### IMPROVING CARE AT THE END OF LIFE: AN AUTOMATED CASE-BASED REASONING APPROACH

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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 "errorreducing" reforms at vulnerable populations (who are disproportionately affected, both in terms of incidence and severity) can improve the quality of care delivered to patients at the end of Recent developments in health their lives. informatics, particularly the application of artificial intelligence (AI) techniques such as data mining, neural networks and case-based reasoning (CBR),present tremendous opportunities for identifying and mitigating errors. We have developed an automated casebased reasoner, CAREN, for palliative care consultation. The CAREN system is a CBR prototype, which uses the open source CASPIAN CBR shell developed by the University of Aberystwyth, Wales, and is available by anonymous FTP. This research will assess the application of automated case-based reasoning (CBR) to facilitate quality improvement in healthcare settings, reduce the incidence of medical error, and disseminate expert level 'know how' to clinicians.

### **1. INTRODUCTION**

We will assess the potential of CBR techniques within palliative care, a model with statistically significant data supporting its ability to improve quality outcome measures for patients who are dealing with life-threatening illnesses [1]. In addition, this research will examine a novel approach to palliative care consultation and training that uses automated case-based reasoning (CBR). CBR has been applied successfully in other aspects of the medical domain [2,3,4].

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. New community-based models, which incorperate intensive case management, are initiating chronic disease interventions "up-stream" in the course illness.

The Quality of Life (QOL) program [1,5] at Metropolitan Jewish Health System (MJHS) is an example of this approach. With the aid of program management, we developed CAREN, a case-based reasoning (CBR) application for palliative care consultation. The information in the system's cases was obtained from program's clinical data forms and informal case notes that were documented in the patient charts. These charts are maintained by the QOL program's Quality Care Coordinators.

The CAREN system is a CBR prototype, which uses the open source CASPIAN CBR shell developed by the University of Aberystwyth, Wales, and is available by anonymous FTP [6]. The CASPIAN system is comparable to commercial CBR tools that can be quite costly; however, the system shell has no graphical user interface (GUI), which compromises its userfriendliness. Although CASPIAN is command line driven and does not operate with a GUI, the CBR shell program is ideal for the rapid development of a CBR prototype. Our rational was, if the CBR prototype we developed with the CASPIAN shell is successful, we will know what features and system requirements will be important to the final, deployable design.

#### **1.1 Palliative Care Expertise**

Deficiencies in education about end of life care are widely recognized [1,7]. 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 [7,8,9].

Cases provide a flexible framework for illustrating the lessons of experience and the dilemmas requiring careful judgment [10,11]. We have carefully selected cases and created our

palliative care library to comprise a "real life" clinical curriculum.

Successful CBR systems have been used to simulate the reasoning of medical experts, for example FLORENCE [2], a care planner for nurses, MEDIC [3] a case-based physician nd CASEY [4], a case-based diagnostician. CBR is particularly effective in managing the implicit knowledge that specialized healthcare professionals gain through experience.

#### 2. APPLYING CASE-BASED REASONING (CBR) TO THE PALLIATIVE CARE DOMAIN

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. 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 [11,12]. Implicit knowledge is commonly employed by professionals for medical decisionmaking [12,13,14].

#### 2.1 Indexing Cases for Palliative Care

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.

### 2.2 Computing Similarity

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 [15].

#### 2.3 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 [13]. 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 [16].

CBR differs from other AI learning techniques in that it integrates the reasoning mechanism with the learning mechanism. Inductive formation of reasoning is only responsible for some of the learning in the case-based reasoner. Generally, as the caseload accumulates, so does the accuracy of the CBR. The system becomes more knowledgeable because it has acquired more cases, through the automated reasoning process.

### **3. RESEARCH METHODS**

The target population for the CBR application was individuals in the cancer trajectory. This group of patients were 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 at random. Data was obtained by manual chart review. In total, 22 attribute values were recorded for each of the 17 patients in the study sample.

### 4. FINDINGS AND RESULTS

To assess the application of CBR in the palliative care domain, we entered 16 participant cases. These 16 cases establish the expert knowledge-base. The 17<sup>th</sup> case, the test case was randomly selected from the sample after the relevant data were extracted form the charts. We will refer to the test case as Patient 178.

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 The first goal, intervention strategies. psychosocial support, had the following suggested interventions: 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 goal is the monitoring of the patient's disease status, achieved with the interventions of continuous medical and social assessment and establishing a relationship with patient\_171's primary care physician. The third goal is effective pain management. Suggested interventions for this goal are medication review by the program's nurse and contact with the patient's primary care physician.

The CBR's solution consists of additional care goals that were not articulated in the case instance of patient 171, the most similar patient case. The rule repair definition identified these additional care goals, that may have been implicit to the care manager; however, there was no documentation to support this assumption in the patient charts. These additional goals included the facilitation of advanced care directives, safety assessment in the home and research into available entitlements or coverage. These rules were fired because the criteria was med by the rule repair definition.

