

Future of Technology to Augment Patient Support in Hospitals

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ABSTRACT

This chapter explores the potential of using computer technology to support and augment psychotherapeutic interventions in hospitals, communities and homes. We describe two applications piloted at Children's Hospital Boston. The first pilot explored how patients with pediatric heart disease used the Storytelling Agent Generation Environment (**SAGE**) computer program to create interactive storytellers and share their personal stories. The second involved youngsters on hemodialysis for end stage renal disease using the **Zora** graphical multi-user environment to create a virtual city and form a therapeutic virtual community. In this chapter we show how computer technology can be used to help patients explore their identity, cope with their illness and provide mutual support and interaction. We also present design recommendations for future interventions of this kind.

INTRODUCTION

Advances in medical care have greatly increased the life expectancy of children and adolescents suffering from a myriad of physical illnesses. Despite these advances, many youngsters must continue to contend with a chronic physical illness and ongoing treatment [1, 2]. It has been recognized that enhancing adaptive coping strategies improves health outcomes and resiliency in many patients. Interventions that provide information, facilitate expression of feelings, and allow mutual support are important components of psychoeducational interventions that have been found to be useful. In addition, there is an emerging recognition that both emotional and physical benefit can be gained through the development, expression, and understanding of an individual's personal narrative or "story"

of a physical illness [3]. Personal narratives often include how a physical illness has changed or not changed who they are, their relationships and life choices, and “what it means to them.”

Parallel to these psychotherapeutic developments in the support of physically ill patients, computer technologies have evolved that facilitate mutual support networks, the exploration of the self, and the development of personal narratives. The recent increase of home pages, chat-spaces, virtual worlds, multi-user environments and Internet-based role-playing games are “real world” examples of these technologies. Turkle [4] suggests that the "Internet has become a significant social laboratory for experimenting with the constructions and re-constructions of self that characterize postmodern life." Despite these technologic advances the challenge remains of how to design environments that leverage the characteristic of the computer to purposefully support explorations about identity that can lead to therapeutic personal narratives and better mutual support.

Identity construction environments [5] can serve this purpose. They are designed following the philosophy of constructionism [6] that asserts that people learn best when engaged in creating meaningful projects that they can reflect upon and share with others. Therefore identity construction environments enable children to design their meaningful computational projects to explore their sense of self. In this chapter we present two examples of identity construction environments, **SAGE** and **Zora**. **SAGE** enables children to design interactive storytellers, while **Zora** provides them with tools to create a virtual city. This chapter describes the use of these two identity construction environments in Children’s Hospital Boston.

SAGE: TELLING STORIES WITH AN INTERACTIVE SOFT RABBIT

SAGE (Storytelling Agent Generation Environment) is an identity construction environment that supports the creation of individualized “wise or sage storytellers” by children. It was developed at the MIT Media Laboratory in Cambridge, Massachusetts to help children "play out" what is happening in their lives by telling and listening to stories. In order to encourage child's emotional engagement, the wise storyteller’s assistant was embodied in an interactive stuffed animal (rabbit) — a *soft interface*.

With **SAGE**, children became the designers as well as users of their creations. Thus, **SAGE** supported two modes of interaction. In the first mode, children share their personal stories with a wise sage, and his rabbit assistant, who “listen” and then offer a relevant tale in response. In the second mode, children can add to the collection of wise sages by designing their own storyteller for themselves and others to interact with. They then write stories for their sage to tell [7].

In order to support children in creating their own characters, a visual programming language was developed to design and program: (1) the scripts that are used by the storyteller, (2) the conversational structure or flow of the interaction, (3) the body behaviors of the interactive toy, which behaves as the pet assistant of the storyteller, and (4) the database of tales that are offered in response by the character. **SAGE** also has multimedia capabilities allowing children to record their own stories and to draw their own characters. **SAGE** was designed to focus on creating stories and storytellers that invite reflection about the child’s inner world.

