

# Patients As Experts: A Collaborative Performance Support System

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***Abstract:** Performance support systems that provide decision support and encourage quality improvement historically focus on physicians as the expert to the exclusion of an active role for patients. This paper outlines an argument for the development of a collaborative expert system in the acute care setting that emphasizes a key role for patients. Patients are not just seekers of information; they remain capable of sharing and integrating their knowledge and expertise actively in an electronically-supported care process. Collaborative use of information technology emerges as a novel variation of consumer informatics. I will define specific domains of expertise for patients and place the proposed collaborative expert system within the framework of Wagner's view of idealized collaborative care for chronic illness. Basic architecture for a patient-inclusive system is proposed with additional detail provided for a patient-level interface targeting pediatric asthma. The benefits of the electronically-supported collaboration include the activation of patients in the information-sharing process, enhanced decision support, a patient-focused needs assessment, and improved communication and partnership between patients and providers.*

**Background:** Performance support systems classically involve the study and incorporation of expert practice into the knowledge base and algorithmic engines that drive the desired output. In the field of medicine, successful examples of expert systems have largely positioned physicians as the focal point of informational input, analysis, and intervention. This is not surprising given the central decision-making roles accorded to the physician. A physician functioning as the "professional expert" does not work in isolation to collect all necessary data. Standardized procedures may allow ancillary personnel and patients themselves to capture and organize data to present to the traditional medical decision-makers.<sup>1</sup>

A more global view of medical care suggests that patients themselves have an important expert role to contribute to the process. Persons living with a chronic disease or caring for someone with a chronic illness can develop expertise in the everyday management of illness.<sup>2</sup> This acquired expertise results from an analysis and application of knowledge that recognizes biomedical principles and incorporates them in the workings of everyday life.

Expert self-care in chronic illness results from an "activated" patient or caretaker. Patients or caregivers who simply provide passive compliance to medical directives cannot fulfill this expert role.<sup>2</sup> A system which separates patients and care-givers from full participation in the exchange and analysis of medical information promulgates a passive role for the "non-professionals."

The advent of the world wide web and improved access to informational resources have narrowed the divide of power between the physician with "esoteric knowledge" and the naïve medical consumer.<sup>3</sup> Physicians are not experts simply because they know it all. Having to look up information does not differentiate the clinician from the non-clinician nor the expert from the non-expert. Access and control of knowledge no longer defines expertise in medicine.<sup>4</sup>

Not all expertise is visible and/or articulated.<sup>1</sup> A patient or care-giver who incorporates data into a prior knowledge framework and makes appropriate decisions but cannot verbally replicate all the steps in that process nonetheless displays behavioral expertise. This aspect of "knowing but not knowing why or how that knowledge was obtained" must be considered in the development of expert systems that machine-code more than the rules espoused by a single expert source.<sup>5</sup>

**Domains of patient/care-giver expertise:** Patients and their caretakers bring to the medical encounter a broad array of experience and data. A non-exhaustive list includes the following:

- 1) symptom report
- 2) response to prior interventions at home
- 3) related previous medical history
- 4) 'generic' past medical history data such as allergies and current medications
- 5) relevant family history
- 6) contributory environmental factors
- 7) patient or care-giver interpretations of current physical signs
- 8) report of existing needs (knowledge deficits in management of illness, lack of resources for optimal provision of care at home)

These data elements are derived from the intersecting spheres of patients, caregivers, family, the home environment, and the community at large. (Figure 1) They represent more than the patient's or caretaker's report of "data." The interpretations and meaning

accorded to the data transforms it into “information,” and the level of experience and unique perspectives of the patient or care-giver allows for the “information” to be considered “knowledge.”<sup>6</sup>

Parents of infants and young children are valid reporters of history of present illness, review of systems data, and past medical history.<sup>7,8</sup> The inclusion of parents as reporters has the potential to improve the completeness of the data collected for consideration in the diagnostic and documentation process. Parents’ independent electronic provision of data specific to the current illness provided more complete data and improved the sensitivity of detecting risk factors for dehydration compared to physician’s electronic charting.<sup>8</sup> Allowing parents to enter data electronically in an unstructured free text format provided relevant historical details in more than 20% of cases when the parents’ input was compared to physician charting.<sup>9</sup> Herein the argument for parental expertise lies not in the mere provision of information, but in its comparability in accuracy to that gathered and charted by physicians.

