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Pediatric Palliative Care in the Age of eHealth: Opportunities for Advances in HIT to Improve Patient-Centered Communication

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Abstract

Pediatric palliative care is an organized method for delivering effective, compassionate and timely care to children with cancer and their families, but it currently faces many challenges despite advances in technology and health care delivery. A key challenge involves unnecessary suffering from debilitating symptoms, such as pain, resulting from insufficient personalized treatment. Additionally, breakdowns in communication and a paucity of usable patient-centric information impede effective care. Recent advances in informatics for consumer health through eHealth initiatives have begun to be adopted in care coordination and communication, but overall remain under-utilized. Tremendous potentials exist in effective use of health information technology (HIT) to improve areas requiring personalized care such as pain management in pediatric oncology patients.

This article aims first to identify communication challenges and needs in pediatric palliative cancer care from the perspectives of the entire group of individuals around the pediatric oncology patient, and then to describe how adoption and adaptation of these technologies can improve patient-provider communication, behavioral support, pain assessment, and education through integration into existing work flows. The goal of this research is to promote the value of using HIT standards-based technology solutions and stimulate development of interoperable, standardized technologies and delivery of context-sensitive information through user-friendly portals to facilitate communication in an existing pediatric clinical care setting.

Keywords

health information technology; palliative care; pain management; quality of care and care coordination; health information exchange

Introduction

Pediatric palliative care is a comprehensive treatment and care aiming to relief suffering and to improve quality of life for children facing serious illnesses. This multidisciplinary care extends beyond merely pain management but encompasses all symptom management and

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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 challenges, as care must be coordinated through various stakeholders including the child, family, health care professionals, chaplains, social workers, bereavement counselors, and school staff.⁴ The seamless flow of information between different parties involved is necessary to enable personalized care of the child.⁵ Information flow to and from the patient is one aspect of a communication environment designed to support true patient-centered care,⁶⁻⁷ and can be facilitated through the strategic use of health information technology (HIT).⁸

The purpose of this special issue is to address the question of how cyberinfrastructure, defined as the next generation of connective information technologies,⁹ can be used to improve consumer health. At first blush, it may not be apparent how the “high touch” practice of pediatric palliative care may be benefitted by an infrastructure of health information technology. We take as our definition of HIT, though, a very broad swath of applications ranging from the public-facing interfaces of “e-Health” (defined as health services and information services delivered or enhanced directly through the Internet¹⁰⁻¹¹) to the clinically oriented service environment enabled by a foundation of meaningful use for Electronic Medical Records (EMRs).¹²⁻¹³ We also include in our sphere of analysis the support afforded directly to patients through secure messaging systems,¹⁴ “tethered” personal health records,¹⁵⁻¹⁶ and patient education portals.¹⁷⁻¹⁹

This paper discusses how the new array of 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. We understand in undertaking this effort that the true contributions from a cyber-enabled healthcare may play out “behind the scenes,” as when the data collected through EMRs can help inform quality improvement⁶ in a true “learning healthcare organization”²⁰⁻²² 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.²³⁻²⁴

To accomplish this goal, we proceeded in three steps. The first was to conduct a needs analysis by going directly to a clinical environment where we are able to observe pediatric oncology care first hand, and where we were able to discuss patients’ communication needs directly with those participating in the care process. The second was to conduct a review of available Health Information Technologies, and from that review create inventory of enhanced capabilities to support ongoing quality improvement in palliative care. The third step was to conduct a systems analysis as a way of creating a blueprint for the use of cyberinfrastructure in supporting optimal care. Each of these steps will be discussed in detail below.

Communication Needs Analysis in Pediatric Palliative Care

Pediatric palliative care recognizes the importance of effective communication and a multidisciplinary approach to caring for the whole family throughout the entire care continuum.²⁵⁻²⁶ 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.²⁷

To obtain a patient's perspective on pediatric care, interviews were conducted at the Lombardi Pediatric Clinic with pediatric patients ranging from the ages of 4 to 17. Children interviewed were at various stages of the cancer care continuum (Figure 1). They were asked

questions regarding communication challenges they faced along with any tools and techniques they used to communicate with the clinical care team, their parents, family and friends. Similar questions were posed to the parents of these children. The care team including the chief oncologist, nurse practitioner, social worker and case worker were interviewed to identify their viewpoint. To maintain anonymity of the participants, we have generalized our findings of communication and information needs into three sections – diagnosis, treatment and survivorship.

