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Review Paper

Patient-centered Information Systems

Abstract: Patient-centered information systems augment traditional approaches to health information management with specific functions designed to support patient participation in health care decision making and treatment activities. In addition to computer-based record systems and business management applications, patient-centered information systems must include functionality that support communication between clinician and patient, and that provide information and peer support in a timely fashion to the patient. Current progress in information systems demonstrates the existence and feasibility of consumer health informatics, patient access to computerized clinical records, and technical and organizational solutions to integrating computerized patient information systems. We are now proposing a model of patient-centered system that incorporates all those components, and provides a vision of the future.

1. Introduction

Patient-centered care represents an emerging theme of health care in the United States. Its scope is broad, ranging from health service activities tailored to the specific health needs of the individual to a holistic philosophy that targets health services promotion to the whole person. Patient-centered care encompasses health care that is attendant to the identified clinical problems of the patient while responsive to individual and family characteristics such as affective states, perceptions, preferences, and resources [1,2]. Patient-centered care demands patient-centered information systems.

A key characteristic of patient-centered care is the active involvement of the patient in the care delivery process. The gradual but deliberate transition of health services from the hospital and clinic to the home and community creates an environment in which patients must independently assess and interpret symptoms, seek appropriate health services in a purposeful manner, and engage in health promotion, disease prevention, and illness management activities. Additionally, the patient's own values and preferences have increased relevance to and influence on selecting treatment options [3]. To accomplish these tasks, patients require access to information about disease processes, credible intervention strategies, and personal health data. Information systems are needed that provide patients with access to these types of information.

Patient-centered care presents nurses, physicians, and other health care providers with new information access and management challenges. Clinicians must better understand the every day health concerns and health practices of their patients. Recognition of the contribution of health behaviors, dietary patterns, exercise routines, and daily stressors in disease prevention demands that clinicians know a great deal about their patients' habits. Because environmental exposure to tox-ins contributes to many diseases, clinicians increasingly need information about the work lives, living situations, and community contexts of their patients. These parameters are rarely captured in contemporary health information systems. Information systems are needed to support clinician access to this wide range of information and to the sophisticated management strategies that integrate personal health information, biomedical research, and environmental contexts.

Patient-centered information systems augment traditional approaches to health information management with specific functions designed to support patient participation in health care decision making and treatment activities. In addition to computer-based record systems and business management applications, patient-centered information systems include a mechanism to support communication between clinician and patient to provide information and peer support in a timely fashion to the patient. Also needed are the tech-

nical and logical functions that integrate information from multiple organizations into a unified, manipulable clinical support tool for use by both clinicians and patients. Patient-centered information systems represent an approach to managing health information that empowers patients as full users of the information systems. The purpose of this paper is to evaluate the state of existing information systems in terms of their progress toward provision of patient-centered systems. Researchers in this study will propose a model of patient-centered information systems and will identify social, political, and technical issues that challenge this model.

2. Progress toward Patient-Centered Information Systems

Viewed developmentally, the state of computer-based information management in health care can be characterized as on a trajectory from transaction-focused systems that record and manage the operational aspect of an institution through computer-based record data systems that delineate aspects of the clinical care encounter to a mature model of patient-centered systems that integrate diverse sources of salient health information to create a dynamic resource for use by patients and clinicians. Evidence exists that suggests a readiness for patient-centered systems: (1) information resources specifically for patients, (2) feasibility and value of patient access to computerized clinical records, and (3) technical and organizational solutions to integrating computerized patient information systems.

2.1 Consumer Health Informatics: Information Resources Relevant to Patients

Patients require information as they engage in self-help, self-care, and dis-

ease management activities. Consumer Health Informatics (CHI) denotes freestanding computer systems and Internet resources, primarily World Wide Web-based (WWW), designed to deliver health information directly to lay persons. CHI is a new strategy in using information technology to provide health information in terms of health education, communication, and clinical data access. Patients can access Internet-based information services from the home or from public computer terminals. Krishna and colleagues [4] categorize computerized patient education into three groups: 1) instructional computer programs, 2) computerized health assessment and history taking, and 3) computerized information support networks. CHI also provides peer communication via supportive groups and professional communication via email. Moreover, CHI provides clinical data to patient as well as lay person, ill or well, who want accurate information in a timely manner [5]. Improving consumer health care involves incorporating the concepts of consumer empowerment and individual preference with health care delivery [6]. CHI has the potential to augment and improve the effectiveness of health information systems and, by extension, health care delivery. Its impact may be even greater when the content is tailored to the salient aspects of the patient. Tailoring refers to the strategies used to map information to an individual's needs, perceptions, preferences, and cognitive strategies [7]. The tailored CHI should provide patients with specific information about their illness and health behaviors, health education related to their needs, and feedback tailored to individual health needs. Tailoring varies in scope from basic diagnosis status to the health counseling process. Consumer health informatics offers promising approaches to matching patient need with information resources [8].

