A NEW HOME TELECARE MODEL FOR CHRONIC HIV/AIDS PATIENTS

C. Caceres*,**, E.J. Gomez*, F. Garcia***, P. Chausa*, J. Guzman*, F. Del Pozo* and J.M. Gatell***

* Bioengineering and Telemedicine Unit, Technical University of Madrid, Madrid, Spain
** Artificial Intelligence Unit, Rey Juan Carlos University, Madrid, Spain
*** Infectious Diseases Unit, Clinic Hospital, Barcelona, Spain

ccaceres@gbt.tfo.upm.es

Abstract: New models of care are needed for adapting to the new situation of chronification of the HIV/AIDS disease. Models that integrate all the aspects of the patient's health (psychological and social as well) and that take advantage of the emerging technologies. An example of an integral telecare system called VIHrtual Hospital is shown in this article. This web-based system helps both professionals and patients to care their illness in a more efficient and comfortable way. The four main services proposed in this model are: virtual communities to empower the collaborative work, a virtual library to provide validated information, virtual consultations to offer the possibility of a telecare system with the EHR integrated, and telepharmacy to follow-up the treatment and send the drugs from the hospital. Evaluation in being held in the Clinic Hospital in Barcelona (Spain) with 20 professionals (doctors, nurses, pharmacists, social workers, psychologists, psychiatrists,…) and 100 chronic and stable HIV patients.

Introduction

Chronification of AIDS is now a fact in developed countries where the newest treatments have reduced dramatically the mortality associated to the HIV infection [1]. This improvement needs a completely new approach in the actual care model of the HIV/AIDS patients. Therefore we could learn from other chronic diseases as diabetes, arthritis or epilepsy how to deal with this new situation. The coordination of the care team and the involvement of the patient in his/her own care, seem to be factors of great importance for a good chronic disease management [2]. Information and Communication Technologies can also contribute to this process of coordination and patient empowerment. Particularly the Internet, seen as a supernetwork connecting people and providing great amounts of information, could be used to improve the quality and reduce the cost for caring of chronic complex illnesses, such as diabetes, COPD or HIV/AIDS.

A multidisciplinary care team is also desirable in a disease like HIV/AIDS [3], where psychological and social factors are having an increasing influence in the patient's health status. Therefore the new homecare model should be holistic, integrating medical doctors, psychologists, nurses, social workers, pharmacists, etc in the same team, with the patient as member as well.

These are the bases for the new telecare model outlined in this article.

Materials and Methods

To support this new home telecare model a telemedicine web system has been developed, covering the care process of the chronic patient as a whole: visits, clinical, psychological and social follow-up, pharmacology, quality of life, etc. This challenge has been faced by the creation of the "VIHrtual Hospital" project. Its main goal is the definition, development, clinical routine installation and evaluation of a telemedicine service that complements standard care with a telecare follow-up for attending stable HIV infected patients, in a chronic phase of their disease, and study if that improves the quality of assistance and the expense per patient comparing to the conventional control that patients usually have.

Figure 1: Main menu of the VIHrtual Hospital

This system has four main services, as shown in figure 1:

Virtual community: meant to create spaces to exchange information about the disease, the project, share their opinions, comment articles, news, etc. Depending on the user's profile (healthcare professional or patient), this tool will offer different information. Exclusive for professionals is the clinical sessions

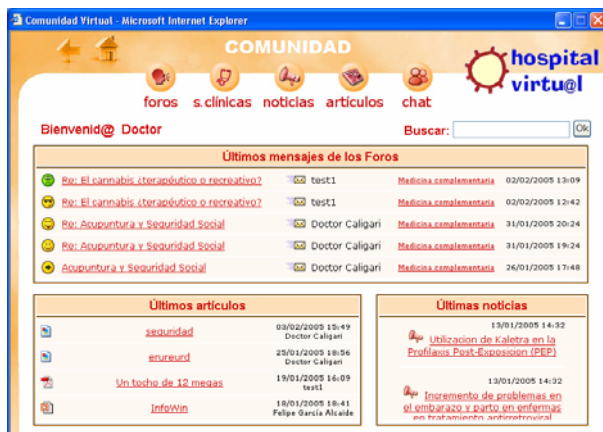option, where they can share opinions about the cases they are covering at the moment.

