A web-based self-monitoring system for people living with HIV/AIDS

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Abstract

Available evidence indicates that the internet is becoming the main source for delivering information on the prevention, control and treatment of HIV/AIDS. This paper presents a further step in the use of the internet to meet the new challenge of managing HIV as a chronic illness. It describes a work carried out under the SEAHORSE EU project to build and test a Web-based self-monitoring system for HIV/AIDS patient care. The user interface has been carefully designed to provide a high-level of interaction and therefore improve some of the current limitations of Web applications. The system comprises three modules: (1) a patient self-monitoring personal diary, to create a follow-up patient record; (2) a data analysis and visualisation tool; and (3) a section to allow patients to ask for advising and remote doctor support. One of the crucial system design issues has been the system security and users anonymity features required in this clinical domain. A feasibility pilot has been carried out to test the system in three organisations involved in the research project: the Immune Development Trust (London), the Lambeth, Southwark and Lewisham Health Authority (London) and Apoyo Positivo in Madrid. The preliminary results of the system evaluation show the potential validity and usefulness of the tool for helping people living with HIV/AIDS to promote and manage their health and for providing health professionals with new means for tele-monitoring and tele-caring patients. © 2002 Elsevier Science Ireland Ltd. All rights reserved.

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1. Introduction

The internet is having a tremendous radical impact on healthcare models and in particular on how healthcare is currently delivered. It is transforming the relationships between healthcare administrations and companies, professionals and patients. Furthermore, patients are using the internet to gather information about diseases and drugs and to communicate directly with their physicians. In fact health-related sites are among the most frequently accessed information sources on the Web [1].

The impact of this internet revolution is also affecting newly discovered diseases that have poorer forecasts, where prevention (i.e. information) is vital. This is the case of the HIV/AIDS. This epidemic was first discovered in the 1980s and today more than 21.8 million people have...
died from it, and there is an estimated 36.1 million people living with HIV/AIDS in the world [2]. The general public is becoming increasingly aware of how HIV is transmitted and how to avoid the infection, but this information has to be broadcast to the greatest number of people possible and in every possible media [3,4]. The best and more universal media used now in the industrialised world is the internet, and in the HIV/AIDS health care domain, there is a wealth of valuable information.

In any case, the main problem now is that the internet hosts thousands of Web pages referring to HIV/AIDS, brimming with information and misinformation [5]. The SEAHORSE II European project [6] aims to provide solutions in this direction by defining and developing a Web site that selects, classifies and validates (with an expert reviewers group) the most interesting HIV/AIDS Web sites. It also allows users to post comments and articles to rate the existing resources.

The work presented in this paper has been developed within the SEAHORSE II project, to extend the possibilities of the internet health care information services, to transmit information on prevention to the community (which is the most common use nowadays in the field of HIV/AIDS) and to provide, both health professionals and patients with tools to improve the illness monitoring [7].

Potent combination antiretroviral therapy has led to steep declines in AIDS-related deaths and opportunistic diseases. AIDS health care professionals have begun to openly share a perception that they have held privately for some time: HIV infection can be transformed from a uniformly fatal disease into a long-term illness [8].

Therefore, HIV infection is becoming chronic but only for those patients who tolerate or have access to those potent treatments. Quality of life is another issue to be tackled, because the power of these drugs involves new side effects, and the newness of the treatments makes it impossible to predict the long-term effects.

As people living with HIV/AIDS become aware of their new health status, they have to learn how to manage their chronic disease. This new situation leads to the incorporation of the self-monitoring concept HIV/AIDS in the domain in order to improve health status and reduce hospitalisations [9]. Within the home care monitoring programmes [10], this is now one of the leading products in the medical industry.

The combination of self-diagnostics, home monitoring and the internet is being demonstrated as a really powerful product for attending chronic patients [11]. This paper describes a new self-monitoring web-based system for HIV/AIDS patients.

2. System design and development

The main objective of this system is supplying people living with HIV/AIDS with a new tool to achieve the follow up of the evolution of their health status. Furthermore, the system allows health care professionals to assess the effect of several therapeutic strategies on the illness evolution.