2.1.1 CHI as the Patient Educational Tool

Using information technology to provide consumer health information is done through implementation of patient educational tools. Their educational effectiveness is based on clinician appraisals of the quality and relevance of the health information provided [9]. An example of a CHI tool is CHESS (the Comprehensive Health Enhancement Support System) [10], which is a computer system designed to offer HIV-positive patients online health information, decision supports, and connections to experts and other patients. Gustafson and colleagues [10] report that CHESS users had significant cognitive functioning improvement and, during CHESS implementation, a reduction in the number of hospitalizations and lengths of stay. Krishna and colleagues [4] have demonstrated that computerized educational interventions can lead to increased knowledge. Brug and colleagues [7] conclude that the computerized nutrition education motivated people to change their diet. Still needed in the literature are studies demonstrating the long-term impact of these interventions on key outcome variables such as health services utilization, clinical parameters (e.g., weight loss) and adoption of new health behaviors. Additionally, information is needed on consumer preferences for health information.

Tang and colleagues have employed a series of focus groups to derive the Personal Articulate Timely Informative Endorsed Next-step Therapeutic (P.A.T.I.E.N.T.) guidelines for providing information to patients. Personal means patients need access to special information regarding their personal health. They also require clarity in the document (Articulate). They want to access their health information in a Timely manner as well. An informative CHI should be tailored to patients' need in terms of specificity to their problems and matching with their

literacy level and language. Patients prefer the information Endorsed by their physicians and want information that provides guidance about the Next-step of their diagnosis and treatment. Therapeutic refers to the systematic use of teaching strategies to improve comprehension and retention of patient information and thereby enhance patient compliance.

2.1.2 CHI as a Home-care Support

Advanced information technology is used to facilitate home health care as well. Brennan's [11,12] research demonstrated the impact of network-based information, communication, and decision support services on homebound persons who were ill and their families. Recently, Brennan and her research team developed a Web-based system for providing tailored, sequenced information for patients recovering from coronary artery bypass surgery [13]. Home-based monitoring of physiological status measures (e.g., electrocardiograms) can be supported through Web-based interfaces [14]. As in the case of educationally oriented CHI, the long-term impact of Web-based monitoring approaches needs to be evaluated to determine whether such systems result in more timely and appropriate access to health care, better clinical outcomes, and cost effectiveness.

2.1.3 CHI to Support Clinical Communication

Network technologies support communication between patients who share similar concerns as well as between health care personnel. Brennan and Gustafson both have demonstrated the feasibility and value of using network technologies to support patient-to-patient communication. Neill and colleagues [15] examine clinician-patient communication through a survey of 117 e-mail-equipped patients at a family-based, university practice center

and found that only 8% had used e-mail to communicate with their physician. Patients identified the following reasons for not using e-mail: no notion to use it; no need to do it; or confidentiality issues. Fridsma and colleagues [16] have showed that approximately 25% of patients in one university-based practice used e-mail to communicate with their physician. Kane and colleagues [17] address concerns of confidentiality by providing guidelines for clinicians when interacting with the patient by e-mail, such as allowing reasonable time for a patient to respond, privacy, permissible transactions and content, categorical subject headers, and the discreet subject header.

Single purpose, single disease-focused CHI services are giving way to network-based integrated CHIs. Coupled with several social trends that have changed patient's roles in health care system, these systems help consumers and patients take more responsibility for their own health. The technology challenges the traditional relationship between health professionals and patients and fosters one of partnership not paternalism [18]. Such realignment supports quality of care through increased patient participation [19]. Full benefit of CHI health education and communication resources will be realized when they are integrated with systems that manage the health data for individuals.

Safran [20] describes the patient as the most important historian and contributor to the clinical record. Patients create furtive record management systems in family Bibles, on note papers and index cards, and through remarks in ledger books to record sentinel health events such as births, deaths, immunizations, allergies, and drug administration instructions. Accordingly, mechanisms are needed to permit patients to directly enter information in to the clinical record and to read and retrieve information from that record. Several innovations over the past 25 years

demonstrate that patients can accurately and responsibly record personal health observations into the clinical record and that they are interested, willing, and able to read and review their clinical records in the course of their care.