Through our interviews, we confirmed the multi-faceted nature of pediatric palliative care communication (as illustrated in Figure 1), which echoes existing literature documenting the critical communication priorities in this care setting.²⁸ It should be noted that the information flow is not only complex in content, but that there is also 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 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 timely), efficient access to test results, and social and emotional support for the whole family (e.g., a child feels included amongst school peers during and after treatment). Specific needs related to diagnosis, treatment, and survivorship will be described below.

Diagnosis

In our interviews, parents and children often began their account of cancer with the date of diagnosis. The usual pattern started 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. The emotional result of receiving the cancer diagnosis was compounded by the need to make treatment decisions quickly. In many cases, this stress was reported to be lessened by the dedication of the care team who make themselves available for follow-up communications afterhours.

Patients and families reported a wide range of communication patterns and preferences. 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 almost exclusively on information delivered directly from the care team. Others described gathering information from outside sources - usually involving the Internet.

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, presenting a potential area for improvement. Multiple parents mentioned a desire to return home and receive test results, especially as routine tests at later stages of treatment often showed no changes. On the other hand, time spent waiting in the clinic does provide opportunities for hospital-provided social support and interactions among families and with the staff (e.g., Lombardi's art therapy program).

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

readily available for the referred physician. Some parents reported it was so time-consuming to get the records transferred between clinics that they preferred to hand-deliver the records themselves.

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 records, while 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.

Survivorship

After treatment, patients return to their pediatricians while being monitored by their oncologists. Patients spend significantly less time in the hospital, though many still reported long waits and cumbersome travel to the hospital for lab results. Patients typically have accumulated a complex medical history involving numerous treatments. Treatment history and personalized symptom management (e.g., a higher dosage of opioids when needed and tolerated) need to be communicated to the primary care pediatrician. 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.

A Review of Clinical Care and Social Support Technologies

There are many existing health information technologies and platforms that offer potential for use in pediatric palliative care. Clearly, ease of use and accessibility are critical features that distinguish a successful solution from this growing list of possibilities.²⁹ So, too, is the degree to which the systems are integrated with each other (i.e., interoperability); the degree to which systems offer full vs. partial views of the underlying data structures; and the locus of permission for access to, or control of the underlying data. In Table 1, we offer a list of some of the primary examples of these technologies along with an indication of the primary targeted user, the permissions generally granted to those users, key functions, and examples of products in place.

In the table we have separated the technologies into two broad camps: (a) technologies intended to support clinical information exchange and (b) technologies designed to offer social support. Under the initial category is the primary foundation represented by the Electronic Medical Record (EMR). The EMR serves as an information system replacement to the traditional paper chart containing the coded laboratory values, patient history, administrative notes, and other types of information populating the functional use of paper-based systems.³⁰ Once deployed, it becomes possible to use the foundation of a functional EMR to trigger reminders for important medical events³¹ (e.g., a life-triggered reminder for a mammography test); to offer cognitive support for decision-making;³² to support case-management, especially in the context of the “medical home” in primary and specialty care;³³⁻³⁴ to provide a conduit for clinical data aggregation;²¹ and to offer a protected channel for person-to-person communication through secure electronic messaging.^{14, 35}

As noted in a 2009 survey, the wide-spread use of fully functional EMR technology has been slow to diffuse, especially to small practice settings, in which providers must often cover the costs of technology maintenance and data entry.³⁶ Nevertheless, in hospital settings in which there has been a full diffusion of the technology, the initial findings are promising that a functional EMR will support better adherence to best practice guidelines and protocols.^{15, 31, 37} There is indication of cost savings too, as administrative waste is replaced with electronic efficiencies and error-prevention routines help avoid the downstream costs of deadly pharmaceutical interactions or medical error.³⁷⁻³⁹

Although a system-specific EMR is a good starting point for improved healthcare, it does not necessarily address the problem of patients leaving one system and traveling to another. 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, 33} 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 Such 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.⁴³ 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.^{31, 37} Some independent Personal Health Record (PHR) systems give ownership of, and responsibility for, personal health information completely over to consumers.⁴⁴ 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 Like Me*” 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

Creating a Blueprint for Pediatric Palliative Care

In light of the communication needs assessment and a review of existing technologies, we would like offer a blueprint to bring a new generation of HIT applications to bear in creating a system of patient-centered pediatric palliative care. In general terms, HIT has the potential in improving 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 between 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.

