MEDINFO 2001
V. Patel et al. (Eds)
Amsterdam: IOS Press

Reinventing Patient-centered Computing for the Twenty-first Century

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Abstract

Despite evidence over the past decade that patients like and will use patient-centered computing systems in managing their health, patients have remained forgotten stakeholders in advances in clinical computing systems. We present a framework for patient empowerment and the technical realization of that framework in an architecture called CareLink. In an evaluation of the initial deployment of CareLink in the support of neonatal intensive care, we have demonstrated a reduction in the length of stay for very-low birthweight infants, and an improvement in family satisfaction with care delivery. With the ubiquitous adoption of the Internet into the general culture, patient-centered computing provides the opportunity to mend broken health care relationships and reconnect patients to the care delivery process. CareLink itself provides functionality to support both clinical care and research, and provides a living laboratory for the further study of patient-centered computing.

Keywords:

Patient-Centered Computing; Patient Education; Internet

Introduction

The term "patient-centered computing" was popularized by Safran to remind the Medical Informatics community of the needs of patients—the most underutilized resource in health care delivery[1]. Early computing systems like CHESS demonstrated that such systems would be well-used and well-liked by patients.[2,3] However, over the past decade, while the health care delivery system has undergone dramatic changes and clinical computing technologies have matured, patients have remained forgotten stakeholders in health care relationships.

We believe that technology can play an important role in restoring relationships between patients and the health care system, and facilitate improvement in quality, cost, and patient satisfaction. The increasing ubiquity of Internet-enabled devices has created the foundation for ***eHealth***, which opens the possibility for revolutionizing health care delivery. In this paper, we describe the current state of patient-centered computing, a framework for supporting patient empowerment, our technical realization of this framework in the CareLink architecture, and the initial evaluation of this architecture in supporting neonatal intensive care.

Patient-Centered Computing

Although patient-centered computing was originally intended to connote the inclusion of patients as important stakeholders in medical informatics, it is more commonly used today to refer to the patient as the focus of the electronic patient record and clinical information system. It is generally believed that physicians can optimize diagnostic and therapeutic management of individual patients if comprehensive views of patient data can be created at the point of care. As these benefits accrue over large panels of patients, such patient-centered information systems can improve the quality of medical care.

Over the past decade, several components of the contemporary clinical information system have evolved to provide benefit to the individual patient. In addition to patient-centric views of clinical data, progress has been achieved in the development of physician order-entry, decision support, and the use of electronic communication such as email. Not only can the physician effectively review clinical data, he can activate a management plan at the point-of-care, receive alerts and reminders, and share this information with the rest of the care team. While such comprehensive systems are now feasible, few institutions have comparable systems in place. Unfortunately, healthcare delivery has also changed dramatically in the past decade, so that comprehensive care is delivered throughout a network of affiliated institutions. While comprehensive systems can be deployed within single institutions, no similar successes can be identified within integrated delivery networks beyond isolated capabilities to share clinical data.[4]

While contemporary clinical information systems have a patient-centered ***context***, it is obvious that these systems are physician-centric. These systems address specific efficiencies during the process of clinical management. However, because these systems do not include patients as important stakeholders, they are unable to create efficiencies over the entire horizon of an illness. Therefore, today's clinical information systems can effect the dosing of expensive medications or identify potential medication interactions, thereby reducing medical error. However, we do not think of the same systems in assisting patients in choosing a particular course of treatment or creating systematic efficiencies that would improve cost and quality over several episodes in the course of an illness. Such systems also do not reach a broad swath of the population where it might be possible to effect behavioral changes that could effect the burden of illnesses such as cancer.

A Framework for Patient Participation

Incorporating patient participation in care delivery requires an underlying framework through which to facilitate participation. Without a model, there is no opportunity for benchmarking or performance comparison. Such a model is also a prerequisite in designing clinical information systems designed to incorporate the patient.

We observe that the processes underlying the creation and maintenance of health care relationships are complex, ill-defined, and executed with varying degrees of success. Patient participation in medical care is information-intensive for patients and their families. Patients, whatever their level of education, must become rapidly educated in medical domains that may be foreign to them. Although time is scarce for specialists, patients must have an ongoing dialog with specialists and the care team. Patients should have mechanisms for validating information that is presented to them. Patients should not be limited by regional variations in the delivery of care. Over time, patients and their families assume greater responsibility in symptom reporting, symptom management, and accessing the health care system. Ultimately, any breaks in this complex system of delivering care manifest themselves in both additional costs and decreased patient satisfaction.