In medical care settings where access to past records for a patient and lack of previous contact with patients/families limits data mining for relevant data prior to actual patient contact, the information offered by patients and care-givers assumes greater importance. In the emergency department (ED) setting, where communication barriers between patients and providers have been well-described, alternative means of data-gathering assume a greater role.<sup>10</sup> The sub-population of patients with chronic illness who present for acute care represent a unique group who may possess disease-specific expertise

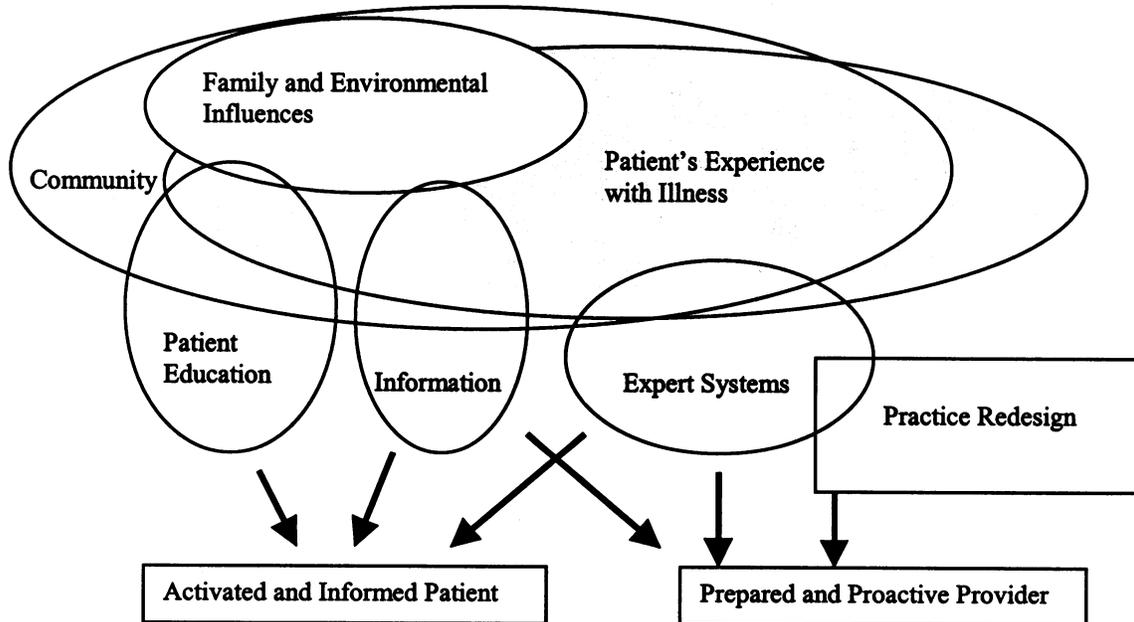
that may be accessed through appropriate patient-direct electronic interfaces.

Pediatric asthma represents a disease-specific domain wherein parents’ knowledge of their child serves as an expert resource. Expert in this context refers to the value of the information provided to inform relevant aspects of diagnosis, treatment, and home management. Parental expertise in this domain is assumed constant regardless of whether the child has been previously diagnosed with asthma or not. Parental report of symptoms related to asthma has been demonstrated to be responsive to changes in the child’s physical condition. The association between parents’ level of experience and the diagnostic relevance of their report regarding historical details has not been studied to date.

