Empowering Children and Families With Information Technology

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Patient empowerment is the enhanced ability of patients to actively understand and influence their health status. Information is the key to patient empowerment. Without information, children and families cannot engage in meaningful discussions or make thoughtful decisions regarding medical care. Information sharing is a model for patient interaction with the health care system that may significantly improve the care of children and families. This article focuses on information technologies that utilize user-centered design principles and interactive capabilities to facilitate information sharing and to empower children and families. Examples include electronic pediatric personal medical records, customized health information systems, and interactive physician offices with electronic mail (e-mail) and telemedicine capabilities. Ideally, these systems would all be integrated. Successful implementation of new technologies will require thoughtful attention and balanced solutions to tensions between information sharing vs security, and curatorship vs censorship. Issues related to access and the digital divide must also be addressed. Acceptance and usability of new technologies is predicated on close collaboration among physicians, researchers in informatics, librarians, educators, and other professionals with expertise in the human-computer interface. Child and family empowerment will be both the driving force and ultimate outcome of information-sharing technologies.


Physicians who provide pediatric care understand that families need information to parent more effectively, make thoughtful health care decisions, and engage in meaningful discussions with health care providers. This basic tenet of pediatric care is also the model for health care interactions that utilize information technology to promote “patient empowerment.”

Patient empowerment is the enhanced ability of patients to actively understand and influence their health status. Information is central to patient empowerment. The emergence of the personal computer, the Internet, and the World Wide Web during the past 2 decades has dramatically increased patients’ ease of access to health information. More than half of Internet users state that they have searched the Web for health information. Of these, close to 50% believe that Web-based health information improved the way they take care of themselves, affected their decisions about treatments and care, and led to more questions for their physician or to a second opinion. Nearly two thirds of patients attending a specialty clinic state that they plan to use the Web as a medical information resource. If one measure of patient empowerment is the extent to which it is simply exercised without formal authorization, then the active participation of children and families at every level of health care decision making is not merely a trend, but a reality. It is essential that physicians understand how the information revolution influences the health care they provide, how it will increasingly help them

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to help children and families, and why their use of evolving information technologies for information exchange with children and families will be increasingly expected.

The patient relationship to the acquisition of health information can be categorized into 3 models of interaction (Figure). The traditional medical model involves the dissemination of information from an authoritative source (physician) to a passive user (patient). Adult learning theory clearly demonstrates that this model does not optimize education or motivation. In the health care consumer model, the flow of information is reversed but remains unidirectional, with patients independently searching the Internet for health information. Although patients who search the Internet are “activated” as consumers of health information, they are not necessarily empowered and may be misinformed since information may not be relevant or accurate. In the health information-sharing model, the flow of information is bidirectional, with interaction and feedback between physician and patient yielding information that is accurate, timely, and patient-specific. This interactive approach has the potential to significantly improve the care of children and families.

Information technologies can empower children and families by providing a mechanism for interaction with physicians and the health care system. Patients’ active involvement in their own health care improves health outcomes and reduces health costs. “Activated patients” are central to both the process and the ultimate outcome of several proposed models for patient empowerment, including informed choice of insurance plan, shared decision making, and self-management. An overview of specific pediatric needs regarding the electronic medical record, decision support, information standards, communication, large database exploration, education, and bioinformatics was recently presented at an expert meeting on Information Technology in Children’s Health Care, sponsored by the Agency for Health Care Research and Quality (Rockville, Md). The digital divide and pediatric-specific barriers to the acceptance of information technologies were also addressed. This article focuses on specific examples of information technologies that utilize user-centered design principles and interactive capabilities to facilitate information sharing and empower children and families. Examples include electronic pediatric personal health records, customized health information systems, and interactive physician offices with e-mail and telemedicine capabilities.