Patient 171 (retrieved case) and Patient 178 (test case) matched on all indices, income group, advanced care status, 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 (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 evaluated as a better fit.

# 5. CONCLUSIONS AND FUTURE RESEARCH

To evaluate the potential of CBR as a tool for automated decision-making in the palliative care domain we compared CAREN's results for the test patient's (178) physical chart and the program's patient management system.

We reviewed patient 178's physical chart and compared the results with the palliative care consultation suggested by CAREN. 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 patient case. This complemented the new care consultation for patient 178 with two additional goals that were identified for patient 178 by the care managers and one that was not, but may be relevant to the patient case.

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. The CBR system we have developed is not as comprehensive as the human expert after the in-depth chart review; however, the system can be useful to one that is unfamiliar with palliative care concepts.

In addition, 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.

#### 5.2 Reducing Medical Errors

Leape et al [17] established an etiology of errors, qualifying them into several categories: diagnostic, treatment, preventative, and other. CAREN could be used to reduce errors that result from inappropriate treatment; for example, CAREN could be used to disseminate the best practices used by the QOL Quality of Care Coordinators for a particular pathology. In addition, we have developed our system for cancer patients who are appropriate for palliative care, but the system could be further developed to include care goals and intervention strategies for patients with Alzheimer's, CHF, diabetes, dementia, and other chronic and life threatening diseases. CAREN can also reduce medical errors, by suggesting better ways to monitor disease or pain status.

As defined by Leape, errors in the "other" category include lack of communication. CAREN recommends that the user facilitate advanced directives if they are not in place and to communicate with the patient's other healthcare providers. Lack of communication is a common barrier to quality care at the end of life. An example of this is when advanced directives are not honored (perhaps because they are unknown) by the physician and patient's family

# 5.3 Quality Improvement to Reduce Health Disparities

To assess the potential of these systems to reduce disparities, we must consider the quality dimensions identified by the IOM [18] and apply these quality elements to the CAREN application. The CAREN CBR has the potential to improve quality in the dimensions of:

- Safety the Quality Care Coordinators identified several cases where ensuring patient safety was a goal. The patients considered were generally those who lived alone. CAREN identifies the need for assessment and intervention to ensure patient safety, medication compliance, and durable medical equipment in its case library.
- Patient Centeredness –If the systems can be used to facilitate data management or disseminate knowledge in the palliative care domain, then they support patient-centered care.

• Equity – The palliative model and supportive information systems can bring equity to vulnerable populations.

#### 5.5 Information Systems and Quality of Life

Our results with the CAREN system suggest CBR is effective for palliative care consultation; however, the system is still elementary and must be more extensively developed before it can be used for palliative care training. If a CBR system could be used to effectively disseminate palliative care expertise, it can be used to improve the quality of care at the end of life.

CBR systems like CAREN can be used to educate health care professionals about "best practices." The success of CAREN suggests the application of other artificial intelligence techniques in the palliative care domain should be assessed and evaluated. Automated CBR applied to end of life care can help users modify habitual process patterns of care that run counter to the established evidence-base by training healthcare professionals with the "know-how" of palliative care experts.

#### **5.6** Conclusions and Future Directions

People with chronic conditions account for 88 percent of all prescriptions filled, 72 percent of all physician visits, and 76 percent of all inpatient hospital stays [19]. Furthermore, the number of Americans affected by serious chronic illness will more than double over the next three decades.

Quality end of life care requires a multidisciplinary team with diversified skills. Healthcare professionals agree that to meet the comprehensive and unique needs of patients at the end of life, first and foremost, the physical symptoms of pain must be effectively treated [20,21]. Effective pain management is often cited as a barrier to improving the quality of end of life care [8, 22-27].

In conclusion of this research project, we feel the next steps with the CAREN CBR system are to :

- 1. Incorporate additional parameters in CAREN's case structure for pain management and to extend the system for the two additional disease trajectories.
- 2. Compare other CBR shells with the performance of CASPIAN.

3. Develop a web-enabled CBR engine with opensource tools.

We have focused on how CBR can be used to improve the quality of care delivered to patients with severe chronic illness. AI techniques can be used to design "intelligent" systems like CAREN. CBR systems 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.

#### References

[1] Nidetz, A., Fishman, E., Jacobs, M., Daniels, C., Tamang, S. "Palliative Care Management Services in a Medicare Social HMO", *Journal of Pain and Symptom Management*, 2005, 29(1), 109-119.

[2] Bradburn, C., Zeleznikow, J., & Adams, A. " FLORENCE: Synthesis of Case-Based and Model-Based Reasoning in a Nursing Care Planning System", *Comput. Nurs.*, 1993 11(1), 20-24.

[3] Gierl, L., Steffen, D., Ihracky, D. & Schmidt, R. " Methods, Architecture, Evaluation and Usability of a Case-Based Antibiotics Advisor", *Computer Methods and Programs in Biomedicine*, 2003, 72; 138-154.

