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A Feasibility Study of a Personalized, Internet-based Compliance System for Chronic Disease Management

X.H. WANG,[1] R.S.H. ISTEPANIAN,[1] T. GEAKE,[1] J. HAYES,[2] M. DESCO,[3] G. KONTAXAKIS,[4] A. SANTOS,[4] A. PRENTZA,[5] and S. PAVLOPOULOS[5]

ABSTRACT

This paper describes a feasibility study on an Internet-based compliance system to provide personalized care for patients suffering from chronic diseases. Relevant medical trials from three different European countries provided preliminary evidence of the feasibility of the system and its efficacy in helping patients to manage their diseases at home. The study discusses further improvements not only for the C-Monitor system, but also for other Internet-based health-care services.

INTRODUCTION

CHRONIC DISEASES, including diabetes, asthma, arthritis, heart failure, and cancer, are among the most prevalent and costly of all health problems. They account for 59% of the 57 million deaths annually worldwide and 46% of the global burden of disease.[1] The incidence of such diseases increases with age. Many older people are living with more than one chronic condition, thus confounding their problems.

Chronic diseases are not, at present, cured, but can be controlled.[2] Successful control of chronic disease requires not only the health care from medical professional, but also the involvement of patients in their own care. Typically, self-management of chronic conditions improves psychological well-being, reduces pain, and lowers depression, thereby improving better quality of life.[3] However, there is evidence that up to 80% of patients are noncompliant with regard to their treatment at some time.[4] Lower rates of compliance tend to make the condition worse and complications are increased.

Recently, several products have been developed to help the patients comply with their medication plans. These products range from simple reminders,[5] telephone-based programs, such as "Heartline" from Aerotel Medical System Ltd,[6] to complicated mobile and Internet compliance programs.

The advent of the Internet has allowed information to flow quickly with some level of security. Since 1999, when LifeMasters launched its Internet-based services for chronic disease management,[7] a few other Internet-based programs have been developed. These

[1]Mobile Information and Network Technologies Research Centre, School of Computing and Information System, Kingston University, London, UK.
[2]Department of Accident and Emergency Medicine, Central Middlesex Hospital, London, UK.
[3]Hospital General Universitario "Gregorio Maranon," Madrid, Spain.
[4]Universidad Politecnica de Madrid, ETSI Telecomunicacion, Dpto. Ingenieria Electronica, Madrid, Spain.
[5]Biomedical Engineering Laboratory, School of Electronic and Computer Engineering, National Technical University of Athens, Greece.

include LinkMedica® for asthma patient care and DV Technology's care system for congestive heart failure.[8,9] These programs can provide a powerful platform for the patients to comply with medication, educate themselves about the disease, and communicate with medical professionals more efficiently. They help patients to manage their own diseases more effectively and improve their quality of life. With the increasing number of people having computer and Internet access at home and willing to send their medical information by Internet,[10] some analysts also predict that Internet-based programs will become the primary venue for remote patient management in the future.[11] The latest survey data from the United States and Europe support this prediction.[12]

With support from the European Commission, an Internet-based system, C-Monitor (A Cost-Effective Solution for Personalized Patient Compliance Monitoring), has been developed to assist patients to comply with their disease management. Partners involved in the development and trial of the system are from several European Union (EU) countries, including Sema Group (Spain), Universidad Politécnica de Madrid (Spain), Hospital General Universitario Gregorio Marañón (Spain), Kingston University (UK), Northwest London Hospital NHS Trust (UK), Institute of Communication and Computer Systems (Greece), Datamed SA (Greece), and Central Clinic of Athens SA (Greece). The system is appropriate for a variety of chronic diseases and management procedures, provides a personalized service for patients, and serves as an information provider—a communication channel between doctor and patient, a monitor to record the medical data, and an alarm system for critical situations. A previous paper has described the infrastructure of the system.[13] This paper focuses on the evaluation of the platform and the services it provides.

