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INFORMATION SYSTEMS AND HEALTH CARE V - A MULTI-MODAL APPROACH TO HEALTH CARE DECISION SUPPORT SYSTEMS

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ABSTRACT

Decision Support Systems (DSS) in health care must be designed in consideration of the empirical context and problem space where they are being applied. However differences such as workflow, clinical expertise and organizational norms make it hard to define the context where a DSS will be used. What is needed is a DSS that is able to enhance health care delivery in different contexts. In this paper we present a multi-modal DSS that supports decision making in different contexts. The paper describes the theoretical basis for the DSS, explores a problem space in palliative care and describes a prototype implementation of the DSS to address the issues from the problem space.

Keywords: decision support system, context, ontology, multi-modal, palliative care

I. INTRODUCTION

Computer-based decision support systems (DSSs) can improve patient outcomes through decision making by providing access to clinical practice guidelines [Grimshaw and Russell, 1993]. In addition to developing DSS applications, DSS research focuses on developing and disseminating standardized computer-based guideline languages and models to promote a shared model for computer-based clinical practice guidelines. One area of emphasis is developing computer-based guideline representation models¹ such as the Arden Syntax, EON, PROforma and the Guideline Interchange Format (GLIF) However, while these formalisms existed for some time they did not receive the initially anticipated level of broad adoption and practical success.

¹ Wang, Peleg, Tu et al, [2002] present a detailed review of guideline models

We believe that one reason for the lack of guideline adoption is that medical guideline language research lacks the means of systematic analysis and methodological formalization of the context of the medical domain. We define a DSS as much more than just guidelines or expert systems but rather a means of supporting health care through a wide range of tasks such as diagnosis, therapy recommendations, communication and practitioner education. However, to achieve those goals, a DSS must be able to:

1. link patient history with guidelines to provide patient-specific decision support,
2. reconcile issues of workflow and how they will be impacted by a DSS,
3. be applied to support different levels of clinical practice expertise and care givers in different roles,
4. be continuously updated with new evidence, and
5. evaluate and monitor the effectiveness of a DSS continuously once it is implemented.

The above considerations illustrate substantial research questions that need to be addressed (in addition to developing guideline coding formalism) in order to lead to broad adoption of DSS technology in practice.

Considerable research results exist on developing theories both on how decisions are made generally in health care (e.g., differences between experts and novices) and how decisions are made in specific domains of health care (e.g., palliative care, policy management). Such theories and the breadth they contain help provide the theoretical architecture of a DSS.

Although the hypothetico-deductive approach was the first detailed model about medical reasoning, and is still a common approach to structuring DSS, it was critiqued for failing to support decision making by experts and novices. We believe the key to DSS design that supports multiple tasks is to make use of the rich theoretical framework around decision making to enable the appropriate decision making theory to be applied in the appropriate contexts.

To achieve broad adoption and success, DSS in health care applications must be designed in consideration of the empirical context and problem space in which they are being applied. In this paper we discuss the design and development of a multi-modal DSS, which goes beyond the typical deductive execution of clinical practice guidelines and addresses issues such as different levels of clinical reasoning, workflow, and evaluation. This paper makes three contributions in the direction of realizing this vision.

1. We discuss three theories on decision making in health care, analyze the similarities and differences within the theories and highlight the key points from each theory that we deem necessary in a DSS (Section II).
2. We study and characterize the problem space of palliative care severe pain management and point out in which different contexts a DSS can make a contribution (Section III).
3. We describe the architecture of a multi-modal DSS (Section IV). We then summarize the multi-modal DSS vision with a prototype example of a DSS framework in the form of a palliative care DSS showing how it addresses issues raised in the palliative care problem space identified previously.

II. A THEORETICAL FOUNDATION OF DECISION MAKING THEORIES IN HEALTH CARE

We introduce three theories on decision making in health care: (1) the hypothetico-deductive approach [Elstein and Shulman, 1978; Kassirer and Gorry, 1978], (2) the argumentative approach [Dickinson, 1998] and (3) a model for making managerial health care decisions in complex, high velocity environments described by Reay [Reay, 2000]. These three theories serve as the theoretical foundation for a multi-modal DSS. Each theory is described briefly and its key points and weaknesses are described (Table 1 in the Summary at the end of this Section). We also highlight the key points from each theory that are incorporated in our DSS framework.

THE HYPOTHETICO-DEDUCTIVE APPROACH

One of the first models of clinical reasoning is the hypothetico-deductive approach, an iterative process for data collection and hypothesis generation that involves a sequential series of steps consisting of staged data collection, data interpretation, and hypothesis generation [Elstein and Shulman, 1978; Kassirer and Gorry, 1978]. The cycle then starts over with the existing hypothesis influencing the selection of the next set of data. The cycle often results in a set of competing hypothesis called the “differential diagnosis”. Medical reasoning based on the hypothetico-deductive approach bodes well for support by a DSS because of the complexity of medical decision making and the number of data elements that could be considered at any one time. A DSS could support the retrieval of data for hypothesis generation and for formulating alternate hypothesis. However, presenting the hypothetico-deductive approach as a model for all users is problematic. Experts and sub-experts will approach decision making differently. Patel, Arocha and Kaufman [2001] illustrated how experts take a more direct approach to problem solving whereas novices tend to take a less direct path, often assessing data elements that are not relevant to the decision at hand.