SAGE seeks cognitive and emotional engagement. Hence, the decision to embed the assistant of the sage storytellers in a programmable interactive stuffed animal (see figure 1). The stuffed animal is capable of some of the types of nonverbal behaviors that humans use to indicate engagement and which are commonly found in conversational narratives between people (i.e., the rabbit moves as the children converse with it). In design mode, children are able to decide on the toy’s communicative behaviors as well as the different personalities it might have.



Figure 1: Interactive programmable stuffed rabbit

Stories From The Heart

Patients admitted on the hospital’s cardiology ward (ages 7 to 16) were asked to use the **SAGE** to tell their stories and to create interactive characters. Informed consent was obtained from all families as part of a larger project by the authors to understand and promote family coping with cardiac illness, hospitalizations, and invasive medical procedures. The aim of this project was to explore the feasibility of physically ill children to use SAGE as well as its usefulness and safety in the hospital setting.

To engage hospitalized youngsters in the project, we created special characters for **SAGE** that could tell stories relevant to the medical environment. This began with “Mrs. Needle” who was a cartoon-type character that engaged children around the common child fears of “needles or pokes.” This character used humor as a way to “break the ice” with these children. These characters proved quite successful as evidence by the creation of new hospital characters, e.g., “Mr. Tape”, by the children themselves. Interestingly hospital professionals even created their own characters, e.g., “Mr. Squeeze”.

The following are two examples of how two patients used the system to write stories of their medical experiences.

- Lisa created a character (herself) called "Sadly Alone." The character asks the user, "Are you feeling sad?" and then told Lisa a story. In response, Lisa worked on her own story with a close family member. Lisa was gravely ill when working with **SAGE** wrote the following.

"My name is Lisa, and I have a problem. I'm 16 years old and I have a real bad heart problem and I am getting ready to have a heart transplant really soon but the hardest thing is my mother [is very sick] And I have a little brother, so it's so hard to leave them alone so I just stay strong and do what I have to do and if you ever have this kind of problem just stay strong for your family and think of me."

- Samuel is a 13-year-old boy who had had a successful heart transplant. He wrote three stories about this experience and put them together into a trilogy called "The heart transplant dictionary".

"At first I felt very sick and I had to go into the Emergency room. First I had an IV which I never had before which I was pretty scared about and then I had a blood test on my arm and I never had one of those either which I was very scared about too but the IV was much scarier because I didn't know how much it was going to hurt. And another scary part was a lot of different doctors coming in all the time and that made me nervous because it made me think that there was something very wrong with me [...] but then I got better and I got to go home and I thought that everything will be OK but then I got sick again and I had to go back to the hospital and then they realized that I had to have a heart transplant.

After my heart transplant I was very sick because my body was rejecting my heart and it made me feel very sick and I had to go in for medicine and get biopsies twice a week where they go

through a vein in your neck with a needle and they thread a catheter through and then they scrape a little piece of the heart tissue to see if you have any rejection. Rejection is when your white blood cells do not recognize your heart and think it is some bad virus or disease because it is not your original heart and your white blood cells try to attack your heart. So I kept having rejection [...] so they sent me to [another hospital] to go on a experimental drug [...] and felt better and the new drug is working very well and now I have no heart rejection at all [...]

The following example is from actual **SAGE** logs of interactions that a 16-year-old patient had with different storytellers (some already existing and others created by the patient). Interaction between the patient (*CHILD*) and **SAGE** happens through the keyboard (i.e., typing input and text-to-speech or recorded output).

- This is a log of an interaction between Damian and the rabbit, best friend of “Mrs. Needle.”

