Information and Social Support for Semi-Literate People Living with HIV

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Our team has been investigating how to use Virtual Environments (VEs) to support people living with HIV and AIDS since 2001 [3][4][5]. South Africa and other developing countries have an enormous shortage of trained professional people, and information and communications technology (ICT) can in some cases distribute scarce knowledge resources to more deprived communities [1][2].

We have been asking ourselves how effective desktop VEs could be in providing emotional and information support to people who are living with HIV. How would communities respond to a support system in an environment where very few people have ever touched a computer and who might have very inadequate schooling? Can they use the systems? Can they gain from the information we are trying to convey? Can they use computers, and how do they feel about using the technology? How will they respond emotionally?

The HIV pandemic is urgent and large in Southern Africa, and it is having a serious impact on people. There is a shortage and maldistribution of health care workers, which is worsening due to the impact of HIV and emigration of health care workers to more developed economies.

Isn't Virtual Reality Too Expensive?

While on the face of it VEs might seem a rather expensive approach, we have made a concerted effort to drive down the costs of producing and deploying such technology. We believe that advanced technology can be cost-effective and that technology, per se, is often not the determining factor in the overall cost of deployment. We have developed both a methodology and software support tools to assist authors in creating VEs.

All the prototypes in these studies used a consumer-grade desktop PC with stereo headphones for audio. We anticipated that our participants' prior experience with computers would be limited (if they had any experience at all) and thus decided to use minimal input—a mouse to change the viewing direction, and a single key for walking forward.

Building Systems and Testing Them

Our approach is to build systems and then to reflect on the experience of using such a system. We developed our research over the course of three studies—covering emotional support through stories of diagnosis, simulation of the action of the virus, and information support about diet and hygiene. People from the impoverished townships around Cape Town, who were mostly HIV-positive themselves, evaluated these environments. A clinical psychologist and trained HIV counsellor was available to the participants for the entire duration of the study.

Virtual Support Group

We first undertook a social support study of the subjective response of people living with HIV to illness narratives in virtual reality; such support has been shown to improve the quality of life of HIV/AIDS patients. The environment gave a walkthrough experience of a tranquil campfire in a forest (Figure 1) with four interactive agents who related narratives compiled from counselling sessions with HIV/AIDS patients. These narratives cover three aspects of HIV infection: receiving an HIV-positive diagnosis, intervention, and coping and living with HIV-positive status.

Seven semi-computer-literate HIV-positive volunteers from townships around Cape Town evaluated the system. The participants had been diagnosed as HIV-positive in the six months prior to using the VE. Immediately after experiencing the VE, a clinical psychologist conducted an unstructured interview with each participant. Following the interviews we performed a discourse analysis of the data.

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

Simulation of the HI-Virus

We followed with an Informational Support study investigation of the usefulness of a VE that showed the action of the HIV virus on an infected person's immune system and the outcomes of user actions such as exercise or drinking alcohol (Figure 2).

The system was tested by ten female HIV/AIDS counsellors of various ages and counselling experience. They worked in various AIDS-relief clinics in and around Cape Town. Almost all the subjects had either very little or no experience using computers and were largely unfamiliar with the action of the virus in the body. Several were HIV-positive themselves.

Social and Informational Support to HIV-Positive Pregnant Women

The final study included the previous contributions and is expandable to permit further enhancements. We modelled a VE with a house that presents contextual information in different rooms. We wanted an environment that users would find familiar (Figure 3), so the design was based on a township house, and local voice actors recorded the voices of the agents in the VE to

VIRUS

The virus attacks helper T4 cells and uses the T4 cells to reproduce itself.

Figure 2: Screenshot of the blood vessel VE. To the right one can see a list of actions. At the top is the text spoken by the narrator.

Figure 3: A more well- to-do township house (below) and the VE model derived from it (above). The skybox shows a typical Cape Town backdrop; in the doorway is Andile, who greets the user.

reflect a cross-section of local accents.

We presented the narratives of Study 1 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. This third study included an extensive knowledge of nutrition and hygiene, presented in the kitchen (Figure 4).

Possible extensions include the provision of educational content on sex issues (the bedroom), issues relating to mother-to-child transmission (MTCT) in a baby room, and information relating to antiretroviral therapy in the bathroom[1].

For this trial, the experimental subjects were pregnant women. We selected this target group because many HIV-positive pregnant women attend support groups and are thus an accessible population and, second, young pregnant women are highly over-represented in HIV-positive populations.

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

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[1] Providing this will depend on obtaining further funding for the project

We have presented the analysis covering ease of use and quality and accessibility of the information [3]. What is left is user-experience analysis. We present qualitative results gleaned from the semi-structured interviews conducted directly after experiencing the VEs emphasizing two aspects: the value of virtual reality in dealing with the stigma associated with HIV and AIDS, and the sense of empowerment (rather than intimidation) that the users felt when they used the system.

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. A participant in the first study (an HIV counsellor) suggested 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."*

Another remarked:

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

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.

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 of being entitled to a future, just 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 [the computer] 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 are talking about. So, I 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 on '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 saw the use of computer technology not as threat but rather as part of an invitation to a new future.

Conclusions

We tested our systems with real users drawn from more deprived communities to make sure that our VE provides the intended experience. We iterated the design with continuous user testing since none of the design methods we used can guarantee an effective virtual environment. The idea then is to engage users as designers. However, as we remarked elsewhere [1], users cannot be expected to easily understand the potential of the technology.

A theme we did not anticipate was the psychological impact of the medium on the participants. Participants felt privileged to be 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. 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 support group to a virtual one. Participants indicated, however, that the VE could augment counselling tools, especially in those circumstances where resources are not available or where people fear seeking help because of the stigma attached to HIV.

References

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Edwin Blake is a Professor in the Department of Computer Science at the University of Cape Town. His current research interests cover subjective experiences of Virtual Reality and the use of Information Technology for Development.