Virtual Environments to Support People Living with HIV

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Abstract: South Africa's health sector resources are stretched trying to cope with one of the world's highest HIV prevalence rates. Novel Information Technology solutions can assist with the provision of information and social support. We have developed three prototype applications using an adapted user centred design method to provide emotional and informational support to people living with HIV. Our prototype virtual environments (VEs) provided narratives of responses to HIV diagnoses, factual information related to the virus within the human blood stream, and nutritional information. The prototypes were tested in Cape Town, South Africa in three separate studies. Despite the subjects' low computer literacy, the systems were found to be usable and empowering. A particular advantage of the VEs was the anonymity provided to the users, since many infected individuals are afraid of disclosing their HIV status, and so do not receive conventional support. In general, it seems that the system will be a useful adjunct to peer support groups.

Keywords: Virtual Reality, Social Support, Emotional Support, Informational Support, South Africa, HIV, Aids.

1. Introduction

The HIV/Aids pandemic is an issue on the minds of many policy makers in developing countries due to the significant negative effects on economic and social development that are associated with high prevalence rates. A macroeconomic model of Aids effects in Tanzania suggests that by 2010, the GDP may be reduced by as much as 25% [5].

The Collaborative Visual Computing Laboratory has been investigating the use of Virtual Environments (VEs) to support people living with HIV and Aids since 2001 [3][4]. This paper gives an overview of the experiences gained from this research from the point of view of using Information Technology (IT) to support Socio-Economic Development. The work has covered the responses of people living with HIV to illness narratives in VEs, educational issues relating to the reaction of the virus in the human bloodstream and lastly, nutritional support to HIV positive (HIV+) women. Both emotional and informational support was provided in the first two prototypes. The third and final prototype is a synthesis of the previous two; and includes additional content and social support. The prototype systems were all deployed on a desktop PC, and input to the system was through minimal keyboard and mouse usage.

It has been argued before that the power of IT in the developing world derives from its ability to make scarce knowledge resources decentralized and thus widely available [1][2].

If a low cost Virtual Reality (VR) support system were effective, it could greatly increase the number of HIV/Aids patients receiving support. Due to a number of socio-economic factors, computer literacy in many South African communities is low. We are interested in investigating whether VR is an effective information dissemination technology for individuals with minimal (if any) prior computing experience.

One of the perceptions concerning VR is that it is an expensive technology. Our research has specifically targeted low-immersion, low-cost platforms and investigated ways to reduce the costs of authoring VEs. We are now able to offer solutions ranging from desktop VR to stereo projection-based displays using cheap polarizing glasses, plexiglass screens and low-cost projectors. The wide availability of consumer grade 5.1 and 7.1 surround sound systems (often natively supported on motherboards) means that spatialized audio is now standard on most computer systems; the same is true for dedicated three-dimensional graphics hardware. We have developed both a methodology and software support tools to assist authors in creating Collaborative Virtual Environments (CVEs). CVE authoring costs are driven by the conflicting demands placed on VR authors. They have had to be artistically creative and have good computer programming skills, a rare combination for which there is far more demand than supply. The only alternative is to have a team that incorporates the diverse skills required for authoring these environments. Such teams are used to create computer games but are too costly for typical VR applications, particularly in the developing world - commercially produced games have budgets of millions of dollars.

2. Method

Our approach has always been to build systems and then to reflect on the experience of using such a system: this is the normal approach of experimental computer science. The system was designed using User-Centred Design methods [2]. While Blake and Tucker [2] propose a sophisticated software engineering method, this project adopted more of the Human-Computer Interaction (HCI) related aspects of that methodology. The field of HCI has a long history of user involvement, or user-centred design. The other design methodology that is appropriate for VR comes from game development and the animation industry.

Many classical HCI and Animation heuristics and techniques can be tailored for use in developing world situations. We have employed techniques such as paper prototyping and storyboarding. These were developed further for use in Virtual Reality, see Section 7.3 for more on testing and design.

