Title:

A Low cost VR group support system for people living with HIV

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Abstract:

Social support has been shown to improve the quality of life of HIV/AIDS patients, and HIV/AIDS counseling and support groups have traditionally been used as a means of providing social support to patients. Given the high HIV infection rate, South Africa faces a shortage of counseling resources. This study investigated the possibility of using virtual reality technology to provide emotional and informational support to HIV/AIDS patients. Our system was partly motivated by other systems which have been successfully used to provide support for breast cancer patients (eg. *Breast Cancer Lighthouse* and *Easing Cancer Park*). If a low cost VR support system were effective, it could greatly increase the number of HIV/AIDS patients receiving support.

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. The scene contains four interactive avatars who relate narratives compiled from HIV/AIDS patients. These narratives cover the aspects of receiving an HIV+ diagnosis, intervention, and coping with living with HIV+ status. To evaluate the system, seven computer semi-literate HIV+ volunteers from townships around Cape Town used the system under the supervision of a clinical psychologist. The participants were interviewed about their experiences with their system, and the data was analyzed qualitatively.

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. 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. The system highlighted the potential benefits of joining a support group, and motivated some participants to make more use of support groups. In general, participants found using the system an uplifting experience, reinforcing their strength in coping with HIV. As compared to other forms of therapeutic intervention, 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 are not receiving support. The participants generally preferred real support groups

rather than 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.

Our study establishes the usefulness of low-cost VR systems in the counseling of HIV/AIDS patients in developing communities. 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, have encouraged the further development of our system by extending the degree of informational and emotional support it provides.

References:

- 1. Brennan, P.F., Ripich, S. & Moore, S.M. (1991). The use of home-based computers to support persons living with AIDS/ARC. *Journal of Community Health Nursing*, 8, pp. 3–14,
- 2. Bystrom, K., Barfield, W. & Hendrix, C. (1999). A conceptual model of the sense of presence in virtual environments. *Presence: Teleoperators and Virtual Environments*, 8, pp. 241–244
- 3. Douaihy, A. & Singh, N.(2001). Factors affecting quality of life in patients with HIV infection. *The AIDS Reader*, 11, pp. 444–449
- 4. Fencott, C. (2001). Virtual storytelling as narrative potential: Towards an ecology of narrative. *Proceedings of the International Conference ICVS 2001*, pp 90-99.
- 5. Frank, A.W. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago/London: The University of Chicago Press
- 6. Friedland, J., Renwick, R. & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care*, 8, pp. 15–31
- 7. Greene, D.D. (1998). Personal stories within virtual environments: Creating three experiences in cancer information software, In G. Riva, B.K. Widerhold & E. Molinari (Eds.), Virtual Environments in Clinical Psychology and Neuroscience: Methods and Techniques in Advanced Patient-Therapist Interaction, Amsterdam, The Netherlands: IOS Press
- 8. Heeter, W. (1992). Being there: The subjective experience of presence. *Presence: Teleoperators and Virtual Environments*, 1, pp. 262–271
- 9. Hodges, L.F., Kooper, R., Meyer, T.C., Rothbaum, B.O., Opdyke, D., de Graaff, J.J, Williford J.S. & North, M.M. (1995). Virtual environments for treating the fear of heights. *IEEE Computer*, 28, pp. 27–33
- 10. Glaser, B.G. (1992). *Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press
- 11. Glaser, B.G. (1994). *More Grounded Theory Methodology: A Reader*. Mill Valley, CA: Sociology Press
- 12. Greenhalgh, T & Hurwitz, B. (1999). Narrative based medicine why study narrative? *British Medical Journal*, 318, pp. 48–50

- 13. Guerin, N., Labaye, B. & Dohogne, S. (2001). *Doctoon* c A mediator in the hospital of the XXIst century, Proceedings of the International Conference ICVS 2001, pp. 171-180
- 14. Jacobson, D.E. (1986). Types and timing of social support. *Journal of Health and Social Behaviour*, 27, pp. 250–264
- 15. Lombard, M. & Ditton, T. (1997). At the heart of it all: The concept of presence. *Journal of Computer Mediated Computer Communications*, 3
- 16. Molassiotis, A., Callaghan, P., Twinn, S.F., Lam, S.W., Chung, W.Y. & Li, C.K. (2002). A pilot study of the effects of cognitive-behavioural group therapy and peer support/counseling in decreasing psychologic distress and improving quality of life in Chinese patients with symptomatic HIV disease. AIDS Patient Care and STDs, 16, pp. 83–96
- 17. Polkinghorne, D. (1988). *Narrative Knowing and the Human Sciences*. Albany, NY: State University of NY Press
- 18. Ribble, D. (1989). Psychosocial support groups for people with HIV infection and AIDS. *Holistic Nursing Practice*, 3, pp. 52–62
- 19. Rosenblum, L. & Macedonia, M. (1999). Public speaking in virtual reality: Facing an audience of avatars. *IEEE Computer Graphics and Applications*, 19, pp. 6–9
- 20. Rothbaum, B.O., Hodges, L., Alarcon, R., Ready, D., Shahar, F., Graap, K., Pair, J., Hebert, P., Gotz, D., Wills, B. & Beltzell, D. (1999). Virtual reality exposure therapy for PTSD Vietnam veterans: A case study. *Journal of Traunatic Stress*, 12, pp. 263–271
- 21. Shaw, B.R., McTavish, F., Hawkins, R., Gustafson, D.H. & Pingree, S. (2000). Experiences of women with breast cancer: Exchanging social support over the CHESS network. *Journal of Health Communication*, 5, pp. 135–159
- 22. Sikkema, K.J. & Bisset, R.T. (1997). Concepts, goals and techniques of counseling, review and implications for HIV counseling and testing. *AIDS Education Preview* (*Suppl B*), 9, pp. 14–26
- 23. Umaschi, M. & Cassell, J. (1997). Storytelling systems: Constructing the innerface of the interface. *Proceedings of IEEE Cognitive Technologies* 97, pp. 98–107
- 24. Vaux, A. (1990). An ecological approach to understanding and facilitating social support: Special issue: Predicting, activating and facilitating social support. *Journal of Social and Personal Relationships*, 7, pp. 507–518
- 25. Wiederhold, B.K., Davis, R., & Wiederhold, M.D. (1998). The effect of immersiveness on physiology. In G. Riva, B.K. Widerhold & E. Molinari (Eds.), Virtual Environments in Clinical Psychology and Neuroscience: Methods and Techniques in Advanced Patient-Therapist Interaction, Amsterdam, The Netherland: IOS Press