THE ARGUMENTATIVE APPROACH

The argumentative approach by Dickinson [1998] is a theory of evidence-based decision-making that highlights the different types of reasoning (i.e. inductive, deductive and abductive) that take place in different contexts. In particular, the argumentative approach points to literature that shows that diagnostic decision-making does not conform to the hypothetico-deductive approach but is more abductive in nature [Patel, Evans and Kaufman, 1989]. Abductive reasoning starts with a set of observations (such as symptoms) and moves towards an explanatory hypothesis, which differs from deductive reasoning that goes from hypothesis to observations. The argumentative approach also points out that data and information often serve two different purposes in decision making: the basis for the conclusion itself, or the backing or justification of the conclusion. Each of those different purposes requires different research evidence. Dickinson [1998] proposes that research evidence is often inappropriate for the task at hand.

A MODEL FOR MAKING MANAGERIAL HEALTH CARE DECISIONS IN COMPLEX, HIGH VELOCITY ENVIRONMENTS

Reay [2000] presents a framework that focuses on transferring knowledge from research to practice. Reay’s framework involves four stages of how new information can be: recognized and accessed, appraised, adapted for use in another setting, and applied and integrated into the practices of an organization. Reay’s framework takes a different look at health care decisions in that it addresses decisions at the organizational level and identifies the need to adapt knowledge from one setting for integration into another setting. Consideration of the organizational perspective is necessary as workflow and organizational culture cannot be ignored when implementing IS such as a DSS. Reay addresses external influences on the decision making process, which neither the hypothetico-deductive or argumentative approaches address implicitly. External influences can be internal organizational factors and external system-wide influences. Examples of internal influences are organizational factors such as the stress of the circumstance where decisions are made and also who makes the decision (individual, group). External system wide-influences can be government mandated legislation or established medical standards.

SUMMARY OF THE THREE DECISION MAKING THEORIES AND APPLICATION TO DSS FRAMEWORK

Table 1 summarizes the three decision making theories/.. From these theories we identify two specific themes: context and communication, which we believe are fundamental considerations for the design of a clinical DSS. Our use of context implies the need for a DSS to support

Table 1. Key Points and Omissions from the Three Decision Making Theories

THEORY	KEY POINTS	OMISSIONS
Hypothetico-Deductive Approach [Elstein et al, 1978; Kassirer & Gorry, 1978]	Identifies differential diagnosis and cyclical pattern of clinical reasoning	Does not consider decision making in different contexts nor different expertise levels
Argumentative Approach [Dickinson, 1998]	Different types of reasoning take place in different contexts; decision deriving and decision justification require different evidence	Theory is presented as conceptual and not validated through research; does not address evaluation of decisions made
Making managerial health care decisions in complex, high velocity environments [Reay, 2000]	Recognizes adaptation of knowledge for integration into new situation; considers impact of work practices	No evaluation framework or recommendations of how to incorporate the multiple decision making influences

different types of decisions such as caregivers of differing levels of expertise and in different situations such as diagnostic as opposed to therapeutic decision making. We acknowledge that context can take different meanings in different situations. Our use of the term to encompass expertise of users and types of decision being made came from the data analysis during this research as expertise and types of decisions were the two biggest contextual factors that impacted decision making

Consideration of contextual impacts also includes separating conceptual knowledge (knowledge of domain specific concepts) and procedural knowledge (knowledge of how to perform various activities) [Patel, Arocha and Kaufman, 2001]. Studer, Benjamins and Fensel [1998] point out that in pioneer medical DSSs (such as Shortliffe's Mycin system) strategic knowledge such as the order in which goals should be achieved was mixed up with domain knowledge such as the causes of a specific disease. Mixing up different types of knowledge makes it hard to apply the DSS knowledge in different contexts and also makes maintenance of the DSS difficult.

Context also requires the need for evaluation in order to assess the effectiveness of a DSS so that it can continue to evolve to provide utility to those who use it. Detailed evaluation studies such as a randomized control trial or qualitative based approach such as action research are useful for the evaluative details they provide, but such methods are time consuming and involve a long time cycle before their findings can be incorporated into DSS refinement. Although such detailed evaluations are necessary we also advocate using an ongoing evaluation framework that uses data and findings from the DSS to produce meaningful evaluation results quickly.

