Improving End of Life Care: an Information Systems Approach to Reducing Medical Errors

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Abstract. Chronic and terminally ill patients are disproportionately affected by medical errors. In addition, the elderly suffer more preventable adverse events than younger patients. Targeting system wide "error-reducing" reforms to vulnerable populations can significantly reduce the incidence and prevalence of human error in medical practice. Recent developments in health informatics, particularly the application of artificial intelligence (AI) techniques such as data mining, neural networks, and case-based reasoning (CBR), presents tremendous opportunities for mitigating error in disease diagnosis and patient management. Additionally, the ubiquity of the Internet creates the possibility of an almost ideal network for the dissemination of medical information. We explore the capacity and limitations of web-based palliative information systems (IS) to transform the delivery of care, streamline processes and improve the efficiency and appropriateness of medical treatment. As a result, medical error(s) that occur with patients dealing with severe, chronic illness and the frail elderly can be reduced.

The palliative model grew out of the need for pain relief and comfort measures for patients diagnosed with cancer. Applied definitions of palliative care extend this convention, but there is no widely accepted definition. This research will discuss the development life cycle of two palliative information systems: the CONFER QOLP management information system (MIS), currently used by a community-based palliative care program in Brooklyn, New York, and the CAREN case-based reasoning prototype. CONFER is a web platform based on the idea of "eCare". CONFER uses XML (extensible mark-up language), a W3C-endorced standard mark up to define systems data. The second system, CAREN, is a CBR prototype designed for palliative care patients in the cancer trajectory. CBR is a technique, which tries to exploit the similarities of two situations and match decision-making to the best-known precedent cases. The prototype uses the opensource CASPIAN shell developed by the University of Aberystwyth, Wales and is available by anonymous FTP. We will discuss and analyze the preliminary results we have obtained using this CBR tool. Our research suggests that automated information systems can be used to improve the quality of care at the end of life and disseminate expert level 'know how' to palliative care clinicians. We will present how our CBR prototype can be successfully deployed, capable of securely transferring information using a Secure File Transfer Protocol (SFTP) and using a JAVA CBR engine.

Keywords. Information systems, palliative care, management information systems, case-based reasoning, palliative care, quality of care, end of life, electronic health records

Introduction

This research will evaluate the ways in which information systems can improve the quality of care for patients and caregivers who are dealing with severe, life-threatening illnesses. The palliative care model is relatively new and continues to be refined, especially when healthcare interventions are provided outside the physical confines of a hospital [1,2]. Community-based models, which incorporate intensive case management, are initiating chronic disease interventions "up-stream" in the course of illness. The Quality of Life (QOL) program, in Brooklyn, New York is an example of this approach [3].

CONFER QOL is a palliative information system that was developed for the QOL program. The development team consisted of both researchers and information services professionals. CONFER QOL is primarily used as a management information system (MIS). Development of this system began in 2002, and we are currently testing the integration of a new care planning form.

Our second palliative information system, CAREN, is a case-based reasoning (CBR) application. The information in the case library was obtained from the QOL program's clinical data forms and informal case notes, which are found in the patients' charts. These charts are maintained by the QOL program's Quality of Care Coordinators.

1. Patients with Chronic and Terminal Illnesses

Medical errors are alarmingly common, costly, and often preventable [4]. Chronic and terminally ill patients are disproportionately affected by medical errors [5-9]. In addition, the elderly suffer more preventable adverse events than younger patients. Myers and Lynn [6] suggest three key factors that make individuals who are nearing the end of life more vulnerable to medical errors, and the resulting adverse events:

1. These patients interact more with the health care system. This leads both to more medications and to more procedures overall. For example, on average, people with one chronic condition see three different physicians and fill six prescriptions per year, and people with five or more chronic conditions have an average of almost 15 physician visits and fill almost 50 prescriptions per year [9].
2. As a result of their poor health, errors that occur during the course of care are more harmful to the patient's overall health. In addition, these patients are often the least likely to recover from more serious medical error(s).
3. Patients with chronic illnesses are often exposed to organizational or habitual "process" patterns of patient care that, although repeatedly used, run counter to well-substantiated "best practices." Best practices are documented in the literature and establish the evidence-base for clinical pathways.

