

# Use of a virtual community as a psychosocial support system in pediatric transplantation

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**Abstract:** Despite significant interest by pediatric transplant patients in meeting others who have undergone transplantation, geographic distances combined with their daily routines make this difficult. This mixed-method study describes the use of Zora, a Web-based virtual community designed to create a support system for these patients. The Zora software allows participants to create a graphical online virtual city with houses expressing their individuality and objects conveying their concerns and personal stories. Zora allows real-time chat between participants further facilitating communication. Twenty-two post-transplant patients used Zora over nine months. The median number of log ons per participant was 19.50 times (q1 = 5.25, q3 = 41.50), and each participant spent a median of 12.48 h (q1 = 2.13, q3 = 25.55) logged into the program. This represented a median of 18.27 min/wk (q1 = 6.88, q3 = 37.40) per participant. Users created a total of 3736 objects (median/participant = 12.5, q1 = 2.25, q3 = 30) and created 66 virtual houses (median/participant = 2.00, q1 = 1.00, q3 = 3.00). In addition, a total of 14 444 lines of chat were recorded (median/participant = 228.5, q1 = 30.00, q3 = 663.25), and a total 278 messages were sent between users (median/participant = 3.50, q1 = 0.25, q3 = 15.5). Qualitative data show the preliminary success of the project, as three major themes emerged: (i) increased sense of normalcy for the patients, (ii) enhanced sense of self and contribution to the community, and (iii) increased social network. There were no instances of harmful interactions in the virtual world. This study demonstrates the feasibility and safety of a virtual community as a potential psychosocial intervention for post-transplant adolescents.

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With advances in medical and surgical care, patients undergoing pediatric transplants have the opportunity for increased life expectancy and improved quality of life (1, 2). The successful treatment of a chronic disease in adolescents depends not only on the medical interventions, but also on the patients' ability to manage their disease, which is performed by adopting a healthy lifestyle, taking medications, and reducing risk factors. A variety of psychosocial problems including anxiety, depression, helplessness, boredom, and non-adherence (1, 3, 4) have been

reported, with particular risk in the adolescent years (1, 2).

The use of computational Web-based environments may offer an opportunity for adolescents to participate in virtual communities that promote coping with physical illnesses (5). While multimedia-education (6) and Internet-based interventions (7) are available that have been designed to promote coping, they do not specifically focus on the overall goal of positive youth development. Targeting this, Zora is a unique graphical computer environment that has shown promise in the promotion of social interaction in physically ill adolescents (5).

This study examines the feasibility and safety of using Zora, a novel Web-based virtual com-

Abbreviations: q, quartile; SES, socioeconomic status.

munity, to foster and promote the development of a psychosocial support network for adolescents with organ transplants. Zora is a research platform first developed as part of Bers' doctoral work at the MIT Media Lab (8) and then re-implemented by her DevTech research group and Academic Technologies at Tufts University.

## Method

The Zora virtual software

Zora is uniquely designed to support positive youth development among its participants (9). Thus, it has design features that engage users in discovering how they can improve their own lives and at the same time contribute to their communities. The software was designed for use as a psychosocial intervention when a traditional face-to-face community does not work or is impossible because of geography (10). It engages children in the creation of a virtual space that showcases their needs and desires, their fears and feelings, while immersing them in a peer-based virtual community. Zora is an online virtual environment (see Fig. 1). It can be thought of as a combination of a Webpage, an instant chat system (such as America Online Instant Messenger), and a 3-D world that can be navigated and manipulated (similar to SimCity, SecondLife, etc.). The software allows users to design a virtual city, decide its rules, write stories, create 3D characters, chat with each other, and import photos, videos, and sound. Zora requires a PC with a high-speed Internet connection.

A curriculum was designed to engage the participants in learning to use Zora's features as well as build a peer net-

work. Activities in the curriculum were intended to increase awareness about medical adherence and the value of peer social support. Zora was designed with the constructionist principle (11) that gives participants the tools, rather than the content, to learn about specific issues and topics (i.e., medical adherence and clinical issues in this case) in ways that are meaningful to them. So, for example, instead of researchers 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 in building 3-D objects and narratives to communicate their ideas and their research by making their own museum. Zora has been previously studied in pediatric hemodialysis (5), with children in after-school settings (11, 12), with incoming college freshman (12, 13), and with inner-city children all over the world through an international community-based organization (14). While all of these previous studies were aimed at understanding how a virtual world such as Zora could increase interaction, expression, and support, each focused on particular outcomes. For example, in the after-school setting, children used Zora to explore different aspects of their moral identities. Incoming college freshman created a virtual campus of the future responsive to the needs of their neighborhood community. Results showed an increase in participant's civic engagement indicators (12).