We adopted the view that VEs could provide social support to HIV+ people. We developed our research over three studies, which are presented in this paper. The first was a study of the subjective response of people living with HIV to illness narratives in VR (Section 3), this was followed by an investigation of the usefulness of a VE that demonstrated the reaction of the HI-virus in the human blood stream (Section 4). These can be regarded as large-scale iterations that gradually homed in on the user requirements.

The final study (Section 5) was intended to include the previous contributions and be expandable to cater for further enhancements. To do this we modelled a VE with a house where different rooms could be used for different support experiences. Thus the narratives of Study 1 were presented in the lounge, the action of HIV, from the second study, on the (interactive) television in the bedroom, and the other rooms allowed other forms of support and counselling. The third study included an extensive knowledge of nutrition and hygiene, presented in the kitchen. Other possible extensions to this environment would be the provision of educational content on sex issues (presented in the bedroom), issues relating to mother-to-child transmission (MTCT) in a baby room and information relating to antiretroviral therapy in the bathroom (depends on obtaining further project funding). Our

system provided both social support (as in the campfire/lounge) and informational support (reaction of the virus in the bloodstream as well as hygiene and nutrition in the kitchen).

3. Prototype 1: Virtual Support Group (Emotional Support)

Social support has been shown to improve quality of life of HIV/Aids patients, and HIV/Aids counseling and support groups have been used as a means of providing social support to patients. South Africa faces a shortage of counseling resources. Our system was partly motivated by systems used to provide support for breast cancer patients [3].

We developed a low cost, deployable desktop PC based system using custom software. The system implements a VR walkthrough experience of a tranquil campfire in a forest (Figure 1). The scene contains four interactive avatars who relate narratives compiled from counseling sessions with HIV/Aids patients. These narratives cover three aspects of HIV infection: receiving an HIV+ diagnosis, intervention, and living with an HIV+ status.

Figure 1: Forest scene depicting the campfire in the VE. Each member of the group tells a different HIV related story.

To evaluate the system, seven semi-computer literate HIV+ volunteers from townships around Cape Town used the system under the supervision of a clinical psychologist who specializes in HIV counseling. The participants had been diagnosed HIV positive in the six months prior to using the VE. The participants were interviewed immediately after experiencing the VE by the clinical psychologist about their experiences through unstructured interviews. These were followed by a discourse analysis of the data.

In terms of emotional impact, the participants found their experience with the system mostly encouraging, particularly the narratives relating to adjustment and coping. They found it encouraging hearing from other HIV+ individuals rather than from other sources. Generally, participants felt that the VE reinforced the benefits provided by support groups.

The system highlighted the potential benefits of joining a support group, and motivated some participants to make more use of support groups. Participants found using the system an uplifting experience, reinforcing their strength in coping with HIV. As compared to other forms of therapeutic interventions, participants reported that they received a similar cathartic experience. The system was considered ideal for patients who, because of their fear of disclosing their HIV status, were not joining support groups and therefore not receiving any social support. The participants generally preferred real support groups over the VR system, but felt that the system could augment counseling tools, and that it could be

of benefit in places where counseling resources were not available, or in cases where joining a support group was difficult.

The participants liked the availability of the computer system, and found it preferable to TV or pamphlets as a source of information, due to its interactivity and the control it affords over content delivery. The system was also preferred due to the anonymity it provides to those not willing to reveal their HIV status.

Our study highlights the usefulness of low-cost VR systems in the counseling of HIV/Aids patients in developing countries. Such systems cannot replace counseling, but can play a role in steering people towards seeking counseling, as well as providing limited support in cases where counseling resources are not available. Our findings, although preliminary, encouraged the further development of our system by extending the degree of informational and emotional support it provides.