2.1. User requirements

The first stage of the system design was to carry out a comprehensive analysis of user requirements using a user-centred methodology developed by authors in earlier research work [12]. The user requirements collection was realised by a structured questionnaire provided to users, patients and professionals, from the seven pilot sites of the SEAHORSE project, although the main contribution came from the Apoyo Positivo NGO (Non Governmental Organisation) set up in Madrid, Spain. The structured information was further analysed by informal interviews with some clinical experts in Spain to gather their opinion on the integration of these requirements within their own hospital organisations, to achieve the final goal to improve the HIV/AIDS patients treatment.

A summary of the user requirements document is depicted as follows:

- Anonymity: although people are more and more aware of the meaning of HIV/AIDS, there is still a lot of social exclusion, stigmatisation and discrimination on people living with HIV/AIDS. In some countries where information is easily and rapidly broadcasted through
the media (and here the internet has an important role) most people now do not hold stigmatisation views about persons with HIV infection or AIDS. However, a substantial minority still holds that discriminatory attitudes [13] and in other countries this minority becomes the majority [14]. All these lead us to a usual wish of every person living with HIV/AIDS: their anonymity on using and accessing to information systems.

- Easy-to-use: the user interface is one of the most critical components that determine the ultimate success of an interactive end-user system. In our case, most patients have no computer skills at all, so in order to make it easy to learn how to introduce, visualise and manage data, the system must have a very easy-to-use interface that hides the technological complexity as much as possible.

- Impact of the therapies: both patients and health professionals are interested to visualise the impact their therapies have on the health status of the person living with HIV/AIDS.

- Evaluation of the treatment adherence: the HIV treatment compliance is one of the most studied issues nowadays in the field of HIV/AIDS [15]. The biopsychosocial approach [16] is a clear need to improve monitoring procedures of patients. The measurement of the treatment adherence is done by simple questions, displaying graphically the answer results.

- Management of complementary therapies: use of these therapies to complement the traditional treatment is becoming a common habit [17]. One of the SEAHORSE II project pilot sites (Immune Development Trust, London) is specialised in such therapies, so it was decided to include this information on the patient data record.

- Quality of life: patient monitoring requires to collect a short diary, consume profiles (tobacco, alcohol and recreational drugs) and some subjective parameters to be collected. To achieve this task the Visual Analogue Scale (VAS) is commonly used to evaluate the quality of life of the patient [18]. This method is used in hospitals, mainly in oncology to register pain, and is easy to introduce and to visualise.

- Communication with experts: HIV/AIDS patients are increasing their role to manage the illness complications, but at the same time they need better means to increase the frequency and quality of support for health care professionals. Their knowledge of HIV/AIDS issues and the influence that this terrible illness has in their life, foster them to ask for a second opinion [19]. This process of patient empowerment is being supported by new communication channels of doctors and patients through the web [20] and the e-mail is the most used method of information exchange.

- System performance: the system must be as efficient as possible, managing all data and functionalities fast, accurate and properly. Performance is measured mainly with the time response, but interactivity, security and volume of data have also to be considered.

- Costs: minimising costs is one of the objectives of the system [21]. Minimising extraordinary visits to the doctor for asking doubts that could be solved by a telemedicine procedure can be a mean to reduce patient care costs.

- Language: users that will evaluate the system will be English and Spanish, so the tool must be translated into these two languages.

- Technical maintenance: users are mainly working with NGOs, so they usually have few technical maintenance resources. This means that the tool has to be very easy to install and stable.

2.2. System design

The user requirements analysis led to define three application scenarios to be supported by the system: the first one in which the patients carry out the self-monitoring process collecting and consulting personal and clinical data, to continuously update the patient monitoring record; the second one, that provides patients and health care professionals a set of data analysis and visualisation tools to compare and study the evolution of all those follow-up parameters based on the different therapeutic goals; and the third scenario in which the patients can ask for advising to a HIV/AIDS expert on related issues of their illness.
process, based on the available information on the patient record.