SYSTEM DESIGN

The C-Monitor system provides an integrated service aimed at monitoring patients' compliance to therapy at home via the Internet. It consists of three modules and one communal Internet site. The modules consist of scenario management, therapeutic scheme management, and document management. They are installed in the providers' computers to allow them to create personalized therapeutic schemes for their patients, and also to provide medical information and manage other medical staffs and patients involved in the disease management. Patients gain access to the service by a secure Web site. It allows patients to organize their daily activities with respect to therapeutic requirements in a personalized and friendly manner, assists them in improving compliance to therapy, and provides an interactive channel to communicate with doctors online. Patients at home can be reminded about important therapeutic actions (medication, exercises, etc.) by e-mail. They can report in-house examination results, request disease-specific information, log symptoms, and thus support and enhance their compliance to therapy. At the same time, the responsible doctor is always informed, no matter where he is, not only about the patient's condition but also about patient's compliance to therapy and possible deviations. Should the patient fail to report, or the examination measurements are out of the accepted ranges, an alarm is generated and transmitted to the responsible doctor by email.

Scenario management

The scenario management module enables the customization of the platform for different scenarios. This allows doctors to define and maintain each clinical scenario and create the particular domains for the medical staff and the patients. The details of the patients are saved in the database together with the personalized scenario plan. Usernames and passwords are created for patients and other supporting medical staffs to log on their personalized website. Figure 1 illustrates a screen image of the program with full functions of the module.

Therapeutic schema management

This is the core program of the system, which allows the creation of a personalized patient therapeutic plan, including the definition of the risk factor for each patient, and the

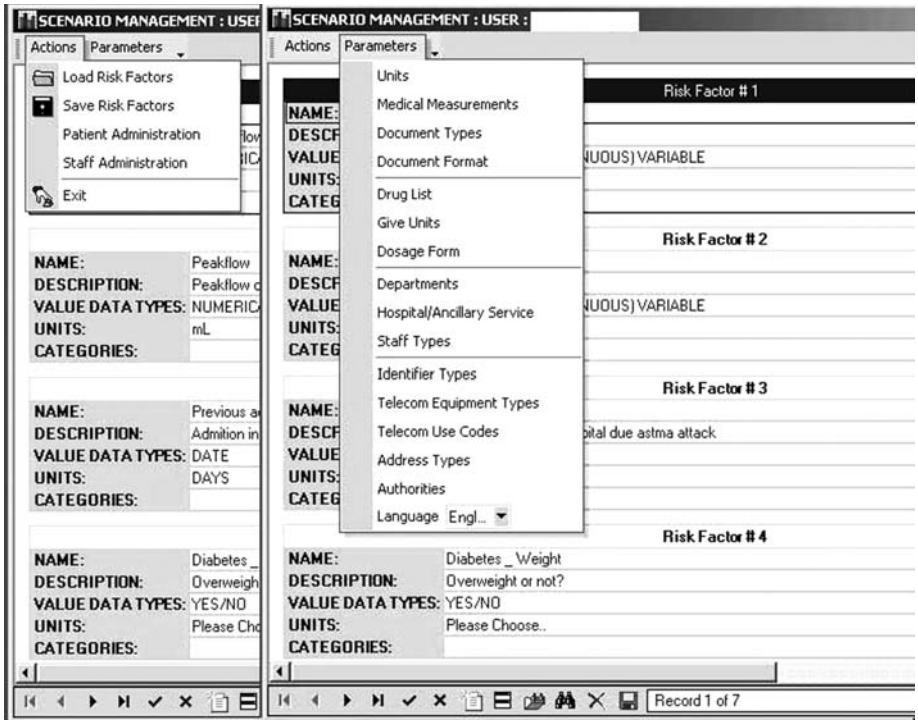

FIG. 1. Interface of scenario management program.

medication and examination plans. The medication plan describes the drugs, dosage instructions, and time schedule for medication use. The examination plan describes the clinical parameters to be measured and the time schedule for home measurements. Each medical parameter has a predefined lower and upper limit. If the examination results exceed one of these limits, an alarm is generated and delivered to the responsible physician via e-mail. Figure 2 illustrates a typical example for diabetes care.

