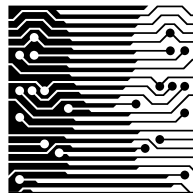


THE SUBJECTIVE RESPONSE OF PEOPLE LIVING WITH HIV TO
ILLNESS NARRATIVES IN VR

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Abstract

This dissertation reports on the results on an exploratory investigation into the *potential efficacy* of VR as both a support mechanism to people living with HIV/AIDS, as well its capabilities as an emotive medium. Two hypothesis were presented viz. (1) VR will be a form of social support and (2) VR will have an emotional impact on participants.

The research builds up on findings which demonstrate the therapeutic effectiveness of telling personal and collective narratives in an HIV/AIDS support group. This fact, together with the tested ability of VR as a therapeutic medium, let to the development of a virtual support group with an aim to test its therapeutic efficacy.

A low cost, deployable desktop PC based system using custom software was developed. The system implemented a VR walkthrough experience of a tranquil campfire in a forest. The scene contained four interactive avatars who related narratives compiled from HIV/AIDS patients. These narratives covered 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 using grounded theory.

The group experiment showed extensive qualitative support for the *potential efficacy* of the VR system as both a support mechanism and an emotive medium. The comments received by the participants suggested that the VR medium would be effective as a source of social support, and could augment real counselling sessions, rather than replace them.

The categories which emerged from the analysis of the interview data were emotional impact, emotional support, informational support, technology considerations, comparison with other forms of support, timing considerations and emotional presence. The categories can be grouped according to the research questions viz.

- The efficacy of VR as an emotive medium (Presence, Emotional Impact, Computer Considerations)

- The efficacy of the VR simulation as a source of social support (Emotional and Informational Support)

Other themes not anticipated by the data included the following: Timing considerations and Comparison with other forms of counselling.

The interviews suggested that both hypothesis 1 and 2 are correct viz that the VR system provided a source of social support, and has an emotional impact on the participants.

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Chapter 1

Introduction

1.1 History and background

With the escalation of the HIV pandemic and the current constraints on support services within communities, there is a growing need for innovative approaches to HIV counselling. With limited human resources available, alternative approaches to HIV counselling need to be considered.

A key to understanding the potential of Virtual Reality (VR) technology is the idea of presence [69]. Presence is most commonly defined in the literature as the user's subjective feeling of being in a virtual environment (VE) [79] [74] [106]. Some researchers postulate that factors which seem to increase presence enhance learning and task performance in a VE [58]. Although this relationship need not be a positive one, there seems to be a tendency that the greater the levels of presence, the more the user will react to a situation in a manner which is similar to real life.

In order to develop appropriate intervention strategies the role of counselling needs to be clarified. HIV counselling is generally seen as providing the client with information, guidance and advice regarding their HIV status, while also providing much needed psychosocial support. Research has shown that the availability of social support directly impacts on the quality of life (QOL) of people living with HIV/AIDS [56].

HIV/AIDS support groups have been one way of achieving similar objectives. From a psychosocial point of view, it has been shown that the telling of personal and collective narratives in an HIV/AIDS support group is greatly beneficial. It provides information and support through shared insights, intense connection and comfort [89], commonly resulting in improved psychological well-being [37]. Through the sharing of experiences and the telling of personal narratives, these provide the educational as well as the emotional support so much needed.

1.2 Purpose

An innovative approach to counselling could include the use of VR. Its efficacy has previously been shown in psychological therapy, specifically in the area of exposure behavioural therapy [104] [14] [65] [93]. The purpose of this study is to examine the efficacy of the VR medium as support mechanism to people living with HIV. It also wishes to investigate the efficacy of VR as an emotive medium by examining factors such as presence and the emotional impact of the narratives on the participants.

Our hypotheses are therefore the following:

1. VR provides a source of social support to people living with HIV/AIDS.
2. VR has an emotional impact on people living with HIV/AIDS.

Support (or social support as it is known in the literature) can be divided into three categories [86]:

1. instrumental/practical such as counting on others for favours eg borrowing money or helping in a crisis.
2. informational such receiving advice or information regarding a variety of issues.
3. emotional (receiving emotional comfort).

This project focuses more on informational and emotional support.

1.3 Importance of social support

There is growing research in the importance of support, often referred to as social support, to people living with HIV/AIDS. This is largely due to the fact that social support is one of the variables impacting on quality of life (QOL) of people living with HIV. QOL has a direct impact on disease progression, and therefore survival time

Several studies show that social support is more readily associated with psychological well-being [37].

The availability and nature of social support reflect prevalent societal attitudes towards and perception of HIV/AIDS. These attitudes include social prejudice and stigmatization [77]. For this reason, individuals find it difficult to obtain certain forms of support and remain secluded from society or opt for non-disclosure. A VR system providing social support could be beneficial to HIV users in that it could:

- Allow people to remain anonymous. This is important since people who opt for non-disclosure are not gaining the support needed [77].
- Allow the user to access the support system at exactly the time they need it. Accessibility to support systems (like support groups) is a problem facing many HIV individuals, especially in rural areas [53].
- Enable them to listen to other people's stories and examine these at their own pace, either at home, within a work environment (e.g. employee assistance programmes) or at a community health care venue.
- Provide a cost-effective approach which could augment existing support structures in communities.

1.4 Methodology

The virtual environment we created consists of four people telling illness narratives, set in a forest around a fire. The narratives being used are fictitious, but draw on personal experiences of South African HIV positive individuals. Each narrative draws on research-based knowledge about factors impacting on QOL. The narratives have been constructed in such a way that they reflect the initial shock and adjustment associated with learning about one's HIV diagnosis, followed by an intervention and consequent process of psychological adjustment. The narratives illustrate typical dysfunctional responses, followed by an informational or educational intervention (carefully woven into the story) and subsequent positive adjustment and improved QOL. The users of the system are people living with HIV who have been diagnosed in the six months prior to being exposed to the VE. The research is addressed qualitatively through unstructured interviews followed by a discourse analysis using grounded theory of the data. The interviews have been conducted by a clinical psychologist.

1.5 Outline

- *Background* — In chapter 2, we discuss the areas of theoretical and practical work relevant to the area of research. This includes concepts related to area of study. We begin by discussing narratives and its relevance to illness and HIV/AIDS in particular. A brief pathology of the HIV/AIDS virus is then discussed. We then present a detailed overview on social support and its importance to HIV. An overview of VR is presented, with particular reference to the area

of presence. The remainder of the chapter is devoted to an overview of previous computer systems for people living with HIV/AIDS.

- *Virtual Environment Design* — Chapter 3 outlines the approach that was taken when designing the VE. We show how the design of the VE was facilitated by the use of storyboards. We then discuss the implementation and features of the VR system viz. tools used, as well as the static and dynamic environment.
- *Experimental Design* — Chapter 4 looks at the methodologies uses for qualitative analysis, viz. grounded theory. It also looks at the material, as well as the procedures followed when conducting the experiments.
- *Results* — In chapter 5 we discuss the results obtained after the data had been analysed.
- *Conclusion* — Chapter 6 draws on the most important facts obtained from this study as well as providing recommendations for future practice.

Chapter 2

Background and Theory

In this chapter I discuss the background work which is relevant to our research, and in so doing I hope to provide a review of VR, storytelling and the importance of social support to people living with HIV/AIDS. Section 2.1 provides an overview of VR with particular reference to presence. Researchers postulate that what sets VR apart from other media is the sense of presence conveyed. It is therefore an important part of VR. I start with a definition of presence followed by the importance of the construct to VR. I then discuss the different presence measures available. I end the section by describing the factors contributing to presence. Section 2.2 provides a description of narratives/stories, the benefits they provide to people, and their importance to ill people's lives. This is followed by a description of VR storytelling applications that have been developed as a support structure for ill people. Section 2.4 provides a brief overview of the pathology of the HIV/AIDS virus. Section 2.5 describes the notion of social support. I begin with a definition of social support, followed by a discussion of the types and sources as well as how the construct is measured. I end the section by describing the effects that social support has on HIV/AIDS. Section 2.6 goes on to discuss computer systems which have been used as support mechanisms. Finally, section 2.7 provides a summary of the main points found in this chapter.

2.1 Virtual Reality (VR)

VR enables users to interact with a computer-simulated environment, known as a Virtual Environment (VE). This interaction allows users to participate or respond to events happening in the environment. The intention is that users respond in a similar manner as they would have if those events occurring in the virtual environment were happening in reality. It therefore becomes important that the user feels that they are part of the VE, that is, that they are 'really there' as opposed to interacting with a computer simulation.

Researchers postulate that what sets VR apart from other technologies is the ‘feeling there’ experience that it provides. This experience is typically measured in terms of presence [105] as defined in section 2.1.1 and 2.1.2.

2.1.1 Immersion

The term immersion is often characterised in the literature as having two different definitions. The first one is more psychological, as is defined by Witmer and Singer who state that immersion is “a psychological state characterised by perceiving oneself to be enveloped by, included in, and interacting with an environment that provides a continuous stream of stimuli and experiences” [19].

The second definition of immersion, as defined by Slater *et al.* [72] is couched in terms of the display quality being used, specifically the degree to which the display can provide an “extensive, surrounding, inclusive, vivid and matching” experience to the user. *Extensive* displays accommodate a wider range of the sensory organs. A more *surrounding* display provides a panoramic experience, feeding information to the sensory organs from all directions, rather than limiting it to a narrow field. A display is *inclusive* the more unaware the participant is of his physical surroundings. *Vividness* is concerned with the “richness, information content, resolution and quality of the displays” [72]. Finally, there should be a match between the bodily movement of the user, and the information on the display. For example, a turn in the head, should result in a change of field of view on the display. Immersion also requires that there be a virtual body representing the user i.e. an avatar. The avatar should represent the person who is doing the perceiving. Slater *et al.* [72] state that immersion describes the qualities that any particular system provides to a user.

In accordance with Slater’s definition, VR systems are typically defined in terms of their immersive qualities. They can be non-immersive, semi-immersive or fully immersive. Semi-immersive systems are systems which do not fully incorporate all of the senses. Examples of semi-immersive systems include fishtank VR, where the VR system is viewed using stereoscopic glasses. Fully immersive systems include CAVES¹ systems as well as head-mounted displays. My project is a desktop VR system, and can therefore be classified as a non-immersive system.

2.1.2 Presence

Researchers, such as Marsh *et al.* [105] believe that a better understanding of presence is the key to understanding and defining VR.

Although there are many definitions of presence, the general consensus between researchers seems to be that presence in VE’s is a sense of ‘being there’, i.e., the user feels that he/she is

¹A Cave Automatic Virtual Environment (CAVE) is a room on which a VE is projected onto all six walls.

physically in the world represented by the VE rather than just seeing the images depicting the world [70, 19, 82, 51, 107, 71].

Creating a “suspension of disbelief that people are in a world represented by the VE rather than where their real bodies are located” [68] has become an important focus of VR theory with the objective of enhancing the sense of presence in the VE. Further details can be found in the subsection entitled “Importance of Presence” below.

Definition and theory of presence

Many theorists have posed related yet contrasting views as to what constitutes presence. For this reason, there is no single universal definition of presence. A literature review conducted by Lombard and Ditton [66, 79] found six different ways in which presence is conceptualised:

- *Presence as social richness.* This is the mood experienced by the user in a medium. This could be “sociable, warm, sensitive, personal or intimate”.
- *Presence as realism.* This is the degree to which a medium can represent objects, events and people realistically.
- *Presence as transportation.* This is the sensation that ‘you are in the VE’, ‘it is here’ and ‘we are together’. The last item is also referred to in the literature as co-presence.
- *Presence as immersion.* This is how readily the senses are immersed in the virtual environment. This refers to the psychological definition of immersion, rather than the technological one (cf section 2.1.1).
- *Presence as social actor within medium.* This can be viewed as the extent to which the nature of the world and surroundings are viewed as a social entity. A typical reaction would be talking to people on the television screen - viewing them as a social entity rather than merely a visual one.
- *Presence as medium as social actor.* This is the response of users to cues provided by the medium. For example, studies showed that because computers use natural language, use real time interaction and assume social identities (like a teacher), people tend to respond to them as social entities [66].

My conceptualisation of presence is more in line with the first three definitions. For the VR environment to be used in a therapeutic manner, it should convey a mood which is warm, sensitive and intimate. The objects represented were created as realistically as was possible, so as to convey the sense of ‘being there’.

Presence itself is often divided into different categories. Heeter [42, 79] divides presence into three categories:

- *Personal presence* — the extent to which the user feels he/she is part of the world depicted by the medium.
- *Social presence* — the extent to which the user feels other people in the VE are part of the VE.
- *Environmental presence* — the extent to which the user feels the world depicted by the VE is real.

The category of presence used in this thesis is that of personal presence as this dissertation wishes to examine the therapeutic nature of the VE and the user's own personal response to the environment. Research into presence continues. However, still no universal definition exists. For the purpose of this dissertation, presence refers to the feeling of 'being there' [107] [51] [19] [82].

Importance of presence

With so much focus on presence, it has become common to question its usefulness in VR research [79]. Firstly, it is an important design goal of a VE, as the distinguishing factor between VR and other media is constituted by the level of presence experienced [51]. Measuring the sense of presence experienced by a user has become a method of determining the quality or effectiveness of a VE [67].

Slater and Wilbur indicate that research into the factors which contribute to presence, can act as a guide for the future of VE technology [69].

Witmer and Singer [19] mention that there are overlaps between factors influencing presence, and factors enhancing learning and performance. Some theorists postulate that there is a relationship between presence and task performance [58]. This relationship is not necessarily indicative of a direct one, but rather, the greater the sense of presence, the greater the possibility that participants will react to the VE in a similar manner had they experienced the situation in real life. This relates to my second hypothesis, which states that presence enhances the efficacy of a VR support system. The greater the sense of presence felt, the more the participant will react to the VR system as he/she would to a real support system.

Presence measures

The abstract nature of presence makes it a difficult construct to measure. There are two types of measures being used: objective and subjective measures. Subjective measures are usually administered via questionnaires. One of the most commonly used questionnaires is that of Witmer and

Singer [19]. However, researchers such as Slater [64] and Schumie *et al* [79] have criticised this questionnaire as measuring the factors which cause presence rather than presence itself. Many of the subjective questionnaires have come under criticism for being invalid and unreliable. Witmer and Singer [19] state that any measure of presence should be both reliable and valid. Reliable means that differences in test scores should be indicative of differences of characteristics being observed, rather than random fluctuations in individuals or testing conditions. Validity is more complex, as there are numerous things which have to be taken into consideration for a scale to be valid [1]. All procedures for determining test validity look at the relationships between performance on the test being conducted, and other independent facts about the behaviour characteristics being studied [1]. In short, a valid scale should measure precisely what it is sets out to measure.

Schumie *et al.* state that an advantage of subjective measures is that it does not limit itself to subjective sensations [79]. Physiological and behavioural responses can be measured as well, although the reliability of these measures are questionable, due to its subjective nature. This information, though, is less reliable due to its subjective nature. This criticism is supported by Slater [64] who states that any self-reported measure of presence varies with users, and is therefore dependent on personal aspects of the user. Even two users with the same levels of computer experience, are unlikely to deliver the same report. Current subjective measures also require a fair understanding of presence by the users. As a result, with most naive users being unfamiliar with the concept of presence, results have shown to be inconsistent across individuals and different rating situations [102]. It has also been shown that the user's subjective rating of presence can be biased by previous experience [49]. Schumie *et al* [79] state that relationships between components of subjective sensations on presence and the presence construct itself is dependent in part on the definition of presence being used, and should therefore not be taken as a given. They further caution that these components depend on the scope of the study undertaken and its related questionnaire.

Objective measures measure behavioural and physiological responses of users to the virtual media. They have an advantage over subjective measures in that they relate to user responses which are produced automatically. Thus, this alleviates the problem of subjects responding to demand characteristics [111]. Insko [45] lists the advantages and disadvantages of objective measures. Behavioural measures measure automatic responses to stimuli exhibited in the virtual environment. A participant's measure of presence is measured in terms of his/her response to stimuli, which if indicative of high presence, should be similar to that exhibited in the real world. For example, if a virtual object was thrown at the user and the user ducks, that would be indicative of a sense of presence. Behavioural measures have the advantage over subjective ones in that they are less biased. They can, however, be subjected to experimenter bias. For example, a person trying to grade the experiment could bias results in favour of the results that he/she wants. Behavioural measures also

contain a certain degree of uncertainty, as it is not sure if the response elicited was caused by something in the virtual environment or by an external stimuli. Physiological measures measure bodily changes to events occurring in the VE. The three most common ways to measure physiological changes are via changes in heart rate, changes in skin temperature and changes in skin conductance. Physiological measures are continuous, so that time-varying changes in presence can be accounted for. However, there are certain things which have to be taken into account when using such measures. Physiological measures vary from person to person. Therefore, absolute values should not be taken, but rather baseline levels and changes to these baseline values. Another consideration is the experimental conditions, which should remain consistent throughout all experiments, regardless of the type of measure used.

