

New Media for New Organs

A Virtual Community for Pediatric Post-Transplant Patients

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Abstract / This article describes an eight-month pilot study in which 19 pediatric post-transplant patients at Children's Hospital Boston, ages 11 to 15, used a computer-based psychosocial intervention developed on the Zora 3D multiuser environment. Zora provides tools to create an online virtual city and populate it with houses and personally-meaningful objects. Users can communicate with each other via real-time chat and participate in open-ended guided activities to create a social network of peers. Preliminary results support the idea that innovative technologies can help adolescent patients to create a support network of peers when face-to-face interactions are impossible.

Key Words / children's virtual community / health care / multi-user virtual environment / online games / real-time chat

Introduction

New media is having an impact in the way children learn, play and communicate. From video-games to virtual tutors, from I-pods to on-line shopping, today's children are immersed in a culture in which computers and the internet are vastly used for most of their needs (Subrahmanyam et al., 2001). Most recently, these needs have also started to expand to health care. In addition to informational websites, innovative interventions are also taking place. For example, playing video games has proven to be effective to supplement cancer treatments (Brown et al., 1997; Lieberman, 2001), and e-mail counseling is in the rise.

This article describes a pilot project in which post-transplant patients at Boston Children's Hospital used a multi-user virtual environment, called Zora, to form a virtual community to share their experiences, combat isolation in the midst of a medical situation that makes it difficult to integrate back to a social life with peers, and to learn from each other strategies for improving their adherence to demanding medical regimes.

Zora is a three-dimensional software that engages youth in building a virtual city, chatting with each other, creating virtual places and characters and writing interactive stories (Bers, 2001). Zora is designed upon constructionist learning principles that

promote children's creation of their own personally meaningful projects and sharing them in a community (Papert, 1980). From a technical perspective, the first version of Zora was developed in 1999 using the Microsoft Virtual Worlds development platform (Bers, 2001). The current version of Zora has been revised and developed using the ActiveWorlds platform (Bers, 2007; Bers and Chau, 2006; Satoh et al., 2006). This platform for developing educational multi-user environments is used by other educational research projects such as Quest Atlantis (Barab et al., 2005) and River City (Nelson, 2005).

Zora has similarities with the growingly popular Second Life[®] virtual world (Ondrejka, 2004) in presenting a three-dimensional environment for users to develop a virtual community. However, unlike Second Life[®], Zora is a secured and password protected world in which only youth engaged with a particular program, such as the Transplant Center at Boston Children's Hospital, can view the world and contribute to it. In the spirit of play therapy, in which children are offered different props to express themselves, in Zora, children can choose to use their preferred digital media to share their inner feelings in the context of a peer virtual community in order to promote overall positive youth development (Bers, 2006).

In the past, most young people needing organ transplants would not survive. Today, advances in medicine make it possible to extend the length of their life. However, while an organ transplant generally improves the overall quality of life, transplantation is not a cure. Children and their families are trading a life-limiting disease for lifelong medications, close medical follow-up, invasive interventions and the side effects of transplantation medications. This intensive treatment may come associated with difficulties to adjust to changes in lifestyle and with non-adherence to demanding medication regimens and dietary restrictions (Brem et al., 1988; Erikson, 1950; Gerson et al., 2004; Penkower et al., 2003; Rodin and Voshart, 1987).

Unfortunately, psycho-social services lag behind medical advances and there is a lack of programs to support young people undergoing these challenges. New media that allow the formation of virtual communities of peers present a unique opportunity as they enable possibly isolated children to form peer networks. Most uses of new media regarding health care are based on cognitive interventions, such as multimedia-education interventions for children with asthma (Homer, 2000; Krishna et al., 2003; Krishna et al., 2006; McPherson et al., 2001; McPherson et al., 2006; Rubin et al., 1986; Yawn et al., 2000), leukemia (Dragone et al., 2002) and diabetes (Brown et al., 1997).

Other computer-based interventions, such as virtual support groups and internet-based programs such as STARBRIGHTWorld (Bush and Simonian, 2002), web-based storytelling environments (Bers et al., 2003; DeMaso et al., 1995; DeMaso et al., 2000) and virtual reality focus on modeling of and permission for adverse affective responses such as fear and anger (Hoffman and Patterson, 2005; Moline, 1997; Schneider and Workman, 2000; Schneider et al., 2004). Most recent interventions are starting to take advantage of everyday media to support medical adherence such as cell phone-based games (Aoki et al., 2005) and daily phone diaries (Modi, 2006).

The project reported in this article presents a pilot psychosocial intervention using the Zora virtual world with children aged 11–15 years old who received the transplant of a heart, liver, lung or kidney at Boston Children's Hospital (Bers et al., 2007). The goals of the project are: (1) to facilitate peer network-building amongst same-age pediatric post-transplant patients, (2) to encourage their medical adherence, and (3) to support

their psycho-social development by assisting to their adjustment to lifestyle changes and medical regime.