We have identified a fourth factor that contributes to the vulnerability of these patients who are confronting serious, life-threatening illnesses:

4. These patients are least able to monitor their own care, especially when they live alone or have no primary caregiver.

Patients confronted with chronic, and life-threatening illnesses are in dire need of safe, reliable and well-coordinated care. Currently, health care and community services are not organized to meet the needs of the growing population of people facing a long period of progressive illness and disability before death [10,11].

Worldwide, people are harmed as a direct result of medical errors that can occur while receiving medical treatment. How can information systems be used to improve the quality of care for patients who are dealing with chronic and terminal illnesses? Does the use of patient data for quality assurance purposes require special measures to protect a patient's privacy? Minimizing potential risks to patient privacy and confidentiality are not only an organizational obligation, but also mandated in the Unites States [12].

1.1 Palliative Care Expertise

Deficiencies in medical education about end of life care are widely recognized [13,14]. Sustaining leadership and disseminating practice guidelines for palliative care requires several approaches including: developing palliative care leaders, improving palliative care curricula, creating standards for competence, and creating and enhancing educational resources for end of life education [1,13,14].

Cases provide a flexible framework for illustrating the lessons of experience and the dilemmas requiring careful judgment [15,16]. We have carefully selected cases and created our palliative care library to comprise a "real life" clinical curriculum. The casework of the palliative care team is the foundation for the automated consultation in the CBR system we developed. Successful CBR systems have been used to simulate the reasoning of medical experts, for example FLORENCE [17], a care planner for nurses, MEDIC [18] a case-based physician and CASEY [19], a case-based diagnostician. CBR is particularly effective in managing the implicit knowledge that specialized healthcare professionals gain through experience.

2. Palliative Information Systems

Lessons learned from the palliative care databases in Hamilton and Halifax, Canada point to the following planning guidelines and system requirements for the software development life cycle of a future palliative information system [20]. We have also expanded this list of requirements to encompass our development experience with palliative information systems and the new government directives in the United States:

- have a clear definition of the uses for which the data is being collected
- decide on a clear set of goals and objectives

- have a short-term and a strategic plan
- select the data you will collect
- allocate the time and resources to collect and enter data
- provide fiscal support for the system's initial and continued system development
- state ownership of and responsibility for the database
- use a relational database system, such as Access, ODBC, or SQL to house the database
- provide the ability to merge information into other databases
- ensure data accuracy and integrity
- communicate with other palliative care programs and services
- enforce HIPAA compliance

2.1 System 1: CONFER: "eCare" Solutions

Different characteristics are associated with different levels of automation within an organization. Automated information systems allow for an organization to do the following tasks: collect detailed computerized patient information, record data, use decision support tools, standardize coding, standardize extraction tools and access a knowledge base via the web. CONFER [21] is based on the idea of "eCare," a process-based application for care management. The CONFER web platform uses XML (extensible mark-up language) to define the systems data. XML is a W3C-endorsed standard document mark up [22]. It defines a generic syntax used to mark up data with simple, "human-readable" tags. Users access CONFER via the company intranet. The application allows the QOL program to store and analyze various data types, and it is robust enough to support enormous quantities of information.

The initial QOL system consisted of two user forms, linked to multiple database tables, built with the SQL language. Continued development in the Research Department included the addition of two user forms, the Referral Log to track referral reasons and outcomes, and the Hospital Log to record and analyze data on participant hospitalizations. Additional changes to the prototype included modifications of the initial two forms, Patient Demographics and Action Log. The Research Department used requirements discovery prototyping to develop the system from the initial prototype. This development methodology is a "quick and dirty" way to develop an information system [23]. It falls into a rapid applications development methodology, which is a fast track to developing a system, usually through use of a working prototype built with code generating tools, that is refined to meet the stakeholders' needs.