Since literacy was a problem, questionnaires were not considered suitable for the test population. Behavioural measures were considered too intrusive to use due to the traumatic nature of the environment. The study used a qualitative approach via semi-structured interviews to explore presence, a process similar to that of Murray *et al* [23]. Researchers have of late been using qualitative research for determining measures of presence [114, 62, 3, 99]. Qualitative research yields rich detailed information which could help to understand a user's experience. Van Buuren *et al* list the advantages and disadvantages of using this approach [52]. An advantage of this is that the participants' responses are constrained or shaped in a way that questionnaires do, but allow users to express their own personal experiences using their own words. A drawback is that data analysis takes a lot of time. The interpretation made by the researcher of the data is also a threat to reliability. It is also difficult to generalize findings. Qualitative measures are often used for explorative purposes.

The open ended questions addressed factors such as a description of their interaction with the environment and with the virtual characters. This was in the hopes of gauging if presence was felt, and to what degree.

Causes of presence

Schumie *et al.* state that knowledge of the factors which contribute towards presence is the key to designing effective and efficient VEs [79]. They conclude that there are three overall factors contributing to presence namely, *vividness*, *interactivity* and *user characteristics*.

Vividness is a technology-based construct which refers to the richness of the sensory information in the VE [51]. Researchers believe that one's sense of presence is a function of the senses the medium provides stimulation for [66] [100]. More immersive VR technologies tend to increase presence. For instance, Widstrom *et al* [54] [79] found that users had a stronger sense of presence in a CAVE than when using desktop VR. Other sensory factors contributing to a higher degree

of presence as reported by Shumie *et al.* [79] include stereoscopy and geometric field of view [21], pictorial realism [88], spatialized sound [22], as well as better haptic [41] and olfactory cues [43]. An important issue regarding vividness is that there should be consistency of the sensory outputs [66] [92]. For example, one should hear a fire crackling, see the flames and smell the smoke simultaneously, that is if all of the sensory stimuli are provided.

Interactivity refers to the degree to which users can interact with, and control parameters of the virtual environment [102]. There are three factors which contribute to interactivity namely [51]:

- **Speed** — which is the rate at which the medium responds to input from the user. The speed of interaction is an important part of a mediated environment, with real-time interaction being the ideal value for this variable. The actions of a user on a mediated environment should be as close to instantaneous as possible.
- **Range** — which is the amount of change which can be attained on the environment. Dimensions include spatial organisation (where objects are placed), intensity (loudness of sounds, brightness of images), and frequency characteristics. The more of the above parameters which can be changed, the greater the range of interactivity.
- **Mapping** — refers to the way in which human actions are related to action in a VE. For example, pressing the left arrow key on the keyboard, might move the user to the left in the mediated environment.

User Characteristics — refers to other personal, idiosyncratic variables which affect the perception of presence. Since presence is a subjective construct, people can experience different levels of presence when confronted with identical environments. User characteristics which play a role in levels of presence include the willingness to suspend disbelief, as well as knowledge and prior experience with the medium [66]. The willingness to suspend disbelief is the ability to lose oneself in a mediated experience, rather than assume one is experiencing a mediated experience [71]. More experienced VE users tend to criticise flaws in virtual environments, or make comparisons between them. They are therefore less likely to experience a high sense of presence than naive users. Lombard and Ditton [66] list the following user characteristics as amongst those influencing presence: personality type, users' preferred representational system, their cognitive style, the degree to which they 'screen' complex stimuli, their level of sensation-seeking, their need to overcome loneliness, their mood before and during media use, and their age and gender.

The above factors are important as they act as design guidelines in the creation of VE's. In terms of vividness, a desktop VR was used in this study. The reasons underlying this was cost-effectiveness and accessibility; for the intended environment use, a desktop VR was deemed more

appropriate and accessible. The VE created was interactive, with speed, range and mapping taken into account.

2.2 Narrative

Over the past two decades, there has been a growing interest in narratives and their relationships to people's lives and social relationships [40] [16]. The term narrative or story is used interchangeably in this chapter, and is taken to mean the same thing, i.e., an account of a series of linked events, whether true or fictitious [95].

2.2.1 A description of narrative

Narrative is the primary form through which people understand and give meaning to their experiences [29]. A narrative allows people to link together aspects of their lives, and allows a personal reflection on events which they have experienced. Narratives can therefore be thought of as a format through which people make sense of their lives, make connections with others, receive validation and transform experiences [89]. This usually takes place over a period of time.

Barths([85] cited in [36]) identifies the following as defining characteristics of narrative:

1. It has levels of meaning i.e. basic units (beginning, plot, conclusion), levels of action, levels of discourse (the way in which the story is told) as well as a linear development of the structure of the narrative.
2. It is unclear as to what causes what, and what follows what. For instance, the word 'it' can refer to many different things in the narrative.
3. If the narrative arrives at a turning point (e.g. change of thought, change of direction) it will always choose the option which will lead to continuation rather than termination.
4. Real time does not exist in narrative — the narrative will not follow at the same pace as the event being described e.g., if the narrative describes an event over a week, the narrative will not span a week.

2.2.2 Benefits of storytelling

According to Viney [63], stories have an impact on people's lives. Firstly, they help them construct and maintain a sense of identity. Telling as well as hearing stories allows people to get to know themselves, and reminds them of their own resources both psychological and material. Secondly, stories guide people in living their lives. They provide people with a means with which they can

recognise their own existence and abilities, as well as broaden their focus on the world. Thirdly, stories help people to order events in their lives chronologically, and help them to maintain perspective rather than be overwhelmed by them. They provide insights into past, present and future events by providing a means in which to link the different events. Fourthly, having other people listen to one's stories, gives one a sense of social power. The narrator who is invited to tell a story, is seen as wielding sufficient power to ensure that such an invitation occurs.

Umaschi states that narratives can be seen as serving three functions [73]:

1. *Cognitive*. Personal stories form an important part of human memory, in which new experiences are interpreted in terms of old stories and generalised story scripts ([35, 94] cited in [73]).
2. *Social*. Stories help to define the social group or culture to which a person belongs. Myths, legends and traditional stories get passed down from generation to generation, thus providing the group continuity over time ([110] cited in [73]).
3. *Emotional*. Storytelling forms an important part of certain kinds of psychotherapy. Storytelling, for example in hypnotherapy, has shown to have emotional value ([97] cited in [73]).

Narratives help people make sense of other people. Viney [63] states that they are comprised of a *personal, social and cultural* aspect. The *personal* aspect, is the way the person projects themselves to others, as well as presenting the events which are important to them. They also serve a psychological function, such as preserving self-esteem or allocating responsibility. Stories link together emotion and action, as well as present and past. The *social* aspect is the context, the sources which confirm or validate the story, and the personal power yielded to the storyteller. The most important *cultural* aspect is the network of information which is shared through it, and the values which they seem to project.

Vinney [63] states that people need for their stories to be told. Often, the audience is family and friends. In other instances, these are extended to a more professional or wider community audience, depending on the content and the implication for the storyteller and others. This often leads to support from other people.

2.2.3 Narratives and illness

In the event of an illness of the body, the telling of stories of illness can be thought of as the attempt to give a voice to that part of an experience that medicine simply cannot describe [16]. The relating of an illness experience does not, however, only impact on people relating their stories. Wilfred Sheed, a sufferer of polio, addiction, depression and cancer of the tongue tells of his longing to

have some account of the same experience told to him in the introduction of his book *In Love with Daylight: A Memoir of Recovery* [112]:

“I would have have sold my soul cheerfully (if I could have done anything cheerfully) just to hear from someone else who had passed this way and could tell me what was actually happening to me and what to expect next. But among all the thousands of inspirational and pseudoscientific words I could find... not one came close to describing what I was going through, or suggesting anything useful to do about it...So I’ve had to write it myself, scene from scene—all the things I would like to have read back then.”

Couser [40] states that there exists a complex relationship between bodily dysfunction and personal narrative. Bodily dysfunction can stimulate autopathography — autobiographical narrative of illness or disability. It does so by making one more conscious of one’s own mortality, threatening one’s sense of identity, and disrupting the discourse of one’s life.

A narrative type can be thought of as the storyline which underlines the plot and tensions of the story [16]. Frank [16] suggests that three main types of narratives relating to illness exists:

- *The restitution narrative.* This is the belief in restorable health. Narratives in this category reflect the illness sufferer’s desire to get well and stay well. The stories of people with chronic illness and disability do not fit into this category, since the illness sufferers’ find it difficulty to tell a story which does not have a happy ending.
- *The quest narrative.* The illness sufferer accepts his/her illness and seeks to use it. They believe that illness is a journey that becomes a quest, and something is to be gained from the experience.
- *The chaos narrative.* This category is in a class of its own, as it can be classified as an unspoken narrative. The chaos story is frequently unheard. It occurs when people become so overwhelmed by the intensity of their illness, that speaking coherently or voicing their suffering becomes impossible. It remains the sufferer’s own story, and it is this loss of voice that perpetuates chaos.

The category of narrative of interest to this project is the quest narrative. Ill people who tell quest narratives see their illnesses as a challenge, and believe that something is to be gained by their illness. Frank states that “People tell stories not just to work their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others —each must create his own—but rather to witness the experience of reconstructing one’s own map. Storytelling is for an other just as much as it is for oneself.” ([16], pg 17).

2.2.4 Narrative and HIV/AIDS

It has been shown that the telling of narratives in an AIDS support group is cathartic to the group members [89]. In a study done by Dean [89], it was shown that narratives had had many meanings and uses in a group of gay men suffering from HIV/AIDS :

- It aided in counteracting negative ideas and images pertaining to their lives and culture.
- It allowed them to confirm, celebrate and create gay culture.
- It allowed them to maintain their integrity and self-worth.
- It gave them an opportunity for sharing each others experiences, thereby creating a sense of community.
- It allowed them to mourn and come to terms with the limitations of their illness in a non-threatening atmosphere.

2.3 VR storytelling applications for illnesses

VR storytelling applications engage users in the VE experience by allowing them to interact with the activities pertaining to the story being told. Four such applications, Doctoon©, Breast Cancer Lighthouse, Easing Cancer Pain and Cancer Prevention Park, deal with providing support to people with illnesses. These are discussed below.

2.3.1 Doctoon©

Doctoon©[18] was developed in order to help children in pediatric wards cope with any psychosocial problems they might encounter. Doctoon©is a virtual animated character (see Figure 2.1), who communicates with the children via their television sets. The virtual character is driven by an animator, who monitors the child's actions via a two-way video and responds with the appropriate dialogue and action.

Exposure to Doctoon©yielded the following psychosocial benefits:

- Reduction in stress levels experienced by the children.
- Change in perception of the children's situation.
- Increase in children's compliance.
- Reduction in feelings of loneliness.

- A mechanism to escape aggressiveness and violence.

The success of the pilot studies done with Doctoon©in January 1999 has lead to the Regional Hospital complex of the Citadel in Belgium to install the programme in its pediatric rooms.

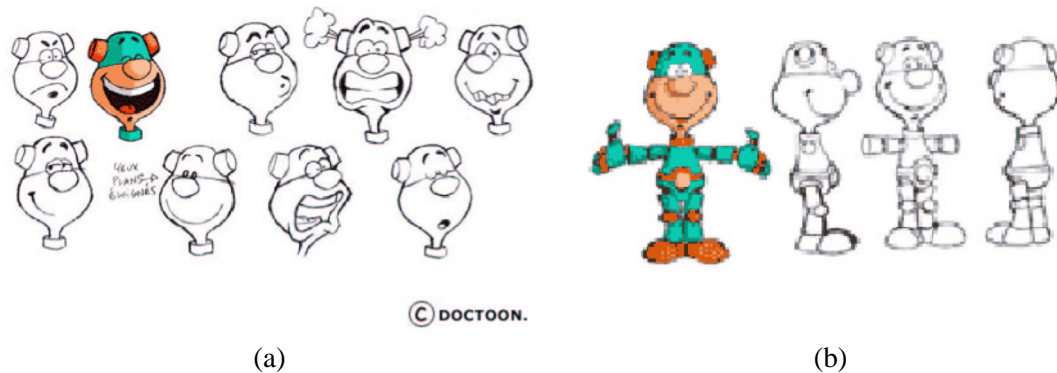


Figure 2.1: (a) and (b) Animated actions and facial expressions of Doctoon ©, a storytelling application designed to help children in pediatric wards cope with psychosocial problems.

2.3.2 Breast Cancer Lighthouse, Easing Cancer Pain and Cancer Prevention Park

Michigan State University Community Technology Lab (CTL) [26] has developed three VR applications to aid women with recent diagnosis of breast cancer. These were the Breast Cancer Lighthouse, Easing Cancer Pain and Cancer Prevention Park [39].

Breast Cancer Lighthouse focuses on personal stories regarding diagnosis, treatment and recovery issues. The scene is set along a sandy beach, whereby the user can meet women who then go on to discuss their personal experiences with breast cancer (cf Figure 2.2). The user is also given the opportunity to explore different paths through a garden, and learn more about issues pertaining to diagnosis, treatment and recovery of breast cancer

In Easing Cancer Pain the user is given the experience of sitting around a campfire listening to personal stories concerning the pain associated with breast cancer. The VE is set in a retreat center (see Figure 2.3(a)). Information about pain management and assessment of pain is available to the user through the exploration of different terrain grounds.

Cancer Prevention Park is set in a theme park (see Figure 2.3(b)), whereby users can play games associated with good cancer prevention habits, listen to stories of how people changed their lives, and gather information about cancer prevention. The four topics focused on were physical activity, exposure to sun, exposure to tobacco and second hand smoke.

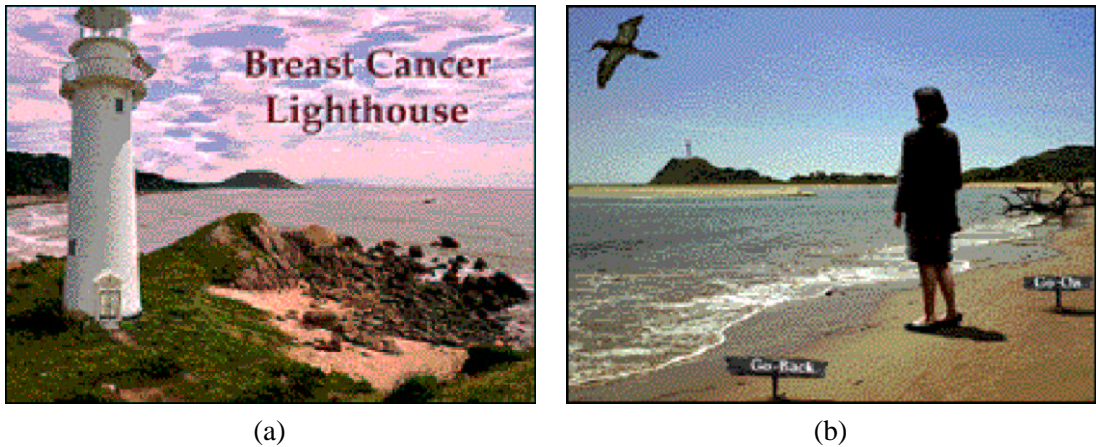


Figure 2.2: (a) and (b) Breast Cancer Lighthouse gives a user the opportunity to meet women along a sandy beach and hear their personal stories.

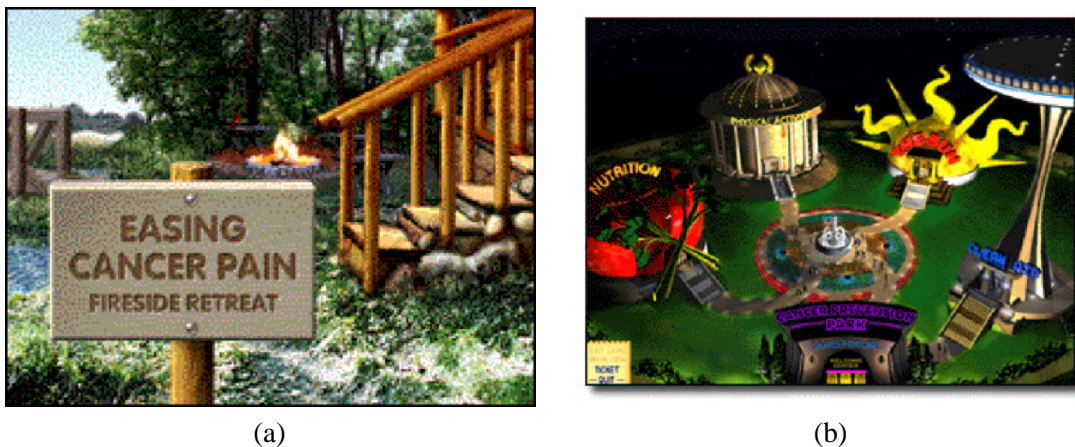


Figure 2.3: a)Easing Cancer Pain is set in a retreat. b)The theme park depicting Cancer Prevention Park where users can play games associated with good cancer prevention habits.

2.4 HIV/AIDS progression

The progression of HIV infection can be divided into three stages viz infection, disease progression and advanced disease progression or full blown AIDS [9].

During the initial stages of infection, the antibodies to the virus are not detectable. This is know as the window period. During disease progression, the virus and the cells which they are attacking are destroyed and reproduced at an alarming rate. Eventually the virus overpowers the immune cells i.e. they attack at a rate faster than which the cells can be replaced. The cells which are responsible for the body's immune response to virus's and other foreign objects, called the CD4 cells, begin to

drop. The person then develops opportunistic infections, which increase in frequency, duration and severity. These opportunistic infections result in the condition called AIDS. The infected person eventually dies as a result of these opportunistic infections.

