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The Patient Advocate: A Cooperative Agent to Support Patient-Centered Needs and Demands

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Knowledge-based monitoring and therapy planning systems were mainly built for the convenience of health care providers. They neglected the consumers of health care, namely, the patients. Our approach is concentrated on the individual patients' demands and needs. We are designing, building, and demonstrating a cooperative agent to support patients' management of their own health-related behavior on a day-to-day basis at home. Clinical treatment protocols are represented in an intention-based time-oriented representation language to overcome the drawbacks of vague or ill-structured problem definitions (e.g., missing functional dependencies). These representations are used to guide the patients, to provide necessary explanations, and to observe and critique whether the patients obey the instructions of the health-care providers. We will present a prototype which supports women with gestational diabetes mellitus.

INTRODUCTION: PATIENT-CENTERED CARE

Health care is one of the most information rich, but cost intensive, areas. Poor or less-educated patients cannot afford the expense for adequate preventive care, early interventions, or temporal clinical observations and interventions. Nevertheless, there are opportunities to improve the quality of health care through more frequent monitoring and consultation with patients and through more active patient participation.

In recent years, several knowledge-based systems were introduced to support health care providers (mainly clinicians) with the monitoring of critical care patients and to assist them with diagnostic decisions and therapy planning [1]. These systems range from simple intelligent alarms to sophisticated systems for anesthesia monitoring or ventilator management (e.g., GUARDIAN [2], SIMON [3], NEOGANESH/GANESH [4], and VIE-VENT [5, 6]).

These systems were built for the convenience of health care providers and neglected the consumers of health care, namely, the patients. Our approach is concentrated on the individual patients' demands and needs. Therefore, a patient-centered system differs from a system for health care providers. It has to provide a user interface according to the patient's needs, expertise, and abilities, has to use a patient-centered vocabulary (e.g., different levels of explanation about the past, current, and future states of the patient's health conditions), and has to perform varied reasoning processes. Additionally, it should be used at home, but should still provide the patient with connections to several resources and facilities. According to these requirements, we are building a patient-centered system called Patient Advocate, which adapts outpatient care delivery according to patients' demands and needs.

In the following we will describe the functionality of the Patient Advocate project and its current prototype.

THE PATIENT ADVOCATE

The purpose of the Patient Advocate project is to design, build, and demonstrate cooperative technologies to support patients' management of their own health-related behavior on a day-to-day basis at home. The Patient Advocate helps patients to comply with physicians' instructions and advice, to exercise health-related common sense, and to monitor themselves for condition-specific danger signs. In general, the Patient Advocate assists in clinical practice by helping patients to get a closer insight into their health conditions (e.g., helping them to identify and report relevant symptoms).

The Patient Advocate's Functionality

In general, the Patient Advocate project supports the following functionality.

(1) Monitoring and consultation regarding the patients' health conditions

There are several kinds of data about the patients' health conditions available from several clinical analyses and devices. All this information is time-stamped and has to be interpreted by the health care providers. In particular, it has to be understood by the patients following the health care providers' advice. Medical consulting time is expensive. Some patients cannot afford the expense or the time for adequate and regular medical consulting

meeting. Nevertheless, a computer-supported advice-giving system can provide the patients with the necessary information and explanations to cope with their health conditions as well as to react to life-threatening situations correctly and in time.

Therefore, the central aim of the Patient Advocate project is to present task-adequate methods to give a global, comprehensive picture of all information available (e.g., observed parameters available at home, physicians'/nurses' instructions and advice) and to provide explanations with respect to patients' demands and experiences and to the degree of severity of a situation. Such a comprehensive picture can be achieved by context-sensitive integration of several knowledge-based approaches to classify input data and by visualization techniques.

The monitoring and consultation tasks consist of data selection, data validation, data abstraction, data visualization, recommendations, and explanations of data.

(2) Facilitating access to web resources

Hundreds of medical information resources around the world are available on the World Wide Web (WWW), including information from federal agencies (e.g., NIH and FDA), clinical guidelines and protocols, literature and library services, medical encyclopedias, continuing medical education resources and, of course, many other non-medical services. Exploring the WWW is a time-consuming and unreliable task because there are too much and too noisy data available. The variety of candidate sites and paths results in failing to retrieve necessary and accurate information in a reasonable time.