Four core elements are essential in facilitating patient participation in their own medical care:

1. Patient Education
2. Information Access
3. Facilitated Communication
4. Community Support

1. Patient Education

Patients must begin with a basic understanding of their disease, its natural history, symptoms, and potential complications. This foundation will be necessary in discussing what may be a wide range of treatment options, from standard therapies through experimental protocols. This patient education should be presented and staged in accordance with the patient's disease state, e.g., the educational requirements of women with a newly discovered breast mass are different from women with recurrent breast cancer. Finally, the patient's provider should guide this educational process, so it is perceived to be an integral part of the overall treatment plan.

2. Information Access

From this basic education, patients should then have access to reference information regarding their disease. Each patient has a unique set of informational needs that he or she will bring into a therapeutic relationship based on individual social, cultural, and familial backgrounds. An ideal library will have materials geared to the layperson. As many patients become knowledgeable about their diseases, they also desire to have access to clinical textbooks and the medical literature. With widespread availability of the Internet, it is not uncommon today to have patients bringing their physicians stacks of printouts from the World Wide Web for further discussion. Like the educational process, it is desirable to guide information access based on the patient's own particular context. Information access should be guided by the need to participate in medical decision-making, as even medical specialists have difficulty keeping up with their own literature.

3. Facilitated Communication

The education process is reinforced by ongoing dialog between patient and the care team. It is generally impossible for a patient and their family to rapidly integrate all the information with which they are presented in an initial sitting or two. Invariably, information will be forgotten and must be repeated, re-explained, expanded upon, or reemphasized. Like the history-taking process itself, ongoing communication between the patient and the care team provides an opportunity to assess the patient's internalization of this knowledge transfer. Additionally, the patient who has been encouraged to maintain an ongoing dialog with his care team may also be expected to be a timely, accurate self-reporter of new or perceived symptoms. Active participation in symptom management should be expected to pay dividends in decreasing discovery time of new complications, decreasing unnecessary emergency room visits, and increasing satisfaction with medical care. [1,6,7]

4. Community Support

Patients can augment their support systems by interacting with peers who are experiencing or who have experienced similar illnesses and complications. From the perspective of the framework presented here, support groups can validate information received, provide additional relevant information sources, and supplement the patient-provider dialog. The collective experiences of a support group are likely to exceed those of any particular care provider. These experiences are likely to be more vivid or practical for the patient as he deals with the day-to-day obstacles presented by his illness. It is likely that a support group can provide answers to questions more quickly than individual research. Therefore, this group experience complements and extends the direct interactions between the patient and his immediate care team.[2,9]

CareLink: Supporting Patients through Technology

The patient empowerment framework described in the preceding section has been realized in a technical architecture known as CareLink. The CareLink architecture originated in the development of a system called Baby CareLink, which is designed to support the needs of families with premature infants. As proof of concept for the resuse of the architecture, we have created prototype environments to support cancer patients in the domains of breast cancer and bone marrow transplant, and are exploring additional domains such as sports medicine.

The CareLink architecture supports the following functionality: asynchronous communication, 'prescribed' education, knowledge exploration, community collaboration, and data integration. The system also includes strong two-factor authentication methods using RSA's SecurId tokens. In its research implementation, Baby CareLink included real-time, ISDN-based videoconferencing. The system is accessible to patients and family over the Internet as a user-friendly web site. The commercial version supports one-way video streaming.

The CareLink architecture lays the groundwork for active participation by patients and families in the care process. Information technology minimizes the additional induced workload on the clinical staff, lowering resistance to adopting this new care model. Once adopted, these kinds of technologies can be time-neutral with respect to staff workloads while conferring additional benefits in terms of patient interaction and evaluation.

The CareLink architecture supports patient empowerment as follows:

Secure, workflow-based, asynchronous communication

CareLink provides a secure Message Center to support dialog between staff and families. The Message center is secure in that message routing occurs over trusted servers; store-and-forward over public servers, which leaves a readable artifact of confidential medical information, does not occur. The Message Center is workflow-based in that message relay follows the workflow of the supported clinical unit. In Baby CareLink, parents forward messages to the staff; any staff member can reply to any of the individuals associated with an infant. Finally, communication occurs asynchronously. Messages can be written and responded to at times that are convenient and appropriate. This asynchronous dialog avoids the onerous burden of having to physically track down busy staff members. With the availability of videoconferencing, families are able to stay in touch with staff without taking up residence in the hospital.

Prescribed Education

Patients and families learn about their conditions, complications, and care in a process guided by clinical staff. A prescribed education module allows staff to assign education material to families and receive structured feedback on their comprehension of the material. Material is presented in a timeline-appropriate fashion, e.g., families of 26-week old infants will be assigned material on respirators, nutritional support, infection, etc., while families of older infants will be assigned materials on positioning, car seat safety, etc. This double-loop learning model allows patients and families to receive just-in-time education appropriate to their status, and lets the staff gauge grasp of material as well as customize pace and content. In the case of premature infants, continuous education prepares parents both cognitively and psychologically for the eventual homecoming of their infant.