2.2 System 2: CAREN Case-Based Reasoning (CBR) Prototype

Practice-based tools, to assist palliative care professionals would be a valuable asset for training novices and care planning. Development of the 'CAREN' palliative care prototype, developed with the CASPIAN CBR shell [24], was inspired by this growing need.

CBR came from research in the cognitive sciences, particularly the work of Schank and Abelson in 1977 [25]. Their group proposed that knowledge about situations is stored in the brain as scripts, which describe information about stereotypical events such as visiting the doctor. However, a weakness of scripts is their inability to provide a complete theory of memory representation. Schank went on to further explore the role of memory in problem-solving and situation patterns or MOPs (Memory Organization Packets) [25].

In the medical domain two knowledge types can be found: explicit or formalized knowledge and implicit or operative knowledge. The formalized knowledge is the knowledge that can be found in textbooks and clinical guidelines. This kind of knowledge is very suitable for rule representation. The operative knowledge consists of individual expertise, organizational practices and past cases. CBR has proved to be a well-suited paradigm for managing knowledge of the operative or implicit type [26,27]. Implicit knowledge is commonly employed by professionals for medical decision-making. Characteristics of CBR systems include [27]:

- the recognize-act cycle
- the use of domain specific knowledge
- a knowledge representation which allows a flexible modification of the knowledge base
- the use of expert lines of reasoning
- the capability of explaining the reasoning process
- inter-disciplinary knowledge in solving a problem

2.2.1 Indexing Cases and Computing Similarity

The ability to understand the new case in terms of old cases consists of two parts, recalling and interpreting. This first part is known as the indexing problem. This problem concerns the proper assignment of indices and ensures that the relevant cases are stored in memory and are called under the appropriate circumstances. The purpose of building an index scheme is to speed up searching. Here, searching means to find a set of cases from the case-base, which are similar to the new case. The final goal of the system is to find the case with the maximum similarity to the new input case. Our design consisted of a final index definition that is found in Appendix A. The definition we incorporated in our final prototype resulted after the evaluation of alternate indexing strategies.

CASPIAN uses the nearest neighbor matching algorithm (NNM). At the conceptual level, the nearest neighbor technique is simple. This algorithm compares the attribute value of each non-indexed case feature in the set of similar cases to every corresponding feature in the new input case. Attribute values used in CAREN include: secondary condition, age, income, advanced directives, visual, speech and hearing status, weight, and the presence or absence of disease-related symptoms. The comparison values are calculated for each feature and then summed for each case to get the total comparison value. NNM can be made more accurate by weighting attributes that are not defined as indices. In CAREN we weighted several case features including: weight, age, income, secondary condition. After the total comparison value is determined for each similar case, the algorithm selects the case with the highest value for similarity to be the best case match [28].

2.2.2 Case Adaptation and Learning

It is rare that a retrieved case is exactly the same as an existing case in the case library. Adaptation is the process of fixing an old solution to meet the demands of the new situations [27]. CASPIANs adaptation rules are divided into global rules, which are checked first, and local repair rules. Several strategies for adapting cases have been implemented in CBR systems [29].

CBR differs from other AI learning techniques in that it integrates the reasoning mechanism with the learning mechanism. For example, in the CASPIAN system the modified case is stored in the case-base by adding the new case to the case library. Inductive formation of reasoning is only responsible for some of the learning in the case-based reasoner. Most of a case-based reasoner's learning occurs through the accumulation of new cases, through the assignment of good indices, case attributes and weight values. Generally, as the caseload accumulates, so does the accuracy of the CBR. The system becomes more knowledgeable because it has acquired more cases, and thus new knowledge, through the automated reasoning process.

3. Research Methods

CONFER QOL and the CAREN case-based reasoner are designed for patients appropriate for palliative care, but are not hospice ready. Patients ready for hospice are referred directly to hospice. A nurse/social work team screens participants and the QOL program’s Project Manager approves intake. CONFER QOL is designed for patients in different disease trajectories and also tracks referrals and patients with a ‘bridge’ status. The current design of the CAREN prototype is more exclusive, and was designed for a subset of the palliative care population.