The Patient Advocate project facilitates a context-sensitive access to these various resources, providing the patient with additional explanation or teaching utilities on request. The guiding principle is that only those sites and resources are activated, which are meaningful for the current patient's health condition. These sites and resources are annotated with an importance ranking to simplify the search process.

(3) Coordinating patient-relevant information

Patients are usually confronted with many coordination issues. They have to schedule new appointments with the health care providers, have to remember scheduled or unscheduled therapies, and more. The Patient Advocate provides the patients with necessary tools to assist these coordination tasks (e.g., an appointment scheduler, email connection to the medical staff, reminder of therapies and medications).

SCENARIOS FOR THE PATIENT ADVOCATE

The following requirements determined the choice of test scenarios: (1) high-risk pregnancy in an early state, (2) parameters could be measured and monitored at home, (3) monitoring a pregnant woman with the Patient Advocate at home offers an alternative to staying at a hospital.

Interviewing obstetricians, nurse practitioners, nurse-midwives, and previously pregnant women as well as studying obstetrical textbooks resulted in choosing two scenarios during high-risk pregnancy which met our requirements: gestational diabetes mellitus and placenta previa.

In the first phase of the Patient Advocate project, we are exploring and implementing the scenario of gestational diabetes mellitus (GDM).

Pregnant women who have never had diabetes before but who have a high blood glucose level (carbohydrate intolerance) during pregnancy are said to have GDM. GDM affects about 3 percent of all pregnant women, i.e., about 100,000 cases in the United States each year [7]. An appropriate controlled observation and treatment of GDM may reduce the risks for several adverse perinatal outcomes including excessive fetal growth, birth trauma, fetal death, neonatal morbidity, hypoglycemia, or hyperbilirubinemia.

The "Sweet Success" California Diabetes and Pregnancy Program (CDAPP)

One aim of our approach is to identify the needs and demands of patients who use the system. A cooperation with the leading members of the "Sweet Success" California Diabetes and Pregnancy Program (CDAPP) at Stanford University Medical Center [8] accomplished our aim. We participated in medical consulting meetings including patients and acquired the necessary knowledge to structure the knowledge base and the graphical user interface. We developed mock-ups of the Patient Advocate’s user interface. Discussing the mock-ups clarifies the Patient Advocate's input and output and its basic functionality.

Additionally, the care protocols developed by the CDAPP and a protocol- and intention-oriented language [9] provide the basis to proceed with our approach in the absence of functional dependencies.

A PROTOTYPE

In the current phase of the Patient Advocate project we are working on a prototype to implement an intelligent assistant performing the monitoring and consultation regarding the patients' health conditions (issue (1) of the Patient Advocate's functionality).

We are using knowledge-based techniques to interpret the raw data, to derive explanations and recommendations, and to visualize the information [10]. It is important that the Patient Advocate run on widely available hosts. Therefore, the current state of the Patient Advocate is implemented in JAVA [11].

The graphical user interface

Figure 1 shows a mock-up of the graphical user interface of the Patient Advocate. It illustrates our guiding principles. The upper part of Figure 1 shows our current prototype of the Patient Advocate's monitoring and consultation component. The medical screening is executed in conjunction with medication, nutrition management, observation of the mother's body weight gain, stress management, fetal evaluation, and women's exercise. A suitable display, a reasoning component, and its interaction with the other components must be added in case of insulin-dependent (Type-I) diabetes. The lower part of Figure 1 illustrates the interactions with several resources (e.g., connection to the nurse, appointment scheduling, medical libraries). This part is subject to further research.

We concentrated on an easily understandable interface design, minimizing the user's input and adapting the graphical principles of the CDAPP (e.g., using icons and colors, which are provided in the "Food Guide", to enter the actual intake). To overcome the limitations of a screen's size, we grouped parameters context-dependently in separate windows. We incorporated as much knowledge as possible in our visualization of data (e.g., marking abnormal ranges of blood glucose). Our visualization techniques provided the patients with multiple views of the observed data to get a closer insight into their clinical condition (e.g., different types of plots).

Figure 1 shows a particular consultation scenario. The first three windows display the observed data and an additional window shows appropriate recommendations. The upper left-hand window displays the medical screening, currently plotting the blood glucose values measured two hours after lunch for the last 10 days. The patient can choose different parameters (e.g., fasting glucose or glucose before lunch) which can be plotted with different chart types (e.g., point graph, histogram). She can explore past and actual measurements by scrolling backward and forward pressing the << and >> buttons, respectively. The plot also includes a gray area which indicates the abnormal region of the measurement. All windows are synchronized. Scrolling in one window, results in changing the time axes in the others to provide an overview about the several components in the same period of time. Additionally, the patient can press the help button (<?>) to get explanations about her health condition.