### USER-CENTERED DESIGN

User-centered design is a process by which a product is developed using feedback from the intended users to modify and improve the product. User-centered pediatric information technologies must be able to accommodate local needs of special populations (eg, Asian, rural, disabled) and special locations (eg, day-care centers, schools), and be compatible with different platforms (eg, computers, personal digital assistants, cellular telephones). Finally, pediatric information technologies must offer information appropriate to a broad range of developmental levels. It is essential that information technologies reflect and support the graduated decision-making capabilities of children and adolescents. A great deal of information has been gathered on user preferences of adults, but there is minimal information for children. One recent study found that cognitive abilities may be key to retrieving information successfully from Web-based systems. Information systems designed specifically for children are in development.

User-centered pediatric information technologies must be contextualized within the milieu of existing child health delivery systems. Children’s medical care frequently has implications for multiple domains of child functioning and for programs provided by other human services sectors. However, system-level interaction among medical, educational, legal, mental health, and public health services are currently either nonexistent or awkward and tangential. The link between medical services and insurance programs is inefficient, with as much as 25% of physicians’ time devoted to paperwork. Duplication of administrative procedures detracts from time spent on the clinical encounter, and lack of service integration functions as a disincentive to both access and quality of pediatric care.

Information technologies have the potential to improve efficiency across health care systems and to optimize child and family access to services. Such improvements will require prioritization of the needs and preferences of physicians and children and families with software programs that incorporate principles of user-centered design. For example, it is technologically possible for data showing an individual child and family eligible for the Medicaid program to automatically trigger eligibility and enrollment for food stamps and the Women Infants and Children program. Likewise, information technologies could automatically update a child’s immunization status with the local school, after-school day-care program, emergency department, and physician’s office. Similarly, the child’s insurer can be billed and data provided for health surveillance to the public health department.

Concern about patient confidentiality in general, and the federal Health Insurance Portability and Accounting Act (HIPAA) in particular, are generally cited as barriers to this type of health information sharing. However, HIPAA may eventually become a major driving force for user-centered design of information technologies because children and families maintain ownership of these information systems.

The HIPAA was introduced to standardize the interchange of all electronic health data for administrative transactions and to protect the security and confidenti-
ality of electronic health information. The act will apply to all (not just electronic) health information. Health care providers will be required to obtain written consent from a patient for the use and disclosure of all health information, including routine and nonroutine issues. Patients will be entitled to a disclosure history, and will have the right to review and copy their own medical records and request amendments or corrections to the record. The effect of HIPAA on health care interactions is hard to predict. However, it clearly will provide patients with greater control over their own health information.

The pediatric personal medical record (PPMR) is intended for individual use and includes personal assessments of health status and linkages with the physician record. It is HIPAA-compliant by definition since patients explicitly decide who has access to their information. The PPMR promotes user-centered information sharing and facilitates the integration of formal and informal systems of care, further empowering children and families. The PPMR is advocated by the World Health Organization and has been implemented regionally in England and Australia. Studies have demonstrated that personal health records are accurate, well-maintained, accepted, and associated with improved health outcomes. An electronic version of the PPMR provides interactive capabilities to further enhance health information sharing.

The exact form of an electronic PPMR is evolving, but it may ultimately resemble personal finance management programs such as Quicken (Intuit Inc, Mountain View, Calif). Personal computer software programs called “health information managers” are widely available and relatively inexpensive ($50-$150), though they currently have limited interactive capabilities. Examples include HealthTracker PC, Health-Minder, HealthProfiler, and Personal Health Record. An interactive PPMR may eventually reside on an individual’s personal computer, commercial Web site, or other commercial system, and part of it may exist in other forms such as smart cards or electronic dogtags. Standards will need to be developed for information archival and retrieval from the PPMR, including translation between technology systems. For example, a physician may use free-text medical language when charting, which is automatically converted into an age-appropriate, controlled medical language system for International Classification of Diseases, Ninth Revision (ICD-9) coding, billing, and quality through compliance standards. This issue is more fully addressed elsewhere.