We further explore four specific issues in the use of HIT and cyberinfrastructure to supportive pediatric palliative care: (a) support for emerging interactions between different systems, (b) building a foundation for standards-based information dissemination, (c) addressing the dichotomy of information representation, and (d) looking to the next generation of PHR improvements.

Emerging Interactions: Tethered Records, Patient Portals and Mobile Devices

A number of new technologies are being developed with the aim to bridge the gap between different types of information technology systems serving patient needs. A secure patient portal (as illustrated in Table 1) would allow patients to view subsets of their EMR remotely⁴⁷ with an interface similar to secure online banking sites. As discussed, families frequently complained about the long wait to receive lab results. A patient portal could reduce this wait time by making test results accessible online. Other similar opportunities are plentiful.

The lines between different types of technology become blurred as vendors strive to increase product functionality. For example, tethered PHRs allow users to enter data into a system that can then be imported into their EMR pending confirmation from both the patient and the clinician.⁴⁸ This method of obtaining patient reported data can facilitate the capturing and sharing of at-home symptom monitoring such as pain level and vital signs, hence improving family-clinician communication. Such patient-generated data has been validated as high quality,⁴³ and could lead to better care management and shared decision-making.

The advent of devices such as the Apple iPhone/iPod/iPad®, Google smartphones, and other mobile computing platforms offers many future benefits to palliative care. A patient can use the same device for educational and entertainment applications, accessing PHRs, and real-time communication with caregivers. Establishing standards for communication that offer the lowest barrier to entry (e.g. Simple Mail Transport Protocol) will be a critical factor towards the success of such applications.

Standards-based information dissemination

Standard data sets enable members of the entire care team across care settings to have access to key clinical data. There are currently many standards development organizations (SDOs) developing specifications and standards to support healthcare informatics, information exchange, systems integration, and a wide spectrum of healthcare applications (e.g., Health Level 7 (HL7), the Health Information Standards Panel (HITSP)). PHR systems allow patients and caregivers to access routine test results and to update their symptoms, health status and advance directives.

Addressing the dichotomy of information representation

Pediatric palliative care is a team-based discipline including 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 targeted content.

Controlled terminologies should be used to describe a patient's condition in an EMR. Controlled terminology enables precisely-defined terms to describe a patient's condition, medications, and treatments prescribed. Use of a controlled terminology such as 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 terminology addresses specialists' need for detailed information while patients and other care providers will appreciate more readily understandable vocabulary.

The second resource is the availability of high-quality medical information targeted at specific audiences. A good deal of content is readily available on the web, but only through custom user or web interfaces. Standardized interfaces to this content enable its reuse in a variety of different healthcare IT settings. For example, the HL7 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.⁴⁹

The next generation of PHR improvements

The future improvement of PHRs could focus 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 logistical characteristics could also be integrated. Such functions of PHRs could help for simplifying the multifaceted care plan in pediatric palliative care.

Conclusions

While pediatric palliative care communication can be improved using eHealth technologies, one recurring theme underlying our needs assessment was that technology interventions must supplement and support, but not replace, direct and personal interactions between the care team and patients and families. Indeed, most interviewed reported that the attending oncologist was their most reliable and preferred source of information.⁵⁰ Further research in age-appropriate technology preferences for clinical communication, the most appropriate content and mode of communication, and standards in the health information communication space should shed light on future directions for HIT product development. For this transformation to be successful, the needs of a variety of stakeholders must be simultaneously addressed.

From a clinical care standpoint, eHealth technologies can improve quality of care provided, reduce medical errors and enable efficient communication between the specialty and primary care teams to support joint decision making. When eHealth technologies are used effectively for clinical care, high quality information can be gleaned at point of care to support future secondary uses of this information, such as for clinical research.