Figure 2.4 [83] shows the progression of the disease by depicting the viral load (or Plasma Viremia) and CD4 counts as a function of time. The graph shows that the viral load is the highest during the acute stage of infection. The notch in the CD4 dashed curve shows the body exhibiting an immune response, thus driving down the viral load. Thereafter, the graph shows the increase of viral load corresponding to a period of clinical latency, the onset of constitutional symptoms, the onset of opportunistic diseases and eventually death.

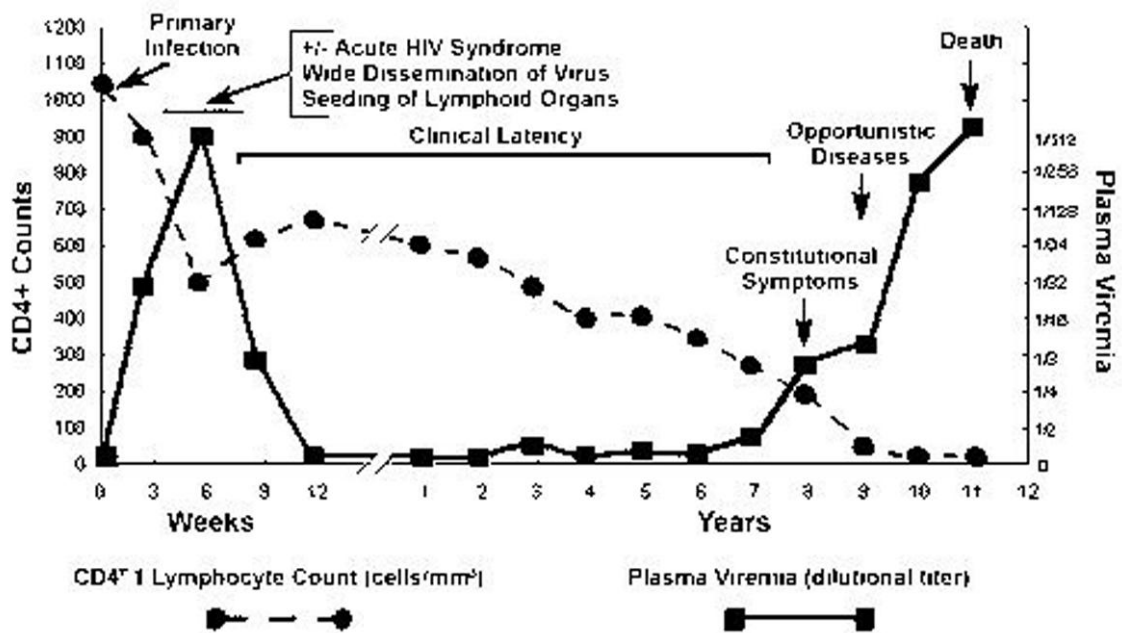


Figure 2.4: Viral Load and CD4 Count over time

2.5 Social support

Social support is one of the variables which impact on the Quality of Life (QOL) of people living with HIV/AIDS. Friedland *et al.* [50] refer to quality of life (QOL) as “the adequacy of material circumstances, or a subjective sense of meaning and purpose in life” ([50], pg15). It can be conceptualised as the ability to function in day to day life, without any medical hindrances. Researchers have studied the impact of social support on health outcomes in a variety of situations.

There are many definitions of social support. Vaux *et al.* describe it as a meta construct relating

to different aspects of social relationships, including the following: [8]

1. the existence, quantity and type of interpersonal relationships (network structure or social interaction).
2. the functional content of these relationships (emotional, psychological, tangible or informational support).
3. the perceived quality or adequacy of this support (subjective appraisal).

Most of the research done on support is grounded in stress theory. Basic to support theory and particular to stress theory, is the model of transactions, transitions and needs which is discussed below [31]. In the 'transaction' model of stress, if perceived demands exceed perceived supply, then negative results on the individuals well-being will occur. Discrete life events or day-to-day hardships might bring about such demands. The details of these demands are insignificant to this model. It is the inability to satiate those demands that brings about the stress. In the 'transitions' model of stress, stress occurs as a result of change. The 'needs' model of stress stipulates that individuals have needs that are met through interactions with other people. An example is the need for attachment being satisfied by marriage, the need for nurturing by parenthood, and the need for guidance through experts and professionals. People encountering stressful situations look to specific support structures to fulfill their needs. According to Jacobson [31], types of support are normally associated with the needs theory of stress.

2.5.1 Types of social support

As pointed out earlier, social support can be divided into three categories [86] [31]:

1. instrumental/practical refer to goods and services which help people solve practical problems such as counting on others for favors eg borrowing money or helping in a crisis.
2. Informational/cognitive support refers to information/knowledge/advice that helps people to understand their circumstances and help people adapt to it.
3. emotional support is the receiving of emotional comfort.

According to Weiss [113], different stressful conditions call for different kinds of support. He differentiates between three kinds of stressful conditions viz:

1. crisis - a situation of sudden onset and limited duration which is perceived as threatening to the individual. It is severe in the stress that it imposes on those exposed to it.

2. transition - a period consisting of relational and personal change [31].
3. deficit - a situation in which there is an absence of provisions which is important to the well-being of the individual.

Weiss [113] states that the above stressful conditions are not necessarily isolated conditions, but can occur simultaneously. People in deficit states normally do experience crises, and a single event can cause crisis and deficit. They can also be related temporally. The order in which they normally occur in is the crisis state followed by a state of transition and finally deficit.

Jacobson states that different kinds of support are called on at different times (as is shown in Figure 2.5) [31].

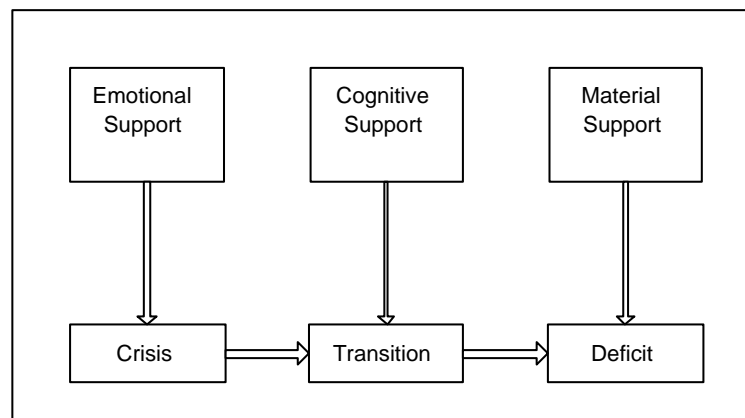


Figure 2.5: Types of support and the sequencing of stressful situations.

In a crisis, the most helpful sort of support is emotional support, where feelings of concern and encouragement are conveyed. Weiss [113] states that this kind of support is in fact helpful in all kinds of situations. He attributes this to the fact that transition and deficit states are usually overlapped with a crisis, whilst people in a crisis are unable to use any other forms of support.

In transitions, the primary kind of support is cognitive, whereby the individual learns to learn and adapt to the circumstances bringing about the stress. In the deficit aid, material support is needed to overcome the balance between supply and demand of resources.

From the model described in Figure 2.5, we hypothesize that the most useful kinds of support given to people who are newly diagnosed with HIV, is emotional and cognitive support. This can be attributed to them being in a state of crisis, or transition. There are varying studies in the literature as to which of these two are more beneficial to people living with HIV/AIDS. A study done by Hayes *et al.* [90] state that informational/cognitive support was most beneficial to people in the early stages of the disease. This is further supported by studies done by Swindells *et al.* [98] [2].

However, other studies point to emotional support as being the most important form of support needed by people living with HIV/AIDS [96] [60] [2].

2.5.2 Sources of support

The type of social support varies according to the source or provider thereof — it could be a friend, parent, health care provider or peers. For example, friends and parents usually provide people with emotional support, whilst health care providers typically provide people with informational support. Support groups (both peer and counsellor facilitated) provide people with a combination of the two.

The aims and benefits of each of the above sources differ. In a counselling setting, the aim is to provide an effective approach, provide a learning experience for the client, and allow the opportunity for clients to express their emotions ([60] cited in [6]). Molassiotis *et al.* [6] state that in a peer support group, the above goals are achieved through discussion with each other and sharing of experiences. Whereas in a counselling approach (group or one-to one) the session is facilitated by the counsellor or therapist, in a peer support group, there is less structure or formality, allowing for an informal atmosphere whereby stories and experiences can be shared. Support groups decrease the level of anxiety and hopelessness associated with the disease, while reducing the isolation associated with the disease [46] [30]. In a study done by Sandstrom [61] involving the utilization of peer support groups by gay men with HIV/AIDS, people utilized support groups in order to gain:

- information and advice, specially pertaining to how to cope with the disease physically, emotionally and socially.
- empathy and emotional relief from others.
- camaraderie and friendship from other people who were more receptive to their emotions.

Some of the benefits experienced by the men included the sharing and addressing of troublesome feelings, the ability to help and support others and the exchange of useful information.

A study done by Molassiotis *et al.* [6] showed a long-term improvement in terms of confusion, depression, overall mood disturbances, tension/anxiety and fatigue in people with symptomatic HIV disease when exposed to peer support groups/counseling. Immediate post-intervention, however, showed a marked decline in the above variables. This could have been attributed to the processes where patients are confronted with the realities of living with HIV through the sharing of experiences. These realities might have been previously denied or underestimated by the patients [6]. Support groups, whether facilitated (by a counsellor) or non-facilitated (as in peer-led groups) are beneficial to HIV-positive individuals. They allow them with an emotional outlet, provide social

contact and they foster information sharing, promote educational and health issues, provide behaviour change information and reinforce positive behaviour changes, motivate individuals and provide psychosocial support [30].

2.5.3 Measurements of social support

There is a lack of consensus on how social support should be conceptualised. This is reflected in the varied approach to its measurement. To date, there is no standard measurement for social support [37]. Each independent study done devises its own measuring scale, depending on the aim and focus of the research. This is further supported by a literary review conducted by Walker [75] who states that studies present social support as a unitary construct, without specifying the type (informational, cognitive, or material) and source (family, friends etc.). Others tend to overlook the fact that there are both costs and benefits to social support. Thus, the measuring scales are as diverse as the definition of the concept. A study has been done by McGough which examined all the known available measures at that time in order to assess the social support needs of people with HIV [80] [37].

2.5.4 The effects of social support on HIV/AIDS

Adjusting to and living with an HIV diagnosis is characteristically highly stressed, leaving the individual vulnerable to depression and anxiety (cited in [37]). Coming to terms with a positive HIV diagnosis requires mental adjustment and change in relationships, and may even involve the construction of a new identity [37, 61]. It is therefore not surprising that social support is identified as being crucial for coping [57, 37].

Cohen and Willis (cited in [10]) suggest three hypotheses with regard to the impact of social support on HIV/AIDS. The three hypotheses are:

1. *Social support directly contributes to health outcomes.* The perception that one is supported by other people has a positive impact on one's psychological state. This in turn positively influences both the immune system and daily functioning.
2. *The support and resources provided by others shield pathogenic effects of stress.* This is known as the buffering hypothesis. This is important considering the heightened stress levels experienced by people living with HIV/AIDS.
3. *Social support acts as a buffer for negative health outcomes that result from stressors.* This includes the stress from serious illness. This hypothesis is an extension of number two above [50].

Several studies show that social support is more readily associated with psychological well-being [37, 91, 78, 44]. In a study done by Hay *et al* [86], satisfaction with each of the types of support (emotional, practical and informational) was shown to be inversely correlated to depression.

Alternatively, poor social support has been related to lowered QOL. For instance a study done by McDonnel, Gielen, O'Campo and Burke, found that HIV positive women in abusive relationships reported lower QOL [59]. A study done by Fleishman *et al* [55] found that conflicting social interactions were positively correlated with social isolation, anger as well as negative mood. They also found that conflict in social interactions was a more important determinant of negative mood.

The fear of disease progression by people living with HIV is matched by the fear of stigmatization [28]. This fear may lead to self-imposed familial estrangement, decreased socialization or withdrawal [76, 37].

Factors which make people living with HIV particularly vulnerable and increase their need for social support include the following:

1. The uncertainty associated with the disease, their fear of decrease in long term body and mental functioning, the high mortality rate, and the debilitating effects of the latter stage of the disease all have social implications for the person living with the disease [87].
2. It is a sexually transmitted disease which has implications for both current and future sexual relations, as well as reproductive behaviour [37, 47].
3. The stigmatisation and social prejudice associated with the disease. These are accompanied by feelings of shame and contamination as well as low esteem.
4. The population affected may already be socially isolated. For example, it is reported that many gay men do not have strong links with a family network [37, 33].

The availability and nature of social support reflect prevalent societal attitudes and perception to HIV/AIDS. These attitudes include social prejudice and stigmatization [77]. For this reason, individual find it difficult to obtain certain forms of support and remain secluded from society or opt for non-disclosure.

2.6 Computer systems providing psychosocial support

The following sections provide an overview of existing systems aimed at providing support to people living with HIV/AIDS.

CHESS

The Comprehensive Health Enhancement System (CHESS) was developed as a computer based health care system by the University of Wisconsin at Madison. Its aim was to provide information, referrals, decision support and social support to people living with HIV/AIDS. The system used personal computers which were placed in users' home and linked together via a modem to a central host computer. The system was created in response to the needs of people suffering from HIV. These include [34]:

1. Extensive needs on the medical, legal, financial, and social aspects of HIV infection.
2. Support in making decisions about disclosure, and changing behaviour regarding HIV status.
3. Knowledge of services available, and how to use them.
4. Social support from other individuals living with HIV.

CHESS integrated information, referral, decision support and social support systems and used colour graphics and simple user prompts to make CHESS a user-friendly system to people with little or no computer experience [34]. The services offered by CHESS included the following [32]:

- *Questions and answers.* These included questions and answers to the most commonly asked questions about infection, life and treatment.
- *Instant library.* These included full-text articles covering a broad range of topics taken from a range of media.
- *Getting help/support.* These included descriptions and directions to health care providers.
- *Referral directory.* These included descriptions and directions to national services that offer information, support and referrals on the health problem
- *Assessment* asked questions about lifestyles, and assessed risks with the view of decreasing risk factors.
- *Decision aid* — helped patients make difficult decisions. Users could learn about the different options available, clarify their values, the consequence of their actions, and helps clear up any misconceptions that they have.
- *Action plan* — helped patients to successful implement decisions, teaching people how to overcome obstacles.

- *Discussion groups* — an online support group which allowed patients and families with similar problems to share information and support.
- *Ask an expert* — Allowed patients to write a question and receive confidential responses from experts. This could be available for everybody to see, if the user so wished.
- *Personal stories* — Real life accounts of people with similar problems, living and coping with the illness.

The system was tested on 209 HIV-positive patients. Users reported QOL improvements with regards to the following: active life, negative emotions, cognitive functions, social support and participation in health care [32]. The CHES system also appeared to be a highly accessed system [34]. However, the research group was unable to secure continued funding from the United States federal government, healthcare providers, or HIV support organizations to maintain and update the content, disseminate the program, or to do continued research. Thus the CHES HIV module is currently not being developed further. CHES have developed other modules for a range of other illness, including breast and prostate cancer [109].

ComputerLink

ComputerLink [84], is a network-based intervention system that was developed by Case Western Reserve University for people suffering from AIDS and Alzheimers syndrome. ComputerLink provided three services to users:

1. *Information* which is organised in an electronic encyclopedia. These encyclopedias consisted of information screens which were designed to promote self-management, give information on home-base treatments of patients and give patient and caregiver understanding of illness-specific issues.
2. *Communication* — This included a bulletin board in which people could post messages, and private electronic mail which people could send and receive messages.
3. *Decision Support* — this helped people make personal decisions.

Participants in the project used computer terminals in their homes which were linked via the ordinary telephone systems to a computer network. The network has a project director which serves as a nurse moderator. The job of the nurse moderator was to visit each participant to assess his/her needs, and train users on how to use the ComputerLink system. The nurse moderator also reviewed electronic messages, monitored user log-on behaviour, responded by e-mail to the users' questions and acted as a facilitator to people's questions.

Experiments were conducted on 60 people living with AIDS during a six month evaluation. The group was randomly halved with one group receiving homecare, and the other group using Computer Link. This was done over a four year period.

Statistical analysis revealed that ComputerLink had a positive effect on decision making and social isolation (only once the effects of depression were controlled).

2.7 Summary

In this chapter I have discussed the background work relevant to my research. I described VR, the sense of presence, its importance to VR, the different ways it was measured, and the factors which contributed to it. Presence was described as a “mental state in which a user feels psychologically present within the computer-generated environment” [48]. There are different theories as to why presence is an important construct in VR. Some researchers postulate that researching the factors which contribute to presence can act as a guide for the future of VR technology [69]. Factors which are known to increase presence include vividness, interactivity and user characteristics [79]. I provided an overview of narratives/storytelling in the lives of people with chronic illnesses. Narratives serve a cognitive, social and emotional role in people’s lives [73]. They also comprise a personal, social and cultural aspect [63]. Three types of narratives relating to illness exist. These are the restitution narratives, the chaos narratives and the quest narratives. The pathology of AIDS can be divided into three stages: infection, disease progression and advanced disease progression. I provided a brief overview of each of these stages. I then discussed the concept of social support, and its effect on HIV/AIDS. Social support is one of the variables affecting quality of life (QOL) of people living with HIV/AIDS. Poor QOL has been linked to the faster disease progression of HIV to AIDS. Social support can be divided into three categories viz. instrumental, informational and emotional [86] [31]. The aims and benefits of social support vary according to the source which could be friend, parent, health care provider or peers. Social support has been shown to be associated with the psychological well-being of people living with HIV/AIDS [37]. I end off the chapter by describing two computer systems which have been known to provide support to people living with HIV/AIDS. This is the CHESS system and the Computerlink system.