Figure 2: Virtual community main menu

Virtual Library: storing validated basic information about the HIV/AIDS disease, as links to other web pages, for both patients and professionals. There are different sections for validated links (links inserted by professionals) and not-validated links (inserted by patients), although the latter could be upgraded to validation by any professional in case they see it is worth it. All links are categorised by their kind of source and are included in different groups according to the subject they refer.

Virtual consultations: these consultations can be delivered using a *videoconference*, a *chat* session or exchanging *messages*. During any of these sessions, both the professional and the patient that are participating have access to the electronic health record. It can be emphasized that we have included psychological and social data to integrate the patient's records seeing their care as a whole. An agenda is also available so that, at the end of the visit, patient and professional can agree and make the next appointment.
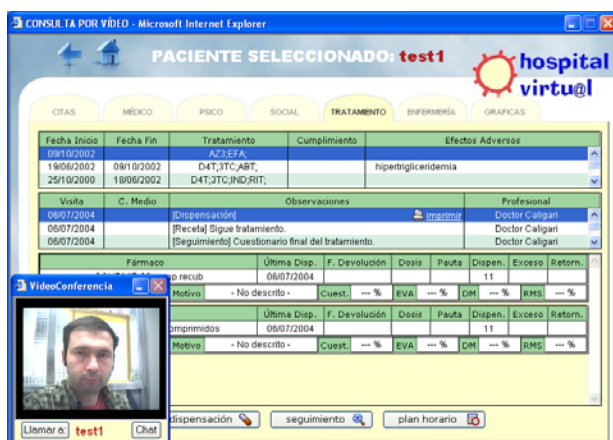

Figure 3: Example of videoconference with simultaneous access to the electronic health record.

For the videoconference, an ActiveX based on Microsoft Netmeeting has been inserted. For the chat, we have implemented and integrated it in the system based on the asp tool ConquerChat. For the messaging tool, messages are exchanged between professionals and patients through the database without using e-mail client programs for anonymity purposes.

Telepharmacy: the pharmacist receives the e-prescription and consults the data introduced by the patient to follow-up the compliance, adverse effects, interactions with other drugs, etc. The medication is sent to the patient's home by courier.

The follow-up of the treatment is done by the doctors and pharmacists and, obviously, the patient. They commonly agree the ideal treatment taking into account multiple factors. This therapy usually consists of three or four drugs that, after a visit, the doctor prescribes to the patient. Up to now the patient goes with those prescriptions to the hospital pharmacy, where the pharmacist delivers the drugs (in Spain antirretroviral drugs are not sold in the usual "street" pharmacies, but only delivered in hospital pharmacies).

Now, with the telemedicine system, the doctor could have visited his/her patient online, so the prescription is sent to the hospital pharmacy automatically by the system. In this case the pharmacist will be informed that the patient needs more medication and therefore consults the compliance data that the patient should have introduced already through the system. With these data the pharmacist can make a significant follow-up of the compliance, adverse effects, interactions with other drugs, etc. Before sending the medication to the patient's home by courier, the pharmacist usually wants to visit the patient and check if is having any problem with the treatment. This is also done virtually, with the videoconference facility of the VIHrtual Hospital system. This new process is shown in the diagram of the Figure 4. The patients can also in this section visualise the evolution of their own treatments on charts and consult basic information on the available antiretroviral drugs.
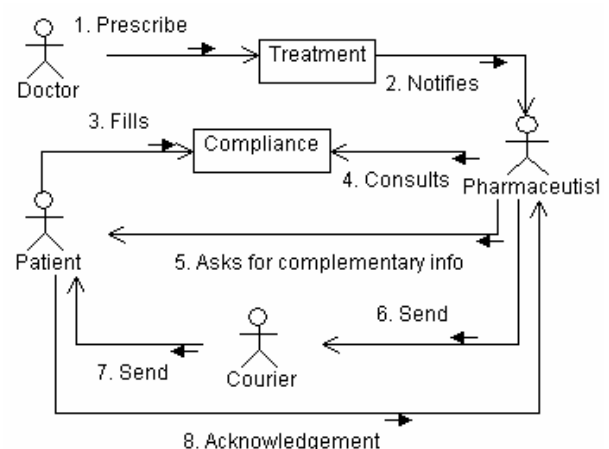