For example, the Maternity Center in Brooklyn encourages the patient to take an active role in her prenatal care [21]. Upon arrival at the clinic, the patient retrieves her own (paper) record from the storage area, assesses and records key data (e.g., on weight, urine protein, and glucose) and provides free-text commentary on her personal status. This is used by the professional and patient together to monitor the patient's progress and determine subsequent treatment plans.

Additionally, computer-delivered interviews of patients result in accurate screening and appropriate presentation of risk-based, health-related information [22]. At the Beth Israel Hospital in Boston, patients in the general medical clinic have used computer terminals to enter information into their clinical records [23]. Patients may be more likely to admit controversial or socially charged ideas, thoughts, and values in a computer-based interview rather than during a face-to-face encounter with a clinician [24]. Through this process, patients demonstrate their ability and willingness to use clinical record systems also accessed by clinicians.

Two key issues are raised regarding the patient's access to the clinical record: (1) Can patients be trusted to reliably enter health data? and (2) Should patients be allowed to view the entire clinical record used by clinicians? Earlier evidence indicates that patients can be trusted to reliably enter health data [25]. The Patient Centered Access to Secure System Online (PCASSO) project addresses the second concern, creating patient access to personal health records in a secure fashion via the Internet [26]. Presently, 50 patients are enrolled in a clinical trial

that is underway to evaluate the utility and effectiveness of the elements of the PCASSO system. Similar trials are underway at Columbia Presbyterian Medical Center [27].

2.1.4 Integration across Institutional Information Systems

Patients rarely receive care from a single institution or care provider. In the United States in 1996, more than 75% of the American public had at least one ambulatory care visit, 50% received prescription services, and approximately 45% received dental services. Thus, visits to three or four distinct health care institutions are not uncommon [28]. Present mechanisms for supporting integration of clinical records across clinical care institutions rely on physical transfer of duplicate paper records. Three computer and network-based strategies have had varying success in the US with electronic transfer and integration of records: 1) Community Health Information Networks (CHINs), 2) Web-based integration of selected elements from disparate databases, and 3) Web-enabled display of data from disparate data sources.

CHINs emerged in the early 1990s as a promising mechanism linking the information flow and communication channels across institutions [29]. The motivation for this integration arose from several areas: market factors, patient health service-seeking behavior, and technical feasibility. A primary advantage of the CHIN model rested in its promise to move data sharing and communication transfer out of the realm of institution-to-institution level and into a common community market place. Individual institutions retained control over the nature, amount, and frequency of data sharing. The integration strategy rested on providing a common, secure communication channel. Barriers such as competing organizational interests and the lack of common language structures relegated the CHIN's initiative to supporting only common-

place, non-secured communication across facilities.

In contrast to the communication pathway approach to building patient-centered systems, more recent strategies have attempted to use publicly available channels to exchange patient-specific data across institutions. The key developments here have been the introduction of data security measures sufficiently strong to ensure access only by authorized users and data integration strategies that overcome language and format disparities across organizations. W3EMRS is an architecture model that uses features of the World Wide Web to construct a single vision of clinical records extracted from multiple institutions [30]. W3EMRS relies on three key components: institution-specific data sources with public exposures, an integrating or consolidating mechanism for merging data from these data sources, and a security system that automatically authenticates requests for information and authorizes release of the information for distribution through secure WWW channels.

CareWeb, developed as an implementation of the W3EMRS architecture, solved part of the problem of creating an integrated view of clinical records across two formerly independent hospitals once they had merged into a single delivery network [31]. The integration challenges included establishing links across unique language systems, connecting legacy databases running under different operating systems, and generating common images of data extracted from distinct systems. Security measures included implementation of strong enterprise -wide authentication, access validation, and multi-organizational audit trails. CareWeb provides integration at the level of viewing data, not at the level of manipulating data. As such, it provides a model for supporting patient-centered care by ensuring that clinicians at a given facility can view patient data that may have originated

at a different facility. Full implementation of patient-centered systems will require additional developments, such as the ability to securely establish integrated views across institutions on an ad-hoc, on-demand basis and the ability to manipulate data from disparate sources. Resolution of these issues is as much organizational as it is technical.

3. A Model for Patient-Centered Information Systems

Current progress in information systems demonstrates the existence and feasibility of consumer health informatics, patient access to computerized clinical records, and technical and organizational solutions to integrating computerized patient information systems. The researchers in this study are proposing a model of patient-centered systems that incorporates those components. Figure 1 presents the model of patient-centered systems. The purpose of this model is to serve as a conceptual framework that identifies specific components and linkages that will engage the patient's perspective in the design of a health information system.