While use of standards, user-specific portals, and mobile health technologies can improve healthcare overall, concerns have been raised that emphasize unfavorable outcomes of technology use. For example, parents commented on the importance of communicating with the attending physicians in person or by phone at the point of receiving a diagnosis and their dispreference for receiving crucial diagnosis electronically. 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.

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References

1. World Health Organization. National cancer control programmes : policies and managerial guidelines. 2nd ed.. World Health Organization; Geneva, Switzerland: 2002.
2. Adler, NE.; Page, A.; National Institute of Medicine (U.S.). Committee on Psychosocial Services to Cancer Patients / Families in a Community Setting. Cancer care for the whole patient : meeting psychosocial health needs. National Academies Press; Washington, D.C.: 2008.

3. Hewitt, ME.; Ganz, PA.; Institute of Medicine (U.S.). American Society of Clinical Oncology (U.S.). From cancer patient to cancer survivor : lost in transition : an American Society of Clinical Oncology and Institute of Medicine Symposium. National Academies Press; Washington, D.C.: 2006.
4. Tercyak KP, Donze JR, Prahlad 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*. Nov; 2006 47(6):825–830. [PubMed: 16333821]
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):104–110. [PubMed: 20386059]
6. Epstein, R.; Street, RJ. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute; Bethesda, MD: 2007. 2007
7. Institute of Medicine (U.S.). Committee on Quality of Health Care in America. Crossing the quality chasm : a new health system for the 21st century. National Academy Press; Washington, D.C.: 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):81–89. [PubMed: 20386056]
9. National Science Foundation. Cyberinfrastructure Vision for 21st Century Discovery. National Science Foundation; Arlington, VA: Mar. 2007 2007
10. Eysenbach G. What is e-health? *J Med Internet Res*. Apr-Jun;2001 3(2):E20. [PubMed: 11720962]
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*. Jan; 2010 38(1):85–88. [PubMed: 20117562]
12. Blumenthal D. Promoting use of health IT: why be a meaningful user? *Conn Med*. May; 2010 74(5):299–300. [PubMed: 20509421]
13. Blumenthal D, Tavenner M. The “Meaningful Use” Regulation for Electronic Health Records. *N Engl J Med*. Jul 13.2010
14. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)*. Jul; 2010 29(7):1370–1375. [PubMed: 20606190]
15. Zhou YY, Unitan R, Wang JJ, et al. Improving Population Care with an Integrated Electronic Panel Support Tool. *Popul Health Manag*. Jul 26.2010
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. [PubMed: 18837999]
17. Mettler M, Kemper DW. Information therapy: health education one person at a time. *Health Promot Pract*. Jul; 2003 4(3):214–217. [PubMed: 14610991]
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. [PubMed: 18984557]
19. Strecher VJ, McClure JB, Alexander GL, et al. Web-based smoking-cessation programs: results of a randomized trial. *Am J Prev Med*. May; 2008 34(5):373–381. [PubMed: 18407003]
20. Abernethy AP, Ahmad A, Zafar SY, Wheeler JL, Reese JB, Lysterly HK. Electronic patient-reported data capture as a foundation of rapid learning cancer care. *Med Care*. Jun; 2010 48(6 Suppl):S32–38. [PubMed: 20473201]
21. Abernethy AP, Etheredge LM, Ganz PA, et al. Rapid-Learning System for Cancer Care. *J Clin Oncol*. Jun 28.2010
22. Etheredge LM. A rapid-learning health system. *Health Aff (Millwood)*. Mar-Apr;2007 26(2):w107–118. [PubMed: 17259191]
23. Hesse BW, Arora NK, Beckjord EB, Finney Rutten LJ. Information Support for Cancer Survivors. *Cancer*. 2008; 112(11S):2529–2540. [PubMed: 18428201]
24. Chou WY, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social media use in the United States: implications for health communication. *J Med Internet Res*. 2009; 11(4):e48. [PubMed: 19945947]