In order to situate the reader in the context of the lives of children after organ transplantation and how the particular group of children we worked with used Zora, I present three vignettes. They depict real events that happened during eight months in our Zora research project. Although the names of the children have been changed to respect their privacy, the descriptions of their doings and their feelings are based on what they have shared with us as well as on the Zora computer logs.

A day in the life of a child with a transplant in Zora

Fourteen-year-old Melanie uses her home computer in Maine to connect to Zora, a multi-user virtual city. There, she has created an avatar, a virtual representation of herself and a virtual home. A visit to Melanie's home on Zora reveals much about the girl: her best friends, her pet, her family's history, her baby picture. By clicking on each of these virtual objects, one can read the stories that Melanie chose to tell. For example, one can learn that Melanie received her kidney from her mother when she was a baby. After working on her own virtual home, Melanie visits other homes in Zora. In the virtual city she meets Jamie, a 16-year-old girl who received her kidney transplant five years ago, and who lives in Massachusetts. The teenagers meet weekly on Zora and engage in lively on-line conversations: strategies to remember how to take their medicines, chat about boys, what makes the two of them different from their classmates. It is the first time the girls have met another child in the same situation. After a couple of months of 'seeing' each other and becoming virtual friends, the girls decide to meet face to face at a mid point in Massachusetts.

Caroline is a 16-year-old girl who received her new liver almost 11 years ago. She connects weekly for an average of three hours to Zora from her home computer in Rhode Island. In one of the virtual group meetings, Caroline shares with the other Zora citizens that she is worried about leaving her home and going to college. In particular, she wonders about how she will remember to take her daily medicines when her mom is not around, and how she will tell her new friends that she had an organ transplant. Michael, from northern Massachusetts, explains to Caroline that he uses an alarm in his cell phone as a reminder for his medicines. Peter, from Maine, uses a colorful stack of cards that he keeps in his room. The three kids engage in a lively on-line conversation about different strategies for medical adherence. Following on this interest on medicines, the Zora co-ordinator suggests to the children to work together in building a virtual pharmacy, so other children in Zora can also learn about this. For the next months, the children in Zora are busy discussing what this pharmacy should have and researching more about their own medicines so they can write the information. Someone suggests to include a message board so all the Zora children can post their own strategies for medical adherence. Someone else makes a virtual health museum next to the pharmacy, so children can learn more about their transplants. Children contribute their own transplant stories to the museum, as well as medical information. They invite one of the doctors and interview her on-line. However, despite all of this information, Caroline is still worried. She is one of the oldest in the Zora virtual community and she will be going to college soon. She has never met a child with a transplant that went to college before. She has so many

questions . . . The Zora team hears this need and asks the Transplant programs to suggest the name of a college-age youth who received a transplant and who would be willing to come on Zora once to discuss this. The next week, 19-year-old Sam comes on-line from his dorm in Connecticut. He talks about his heart transplant and his life in college. Children are very excited and have all sorts of questions for him. Caroline feels relieved. Sam offers to come back anytime. He feels important. He enjoys his role as a mentor. He has something to share with others. He can be helpful to younger children who are going through the same issues he went through years ago. He can help them to feel less lonely.

Seth had his first heart transplant when he was a young child. Now he is in the hospital waiting for a second donor. He is anxious and bored. He requests the hospital staff to log in into Zora from his hospital room. In Zora he had created a virtual room full of his drawings. Although he has never met the other children face to face, he misses them. He got used to virtually meeting with them every week. He wants to talk with them. To tell them that he is in the hospital now waiting for another transplant. He knows they are the only ones who will understand how he feels. Meanwhile, in Zora the word has spread about Seth's situation. Children are busy making virtual get-well cards for him and leaving them in his virtual home. When Seth is finally able to connect to Zora from the hospital, he has already got his new heart. He is very happy to find the cards. He does not feel like talking much in Zora, but he decides to make some drawings and puts them in the virtual city for others to see that he is back. After a couple of months go by, children in Zora hear about another one of them, Paul, who is also in the hospital for some complications with his transplant. Seth knows how he must feel. In one of his own medical check-ups, he decides to visit Paul at the hospital. It is the first time that the two boys meet face to face. But they feel that they have known each other for a long time. They are not sure of what to talk about. Seth gives Paul one of his hand drawings, just like the ones he had put in Zora, and leaves. Paul treasures it in his hospital bedside table. Seth is the first friend who has visited him.

Description of the Project

This pilot project ran for an eight-month period in which the research team led weekly online activities that were designed to foster a community amongst post-transplant patients 11–15 years old, to teach them technological skills, to improve their medical adherence, and to facilitate the formation of a peer social and support network. The research team monitored all virtual activities of the participants.