The patient is the center of the model; the information is integrated to generate the flow of communication. The surrounding elements denote the diverse sources of health information, including encountered health care providers, consumer health informatics, and the patient's furtive record. The circle of communication layer represents the integration of the clinical, consumer health, and personal furtive information for a patient-centered health focus. It includes the static communication of a patient's medical record as well as the dynamic communication generated through e-mail. It also indicates the feature of two-way data flow between the center and the surroundings. Outside the circle of the information flow, but still connected,

exist other information systems developed for use by one health organization, but now part of the free information exchange. What follows is a discussion of each key element in the model.

3.1 Computerized Patient Record

An idealized version of the computer-based patient record (CPR) is seen in digitally stored health care information about an individual's lifetime, including all the information on a patient's history, physical examinations, diagnostic tests, and therapeutic interventions done to support the patient's care. CPR can be manipulated by computer-based tools so that knowledge about care can be used to generate alerts, warnings, and suggestions as well as decision support and can be monitored in a straightforward and timely fashion [32]. CPR is also used to support the continuity of care across all points of care provided with information organized and displayed in a variety of different ways that are tailored to particular clinical or individual needs, including patient and clinicians. Clinicians can use CPR for direct patient care, quality assessment of care, management and planning support, and research and education [33]. The computer applications that extract patient records and present them to the clinicians need to be designed as patient centered with integrated information from all services, providers, and episodes of care to allow providers to focus on patients and not departments [34,35].

3.2 Patient

Patients should also be empowered as participants and central partners in the information flow. Studies reveal that technology is advanced enough to implement patients' rights and responsibilities to access their health data via secured and accountable methods [36-38]. Patients access CPR to understand individual health status, health care history, and furthermore, to seek information about self-management and decision making. This process will enable patients to be more in control and have better health outcomes [39,40]. The World Wide Web creates an appealing and user-friendly medium for patients to access the information. Along with other advanced technology, clinical data can also be collected from a patient's home to be used for remotely monitoring the health status of a patient [41,42] and for supporting individuals correspondingly via e-mail.

Hospitals and Clinics. Due to the diverse nature of the current health care delivery system, timely access and updating of patient records across multiple institutions must be ensured to strengthen the quality of care. Patient records need to be integrated electronically; electronic data interchange (EDI) is the tool used to accomplish this. EDI is e-mail that can be conveyed from one computer to another without manual intervention. Communication depends on the use of messages that are syntactically and semantically understood by both sending and receiving systems. HL-7 (Health Level Seven) and EDIFACT (Electronic Data Interchange for Administration, Commerce, and Transport) are two health care standards used for communication with internal and external systems, respectively. With standardized messages used to transmit data, data exchange become system and application independent. A set of standardization issues [43] critical for a successful electronic data interchange includes the record architecture, terminology (taxonomy) [44], and communication.

3.3 Other Providers

Other than the enterprise health care organizations, there might be independent providers, for example, pharmacists, engaging in the health care deliv-
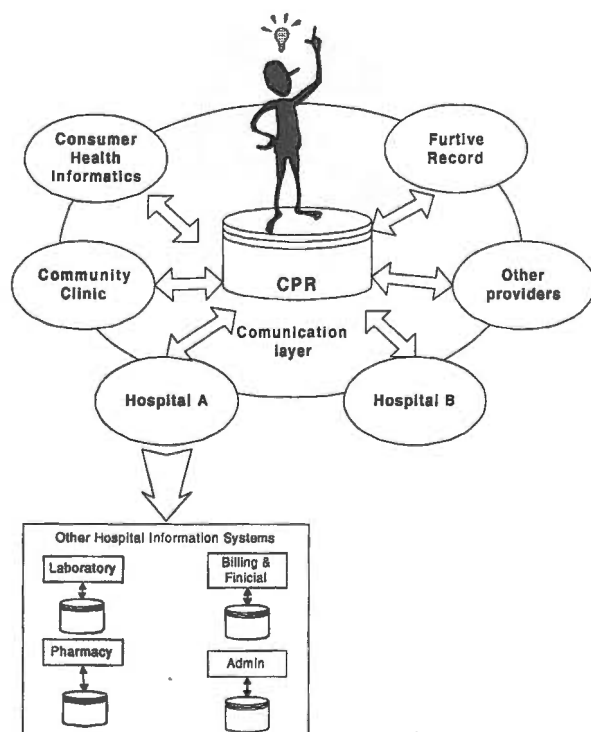

Fig. 1 Patient-centered system model

ery process and need to be authorized to access and update patient records. This could be done via Internet connection and secured World Wide Web-based access [45]. All of the communication in the communication layer is on an ad hoc basis and is transmitted only through patient encounter, which triggers the information exchange.