Documents management

This program allows the delivery of personalized documents to patients depending on their specific circumstances. The documents may consist of either existing materials and reports from medical associations and specialized journals or specifically produced material by the doctor for the occasion. The contents range from general information about diseases to guidelines for a healthy lifestyle, from new discoveries and experimental therapies to suggestions on diet.

Internet area

This subsystem is the interconnection of the C-Monitor system, where only authorized individuals (doctors, patients) can view and update data. The patient can post the symptoms, read the relevant documents regarding specific diseases, and exchange information with the responding medical professionals. The doctor can review the medical and case history of the patient, monitor the patient's compliance with the therapeutic scheme, answer questions from the patient and also provide advice and suggestions for further therapy. Figure 3 shows the Internet area for doctor and patient. Figure 3A shows the total number of the registered doctor and patients and the detail of the patients. If the doctor clicks to see the recording of particular patient, the results will be shown as in Figure 3B. Figure 3C shows the screen that the patient can use to follow the medication plan and report home examination results. Patients can also read the documents forwarded by the doctor and communicate with doctor using a secure communication channel.

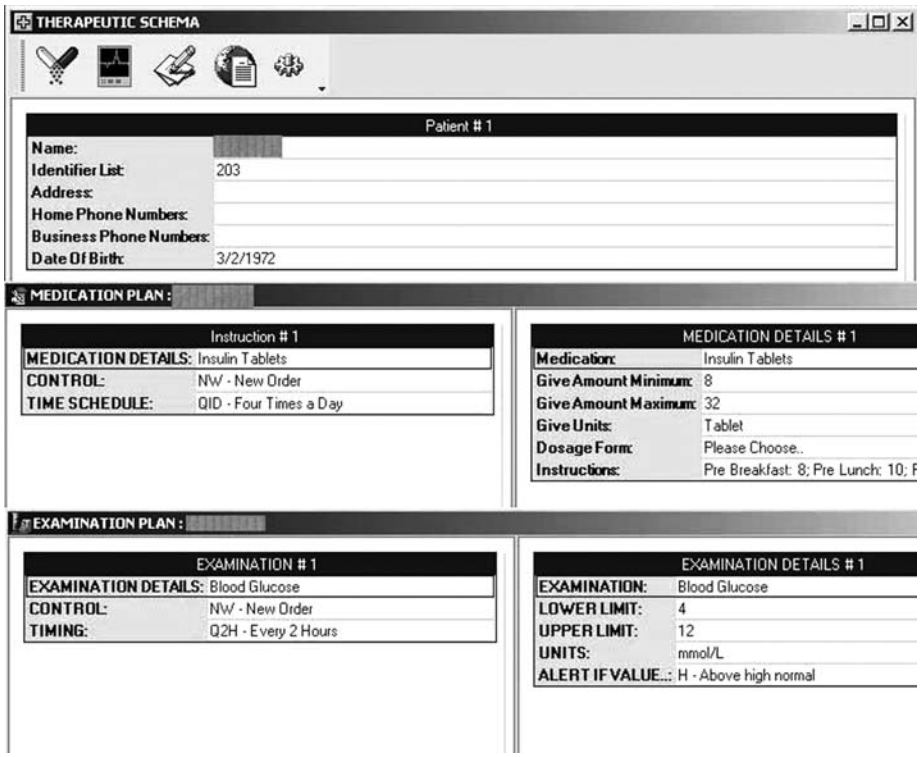

FIG. 2. An example created by therapeutic scheme management for diabetes care.