At any of these scenarios a hierarchical task analysis was performed, following the user-centred methodology mentioned above, to specify the user interface components and structured dialogues. The usage scenario, simplicity and easy-to-use of the tool, the required universal access and interactivity, and a preliminary cost-benefit analysis were absolute priorities both in the design and further implementation of the system. On that purpose, the most suitable technical platform for developing and delivering the system that fulfills the user needs was a highly interactive web-based system. The newest internet programming techniques have been employed with the outcome of a web site hosting the whole system.

2.3. Security and anonymity

To cope with the anonymity requirement, the access to the system is controlled by an alias or username and a password. In order to getting a totally anonymous registration, there will not appear any name, address, telephone number, or even e-mail address. This anonymity is the first level of security, meaning that from the stored data it is not possible to get the real name of the user. Other levels of security deal with the access to the database and the illegal access to different web pages (all this is transparent for the ‘legal’ user).

Access to the database is protected by password and data are encrypted, so that raw data can not be accessed editing the data file.

To prevent someone accessing to pages ‘jumping’ over the control page where the alias and password are asked, session variables were used. This means that, when a correct user is identified, a variable is created and it is destroyed when he/she closes his/her session on the system. So all the pages ask for this variable before returning information to the user and, if the variable does not exist, the server returns an error page.

Protecting the server and the client are important tasks in any web application. The browser cache on the client must be managed carefully since all the web pages the user visits are stored in the user PC, where they could be accessible to other users of that particular PC. The web pages of this system are defined as ‘non-cacheable’ in order to solve this problem.

2.4. Self-monitoring personal diary

The self-monitoring process implies to register a set of health status data that conforms the patient monitoring record:

- Personal data, such as the birth date, gender, city, country, marital status, studies, profession, NGO, sexual preference, HIV detection date, infection date (if known) and risk practice.
- Clinical data: the level of the immune system (CD4) and the viral load (VL), as well as the opportunistic infections the patient has had during the infection (with starting and finishing dates and days being hospitalised). It is recommended that the patient has the complete medical record to fill out all these data, although AIDS patients are very concerned regarding their illness and they usually know all the data.
- Life style data, it implies a short diary for the patient to describe the feelings, and consume profiles of tobacco, alcohol and recreational drugs. The Visual Analogue Scales (VAS) is used for entering and visualising subjective data like pain, fatigue, sleepiness, nausea, interest, appetite, nervousness, breathing, hope, sadness and general feeling. Treatment data referring to antiretroviral or other drugs designed to combat infection, and to complementary therapies (like yoga, acupuncture, vitamins, herbs, …). To evaluate the adherence to that therapy, short and simple questions are used, as for example “do I have any problem with taking this drug?”, “how many times last week did I miss a dose?”, “when I don’t take this drug, this is usually because of… oblivion, timetable difficulty, afraid of side effects, holiday or weekend, confused doctor instructions, …”. The goal is to get an independent self-monitoring record of every therapy annotating the changes of doses, adherence, side effects and subjective benefit.
It is important to remark that all the data the patient has introduced about the evolution of the therapy can be visualised immediately in a simple and complete way, being able to move along the whole record in order to see both the changes of drugs in the therapy and the evolution of every drug.

2.5. Web-based user interface design

The user interface of the system is fully Web-based but as far as possible hides the Web browser to simplify the interaction for people who are not used to computers. The appearance of a folder with different tags, using a real-world metaphor has been selected to increase system usability.

Fig. 1 shows an example of the self-monitoring process user interface, where several areas are described.

The top of the screen is common for the whole system and it includes: the logo of the European project (SEAHORSE) with a link to its web page; a help icon to get help during the use of the tool; and a ‘home’ sign that will let the user go back to the main screen of the system. The user alias will appear as well if logged in.

The rest of the screen is used to introduce and visualise data using the folder metaphor. As shown in Fig. 1, the tag we are showing (‘Life Style’ in this case) is highlighted and a click on another tag is enough to quickly change the visualised data.

In this particular tag, the user can see his/her feelings moving through the dates, just selecting...
them. If the user wants to add new data, clicking on the ‘Add new Life Style data’ will get him/her to a form with a free text box into which the feelings can be exposed as a diary. The tobacco, alcohol and drug profiles are just to note the situation of the user at that moment. The bars on the right are used to enter some standardised fields on quality of life. The user moves the mouse up the bar, like a thermometer, until he/she reaches the point at which he/she believes him/herself to be at that moment. This process should be repeated from time to time so the user can see the evolution of his/her lifestyle.