[4] Koton, P.A. ``A Medical Reasoning Program that Improves with Experience," *Symposium on Computer Applications in Medical Care Conference*, 1998, pp. 32-37.

[5] Hopper, S.S. A Special Report form the United Hospital Fund: Moving Palliative Care into the Community: New Services, New Strategies, New York: United Hospital Fund, 2004.

[6] Anonymous, *CASPIAN Case-Based Reasoning Shell*, retrieved: November 18, 2003, from http://www.aber.ac.uk/compsci/Research/mbsg/cbrprojects/g etting\_caspian.shtml.

[7] Block S.D. "Medical Education in End-of-Life Care: The Status of Reform", *Journal of Palliative Medicine*, 2002, 5(2), 243-248.

[8] Lynn, J., Schuster, J.L. & Kabcenell, A. Improving Care for the End-of-Life: A Sourcebook for Health Care Managers and Clinicians, U.K.: Oxford University Press, 2000.

[9] Brumley, R. "Future of End-of-Life Care: The Managed Care Organization Perspective", *Journal of Palliative Medicine*, 2002, 5(2), 263-270.

[10] Blustein, J., Post, L., & Dubler, N.N. *Ethics for Health Care Organizations: Theory, Case Studies, and Tools,* New York: United Hospital Fund, 2002.

[11] Cox, K. "Stories as Case Knowledge: Case Knowledge as Stories", Medical Education, 2001, 35; 862-866.

[12] Lee, J.K. & Kyeong, J.K. "A Case-Based Reasoning Approach for Building a Decision Model", *Expert Systems*, 2002, 19(3), 123-135.

[13] Kolodner J. *Case-Based Reasoning*, San Francisco, CA: Morgan Kaufmann, 1992. [14] Mintzberg, H. & Westley, F. "Decision Making: It's Not What You Think", *MIT Sloan Management Review*, 2001, 4, 89-93.

[15] Price, C.J. & Pegler, I.S. "Deciding Parameter Values with Case-Based Reasoning", *1st UK Workshop on Case-Based Reasoning, Salford, UK*, 1995, retrieved October 10, 2004, from <u>http://www.informatik.unitrier.de/~ley/db/conf/ukcbr/ukcbr1995.html</u>.

[16] Watson, I. Applying Case-Based Reasoning, San Francisco, CA: Morgan Kaufmann, 1997.

[17] Leape, L.L., Lawthers, A.G., Brennan, T.A. & Johnson, W.G. "Preventing Medical Injury", *Quality Review Bulletin*, 1993, 19(5), 144-149.

[18] Donaldsen, M.S. (Ed.), *Statement on Quality of Care: IOM National Roundtable on Quality.* Washington D.C.: National Academies Press, 1998.

[19] Johns Hopkins University, *Chronic Conditions: Making the Case for Ongoing Care*, retrieved August 8, 2004 from http://www.partnershipforsolutions.org/DMS/files/chronicbook2002.pdf.

[20] Desbiens, N.A. & Wu, A.W. "Pain and Suffering in Seriously III Hospitalized Patients", *Journal of the American Geriatrics Society*, 2000, 45(5), 183-186.

[21] Huskamp, H.A., Buntin, M.B., Want, V. & Newhouse, J.P. "Providing Care at the End-of-Life: Do Medicare Rules Impede Good Care?", *Health Affairs*, 2001, 20(3), 204-211.

[22] Introcaso, D. & Lynn, J. "System of Care: Future Reform", *Journal of Palliative Medicine*, 2002, 5(2), 255-257.

[23] Vietta, L., Kenner, D., Kissane, D. & Sali, A. "Clinical Outcomes in Terminally III Patients Admitted to Hospice Care: Diagnostic and Therapeutic Interventions", *Journal of Palliative Care*, 2001, 17(2), 69-77. Admitted to Hospice Care: Diagnostic and Therapeutic Interventions", *Journal of Palliative Care*, 2001, 17(2), 69-77.

[24] Myers, S. & Lynn, J. "Patients with Eventually Fatal Chronic Illness: Their Importance within a National Research Agenda on Improving Patient Safety and Reducing Medical Errors" *Journal of Palliative Medicine*, 2001, 4(3), 325-332.

[25] Lynn, J. & Adamson, D. White Paper: Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, Rand Health, retrieved on November 30, 2004, from <u>http://www.medicaring.org/whitepaper/</u>.

[26] Myers, S. & Lynn, J. "The Center of Patient Safety at the End of Life: Seeking Reliability and Safety in the Care of Individuals Nearing the End of Life with Serious Illness", *Top Health Information Management*, 2001, 23(2), 13-21.

[27] Lynn, J. & Goldstein, N. "Advanced Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering", *Annals of Internal Medicine*, 2003, 138(18), 812-820.