The target population for the CBR application was individuals in the cancer trajectory. This group of QOL patients was sampled in a purposive manner. The QOL program manager suggested 17 specific cases she believed provided the best characteristics in regard to sample size and improved outcomes. Before the cases were translated into the CASL language, the test case, Patient 178, was selected randomly. Data was obtained through the use of CONFER QOL management information system and by manual chart review. In total, 22 field values were recorded for the 17 patients in the study sample.

3.1 CASPIAN CBR Shell

CASPIAN comes with its own language for defining cases, called CASL. The general syntax of a case is comprised of the following elements:

- Introduction
- Case Definition
- Index Definition
- Modification Definition
- Pre-processing Rule Definition
- Repair Rule Definition
- Case Instance

The case definition provides the key fields in a palliative care case. The weights of case attributes are assigned in the case definition. We have defined weights on the following case features: secondary condition, (4), age (1), income, (4), dyspnea (3), weight, (1), the presence disease related weight loss, (3), presence of pressure ulcers, (1), observer behavioral problems, (2), and the presence of any other disease related symptoms, (2). Any field that is not an index can be assigned a weight value. The case attributes defined in the CAREN case-based reasoner are found in Appendix A.

The index definition consists of the constraints for the retrieved case. All fields defined in the index definition must be an exact match; there is no weighting for similar attributes. After consulting with domain experts from the QOL program, we have identified the following indices as essential features for this prototype: primary diagnosis, living status (does the he/she live alone?), hospice status (is he/she hospice ready?), adl status (what activities of daily living are compromised?), pain symptoms (presence or absence?), and gender.

The rules in the repair rule definition are used in case adaptation. The rules are examined in turn, and if the condition(s) are met by the input case the repair rule's associated actions will be executed. When a repair rule is fired it is flagged, and once all rules have been examined, CASPIAN reviews the rules again. This is repeated until no new rules fire. In the prototype, we have developed preprocessor rules for income status, advanced care planning, and to ensure safety in the patient's home.

A case instance is an individual case definition with a solution. The instance is flexible in that every parameter is not a requirement for validation. The solution in each case instance is comprised of two main case management units, the goals and the suggested intervention strategies. The compiled case library is subjective to the Quality Care Coordinators who provided the documented consultation services. Each goal has at least one intervention strategy.

4. Findings and Results

Web-enabled, real-time information management systems like CONFER QOL can facilitate the process of participant tracking. Iterative improvements are periodically made to improve patient tracking and outcome measurement. CONFER QOL's main contribution has been its efficient and accurate reporting capabilities. Currently, the system provides formal reports that are viewed through a report editor including: participant demographics, patient process histories, participants program status, referral sources, diagnoses, hospitalizations, service referrals and palliative care resource intensity (e.g., types of contact, goals of contact, duration of contact, and types of actions by different care constituents including nurses, social workers, interns and physicians). Ad hoc reporting is also used to report detailed service utilization, referral outcomes and site of death research. Conifer's reports have been used to support management decision-making and assign organizational value to the "black-box" of social interventions in a predominantly "medically" oriented healthcare system.

To assess the application of automated case-based reasoning in the palliative care domain, we entered 16 participant cases. One of these cases did not have a primary diagnosis of cancer, and this was used as a control marker. If this case was ever returned by the system, we knew something was definitely wrong. These 16 cases comprise the expert knowledge base for which the CBR application will calculate the cases best match given the index definition and the assigned attribute weights.

4.1 Applying Automated CBR for Palliative Care Consultation

In the first phase of the case-based reasoning cycle, CAREN retrieved the case that was most similar to our randomly selected test case, Patient 178. The best case match in the CAREN case library was Patient 171. In the second phase of the CBR cycle, the prototype applied the preprocessing rules and then reused the solution part of Patient 171's case definition.