At the acute care visit, parents are the sole resource able to identify environmental risk factors for persistent symptoms (smokers in the home, pets in home, etc.) or relevant family history. For parents of children who already carry the diagnosis of asthma, their report of how the child has responded to previous treatment, and how this current episode compares to previous exacerbations remains integral to decision-making efforts. Current guidelines for acute and chronic therapy for pediatric asthma rely heavily on the reported symptoms of illness to classify and recommend appropriate therapy.<sup>11</sup>

**A Collaborative Expert System for Pediatric ED Asthma Care:** The idealized framework for collaborative care in chronic illness proposed by Wagner provides an appropriate infrastructure for the

**Figure 1. Idealized Collaborative Care (after Wagner)**



development of a collaborative performance support system in pediatric asthma (Figure 1).<sup>12</sup> Wagner detailed factors which promote idealized versions of the patient (“activated and informed”) and the provider (“prepared and proactive.”) Previous research documented the beneficial impact of priming a patient or care-giver with visit-related information prior to interactions with providers.<sup>13-15</sup> The prepared acute care provider is one who has the informational resources available to efficiently provide comprehensive care which meets current standards of quality. The acute care physician’s role may be augmented through the use of expert system that organizes and reinforces elements of best practice. Known benefits to the use of expert systems include improved process measures of quality regarding adherence to guidelines.<sup>16-18</sup>

The proposed collaborative expert system for pediatric asthma management (CSPAM) links the parents and providers through shared information. Compared to groupware technology which assumes all parties are simultaneously engaged in cooperative work,<sup>19,20</sup> the proposed system will operate in an asynchronous but cooperative fashion (Figure 2). Multiple informants (nurse, parent, and physician) will provide data to a centralized repository, and, at specified intervals, certain informants (parent, nurse, physician, social worker) will receive output from the system targeted at their area of expertise and participatory role. In this manner, all informants function as experts within specified domains of data-sharing. Each informant accesses the data repository under a specified role that defines what data is required for input, and what output the informant receives from the system. The output from the system reinforces ideal management through simple rule-based inferences run on the entered data. The architecture for the data repository will be established

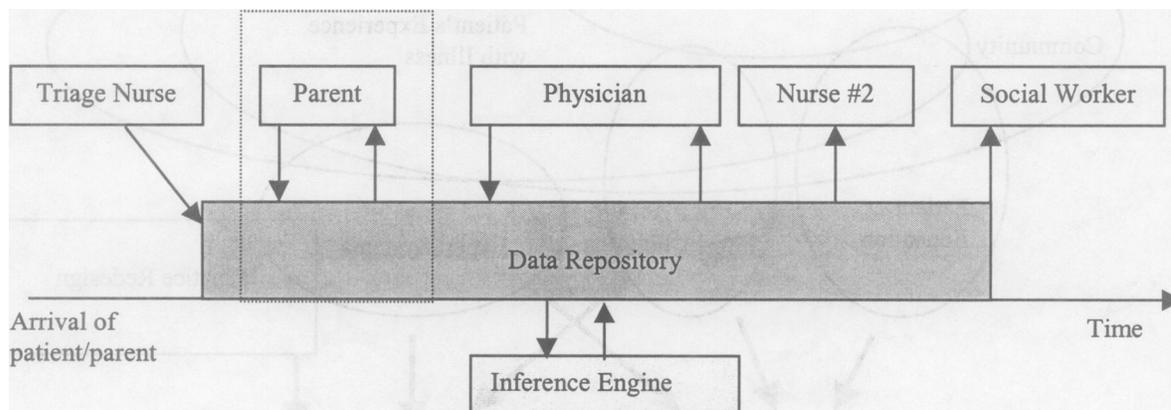
based on the Personalized Internetworked Notary and Guardian (PING) project developed at Children’s Hospital.<sup>21,22</sup> PING provides for role-based, secure interactions between multiple informants to a central data source across the web.

**Parent Interface:** The interface established for parents will be based in the nursing triage area of the ED. A touch screen interface will be augmented with an auditory module to minimize the impact of illiteracy. The interaction between the parent and the data repository (dotted box in figure 2) will occur immediately after triage nursing assessment and initial record entry into the data repository.

Parents will enter symptom data based on a scale reported by Lara et al that measures control of asthma symptoms in English and Spanish speaking populations of low literacy.<sup>23</sup> Item-level answers from the Lara scale correlate with elements of the severity classification scheme proposed by the Expert Panel 2.<sup>11</sup> This direct incorporation of parental report with guideline-supported management augments the validity of the parental perspective. Additional data entered by parents will include past medical history and relevant environmental and family history specific to asthma. The parental interface will also prompt parents to self-report needs regarding home care of asthma.