An example of context is a situation in which a caregiver wants to access information that represents a potential explanatory diagnosis matching his patient's signs and symptoms. This example is in line with abductive reasoning. A different context is seen through using the DSS as quality assurance for decisions where a less experienced caregiver develops a preliminary hypothesis of what the diagnosis could be but wants the DSS to provide information to refute or validate his diagnosis. In that context, the DSS acts in a deductive manner as a teaching tool and would need to provide explanatory information about how well the caregiver's clinical reasoning matches with the DSS.

Communication is crucial because providing health care is a continuous act. A patient care episode usually draws upon past care and impacts future care. Despite a long history of DSS, availability the results achieved are rather modest, and dissemination of systems into health care practices progressed only slowly [Reisman, 1996]. For a DSS to be used in care delivery, it must act as the means to care delivery and not the ends. Simply accessing a computer-based guideline that does not draw on previous patient data nor allows for incorporation into future care

episodes will be of limited use in clinical practice. A DSS must do more than just present the guideline, it must support the users of the guideline and communicate and share its information.

III. PROBLEM SPACE EXPLORATION- PALLIATIVE CARE CASE STUDY

Palliative care, defined as care provided to patients when curative therapies are no longer an option, was only formally conceived in the late 1960's. Despite being a new domain of medicine, our aging population will require an increasing amount of palliative care services in the years ahead. Development of information system (IS) artifacts such as DSSs is a practical way of enhancing palliative care delivery. However, largely because it is a new domain of medicine, IS for palliative care is not as developed as more established fields of medicine, such as intensive care. That provides an excellent opportunity for research such as our multi-modal (DSS).

Palliative care presents a good example of a field where context and communication are essential to decision making. Our current palliative research is in severe pain² management and is the source of the example. Enhanced severe pain management is needed as 20-40% of severe pain episodes are not managed properly [Franks, et al., 2000]. As part of our exploration of the problem, space in palliative pain management one of the authors spent over 50 hours observing pain management on the clinical ward and analyzed pain data from an 88 patient chart audit to scope the DSS design [Kuziemsky et al., 2005]. This work helped understand:

- the problems that occur clinically during day-to-day practice,
- what data are collected around those problems and
- how to implement a DSS with minimal disruptions to workflow.

The specific problems that we focus on are a lack of consistent pain assessment and a lack of follow up after initial assessment. We believe a focus on context and communication will help alleviate these problems. The context of palliative pain management is important because palliative patients are nearing end-of-life and they often suffer from numerous medical problems (e.g. metastasized cancer). Unlike pain management strategies for post-surgical pain where the pain has a defined etiology (the surgery) that can be easier to manage, palliative patients often exhibit more than one type of pain. The literature reports that up to 40% of patients suffer four or more pains [Twycross, Harcourt and Bergl, 1996]. Therefore assessment and management cannot just focus on one etiology of pain but rather needs to consider many etiologies. A further complication is that palliative pain management does not just involve physical types of pain (such as pain from bone cancer) but also considers spiritual and psychosocial types of pain (such as anxiety and distress), which are common in palliative patients. Therefore a large number of data elements need to be considered to determine what is causing a patient's pain and how to best manage it. Enhanced decision making about severe pain needs to emphasize management. Existing quality improvement (QI) initiatives in pain management focus more on assessment and documentation and less on management [Gordon and Dahl, 2004].

Because diseases of palliative patients are not treated actively, much of the pain they experience is ongoing until death. Therefore, an ongoing record of pain occurrences and management would facilitate communication about a patient's pain such as what triggers and resolves the pain and any specific circumstances about the patient. The chart audit data we collected allowed us to study how data that is currently collected supports pain management and what data are missing for ideal pain management. Among the findings from the chart audit was that, although there was considerable data collected on pain, it is currently documented in a paper chart. As a result it is hard to access at point of care. We included chart audit data in our DSS framework because when the framework is implemented (such as through a portable computer) it will allow chart audit data to be accessed at point of care, making it easier to incorporate such data into practice.

² Severe pain is defined as 8,9 or 10/10 pain on a 10 point numeric scale

There were also variations in the semantics of the data, such as patient cognition being charted as mild confusion, slight confusion and mildly confused in different patients. Reconciling charting data would help with consistent pain assessment. However that introduces a workflow issue in that caregivers do not want to collect the additional data. Therefore it makes sense to develop the intelligence of the DSS from existing data that is collected through day-to-day assessment.

We also identified variations in how pain is assessed and managed. A number of data elements can be assessed in pain management. However, how those elements are assessed depends on the context. If a caregiver is assessing a patient for the first time they will likely collect a number of background data elements such as disease history, family history, and hopes and expectations. Such information is valuable for defining the context of a patient's pain as family relations and a patient's hopes and goals can help differentiate physical and non-physical pain. However, if a caregiver recently attended to the patient, they will probably assessed and documented background information previously and will not want the DSS to prompt them to do so again. But if it is a first time assessment then a prompt to collect such elements should be called to the caregiver's attention. Therefore the DSS must differentiate background and diagnosis-specific information. Decision making about severe pain also needs to support both deductive and abductive reasoning as expert caregivers generally want only the diagnosis of the cause of pain and how to manage it whereas less experienced caregivers often want the diagnosis and supporting evidence about the diagnosis, such as explanations about particular signs or symptoms, or current evidence on medications for pain management.