Patient_171 matched on all indices (primary diagnosis, gender, pain status, living status, and activity of daily living status), income group, advanced care, speech and hearing, oxygen, cpap, insulin, weight changes, absence of pressure ulcers and hospice readiness. The new case differs in secondary condition, 18 years of age, visual limitations (not a weighted attribute), presence of additional disease symptoms and behavioral problems (Patient 171 had compliance issues with her medication), and the advanced directives. One other case matched all index constraints, but after the similarity calculation patient 171 was determined as the most similar case.

To evaluate the potential of CBR as a tool for automating decision-making in the palliative care domain we compared CAREN's prospective consultation to a retrospective chart review. In addition, notable features about the test case, Patient 178, were also retrieved form the CONFER QOL information system.

The test patient's closest match, calculated and retrieved from the case base of cancer patients who are appropriate for palliative care, is also a female who lives alone. In addition, Patient 171 and 178 are both burdened by the increasing complexity of their life threatening illness. The solution part directly derived from patient_171's case instance includes: a brief patient sketch, which is mainly a summary of the indexed fields and can be used for debugging, as well as four goals with their corresponding intervention strategies. The first goal is psychosocial support, achieved through the interventions of individual support therapy by the care managers, telephone check-in support, assistance with the activities of daily living, and coordinating access to available social services. The second is the monitoring of the patient's disease status, achieved with the interventions of the program's medical and social assessment and establishing a relationship with patient_171's primary care physician. The third is effective pain management, achieved through medication review by the program's nurse and contact with the patient's primary care physician and the fourth goal is of advanced care planning.

After reviewing Patient 178's case history and comparing the results with CAREN's palliative care consultation, we conclude that automated CBR can be applied effectively in the palliative care domain. The automated case-based reasoner created a care plan with many of the goals executed in the field. Goals that CAREN identifies that are confirmed in Patient 178's chart are:

Goal 1: to facilitate entitlements or coverage
Goal 2: psychosocial support
Goal 3: monitoring disease status
Goal 4: to ensure safety in the home
Goal 5: effective pain management

The adaptation rules modified the most similar case, Patient 171, to fit the new case. This complemented the new care consultation for Patient 178 with an additional goal to research entitlements and coverage due to their self-reported annual income. This goal was not documented in the case history of Patient 178 by the care managers.

These preliminary results suggest CBR can be used to disseminate domain-specific knowledge. The CAREN application can be used to identify care goals and suggest appropriate interventions for patients dealing with life-threatening illnesses; however, we do feel it is not as comprehensive as the human expert after the in-depth chart review.

The CAREN case-based reasoner did not identify goals or interventions directly related to the patient's needs of self-care and medication education. In addition, it is noteworthy that the patient was suffering from clinical depression. The human reasoner addressed the patient's mental and physical decline in relation to a traumatic life experience; the automated reasoner did not. CAREN's results consisted of an applicable care plan, but results suggest that the CAREN application could be improved to more extensively incorporate the "know how" of a palliative care expert.

Conclusions

The CONFER QOLP palliative information system makes past palliative information systems appear simplistic. All the necessary components and requirements defined by the Halifax system [20] are integrated, but CONFER is a HIPPA compliant, XML-based, "eCare" version. CONFER has followed many similar logical and software development guidelines learned by adhering to the shortcomings of past systems. Many of the same goals were identified to meet problems that are generated by the complex nature of healthcare delivery. These problematic issues include: inadequate tracking, compromised data integrity, decentralized data and inefficient access and retrieval. Implementation of CONFER shows that information-gathering methods must also be addressed, to ensure that the system is monitoring valid and relevant actions and events. A method of quality control should also be incorporated into a palliative information system development guideline.

We have focused on how different IS can be used to improve the quality of care delivered to patients with severe chronic illness. Information systems like CONFER can play a critical role in measuring and reporting quality, but lack 'intelligence'. AI techniques can be used to design intelligent systems like CAREN. The CAREN CBR system can be used to disseminate guidelines for best practice and appropriate treatment and have the potential to be used in palliative care educational initiatives for novices and healthcare professionals unfamiliar with the concepts of palliative care. An ideal palliative information system would be web-enabled, efficient, accurate, reliable, user-friendly, and intelligent, merging many of the important features of the systems we have analyzed.