The C-Monitor platform is entirely built on Microsoft .NET Framework (Microsoft, Redmond, WA). Many state-of-the-art software development techniques were used throughout the developmental phase. The approach is "object-oriented," and the main functionality of the platform is served by a core library of reusable and tested software modules. The architecture of the platform is based on a four-tiered distribution offering high scalability and a robust security model. Two important issues are especially addressed in this platform. They are mobility and security. For example, the use of Extensible Markup Language (XML) notation enhances the interoperability of the platform, e.g., the use of XML alerts makes the alarm service extensible to a wide variety of devices, such as PDAs (Personal Digital Assistants), mobile phones, etc. The platform also enables the translation of the services into any language after the initial setup. The translation can be done stepwise and integrated into the service. Users can edit XML files to provide their own translation, which is afterwards integrated into the software without recompiling. The infrastructure of C-Monitor is illustrated in Figure 4.

Privacy and security are important. C-Monitor offers a robust security infrastructure based on proven standards, such as SSL (Secure Socket Layer) secure communication channels between Internet clients and the services and emerging standards, such as Global XML Internet Services Architecture (GXA) for the communication between the Internet server and the application server. The calls to the Internet services are only accessible by the authenticated users.

SYSTEM EVALUATION AND RESULTS

To evaluate the performance of the platform, its effectiveness in compliance, and the attitudes of the medical professionals and the patients, three pilot trials have been completed in Spain, the United Kingdom, and Greece. The trial monitored oral anticoagulation treatment in Spain, asthma care in the United Kingdom, and morbid obesity care in Greece.

A total of 25 ($n = 25$) adult patients were selected to participate in the trials from three different countries. All patients had access to a