It is important to note that a very strong design effort was made to preserve the appearance of the visualisation form in the input form in order to make the users’ learning process easier.

After the patient has recorded his/her life style, the treatment section allows collection and consultation of the therapy he/she is following (see Fig. 2).

This ‘Treatment’ tag is one of the most complex, as the user has to enter the treatment evolution through the time he/she has been treated. The page is divided into two sections: on the left side the whole treatment at a certain moment is provided, i.e. a complete therapy diary where any changes are recorded (new therapies being added or the end of others) on any treatment (antiretroviral, other infections or complementary therapies), so that the user can move (using the arrows) through the dates where it changed; and see information on the right about the particular selection made or the input forms to introduce new data into the system. The main functionalities from this tag are:
Enter new therapy: depending on the kind of therapy (antiretroviral, for other infections or complementary) the user wants to enter, he/she will get different forms. With these forms, when the user enters the drug name, the tool automatically shows the common use of that drug (which may not match with the particular use): the starting date, the quantity and frequency of the dose, the problems that appear, the times and reasons for missing doses, side effects and benefits.

It is important to note that the user must fill in these fields. So, to enter a new therapy, the user must have taken the drug for at least a week.

To see the details of a specific therapy, users simply have to click on it from the list. Then the user will get that particular information on the right hand side of the window, as shown in Fig. 2 for VIDEX (a particular antiretroviral drug). From these new windows, the user can:

- View the evolution of that particular therapy: as the user changes the date, the doses, problems, side effects, ... change to the values of the selected date.
- Add new drug data: the evolution of a particular therapy can be registered by clicking here and filling the form on other date. Every time the user notices any change regarding a therapy he/she is taking, it must be registered here.
- End this therapy: clicking here will register the ending date of that particular therapy, so it will no longer appear from that date on.

2.6. Data analysis and visualisation

In this module the user can visualise all the parameters introduced earlier in order to study the evolution of the infection and the impact the different therapies have on it with the possibility of over striking all the parameters in the same graph. An example showing the features of this function is displayed in Fig. 3, the visualisation of the impact that a certain therapy has on the viral load or on the defence level.

Clicking on the boxes that appear in the upper part of the screen will represent the parameters selected by the user. Another menu will appear with all the therapies the user has had through the whole of the infection’s life, and from them the user selects those that will be represented according to the following notation: a vertical line will note the start and end of a therapy and in between them, the line will represent the compliance the user had on that particular treatment. This adherence representation helps the user to see the real impact of the treatment on the parameters shown. If the adherence is low on a particular drug, it cannot influence the parameters as much as it could if the compliance was high. If there is no end line (as the second time the user ‘Coco’ took Epivir or with Norvir) it means that the therapy is still being taken. We can see in the example of Fig. 3 with real data, that the second time ‘Coco’ took Epivir the viral load (VL) dropped to undetectable levels in 8 months time and that this drug has a real impact on the parameter because the adherence to it has been kept high.

The user can also use the zoom or decide the timeline range in order to see the details of the graphic. Compliance and all the life style data will use the left vertical axis (from 0 to 1.000) as a reference, although these values are from 0 to 100.

2.7. Communication with expert utility

Communication with the expert is provided to the patient for him or her to make any consultation or ask any question. This means that a group of experts, having all the data on the screen collected by the patient, could advise and help with the questions the patient has.

The main advantages this system of ask-an-expert has over the usual system on the internet are: (a) on the e-mail there is complete anonymity (there is no name or e-mail address) and the personalisation of the answer is much better. The experts that usually respond to these questions on the internet tend to give vague or too general advice as they do not have sufficient knowledge of the patient’s situation. By visualising the patient data, the expert can make more specific answers as well as evaluating the effect that different therapeutic strategies have on different people living with HIV/AIDS.
It is important to notice that the expert could also be a psychologist or a social worker, not just a physician, as people living with HIV/AIDS have a lot of questions on these issues too.