Future Directions

The experimental results of the CAREN CBR prototype suggest CBR can be used to disseminate domain-specific knowledge. The CAREN application can be used to identify care goals and suggest appropriate interventions for patients dealing with life-threatening illnesses; however, we do feel it is not as comprehensive as the human expert after the in-depth chart review.

Our next phase with the CAREN prototype is deploying the program on a secure web-based platform using opensource software. To transfer the individual patient cases, or electronic health records, and decided to use secure file transfer by encrypting the data (FTPS/SFTP). We considered several options, and we tested one of them. Company Bitvise Limited provides a product WinSSHD version 3.31, which is a SSH server for Windows with secure remote access and file transfer. It supports public key authentication, SCP, SFTP [30]. We can use any SSH client, which supports SSH protocol version 2, to log into WinSSHD. We tested the file transfer using CuteFTP Pro and PuTTY clients, but choose the Java client, which we found easy to install and use for Windows and MacOS, the most popular OS among Internet users.

The Java client has been built on a Secure FTP Factory from JSCAPE: a set of Java based client components for exchanging data between machines. It includes FTP (File Transfer Protocol), FTPS (FTP over SSL) and SFTP (FTP over SSH) components. The Java client has features such as ability to resume interrupted file transfers, progress monitor, and a built in event listeners to track the progress of file transfers [31].

Currently we are assessing Java CBR engines to implement the case-based reasoning cycle. Our future research will be to develop and evaluate and discuss the potential value a web-base case-based reasoner for palliative care consultation. We will describe how any collection of palliative care cases, or other electronic health record coded in XML format, can be incorporated into the framework we have defined in the CAREN prototype.

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Appendix A: CAREN CASL Case Attribute Definition

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case definition is

field prim_diagnosis type is (CA, CHF, CVA, Dementia, DM, ASHD, HTN, FX,
               CVA_or_CHF, CVA_or_ASHD, ASHD_or_CHF)
               prompt is ['Primary Diagnosis:'];
field sec_condition type is (CA, CHF, CVA, ASHD, Dementia, DM, HTN,
               Seizures, Retardation, Pancreatitis, NA) weight is 4
               prompt is ['Secondary Condition:'];
       field gender type is (male, female, transgender)
               prompt is ['Gender Identification:'];
       field age type is number weight is 1
               prompt is ['Patient Age:'];
       field pain_sympt type is (yes, no)
               prompt is ['Symptoms of Pain?'];
       field income type is number weight is 4
               prompt is ['Income Group:'];
       field adv_care type is (yes, no)
               prompt is ['Advanced Directives:'];
       field lives_alone type is (yes, no)
               prompt is ['Does Patient Live Alone?'];
       field visual type is (yes, no)
               prompt is ['Visual Limitations:'];
       field speech type is (yes, no)
               prompt is ['Speech Limitations:'];
       field hearing type is (yes, no)
               prompt is ['Hearing Limitations:'];
       field dyspnea type is (yes, no) weight is 3
               prompt is ['Symptom of Dyspnea?'];
       field oxygen type is (yes, no)
               prompt is ['Patient uses Oxygen?'];
       field cpap type is (yes, no)
               prompt is ['Patient CPAP or BICP?'];
       field pat_weight type is number weight is 1
               prompt is ['Patient Weight:'];
       field weightchange type is (yes, no) weight is 3
               prompt is ['Recent Weight Changes?'];
       field insulin type is (yes, no)
               prompt is ['Insulin Dependent?'];
       field pu type is (yes, no) weight is 1
               prompt is ['Presence of Press Ulcers?'];
       field adl type is (yes, no)
               prompt is ['Compromised ADLs?'];
       field behavior type is (yes, no) weight is 2
               prompt is ['Behavior Problems?'];
       field other type is (yes, no) weight is 2
               prompt is ['Other Symptoms Evident?'];
       field hospice type is (yes, no)
               prompt is ['Patient Hospice Ready?'];

end;
```