## Study participants

Between June and August 2006, all patients with solid organ transplants between the ages of 11–15 yr receiving treatment at Children's Hospital Boston were informed of the study. Patients with severe disabilities, either physical or developmental, were excluded. Admission to the project was on a rolling basis throughout the project period as hospital staff



Fig. 1. The Zora virtual environment.

could recommend new participants at any point. Participants varied in their time since transplant status, between 17 and 151 months (Median = 111 months, or 9.25 yr).

There were 54 eligible patients who were contacted through phone calls and mailings; 31 patients verbally agreed to participate, and 25 returned the necessary consent and assent forms. To avoid exclusions based on SES, we offered a free computer and Internet connection for the duration of the study to all participants in need. We provided a computer to one participant and Internet service to two participants so they could connect from their home. Additional equipment was put on reserve at the collaborating hospital for use by any participants while they were in clinical care. Three patients who consented to participate in the project were excluded because of lack of high-speed Internet access from their remote rural homes. Thus, a total of 22 patients made up the final composition of our pilot project.

### Procedure

Data collection for study spanned from September 2006 to May 2007. During this time, participants started using Zora for the first time at various dates from September 2006 until January 2007. By logging into Zora from their homes, participants got to know each other through real-time chat and asynchronous postings in the Zora virtual world. They engaged in collaborative activities to create virtual houses and populate the virtual world with objects, pictures, videos, and stories about themselves. In addition, some used the virtual community as a starting point for face-to-face communication. For example, twice families came together in a Zora team to participate in a walking fundraiser for the hospital.

The study team led weekly online group activities that were designed to foster a community among the participants, to teach them technological skills, to engage them in discussions about medical adherence, and to facilitate the formation of a peer social and support network. Some examples of activities include “creating a *Transplant* house,” “posting messages for others,” “building a health museum,” “building a *Halloween* house,” and “writing stories about the transplants.” The study team monitored all virtual activities of the participants. All chat conversations, story additions, virtual objects, and any other online activities were logged for study purposes and monitored for appropriate use of language and content.

Group activities were conducted twice a week, to accommodate diverse schedules and time zones. Participants were encouraged to log any other time of the week to Zora. The study was approved by the Institutional Review Board at Children’s Hospital, Boston.

### Measures and data analysis

Data were collected using a mixed-method approach that combines quantitative and qualitative data sources. We conducted quantitative data analysis of the Zora system logs for amount of time each participant was logged and how many houses, objects, and lines of chat each participant created. Median and percentile statistics are reported as measures of central tendency given the small sample size. We examined qualitatively transcripts of interviews, text produced by the participants and captured in the Zora system logs, and notes from home visits. Individual interviews were completed over the phone and were based on a 20-question semi-structured interview protocol that focused

on feedback on user experience with Zora. In addition, interviews also targeted questions related to impact of Zora on their health, adherence, and knowledge about transplants and medication such as, “Please name your medications and dosages.” Three participants located within driving distance of the university were also randomly selected for a home visit in addition to their phone interviews to assess the home context of Zora use, with particular attention to placement of computers while participating in the Zora experience and the level of noise and privacy. The same researcher completed all three home visits and documented observation notes. At the end of each home visit or phone interview, parents were also reached for open-ended comments and feedback. Transcripts and observation notes from phone interviews and home visits were entered into Atlas.ti 5.0 for analysis by two researchers following grounded theory principles.

### Results

Of a total of 22 post-transplant patients who participated in this nine-month study, 45% of the participants were women. The average participant age was 13.7 yr (median = 13.0). There were 13 participants from the heart transplant program, three from liver, and six from renal. This group came from across the East Coast: 12 participants were from Massachusetts, one from Florida, one from Maine, three from New Hampshire, two from New York, and three from Rhode Island.

Participants logged onto Zora at their discretion from their home computers. They also took part in weekly or bi-weekly one-hr online group activities with the study coordinator that ranged from “icebreakers” to “discussions about medicines and school transitioning.” Examples of these collaborative group activities included: (i) creating a *Halloween* house where stories about “*the things they were most afraid of*” were posted, (ii) building a *Transplant* house where personal transplant stories were shared and a *pharmacy* where strategies for “*remembering to take their medicines*” were discussed, and (iii) constructing a *Legislature* house where recommendations for hospitals to ease the stay of the patients (e.g., “*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 (e.g., teachers should become more informed “*so kids don’t have to tell stories so many times*”) were outlined.