Figure 4: Collaboration process in telepharmacy

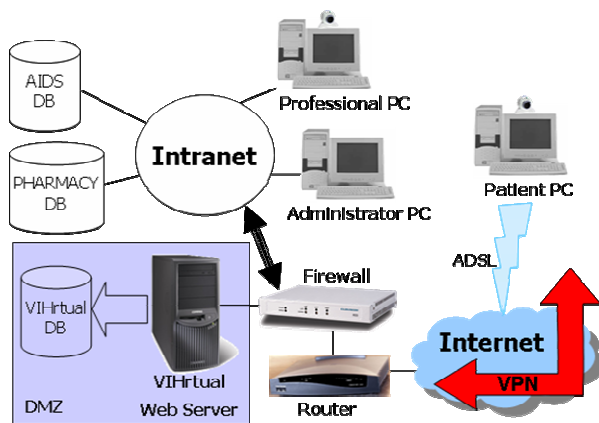The architecture implemented in the Clinic Hospital in Barcelona follows the schema shown in Figure 5.

Figure 5: Architecture of the implementation

On the left side we have the hospital infrastructure, where we added our server to the existing DMZ of the hospital protected by a firewall. Professionals involved in the project access this server using their work PCs through their intranet. The existing infrastructure of the hospital network has been used whenever possible, in order to prevent creating a parallel network exclusively dedicated to the project. It is important to note that one of the main difficulties for the integration of the system in the hospital has been the synchronization of our database with the existing databases of the hospital. The VIHrtual database is the new database created for the telemedicine system, where the data of the patients involved in the trial are stored. This database is filled and synchronised with the HIV/AIDS database, which the Infectious Diseases Service of the Clinic Hospital has been using over the last 15 years where more than 3.000 HIV/AIDS patients are registered. Finally, the server is also connected to the Pharmacy database, where all the available drugs are recorded and kept up to date by the pharmacists.

On the right side of the architecture figure we have the patient at home, accessing our server with a basic ADSL connection (512/128 Kbps) through a VPN tunnel for securing the communication.

The technologies that have been used are, on the server side, Microsoft Windows Server 2003, including the Internet Information Server 6.0 that processes the ASP pages that form the system; and on the client side, the system is optimised for the Internet Explorer browser.

This web-based system has been developed with a special effort in the selection of the equipment for the patients, trying to integrate them as much as possible in a home environment (size and "look and feel"). The graphical interface has also been carefully designed in order to ease its use for professionals and patients, as can be seen in Figures 1, 2 and 3.

Other main goal has been developing a low cost system in order to being able to increase the number of patients for the clinical trial. Therefore, low price home

web cams and ADSL were some of the chosen technologies for the implementation, with more than acceptable results.

Security has been one of the most carefully designed aspects of the project, mainly because of the experimental nature of the project and the characteristics of the disease it is dealing with. As well as securing the communications, as mentioned before, with VPN tunnelling, patient's data is also encrypted and anonymized (all personal identification data is removed by the user administration tool) so that any improbable break in the server will result to be harmless. Users may have a complementary fingerprint recognition device when needed (shared PCs) that jointly with the login and password will be checked to access the system. All accesses to the system are being monitored and the system sends automatically an alert e-mail to the technical responsible in case of recurrent access, in order to estimate the risk of the situation and check the identity of the possible attacker.

Results

For evaluation purposes, a randomised crossed open clinical trial has been developed, where 100 patients are involved, randomised in two branches, 50 with the new telecare model and 50 with the usual care model during two years, crossing in a year time. This evaluation started in January 2005 and is being carried out by the Infectious Diseases, Mental Health, Pharmacy, and Social Services of the Clínic Hospital of Barcelona (Spain), involving a total of 20 healthcare professionals (eleven HIV/AIDS specialist doctors, a psychologist, a psychiatrist, two nurses, four pharmacists, and a social worker).

The evaluation is being monitored by an independent quality of life expert and the maintenance of the system is guaranteed by the development team and a company responsible of the installation and maintenance of the patient's equipments.