CHILD: I guess yes

SAGE: Well, Mrs. **SAGE:** *Hi, what is your name?*

CHILD: Damian

SAGE: *Welcome, Damian. I am Bunny, the best friend of Mrs. Needle. She hides in the computer because she is a little shy. She thinks that all the kids hate her. So she asked me to talk on her behalf. Is that OK with you?*

CHILD: yes

SAGE: *Wonderful, wonderful, Damian! Mrs. Needle is worried because kids scream when they see her. But, have you met Mrs. Needle before?*

Needle is my best friend and she hides in the computer. Tell me, Damian, how old are you?

CHILD: 16

SAGE: *Damian, you are older than me. I wonder if you are you scared of needles as I am ? I hate them, all except my friend Mrs. Needle. What about you?*

CHILD: They are all right

SAGE: As I was telling you, Damian, I am Mrs. Needle's best friend and she asked me to find out why children hate her so much. She thinks that it is because she stings, but she is not sure. What do you think?

CHILD: yes no kid is excited to get any needles

SAGE: I see Damian ... what else can you tell me about this?

CHILD: the kids are afraid of it because it hurts and they don't like it to hurt and I guess that is it

SAGE: Well, Damian, let me see if I understand. I am sure that Mrs. Needle is very happy to hear what you have to say. Yes no kid is excited to get any needles the kids are afraid of it because it hurts and they don't like it to hurt and you guess that is it. Am I right?

CHILD: yes

SAGE: Guess what, Damian? Mrs. Needle has a story for you. She is shy but she loves to tell stories. She always says that they have power...Listen to her...

Ms. Needle's Story: They built me to sting, but that is not all I do. If you were a flower I could water you without hurting you. But you are not, and I am not a water pot. My nose is like a hose or like a straw and my belly has goodies that can help you to heal. When my belly is empty, the goodies are yours and you can feel better. But sometimes it is the other way around. My belly starts completely empty, and then it becomes full with your goodies. You can think of me as a someone that only stings, but I also do good. The problem is that this is not always immediately obvious.

SAGE: I loved Mrs. Needle's story, but how about you? Does it somehow relate to what you told me before, Damian?

CHILD: yes it does

SAGE: I see, Damian, please explain me the connection. I don't get it.

CHILD: The children don't realize that the stuff can help them, the medicine.

SAGE: I see, Damian, you got the power of the story. I am sure my friend Mrs. Needle will be very happy. I wish that you will always have the courage to keep telling and listening to stories. I hope to see you soon....Bye !

- After playing with “Mrs. Needle”, Damian decided to create his own character called “Mr. Tape.” He created the conversational structure, the scripts that “Mr. Tape” says, and also the stories that he tells. After, he interacted with the character and invited other people in the Cardiac Unit to play with him. This is a saved log of Damian’s interaction.

SAGE: Hi my name is Mr. Tape. What is yours?

CHILD: Damian

SAGE: Well hello, Damian, my name is Mr. Tape. I am very sticky, as you probably may know, a lot of children don't like tape because when you have to take it off it hurts. Some kids like me to put me anywhere, like the face, hands, just for fun. Do you like tape?

CHILD: no

SAGE: I am sorry, why don't you like me. Does it hurt you?

CHILD: sometimes, yes

SAGE: Well, I am good for taping things up that are broken and I come in different kinds. I try to do the best I can with making things back to normal. So, Damian, how old are you?

CHILD: 16

SAGE: You are lucky to be able to live that long. My life expectancy is only two to three years. Some people use me up fast and sometimes I am forgotten in the junk drawer. I get pretty lonely in there. Would you like to hear my story?