3.4 Consumer Health Informatics

The model for patient-centered information proposes that consumer health informatics needs to be integrated with the CPR as well. Application programs should be built so that patients can locate information that engages them in self-help, self-care, and disease management activities [46-48}. The information should be integrated with the patient's CPR and presented in a manner that augments the patient's needs and preferences. For example, a patient diagnosed with an early stage of breast cancer could explore available treatment as well as related information on the psychological impact of the disease. Also, patients could explore aspects of the disease along life's continuum: promotion, prevention, diagnoses, treatment, and rehabilitation.

3.5 Furtive Record

Records held informally become increasingly important in a patient-centered system. These furtive records contain important content relevant to both the patient's and the provider's views of the health care process. Commercial developments already exist that provide network-based patient record management systems with the patient as the nucleus.

4. Challenges for Future Research and Development

This patient-centered system model proposes the integration of various lev-

els of information on anyone participant in the health care delivery process so that the information can be shared and decision support can near its logical point of use. It represents an interactive, dynamic process to managing health information systems uniformly with health care delivery. It is a unified system that integrates information from patients, health providers, consumer health informatics, and other geographically distant informational resources. It supports an ongoing process of continual monitoring, education, and communication. Patient-centered systems will enable patients to actively participate in decisions about their own health through self-help, self-care, and disease management activities, while health professionals at all the stages can use this system as a powerful clinical support tool to facilitate patient-centered care.

4.1 Concerns for Language Implementation.

Concomitant with the special purpose approach to development of computerized health information systems was the development of formal languages and terms that characterized health problems and clinical interventions. Adoption of these languages has been slow, even in highly automated clinical information systems. Many facilities continue to use idiosyncratic terminologies, thus posing a significant barrier to development of fully integrated patient-centered information systems. Solutions have focused on evaluating the malleability of vocabularies [49,50] and creation of reference terminologies that allow mapping from the colloquial language of individual records to standardized words and phrases [51] adapted to the information systems. Further work will be needed to expand vocabularies to include not only the concepts relevant to the clinical practice of professionals but also those terms expressive of the experiences and environment deemed relevant to patients.

4.2 Information Infrastructure

Clearly, patient-centered information systems rely on a solid technical infrastructure that supports the security, quality of service, and bandwidth requirements necessary to provide integration of information across multiple institutions. The Internet, as it exists today, lacks the capacity to support a full implementation of patient-centered systems. Notably missing is the ensuring of security and bandwidth on demand that permit using a public infrastructure for industry-specific applications. The emerging configuration of the next generation Internet holds the potential to support a powerful vision of patient-centered systems.

5. Sociotechnical Issues: Privacy, Accessibility, and Usability

Sociotechnical issues of privacy, accessibility, and usability must be resolved or, at the very least, addressed for successful transmission of patient-centered information. First, security of patient-centered information systems to ensure an appropriate and consistent level of information must be established in order to ensure an appropriate and consistent level of information. Security strategies include multi-factor authentication, role-based access control, transmission confidentiality, high-assurance server, and client protection from both patient and clinician perspective. Second, a patient-centered information system should be equitably accessible to health professionals as well as targeted populations. The National Telecommunication & Information Administration (NTIA) [52] (1999) has found that there is still a significant "digital divide" separating American information "haves" and "have nots." Third, the capability of a system to be used is based on five attributes: learnability, efficiency, memorability, a low error rate or

error-forgiveness, and satisfaction [53]. A patient-centered information system serves multiple users simultaneously. User skill and motivation must be augmented with innovative, flexible interface design strategies to meet these diverse needs.

6. Summary

Health care is not only prepared for, but demands and needs, patient-centered information systems. Demonstrable skill levels among patients and available technologies portend a readiness for designing clinical record systems based on patient-centered philosophy. Key characteristics of the system include:

1. System functions are accessible by patients.
2. Patients can gain access and can contribute meaningfully to the system.
3. Patients and clinicians access all information relevant to the patient's health state, community context and life experience.
4. Desirable features include:
   - general search
   - random access
   - tailored presentation
5. The system delivers important parts of the patient clinical record at the site of care. independent of the source of information.
6. Clinicians benefit from the integration.
7. The system provides information access and retrieval at the site of care.

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