25. Knapp C. e-Health in pediatric palliative care. *Am J Hosp Palliat Care*. Feb; 2010 27(1):66–73. [PubMed: 20124252]
26. 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*. Apr; 2009 12(4):343–349. [PubMed: 19327071]
27. Foley, KM.; Gelband, H.; National Cancer Policy Board (U.S.). National Research Council (U.S.). Improving palliative care for cancer : summary and recommendations. National Academy Press; Washington, D.C.: 2001.
28. 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*. Apr; 2010 13(4):421–426. [PubMed: 20144024]
29. Stead, WW.; Lin, HS., editors. Computational technology for effective health care : immediate steps and strategic directions. National Academies Press; Washington, DC: 2009.
30. Shortliffe, EH.; Cimino, JJ. Biomedical informatics : computer applications in health care and biomedicine. 3rd ed.. Springer; New York, NY: 2006.
31. 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*. Oct 6; 2009 151(7):456–463. [PubMed: 19805769]
32. Patel VL, Zhang J, Yoskowitz NA, Green R, Sayan OR. Translational cognition for decision support in critical care environments: a review. *J Biomed Inform*. Jun; 2008 41(3):413–431. [PubMed: 18343731]
33. 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):31–37. [PubMed: 20386052]
34. 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. [PubMed: 20386048]
35. Beckjord EB, Finney Rutten LJ, Squiers L, et al. Use of the internet to communicate with health care providers in the United States: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *J Med Internet Res*. 2007; 9(3):e20. [PubMed: 17627929]
36. Jha AK, DesRoches CM, Campbell EG, et al. Use of electronic health records in U.S. hospitals. *N Engl J Med*. Apr 16; 2009 360(16):1628–1638. [PubMed: 19321858]
37. 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)*. Mar-Apr;2009 28(2):323–333. [PubMed: 19275987]
38. Cutler DM, Davis K, Stremikis K. Why health reform will bend the cost curve. *Issue Brief (Commonw Fund)*. Dec.2009 72:1–16. [PubMed: 19998565]
39. Cutler DM, Davis K, Stremikis K. The impact of health reform on health system spending. *Issue Brief (Commonw Fund)*. May.2010 88:1–14. [PubMed: 20491172]
40. Brailer D. Interview with National Health Information Technology Coordinator David Brailer, MD, PhD. *BMJ*. Oct 16; 2004 329(7471):E328–329. [PubMed: 15485937]
41. Brailer DJ. Translating ideals for health information technology into practice. *Health Aff (Millwood)*. Jan-Jun;2004 :W4–318-320. Suppl Web Exclusives. [PubMed: 15451963]
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):110–112. [PubMed: 20856747]
43. 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*. May; 2008 77(5):291–304. [PubMed: 17951106]
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*. Jul; 2010 98(3):243–249. [PubMed: 20648259]
45. Rheingold, H. The virtual community : homesteading on the electronic frontier. Rev. ed.. MIT Press; Cambridge, Mass.: 2000.
46. Goetz, T. The decision tree : taking control of your health in the new era of personalized medicine. Rodale : Distributed to the trade by Macmillan; New York, NY: 2010.

47. The National Alliance for Health Information Technology. Defining Key Health Information Technology Terms. The National Alliance of Health Information Technology; Washington DC: 2008.
48. Daniel, J.; Posnack, S. Health Information Security and Privacy Collaboration: Plain Language Guide. Health Information Security and Privacy Collaboration; Washington DC: 2009.
49. Cimino JJ. Infobuttons: anticipatory passive decision support. AMIA Annu Symp Proc. 2008;1203–1204. [PubMed: 18998777]
50. Hesse BW, Moser RP, Rutten LJ. Surveys of physicians and electronic health information. N Engl J Med. Mar 4; 2010 362(9):859–860. [PubMed: 20200398]

Figure 1.
Information Flow within the cancer care continuum.

Figure 2.
Clinical care and Patient reported systems.

Table 1

HIT Examples: targeted user, access, key functions, and sample products.

Type of Health IT	Primary User (s)	Permissions	Key Functions	Examples of commercial and organizational solutions
Electronic Health Record	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 EHR (ex lab results), request appointments, or submit intake forms	Medical Web Experts Patient Portal, GE Centricity Patient Online
Personal Health Record	Patient	Full Read / Write	Patient-controlled record where information is imported from other types of records or entered by the patient	Google Health, SmartPHR
-Tethered PHR	Patient Clinical Team	Read + supported interactions Full Read/Write	Typically sponsored by an employer, health care 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
Information Sharing Portals	Patient or Immediate Family	Read/Write	Ability to share news of treatment with many by only entering data once	http://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	http://candlelighters.org