Chapter 3

Virtual Environment Design

The main objective of the VE was to examine the efficacy of the VR medium as both a support mechanism and an emotive medium to people living with HIV/AIDS. My wish was to use the features of VR to simulate a therapeutic environment in which stories depicting experiences with the HIV/virus was shared.

The VE was conceptualised in the following way : The user is introduced into the VE by an agent. The agent introduces himself and asks the user to join him and a number of other people at a campfire. The user then follows the agent to the campfire where introductions are made. Each agent around the fire has a story to tell about adjusting to HIV. Each story is divided into three parts; a general introduction which introduces the initial period after learning about his/her HIV status. The next phase depicts the process of adjustment and the final part conveys the agent's current functioning, living positively with HIV.

The implementation of the VE was facilitated by the use of storyboards. This was used to plan the sequence of events as experienced by the user. The creation of the VE required the design and implementation of the following features:

- The writing of the narratives to be used.
- The static environment consisting of the forest.
- The dynamic environment consisting of the fire, sound and actors.
- The actors as well as their corresponding movements.
- The recordings of the narratives to be used.

3.1 Storyboarding

In order to conceptualise the VE, a storyboard was created. A storyboard can be thought of as an expression of everything that will be contained in the program [5]. Storyboards are most commonly used in industry in areas such as advertising and film design. It is helpful in that [5] it allows people to visualise the conceptualised story and allows people to give feedback about the program before implementation. It also highlights potential flaws in the design of the VE, which might not have been easily picked up otherwise.

Storyboarding a VE differs from the traditional storyboarding of advertising and media. This difference can be attributed to the interaction involved in VR by the user [101]. The layout of the storyboard of a VR environment depicts the plot of the story rather than a step-by-step sequence of events that would have been followed by the user.

The design of the storyboard was created using the methods described by Shulman [7] and Brown *et al.* [101] which were:

1. *Analysis* - breaking the story down into component parts. In this project, it included breaking the sequence of events experienced by the user into different parts.
2. *Evaluation* - this includes components such as lighting, camera angles and length of story.
3. *Synthesis*- developing and putting the storyboard together.

3.1.1 Analysis

The VR experience was broken up into four parts. Firstly, the user is introduced into the scene by an agent. Secondly, the user then follows the agent to the campfire, where introductions are made to each member. Thirdly, the user chooses which agent to listen to, and which aspects of the story to hear.

3.1.2 Evaluation

During the evaluation stage, four questions have to be asked [4] [101].

1. What are you trying to communicate?
2. Who will be the audience?
3. What are the objectives for the story?
4. How will you tell the story?

The answers to the above questions are important as they help to dictate which approach to take when creating the storyboard. Flaws in the script of the storyboard can usually be eliminated by continuously going back to these four questions.

The questions above were answered as follows:

1. The VE is trying to communicate illness narratives of people living with HIV.
2. The audience will be people who have been diagnosed with HIV and have little or no computer skills.
3. The objective is to investigate whether the stories told in the VE can elicit an emotional response from people living with HIV.
4. The story will be told around a campfire in a forest using audio.

3.1.3 Synthesis

The storyboard shown in Figure 3.6 was created by Mary-Lynne Hallot, an artist who worked in the UCT Computer Science Collaborative Visual Computing Laboratory.

3.2 Evaluation revisited

Once the storyboard was completed, two problems were highlighted and had to be addressed. First, was the overall size of the VE. Since the experimental group would possibly have little or no computer experience, it was decided to make the environment small, so that navigation around the VE was limited and therefore easy to control.

The second issue which had to be taken into consideration was the positioning of each agent around the fire and the placement of the agent welcoming the user into the VE. To allow for minimal movement of the user, the user should face the agent and campfire when introduced into the scene. The agent would therefore be facing the user, with his back faced towards the campfire. It is therefore the agent which turns around and walks towards the campfire. The user walks along a straight line towards the campfire. ¹

3.2.1 Selection of stories

The narratives being used are fictitious, but draw on personal experiences of South African HIV positive individuals. These stories can be found in Appendix A,B,C and D. The narratives have

¹The movement to turn around is complex and involves using the mouse and the arrow keys. Novice users might find it a bit difficult.

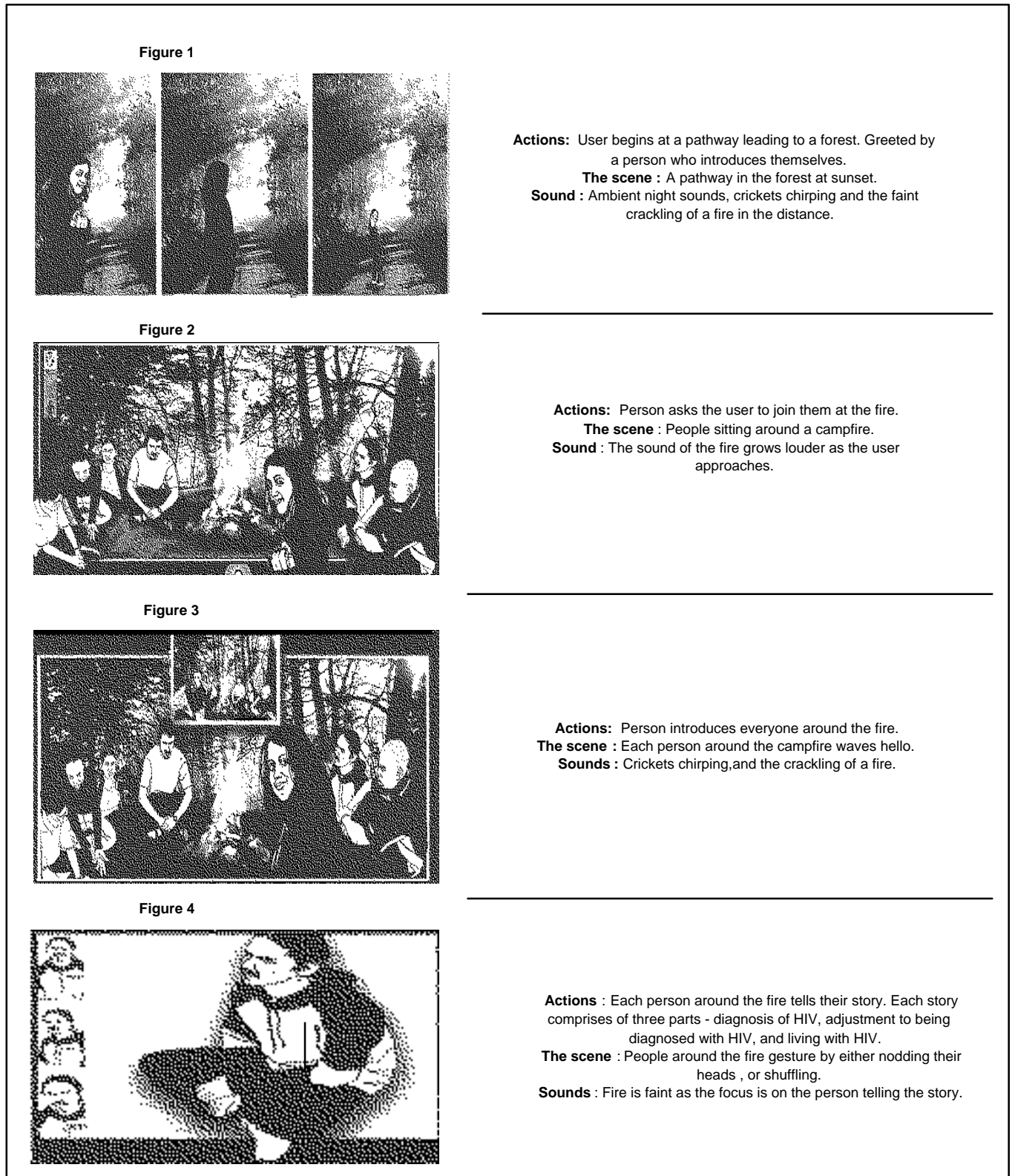


Figure 3.6: Storyboard describing stages followed in the VE

been constructed in such a way that they reflect the initial shock and adjustment associated with learning about one's HIV diagnosis, followed by an intervention and consequent process of psychological adjustment. Each narrative draws on research-based knowledge about factors impacting on QOL. The narratives illustrate typical dysfunctional responses, followed by an informational or educational intervention (carefully woven into the story) and subsequent positive adjustment and improved QOL.

3.3 Implementation

Presence is an important design goal of a VE, as the distinguishing factor between VR and other media is constituted by the level of presence experienced [51]. Schumie *et al* state that knowledge of the factors which contribute towards presence is the key to designing effective and efficient VEs [79]. They conclude that there are three overall factors contributing to presence namely, *vividness*, *interactivity* and *user characteristics*. These are discussed in detail in Chapter 2, Section 2.1.2 Each of these constructs are discussed below in the context of the design of our VE;

- *Vividness*– A desktop VR system was used, as this would be a viable option if the VE had to be implemented in clinics.
- *Interactive* – The VE was interactive in the sense that the user could control his own movements in the environment, as well as to an extent the actions of the other avatars.
- *User characteristics* – The VE represented a novel experience for the users, and thus the users had no prior VR experience with which to compare and hence criticise flaws.

3.3.1 Tools

The virtual environment was created using Genesis3D [13], a real-time 3D rendering environment. The engine supports highly detailed models and is based on a Binary Space Partition (BSP) system which ensures fast rendering of environments. In order to use Genesis3D, four things are needed viz, the Genesis3D engine, a windows compiler, a 3D modelling package, and a BSP level editor.

The tools used in the creation of the HIV/AIDS VE were:

- *Compiler* — Microsoft Visual C++ 6.
- *Modelling packages* — Discreet 3D Studio Max [12] and Milkshape 3D [15].
- *BSP level editor* — GenEdit Classic.

3.3.2 The static environment

GenEdit Classic was used to create the BSP file for the environment. The BSP file contains the basis of the VE namely the world geometry, texture and static lighting information.

To give the impression of ‘open space’, a skybox was used. A skybox is a textured cube surrounding the mapped environment, which gives the impression of a more extensive world beyond the boundaries of the environment. The textures mapped onto the cubes representing the skybox was that of a forest scene. Other objects placed in the VE were logs (for the fire) and rocks. To add to the ambience of a sunset theme, the lights added were dimmed to create a dusk effect.

Figure 3.7 shows the static environment.



Figure 3.7: Perspective view of the static environment used in the VE depicting a forest. The logs shown are where the fire is positioned.

3.3.3 Dynamic environment

Unlike the static elements, which Genesis stores, the dynamic elements all have to be coded. The dynamic elements include dynamic lights, temporary objects, agents and objects which react to user input such as the movement of the user.

Genesis3D provides the API for creating dynamic elements. These include initialising them, adding them to the world geometry, removing them from the world as well as object manipulation. The dynamic elements coded for were actors, sounds and billboards.

The Sound class contains the functionality to add 3D sound to the world geometry. This includes

ambient and point sound. In order to create directional sound, the volume of each sound can be altered as the user moves around the environment. The sound can either be looping (as in the fire crackling or the sound of the crickets) or played once (as in the narratives).

The Actor class contains the functionality to initialise objects, add them to the world geometry, and manipulate their movements. Appendix E shows a behavioural specification of each of the four actors, drawn as a finite state machine (fsm). The behavioural specification shows the movements coded for each actor.

The Billboard class was used to create the fire. A billboard can be described as a textured 2D polygon that appears 3D, because it is always oriented to face the user, no matter what his or her position [101]. The billboard made use of 15 fire bitmaps, which were changed during every frame to create the illusion of an animated fire. To give it a more realistic feel, a dynamic light was added to the fire to give the illusion of a flickering fire. This was done by moving the light around randomly inside an area delimited around the fire. Figure 3.8 shows the fire.



Figure 3.8: Scene depicting the campfire in the VE

3.3.4 Actors

Animated meshes rendered by Genesis are called Actors. An actor can contain any number of poses such as standing, walking, sitting etc. Actors are created using a modelling package such as 3D Studio Max [12] or Milkshape 3D [15]. Actor Studio is a tool which converts animations in 3DS Max or Milkshape 3D format into a format which the Genesis3D engine can recognise, namely

.act format.

The agents used in the environment were all created with 3DS Max using pre-existing Character Studio models. Character Studio is a plug-in to 3DS Max which allows free-form animations to meshed models. The movements of each actor were altered from existing character studio movement files and tailored to support the actions mapped out by each actor's FSM diagram. Figure G.15 shows the four agents that were created with 3DS Max and Character Studio. The four agents were named Andile, Sarah, Ziggi and Godfrey.



Figure 3.9: Actors around fire from left to right: Andile, Ziggy, Godfrey and Sarah. Each actor tells their own story of being HIV positive.

To add to the appearance of a forest setting, numerous free models were taken from the internet, imported into 3DS Max and subsequently converted into .act file format by Actor Studio. These models include the trees which were placed on the periphery of the skybox, as well as various other miscellaneous objects.

3.3.5 Sound

Each actor in the VE was given a voice by a different voice actor. Three stories per person had to be recorded, that is, the diagnosis story, the adjustment story and the living with HIV story. Andile had extra recordings as he also welcomed the user into the environment and introduced them to the other agents.

Ambient sounds such as the sound of crickets chirping and general outdoor noise were also

added to the scene. These were free .wav files taken from the internet. The fire had a crackling sound associated with with it. This was also a free .wav file obtained form the internet.

3.4 Summary

In this chapter we have discussed the procedure followed in designing the VE. The overall design process was facilitated by the use of storyboards. From the storyboard, the VE could be planned and structured, and potential design flaws could be highlighted. We then discussed the creation of the VE, which required the design and implementation of the following features:

- The writing of the narratives to be used.
- The static environment consisting of the forest.
- The dynamic environment consisting of the fire, sound and actors.
- The actors as well as their corresponding movements.
- The recordings of the narratives to be used.

Chapter 4

Experimental Design

In this chapter I discuss the design methodology used in my research. Section 4.1 discusses qualitative research, paying emphasis on the methods used for grounded theory. Section 4.2 describes the external experimental conditions viz. the venue, the equipment used, and the recruitment of subjects. Section 4.3 discusses the procedure followed by the participants. First, it describes the introductory stage whereby participants were prepared for their exposure to the VR. It then describes the training stage, the exploratory stage, and finally, the interview stage. Finally, section 2.7 provides a summary of the main points found in this chapter.

4.1 Methodology

Qualitative research, and specifically Grounded Theory [24], is ideally suited to discover and understand what lies behind a phenomenon of which little is known as yet [11]. Since this study is a novel attempt to discover the subjective response of a person living with HIV to a VR scenario, it lends itself more to qualitative research than a quantitative one. Qualitative methods delve deeper into a phenomena, providing intricate details about an area of study. A more in-depth understanding of experiences of participants can therefore be achieved, paving the way for future research done in the area of HIV/AIDS and VR.

4.1.1 Qualitative research

Qualitative research can best be described as an analysis that provides findings or concepts which are not necessarily arrived at by statistical methods [11]. There are three major components of qualitative research [17]. Firstly, there is *data collection*. Secondly, there is the *methods analysis* used to arrive at the findings or theories, and finally the third part which is the verbal or written

presentation of the findings.

4.1.2 Grounded theory

A grounded theory is developed and verified through data collection and analysis of data pertaining to the phenomenon it represents [11]. It involves collecting, coding and analysing data. Coding is the process of categorising and sorting data. Codes serve as shorthand devices to label, separate and compile organised data [25]. Glaser states that the “grounded theory approach is a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive theory [17].”

Grounded theory differs from other methodologies such as content analysis, phenomenology or narrative analysis in that [103] :

1. All concepts found are generated from the data under study, rather than from previous studies. Previous studies are however used, for instance, to verify data or augment concepts.
2. It allows the researcher to discover concepts from the research scene rather than describing the research area under study.
3. It compares pieces of data with each other rather than comparing totals of indices.
4. It allows the collection of data to be modified, according to how the research is advancing. False leads are eliminated, and more questions are asked if necessary.
5. It does not adopt a linear process, but rather the investigator works with a matrix in which several research processes are in operation at once. For example, the data is examined, coded, categorised, and conceptualised as they arrive. The researcher also writes down thoughts about the research almost from the beginning.

Below follows a brief description of the grounded theory method [103] [25] [11].

Collection of empirical data

Unlike other approaches to qualitative research, it is not important to review all background information pertaining to the study. The reason underlying this is because too much background information might skew the research — i.e. categories and relationships among them want to be explored in new ways rather than the standard ones conformed to in the literature. However, some forms of background information are useful as is described below [11]:

- Theories found in the literature can provide a means of interpreting data. The theories pertaining to the positive effects of group support can be compared to the data obtained from people attending a virtual group support.
- Material such as quotations from interviews and field notes, as well as descriptive materials concerning events, actions, setting and actors' perspectives can be used as secondary sources of data.
- The literature can also direct the researcher to sources important to the development of the theory.
- It can be used to validate theories.

Data can be collected from different sources such as interviews, observations or a combination of these.

