Designing an Internet-based Collaborative Environment for Cystic Fibrosis Treatment

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1 Introduction

The Internet and Internet-based services, like the World Wide Web, email, ftp, etc., are emerging as universal platforms for information dissemination, sharing, archiving and computer-mediated communication. Low-cost access to this global networking infrastructure and to ubiquitus computer-mediated communication tools is opening new opportunities for solutions to numerous problems in a wide range of human activities, including medicine.

In this paper we propose the application of state-of-the-art Internet and Data Base technologies in the battle against *Cystic Fibrosis*, which is a rare, fatal, genetic dicease. We present some basic facts about the disease, its epidemiology and treatment conditions in Greece and Cyprus. Taking into consideration the current and the projected state of affairs vis-à-vis cystic fibrosis and the human and financial resources dedicated to the battle against it, we argue that the procedures for treatment, patient monitoring and doctor retraining require a major collaborative effort on behalf of medical specialists and specialized medical centers. The Internet, its successful groupware applications (email, ftp, usenet news, etc.) and the World Wide Web represent an obvious choice and an opportunity for supporting this effort, at a low cost.

Nevertheless, Internet services per se are not sufficient to support the collaboration requirements of cystic fibrosis treatment. What is needed, instead, are tools that provide medical centers and doctors with an environment for information sharing [EGR91] and coordination [MC94]. Although the prospect of combining Internet services into this sort of environments appear bright, one must take into account known problems and challenges related to the implementation of *Computer-Supported Cooperative Work* (CSCW) tools [Gru88, Gru91, EGR91, Kyn91, Nor91, Gru94] and to the introduction of new network technologies [Rag97, KF97, Ste97, Sch96, BHST96, LH97].

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2 Cystic Fibrosis

Cystic fibrosis is the most common genetic disease of the caucasian race; its gene was discovered in 1989. In Greece, cystic fibrosis occurs in approximately one out of every 2,500 live births. It comes second in frequency after thalassaemia but is expected soon to take its place, given the successful containment of thalassaemia due to the adoption of systematic prenatal checks [Pou97]. The estimated number of cystic fibrosis patients in Greece is around 1,000. However, only 600 of them approximately are diagnosed and treated in specialized medical centers. Furthermore, an estimated 5.2% of the greek populace are symptomless carriers of the defective gene, which is responsible for the disease [Pou97]. Cystic fibrosis is fatal; in North America, the mean life-span of a patient is 29.4 years and the 1/3 of patients are over 18 years old (1992 data) [Pou97].

In the past, most cystic fibrosis patients could not survive childhood and therefore the disease was diagnosed and treated mainly by pediatricians. Nowadays, the prognosis has changed drastically and patients live longer. Adult patients are being treated by pneumonologists, since the disease typically causes severe pulmonary complications, which dictate its final prognosis.

3 Collaborative Aspects of Cystic Fibrosis treatment

Due to the rarity of cystic fibrosis, most medical practitioners in Greece and Cyprus are not trained to treat patients or even diagnose the disease. There are, however, a few specialized doctors in Athens, Thessaloniki, Patras or Lefkosia. Most of them work in the five national cystic fibrosis centers, three of which are in Athens and two in Thessaloniki. Two of the cystic fibrosis centers of Athens treat adults and one treats children. The two cystic fibrosis centers of Thessaloniki are pediatric. The establishment of another center for children and adults is underway in Lefkosia, Cyprus.

People from all over Greece (and in some cases from Cyprus), who are diagnosed with cystic fibrosis, are referred to the special centers of Athens and/or Thessaloniki for tests, monitoring and treatment. Given the seriousness of the disease, it is imperative to conduct various medical tests (blood, saliva, urine, etc.) on each patient once a month, or every two, three or four months, depending on her condition. Furthermore, patients undergo physical therapy on a daily basis and have to follow special diets. The necessary coordination between the hospital and the patient's home is undertaken by nurses.

The fight against the illness requires intensive collaboration between specialized pediatricians, pedo-pneumonologists, pneumonologists, physical therapists, dietologists, nurses and treatment centers. This collaboration is critical, especially for patients between 13 and 17 years of age, who switch from pediatric to adult treatment centers. So far, collaboration and patient monitoring are realized through meetings that entail frequent travelling of medical specialists from Athens to Thessaloniki and Patras. Furthermore, doctors interact by speaking over the telephone and by exchanging parts of medical records and medical examination results via fax or regular mail. However, the frequent travelling of medical professionals to distant locations is costly, inefficient and puts a severe strain on the operation of central medical centers. Consequently, doctor travelling is being substituted by periodic visits of cystic fibrosis patients to Athens, which has the only national centers for adult treatment. This raises treatment expenses and the discomfort felt by patients; especially those that live far away

from Athens and are normally monitored in Thessaloniki, Patras and Lefkosia.

In recent years, the number of patients under treatment is growing due to the increasing awareness of the medical community on cystic fibrosis symptoms and a prolongued life expectancy achieved with better monitoring and new drugs. Consequently, the old means of collaboration are quickly becoming inadequate. Hence, there is a need for a new environment that will enable doctors to update patient files remotely, to participate in a simultaneous review of patient records and to engage in interactive electronic discussions.

