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Zora: A Pilot Virtual Community in the Pediatric Dialysis Unit

Marina U. Bers[a], Joseph Gonzalez-Heydrich[b,c], Darcy Raches[b], David Ray DeMaso[b]

[a]MIT Media Laboratory, Cambridge, USA
[b]Department of Psychiatry, Children's Hospital, Boston, USA
[c]Children's Hospital Informatics Program, Boston, USA

Abstract

We describe a five-month pilot project conducted in the dialysis unit at Boston's Children's Hospital. Pediatric patients with renal disease used the Zora therapeutic community program while undergoing hemodialysis. Zora is a 3D multi-user computer environment designed at the MIT Media Laboratory to help young people explore issues of identity, while engaging in a virtual community. Users build "virtual rooms" and populate them with objects and characters, program them with storytelling behaviors, and converse with other young people in real-time through a virtual character representing themselves. It was specifically designed to help young people explore issues of identity, while engaging in a participatory virtual community. This paper presents the experience and evaluates the feasibility and safety of using Zora in a hospital setting. It describes how Zora facilitated explorations of identity and mutual patient support and interaction. Finally it also presents design recommendations for future interventions of this kind. More generally, this paper explores the potential of technology specifically designed with therapeutic purposes to help patients cope with their illness.

Keywords

Multi-user virtual environment; pediatric patients; dialysis, therapy; identity; storytelling; virtual communities.

Introduction

Zora is a 3D graphical multi-user environment that was designed to help young people explore issues of identity, while engaging in a participatory virtual community. Users build virtual rooms and populate them with objects and characters representing aspects of themselves, program them with storytelling behaviors, and converse with others in real-time through an avatar [1, 2]. This paper describes a pilot study of the feasibility and safety of allowing pediatric patients with end-stage renal disease (ESRD) to use Zora while undergoing hemodialysis.

Young patients with ESRD come to the dialysis unit at Boston's Children's Hospital three times a week for approximately four hours per session. The treatment often significantly disrupts the social, emotional and academic experiences of young people [3, 4]. Multi-user environments represent a potential innovative technique to respond to the medical crises and social isolation faced by young people with ESRD. We sought to use Zora to facilitate expression of emotions, working on relationships, being involved in meaningful activities and seeking support from others with similar experiences, all goals identified as helpful to patients [5, 6]. The questions this pilot study looked to address were:

1. Is Zora safe and satisfying for children with ESRD on hemodialysis?
2. Is there a connection between using Zora and self understanding of illness?
3. How can multi-user environments best help children and families cope with the stresses of having a serious illness?

Materials and Methods

The Tool: Zora

Within Zora's 3D multiuser space, users are graphically represented by avatars with an image chosen by the user. Children can visit each other's homes and can communicate in real-time through their avatars via text or gestures. Avatars can gather in the City Hall to decide the laws of the virtual city as well as to discuss cases related to community self-government and current controversial news. Users construct the city's private and public spaces: personal homes, community centers and temples. Temples are shared public spaces that represent cultural traditions or interests.

Zora is an object-oriented environment, implemented using Microsoft's Virtual Worlds research platform, a software development kit for building distributed multi-user environments [7]. In the same spirit as other constructionist virtual communities such as the text-based MOOSE

Crossing [8] and the 2D Pet Park [9], kids can program behaviors for their own creations and draw pictures.

Patients:

The hospital human subjects committee approved this study. During the five months of the study, the dialysis unit child life specialist and social worker identified potential participants based on their personal interest. No computer expertise was required. 12 patients from the dialysis unit agreed to have a single demonstration session with Zora. Of these patients 5 decided not to participate further. They cited various reasons including changes in their medical condition, lack of interest in computers and feeling tired and sleepy during dialysis. The remaining 7 patients' ages ranged from 7 - 21 years (Mean $\pm$ SD, 15.4 $\pm$ 4.31 years). There were 4 Females, 3 Males. Their mean duration of chronic dialysis was 18.9 $\pm$ 8.0 months.

Procedures:

The patients and their parents signed an agreement to respect a code of conduct in using Zora. The Zora system was only accessible by the patients and staff in the dialysis unit, physicians in the Department of Psychiatry and researchers at the MIT Media Laboratory. Computers in the unit had installed the Zora environment, a graphical software and an Internet filtering system. They were mounted on tables suitable for bedside use in the hospital. A digital camera was also provided.

The work in the unit had three different phases.