Each participant logged into Zora a median of 19.50 times (q1 = 5.25, q3 = 41.50) over the entire study. This represented a median of 0.56 log ons per week (q1 = 0.25, q3 = 1.15) per participant. Each participant logged into the program a median of 12.48 h (q1 = 2.13,

q3 = 25.55) over the nine months of the study or a median of 18.27 min/wk (q1 = 6.88, q3 = 37.40). Participants' time spent online varied slightly across the nine months, ranging between 56.50 and 73.00 min/month per participant, with heavier participation in the initial and last months (68.00 and 73.00 min/month per participant, respectively) and lower participation in the middle months during January and February (56.50 and 58.50 min/month per participant, respectively) because of vacations and time away from home during the winter break. Over the course of these nine months, participants created a total of 3736 objects (median = 12.5, q1 = 2.25, q3 = 30), representing a median of 0.37 objects/wk per participant (q1 = 0.05, q3 = 0.73). In addition, over the study participants created 66 virtual houses (median = 2.00, q1 = 1.00, q3 = 3.00).

The Zora environment allowed participants to communicate synchronously through real-time chat and asynchronously through message boards. As such, a total of 14 444 lines of chat (median = 228.5, q1 = 30, q3 = 663.25) were recorded; this represented a median of 5.57 lines of chat per week (q1 = 0.73, q3 = 20.4). In addition, a total of 278 messages were sent between users (median/wk = 3.50, q1 = 0.25, q3 = 15.5).

There were a number of differences between older and younger participants in their use of Zora based on data from the automatic Zora log. In particular, older participants on average logged on for more times per week [ $t(20) = 1.55$ ,  $n < 0.01$ ], wrote more stories [ $t(20) = 1.65$ ,  $n < 0.01$ ] and value definitions [ $t(20) = 0.77$ ,  $n < 0.05$ ]. However, participants of both age groups did not differ in the number of objects created. This might suggest that certain aspects of Zora such as writing about values and stories attracted older participants more than younger participants.

While the virtual environment affords tools for participants to express themselves individually, group activities were important in creating a community. One example of a successful collaborative activity was the production of a monthly newsletter that the participants named the *Transplant Times*. The participants assumed the roles of writers and photographers to report their experience and activities in Zora. The *Transplant Times* was printed out and distributed to their families and physicians as a means for the community share their experiences.

Participants used Zora to gather information relevant to their transplant and to alter existing

and/or establish new relationships in the real world outside Zora. For example, this was most evident in a Zora visit from one of their physicians for an online interview. Another example occurred in the groups' interest in understanding what would happen to them when they go to college. Most of the participants expressed that their parents remind them to take the medications and had shared in Zora their concerns about what will happen when they live away from home. This led to an invitation to a college freshman who previously had a transplant. The group interviewed him online and then wrote a story for the *Transplant Times*. The following is an excerpt of that story:

On February 5, Zora got a visit from a friendly man named C. C is a transplant recipient just like us residents in Zora. He is a freshmen in college, and he was here to help answer any questions we may have had for him. He explained to us how much more difficult it is to remember to take our medications when we leave our homes and our remindful parents. C. made sure to remind us that even though we may be far away from home, that it is still important to take our medication. He introduced different techniques for us to remember to take our medicines. He told us that cell phones are one of the best inventions ever...Along with our medication, C. informed us that we need to make sure that our college of choice is located within a close radius of a transplant hospital, with doctors on hand in case of a medical emergency. C. was a great visitor to have on Zora. He was not only unbelievably friendly, but gave us important insight we will need when we attend college.

Much of the success in the use of this pilot program is found through the qualitative data that were recorded in the participant chat log as well as interviews with participants, parents, and medical staff. From this qualitative data, three broad themes were identified: (i) increased sense of normalcy, (ii) enhanced sense of self and contribution, and (iii) increased social network.

#### Increased sense of normalcy

The theme of improvement in feelings of normalization was shown in patients who felt that meeting other patients who had gone through similar experiences increased their sense of normalcy. For example, one parent shared with us:

[Zora]...has made noticeable changes in A. I will be sad to see it end...last night his therapist noticed a change in A. He is puzzled with A seeming more comfortable this time. A 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 A's life is Zora. And well A 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, the impact of Zora may extend beyond the virtual world into the day-to-day lives of children.