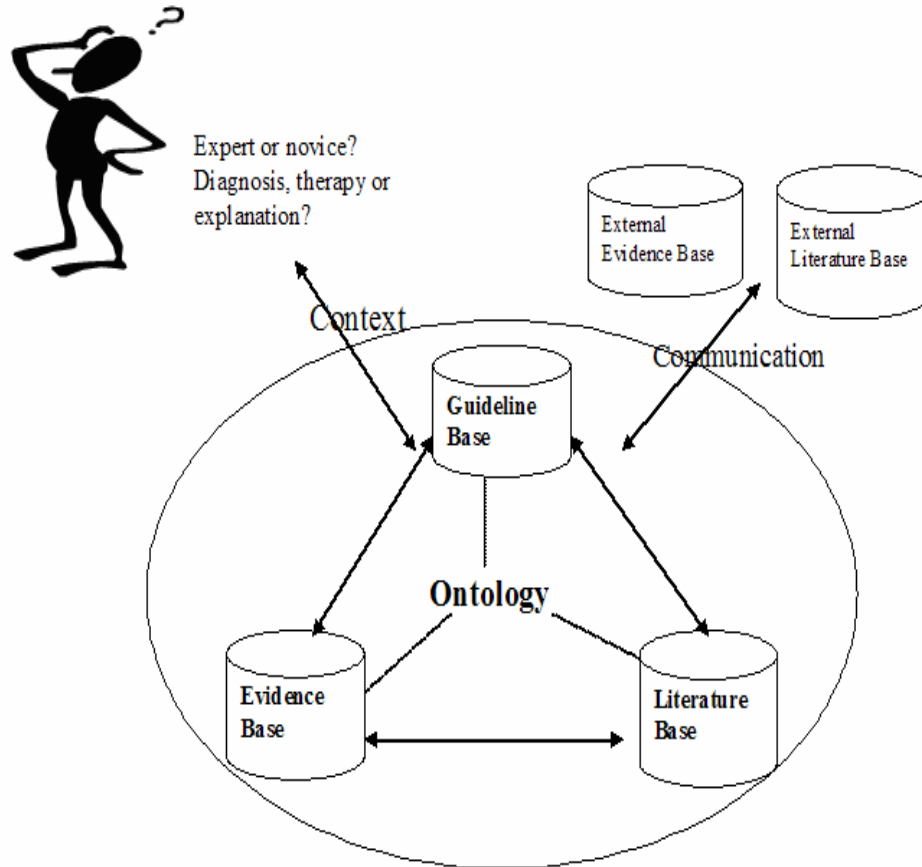
IV. MULTI-MODAL DSS FRAMEWORK

The multi-modal DSS framework we present combines the strengths of the three theories presented in section II, but extends the theories by focusing on context and communication, which we identified as crucial for a DSS. This section describes the DSS framework from a conceptual perspective. The next section details an instantiation of the DSS as a palliative care prototype. The DSS framework, shown in Fig 1, contains four major components: ontology, guideline base, literature base, and evidence base. Each component is introduced briefly.

ONTOLOGY

The ontology is the centre piece of our framework and is the means of structuring the concepts and relationships for our DSS framework. The ontology represents the formalization of the concepts and relationships and provides both a hierarchical structure and a controlled vocabulary for the concepts and relationships to enable them to be applied to DSS development. One result of developing guidelines is that they are abstracted into a structured format (such as GLIF syntax). The result of that abstraction is the guideline may not be applicable in different contexts, which we believe is an obstacle to widespread adoption of such guidelines. An expert palliative physician may make sense of the guideline but it might be too abstract for a novice. Furthermore, as indicated in the problem exploration in section III, inconsistent charting of pain data and minimum interruption of caregiver work routines when using the DSS are problems the DSS hopes to reconcile.

The ontology helps overcome issues such as abstraction as it provides the interconnectivity from assessment to guidelines and rules to management and finally to education. That enables rules to be interconnected to supporting information that can be applied if necessary. When data are collected in the evidence base during pain assessment the data are applied to rules in the assessment. The rules can be expanded into detailed management and education strategies



Note: Components are enclosed in circles

Figure 1. Components of the DSS Framework Showing Linkages for Communication and Different Decision Making Contexts

through the literature base in case educational material is requested to support deductive reasoning.

GUIDELINE BASE

The guideline base contains the rules for the DSS and the logic that links the rules to the evidence and literature bases.

EVIDENCE BASE

The evidence base consists of the patient data. The patient data consist of two components: active cases and historical cases. Active cases are data on current patients collected through assessment. In our current prototype, the historical cases consist of retrospective chart audits of 88 patients who had an episode of severe pain. The historical cases are used both for developing the rules and for education through cased-based reasoning.