4.1.3 Coding/Analysis of data

Coding is described as the process by which data is broken down, conceptualised, and put together again. During coding the data is broken down into parts. This means that each idea or event or incident found in a sentence or paragraph, and representing a phenomenon, is given a label. Labels pertaining to the same phenomenon are then grouped together and categorised, and given a name. Categories are commonly developed in terms of their properties, which can be dimensionalised. For example, the category colour can be developed in terms of its shade, intensity and hue. Each subsequent subgroup under colour can therefore be dimensionalised in terms of its shade, intensity and hue.

4.1.4 Production of the research report

It is important for the researcher to keep a record of the above process. These are done via memos and diagrams. Memos contain the details and outcomes of the coding process as well as summarizing notes about the procedure. These, as well as the hypothetical theories formulated during selective coding, serve as aids in the writing of the final report.

4.2 Materials

4.2.1 Ethics Committee Approval

According to the standards set out by the University of Cape Town (UCT) [108], experiments involving human subjects must be approved by the University Ethics Committee. Approval was

obtained subject to the following conditions:

- The participants' consent to participate in the experiments should be informed and uncoerced.
- The participant has a right to refuse to participate in the research or to withdraw at any stage.
- There should be a support mechanism in place to protect the participants against any foreseeable physical, psychological or social harm which might be experienced during the experimental process. A psychologist will be present throughout to conduct the interviews.
- Personal information pertaining to the participant, must be kept confidential.

All the above conditions were adhered to when recruiting participants for the study.

4.2.2 Venue

The experiment was conducted in a private office where lighting and extraneous noise could be regulated. The room was partly partitioned into two areas. The experimenter could stand at one end of the partitioned room and observe the participants without causing a distraction to them. Interviews were conducted in a office opposite to the experimental room.

4.2.3 Subjects

Seven participants took part in the study. Participants for the study were HIV-positive volunteers were all referred to by community counsellors (based at community clinics) who have been professionally involved with the participants. Mignon Coetzee supervises and mentors these counsellors, and was therefore available to offer them and their clients support, both during and after the experiments. The participants' identities remained confidential at all times and pseudonyms were used during the course of the experiment. Each participant signed an informed consent form, explaining the purpose and nature of the experiment. Post-experimental counselling was available to participants, immediately after the VR experience as well as for a longer period, if needed.

4.2.4 Computers

One dedicated computer was used for the experiment. The computer, named ZORRO was equipped with the following hardware and software:

- Compaq EVO W8000 Workstation
- 2305 MB Physical Memory (RAM)
- GeForce4 TI4600 Graphics Card

- 19 Inch Monitor
- Windows XP Professional
- Creative Audigy Sound Card
- Keyboard and Mouse
- Dual Pentium III Xeon 1.7G

4.3 Participant procedure

4.3.1 Introduction stage

The participants were taken into the experimental venue and told that they would be taking part in a VR experiment to further VR research. The experimenter explained that it was a storytelling application, whereby everyone around the fire had a story to tell. The participants were told that that their role in the evaluation of the system was to explore the VR environment as they wished.

4.3.2 Training system

The participants were given an information sheet detailing the keyboard and mouse controls of the system. The experimenter then displayed the environment to the participant, explaining the movement interface. The experimenter started by giving the participant an arbitrary task to complete, usually the finding of the computer room (See Figure 4.10(a)). The experimenter would then leave the participant alone with the system for five minutes to explore at whim. The experimenter then exposed the participant to the second part of the test environment, which consisted of following an agent into a room where people were dancing. In the room, there was a jukebox playing a particular song (See Figure 4.10(b)). The user was able to change the song playing on the jukebox, by toggling the function keys F1, F2 and F3. Each key was associated with a particular song. The experimenter was available in the room during the training session to help with any problems encountered. Only once the experimenter felt the participant was comfortable with the movement interface, did the exposure to the real environment take place. Appendix F shows images taken from the VE.

4.3.3 Exploration stage

The environment was started with the experimenter explaining the procedure in the environment. Participants were told they could leave at any moment, and that completion of the entire VR application was not compulsory. The experimenter remained in the room with the participant, to provide



Figure 4.10: a) The computer room b) Girl dancing to a tune playing on the jukebox

assistance if needed. The dividers separated the experimenter from the participants. Appendix G shows images taken from the VE.

4.3.4 Interview stage

The data collected were obtained by means of semistructured interviews. All of the interviews had a preset list of questions all focusing on three themes — presence, social support (emotional, tangible, and informational), although any new topics which arose were probed. Each interview ranged from 30 to 60 minutes, with each interview being audiotaped and then subsequently transcribed.

4.4 Summary

In this chapter, I discuss the experimental design pertaining to our research. I looked at qualitative research, specifically grounded theory, and the reasons underlying its choice as experimental method. Qualitative research, and specifically Grounded Theory [24], is known to be ideally suited to discover and understand what lies behind a phenomenon of which little is yet known [11]. Since this study is a novel attempt to discover the subjective experience of a person living with HIV to a VR scenario, it lent itself more to qualitative research than quantitative research. I provided an overview of the grounded theory method, viz data collection, coding and the writeup of the report. Coding is described as the process by which data is broken down, conceptualised, and put together again. I then looked at the materials needed for this experiment, viz venue, equipment and the recruitment of participants. I also discuss the terms and conditions agreed upon for ethics committee approval. Finally, I discussed the procedure followed by the participants. There were four stages

which were followed by the participants viz. an introduction stage, training stage, exploration stage and interview stage. During the introduction stage, the participants were briefed on the procedure which was going to be followed. During the training and exploratory stage, the participants were introduced to the training and exploratory VR respectively. The participants were then subjected to an interview.

Chapter 5

Results

The VR environment aimed to test the following:

- The efficacy of VR as an emotive medium.
- The efficacy of the VR simulation as a source of social support.

I hypothesise the following is true:

- VR provides a source of support to people living with HIV/AIDS.
- VR has an emotional impact on people living with HIV/AIDS.

As mentioned in the previous chapter, there are three stages in qualitative research, viz. data collection, analysis and the writeup of the final report.

The analysis of the data collected via interviews went through three different phases. Firstly, each interview was broken down into categories. The second phase consisted of the clustering together of categories in each interview pertaining to a common phenomenon. The third phase consisted of clustering of phenomena between interviews into categories. The categories were each examined in turn for overlaps, and dimesionalised according to their properties.

The final emergent categories were emotional impact, emotional support, informational support, technology considerations, comparison with other forms of support, timing considerations and emotional presence. The quotes relating to these themes can be found in Appendix H.

The categories can be grouped according to the research questions above viz.

- The efficacy of VR as an emotive medium (Presence, Emotional Impact, Computer Considerations)
- The efficacy of the VR simulation as a source of social support (Emotional and Informational Support)

- Additional themes(Timing considerations, Comparison with other forms of counselling, Comparisons with other Media of Support)

What follows below is a discussion of each of the categories.

5.1 The efficacy of VR as an emotive medium

5.1.1 Emotional impact

In order to determine the efficacy of VR as an emotive medium, the emotional impact of the environment on the participants was explored. The emotional responses were on a continuum from very positive to very negative. From the responses received, there seemed to be a correlation between the emotions elicited by the stories and participants' emotional state at the time the experiment was conducted, as well as their recollection of their emotions at different stages of their own adjustment to their HIV status.

As one participant explained, the VR experience is a:

little bit emotional at times...if your're at a certain level that experience is okay. It's a matter of what stage you are at, what is your understanding. (Participant 1)

The negative responses were associated with certain aspects of the stories, in particular the aspects dealing with the shock of learning about one's HIV status. Participants reported that they found this distressing as it reactivated memories of their own shock. Participant 2 explained:

I listened to him [VR character], it made me think back.....about the diagnosis....I didn't want to take [accept] it.....I was also back there.

Other responses confirmed the fact that this particular part of the stories had a strong emotional impact, but was negatively experienced. Participant 4 stated:

The diagnosis (upset me).

and Participant 7

It [the diagnosis] touched me (Participant 7)

What became evident was that the diagnosis aspect of the stories served as a reminder of the emotions elicited at the time of the individuals' diagnosis. This moment is often associated with trauma (shock, despair, acute anxiety, depressive reactions,) [28]. Of note is the fact that participants experienced a reasonable amount of control over their environment and actively chose to avoid those aspects of the VR stories they found distressing.

As was reported by Participant 7:

Its been a trauma from me...so I skipped it.

From the responses recorded, it was clear that participants related to the VR characters and stories in very individual ways. The stories themselves drew on different experiences and responses of HIV positive people, and thus triggered some personal associations for participants. A wide range of emotional responses were recorded. Depending on their own life stories, participants related to the different VR characters in unique ways.

The various input from the VR characters in terms of coping styles, also added to the emotional impact of the experience. As Participant 1 commented:

[What made me emotional was] the different stories that they [VR characters] were telling, the different views, how they coped, the way they broke the news to their friends, also how they were planning to move forward with their lives.

In general, participants found it encouraging to hear first hand knowledge from other HIV individuals rather than from other sources. Participant 1 remarked that the experience was useful:

because it was not just from a theoretical point of view, but practical. Because those are the people that it affected.

In summary, in addition to the usefulness of the content, the VR interaction with HIV positive individuals together with the ability to engage and disengage with characters at will (and in a personalised manner), added to the overall emotional impact.

5.1.2 Presence

The statements made by the participants seemed to indicate that they experienced presence. Reference was made to both the forest environment and the interaction with characters. Participant 1 described it as being as if “*you are talking face to face, like you [interviewer] and me*”

Others reflected:

I was there in the forest (Participant 3)

..I felt that I'm with them...when I was listening I felt like I was also with them in the forest (Participant 4)

Its like I'm there with them....I feel I'm there by the fire. (Participant 7)

There was mention of the the forest environment being ‘real’ (Participant2) or as Participant 6 remarked:

To me, it was like I'm in the forest...I was feeling like I was in there.

Not all of the participants felt presence. Participant 5 reflected the following:

No (It did not feel like I was in the forest with them).

The statements made above are in line with the definitions and uses of presence most commonly being used in the literature viz. that presence in VE's is a sense of 'being there', i.e., the user feels that they are physically in the world represented by the VE rather than just seeing the images depicting the world [70, 19, 82, 51, 107, 71].

5.1.3 Psychological impact of computer

The majority of the participants had never used a computer before. They met this challenge with varying degrees of excitement and trepidation. The practice session provided the participants with an opportunity to acquaint themselves with the technology and familiarise themselves with the navigation skills needed in the VR environment.

Participant 2 commented the following:

...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."

This comment introduced a theme not anticipated by the research objective, namely the psychological impact of the medium on participants. In her reflection, Participant 2 reveals a sense of the virus having limited her dreams and ambitions - as if having the virus affects her own and others' view of her right to growth opportunities. She expresses the value of exposure to learning (in this instance, the computer interface) in her comment of "even if you are HIV positive". She sees it as an affirmation or reminder of being alive and of being entitled to a future, just like those who are HIV negative.

Despite being novice users, they found the interface easy to use, mastering the skills needed very quickly after being given a brief training session.

No, it was not. [complicated to use the system] ...The instructor showed me how to use the computer, so it was very easy for me. (Participant 2)

It was very quick [to learn], because I understood it better [well]. (Participant 7)

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 education and consequent employment opportunities - a chance for a better future, so to speak. Participants therefore felt privileged at being given the opportunity to use a computer. It instilled in them a sense of power and achievement, and served as a morale booster.

5.2 The efficacy of VR as a source of social support

The stories shared by the VR characters in the VR environment were constructed in a such a way that they illustrated and reinforced coping skills that have been found to correlate with better adjustment and subsequent improved quality of life.

As pointed out earlier, social support can be divided into three primary categories [86] [31]:

1. instrumental/practical social support refer to goods and services which help people solve practical problems.
2. Informational/cognitive support refers to information/knowledge/advice that helps people to understand their circumstances and help people adapt to it.
3. Emotional support is the receiving of emotional comfort.

HIV support groups are known to be a valuable source of all three forms of support. Thus the environment simulated is that of a VR support group, and I aimed to see to what extent the simulation could provided the same benefits as a real support group.

5.2.1 Informational support

Generally, it was felt that the VE reinforced benefits provided by support groups. These were similar to those stated by Ribble [30] such as behaviour change information and reinforcement for positive behaviour changes, motivation and information sharing.

Participant 2 remarked about the informative nature of the experience

It gives you information on how to live it.

Although the importance of the availability of information independent of its mode of conveyance was empahsised, participants did remark on the effectiveness of the VR scene as a source of informational support. This is supported by Participant 2 who remarked that:

Ja, reading is also different, but I think I prefer this, because maybe I (just) like it.
(Participant 1)

By simulating a support group, participants got a sense of the nature of group counselling, and its potential benefits. Prior to the experience, Participant 6 had viewed counselling as being potentially hostile and discriminatory, remarking on the fact that exposure to such groups meant disclosure. However, exposure to the VR simulation presented an alternative viewpoint. Having seen the VR group, Participant 5 was inspired to visit a real group and commented the following:

I want to find a support group in my area...Seeing the computer, I think it is better going to a support group.

The results are in accordance with studies done by Hays *et al* and Swindells [98, 86], who state that informational support is beneficial to people at early stages of the disease. The participants' views on the benefits of the VE programme in terms of information support are reflected in the literature pertaining to support groups providing informational support [30, 61].

5.2.2 Emotional support

Despite the diagnosis aspect of the stories having a negative emotional effect, participants felt the stories on the whole were emotionally uplifting, as it helped them reaffirm their strengths in coping with HIV and disclosing their status to other people.

When asked about the effect the environment had on them, the participants had the following to say:

The computer thing encouraged me.....I must be more comfortable with myself....It [the stories being told] made me strong. (Participant 3).

For me it made me proud of myself..... (The effect the stories had on me) made me strong (Participant 7).

Now I'm not afraid to tell the people (Participant 4).

Research findings indicate that the emotional benefits of attending support groups include amongst other things information and advice pertaining to how to cope with the disease on a physical, emotional and social level [61]. Similar benefits were noted by participants when listening to the stories told in the VE. The experience highlighted the emotional benefits of sharing information with other people, specifically those who are also HIV positive.

Those people there [the virtual characters], they're not afraid to confirm about it [HIV status],.....they strong enough to work as a team. (Participant 4)

One participant remarked that the VR experience had encouraged her to seek the help of support groups, so that she would receive the emotional benefits exhibited in the VE.

So now by listening to that story, I feel that I can go to the support group.....Its because everyone shared their feelings. (Participant 7)

Studies point to emotional support as being the most desirable form of support. It is also more often used than any other forms of support [2]. Support groups offer an emotional outlet in an

environment where they can address troublesome and emotional issues. There are two phases to emotional support - hearing from others and being encouraged by it: and having an opportunity to share your story with others. A limitation of the VR experience was that participants did not have a chance to relay their own life stories. The importance of having an emotional outlet was mentioned by Participant 3 who felt that “I must leave for the next person information”. This is also an indication of seeing others as benefiting from her life story.

5.3 Additional themes

5.3.1 Comparison with other forms of support

Most of the participants had received post diagnosis counselling and a few still attended occasional counselling sessions. The participants compared the counselling that they received to the cathartic effects the stories had when listening to them.

Participant 2, despite being HIV positive herself, provides post diagnosis counselling to HIV positive people. She remarked that

the way that he was expressing it [his way of coping] was like the way we as counsellors are giving people advice about AIDS effects...Its the same thing as what I am doing.

This was further supported by Participant 4, who commented that the experience was a very positive one - similar to the cathartic experience with a counsellor.

When I was listening to their stories, the way the counsellor did counsel me, it was like that.

It was suggested that this was an ideal support tool for patients who were afraid of disclosing their status and were thus prevented from receiving the support that they need. Participant 2, who is also a counsellor, reflected on the unique value of the VR experience:

Its a good idea for my client who hadn't accepted it. Participant 2

Some participants saw the VR environment as a resource which augmented counselling and support groups, rather than replace them.

This was supported by Participant 5 and Participant 1 who said respectively:

Its easier to listen to that before you go into the support group. (Participant 5)

I should think counselling first, going through different sessions with a counsellor. To get a clearer, broader picture. Then that (would) sort of add to what a counsellor can do. (Participant1)

One participant 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 your're sitting there. (Participant 6)

Although the participants drew parallels between the VE and a real support group and 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. However, as participants indicated, 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.

5.4 Timing considerations

There were mixed feelings as to when to introduce a system like the VE to people diagnosed with HIV. One participant relayed that it was dependant on a person's mental adjustment to his HIV status, and thus should be used with caution immediately following a diagnosis.

Well, I think as far as my own experience is concerned, at that point I don't think it would have been useful, because emotionally, when people come to you with this and that, it's not necessarily that you don't want to listen, but you're too emotional. I mean, the day when the news was broken to me, if someone had said: "There's a computer in the next room", that would have been useless at that moment. So I should think that it's imperative to give someone time to adjustAt a very much later stage, approximately after six months, I would say, depending on how one adjusts and accepts, accepts the facts.....Yes, you have to pass certain stages first. (Participant 1)

Participant 2 suggested it was dependant on the emotional support the person got from his friends and family.

...at the point where the family says it's time, you must go.

However, there were some participants who thought that such a tool would be helpful immediately.