The upper right-hand window shows the nutrition management of a day. The nutritionist develops a diet management plan based on the patient's weight, activity level, and number of fetuses, including the recommended nutrient intake for a day. Usually, the diet should include regular meals (three main meals and three snacks) with sufficient nutrients to support the target weight gain. The recommended diet plan is plotted in gray rectangles using the most important nutrients, namely carbohydrates, protein, and fat. The patient can choose alternative parameters, such as vitamins (pressing the button <parameter>) or display the entire parameter set (pressing the button <entire>). The thick black lines display the actually consumed nutrients during the current day. The striped rectangles estimate the amount which has been burned by exercise. Therefore, the patient gets a comprehensive picture of how she has obeyed the medical advice. In the current example, the patient has eaten too many carbohydrates and too much fat, but she has performed enough exercise to stay within the tolerance level. Otherwise, a recommendation to change her eating habits would have been triggered. Again the patient can get explanations of the circumstances by pressing the <?> button, or can explore previous days.

The lower left-hand window displays the fetal movement. The pregnant woman counts the fetal movements in a two-hours period. If the baby does not move ten times in two hours, or if there is a sudden decrease in movements, the Patient Advocate recommends her to call the doctor. The patient can scroll to previous days, use different chart types, or ask for an explanation by pressing the <?> button.

The window on the lower right-side in Figure 1 displays the recommendations. Currently, the Patient Advocate reminds the patient to schedule an appointment with the nutritionist (e.g., follow-up meeting every one to four weeks). No other recommendations are listed because the patient's health condition is normal.

In the background the additional components are displayed, namely those dealing with medication, body weight gain, exercises, and stress.