The expert enters the system with his/her own alias and password and will get to a first screen with a list of all the users that asked a question which has not yet been answered. It is important to note that the expert will access only the data of those patients with unanswered questions. The expert can then move through the whole selected user’s data freely and see the questions to answer in the ‘Ask expert’ tag, where it can be replied easily from a form.

This functionality is very similar to the e-mail service: every message has the date, a subject and a body. There is a list showing the messages sent where we included a flag ‘★’ to indicate to the patient that the message had already been answered. If the message is red, that means that it has not been read yet. The patient can write a new message, view an old one or delete any of the listed. There is no need of addresses as here the message posted by the patient is stored in the database awaiting the reply of an expert. And when this happens, the answer is also stored in the database until the patient enters the system again and reads it.

2.8. Technical implementation

The chosen system technical platform added several development challenges taking into account the required interactivity and other usability issues.
Providing this interactivity and usability through the internet was an important challenge and we coped with it by developing the system using the Microsoft Notepad. That simple program gave us entire control of the code we wrote, meaning that we knew that the code we wrote was the code the users would get on their computers (for example other development tools such as Microsoft FrontPage, Microsoft Visual Interdev or Netscape Composer wouldn’t guarantee that). On the other hand, this meant that writing and debugging the code was very much more tedious and complex.

A base screen resolution of 800 × 600 was used during the design of the system, which is the most commonly used resolution nowadays, although higher resolutions are supported.

DHTML (Dynamic HTML) was used for the animation of the system, writing the functions in JavaScript language and using different layers. The tool is developed mainly for the Microsoft Internet Explorer browser and the system is compatible from its version 4.0 on.

Active Server Pages (ASP) were used for the database connection with Microsoft Access. Using VisualBasicScript language and SQL sentences through ODBC facilitated the access to every data stored in the database. As explained before, this database is encrypted to prevent someone accessing the data by simply editing the file. It is also protected with a password, to prevent accessing with Microsoft Access. Note that using ASP forces the server to be a Microsoft Internet Information Server.

For the graphical analysis, we needed more functionalities than HTML, or even DHTML, can give. Therefore an ActiveX component was designed and developed with Borland Delphi in order to embed it into the web page and use it to show graphical data, so that unlimited different lines could be displayed at the same time.

3. Status report

Since July 2000, the self-monitoring system has been installed in several trial sites of the SEA-HORSE II project to carry out a feasibility pilot study. Three AIDS organisations participated in the system evaluation: Lambeth, Southwark and Lewisham Health Authority, Immune Development Trust and Apoyo Positivo.

Lambeth, Southwark and Lewisham Health Authority is one of London’s largest Health Authorities, with responsibility for the healthcare needs of a significant proportion of the UK capital’s population. The authority provides healthcare for the second largest concentration of people living with HIV/AIDS in the UK. To this end, it is actively pursuing policies and experiments aimed at developing home-based telecare for people living with HIV/AIDS. Ten ‘home alone’ HIV patients, with donated computers connected to the internet, and two health professionals (physician and nurse) have evaluated the system.

Immune Development Trust is a London-based Non Governmental Organisation (NGO) for HIV/AIDS, attending 200 patients with HIV/AIDS, specialising in complementary therapies (13 complementary therapists in 13 hospital sites). Ten HIV patients using the system from a PC with internet connection in the NGO, and two complementary health advisers made the evaluation.

Apoyo Positivo is a Madrid-based NGO, providing support and information services for HIV/AIDS, with a particular targeting strategy towards families affected by HIV, and intravenous drug users. More than 300 patients and their families are attended by this organisation that participated in the evaluation of the system. Ten HIV patients used the system from a PC with internet connection in the NGO and three health professionals (physician, psychologist and social worker) made the evaluation.

The evaluation was carried out by subjective methods based on two questionnaires: a pre-test and a post-test, completed by thirty seven users. Questions achieved aspects like personal data, knowledge of HIV/AIDS issues, health status, usage of the system and rating of its services. Furthermore, we also used a direct observation evaluation method for the users and focus groups for patients and professionals separately [22].
This preliminary evaluation has provided some encouraging results. Users felt that the tool was valuable and that it could provide a useful guide to managing unpredictable and rapidly changing circumstances. It was also agreed that it was easy to use and the graphics could be easily understood. The feedback provided by the system, even with limited inputs, shows a clear picture of the effects of different interventions. Service users also felt that they were in greater control of their situation and could recognise which interventions had assisted in promoting or maintaining their health.