It would have helped me (day I got the diagnosis, or a week or two after that) (Participant 3)

In a study done by Molassiotis *et al* [6], immediate peer-support/counselling correlated with a decrease in every domain of psychological functioning (e.g. confusion, depression, overall mood disturbance, tension and anxiety). This study supports the comments made by Participant 1 and 2 - a period of mental adjustment is needed before the participant is ready to be exposed to any intervention programme such as the VE.

5.4.1 Comparisons with other media of support

The participants stipulated that they preferred the VR technology over other media, because it allowed them freedom of control, as well as interactivity. When asked how the VR intervention differed from the videos sometimes screened at community clinics, participants consistently preferred the VR medium. One of the participants reflected on the advantage of an individualised VR experience as opposed to the more public video screenings

It is because of the action. (Participant 3)

To me the computer thing is much better, because you can listen [you can] start and stop. Sometimes when you're watching the video other people are making a noise around. (Participant 6)

Participants also made reference to the visual impact of the VR medium, as well as the interactivity factor:

On the computer you can walk around and move around the fire. (Participant 7).

(the computer) is more visual. (Participant 1)

One participant made a reference to printed media, expressing his preference for the VR experience.

Ja, reading is also different, but I think I prefer this (Participant 1)

The participant also referred to the computer experience as affecting him more emotionally than television or printed media. His reasons were the following:

Because that is not just from a theoretical point of view, but practical. Because those are the people that it affected. (Participant 1)

Not all participants felt the difference between the different media. One participant remarked that:

Like looking (at) something on the TV (Participant 5)

The participants indicated a strong preference for the VR experience, stating interactivity, degree of control and visual stimulation as their reasons. Interactivity, is also a key factor contributing to presence [79] and presence is seen as the difference between VR and other media.

5.5 Discussion

The emergent themes above highlight the potential of VR as a therapeutic medium and potential support tool for people living with HIV/AIDS.

5.5.1 Efficacy of VR as an emotive medium and as a source of social support

The process of coming to terms with an HIV diagnosis requires a change in relationships, psychological outlook, view about the future and everyday life and a mental adjustment [27]. Once diagnosed HIV positive, uncertainty about the reason the disease has stuck and future expectations can be reduced by searching for similarities between their situations and those of fellow sufferers. Although, the stories in the VR environment were limited to four, participants still found connections with their own situations and admitted to finding the stories comforting and cathartic.

In a study conducted by Sandstrom [61], it was found that people chose to get involved in HIV-related support groups because they were searching three kinds of support, viz.

- Information and advice on how to cope with the physical, emotional and social issues pertaining to HIV.
- empathy and emotional relief - a place which could serve as an emotional outlet that promoted the sharing of problematic feelings and experiences.
- camaraderie and friendship (i.e. intimate ties with others who could empathise with their situations and did not feel threatened by their health status).

With the exception of the third point, participants received the same kinds of benefits highlighted above. It can thus be concluded that VR can be used a mechanism to provide emotional and informational support similar to those provided by support groups.

DiPasquale in her study of the psychological effects of support groups on individuals infected by the AIDS virus [46] states that one of the impacts of society should be to educate individuals with AIDS and professional personas who work with HIV positive people to be aware of the psychological benefits that support groups can provide. Several of the participants reported seeing the benefits of attending support groups after exposure to the VE. One of the participants also reported that the VE had changed her perceptions of a support group from being threatening and hostile, to being supportive.

Although many of the participants had never used a computer before, they quickly mastered the skills needed to use the VR system. Many of the participants viewed the computer as being part of the world of the educated and privileged. It was therefore a confidence booster that they were given the opportunity to use a computer, and master the skills needed.

With the escalation of the HIV pandemic and the current restraints on support services within communities, there is a growing need for innovative approaches to HIV counselling. With limited human resources available, alternative approaches to HIV counselling need to be considered. The VE above demonstrates a novel way of providing some of the proven benefits of support groups. Although such a system would not replace counselling, it could play a major role on augmenting counselling or steering people towards counselling.

5.5.2 Hypothesis 1: VR provides a source of social support to people living with HIV/AIDS

Generally, it was felt that the VE reinforced the supportive benefits provided by support groups. The participants affirmed that the VR environment acted as a source of social support - both directly as information and emotional support and indirectly as cognitive support. The interviews suggest that the hypothesis is correct, viz. that the VR system provides a source of social support to people living with HIV/AIDS.

5.5.3 Hypothesis 2: The VR system will have an emotional impact on people living with HIV/AIDS

The VR interaction with HIV positive individuals together with the ability to engage and disengage with characters at will (and in a personalised manner) added to the overall emotional impact that the participants experienced. The emotional responses were on a continuum from very positive to very negative. From the responses received, there seemed to be a correlation between the emotions elicited by the stories and participants' emotional state at the time the experiment was conducted, as well as their recollection of their emotions at different stages of their own adjustment to their HIV status. With the exception of one participant, participants all reported to experiencing a sense of presence in the VE. They reported to feeling as if the environment was real, as if they were really there. This is consistent with the common definition of presence used by researchers i.e. presence as defined as the sense of 'being there' [70, 19, 82, 51, 107, 71]. The participant who reported no feeling of presence also indicated that the experience traumatised her, and was hence not supportive although it did highlight the importance of going to a support group.

Chapter 6

Conclusions

This report presented an exploratory investigation into the efficacy of VR as an emotive medium, as well as the efficacy of VR as a source of social support. Two hypothesis were presented viz.

- VR provides a source of social support to people living with HIV/AIDS.
- VR has an emotional impact on people living with HIV/AIDS.

The project built up on the findings of previous psychological research which showed that the telling of personal and collective narratives in an HIV/AIDS support group is greatly beneficial in providing information and support through shared insights, intense connection and comfort [89].

This fact, together with the tested ability of VR as a therapeutic medium, led to the development of a virtual support group. The scene was set around a campfire, whereby the virtual characters shared their own personal experiences of HIV/AIDS. The users to the system were people living with HIV who had been diagnosed in the six months prior to being exposed to the VE. The research was addressed qualitatively through unstructured interviews, followed by a discourse analysis of the data. The interviews were conducted by a clinical psychologist.

This chapter draws conclusions on the various findings by first presenting the potential of VR as an emotive medium, then discussing the potential efficacy of VR as a source of social support. Conclusions gained from themes not anticipated are also drawn. We then illustrate the findings with regard to the two hypothesis stated above. It then concludes by summarising the report's suggestions for future work.

6.1 The Efficacy of VR as an Emotive Medium

The experiment showed extensive qualitative support for the VR system's ability to elicit emotional responses from users. Two responses were gauged — a positive emotional response and a negative

one. These responses corresponded to the users feelings at specific stages of their experiences with HIV. The diagnosis aspect of the stories in particular was particularly traumatic, as it triggered connectional feelings which are known to be the most traumatic. The stories associated with adjusting to HIV, as well as living with HIV, gauged a positive response, one which promoted encouragement. A theme not anticipated by the research objective was the psychological impact of the medium on the participants. Participants felt privileged at being given the opportunity to use a computer. It instilled in them a sense of power and achievement. Participants did experience a sense of presence, although the levels of presence was difficult to measure qualitatively. This will be discussed later in section 6.3.2

The statements made by the participants suggest that VR has a strong efficacy as an emotive medium.

6.2 The Efficacy of the VR Simulation as a Source of Social Support

Participants felt that the VR simulation did act as a source of social support — both directly as information and emotional support and indirectly as cognitive support. Generally, participants felt that the VE reinforced benefits provided by support groups. Participants felt that the VR environment were an effective medium to relay information about HIV due to factors such as locus of control and interactivity.

Although the diagnosis were emotionally disturbing, participants found the the ‘living with’ as well as ‘Adjustment’ stories emotionally uplifting and a great source of emotional support. The participants felt that the stories on a whole were uplifting as it helped them to reaffirm their strengths in coping with HIV and disclosing their status to other people. However, a limitation of the VR experience was that the participants did not have a chance to relay their own life stories.

Although the VE did not provide cognitive support, it did encourage them to seek the support of peers, family and friends.

It can be concluded that the VR system does have the potential to act as a source of social support for people living with HIV/AIDS.

6.3 Additional Themes

Two themes were not anticipated by the VR medium; comparisons to other forms of counselling and timing considerations.

Comparisons were made with traditional forms of support, specifically counselling. Although preference was made to the tangible counselling sessions, participants felt that the VR simulation

could act as a tool which could augment traditional counselling sessions. The benefits highlighted included easy access and acclimatising patients to real therapy sessions.

The issue of when to introduce such a tool was mentioned, with some participants remarking that it would be ideal post-diagnosis. However, one participant did feel that a period of adjustment was needed before introducing the VR medium.

The third theme, comparisons with other media of support will be discussed in context of the hypothesis below.

6.3.1 Hypothesis 1: VR provides a source of social support to people living with HIV/AIDS.

The interviews suggest that the hypothesis is correct viz that the VR system did provide a source of social support to people living with HIV/AIDS. Contributing factors were the degree of control and interactivity the VR experience provided. Comparisons were made with television, with participants preferring the VR medium.

6.3.2 Hypothesis 2: The VR system will have an emotional impact on people living with HIV/AIDS.

The interviews demonstrated that the VR system did have an emotional impact on the participants. These were on a continuum from positive to negative, with participants being reminded of their own experiences.

6.4 Future Work

The following possibilities for future work were identified during the course of this project:

- **An outlet for participants to relay their own stories** There are two phases to emotional support - hearing from other people and being encouraged by it: and then having an opportunity share one's story. The VE experience made people realize that it was not important to gain knowledge about the disease, but also to share experiences and information with other people. This could possibly provide a more cathartic experience to people living with HIV.
- **Relationship between presence and levels of social support received** This would be a quantitative research, with a comparisons between high and low presence situations.
- **A more broader representation of users.** South Africa is a multi-cultural, multilingual country. The agents who tell the story could be more representative of the cultures found in South Africa. The stories being told can also be translated into other languages.

- **Collaborative storytelling.** A collaborative environment across a network would facilitate multiple users, allowing the sharing of stories and discussion groups.
- **Additional themes.** Other themes which could be introduced include a depiction of how the virus works, health issues, different treatment issues. A visual representation of each of these issues could prove to be effective.

In conclusion, VE's have been proved to be emotive mediums and effective in relaying information about HIV. Therefore, its uses can incorporate both people living with HIV and those who do not have HIV.

Appendix A

Andile's Story

A.1 Diagnosis

I can still remember the day so clearly.... I did not just get up that morning and decided to go to the clinic, it was something I had prepared myself for for days and days. When I look back now I think there was something in me that knew what the test result would be. I tried to put it out of my mind for a long time and I think that it made it worse. I was trying to carry on with my life as if everything was fine, but inside me I was so scared.

The week before I went for the test we had an HIV counselor do a talk at work. We all got together in the factory cafeteria and this woman spoke to us about AIDS and what the symptoms are and how to practice safe sex - all the normal things that you always hear on TV. But my heart stopped beating when she talked about the symptoms. I felt the fear inside me get stronger and stronger, every symptoms she listed I recognised. She was talking about me! That was the moment I knew for certain.

But it still took me a week to get enough courage to go for a test. These things are difficult.... I walked around in a daze all week long, and then on the Friday morning I went to the clinic. The waiting felt like forever. The woman who counseled me talked about everything, I only remember small pieces of the conversation. And then I had the test, and waiting again. When she called me in to give me the results I tried to read her face to see if there was a sign that could tell me the news. The next few minutes was like a dream. 'Andile, your test came out positive.' The words echoed in my head, Andile, your test came out positive, your test came out positive... I heard nothing else. I know she spoke, but I did not hear a word. The only thing I remember was when she said, come and see again on Monday Andile.

When I walked out of there I did not know where to go. So many decisions had to be taken, so many questions. Is it true? What do I do now? Who should I tell? What will my girlfriend say, how

can I ever tell her? What will this do to my mother? Why did it have to happen to me? I have been a good person, why must it happen to me? Will I die alone? It felt like I was dead already.

That weekend I spent most of my time alone. I needed to think about this HIV thing and I was feeling so much sadness. And then the sadness would become anger, rage! I wanted to shout 'why me!!' It is unfair, I do not deserve this. But there was no-one to be angry with, just myself. And that weekend I hated myself. I sat in my room thinking of ending my life. It was the darkest day of my life, I could not see how to move on. It felt as if everything was over anyway and I would be better off just dying.

I know everybody in the house wanted to know why I was so quiet and why I kept away from them, but I could not speak, not then. On Sunday I went to church, something I didn't often do, and sitting there I felt things inside my heart get easier. I thought of the virus in my body, how small it is and suddenly it seemed possible to fight it, to keep it under control and not let it take over my life. That was a turning point. While sitting in church I decided to go back to the clinic, to the woman I spoke to. She was the only person who knew about my status, and maybe she could help me do this. She had all the information and she seemed to think it was OK.

A.2 Adjusting to HIV

On Monday I was back at the clinic. I had to phone work to tell them I could not come in. It is the little things like this that is hard. You think maybe someone will get suspicious and they will know you are HIV positive.

At the clinic I waited again, but it was easier, I knew the answer and I started to see the future again. From thinking that death was the only option I started to imagine living. The counselor - her name is Patricia - I got to know her over the past months, was smiling when she saw me. I don't think she could ever know how much that smile meant to me. We sat in her office and she slowly talked through everything with me. She explained again how the virus works, how my immune system is like little soldiers fighting this virus. She showed me my CD4 blood count and explained how I need to keep it high. I learnt that I had to build my immune system to stay strong and healthy.

I listened to what she said about exercising, eating good food, resting enough and all that stuff. It sounded good, these were things I always wanted to do anyway. I even felt a little bit excited.

But then she spoke about sex and telling my partner about my status and everything looked impossible again. Never having sex without a condom. Yes, I knew I should have done that before, now I have no choice. But what about my darling Pumza. We have been in a relationship for just over a year and I could not believe how lucky I was to have someone like her love me. She is the kindest woman, with big eyes. When she laughed she looked like an angel. What if I infected her, how would I tell her, and I would have to tell her. I cannot hide this from her, she will notice. And

she deserves to know, this thing affects her too.

Patricia helped me see how important it was for me and for Pumza to know everything. As much as I wanted to keep Pumza out of this it was impossible. She was already a part of it. I was just so scared of losing her. My mind was so full of thoughts about infecting her, losing her, infecting her. But slowly Patricia helped me calm the thoughts down and we discussed how I could tell Pumza. Patricia's smile gave me courage, she seemed to know exactly what to do when I was feeling so scared. She said I could bring Pumza along to talk and to be tested if she wanted to.

Telling Pumza was the first step to accepting my status and living with it. I prepared myself that evening. Pumza arrived after work and we sat in my room. She knew something was wrong. And then I said it... Her face was frozen for a moment. And then I saw a tear roll over her cheek. She looked at me, questioning, and then her hand slowly reached out and touched mine. 'We will live with it Andile, you and I'

A.3 Living with HIV

After telling Pumza it was easier to tell other people too. Not everyone reacted like Pumza. My sister pulled away and still cannot hug me as before, my mother is suffering, I can see that. I am her only son and it is painful for her. She watches my health like a hawk, she checks that I eat every meal and when I look a little tired she will make me rest.

I have not told too many people about my status, but as time goes by I do share it. I see people are scared when I tell them, not scared of me, but scared for their own lives. It helps me to talk to them because I have learnt something from my situation. If my story can help someone else it is worth it.

It is now 18 months since I found out that I am HIV positive. A different Andile is sitting here with you today. Having this virus in my body has changed so many things. When people hear that I am HIV positive they think it is a tragedy and I can see they feel sorry for me. But I have come to see this virus as an opportunity to change my life. And so much has changed for the better. There are difficult things. The hardest was finding out that Pumza was positive too. My dearest Pumza, without her it would have been so much harder.

But in my life I can now see how to keep myself strong and how to live. I see other HIV positive people who are not able to fight back and I see how they die, slowly slowly. I know that my mind is the best medicine I can get. I talk to myself, I tell myself that I can fight this virus, that I am able to keep my immune system strong by being positive. I say, Andile, you are able to control how you feel and what you think. When you feel down you can change it. I know I need people too, so I try to speak to people, some are also HIV positive, some are not. And by talking about my feelings I find it gets easier. Sometimes I will tell someone how scared I am of getting sick, you know, really

sick, and what if there is no-one to look after me. If I sit with that fear all alone it gets bigger and bigger. And that is the kind of thing that brings me down. But then I find someone who can listen and it helps to share the burden.

I am not on any drugs, but I make sure that I eat well. There is not always money for fresh fruit and vegetables, but I do my best. It is a priority in my life. It was difficult for me to stop smoking and drinking. But I know from everything I have read that if I choose life I must not do things that will break me down. Pumza and my mother are very happy about this; they never liked my smoking and drinking anyway.

I visit the clinic regularly and often pop in to speak to Patricia, the counselor. They are starting a support group for HIV positive people and she really wants me to join. She believes my positive attitude is what is keeping me healthy and she thinks other people can learn from me. It makes me feel good when she says that. I have never been very good at anything, one of those lazy students who just gets through. After school I struggled to get work and finally my uncle helped me get this job at the factory. And there I am just one of hundreds doing the same thing. But here I have found the thing I am good at, I am able to keep my mind positive and live a good life, full of love and happiness - even if I am HIV positive.

