

Improving the Quality of Patient Care: The Role of Patient Preferences in the Clinical Record

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ABSTRACT

Patients are an important but overlooked participant in health information management. Patients serve as a source of self-monitoring data and for self-report of essential judgments such as preference for treatment and preferences for clinical outcomes. As the deliberations regarding the Computer-Based Patient Record initiative continue, decisions must be made about what patient-specific information will be entered in the record. In consideration of the mounting evidence that patient preferences represent an essential component in many health care decisions, it is timely to advocate for including patient preferences in the patient record. This represents one aspect of the patient role in health care information management.

INTRODUCTION

Safran labels patients "...the largest and least utilized health-care resource (and a potential ally)... frequently overlooked...[and] like their physicians and nurses, need access to information to help make health-care decisions" [1]. Patients also require the opportunity to provide information that will facilitate collaborative decision making with the health care practitioner. Traditionally, health care providers mediated patients' accesses and contributions to the medical record. Nurses and physicians selectively recorded the subjective verbalizations of patients, and provided patients with a filtered, and somewhat translated version of information from the clinical record.

It is timely to reconsider the role of the patient as a full participant in health care information processing and to remove barriers to patient input into the clinical record. It is the thesis of this paper that patients require unrestricted access to their health care records to contribute information through health care providers and through direct input. While it may be timely to provide patients with full and unrestricted rights to read their records; this latter authorization is

fraught with controversy and lacks substantial research support (in this country) to advocate it. The change toward increasing patient participation must begin by exploration of the evidence supporting entry of information into the clinical record deemed important and relevant to patients.

The work of the Computer-Based Patient Record (CPR) initiative will be used to document the need for the paradigm shift that now affords a reconsideration and expansion of the legitimate users of and contributors to the patient record. From an examination of the research on patient preferences will come illustrations of the type of information likely to be obtainable only from direct patient input. Finally, challenges to the implementation of direct patient entry will be examined.

It is important to note two issues that will not be addressed in this paper. First, the paper considers only one type of patient data, preferences, and does not address other types such as self-monitoring and triage. Second, the paper does not examine the issues and challenges around patient review of information in the record. Because the clinical record, by convention, serves many purposes, there is no standard by which anyone, much less a person without clinical training, could interpret the record. Because the lack of standard purposes for documentation pose severe barriers to the lay interpretation of clinical information in the record, direct review of chart-based information by patients cannot be implemented under our present system. These two restrictions are limitations on the substance presented, not on the philosophy espoused.

The fundamental assumption underlying this paper is that the patient is the best informant regarding his/her individual preferences and values, and that this information must be recorded in the clinical record [2]. The imminence of the computer-based patient record affords an unprecedented opportunity to incorporate this long overlooked aspect of health care

documentation. Health care providers and health informaticists must capitalize on this opportunity. This paper grounds the conceptual issues surrounding direct patient input to the computer-based patient record in the context of improving the quality of decision making and of patient care.

COMPUTER-BASED PATIENT RECORD

The computer-based patient record, as proposed by the Institute of Medicine (IOM), arose in part from an awareness of the inadequacies of the existing paper record system and a recognition of the central role of the patient record in supporting and promoting clinical decision making and quality patient care [3]. The CPR has the potential of bringing about three changes in the medical record: (1) the content will shift and expand to compensate for existing inadequacies; (2) the form will change, taking advantage of computer technology to construct a record that affords easy entry, retrieval, and storage; and (3) the record will become a multidisciplinary tool for treatment planning, recording, and quality monitoring.

Commonly identified content inadequacies include inaccuracy, lack of comprehensiveness, and lack of utility of information. The existing record as a repository of often disorganized and isolated facts will be replaced under the new initiative. Computer-based patient records have the potential to provide an explicit framework for the active participation of patients in their care. While under the traditional model, this change may only be an expansion of the data elements that providers obtain and record; a logical extension of the current work will lead to patients directly entering data into the computer-based patient record of the future.