CHILD: yes

SAGE: *When I am used as medical tape I am the number 1 user for nurses and doctors. I go on IVs and wrap things up. I am good to write on for the nurses to put on IV medication. You can use me just about everything in the hospital but I am not very sticky for heavier objects. I could be colored on and used for decorations for kids that are very bored. Some people just throw me around and drop me which hurts my feelings, I can't pick them up and drop them, but I thank them for using me as their number one choice. Well it was nice talking to you, maybe you will talk to me again and listen to my story. Bye*

As shown in these examples (as well as many others) youngsters with pediatric heart disease were able to readily use the **SAGE** to express significant fears and feelings. **SAGE** proved feasible, safe, and useful. It enabled children to adaptively express emotions through the creation of stories and narratives along with the development of innovative and interactive characters with whom they could converse. Nevertheless the **SAGE** did not engage children in sharing their stories with others in a community. When an individual is facing adversity it can be helpful to share one's personal narrative and becoming part of a social network that shares similar concerns. Recognition of **SAGE**'s limitation in developing a supportive community led to the next prototype, **Zora**.

ZORA: DESIGNING AND INHABITING A VIRTUAL CITY

Zora is a 3D graphical multi-user environment designed at the MIT Media Laboratory [8]. 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. Young patients used **Zora** in the hospital's dialysis unit. These patients form a community because they share a common medical condition and treatment in their end stage renal disease. Yet, at the same time there is little opportunity for social interaction with each other as they are confined to a single bedspace

where they are attached to a dialysis machine for several of hours three times each week. The aim of this project was to explore the potential of the **Zora** identity construction environment to facilitate mutual patient support. In order to investigate this potential, the study examined the feasibility and safety of using the **Zora** virtual environment in a hospital setting.

Zora is a 3D graphical multi-user environment designed to support the exploration of identity through storytelling and programming. Users can create a virtual city and populate it by designing spaces, objects and interactive characters that can be programmed to engage in interactions with other users. The environment also has a story writing capacity. The name **Zora** was inspired by one of the cities that Italo Calvino describes in his book Invisible Cities, *“This city is like a honeycomb in whose cells each of us can place the things we want to remember...So the world's most wise people are those who know Zora.”* [9].

Users are graphically represented by avatars with the owners’ image. 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 cannot only navigate around the 3D virtual city, but also 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. Both personal homes and temples are spatial representations of identity composed by artifacts symbolizing intangible aspects of the self.

Zora is an object-oriented environment, meaning that users can make new objects by cloning existing ones and inheriting its attributes. Objects have the following attributes: 1) presentation attributes,

graphical appearance and motion; 2) administration attributes, *ownership*, which determines who owns the object and therefore can edit it, and *permissions*, which set if the object can be cloned; and 3) narrative-based attributes, *textual description, stories, values and conversations*. **Zora** is implemented using the Microsoft's Virtual Worlds platform, a development kit for building distributed multi-user environments [10].

A Virtual City in the Hemodialysis Unit

During a five months pilot study in the hospital's hemodialysis unit patients had access to a networked computer at their bedside and used it to create their own virtual city (see figure 1). The unit staff was also involved in participating in the study. Informed consent was obtained from all participants.



Figure 1: the Zora computer and the dialysis machine

During this study, participants designed a total of 16 virtual places (see figure 2). Interestingly the hospital staff created 3 spaces including the *Nurse's Room* and the *Temple of Feeling Better* (described by the staff as a place to tell each other ways to cope with hard things). The MIT Medial Laboratory staff created 3 spaces including *the Restaurant*. Patients designed personal homes as well as several

common spaces including the *Music Room* and the *Renal Rap* (described by the patients as a virtual space for dialysis patients to get together do fun things).



Figure 2: The Temple of Feeling Better

Participants made a total of 94 objects ranging from pictures of the hospital staff to favorite cartoon characters to video games. Overall, the patients created 14 characters generally cartoon characters that they called “heroes.” The values dictionary of the city had 13 values with their definitions, e.g., *“friendship”*, *“doing something positive to help myself or someone else”* and *“respect”* with the definition *“people should be aware of what they do to other people's things.”*

During the study, the patients created 5 “cases” which 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. For example one case dealt with setting up the social organization of the virtual city, e.g., *“...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...”* Participants posted in the bulletin boards 17 messages e.g., *“I really liked what you guys have done with the renal rap room”*. They engaged in interactions with each other more on an asynchronous way than on a real-time way. This is not

surprising since not all the participants were in the same dialysis shift and not all of them felt healthy to use Zora at the same time.