The challenge is to make the PPMR function also as a customized health information system that facilitates information sharing. Preliminary efforts to integrate health information with online patient records are promising. In addition, several companies offer interactive personal “disease records” for patients with chronic conditions. For example, http://www.diabetes.com provides the convenience of a pharmacy, support group, periodic preventive-health information, and ready access to a variety of experts for nonurgent questions about diabetes mellitus. These online “disease management” services provide customer convenience, access to expertise, and a feedback loop for self-monitoring. Disease management programs have been criticized because they bypass primary care and do not accommodate medical complexity. An interactive PPMR that is tailored to the patient rather than the disease is a more challenging goal. This would involve the integration of personalized consumer health information with the PPMR and the development of interactive online physician offices. The ideal PPMR would do much more than document physician-patient interactions; it would be the actual mechanism for these interactions.

INTERACTIVE CAPABILITIES

Information technologies with interactive capabilities are necessary to facilitate information sharing and empower children and families. Families currently receive their medical information from friends, family, television and magazines, and in the form of physician-family interactions and parent handouts. Increasingly, the Internet is a source of health information. There are now more than 500,000 pediatric-related Web sites on the Internet. Because the Internet is unregulated and rapidly changing, the quality of this health information varies greatly. Three strategies are available to address this issue: Web site “seal of approval” standards; patient assessment tools for Web site evaluation; and formal organization and maintenance of health information on the Web (ie, curatorship).

Curatorship of digital libraries includes the organization of digital information to meet the specific needs of children and families and the maintenance of this information to assure overall quality and accuracy. It has been demonstrated that appropriate organization of consumer health information leads to increased utilization of pediatric-related information. Some excellent prototypes for pediatric digital libraries include KidsHealth, PEDINFO, and generalpediatrics.com. However, digital libraries are just one component of interactive information technologies. Ideally, such technologies would provide both medical and nonmedical information and access to both formal and informal systems of care. For example, access to quality measures by which to rate insurance companies can empower families to make an informed choice of insurance plan, and information on educational and recreational opportunities can empower children and families to take advantage of community resources. Finally, links to informal electronic support groups can offer access to the “gray literature” of unpublished medical information and the informal expertise of families who have first-hand experience with new research and treatment. Electronic support groups may be accessed via open (eg, listservs or Internet e-mail discussion groups) or closed information technologies (eg, Starbright World). If families and physicians share access to customized, child-specific health information, all parties will be better informed when making therapeutic decisions. Thus, the real challenge for information technologies is not so much content or curriculum development, but the development of interactive mechanisms by which to make information individually tailored, timely, and relevant (ie, a system that promotes information sharing).
An interactive physician office with links to patients' personal health records can serve as an important information hub for physicians, children, and families. Physician e-health networks such as Medem, http://www.beansprout.com, and http://www.kidsgrowth.com integrate high-quality online health information with point-of-care services. For example, parents of children with gastroenteritis can turn to their physician's Medem Web site for the office (and American Academy of Pediatrics) policy on oral rehydration and American Medical Association-sponsored updates on newsworthy medical issues. This information is validated by the physician encounter and can reinforce treatment recommendations and increase adherence. Yet information technology that merely functions as an electronic version of the parent handout does not take advantage of unique interactive capabilities available online. E-mail and telemedicine are interactive technologies that permit information sharing. These technologies provide a mechanism for shared decision making. They also facilitate physician-patient partnerships by promoting self-care and self-management skills.