This pilot study was conducted in collaboration with the Pediatric Transplant Center and the Department of Psychiatry at Children's Hospital Boston. Throughout the project there was 'rolling' admission, as staff could recommend new participants at any point. Patients who did not have access to a computer or high-speed internet connection were provided with equipment for the duration of the program. Of the 54 patients who were originally contacted, we worked with a total group of 22. There were 13 participants from the heart transplant program, 3 from liver, and 6 from renal. This group also represented a diverse group across the East Coast: 12 participants were from Massachusetts, 1 from Florida, 1 from Maine, 3 from New Hampshire, 2 from New York, and 3 from Rhode Island.

For a period of eight months participants logged on to Zora at any time they wished from their home computers and took part in weekly one-hour on-line group activities that ranged from icebreakers to discussions about medicines and school transitioning. These activities and discussions were continued throughout the week when participants signed on at their own time. Online activities, as recorded by an automatically-generated log system, were reviewed daily by coordinators to ensure safety.

In the spirit of the constructionist philosophy of learning (Bers, 2001; Bruckman, 1998), the on-line group activities followed an open-ended, child-centered curriculum. For example, the group created a Transplant House and a pharmacy where participants shared their stories. They also produced a printed monthly newsletter, *Transplant Times*, in which patients assumed the roles of writers and photographers to report their experience in Zora.

In addition to building a peer network, activities in the curriculum were also intended to promote certain assets in participants in the hope of increasing medical adherence and quality of life. One of the features of Zora is that participants are given the tools, rather than the content, to learn about specific issues and topics (i.e. medical adherence and clinical issues in this case). For example, instead of planting a 'Health Museum' that is dense with information delivery, participants were guided in researching about their own or other people's transplant stories and built 3D objects and narratives in making their own museum.

Of the 22 enrolled participants, 19 post-transplant patients became Zora users, while 3 of them never logged in. During the eight-month period of the project, each user logged into Zora an average of 60 times and spent an average of 39 hours logged into the program. This represents almost seven hours more online than we had anticipated, as we had planned weekly on-line activities for 32 hours. Users created a total of 4027 objects and made 75 virtual houses. For example, they created a Legislature House where they put recommendations for hospitals to ease the stay of the patients, such as 'soft pillows', 'beds with comfortable mattress pads on them . . . especially in the cardiac cathlab, where you have to lay flat for six hours' and suggestions for schools to ease transitions after prolonged hospitalizations, 'so kids don't have to tell stories so many times'.

Zora allowed participants to communicate both synchronously, through real-time chat, and asynchronously, through message boards. As such, a total of 251 messages were sent between users who logged in asynchronously and a total of 14,566 lines of chat were recorded. Several Zora guests attracted children's participation. For example, a cardiologist came into Zora so participants could interview her on-line and establish a different type of rapport, and a college freshman who had had a transplant several years before shared his experience regarding how to handle transition from home to college. While this is a difficult topic for most adolescents, it becomes even more complicated when home represents the security of parents' daily reminders to take the medicines, and college is a shift in responsibility towards medical treatment.

Much of the success in our pilot program is found through the qualitative data that was collected via home visits, interviews, notes from parents and medical staff, and analysis of the participant chat log. For example, one parent wrote:

[Zora] has made noticeable changes in xx. I will be sad to see it end . . . last night his therapist noticed a change in xx. He is puzzled with xx seeming more comfortable this time. xx even laughed and made jokes about how awful his last biopsy went several months back. I have seen a change in his

comfort level also. The only new thing in xx's life is Zora. And well xx for the first time in six years has contact with other transplant kids. Making him 'normal', not the 'transplant kid'.

As noticed by this parent, we have seen some impact of using Zora, not only in the virtual world, but also in the real lives of children who participated in our pilot study. For example, a 15-year-old girl shared with us:

I believe that taking part in Zora did give me inspiration. I only had a liver transplant, and I can not have tunnel vision that there's only me, but there are a multitude of other kids that have gone through similar experiences as myself. They inspired me to help educate others about organ donation, because there are kids like us whose lives have been saved through the gift of organ donation.

As a result of her participation in Zora, this girl made a PowerPoint presentation for her school to teach about organ transplantation and organ donation. Following is an excerpt from the computer log: 'I really want them to know that being an organ donor is like a positive thing // and not go to drivers ed // and get the wrong impression// it shouldn't be a 'drag' to them // and i felt kind of insulted when the teacher was like apologizing for having to teach it // without that organ i wouldn't be alive now'.

During the project, two of the participants underwent a second heart transplant – in both cases, friends that the patient had made in Zora visited them in the hospital, sent them virtual get-well cards, and offered encouragement. Both patients requested to use Zora from their hospital bed to connect to the virtual community.

In summary, children, parents, and medical staff found this pilot project to be a success based on the high participation in the Zora virtual world and the general satisfaction and changes it brought about in some of the patients. As the internet becomes more widespread and children use it for all sorts of purposes, the health care community needs to develop innovative ways to leverage this potential and craft internet-based psychosocial interventions.

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