Appendix B

Godfrey's Story

B.1 Diagnosis

Learning about the diagnosis Two of my close friends died before my eyes. I think we all knew they had AIDS. And yet, during those months of their illness no-one ever mentioned it. People hushed around their beds and whispered something about cancer or TB, but never was AIDS mentioned. I also preferred to pretend it was not there. It was too frightening to even consider.

It was not long after the second one died that I noticed I was having regular health problems. I cannot explain this to you but it was as if I tried to ignore the truth of what was going on one hundred percent. All the symptoms were there but I made myself believe that it was nothing - I explained it every other way I could: you are just a bit too tired and burnt-out; you've been working too hard, you'll get over it.

I tried to stay busy and go out and have fun, but my body would collapse from tiredness. I would tell myself: you've just been drinking too much, too many late nights. But it got so bad that I could not run away from it anymore. Finally I went to see a doctor. I think he just gave me one look and decided that I had to be tested for HIV. It was still not something I wanted to consider, maybe because deep down I knew it so well already.

Yes, I tested positive. It was almost a relief to get confirmation of it. I had been fearing it so much that knowing was almost easier. There was a lot to absorb when the doctor told me. What does one do when you hear this news? I sat there wondering how other people respond to this moment. I felt dead inside and one of the first thoughts I had was to kill myself, now, to end it all immediately. I walked home that day, my head spinning, looking for solutions and finding only one: suicide.

B.2 Adjusting to HIV

Somehow I did not end my life. I am not sure what prevented me from killing myself. Perhaps it was the wind in the trees, or the sound of children playing in the street, or my dog looking at me as if he understood all my feelings. But I got through the first few weeks, somehow.

I must be honest with you, I did not cope very well in the beginning. There was a period of some weeks when I got very depressed. I withdrew from the world and spent a lot of time on my own, drinking and smoking in an attempt to forget. Naturally this did not help my health in any way. I got very thin and ill and landed up in hospital for a few days.

As I lay there I heard one of the nurses speak to the man in the bed next to me. He was coughing badly, I suspect he had TB. The nurse sat at his bedside every day and would talk to him about how he needed to eat healthily and avoid alcohol and cigarettes as these were very bad for the immune system. I heard them speak about HIV and suddenly I wanted to get every word they said. She told him how it is natural for people to go through a process of grieving after hearing they are HIV positive. I don't remember it all but she said it was like having to deal with a loss. You first deny it, pretend it does not exist, run away from the reality as much as you can. And then you start feeling anger because it has happened to you, sometimes even that life is unfair. It is also common to feel depressed for a while and then finally you reach a point where you start to accept things as they are. That is when you can take control of the situation. Before that people often feel that they have no control, that this is something that has been done to them. This is a very painful time because you feel so powerless and despairing. You think there is nothing you can do because this thing has defeated you. But once you see you are not defeated things start changing.

This nurse seemed to know a lot and I could have listened to her for hours. I recognised all my reactions and it was a relief to know that I was feeling the way many other people do. Slowly I got involved in their discussions and it became our daily pep talk. By the time I left the hospital I was very inspired and positive. I did not feel so depressed about my situation, in fact, I felt excited to start living my life in a positive way.

B.3 Living with HIV

My friends must have thought I was mad because all of a sudden I was busy preparing meals and going for walks and singing in the shower. I had learnt that these were important aspects of staying in control of my body and of the virus. It was not always easy because I still had days of depression, particularly when I was ill. But I knew that I had to lift myself out of the depression in order to stay healthy.

I finally decided to break the silence with my friends and tell them that I was HIV positive. It

was tough, but it was good. Slowly I encouraged them to be tested. At first they said they preferred not to know their HIV status, but when I explained about the importance of living a healthy life and the danger of infecting others, they started to see my point. The result was that one of them tested positive, the rest negative. But at least they are now aware of the danger of infection and they will be more careful in future.

I don't know what the future holds, but for now I enjoy this new life style. From that sickly man I was in hospital I am now healthy and fit, 5 kilograms heavier and I can even say, happier. I never thought it would take something like HIV to change my life.

Appendix C

Sarah's Story

C.1 Diagnosis

Learning about the diagnosis I knew a bit about HIV, but it was never really something that I considered as my problem. But then it happened to me at a time in my life when I least expected it. Well, I guess one never expects it. I got a letter from an old boyfriend who I had not seen in years. It just said: I am very ill and am dying. Please go for an HIV test. My heart stopped. I kept hoping it was a joke, but something inside me knew it was for real. I immediately remembered every cold I had, every little detail about my health over the past few months and was terrified.

The first days few after I heard about my HIV status I just could not stop thinking about it for one minute. I remember lying awake in my bed at night trying to work out when I got infected, how long I had been carrying the virus, who else I could have infected. There were no answers, just more questions.

C.2 Adjusting to HIV

I was not ready to speak to anyone yet, perhaps because I first needed to get it clear in my own head. And I was not sure who to tell anyway. These were very painful days. I spent days on my own, just thinking or lying on my bed. It was a Saturday morning and I did not feel like going out. I stayed in my room, listened to the radio and actually felt very scared and alone. This was not the life I had imagined to have at 27.

And then I heard a voice on the radio saying something about HIV. I immediately paid attention, this was my problem they were talking about. I think this programme was sent to me especially. It was a woman who spoke about living with HIV. I will never forget her words: Don't focus on dying of HIV or AIDS, focus on living. You are still the same person as what you were yesterday. The

fact that you have HIV does not mean that you are not capable of laughing and loving and being loved. If you are HIV positive and feeling lonely today, reach out to someone and give them love. It might just help you too.

These words struck me very deeply. I thought about it for a moment and decided that she was right. I am not dead, in fact I am not dying any more than anyone else. Everybody will die one day, but for now I am alive! This was the moment I started accepting and dealing with being HIV positive. And it was the moment life got easier, even happier. I started looking for someone to love and take care of. And soon it appeared.

C.3 Living with HIV

Now I am involved with a group who takes care of sick people in their homes. I do home visits, take food to people who are too weak to go out, and sometimes read to them or just help them with little things. There is one patient who has meant a lot to me. She is a young woman, just like me, who has AIDS. At first it was very difficult for me to go and see her. She was quite ill and by looking at her I could see what lay ahead for me. I have watched her get weaker, but as her body deteriorates her spirit gets stronger. She has taught me so much about thinking positively and seeing this illness as a challenge and an opportunity to appreciate every moment. She reads a lot and tells me about the immune system and how being depressed and feeling hopeless makes my immune system weak and the virus strong.

Sometimes she tells me to imagine what the virus looks like in my body. I then close my eyes and see these little black spots all over. And then she tells me to imagine a way of removing these little black virus spots until my whole body is clean. It get very relaxed and sit there with my eyes closed. I always imagine using a vacuum cleaner and sucking the black spots up, bit by bit, in every nook and cranny of my body. When I finish I always feel stronger, as if I have destroyed the virus.

She reads in her books that this is a good way of making the immune system stronger. We drink tea and talk for hours about ways to fight the virus and keep the body strong. It gives me enormous hope.

People like her keep me strong and remind me that I am in control of this virus. If I choose to let it win I will die, but as long as I choose to be in charge I will live. When I feel a little bit ill I imagine myself vacuum cleaning my body. It works for me.

I also make sure that I eat healthily and exercise a little bit every day. I am also trying to read as much as I can about the illness. I believe that the more information I get the better I will know how to take care of myself. I am thinking of starting a support group for a few of us. There are about 5 girls in my street alone who are HIV positive. We now know each other and I think we could help each other by talking. I have learnt that people are one the most important ingredients in living with

HIV. If I have people around me who share my experience I keep illness away.

Appendix D

Ziggy's Story

D.1 Diagnosis

Learning about the diagnosis For me the story of HIV started when I met this wonderful man, Zake. He was my first real love and I could not believe that I could be so lucky. Having a man like him was something I thought I could only dream about. I didn't grow up with much love, so having him in my life was like being in heaven. It was too good to be true.

But Zake literally was too good to be true. I started to notice that he was seeing other women behind my back. When I complained he would get angry and tell me I was being too demanding. I knew it was wrong but I could not bear the thought of losing him. So I just tolerated it, hoping that something would happen to make him be faithful.

The day I realised I was pregnant I was scared and excited. I thought, maybe this would be the thing that would finally make him mine.

He was happy about the news and for a moment I could see a future with him. But there is another part to my story which changed the happiness in an instant. I went to the clinic for tests to see if the baby was healthy. The sister asked me if I would be interested in an HIV test. I agreed without thinking about it, why should I worry anyway, I said to myself. And then came the news: You are HIV positive!!! I sat there unable to breathe, I could feel my body go cold and then hot, and all I could think of was to tell Zake. What was going to happen to our baby, to me? Will he stay with me if I get ill?

Zake's reaction was strange, almost like he was not shocked or surprised. He just stood there, looking at me with no emotion. I asked him to be tested but he refused. I now think he was too scared, or maybe he already knew. But from that day onwards Zake just drifted away from me. I was desperate to hold on to him, but he was with other women more and more. I had a lot to deal with, being pregnant, losing Zake and being HIV positive. The fact that I was pregnant saved me.

I kept thinking of my little baby who needed me to be healthy and happy. I simply could not allow myself to be depressed and sick, I had to stay positive throughout my pregnancy in order to make sure my baby was OK.

D.2 Adjusting to HIV

I went to the clinic often to get information, and the rest of the time I tried to eat healthy food and get some exercise. Every day I would say to myself: Smile girl, it is good for your immune system and good for your baby. But it was not easy, I missed Zake with all my heart and I was scared of having a baby all alone.

It was at this time that I decided to tell my family about my HIV status. I thought it was the wise thing to do, they needed to know as I would be leaning on them for help. I never expected them to be so understanding and supportive. My mother was wonderful, she carried me through those months. And I learnt to live life with a smile. My baby was my motivation.

I heard later that Zake was very ill and about two weeks ago he died of AIDS. I went to his funeral with our baby in my arms and wished that he could see our lovely little boy. But Zake had given up on life. He could not get himself to live positively and take care of himself. I believe he decided to die.

D.3 Living with HIV

I want to tell you about the baby and where we are today. My baby was born at the day hospital, a healthy little boy. I listened carefully to everything the doctors and nurses told me and tried my best to protect my child. I was lucky to get Neveapine in hospital and always gave the baby formula milk. I would go to the clinic to collect information and then I would follow it carefully. My life revolved around protecting my child from illness and specifically HIV. He is now almost 2 years old and tests HIV negative. It is like a miracle in my life. I watch him grow and it brings a smile to my face.

It has been very difficult at times because I have not always been well. In fact, shortly after his birth I had pneumonia and the doctors were scared that it was TB. For a few weeks I was almost too weak to hold him and the help I got from my mother was wonderful.

People often ask me how I manage to live being HIV positive. I have thought about it and the answer is simple: It is not that I deny that I am HIV positive, but I tend to push it to back of my mind and focus on living life to the fullest. I never appreciated life as much as I do now. Before days would pass and I would be moody or sad or irritated. Now I think of how precious time is and

I try not to waste a single minute on negative feelings. It sounds strange, but in many ways my life is better now that I am HIV positive. And I definitely appreciate it much much more.

Appendix E

Finite State Machines (FSM's) showing behavioral specifications of each actor

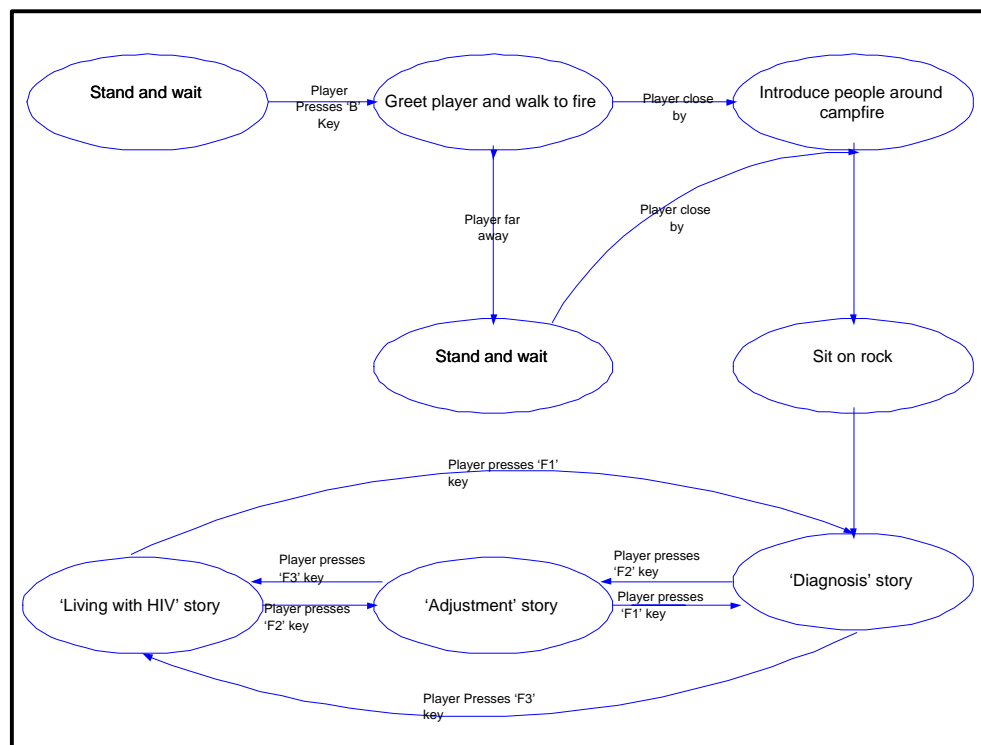


Figure E.11: Behavioural specification of the agent called Andile

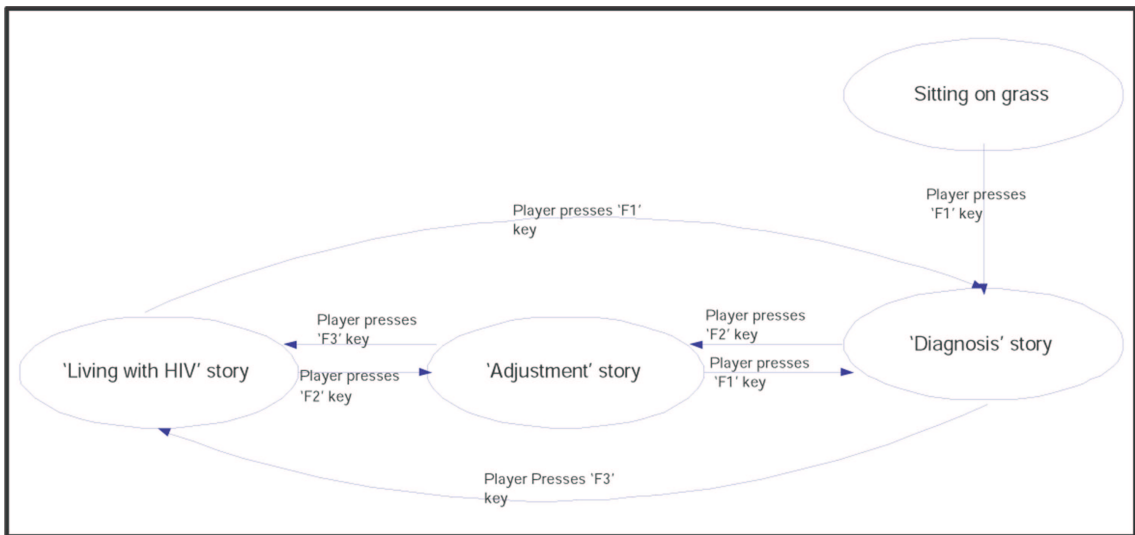


Figure E.12: Behavioural specification of the agents Sarah, Ziggy and Godfrey

Appendix F

Images from the Test Environment

Figure 1



Scene: User is greeted by Mwelwa at the top of a staircase in a house.
 Dialogue: Hi, I'm Mwelwa. Follow me if you want to join the party.

Figure 2



Scene: Mwelwa is walking towards the room where the party is being held.
 Intended User Action: User must follow Mwelwa

Figure 3



Scene: The room where the party is being held. There is lady and a child dancing. The jukebox behind the lady is playing a song.

Intended User Action: User can change the song playing, by toggling the F1, F2 and F3 keys.

Figure F.13: Images taken from the test environment

Figure 4



Scene: The room where the party is being held. The scene shows a child dancing.

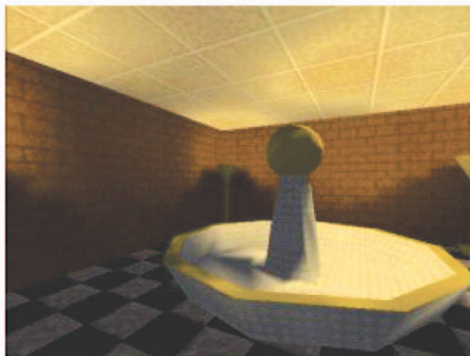
Intended User Action: User can change the song playing, by toggling the F1, F2 and F3 keys.

Figure 5



Scene: One of the hallways in the house.
Intended User Action: Users can explore different rooms.

Figure 6



Scene: An arbitrary room in the house.

Intended User Action: Users can explore the room.