Feasibility and safety

In order to assess the feasibility and safety of using Zora in a hospital, in the midst of the hemodialysis treatment, participants (both patients and staff) 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". Descriptive statistics were calculated for each of these rating scales. Participants were also asked several open-ended questions.

Feasibility

The patients (n=7) reported that they were very satisfied with Zora (mean = 5.3; standard deviation =1.3) and that they enjoyed very much participating in the experience (mean = 5.7; standard deviation =1.6) (see figure 3). *"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 15-year-old patient.



Figure 3: Satisfaction of Using Zora

When designing this pilot study there were some doubts about how patients, who are usually tired or sleep during most part of their treatment, would engage with Zora and if they would even use it at all. Zora was found not only feasible to use with patients undergoing hemodialysis treatment, but that was also an enjoyable and positive experience.

Hospital staff rated the experience very high (mean = 6.5; standard deviation =0.58) (see figure 3). For example, one staff member noted that being involved with the project helped her learn about the infinite potential of computer applications designed with a structure that might support different forms of therapy. Nurses did not find that **Zora** interfering with the patient's medical care. 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."*

Nurses also enjoyed being involved with different logistical tasks, such as helping kids move the computers around and connect to the Internet. At a personal level, the hospital staff enjoyed the fact that **Zora** helped them learn new computer skills. They regretted that they could not devote more time to participate in the experience and the lack of a dedicated computer.

Safety

Overall, the seven patients reported that **Zora** was safe (mean = 5.93; standard deviation =1.84) and that participating in the experience was not hurtful (mean = 1.43; standard deviation =1.13). When asked about the safety of using **Zora**, a 17-year-old 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."* Safety was a significant concern given the multi-user and open-ended nature of **Zora** and the fact that it runs on the Internet where children could easily find inappropriate content. This patient's response shows the importance of having in **Zora** as a space for community participation and democratic decision-making. In his perspective it was the patients' responsibility to make **Zora** a safe space, and not just a matter of obeying a code of behavior imposed by outsiders.

Hospital staff reported that using **Zora** was safe (mean = 5.63; standard deviation =1.49) and they all agreed that participating in the experience was not hurtful at all (mean = 1; standard deviation =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 and punching a wall they had an opportunity to discuss things and to learn and to ask anything in Zora."* Another staff member agreed but pointed out the importance of supervising what children 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 of intervention. However, the community of users was small and they all belonged to the same institution.

Exploration of personal identity

When the study was designed it was hypothesized that patients would use **Zora** to explore their illness as a key component of their identity. We imagined kids would build virtual rooms populated by kidneys, dialysis machines and nurses. However, this did not happen. On the contrary, all of the patients consciously avoided any mentioning of hemodialysis in their virtual rooms. As a 15-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; standard deviation =2.30).

Children used **Zora** as a way to escape from the harshness of dialysis, not to think about it. Patients escaped 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. Patients decided where to go and visit in the virtual city and were able to make decisions regarding how long to stay in the

different places. This sense of autonomy and control was one way of escaping the frustrations of dialysis where there is no possibility to move around in a free way, neither to make many choices.

Second, patients escaped the harshness of dialysis by using their rooms to represent aspects of their identity that are usually underplayed during treatment. In general while undergoing hemodialysis, patients spend their time sleeping or watching TV. Their identity is represented by “passive” activities. However, when outside the hospital, like most people of their age, they participate in active endeavors, such as working, going to school or going out with friends. Their image of themselves is not the same inside and outside dialysis. **Zora** provided a way to bring back the self-image of patients as active agents. It offered a different venue of how to use their extensive time in dialysis in a creative and fun way by engaging in the creation of a personally meaningful project. When asked what she learned during the experience, a 14-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."*

Since undergoing dialysis was a common factor for all of the participants none of them felt the need to make it explicit in their rooms. Instead they chose to represent other aspects of their identity. For example, Sharon created an Elvis Presley room with animations of the singer performing in the walls while Rina created a horse haven, with stories and pictures of her horse at home. 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?