LITERATURE BASE

The literature base contains supporting evidence for the guidelines as detailed management strategies and literature on medications or alternate forms of pain assessment.

V. PROTOTYPE PALLIATIVE CARE DSS

The conceptual DSS framework described in section IV is illustrated in this section as a prototype palliative care DSS. The prototype DSS addresses the issues in palliative severe pain management described in Section III, including supporting different types of reasoning, providing educational and supportive material during diagnosis, and enhanced assessment and charting of pain while using existing data to minimize impacts on clinical workflow. The prototype DSS is discussed in seven subsections: ontology development, DSS formalization, assessment and data collection, pain categories, historical cases and reasoning, summary of multi modal decision framework and evaluation framework. Although the prototype DSS is not yet been implemented as a complete system the various sections (e.g., ontology, rules, pain categories, historical cases) are all developed.

ONTOLOGY DEVELOPMENT

Figure 2 shows a high-level view of an ontology for palliative severe pain management that was designed from the information we elicited through our palliative care research [Kuziemy, 2005]. The ontology is the collective results of observations of care delivery on the clinical ward, discussions with palliative clinicians, and details that emerged from the chart audi. It is a map for the solutions space that addresses the problem space described in Section III. For example the ontology shows the incorporation of different aspects of pain management (assessing both physical and psychosocial pain and incorporating educational material into pain management). It also makes a distinction between collecting triage data, (which is historical data such as diseases and previous pain episodes and therapies used) and assessment data related to the current pain episode (e.g., site, duration and description of the pain). The ontology also contains an explicit linkage between assessment, diagnosis, and management, factors identified in Section III as lacking in current pain management initiatives. Figure 2 also shows a detailed example of how

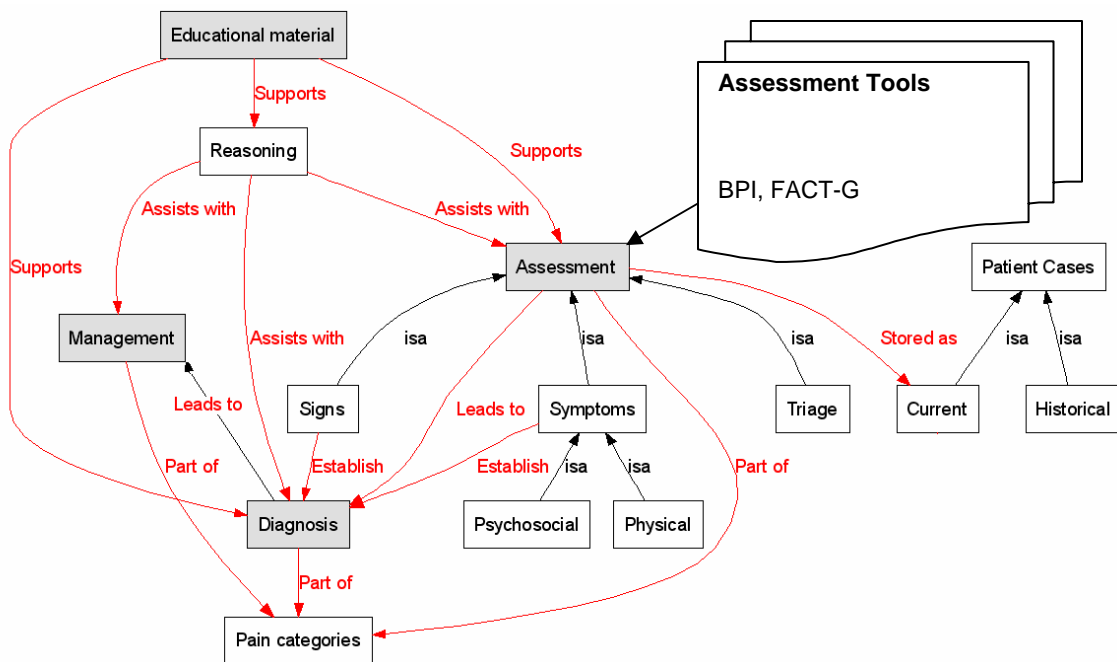


Figure 2. Ontology for Palliative Care Severe Pain Management: Illustrating the Full Cycle of Pain Management Going From Assessment to Diagnosis to Management and to Education³.

³ The cycle is shown in gray in the model

the ontology interconnects all the components of the DSS framework (as described in Section IV). In Figure 2 the ontology concept educational material represents the literature base, reasoning represents the guideline base and the patient cases represent the evidence base. The ontology also contains other concepts that were established as necessary based on the needs of the clinicians. For example the pain categories concept is the means of organizing the severe pain management information as the assessment, diagnosis and management concepts are all linked to a pain category.

DSS FORMALIZATION FROM ONTOLOGY

The concepts within the ontology are formalized to develop the DSS. The next three subsections (assessment and data collection, pain categories, and historical cases and reasoning) all pertain to DSS formalization from the ontology. A fourth subsection summarizes the multi-modal decision making capabilities of the DSS.

