitive support for decision making³⁵; support case management, especially in the context of the “medical home” in primary and specialty care^{36,37}; provide a conduit for clinical data aggregation³⁰; and offer a protected channel for person-to-person communication through secure electronic messaging.^{14,38}

One of the primary challenges in advancing the utility of HIT has to do with creating an interoperable ecology in which data from the various components within the ecosystem can interact effectively and reliably.^{27,39} This is why a key part of the national strategy is to promote interoperability of electronic records into a health production system based on electronic health records

(EHRs).^{12,13,40,41} Because of their transportability, EHRs could follow a pediatric cancer survivor throughout life across systems and places.^{8,36} Such a system could be built on the premise of a proactive survivorship care plan to ensure that quality of care does not lapse between health systems.³ This is the premise behind the pilot program “Passport for Care,” an Internet-based pilot program designed to undergird all future care decisions with a persistent record of care and a ubiquitous reliance on a proactive care plan.⁴²

Many systems are beginning to experiment with ways of opening up the value of the EMR and EHR to health-care consumers.²⁶ Integrated, or tethered, patient portals allow consumers to peruse vetted health education material online as needed for general information and emergencies.¹⁶ Others allow consumers to order prescription refills, make an appointment, report symptoms with an advice nurse, or communicate with physicians online.^{34,43} Some independent PHR systems give ownership of, and responsibility for, personal health information completely over to consumers.⁴⁴ While tethered records and patient portals offer similar functionalities, tethered PHRs are often used by clinical care teams to import relevant patient-entered information into an electronic health record for the patient and maintained by the clinical care team. These systems typically work best for the technologically savvy patient, as they require proactive care online with the patient or caregiver at the helm.

Nowhere has the social side of Internet-based technologies been more longstanding and useful as it has been for individuals suffering from an illness. Online support groups around a disease go back as far as the initial days of the Internet (the “electronic frontier”), but have expanded in reach and functionality with the popularization of social media.⁴⁵ Sites like “Caring Bridge” and “Candle Lighters” provide patients, families, acquaintances, and caregivers with an online forum for sharing experiences and expressing peer-to-peer social and emotional support. More recently, sites such as Patients-LikeMe have given individuals diagnosed with a specific illness (e.g., pediatric leukemia) access to an online venue for sharing data on conditions and comparing their responses to that of the larger group. The new models of patient engagement and data transparency are anticipated by many to continue to emerge as the population becomes more active in health-related issues online.⁴⁶

While the results show that pediatric palliative care communication can be improved using eHealth technologies, one recurring theme was that technology interventions can and must supplement and support, but cannot replace, personal interactions between the care team, patients, and families. Indeed, most of those interviewed reported that the attending physician was their most re-

liable and preferred source of information.⁴⁷ Further research into age-appropriate technology preferences for clinical communication, as well as modes of communication and standards in the health information communication space, should shed light on useful future directions for HIT product development. For this transformation to be successful, the needs of a variety of stakeholders must be simultaneously addressed.