Knowledge Exploration

A freestanding digital library complements the structured educational process. Reference materials describe medications, procedures, and conditions in lay language. Staff can customize the library to include additional materials or hyperlinks to recommended auxiliary materials. A staff-provided library facilitates guided exploration, so that families may access materials that have been judged to be clinically sound.

Community Collaboration

First-hand advice can be quickly gained from patients and families having undergone similar experiences. Moderated chatrooms complement the knowledge and learning obtained from other CareLink modules, and provide yet another form of support. Peers can quickly provide resource recommendations, validating and contrasting points of view, as well as psychological support.

Data Integration

In the research implementation at Beth Israel Deaconess Medical Center, CareLink is integrated with clinical systems in order to share data with families. In Baby CareLink, this integration allows the creation of a multimedia record that includes a photo library of the infant and growth charts. This concept can be extended to create a 'personal' medical record by presenting a synopsis of relevant data from the patient record.

System Evaluation

The effect of the use of Baby CareLink on length of stay and patient satisfaction was evaluated in a randomized controlled trial in low birth weight infants.[10] Between November 1997 and April 1999, 30 control and 26 study patients were enrolled from a total of 176 eligible infants at Beth Israel Deaconess Medical Center. Families in the study group were given access to Baby CareLink while families in the control group received care as practiced in the unit. For families in the study group, a technician installed a PC enhanced with a videoconferencing unit and had an ISDN line installed at their home.

The CareLink group reported higher overall quality of care. Only 3% of families in the CareLink group noted one or more problems or issues with care, compared to 13% of control families ($p<0.05$). CareLink families also reported greater satisfaction with the unit's physical environment and visitation policy (13% vs. 50% reporting problems, $p < 0.05$). The frequency of family visits, telephone calls to the NICU and holding of the infant did not differ between groups. The duration of hospitalization until ultimate discharge home was similar in the two groups (68.5 ± 28.3 vs. 70.6 ± 35.6 days, $p \geq 0.05$). Among infants born weighing less than 1,000 grams (n=31) there was a trend toward shorter lengths of stay (77 ± 26.2 vs. 93 ± 35.6 days, $p=0.13$). All infants in the CareLink group were discharged directly to home whereas 5/30 (17%) of control infants were transferred to community hospitals prior to ultimate discharge home ($p<0.05$).

CareLink significantly improved family satisfaction with inpatient newborn care and definitively lowers costs associated with hospital to hospital transfer. The study suggested that the use of the Internet supported the educational and emotional needs of families facilitating earlier discharge to home of low birth weight infants.

Discussion

Through our initial deployment of the CareLink architecture in the support of neonatal intensive care, we add to the work of Gustafson and others in that patients like and will use patient-centered computing systems when they or their families receive medical care. We extend this body of work to demonstrate that patient-centered computing can impact clinical outcomes and patient satisfaction with care delivery. Because we base our technical architecture on a generic framework for patient empowerment, we believe these kinds of systems can be easily extended to analogous clinical domains, such as Transplant medicine, including solid organ and bone marrow. Additionally, because CareLink becomes a tool which patients are motivated to use in managing their own health, we also believe the environment can be extended to support the collection of research-quality outcomes data from patients during the process of care delivery.

The CareLink model illustrates that patient-centered computing should be a cornerstone for the next generation of clinical computing systems. By this we mean systems that patients directly interact with. By empowering patients to participate in care, these kinds of systems support both the missions of clinical care and research. As important to the Medical Informatics community, systems like CareLink derive strength from implementing an underlying framework for supporting health care relationships. Given such models, these systems can be quantitatively evaluated and scientifically validated. For example, while the informatics literature generally supports multimedia-based patient education, a system like CareLink provides the framework in which to trial alternative educational methods in the context of care delivery.[11] Such data will be invaluable when deciding how to invest in large population-based interventions such as promoting cancer screening through advanced technology.

A decade ago, the informatics community recognized that technology could play a role in improving strained relations between patients and the health care system. Our findings with CareLink suggest that the disenfranchisement of patients from the health care system through recent upheavals in the American health system likely increase the burden and suffering of illness, ultimately increasing health care costs. Advances in information technology and widespread adoption of these advances in the general culture have provided the critical foundation for systems that can mend broken relationships between patients and the health care system. Patient-centered computing provides a remedy to reconnect patients to the care delivery system, and revitalize the use of these most valuable stakeholders.

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