ASSESSMENT AND DATA COLLECTION

The ontology concept 'assessment' consists of data that is collected through day-to-day practice. By adapting data elements that are already collected in practice into our ontology and DSS, we are able to reduce the burden on caregiver workflow. Reconciliation of the DSS with clinical workflow draws on the model by Reay [2000] described in Section II. We made a conscious effort to adapt current practices of data collection into the DSS rather than altering current practices to satisfy the DSS. For example the Brief Pain Inventory (BPI) is a pain assessment tool used to collect physical pain assessment data such as pain frequency, (intermittent), onset (sudden) and description (burning, stabbing, sharp). The Functional Assessment of Cancer Therapy General (FACT-G) assessment tool is used to capture psychosocial assessment data such as how pain affects mood, sleep, relations with family members, and other impacts on quality of life. Using BPI and FACT-G to collect data for the DSS will not only supply standard terms for the DSS but promote consistent pain assessment to reconcile the problem of inconsistent charting. An electronic record of current patient assessment data will also help communication between caregivers such as during shift change as data elements such as background information about a patient will be more readily accessible. That enhanced communication will help support ongoing management of a patient's pain and improved follow up assessment after initial pain assessment, both of which were identified in the problem exploration.

PAIN CATEGORIES

The 'pain categories' concept is the central linking concept in the ontology. That concept comes from the need to provide meaningful structure to the material presented through the DSS to enhance information retrieval. A group of palliative practitioners including two physicians, three nurses and three counselors structured the details about severe pain occurrences and management into a categorization scheme that contains 11 categories of severe pain based on different etiologies of pain [Black and Kuziemy, 2004]. Each category of pain is presented as a management and education table that is differentiated by the symptoms and signs it presents with as well as how to diagnose and manage pain within the category. The scheme provides an explicit way of relating the signs, symptoms, diagnosis and management for different types of pain as well as making supporting educational material available. Each category represents a common consensus as the category details (e.g., signs, symptoms.) were established after much discussion among the physicians, nurses and counselors. As part of the DSS, the scheme will be made available through a computer based tool, which allows it to be used at point of care such as the patient's bedside.

Table 2 provides a detailed example of the two of the pain categories from the severe pain categorization scheme. Some of the text in Table 2 is shown in gray to illustrate how the scheme enhances decision support for both diagnosis and management of severe pain management. Sudden Medical Crisis is caused by an acute medical crisis and presents with a sudden onset of pain and possibly patient confusion. It is managed by rapidly increasing or stacking pain medica-

Table 2. Detailed Management and Education Tables for the 'Sudden Medical Crisis' and 'Incident Pain' Pain Categories.

a. Sudden Medical Crisis Category

<p>SYMPTOMS</p> <ul style="list-style-type: none"> • Intermittent severe pain related to one or more activities or procedures • Pain subsides shortly after action • Probably comfortable except during precipitating physical factor • Often pain is recurrent and predictable • Can locate and describe pain accurately 	<p>SIGNS</p> <ul style="list-style-type: none"> • Severe pain directly related to one or more specific actions • Patient may become rigid, tense, resistive or yell out during incident • No evidence of acute medical crisis • Confusion/Delirium not present (unless compounding factor) although pt may be very agitated and restless during pain episode 	<p>DIAGNOSIS</p> <ul style="list-style-type: none"> • Type and quality of pain is specific to the actual etiology e.g. bone pain with movement or position change; bowel care; dressing change • True incident pain is predictable, both to onset and duration. It is a subset of breakthrough pain (BTP) but requiring a different approach 	<p>MANAGEMENT (INTERVENTION)</p> <ul style="list-style-type: none"> • Preemptive use of short or ultra-short acting opioid i.e. once incident pain is identified, then focus on use in prevention • Modify action or procedure if possible to reduce pain intensity • Additional adjuvant supports such as distraction, hypnosis, imagery, music Use short-acting sedation with analgesic if necessary
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b. Incident Pain Category

<p>SYMPTOMS</p> <ul style="list-style-type: none"> • Sudden onset of frequent yelling, screaming related to pain • Able to locate pain • Can describe pain but may limit 'conversation' due to severity 	<p>SIGNS</p> <ul style="list-style-type: none"> • Extreme pain clearly evident as indicated by acute crisis such as : <ul style="list-style-type: none"> – Behavioral - either very restless and agitated or lying rigidly; – Physical signs - acute, rigid abdomen; visible fracture; bleeding; etc • Cognitive - If imminently dying, confused and disoriented, followed by drowsiness and coma 	<p>DIAGNOSIS</p> <ul style="list-style-type: none"> • Type and quality of pain is specific to the actual etiology e.g. bone pain with movement or position change; bowel care; dressing change • True incident pain is predictable, both to onset and duration. It is a subset of breakthrough pain (BTP) but requiring a different approach 	<p>MANAGEMENT (INTERVENTION)</p> <ul style="list-style-type: none"> • Preemptive use of short or ultra-short acting opioid i.e. once incident pain is identified, then focus on use in prevention • Modify action or procedure if possible to reduce pain intensity • Additional adjuvant supports such as distraction, hypnosis, imagery, music Use short-acting sedation with analgesic if necessary
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tion. Incident pain presents with intermittent pain due to a specific activity and there is no evidence of either an acute medical crisis or confusion. Incident pain is also managed much differently with a combination of short or ultra short acting opioid at time of incident as well as other adjuvant interventions such as imagery or music.