Facilitating mutual patient support and interaction

In order to facilitate mutual patient support and interaction, **Zora** provided both synchronous and asynchronous ways of communicating and sharing experiences. The patients talked 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 using **Zora** helped them make friends or get support from other kids on dialysis in a moderate way (mean = 3.86; standard deviation =2.41). At the same time, they reported that it greatly helped them to feel more part of a group on dialysis (mean = 4.43; standard deviation =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 perceived that using **Zora** helped patients a lot to make friends (mean = 4.50; standard deviation =1) and a little less in making them feel part of a group (mean = 3.75; standard deviation =0.5) (see figure 4).

Synchronous Communication: A Private Way to Talk in a Public Space

The hemodialysis unit is a public noisy space where patients are physically together for long periods of time. However, since their beds are far apart from each other, they cannot communicate with each other in a private way. Although the dialysis patients have all the characteristics to form a community, they lack the means to converse while undergoing treatment. Most of the patients particularly liked the fact 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-year-old patient. On-line conversations were not about dialysis per se, but about favorite video games, movies and activities done during the weekend. Most of the conversations were task-oriented such as helping each other to resolve technical problems and use some of the Zora features.

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 facilitated the creation of a social network by providing a space for 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, one of the hospital staff noted that Larry was upset and could not 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 (a physician) 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.

Zora Design Recommendations

A crucial study outcome was to identify not only the positive aspects of **Zora**, but also problems. This is important to the design of future interventions tailored to the particular needs of this complex real-world setting.

- **Need of a broader community.** In each dialysis session only three patients were able to connect to Zora at the same time. This was due, on the one hand, to the lack of computers, and in the other hand, to the lack of motivated participants in the required age range and the difficulties of having a broad patient population feeling up to work at the same time. Therefore the Zora community logged in on real-time was very small. *"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 rather talked anonymously. In the future it might be important to increase the number of Zora participants such as involving other dialysis units. Another possibility would be to extend the experience to a large community by including renal transplant and/or at home dialysis patients.
- **Need of more intervention.** Another goal was to observe how patients would use Zora on their own and how they would create a participatory community. However, this patient population requires a lot of direct intervention and guidelines in order to be engaged and motivated in any

activity for long periods of time. As the child life specialist noted *"after a point in time the kids get bored with anything, they want bigger and better to keep them entertained, and a lot of them just want to sleep... they don't want to do anything because they are not feeling good."* In future experiences it would be helpful to designate a project coordinator that would propose a tailored syllabus. The creation of a syllabus is a big challenge because, due to their medical treatment, not all the patients can engage in the same type of activities at the same time.

- **The question about dialysis content.** All of the patients agreed that 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 MIT Media Laboratory staff set up the virtual space and asked patients to create the menus. For 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 'shrugs' ||

Vitor says 'What drinks do you think we should have in the menu?'

Washu says 'coffee, tea, ice water, etc....'

Vitor 'Which ones do you like best? '

Washu says 'I like tea with cream and sugar'

Vitor says 'I've never tried that, what about desserts'

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'

The question is how to create spaces that engage children in learning and talking about dialysis. These spaces should go beyond displaying information produced by professionals. Patients need to take an active role in their creation. For example, they could be the ones who, working together with the professionals, design the virtual rooms to teach visitors about dialysis. For this to succeed it is important that the activity be authentic, namely real visitors should be invited to walk around these rooms and engage in conversations with the patients. For example, visitors can be kids recently diagnosed with end stage renal disease, medical staff, parents of patients, elementary and high school students interested in medicine.