Direct patient input of information to the record is proposed as a mechanism to increase the accuracy (quality), comprehensiveness (quantity) and utility of record information for all users. Computer technology will facilitate this goal of direct patient entry. Not only will the CPR provide the mechanism for increasing patient participation in health information processing, it will force the reconceptualization of the very nature of what constitutes patient data.

Patients hold unique insights into their preferences and desires for health care and clinical outcomes. There is growing cognizance of the lack of representativeness in the existing record of these insights [4-6]. This patient-focused information is

needed to enable the provision of quality health care. Therefore, the benefits of the CPR can be realized in this reconceptualization of patient data in the clinical record even before extensive computerization occurs.

PREFERENCES AS PATIENT DATA

The increase of decision analysis research and the emergence of health outcomes research in the last decade has resulted in a growing body of evidence supporting the importance of the incorporation of patient preferences in health care decision making and in the assessment of the quality of health care [7]. Quality of health care is no longer defined solely in terms of physical outcomes, such as unexpected death or surgical complication. Quality of health care is expanded to encompass individual preference and is more richly defined as a function of those patient preferences. Achievement of patient goals or, in the absence of goal achievement, the perceived capacity of treatments to achieve those goals [6] serves as an additional criterion of quality. The assessment and documentation of patient preferences and goals is essential for appraising health care quality yet this information is not routinely collected [8], and, if collected, does not appear in the existing record.

Research indicates that patient preferences may be related to treatment strategies, treatment outcomes or some interaction of these two factors. Patient preferences in treatment decisions have been most extensively studied in women with breast lesions and men with prostatism. These studies provide insight into the complex nature of patient preferences. For example, when presented with two surgical interventions possessing similar outcomes, women with breast lesions demonstrate differential preferences for lumpectomy vs. mastectomy [9]. Men coping with prostatism appear to express treatment preferences based on a complex interaction between intervention-associated risk and desirability of outcomes [10]. In addition, the recently-enacted federal mandate for Advance Directives require that providers seek and follow patient preferences for life support decisions.

Results of health care outcome studies indicate cross-individual variation in preferences related to intervention choices and outcomes such as quality of life, length of life and functional status [11]. Therefore, it is incumbent on the provider to explore patient preference and incorporate these values in decision making. The clinical record provides a repository of these preference elicitation, serving two purposes: informing others about patient preferences

and documenting that preferences were employed to guide treatment decisions.

Provider-obtained preferences suffer from the (potentially unrecognized) biases of the person gathering the information. Patients are able to express preferences for treatment choices. The elicitation and utilization of patient preferences in decision making is primarily in the hands of the researchers. A variety of methods have been successfully used to assist patients in identifying preferences in clinical situations [12]. It is time to consider how to apply what was learned in the research to the realm of clinical practice. Elicitation techniques could be used to structure input screens for direct patient entry.

CHALLENGES TO IMPLEMENTATION

Despite the opportunity offered by the CPR, and the evidence arising from the preference research, barriers to patient access and contributions to their records remain [13]. Provider reluctance to allow patients to access their records continues to be a significant obstacle. This reluctance is based on a variety of concerns including: the validity of patient provided information [14], potential adverse effects of sharing information with patients [15], and fear of increased litigation [16]. Actual experience with affording patients unrestricted access to their record or having patients directly input data indicate that these concerns are unwarranted [15, 17, 18].

Direct entry of patient information into the record does not supplant, but rather supplements, the clinical interview as a means of assessing patients. The emerging work in the development of Shared Decision-Making Programs demonstrates the effectiveness of sharing information with patients, patient direct input of values/preferences, and their impact on the quality of care [19]. This work can serve as a prototype for future developments.

CONCLUSION

CPR makes possible the reconceptualization of the patient record as an interactive dialogue between the patient and provider(s) of care. Ongoing research in the areas of patient preferences and quality of care demonstrate the need for this reconceptualization. In turn, resolving patient direct entry issues ensures that patient preferences will assume greater utility than merely research data.

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