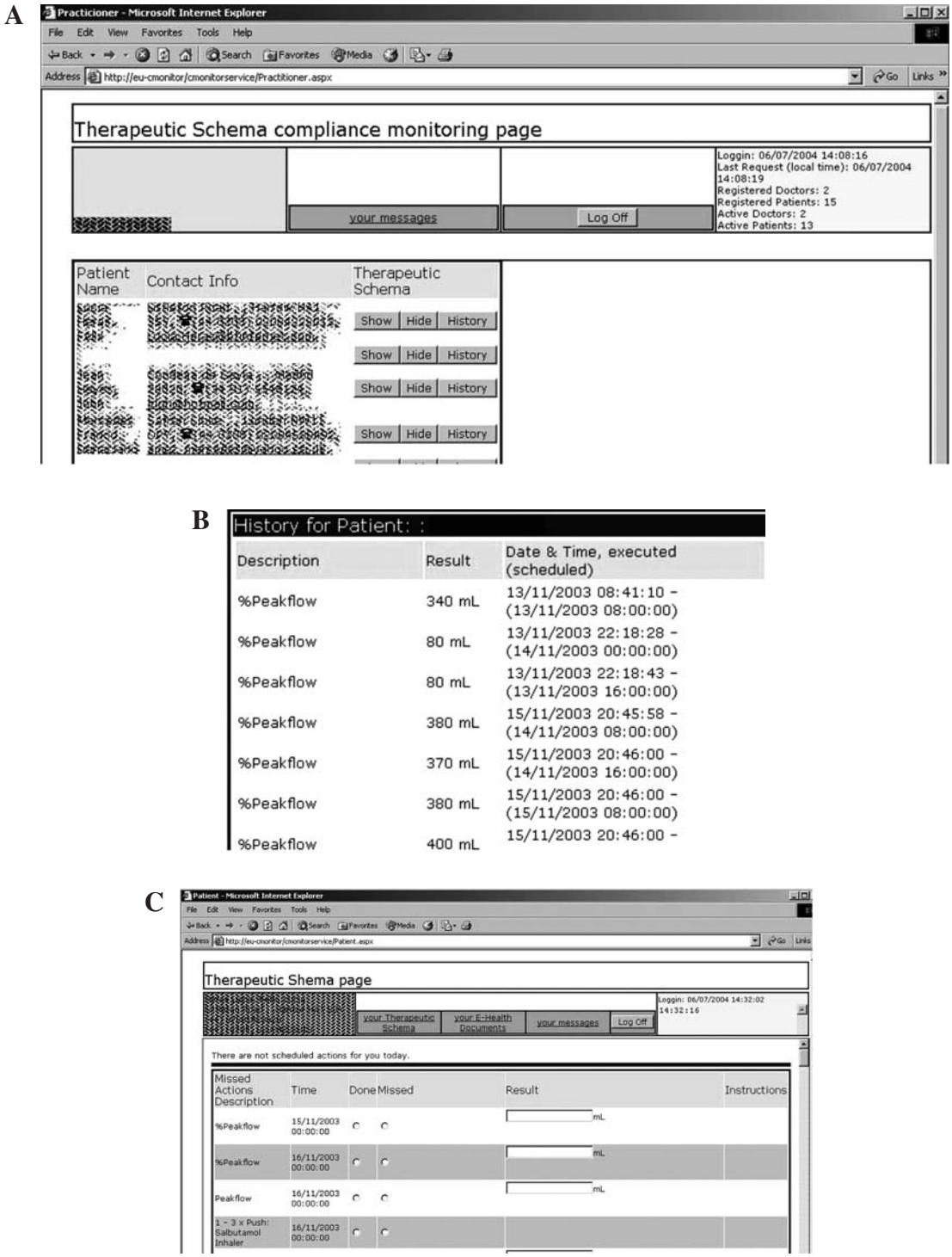

FIG. 3. Patient's and doctor's Internet site. (**A**) Doctor's Internet site. (**B**) Patient-recorded data. (**C**) Patient's Internet site.

personal computer and the Internet at home. They were computer literate and able to manage the C-Monitor Internet service after proper training and were able to use the medical devices, such as a digital scale, metered dose inhaler, and so on, at home. The trials were carried out independently of the patients' level of formal education or social background and also approved by the Research Ethics Committee of institutions where the trials were conducted.

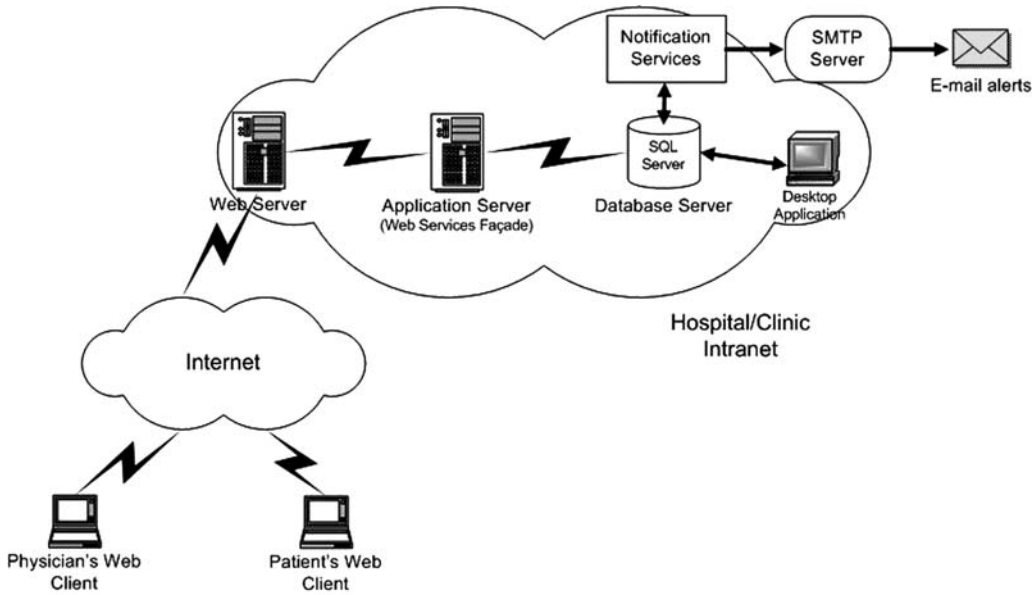

FIG. 4. Infrastructure of C-Monitor.