The inference engine will produce a chronic severity classification of the child’s asthma using parental symptom report and compare it to current medications. This will generate recommendations to the nurse and physician regarding alterations to asthma management. An educational sheet that suggests new medications or changes in existing medications for chronic control will be generated for parents. This paper-based communication will encourage parents to discuss these medicines with the

**Figure 2. CSPAM**



physician and nurse. The sheet will also encourage parents to discuss other concerns with the clinical team. This emulates prior successful interventions that activated patients to participate more fully.<sup>13-15</sup>

The second level of analysis completed by the inference engine will address non-use or over-reliance on beta-2 agonist medications prior to arrival in the ED. Parents' entry of medication will include their report of number of nebulizer treatments given on the day of presentation to the ED. Parents who report access to beta-2 medications but who either gave a) no treatments, or, b) treatments more often than every 3 hours on average for the day of presentation will be flagged by the system as in need of education regarding beta-2 agonist use. This aspect of the inference engine supports the refinement of parental expertise in asthma management through verification of their appropriate use of medications.

Environmental risk factors and parental report of unmet needs will be viewed as alerts by the inference engine and highlighted for physician and nurse review. Parents' willingness to have social work follow-up will be tracked by the system and notifications delivered on a daily basis to the social worker based in the ED.

**Discussion:** The proposed patient interface captures the expertise of parents in their report of symptoms and concerns and invests the information with additional value using a structured series of questions to appropriately categorize the chronic severity of disease. As such, the parent who may not directly be able to answer the question – "What severity classification does your child manifest?" is nonetheless able to provide data in support of the answer. The expert system allows for unstructured knowledge to manifest itself as an expert contribution.<sup>24</sup>

CSPAM will promote idealized communication through asynchronous collaboration of information from multiple sources. Prior research in technology-assisted collaborative work has raised two major concerns: bandwidth limitations and replication of work spaces.<sup>25</sup> CSPAM will collect data intermittently over time and matches informational needs for input and output with specific participants. The total number of participants actively entering or retrieving data from CSPAM at a given moment in time will be significantly less than the total number of participants for a given time period of care. This lessens the impact of bandwidth for deployment of CSPAM at the local level.

With regard to replication of work spaces, CSPAM provides for a parsed approach to domain areas of expertise such that specific informants

provide data limited in scope according to its inherent quality and relatedness to treatment decisions. The CSPAM architectural plan calls for bi-directional flow of data. Accordingly, the system includes targeted feedback to all decision-makers including patients, and thus electronically supports partnership between parents and providers. The virtual work space created by CSPAM does not allow for needless replication of information as each participant in the data exchange process maintains a profile of accepted input and output elements that they may send or receive from the central repository.

The enhanced decision-support proposed for CSPAM reorients the focus of treatment decisions on the perspective of chronic illness.<sup>26</sup> Prior research in pediatric asthma points to deficiencies in ED care that ignores more longitudinal aspects of the disease and results in sub-optimal care.<sup>27</sup> Aspects of previous history, indicators specific to quality of life, and other historical elements not conducive to capture using quick closed ended questioning typical of ED-based communication are amenable to electronic input. Parents, as the experts on the child's prior history of symptoms and response to treatments, are ideally suited to provide this data to acute care providers.<sup>28</sup>

The unique perspective of the patient has been neglected as informatics narrows its focus from the human organism as a whole down to the analysis of DNA encoded on a chip. "Phenotypic" data specific to an individual regarding symptoms and response to therapy remains variably expressed with multiple environmental, social, and experiential factors confounding reliable capture of the information. However subjective, the voice of the patient retains value. Patients' report of data possesses more than face validity as to the meaning of the shared information. In one study, the health data reported by adult patients demonstrated predictive value for their own mortality even after controlling for commonly accepted predictive variables.<sup>29</sup> Information design for health care systems should attend to all participants in the exchange of data to optimize comprehensive capture of relevant and accurate data.

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