4. Prototype 2: Simulation of the HI-Virus (Informational Support)

This study visualized the human circulatory system by modelling a blood vessel and the action of the HI-virus in the bloodstream. The progression of the virus can be divided into three distinct stages: 1) Infection; 2) Virus Progression; 3) Advanced Virus Progression - referred to as "Full Blown Aids". In this project, stages 1 and 2 were modelled and interactively showed the effects of the virus on an infected person's immune system. Recommendations of good behaviours and activities (such as exercise and eating well) were given within the environment, and the effects of these were interactively experienced by the user. Additionally, behaviours or stimuli which were harmful and would further worsen the effects of the HI-virus (such as alcohol consumption) were also demonstrated to the users.

The system was tested by nine volunteer HIV counsellors who had little prior computer experience. An orientation session, using Microsoft Powerpoint presentation slides, introduced the user to concepts of the virus and blood before entering the VE. The entire VR experience was broken into four phases. These were:

- An initial training session where only one of each type of cell was shown and the user practices movement and interaction in the VE.
- A transition period between the training session and simulation where example cells float out one end of the blood vessel and actual cells float in from the other end.
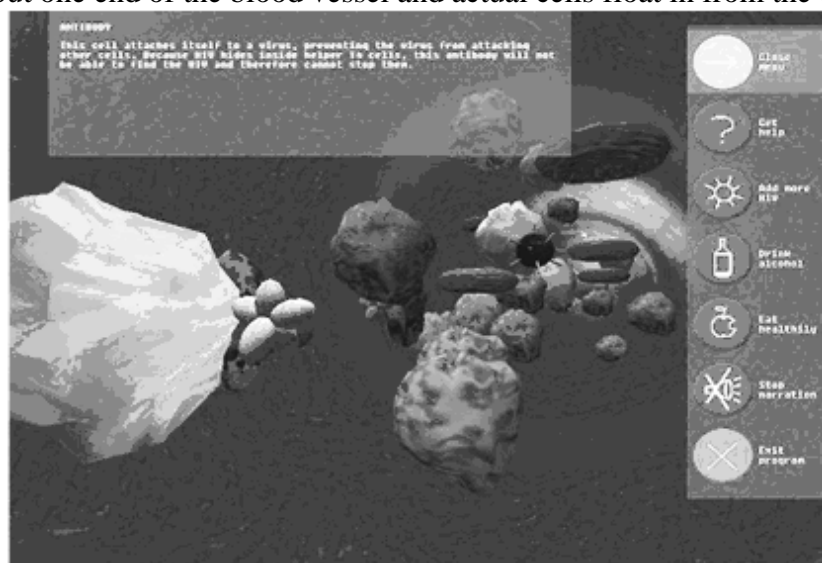

Figure 2: Screenshot of the blood vessel VE. To the right one can see a slide-out menu that appears whenever the user clicks on that cell. The top text shows the text spoken by the narrator.

- A narrative period once the simulation starts.

- A period of exploration in the environment where the user is able both to learn more about the actions of the virus during the early stages of its progression in the blood, to view the responses of the cells in the immune system and to witness the effects of certain stimuli (see Figure 2 above).

A clinical psychologist conducted interviews with each participant on completion of the VR experience. About half the users were scared by witnessing the effects of the virus in the simulation. All participants felt the information they gained was useful and interesting. Several raised more questions about the virus, showing that more information could be built into the simulation. The participants gave mixed impressions about the ease of use of the VE, probably due to their general lack of computing experience prior to their use of the VE. On the experience of being inside the virtual blood vessel, users generally felt that they were really inside the body and felt that the simulation of fluid motion was effective.

5. Prototype 3: HIV House (Social and Informational Support) to HIV+ Pregnant Women

An HIV diagnosis often implies changes in most aspects of a person's life. For the third prototype, we wanted to create an environment that included information on many aspects of everyday life, and chose to focus on nutritional information initially. Improving the nutritional status of an infected individual can have a significant impact on HIV prognosis (see for example [9][12][13]).