Moreover, the rapid expansion and change of medical knowledge raises many barriers to knowledge diffusion from research establishments to clinincs and individual doctors [DS97]. These barriers are even greater for rare illnesses like cystic fibrosis. Therefore, an Internet-based environment for information sharing and collaboration on cystic fibrosis treatment, can and should be used as a means for medical training regarding the disease.

4 Developing a Collaborative Environment for Cystic Fibrosis: Issues and Requirements

Given our assessment about the collaborative aspects of cystic fibrosis treatment, we are working towards the design and implementation of an Internet-based *Computer-Supported Collaboration Environment for Cystic Fibrosis* (CSCE-CF). This environment will enhance the collaboration among medical specialists treating the disease in major national medical centers of Greece and Cyprus. Putting such a tool at work will enhance the monitoring of patients that live in remote areas, relieving them from the necessity of costly frequent visits to treatment centers of Athens and Thessaloniki.

The effective support of collaboration, demands that physicians share information about cystic fibrosis patients. This information lies at the core of CSCE-CF and is being encoded in a national database of electronic medical records of cystic fibrosis patients. A record contains all medical data that are necessary to monitor the condition of a patient, including some standard personal characteristics (e.g., gonotype, sweat test) and results of a series of medical examinations conducted periodically (blood, urine, chest X-rays, ECG, etc.).

The fundamental "cooperative" feature of CSCE-CF will be to provide specialized physicians with remote access and update rights to this database, through the World Wide Web and its *HTTP* protocol. Clearly, a solution using WWW forms and the *CGI* features of HTTP is not sufficient and therefore we are working towards the architecture presented in Figure 1. Consequently, we need to address the numerous problems of designing and implementing a "web database" containing medical information [LH97, Dua96, HM96, KF97, Ste97]. Furthermore, we need to extend this tool with features that enable users to simultaneously review parts of the same record and be aware of each other's comments [EGR91]. These features will provide users with the shared environment that unobtrusively offers up-to-date group context and explicit notification of each user's actions, when appropriate.

Such features require the integration of *communication* and *coordination* capabilities into the CSCE-CF environment. Unfortunately, typical computer-mediated, asynchronous communication tools such as electronic mail and usenet news are not yet fully integrated with synchronous forms of communication, like telephone and face-to-face conversations. Furthermore, the typical electronic mail and usenet news systems transmit messages but provide few environmental cues. Therefore, given the limited integration of *desktop teleconferencing*

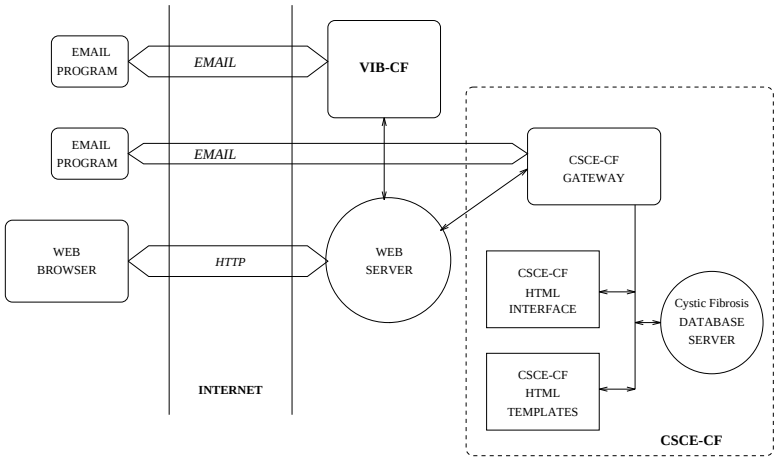

Figure 1: CSCE-CF Architecture.

systems with Internet, the communication requirements of CSCE-CF usage will be covered by a hybrid scheme of regular telephone conversations and a WWW-based system for collecting and distributing comments via electronic mail. Furthermore, for reasons of implementation simplicity, CSCE-CF will not incorporate *explicit* coordination features. Instead, coordination among distant medical centers and physicians will be carried out as usual, via personal telephone contacts. We believe, however, that implicit coordination will be enhanced by the information sharing and communication provided by CSCE-CF.

5 Developing a Virtual Information Board for Cystic Fibrosis

Along with the implementation of a computer-supported collaboration tool, we plan to establish an Internet-based, hypermedia-oriented *Virtual Information Board for Cystic Fibrosis* (VIB-CF). This board will be used to collect, review and disseminate information about the disease on a permanent basis.

The primary goal of VIB-CF is to provide general practitioners with *continuous education* on cystic fibrosis, that is, with up-to-date information on clinical symptoms, diagnostic methods, treatment, and treatment centers. Moreover, VIB-CF will give patients and their families the opportunity to communicate with specialists, to exchange views and receive timely and accurate information on treatment alternatives, suggested living conditions and existing treatment centers.

6 Conclusions

Recent advances in computer and telecommunication technologies, along with rising health care costs and the rapid expansion of medical knowledge, have generated an intense interest on how to employ information technologies in health care [Rag97]. Research projects like the one undertaken for Cystic Fibrosis not only will provide for the technological "know how" that is required to respond to pressing health care needs, but also will address open questions in Computer Science research. It is interesting to explore ways for combining

medical content, computer science methods and software technology to implement computer-supported cooperative environments, "virtual" patient records, web databases and medical knowledge diffusion systems.

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