Phase 1: building interest around the Zora project. For a month, study staff went to the Unit to meet the patients and staff and introduce them to Zora.

Phase 2: hands-on work with Zora. Study staff worked one-to-one with patients and the unit staff on how to use Zora. Within this phase, a field trip to the Media Lab was organized.

Phase 3: working remotely. Once patients became familiar with the technology, they were able to use Zora by themselves.

The work with Zora did not follow any specific syllabus. The idea was to engage patients to use Zora in any way they wanted to, whenever they wanted to, accommodating to their medical, mental and physical needs.

Evaluation methods:

The evaluation methodology was based on an ethnographic approach aimed at gathering a rich set of data to construct a "thick description" of how Zora was used [10]. We did observations of on-line and face-to-face interaction, and analysis of the system logs that recorded, with date and time, everything participants said or did on-line. The log of the on-line interaction was analyzed for recurrent themes, ideas, or patterns. Logs were parsed to assess the number of objects, characters and virtual spaces created as well as the number of on-line interactions that occurred during the study. These observations were compared to those of Zora's use by healthy children at an MIT "summer camp" experience [2].

Semi-structured personal interviews were conducted with both patients and staff. Participants were asked to rate the application using a 7-point Likert scale anchored at one end by "1=not at all" and at the other end by "7=a great deal". Participants were also asked several open-ended questions. Transcripts were coded to identify recurrent themes. Participants were videotaped talking about their general impressions and their evaluation about their participation in the project. These videotapes were also analyzed following a qualitative methodology.

Results

The seven patients who participated in the study used Zora an average of six sessions that lasted on average an hour (range 15 minutes to 3 hours). Patients had access to three networked computers that could be moved to their bedside, thus a maximum of three children were able to connect to Zora at the same time. The child life specialist and three nurses took an active role in participating in diverse aspects of the Zora project.

During the pilot experience, participants designed a total of 16 virtual places. The hospital and study staff created 6. Patients designed personal homes and common spaces such as the Music Room and the Renal Rap, *"a virtual space for dialysis patients to get together do fun things"*.

Patients made a total of 94 objects, including 14 characters that they called heroes and 13 values with their definitions, such as "friendship", "doing something positive to help myself or someone else. Patients created 5 cases. Cases are special types of objects representing events or circumstances to be discussed and agreed upon. They require community members to take action to resolve them. Some dealt with setting up the social organization of the virtual city, such as *"someone changed the appearance of my door and I don't understand why. I would like to suggest as a rule that there is no tampering with other people's stuff"*, while others were about personal medical problems. Participants posted in the bulletin boards 17 messages such as *"I really liked what you guys have done with the renal rap room"*.

Feasibility

Overall, the seven patients reported that they were satisfied with Zora (mean = 5.3; standard deviation =1.31) and that they enjoyed participating in the experience (Mean 5.71$\pm$1.60*). "It was really nice to have something fun to do at the hospital that could keep my mind off dialysis and that it was not schoolwork, but entertaining"*, said a fifteen year old patient.

Hospital staff also reported that they very much liked participating in the experience (Mean 6.5 $\pm$ 0.58). Nurses did not see Zora as interfering with their medical routine. On the contrary, they enjoyed seeing their patients using

Zora. One of the nurses said: *"I liked it a lot because I noticed that kids could say things in the computer that they might not say face to face and this has a lot of potential. It is a wonderful program for kids who are restricted and limited to the outside world."*

Safety:

Overall, the seven patients reported that Zora was safe (Mean 5.93 ± 1.84) and that participating in the experience was not hurtful (Mean 1.43 ± 1.13). When asked about the safety of using Zora, 17 years old Larry *replied "It might be unsafe if you put certain things in your room that younger kids shouldn't see. But that's the whole point with having the [virtual] city hall, where we set the rules and laws for Zora. I don't think it's not safe for kids.*" None of the patients referred to the code of conduct they signed before engaging in the experience as having had any impact in making Zora a safer space.

Hospital staff also reported that using Zora was safe (Mean 5.63 ± 1.49) and they all agreed that participating in the experience was not hurtful at all (Mean 1 ± 0). One of the nurses said: *"Zora was a safe place and a safe way for patients to get their feelings out. It was an appropriate way to discuss their feelings. Rather than going out an punching a wall they had an opportunity to discuss things and to learn and to ask anything in Zora."* The child life specialist agreed with this but pointed out the importance of supervising what kids were doing and saying, in case that intervention from an adult was needed. In the five months that the program was running, there was no need for staff intervention.