For this trial, the experimental subjects were pregnant women. The specific target group was chosen for several reasons. Firstly, HIV status, due to social stigma, is usually kept secret, making it difficult to find volunteers. Many HIV+ pregnant women, however, attend support groups, and are thus an accessible population of HIV+ participants. Secondly, young pregnant women are highly over-represented in HIV+ populations (at the end of 2005 in the Western Cape province, South Africa, HIV prevalence was estimated to be 15.7% amongst pregnant women attending public sector clinics, and 30.2% in South Africa overall [6]), making the development of support tools for this group an important goal.

The aim of this VE was to incorporate experiences gained in previous prototypes, while incorporating new material; we therefore chose an expandable design. We also wanted an environment users would find familiar (Figure 3). We designed a council house in which each of the rooms could be made to serve a different function and contain information and interactions corresponding to the activities that are associated with that room.

Figure 3: A typical council house (left) and the VE model derived from it (right). The figure in the doorway in the VE is Andile who greets the user.

The house contained four rooms in which information is contextually presented. The rooms contain virtual actors and points of interaction. In the current version the lounge and the kitchen have been fully implemented. The speech of the agents in the VE was recorded by local voice actors to reflect a cross-section of local accents. Appropriate ambient sounds were used throughout.

The user starts her VR experience outside the house and is greeted by an agent named Andile who encourages the user to follow him, giving a basic description of the four rooms, and how to interact with each. In the lounge the user meets two other agents in a casual support group (Figure 4 below). The user can listen to their discussions about their HIV experiences; this is a derivative of the VE developed in the first prototype (see section 3).

If the user enters the kitchen, she is greeted by an agent called Sandi. Sandi presents interactive areas where the user can explore the concepts of food groups, cleanliness and hygiene (Figure 4 below). Information presented in the kitchen was compiled primarily from *Positive Health*, a booklet distributed to HIV patients in South Africa [6]. Documents from the South African Department of Health [10] and United Nations Food and Agriculture Organization (FAO) [7] were also used.

Figure 4: The Casual Support Group in the Lounge (left). Sandi (right) introduces food groups. Both scenes are interactive.

6. Technology Description

All the prototypes the VE used a consumer-grade desktop PC, with stereo headphones for audio display. We anticipated that our participants' prior experience with computers would be limited (if any at all) and thus decided to use minimal input - only the mouse to change the viewing direction, and a single key for walking forwards. The update rates varied with scene complexity, ranging from 12Hz to 40Hz. The studies and evaluations were all run in dedicated rooms. Additionally, a trained HIV counsellor was on-site and available to the participants for the entire duration of each study. During each participants' VR experience, a researcher was available to deal with queries and technical issues.

7. Results

We have previously presented the analysis of the system from the point of view of ease of use and quality and accessibility of the information [3]. Here we wish to emphasize two other aspects: the value of VR in dealing with the stigma associated with HIV and Aids, and the sense of empowerment (rather than intimidation), which the users felt when they used the system. We present qualitative impressions gleaned from the semi-structured interviews conducted directly after experiencing the VEs.

7.1 - The Fear of Stigmatization Associated with HIV

One of the major benefits associated with a VE is that users can meet (virtual) people who are open about their HIV status. The importance of this was illustrated by the difficulty we faced in getting actors to be photographed as models for the virtual characters. We found that many individuals were not comfortable being represented as an HIV+ person, in the VE. Thus, the agent Sandi was based on artistic conceptions, rather than photographs of real people (such as the three characters in the lounge).

It was suggested by a participant in the first study (who was also an HIV counsellor) that a VE was an ideal support tool for patients who were afraid of disclosing their HIV status and were thus prevented from receiving the support that they need. She reflected on the unique value of the VR experience:

> *"It's a good idea for my client who hadn't accepted it."*

One participant in the first study remarked that the environment would serve as an ideal tool for the home especially for decision support, thus alleviating the problem of actively seeking support structures.