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References

1. WHO. National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva, Switzerland: WHO, 2002.
2. Adler NE, Page A, National IOM (U.S.). Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. Cancer care for the whole patient: meeting psychosocial health needs. Washington: National Academies Press, 2008.
3. Hewitt ME, Ganz PA, IOM, American Society of Clinical Oncology (U.S.). From cancer patient to cancer survivor: lost in transition: an American Society of Clinical Oncology and IOM Symposium. Washington: National Academies Press, 2006.
4. Tercyak KP, Donze JR, Prahlah S, Mosher RB, Shad AT. Multiple behavioral risk factors among adolescent survivors of childhood cancer in the Survivor Health and Resilience Education (SHARE) program. *Pediatr Blood Cancer* 2006;47(6):825–30.
5. Taplin SH, Clauser S, Rodgers AB, Breslau E, Rayson D. Interfaces across the cancer continuum offer opportunities to improve the process of care. *J Natl Cancer Inst Monogr* 2010;2010(40):104–10.
6. Epstein R, Street RJ. Patient-centered communication in cancer care: promoting healing and reducing suffering. Bethesda MD: National Cancer Institute, 2007.
7. IOM Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century. Washington: National Academy Press, 2001.
8. Hesse BW, Hanna C, Massett HA, Hesse NK. Outside the box: will information technology be a viable intervention to improve the quality of cancer care? *J Natl Cancer Inst Monogr* 2010;2010(40):81–9.
9. National Science Foundation. Cyberinfrastructure vision for 21st century discovery. Arlington, VA: National Science Foundation, 2007.
10. Eysenbach G. What is e-health? *J Med Internet Res* 2001;3(2):E20.
11. Atienza AA, Hesse BW, Gustafson DH, Croyle RT. E-health research and patient-centered care examining theory, methods, and application. *Am J Prev Med* 2010;38(1):85–8.
12. Blumenthal D. Promoting use of health IT: why be a meaningful user? *Conn Med* 2010;74(5):299–300.
13. Blumenthal D, Tavenner M. The “meaningful use” regulation for electronic health records. *N Engl J Med* 2010;363(6):501–4.
14. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)*. 2010;29(7):1370–5.
15. Zhou YY, Unitan R, Wang JJ, et al. Improving population care with an integrated electronic panel support tool. *Popul Health Manag* 2011;14(1):3–9.
16. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak* 2008;8:45.
17. Mettler M, Kemper DW. Information therapy: health education one person at a time. *Health Promot Pract* 2003;4(3):214–7.
18. Strecher VJ, McClure J, Alexander G, et al. The role of engagement in a tailored web-based smoking cessation program: randomized controlled trial. *J Med Internet Res* 2008;10(5):e36.
19. Strecher VJ, McClure JB, Alexander GL, et al. Web-based smoking-cessation programs: results of a randomized trial. *Am J Prev Med* 2008;34(5):373–81.
20. Knapp C. e-Health in pediatric palliative care. *Am J Hosp Palliat Care* 2010;27(1):66–73.
21. Zhukovsky DS, Herzog CE, Kaur G, Palmer JL, Bruera E. The impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions in pediatric patients with cancer. *J Palliat Med* 2009;12(4):343–9.
22. Foley KM, Gelband H, National Cancer Policy Board (U.S.), National Research Council (U.S.). Improving palliative care for cancer: summary and recommendations. Washington: National Academies Press, 2001.
23. Knapp CA, Madden VL, Curtis CM, Sloyer P, Shenkman EA. Family support in pediatric palliative care: how are families impacted by their children’s illnesses? *J Palliat Med* 2010;13(4):421–6.
24. The National Alliance for Health Information Technology. Defining key health information technology terms. Washington: The National Alliance of Health Information Technology, 2008.
25. Daniel J, Posnack S. Health information security and privacy collaboration: plain language guide. Washington: Health Information Security and Privacy Collaboration, 2009.
26. Hayrinen K, Saranto K, Nykanen P. Definition, structure, content, use and impacts of electronic health records: a review of the research literature. *Int J Med Inform* 2008;77(5):291–304.
27. President’s Council of Advisors on Science and Technology. Realizing the full potential of health information technology to improve health-care for Americans: the path forward. Washington: Executive Office of the President, 2010.
28. Cimino JJ. Infobuttons: anticipatory passive decision support. *AMIA Annu Symp Proc* 2008:12034.
29. Abernethy AP, Ahmad A, Zafar SY, Wheeler JL, Reese JB, Lyerly HK. Electronic patient-reported data capture as a foundation of rapid learning cancer care. *Med Care* 2010;48(6S):S32–S38.
30. Abernethy AP, Etheredge LM, Ganz PA, et al. Rapid-learning system for cancer care. *J Clin Oncol* 2010;28(27):4268–74.
31. Etheredge LM. A rapid-learning health system. *Health Aff (Millwood)* 2007;26(2):w107–118.
32. Hesse BW, Arora NK, Beckjord EB, Finney Rutten LJ. Information support for cancer survivors. *Cancer* 2008;112(11S):S2529–S2540.
33. Chou WY, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social media use in the U.S.: implications for health communication. *J Med Internet Res* 2009;11(4):e48.
34. Friedberg MW, Coltin KL, Safran DG, Dresser M, Zaslavsky AM, Schneider EC. Associations between structural capabilities of primary

- care practices and performance on selected quality measures. *Ann Intern Med* 2009;151(7):456–63.
35. Patel VL, Zhang J, Yoskowitz NA, Green R, Sayan OR. Translational cognition for decision support in critical care environments: a review. *J Biomed Inform* 2008;41(3):413–31.
 36. Han PK, Rayson D. The coordination of primary and oncology specialty care at the end of life. *J Natl Cancer Inst Monogr* 2010;2010(40):31–7.
 37. Taplin SH, Rodgers AB. Toward improving the quality of cancer care: addressing the interfaces of primary and oncology-related subspecialty care. *J Natl Cancer Inst Monogr* 2010;2010(40):3–10.
 38. Beckjord EB, Finney Rutten LJ, Squiers L, et al. Use of the Internet to communicate with health care providers in the U.S.: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *J Med Internet Res* 2007;9(3):e20.
 39. President's Council of Advisors on Science and Technology. Designing a digital future: federally funded research and development in networking and information technology. Washington: Executive Office of the President, 2010.
 40. Brailer D. Interview with National Health Information Technology Coordinator David Brailer, MD, PhD. *BMJ* 2004;329(7471):E328–9.
 41. Brailer DJ. Translating ideals for health information technology into practice. *Health Aff (Millwood)* 2004;Suppl web exclusives: W4-318–20.
 42. Horowitz M, Fordis M, Krause S, McKellar J, Poplack D. Passport for care: implementing the survivorship care plan. *Journal of Oncology Practice* 2009;5(3):110–2.
 43. Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood)* 2009;28(2):323–33.
 44. Jones DA, Shipman JP, Plaut DA, Selden CR. Characteristics of personal health records: findings of the Medical Library Association/ National Library of Medicine Joint Electronic Personal Health Record Task Force. *J Med Libr Assoc* 2010;98(3):243–9.
 45. Rheingold H. *The virtual community: homesteading on the electronic frontier*. Rev. ed. Cambridge MA: MIT Press, 2000.
 46. Goetz T. *The decision tree: taking control of your health in the new era of personalized medicine*. New York: Rodale: Distributed to the trade by Macmillan, 2010.
 47. Hesse BW, Moser RP, Rutten LJ. Surveys of physicians and electronic health information. *N Engl J Med* 2010;362(9):859–60.

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