Figure F.14: Images taken from the test environment

Appendix G

Images from the AIDS Scenario Environment

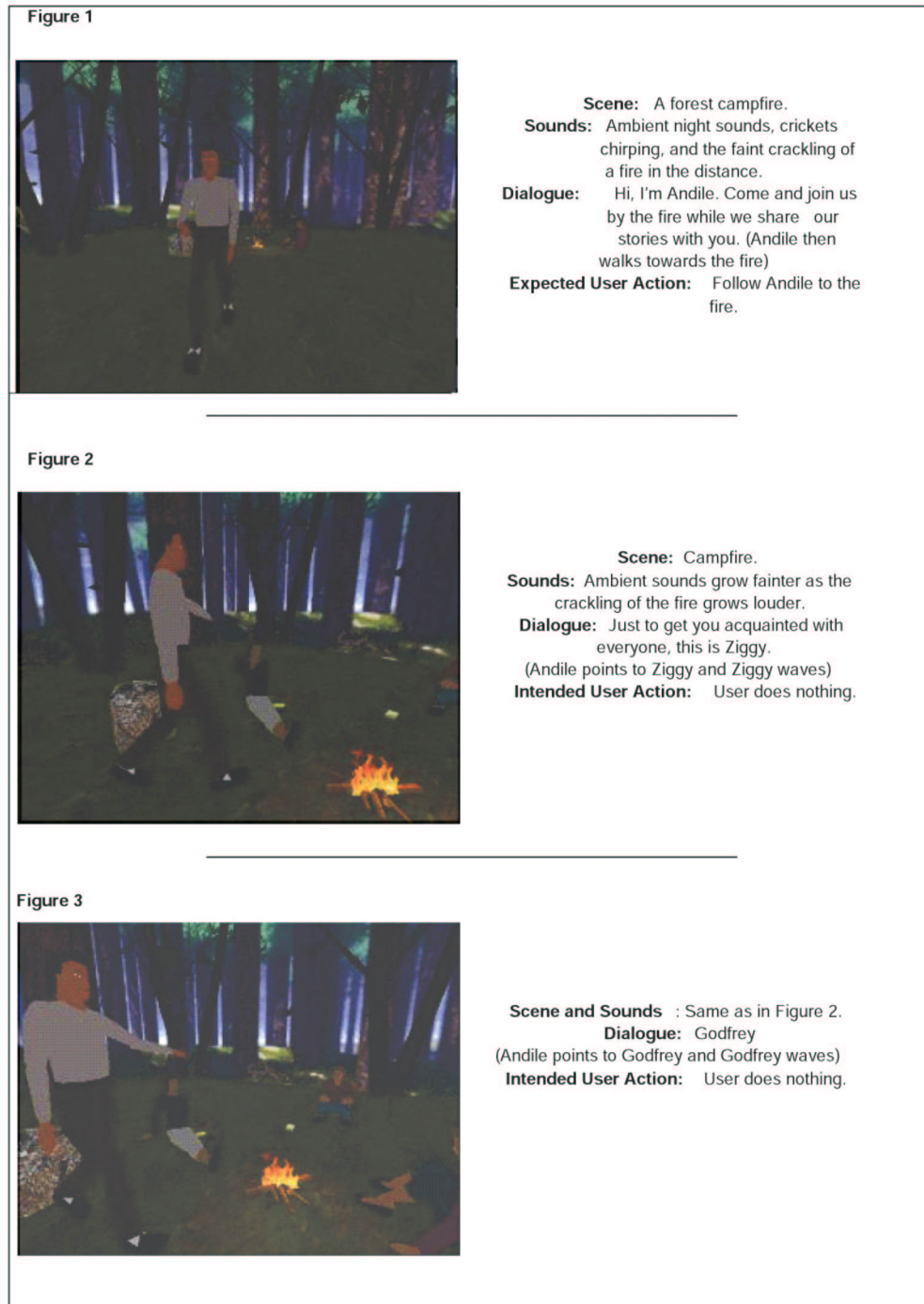


Figure G.15: Images taken from the AIDS Scenario Environment

Figure 4



Scene and Sounds : Same as in Figure 2.

Dialogue: and of course Sarah.
(Andile points to Sarah and Sarah waves)

Intended User Action: User does nothing.

Figure 5



Scene and Sounds: Same as in Figure 2.

Dialogue: We have been discussing how each of us cope with living with HIV. Let me begin by telling you of my experience.
(Andile then goes on to narrate the story appearing in Appendix A, under the heading Diagnosis.)

Intended User Action: The user has the following options by pressing the following keys:

'Q' - Stops the current story narrated.

'F1' - 'Diagnosis' Story

'F2' - 'Adjustment to HIV' Story

'F3' - 'Living with HIV' Story

or

Hear somebody else's story.

Figure 6



Scene and Sounds : Same as in Figure 2.

Dialogue: Depends on user's action.

Intended User Action: Same as in Figure 5. In order to activate the story, the user stands in front of an agent. The dialogue of each agents story can be found in Appendix B, C and D respectively.

Figure G.16: Images taken from the AIDS Scenario Environment

Appendix H

Interview Themes

Interview Question	Quote	Participant
Now, when you were sitting there with the computer and you were going into that forest with the fire, how did it feel for you? What was happening inside?	I will say it (flashes one back), but also a little bit emotional at times. If you're not (much) most normally you'd (stop the tape). Again, if you're at a certain level that experience is okay. It's a matter of what stage you are, what is your understanding	1
What made you emotional? When you were in that forest with them, what made you emotional?	The different stories that they were telling, the different views, how they coped, the way they broke the news to their friends also, how they were planning to move forward with their lives. Because that is not just from a theoretical point of view, but practical.	1
Why do you think that it makes you emotional?	Because those are the people that it affected.	1

<p>Now I want to talk a little bit about what you did on the computer. How was it for you?</p>	<p>The second one, when the man was telling his story, I listened to him, it made me move back, you know, thinking about what had happened to me, you know, the first time I went to the hospital, and then what happened to me, you know, about the diagnosis, meeting the counsellor, (as he was) telling his story about being accepted. So I was thinking back about myself, seeing that I have accepted my status also. But when he telling that story it made me move back again. It's just like (sort of) counselling. Seeing that I'm a counsellor, it was the same as what I'm doing.</p>	<p>2</p>
<p>Yes, I see what you mean. If you think back to Andile's story, what part of his story touched you emotionally? Where did you have feelings?</p>	<p>Mm, by the time when he was saying "I went to the hospital", and then coming back to the counsellor. You know, that time it did touched me, I was thinking about myself, I was also back (there).</p>	<p>2</p>
<p>Of the stories you listened to, which one upset you?</p>	<p>The diagnosis</p>	<p>4</p>
<p>And the learning about the diagnosis, how was that for you? Did you listen to that part of the story?</p>	<p>Yes, I was listening to that, but I didn't want to listen (to) all of them, because it touched me. I passed it.</p>	<p>7</p>
<p>So to listen to that traumatised you.</p>	<p>Yes. Yes, I think when I'm listening it's been a trauma for me. So I skipped it.</p>	<p>7</p>

Table H.1: Interview Quotes Relating to the Theme *Emotional Impact*

Interview Question	Quote	Participant
So did it feel like you were just looking at a picture, or did it feel a bit like a movie?	It sort of gives you a feeling like you're watching a movie, not necessarily listening to this person, but you are talking face to face like you and me.	1
If you were to think of being there in that environment with the camp fire and people, did it feel real to you, or did it feel like you were just watching a picture?	No, it's real.	2
When you were at the computer, did it feel to you like you were just looking at a picture, or did it feel like you were there in the forest at the fire? And did it feel to you like you were sitting in a room looking at a computer, or did it feel like you were in the forest at the fire?	I was there in the forest. Ja, when I was listening I felt like I was also with them in the forest	3 4
So did it feel like you were there with them?	Ja, I felt that I'm with them.	4
The feeling you have when you watch something on TV, is it the same (as) when you were on the computer? Did it feel to you like you were in the forest with them, or did it feel like you were just looking at something on a screen?	Just looking like something on a screen	5
So it didn't feel like you were there in the forest with them?	No	5

<p>When you were looking at the computer, did it feel like you were just looking at a picture, or did it feel like you were really there in the forest?</p>	<p>To me it was like I'm in the forest. Because the first thing is what they communicate about everything. Because (at) the beginning, when you see your status, (it's) like blank, something like a knock on the head, because you don't know what you're supposed to do and what you're going to end up with, because you don't know if you're going to die immediately and what is going to happen in your body. But when I (was) sitting there listening to those words and (looking at) that place, that environment, It was just I was feeling (like) I was in there</p>	<p>6</p>
<p>If you think of the computer, did it feel to you like you were there in the forest with them, or was it just like watching something on TV?</p>	<p>No, it's like I'm there with them</p>	<p>7</p>
<p>How? Why do you say that?</p>	<p>It's because of that man who said that he didn't know the difference between positive and negative. It's like the same to me, and I feel I'm there by the fire.</p>	<p>7</p>

Table H.2: Interview Quotes Relating to the Theme *Presence*

Interview Question	Quote	Participant
What do you think are the disadvantages about the computer thing? What do you think isn't good about it?	It is good, so that the other people (who) don't want to talk, they can also learn things from the computer, learning that you can do more things even if you are HIV positive.	2
Is there anything else about it that you think we should think about?	I think not for me. If you're HIV positive you can do anything, you are still a full you're just living with a virus. You can do anything. And for me, sitting with that computer, you cannot say that I'm HIV, I'm going to die, I cannot do anything. I think that computer is also there for people to know that "I'm still living, I can do what the other people who have got HIV positive (do), I can do it, like this computer thing.	2
Back to the computer: how did it feel to work on the computer?	It was very quick, because I understood it better.	7

<p>Now I want to talk a little bit about what you did on the computer. How was it for you?</p>	<p>When I was in the first one, the first song, (I was doing computers before, but I couldn't finish my course), I was seeing myself like as I was, hearing that thing, hearing the songs, I was seeing myself: "I can be a DJ", I don't want to say "I cannot do this thing." You know, anything I want to try. It's never been too late for me, you know, even (now) I'm HIV positive. There are things which I can do. So the instructor showed me how to use the computer, so it was very easy for me. So as I was looking there I thought about my kids, you know, like if I could see one of my kids having this thing and being a DJ, maybe something in one of the radios, with the first one that was the song.</p>	<p>2</p>
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Table H.3: Interview Quotes Relating to the Theme *Psychological Impact of Computer*

Interview Question	Quote	Participant
Do you think you would have felt the same if it was just a video you were watching, if you weren't moving yourself	Ja, reading is also different, but I think I prefer this, because maybe I (just) like it.	1
Do you think it could traumatise patients?	No, it's not traumatising the patient. It's just telling the stories that you know, but you're not concerned about it. You are concerned about the story, but you're not going to quit that story, because you've been (there) already in that story, but what (do) you want to do now? So maybe it gives you (other) information on how to live with it. Some of the patients, they don't listen to things, because they have fear and they're scared, because what will they do? I think like now for the thing on the computer you can also have more things to do.	2
When you came to the support group [in the forest], how was that for you?	After the diagnosis I didn't see the support group, how to run the support. Now I think I want to find a support group in my area	5
Did the computer make you think that, or did you think it before?	Seeing the computer I think is better going to a support group.	5

Table H.4: Interview Quotes Relating to the Theme *Informational Support*

Interview Question	Quote	Participant
Can I ask you about the computer thing you looked at? How was that for you?	The computer thing encouraged me, and it just (provided) me. I must be more comfortable with myself	3
Was it painful to listen to the computer?	Yes, it was. But for me it just (made) me strong.	3
How did you feel? What was happening in your heart and in your mind when you were listening to those stories?	When I was listening to their stories, the way the counsellor did counsel me, it was like that. (Now) I'm not afraid to tell the people. I'm not shy. And then to know that I must either commit suicide, (or) I can also live a long life. And also I mustn't change my girl friend or my wife if I'm HIV positive. I must love my wife the way I used to do before. That (is) my strength mentally, spiritually and physically.	4
And if you think of what you saw on the computer, what you experienced round the fire, is it useful to you? Not from the computer side, but emotionally, with your HIV status. Is it useful, or do you think not really? How is it useful? Okay. Now, the rest of the story, how did that make you feel?	Those people there, they're not afraid to confirm about it, The group of the people. And they're also being counselled by one person, so the group of the people, they're strong enough to work as a team For me it made me proud of myself. Because I think that it's only me who has that present. So now I'm proud.	5 7
What the people said in the stories when they were speaking about adjusting to the diagnosis, did that have an effect on you? Did it make you feel anything?	Yes, they made me strong.	7

Now, the rest of the story, how did that make you feel?	Like for instance my counsellor there at the clinic told me that there's a support group, but I didn't want to go to the support group. I only (told) my friend that I was HIV positive. So now by listening (to) that story I feel that I can go to the support group.	7
Why? What about the story made you think that you can go to the support group?	It's because everyone shared their feelings, you know. So at least (that) was happening.	7

Table H.5: Interview Quotes Relating to the Theme *Emotional Support*

Interview Question	Quote	Participant
What would make you ready? I mean, for you six months What is it that has to happen first before you would be ready to listen to other people's stories?	I should think counselling first, going through different sessions with a counsellor. To get a clearer, broader picture. Then that (would) sort of add to what a counsellor can do.	1
Do you think it would help the client to listen to someone else's story, to listen, say, to the characters on the computer, would it be good for your client to hear that?	Yes, I think that for my client who (hadn't) accepted it	2
How was listening to the rest of the story, when you listened to the part about how he adjusted and where he is now? How was that for you?	O, just fine. It was fine. The way that he was expressing it was like the way we as counsellors giving people (advice) about AIDS effects, all those things. It's also giving us input into what we are doing.	2
From the counsellor's point of view?	From the counsellor's point of view, and for myself as well. It's the same thing as what I am doing.	2
How did you feel? What was happening in your heart and in your mind when you were listening to those stories?	When I was listening to their stories, the way the counsellor did counsel me, it was like that. (Now) I'm not afraid to tell the people. I'm not shy. And then to know that I must either commit suicide, (or) I can also live a long life. And also I mustn't change my girl friend or my wife if I'm HIV positive. I must love my wife the way I used to do before. That (is) my strength mentally, spiritually and physically	4

<p>Do you think if we had something like this in the clinics or in the community centre, do you think if it was there when you got diagnosed, would it have been good for you just after your diagnosis to listen to something like that?</p>	<p>It's easier to listen (to) that before you go into the support group. Even if you're diagnosed, you're sitting in the house, and then when you get sick you just think, "O, I must go to a support group," because you don't have a choice. But if you're diagnosed, even if you're working for your results, (and) there's a programme like that on the TV, like on (a) programme, whatever, 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. Maybe you're going to think, "O, maybe I must go somewhere out there before I'm going to start in my community, to get strong. And then, when I go back to my community, I won't care what they say about me, because I'm positive anyway."</p>	<p>6</p>
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Table H.6: Interview Quotes Relating to the Theme *Comparisons with Other Forms of Support*

Interview Question	Quote	Participant
If you think back to when you heard your diagnosis, would it have been good or bad for you to do the computer thing? At the time, if the doctor said to you: "This is your status, let the counsellor give you some information, go and listen to other people's stories", and they then invited you to go and sit in this little room to listen to other people's stories, would it have been useful to you or not?	Well, I think as far as my own experience is concerned, at that point I don't think it would have been useful, because emotionally When people come to you with this and that It's not necessarily that you don't want to listen, but you're too emotional. I mean, the day when the news was broken to me, if someone had (said): "There's a computer in the next room", that would have been useless at that moment. So that it's imperative to give someone time to adjust.	1
Do you think that it would have been useful later?	At a very (much) later stage, approximately after six months, I would say, depending on how one adjusts and accepts, accepts the facts. Yes.	1
So you really have to be ready for it.	Yes, you have to pass certain stages first	1
At what point, do you think? Immediately after diagnosis, later on? When do you think people would be ready, and when will it be useful?	I think sometimes at that point maybe it's when the family says it's time, you must go, so that it will not do anything, you understand	2
On the day you got your diagnosis, or a week or two after that, would it have helped you if you had the computer thing to look at? Would it have been good for you? Would it have helped you?	It would have helped me	3

Table H.7: Interview Quotes Relating to the Theme *Timing Consideration*

Interview Question	Quote	Participant
Tell me, if these stories were on a video, or you were watching it on TV, would it have the same effect as it had on the computer?	It wouldn't have been that much different, (except) maybe on the listening side, because (the computer) is more visual, depending on how it is. Maybe someone would cry, stuff like that, that would (feel) different.	1
And if you were to say read something or watch something on TV, compared to the computer thing, which one moves you most? Which one makes you more emotional?	It's the one that I had on the computer. Because that is not just from a theoretical point of view, but practical. Because those are the people that it affected.	1
What about the picture makes the difference?	It's because (of) the action.	3
Do you think you would have felt the same if it was just a video you were watching, if you weren't moving yourself : And if you were just reading or listening to a tape?	Ja, reading is also different, but I think I prefer this, because maybe I (just) like it.	1
So if we put something like that in the community clinic, do you think we must make it just like a TV programme, or must we make it so that the person can move around with the arrows and walk around the fire? What will be better, just a video that you watch, or the computer where you can move around?	To me the computer is much better, because you can listen, (you can) start and stop. Sometimes when you're watching the video other people are making a noise around.	6
Which one would be better for listening to stories, watching it on TV or being on the computer?	On the computer you can walk around and move around the fire.	7
When you were looking at the computer, did it feel like watching something on TV, or did it feel like you were there at the fire?	Like looking (at) something on the TV.	5

Table H.8: Interview Quotes Relating to the Theme *Comparisons with other Media of Support*

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