Exploration of personal identity:

All of the patients consciously avoided any mentioning of dialysis in their virtual rooms. As a fifteen year old said: *"I am already on dialysis and I don't want to put things in my [virtual] room that remind me of dialysis; I don't want to go to other rooms that have that kind of stuff either."* It is not surprising that, when asking kids if participating in Zora helped them gain perspective about their illness, most of them replied that it did not (Mean 2.43 ± 2.30).

All of the patients said they did not want to encounter in the Zora virtual city any content related to dialysis. They wanted Zora to be a space to escape from dialysis. However, all hospital staff had exactly the opposite opinion. They thought that Zora would be an excellent medium to teach kids about dialysis and to engage them in thinking about the process. For example, one of the social workers suggested the creation of a restaurant because food is a big issue for kids undergoing dialysis. The study staff set up the virtual space and asked patients to create the menus. To our surprise, none of the created menus took in consideration the particular dietary restrictions of this patient population. Following is an excerpt of a conversation that happened in the virtual restaurant:

Vitor says 'Washu, do you have any idea about what should we have in the menu?' ||….

Washu says 'ice cream and there is a Chinese dessert that all the nurses love' ||

Vitor says 'What kind of food do you like?' ||

Washu says 'I like Chinese food and Italian foods…noodles and fried rice spaghetti and meat balls" ||

Marina says 'I wonder if there should be a special menu for people on dialysis...what do you think?' ||

Washu says 'I guess that is helpful to people but I don't like to be reminded that I need different food' ||

Children used Zora as a way to escape from the harshness of dialysis in two different ways. First, they used their avatars to "move around" the Zora virtual city, while being "tied down" to bed and hooked up to the hemodialysis machine. Second, patients used their rooms to represent aspects of their identity that are usually underplayed during treatment. When asked what they learned during the experience with Zora, a fourteen year old said: *"I learned new things about computers, like how to work with pictures and design my room, but I guess that I also learned about myself because I realized the things that I really care about and what my interests are and how to talk to others about that. In my room in Zora I could put both computers and other things I like."* In two other examples, Sharon created an Elvis Presley room with animations of the singer performing in the walls and Rina created a horse haven, with stories and pictures of her horse at home.

Facilitating mutual patient support and interaction:

In order to facilitate mutual patient support and interaction, Zora allowed patients to talk with each other in real-time through their avatars and they also posted messages and wrote stories for their objects and characters.

Patients reported that to a moderate extend they felt using Zora helped them make friends or get support from other kids on dialysis (Mean 3.86 ± 2.41) and helped them to feel more part of a group on dialysis (Mean 4.43 ± 1.62). *"I think that I always was part of the dialysis group but using Zora helped me to get to know the people better because I could talk with them and see their interests, what they like and do not like by going to their virtual homes"*, said a 13 years old patient. Hospital staff also perceived that using Zora helped patients to make friends (Mean 4.50 ± 1) and made them feel part of a group (Mean 3.75 ± 0.5).

Synchronous communication: a private way to talk in a public space

Analysis of transcripts of interviews revealed that patients particularly liked that Zora provided a good way to communicate with each other in a private way, while undergoing the public event of dialysis. "*I really liked that I could use Zora to talk to other kids who were at a distance. Otherwise I would have to yell across the room. But using Zora was great because others could not eavesdrop on my*

conversation and I felt more comfortable discussing things. I particularly liked to talk with others about our favorite nurses, without being heard", said a 13 years old patient.

Asynchronous communication: a space to voice opinions

Patients used Zora to post messages in each other message boards and to write stories for their objects and characters. This asynchronous way of communicating their feelings was, as one of the nurses noted, *"a way to help patients that weren't on the same shift together to get an understanding of the other patients when visiting their rooms"*.