HISTORICAL CASES AND REASONING

The ontology concept 'patient cases' includes two components, the current patient cases described earlier in the assessment and data collection section and the historical cases. The

historical cases component currently consists of the 88 chart audit cases and serves as both a set of teaching cases through case-based reasoning as well as the means for establishing the rules in the guideline base. The data extracted from the historical cases was determined by the palliative caregivers we are working with and included data related to the patient (demographic and disease data), the pain episode (time, date, quality/location of pain) and the medication regimen taken by the patient prior to, during and after the pain episode. The historical cases also allowed us to identify where different terms were used for similar concepts (such as mild confusion vs. slight confusion for describing cognition) to help identify common nomenclatures for consistent charting.

Although the categorization scheme described earlier is valuable as a teaching tool there is also a need to condense the material for easy access and use at point of care. Expert physicians may not require the detailed scheme and would prefer a condensed set of rules to assist with assessment or management. We triangulated the knowledge from the historical cases and what was observed and documented from the caregiver observations from the clinical ward in the form of rules. The rules are represented through the ontology concept 'reasoning'. The crystallization was done in such a manner that the different types of knowledge (conceptual or procedural) has been separated which helps keep the knowledge manageable and also helps a caregiver easily obtain the type of knowledge (conceptual or procedural) they require. The rules and the algorithms that associate the assessment data with the rule comprise the ontology concept 'management'. The rules were established by querying the historical cases and establishing what categories of pain were returned by the query. For example querying the historical cases for intermittent onset or movement related pain returned cases where the pain was categorized as incident pain. The historical cases also provide a validity check for the rules as we were able to compare the management or intervention strategies from the historical cases against the management strategies that were identified from the caregiver observations or in the literature base. Figure 3 shows an example of the rules that were developed using the GLIF ontology in the protégé 2000 ontology editor. Fig. 3 shows a management rule that starts with the onset of pain (sudden or intermittent) and then looks at further details to try and establish whether it is incident pain or sudden medical crisis. The rule also provides action steps with opioid management strategies depending on the diagnosis.

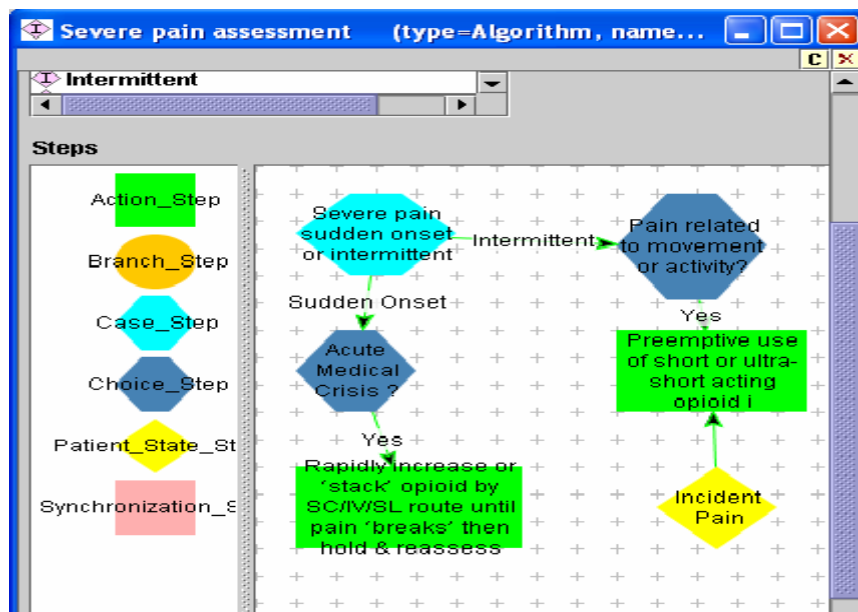


Figure 3. GLIF Coded Management Rules for 'Sudden Medical Crisis' and 'Incident Pain' Categories of Pain.

SUMMARY OF DSS SUPPORTED MULTI-MODAL DECISION MAKING

The palliative severe pain prototype described in this section illustrates how the DSS supports multimodal decision making. The DSS can be applied in different contexts.

Mode one: An expert caregiver may only want to access the management rules (such as shown in Figure 3) because they possess the underlying tacit knowledge to supplement the rules where necessary.