- **Visualizing data.** Patients reported that using Zora did not help them gain perspective or understanding about their illness (mean = 1.86; standard deviation =1.21). At the psychological level, children did not use **Zora** to talk about dialysis, but as an escape from it. At the physiological level, **Zora** did not support patients to explore what happens in their bodies while undergoing dialysis. However, Zora can support both types of interventions in future experiences. On the one hand, a mental health professional can coordinate virtual meetings in the same style than therapeutic communities. On the other hand, the Zora environment can support

the collection and display of physiological data provided by the dialysis machines and other medical charts. This data indicates progress in the treatment as well as the level of compliance between visits. If patients were encouraged to pay with this data in a friendly, creative and educational way they could explore “what if” possibilities regarding their own health care. And it would allow researchers to investigate correlations between engagement with **Zora** and successful medical compliance.

DISCUSSION

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 Internet to support therapeutic work already going on in medical facilities. Identity construction environments, such as **SAGE** and **Zora**, open up new possibilities for health care. As shown in this chapter, the use of well designed computer technologies to implement well grounded psychotherapeutic interventions is feasible, safe, and useful to patients and staff. Introducing a fun, self-exploratory and community-building computer activity can provide patients with the opportunity to be creative. It help them express themselves and explore aspects of their identity in ways that are generally underplayed and even avoided in the medical setting.

A computer based application that promotes increased coping and resiliency in the face of pediatric illness can make accessible psychotherapeutic interventions that otherwise is only available to those living geographically close to a major pediatric medical center. Identity construction environments such as **SAGE** and **Zora** can provide an important opportunity for patients and staff to participate in the process of gaining self-understanding and shared understanding, which are cornerstones to coping and resiliency [11].

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REFERENCES

1. Brem AS, Brem FS, McGrath M, Spirito A. (1988) Psychosocial characteristics and coping skills in children maintained on chronic dialysis. *Pediatric Nephrology* 2:460-465.
2. Brownbridge G, Fielding DM. (1994) Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatric Nephrology* 8:744-749.
3. Gonzalez-Heydrich J, Bromley D, Strohecker C, Marks J, DeMaso DR, Ackermann E, Gibson S, Shen C, Umaschi M. (1998) "Experience journals: Using computers to share personal stories about illness and medical intervention." *MedInf'98, 9th World Congress on Medical Informatics*. IOS Press. 1998, pp. 1323-1327.
4. Turkle, S. (1995) *Life on the screen: Identity in the Age of the Internet*. NY: Simon & Schuster
5. Bers, M. (forthcoming) " We Are What We Tell: Designing Narrative Environments for Children " In *Narrative Intelligence*. Edited by P.Sengers & Mateas. Amsterdam: John Benjamins.
6. Papert S. (1980) *Mindstorms: Children, Computers and Powerful Ideas*. New York: Basic Books.
7. Bers, M.; Ackermann, E.; Cassell, J.; Donegan, B.; Gonzalez-Heydrich, J.; DeMaso, D.; Strohecker, C.; Lualdi, S.; Bromley, D.; Karlin, J. (1998) "Interactive Storytelling Environments: Coping with Cardiac Illness at Boston's Children's Hospital" In *Proceedings of Computer-Human Interaction (CHI'98)* ACM,pp.603-609.
8. Bers, M. (1999) "Zora: a Graphical Multi-user Environment to Share Stories about the Self." In *Proceedings of Computer Support for Collaborative Learning (CSCL'99)*, pp. 33-40.
9. Calvino, I (1972) *Invisible Cities*, NY: Harcourt Brace Jovanovich
10. Vellon, M. Marple, K. Mitchell, D. & Drucker, S. (1995) "The Architecture of a Distributed Virtual Worlds System". Virtual Worlds Group. Microsoft Research.
11. Focht L, & Beardslee WR (1996), "Speech after long silence": The use of narrative therapy in a preventive intervention for children of parents with affective disorder. *Family Process* 35:407-422