Asynchronous communication allowed patients to voice their opinions, without the burdens of face-to-face and real-time conversation. For example, 17 year old Larry dropped a case in the "Temple of Feeling Better" in which he complained about the increase of his time on the dialysis machine: *"I believe that my time on dialysis is too long. Most of the patients are on for only three and half-hours . Maybe you can pull some string and get it cut back. Thank you. Please reply in caza's room . Leave a message on the bulletin board"*. He attached the value "pity" to the case but did not define it. At first Larry made his case very small and hid it behind other objects in the virtual temple. Only a very skilled Zora user could find it. Meanwhile, the child life specialist noted that Larry was very upset and couldn't talk about what was bothering him. When we pointed out to her the case that he created in the virtual temple, she used it as a jumping board to engage in a conversation with Larry. Shortly after, Larry made his case big and put it in the center of the temple, thus recognizing the legitimacy of his feelings. Later, Larry engaged with Dr. Joe in an exchange by leaving messages in each other's rooms and expressed that he was very happy to be able to voice his opinions and be heard.

Comparison with healthy children's use of Zora

Zora had previously been piloted with a group of similar aged children who applied to participate in an MIT computer summer camp weekend [2]. Comparing the use of Zora by these children to that of the participants from the dialysis unit we observed that the patients in the dialysis unit made more use of fantasy in creating their rooms. While the healthy children often used their own picture and name for their avatar, the none of the dialysis patients did this, using cartoon characters instead. Self-reports indicated that this was a way for the dialysis patients to distance themselves from the dialysis. The dialysis unit patients needed more encouragement and time to learn to use Zora. This seemed to be related to being tired and not feeling well generally.

Need of a broader community:

In each dialysis session only three patients were able to connect to Zora at the same time. Often there were not three patients who were feeling up to logging on at the same time. *"It is kind of lonely in there [Zora] because when you get on there are not many people with you and it is hard to talk with others"*, said a 15 years-old girl. Other patients pointed out that they felt embarrassed to talk with kids they see everyday about their feelings towards dialysis. They requested that in the future children in other units should be involved in Zora at the same time.

Discussion

One goal of this pilot study was to learn more about how to create spaces that engage children in learning and talking about serious illness. We needed to demonstrate that virtual spaces were both feasible and safe in a medical environment such as the dialysis unit. We were concerned about the multi-user and open-ended nature of Zora and the fact that it runs on the Internet where kids could easily find inappropriate content. We had no incidents of inappropriate use of Zora. This may have been due to the small community of users in this study and to the fact that Zora was being used in an open dialysis unit with staff nearby. However, the patients themselves cited Zora having been set up as a space for community participation and democratic decision-making as contributing to this positive outcome. While we had the participants sign a code of conduct, they denied that this influenced their behavior.

We were concerned that the patients in dialysis would be too tired to use Zora. They did indeed need more time and encouragement than healthy children; however, they did use and enjoy Zora. Thus we believe that we have demonstrated that Zora is both safe and feasible.

Patients reported that using Zora did not help them gain perspective or understanding about their illness. At the psychological level, children did not use Zora to talk about dialysis, but as an escape from it. However, Zora did not specifically support patients' exploration of what happens in their bodies while undergoing dialysis. However, Zora can support both types of interventions in future experiences. The Zora environment can support the collection and display of physiological data provided by the dialysis machines and the laboratory. If patients were encouraged to not only look at this data but also manipulate it in a friendly, creative and educational way, it may be possible to use Zora as a medium for patients to learn about their disease.

Patients requested a broader community for Zora. In future studies it might be worth looking at what happens if patients create a Zora city together with kids that do not share their medical condition and treatment. Will they want to highlight the fact that dialysis is part of their identity? Or will they prefer to ignore it? Another question is what would happen if kids were using Zora at home instead of at the hospital. By being removed from the machines, would they use the opportunity to reflect about their experiences? Another possibility would be to extend the experience to a large community by including renal transplant and/or at home dialysis patients.

Conclusion

More and more hospitals are acquiring the means to connect to the Internet. However, connectivity by itself is not enough. We should ask ourselves how can we use the potential of the computer and the Internet to support patients. Identity construction environments, such as Zora, open up new possibilities. As shown in this paper, this is both feasible and safe in the context of a hospital setting such as a dialysis unit. Introducing a fun, self-exploratory and community-building computer activity had several positive benefits. Patients used their extensive time in dialysis in a creative way by expressing themselves and exploring aspects of their identity that are usually underplayed during treatment. They were able to interact with others in similar situation in a private way and, at the same time, voice their opinions about their medical treatment. In the same spirit as therapeutic communities, identity construction environments such as Zora provide the opportunity for patients and staff to participate in social support networks.

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Address for Correspondence

Marina U. Bers

MIT Media Laboratory, 20 Ames St. E15-320A

Cambridge, MA 02139 USA

(617)253-0379

marinau@media.mit.edu