After the trial, all patients were required to complete a questionnaire. The completion of the questionnaires was guided by the medical professionals by phone to make sure the patients understood what was being asked. All patients completed the questionnaire, with the one exception. At the same time, the medical professionals who were responsible for the trials were also requested to complete a questionnaire. In total, distribution of the responses to the questionnaire was 3 from Spain, 9 from the United Kingdom, and 12 from Greece. Medical professionals responding numbered 5, one from Spain, three from the UK and one from Greece.

The effectiveness of helping compliance in disease management was assessed by the medical professionals who were in charge of the trials. All credited the system for the ability of creating personalized therapeutic schemes, providing an efficient communication channel with patient, and satisfactory monitoring of compliance with disease management. The alarm system raises their attention whenever the patient was in a difficult situation.

However, not all of the doctors liked the C-Monitor for its ability to provide educational material. This is probably because the doctor has to upload and forward the specific information to each patient, a task that proved to be cumbersome. Also, because the doctor could communicate with the patient by online message, it was not necessary to provide extra information for each patient. It was suggested that all the relevant documents should be placed on the Web site, and that the patients download information themselves. If they fail to find the relevant information, they could then ask the doctor.

The performance of the system was assessed by all participants. Medical professionals assessed the whole system, whereas the patients assessed only the Web site. The system was assessed regarding friendliness/operability, access control, fault tolerance, understandability, and entry and learning requirements.

Most of the participants gave positive responses regarding the performance of the system. They particularly addressed the ease of use and the full functioning of the system. Ninety percent of participants were able to use the platform without problems. A few patients, particularly two elderly ones had limited knowledge of computers and reported that they needed help from doctor during the first week of using the service; however, after

proper training, all the participants understood what they were required to do. About 80% of the participants did not experience any errors at all. Some patients reported some problems, but they arose from medical devices, system administration problems, and other outside effects, such as down-time of the Internet and power. There were no serious problems with the C-Monitor itself.

After the trials, most of the patients agreed that C-Monitor system provided a more valuable service than the traditional ambulatory system and they would like to use the C-Monitor service in the future for disease management. They liked the idea of receiving health care at home and would like the authorities to provide this kind of service so that they could avoid traveling to the hospital and thus improve their quality of life.

Some patients still preferred traditional healthcare services. For example, one patient liked the traditional ambulatory service and one preferred to speak with the doctor rather than communicate by messages. One patient also disagreed that C-Monitor system could provide useful information to him. But this did not decrease the value of the C-Monitor system. Most patients showed confidence in the C-Monitor service and would recommend the system to others. They also suggested improvements, such as sending comments and concerns to the doctor by e-mail, providing an automatic message to the patients after the doctor received his message, and providing videoconferencing for better communication between patients and doctors.

All medical professionals agreed that the level of C-Monitor performance was very good. All would like to influence the authorities to provide tele-assistance in health care and would use the C-Monitor system in the future. Some suggestions for improving the platform included: eliminating data entry by keying, providing templates for therapeutic scheme in the most frequent pathologies, implementing videoconferencing for a better communication between doctor and patient, modifying the scenario and therapeutic scheme from the Internet rather than their own computers, and providing more alerting methods, such as mobile SMS (Short Message Service).

CONCLUSIONS

The C-Monitor platform aimed to provide health care for chronic disease patients at home. Feedback from the patients and medical professionals suggests that the C-Monitor platform was fully functional, provided services for the medical professionals to monitor the patients suffering from different chronic diseases, to allow them to create personalized therapeutic plans, monitored the patients' compliance with disease treatment, and provided educational material for the patients. The platform reminded patients to take their medication and complete examinations on time and record all the relevant data. Above all, it provided an efficient channel for the doctor and patients to communicate with each other so as to keep the patients active in their disease management.

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Address reprint requests to:
Dr. X. Wang
School of Computing and
Information Systems
Faculty of Technology
Kingston University
Kingston upon Thames
Surrey, KT1 2EE, UK

E-mail: Xinheng.Wang@kingston.ac.uk