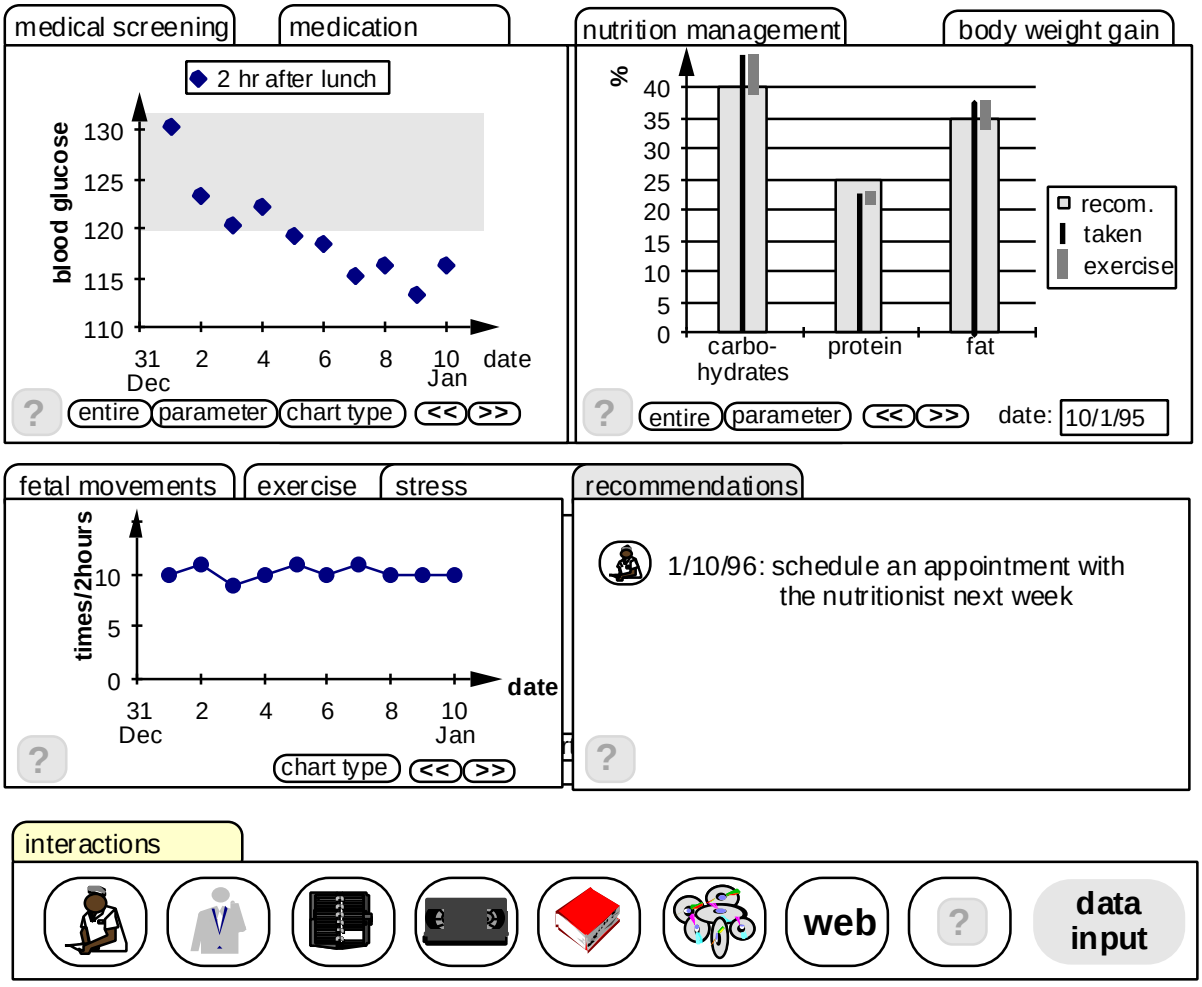

Figure 1: Mock-up of the Patient Advocate's user interface (scenario GDM Type II)

The reasoning component

The underlying principle of the Patient Advocate is to guide the system's user toward a reasonable explanation or solution, as opposed to presenting a solution. The straightforward expert system technology is too narrow [12]. The Patient Advocate is an intelligent assistant, which is able to cope with vague, ill-structured, and incomplete problem definitions. Currently, we are evaluating an intention-based temporal representation of a treatment protocols language [9] to overcome the drawbacks of vague problem definitions. The representation of treatment protocols captures their preferences (e.g., utility preferences), their intentions (e.g., overall action pattern), their conditions (e.g., filter condition, suspend condition), their effects, and the durative behaviors of actions (e.g., performing actions in parallel, cyclic actions). These temporal representations are used for a variety of purposes:

- to execute and recommend a behavior based on a clinical protocol;
- to suggest modifications of protocols and alternative candidates;
- to observe and critique whether the patients follows the instructions of the health-care providers;
- to explain the patients' health condition on different levels (past and current);
- to project the future development of the patients' health conditions.

Therefore, we distinguish between levels of interpretation based on: (1) the **observed data**, (2) the **underlying intentions** of recommended therapeutic actions, and (3) the **expectations** of changing the patients' health conditions caused by performed actions. The actual parameter readings (observed data) are used to abstract the patients' health condition over time (e.g., high blood glucose level in the last three days). The intentions of therapeutic actions are represented in the clinical guidelines and represent high-level goals (e.g., patient should have less than one high glucose value per week).

The intentions are used to explain the patients' health condition and are compared with the actual parameter readings. The expectations of parameters are calculated to forecast developments in the patients' health conditions. The expectations are represented as two different kinds of effects in the clinical guidelines: first, as functional dependencies between guidelines arguments and measurable parameters, which are seldom available in the GDM domain; second, as general effects, which describe a qualitative approximation.

RELATED APPROACHES

Several knowledge-based monitoring and therapy planning systems were introduced in the last years to support medical staff during their daily routine (such as GUARDIAN [2], SIMON [3], NEOGANESH/ GANESH [4], and VIE-VENT [5, 6]). A different view of automated support of health care is the critiquing approach: the program critiques the physician's plan rather than recommending a complete one of its own [13]. All these systems were built for the convenience of health care providers and ignore the needs and the demands of the patients. Currently, few approaches concentrate on individual patients' needs [14] or on improving the information exchange between health care providers and patients [15].

CONCLUSION

We have demonstrated a prototype of patient-centered intelligent assistant — called Patient Advocate —, which helps patients to get a clearer insight into their health conditions and to cope with medical instructions and advice on a day-to-day basis at home. The Patient Advocate project applies knowledge-based, cooperative technologies to interpret raw data, to derive recommendations and explanations, as well as to visualize the necessary information with different views depending on patients' demands and needs.

In the next steps we will enhance and implement our knowledge-base to represent more intention-based clinical care protocols, to test their applicability for our purposes, and to evaluate the Patient Advocate with patients.

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