4. Discussion

There are many issues to be taken into account in the development of a web-based self-monitoring system for people living with HIV/AIDS.

First of all, being a web-based system involves universal access to it. This has pros and cons as the wider access implies lower security and, as we are dealing with clinical data, which are very sensitive, the security issue was one of the most important in the development of the system. First solution was not to include the name, address, telephone number or even e-mail address in the system. This solves the problem of anonymity and the security was then taken to the already solved field of mere access to pages without permission.

Using the internet as the framework of the development is also time and money consuming. As the amount of data grows, the size of the files to transfer gets bigger, and although we tried to reduce size as much as possible, it can be reduced even more by developing the web pages directly this size. The amount of time the user had to be online to fill in the data was also criticised, but costs have changed nowadays with the flat rates that the Internet Service Providers are offering.

There is another interesting issue about the users group of the system. As this system was created to be implemented within an European project, the cultural and social divergences of the users had to be taken into account. For example, in Spain there is a very different HIV/AIDS patients profile (most of them are intravenous drug users) than the rest of the EU. Furthermore, patients and health professionals want to monitor different parameters depending on the ‘country profile’. For example, in England complementary therapies are used more frequently than in other countries, so users are more interested in this aspect of the system.

Finally, the Spanish profile shows poor computer awareness, so the easy-to-use quality of the system is really crucial in this country. Feedback from users from the evaluation results indicate that the system interface is comprehensive enough and easy-to-use.

The socio-economic profile of the user and the country also influences the implementation, as access to the internet is not as universal as pretended.

4.1. Future work

Although most of the system functionalities have been evaluated with very good results, more functionalities have been suggested, after the evaluation of the system, that could be added and we are working in that direction. The following suggestions are:

- New functionalities: (1) to improve the graphical representation and the expert user interface; (2) to provide automatic advice assessed by data mining tools that classify users with profiles personalising the system. (3) Saving to disk all the data in order to take it to other health professional without internet access. (4) To extract all the anonymous data from the server for statistical analysis purposes and for quality assurance purposes. (5) To add more questions to collect more medical, psychological and social data, getting a complete anonymous clinical record of the patient.
- Introduce new technologies to facilitate the universal access to the system, incorporating existing solutions to transform the system into a multi-access architecture system [23] (Computer-Telephony Integration, WebTV, WAP/UMTS, …).
4.2. Clinical benefits

The system is envisaged to offer many benefits, depending on the user, related to the improvement of health and quality of life through the use of the internet.

- For patients, friends and families: to have their own clinical record with the possibility of a second opinion from different experts, optimising the time and money spent on the care service. The internet also removes discriminating factors in the access to services such as distance, getting better advice from several sources anywhere, getting the right knowledge at the right time.

- For health care providers: to enrich their knowledge on the HIV/AIDS disease and on the patients management process through the access to the information they collected. They can also disseminate good clinical practice that enables the availability of guidelines and of second opinion consultation services. This can improve co-operation between different organisations (hospitals, community health managers and NGOs) working on HIV/AIDS.

5. Conclusion

This paper has addressed the development, implementation and evaluation of a new web-based self-monitoring system for people living with HIV/AIDS.

There are many difficulties in the follow-up of HIV/AIDS patients and one of the aims of this system is to facilitate this monitoring through the use of the internet technologies. The developed system has been adapted to the user requirements and provides both patients and professionals with an easy-to-use tool to measure the impact of their health strategies and a complementary communication to enable a second opinion.

The SEAHORSE European project has been a perfect framework for this development because it gave us the opportunity of getting requirements from a larger number of users and making the evaluation in three different scenarios.

As exposed earlier, the evaluation results are encouraging. New functionalities, parameters and technologies will be addressed in the near future to improve the system and a further evaluation is already scheduled to cope with the final goal to provide a better support for patients and health professionals on the new approaches to manage HIV/AIDS as a chronic illness.

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