> *"...speaking about the diagnosis, and after diagnosis, and you just listen to that nice, lonely voice there, (with then all that going on in your head). Then you can take your choice while you're sitting there."*

Although the participants drew parallels between the VE and a real support group and highlighted some of the unique benefits of the VEs, the general feeling was that they preferred a real tangible support group to a virtual one.

7.2 - Empowerment

The majority of the participants had never used a computer before. They met this challenge with varying degrees of excitement and trepidation. The very medium had a psychological impact that we had not anticipated: the users generally felt strengthened and empowered. One of the participants in the first study commented:

> *"...they [other HIV positive individuals] can also learn things from the computer, learning you can do more things even if you are HIV positive....I think that the computer is also there for people to know that "I'm still living, I can do what the other people who haven't got HIV do, I can do it, like this computer thing."*

In her reflection this participant reveals a sense of the virus having limited her dreams and ambitions. She expresses the value of exposure to the computer interface as an affirmation or reminder of being alive and entitled to a future, like those who are HIV negative.

In the third study we had comments such as:

> *"For me I like a computer. I like a computer – I don't want to lie. For me. Because in the computer ah, I do all these, ah, I drive this cat by myself, you see? Like, it's a, some sort of, a training because I've never used a computer – so, so interesting that um, I'm trying to get all this, all you talking about. So, have to use my mind and focus on what I'm doing while on a TV I'm just going to sit down and watch. Sometimes I focus 'What did he say?' You see?"*

> *"Yoooh it was very …. First it was a great opportunity because it's my first time (using a computer) and it is interesting. I wish I can do more, so that I can learn more … so interesting."*

In general the users were clear that they favour real support groups over virtual ones, but were very positive about the ancillary role of the VR system.

Of course, it was the intent of the VE to help the participants with practical aspects of being HIV positive, and that also happened. When asked about the effect the VE had on them, the participants in the first study had the following to say:

> *"The computer thing encouraged me.....I must be more comfortable with myself.... [the stories being told] made me strong."*

> *"Those people there [the virtual characters], they're not afraid to confirm about it [HIV status] ...they strong enough to work as a team."*

7.3 - Reflections on User Testing and the Impact on Design

The testing of all our systems on real users drawn from deprived communities is to make sure that the VE that has been created provides the intended experience. This is more than usability testing and is more appropriately User Experience Testing (but this is not yet well

developed [15]). We have used an iterative design with continuous user testing since none of the design methods can guarantee to produce an effective virtual environment.

The idea then is to engage users as designers, however as we remarked elsewhere [1] users cannot be expected to understand the potential of the technology easily. They certainly would find it difficult to understand a design document such as that advocated in the games and cinema industry. The notion then is to have a shared artefact to visualize the interactions within the VE. This also serves to give users a realistic idea of what is possible and avoids disappointment. To this end we have ended up with a "Cardboard Lab". It is essentially a whiteboard placed horizontally on a table on which we can sketch a floorplan and place model figures and physical objects that represent the assets of the final VE. The horizontal whiteboard as floorplan allows sketching of interactions. The essential idea was to create fast cheap prototypes of VEs.

8.   Conclusions

A theme not anticipated by the researchers was the psychological impact of the medium itself on the participants. Participants felt privileged at being given the opportunity to use a virtual environment. It instilled in them a sense of power and achievement. The ongoing socio-economic disparity in South Africa has resulted in limited access to technological innovations such as computers and the internet for many. Computers are associated with a chance for a better future.

Although the participants highlighted some of the unique benefits of the VE, the general feeling was that they preferred a real tangible support group to a virtual one. Participants indicated however that the VE could augment counselling tools, especially in those circumstances where resources were not available or where people were afraid of seeking help because of the stigma attached to HIV.

The current system, with its expandable design, allows for the creation of supplementary rooms that can provide additional support to its users. Some preliminary work has already been completed to create an ARV Room, in which users are informed of guidelines and recommendations surrounding antiretroviral treatment. This informational content is particularly important in the current realm of HIV/Aids in South Africa. However, additional funding is required to continue research and further development of this content.

Acknowledgements

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