Unlike telephone conversations, which require that physician and patient be available at the same time, e-mail is an asynchronous communication mode that allows continuous access to the health care system for nonurgent matters such as care coordination, augmented screening, symptom monitoring, and self-management. E-mail is also self-documenting. A message can be printed by patients who wish to refer to instructions, and by office personnel for placement in the paper or electronic medical record. Appointment scheduling by e-mail could decrease the amount of time parents of a medically complex child spend on the phone. E-mail would also save time and add focus to in-person encounters if parent-completed developmental screening measures were distributed electronically prior to well-child care appointments and if children with attention-deficit/hyperactivity disorder, who require titration of medications, could fill out a customized e-mail template for daily symptom monitoring. E-mail has been used effectively to promote self-management and self-monitoring among adults with human immunodeficiency virus and may be particularly useful for chronic conditions, that require frequent monitoring and therapy adjustments.

Whether e-mail between physicians and patients can have advantages for the therapeutic relationship is an important research question, but it seems intuitively valid given the growing patient demand for online access to their physicians. One half of Internet users state that they are interested in e-mailing their physician's office, and 33% of this group state that they would switch physicians for interactive physician offices with e-mail capabilities. Guideline recommendations are now established to help physicians with the clinical use of e-mail. Interface designs to address issues such as excessive use and queries from unknown patients can be built into office-based e-mail systems. Clear office policies regarding patient-physician e-mail communication are also recommended.

E-mail communication offers several advantages over telephone communication, but it is relatively unsophisticated as an interactive health care tool. Interactive personal medical records that are integrated with point-of-care services would benefit all children and families, particularly children with chronic conditions and their families. New models for long-term care delivery systems recognize that families' information needs must be met if productive interactions between "activated" (empowered) patients and "proactive" practice teams are to occur. A convincing literature on self-management programs for adults with chronic conditions suggests that interactive strategies to promote self-efficacy and self-monitoring are superior to traditional didactic formats. Self-management may become one of the most exciting areas for innovation in information-sharing technologies since it is predicated on patients' involvement in their own health care.

The Baby Care Link program uses telemedicine as part of an innovative self-management support service for families of premature infants. The program provides desktop video conferencing between the home and the intensive care unit; interactive parent information; and access to an online parent support group. Parents report greater satisfaction and comfort with their infants' care, allowing earlier intensive care unit discharge of infants and fewer transfers to community hospitals for intermediate care. Video conferencing would also benefit home care personnel and family caregivers of medically complex children, for whom transportation to multiple specialists is costly or burdensome. Video conferencing is useful in situations in which motion or intangibles are important (eg, where body language and mood are conveyed), such as remote psychiatry and remote monitoring for seizures or apnea (R. S. Bakalar, MD, e-mail communication, August 2000). Other applications might include telemonitoring for developmentally disabled adolescents and young adults transitioning to independent living. The technological advances from the Next Generation Internet Initiative projects are expected to supply the types of connections necessary to do high-quality, real-time video conferencing on the Internet. Telemedicine issues to be considered include convergence of practice standards for patient evaluation, treatment and prescriptions, and practice standards for licensing and compliance.

**CONCLUSIONS**

The information technologies outlined throughout this article facilitate information sharing, and thereby empower children and families and physicians as well. They have the potential to reframe traditional power relationships with interactions that promote information sharing, a process that recognizes and supports the unique nature of child-family-physician partnerships.

Implementation of information-sharing technologies will require thoughtful attention and balanced solutions to tensions between information sharing vs security, and curatorship vs censorship. Specifically, this will include rigorous evaluation of the economic effect of information technology for all constituencies; the development of appropriate practice standards for patient privacy and confidentiality; the creation of new legal modi-
Patients' active involvement in their own health care improves health outcomes and reduces health costs. Information is central to patient empowerment. The emergence of information technologies has increased patients' access to health information.

This article discusses examples of information technologies that utilize user-centered design principles and interactive capabilities to facilitate information sharing that can empower children and families and physicians.

Successful implementation and long-term usability of new technologies will require close collaboration among physicians, researchers in informatics, librarians, educators, and other professionals who have expertise in issues related to the human-computer interface. It will also require that the voices of children and families be heard at every stage of design and development. Their empowerment will be both the driving force and ultimate outcome of information-sharing technologies.


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