Mode two: Novice caregivers, or experts that want more detail than offered by the rules can access the detailed management and education tables from the categorization scheme (as shown in Table 2) or use links through the evidence base to find additional supporting material.

Mode three: The historic cases can also be viewed as a set of teaching cases to facilitate case-based learning.

Mode four: The DSS also supports different types of reasoning such as assessment reasoning leading to diagnosis and management reasoning to determine different approaches for managing pain. The different action steps shown in Figure 3 ('stack opioid' for sudden medical crisis and 'preemptive use of short acting opioid' for incident pain) would have linkages to information to support those strategies.

EVALUATION FRAMEWORK

Although we did not evaluate the palliative care prototype formally, one of the context implications identified in Section II was the need for an ongoing evaluation component to allow short turnaround time of evaluation results. The rules and reasoning concepts that are established need to be validated by palliative practitioners. To achieve that, we are adopting an assessment method used in another palliative care application called the Bowel Performance Scale (BPS) [Downing and Carter, 2004]. BPS is a scale for collecting assessments about a patient's bowel status with a -4 to +4 scale (-4 being total constipation, +4 being total diarrhea). Similar to the palliative pain prototype the BPS offers a series of rules on bowel performance and collects caregiver assessments that are stored as a series of cases. The BPS and the rules within it were designed to be used by caregivers of all levels of expertise. We validated BPS by asking 40 Caregivers to assess a set of 20 patient cases twice with a one week interval between assessments [Downing and Carter, 2004].

After the cases were assessed, the database of cases was sent to a statistician to assess how consistent caregiver's scores were from one assessment to the next in order to establish inter-rater reliability. However, the statistical analysis provided a surprise assessment result in that it showed that some of the rules are too vague and were misunderstood by some caregivers. The statistician doing the analysis pointed out that some of the cases had a range of scores from -4 to +4 which means different caregivers were scoring the same case as having total constipation or total diarrhea. Subsequent discussion with the expert physicians who developed BPS concluded that the rules were being misinterpreted by some caregivers, which confirms the need for rules to support different levels of expertise. The statistical analysis provides a valuable example of how computer-coded data can be evaluated to identify flaws in how DSS rules are presented.

VI. DISCUSSION AND FUTURE WORK

This research presented a DSS framework that facilitates consistent data collection and supports education and different levels of decision-making expertise. As shown in Section V, DSS material can be presented ranging from a detailed education perspective for novices (Fig 2) to condensed rules for experts (Figure 3). Because IS should be supportive of work practices, we illustrated how to integrate data that is collected on a day-to-basis into the DSS.

The accumulation of cases in the evidence base also provides a good way of developing case-based reasoning. In Section V we described how the cases in the system were used both for educational purposes and for developing the rules for the guideline base. We also identified an approach to evaluation that uses statistical assessment of rule comprehension from the DSS. The historical cases component of our DSS prototype will be used for a similar evaluation as DSS users can test the rules against the historical cases and the results can be analyzed to see how rules are being interpreted. This assessment enables us to determine whether rules are structured appropriately for different users and to obtain quick turnaround time for evaluation results.

Research implications of our work include using the DSS framework in other domains of medicine. Although the prototype DSS was designed for a particular purpose, the enhancement of palliative severe pain management, the DSS framework can be applied to other domains both in and outside of palliative care. Instead of collecting and using pain assessment data within the DSS the framework could collect data for decision making in intensive or primary care. In that manner the DSS framework could be integrated with a more general patient medical record to support patient care related to chronic disease management such as diabetes.

Although the overall DSS framework we present is complex, we intend to leverage existing applications as much as possible rather than redeveloping existing applications. For example, we are waiting for the release of the Guideline Execution Engine (GLEE) which is a GLIF execution engine being developed at Columbia University [Wang et al. 2004]. One of the other projects we are collaborating with is the Vancouver, British Columbia based Evidence Based Guidelines and Decision Support Systems (EGADSS) project (<http://egads.org>). EGADSS is developing a tool for guideline development that works with electronic medical record (EMR) systems. We are exploring the extent to which our severe pain guidelines and our multimodal prototype fits with the EGADSS framework and how we can leverage data collected in EMR applications. The contribution from the prototype DSS we have illustrated is how to bring the various components together (evidence, cases and guidelines) to support multimodal decision making.

VII. CONCLUSION

In this paper we described general decision making theories in health care, explored the palliative problem care problem space and illustrated a DSS prototype that addresses the problem space. We believe there is value in leveraging knowledge from theories on health care decision making because that allows the DSS framework to be informed by research on how health care decisions are made. Combining the theoretical knowledge with practical knowledge of palliative care through chart audits and caregiver observation allowed us to understand better the decision making needs in palliative care, and how to deliver support to those needs.

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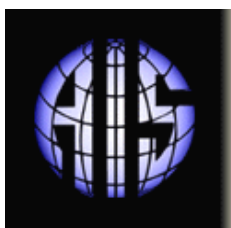
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