First results of the evaluation of this care model are showing an increasing coordination between the members of the care team, and a tighter control of the patients by themselves and the healthcare professionals. It is still too soon to do the cost-effectiveness study, but the trial shows that we are already reducing costs for patients. In December 2005, when the group's cross-over takes place, we will get the first evaluation report with promising results.

Discussion

Although maybe it's too soon to discuss the results, there are some points of the model that are already being questioned, as will be described now.

First of all, the integration of the system with the hospital infrastructure is taking too long. Although we have successfully connected our system to some hospital databases, there are still other databases, such as the laboratory for the analytics, that should be added.

The process for this integration is too laborious and requires a lot of work and patience.

Working with so many professionals (up to twenty) is also another handicap. The coordination of the care team is sometimes difficult, especially when they have to change their method of working from an isolated and conventional care to a collaborating telecare. There have been problems like forgetting that they had a virtual appointment or answering a message in time (before 48 hours). This is now being solved with an alert system that is being integrated in the VIHrtual Hospital. Both professionals and patients can configure these alerts to be sent by e-mail or SMS to their mobiles in case of certain events occurring.

Consultations via chat have been also one of the weak points of the system. This kind of consultations was supposed to be an extra resource for the patients in case they wanted to ask a relatively urgent question. There was a timetable where every day some professionals would be available, waiting for any question from the patients. This has shown inefficient, as the professionals wouldn't fulfil the hours arranged claiming that they were wasting time there waiting. So this section is now being converted into an instant messaging tool that will allow professionals to work in other tasks while they are available in the chat. To develop and integrate this IM tool in the system is taking more time than expected.

There are other aspects like the coordination of the e-prescriptions, the pharmacist consultation and the sending the drug by courier to the patient's home that have been quite hard to achieve, although we finally did.

Conclusions

Nowadays, caring chronic HIV/AIDS patients involves a tighter control that implies several visits a year for the blood analysis and clinical follow-up. These visits are complemented by other visits (psychological, social, prevention, doubts…). Even more, patient self empowerment [4] and the coordination of the care team are mandatory within these care models.

Integration of a new technological service in a hospital is always difficult and implies a great effort. The integration of this telemedicine service into the Hospital Information System network has created a new architecture that must deal to satisfy the necessities of the new service without generating any conflict with the existing services.

One of the most important aspects is the data access security, as clinical information needs the highest level of protection by the Spanish law [5]. This project has been exceedingly cautious about the security facts, due also to the nature of the disease.

The evaluation will show when telemedicine is feasible for HIV/AIDS home-care and when it is not, depending on the patient health status, location or knowledge, or coordination difficulties between the care team or even our own system limitations. The results will allow us to know if it is possible to follow certain chronic patients at home, reducing the number of visits to their reference hospital and improving care from every health professional (physical, psychological, social, prevention, etc. improvements).

To sum up, a new home telecare model for chronic HIV/AIDS patients has been created and has been implemented through the telemedicine system described in this article. The architecture of this web-based system fulfils the demanding security and integration requirements of the Informatics Service of the Clínic Hospital. An easy-to-use graphical interface for both patients and professionals has also been developed. The low costs of the system allow us to cover a wide range of patients, where we hope to get promising results about the use of telemedicine systems for improving the follow-up of chronic HIV/AIDS patients and for creating a new care model for this disease.

Acknowledgement

References

[1] PALELLA, F. J. (1998): 'Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection', *N. Engl. J. Med.*, 338, pp. 853-860

[2] REITER, G. S. (2000): 'Comprehensive clinical care: Managing HIV as a chronic illness', *AIDS Clinical Care*, 12(2), pp. 13-20

[3] WINTER, T. et al (1998): 'HIV and managed care: cost-effectiveness of an interdisciplinary disease management team'. Proc. of 12th World AIDS Conf. Geneva, Italy, 1998, p. 857

[4] HOLMAN H. R., LORIG K. R. (2000): 'Patients as partners in managing chronic disease', *BMJ*, 320, pp. 526-527

[5] Spanish Organic Law 15/1999, December 13th 1999, for protecting personal data