#### Enhanced sense of self and contribution

The theme of enhanced sense of self and contribution was shown in the qualitative data by participants who demonstrated that this project had changed how they viewed themselves in relation to their transplants and resulted in an increased feeling of wanting to contribute to others. For example, a 15-yr-old girl with a liver transplant shared the following:

I believe that taking part in Zora did give me inspiration. I only had a liver transplant, and I cannot 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 Zora participation, this patient made a didactic presentation using technology in her school designed to educate her teachers and classmates about organ transplantation and donation. As part of her school project, this girl created a Zora information booth where she placed this presentation, as well as others, so other Zora children, who wanted to advocate for donor organ programs, could borrow them. During a visit to Zora, she shared with the online group her rationale for her educational efforts at school:

...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...

#### Increased social network

As described in the introduction, pediatric transplant patients can often feel a sense of isolation. However, the qualitative data from several participants indicated that Zora was a tool that allowed the formation of a virtual community, which in turn facilitated an increase in their social network with other pediatric transplant patients. For some participants, friendships were formed online that later resulted in shared offline activities. For example, two 15-yr-old girls reported that Zora helped them meet other transplant recipients of their own age and gender. They met each other for the first time at the start of the study and became "quick friends." When asked how Zora had made an impact on her life, one of the girls said:

I met that one girl who actually was my age and could relate; she was in High School, she had a kidney transplant, had the same interests as me, things like that. I would recommend kids to meet others of the same age and talk in groups...

Although Zora seemed to have made a quick impact in these girls' lives, their use of Zora stopped after three months. In follow-up interview regarding their experience, the study team learned that the girls realized they lived close to each other. Their online friendship moved to an offline friendship that included hanging out at the mall and sharing hobbies. They reported that they "got what they wanted out" and did not feel a need to return to Zora. While the study intended for participants to continue throughout the entire study, these girls appeared to gain the dosage and benefits out of Zora as appropriate for their particular needs.

Another example of Zora promoting an increased social network via offline connections happened in the hospitalized setting. During the study, two participants underwent a second transplant – in both cases, friends that the patients 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 with the virtual community. While difficult to capture quantitatively because of the fluidity between their online experience and their offline friendship, the supportive nature of this interaction was readily apparent to parents and medical staff.

#### Participant experience with Zora

There were no complaints and/or reports of adverse experiences. Importantly, as they agreed

before starting to use Zora, participants adhered to the *Zora Code of Conduct*. This code had rules regarding protecting privacy, using polite language, and avoiding hurtful behaviors, as well as referring potential unsafe events to project coordinators. Because project coordinators were a central part of the study and lead weekly online meeting as well as established personal online relationships of trust, participants did not have any issues sharing personal information. The role of the coordinators was key in providing a safe online environment. Every line of chat and interaction on Zora was reviewed, and there were no instances of participants engaging in potentially harmful interactions such as cyberbullying.

A number of participants signed up for the program but did not consistently return to scheduled meetings. During periodic and exit interviews, several of these participants were reached for comments. Some feedback cited time inconvenience (e.g., “*we were busy and stuff*”) as their reason for not participating. Although before beginning the intervention we collected scheduling information from all participants, it was difficult to work across time zones given that all coordinated activities must be held after school hours. Two of the participants were regular users at the beginning of the program but did not continue using it after a short period of time. They reported their choice of “not coming back” because they found a friend in each other via Zora and they had since then met and communicated via other means such as e-mail and face-to-face visits at a local mall. One participant reported that he went on Zora inconsistently because most of the time there were “*not many people and not many sounds*” and that there was too much reading to do on Zora. One last participant who we were able to reach for comments regarding attrition reported, “*The graphics weren’t good enough.*”

Feedback from open-ended interviews highlighted several areas for improvement in Zora. There were 51 comments regarding Zora that divided into affirmative comments (59%) and improvement comments (41%). The affirmative comments centered on the benefit of the peer-to-peer connections and sense of community built within Zora. The following two examples summarize the positive experience: “[*Zora*] *made me feel comfortable that I’m around kids who have been through what I have*”...“*Some kids older than me were talking about getting prom dresses and licenses so I thought if I stayed healthy I could get those things too.*”

The improvement comments focused on the need to further enhance and develop the curriculum. The following examples were characteristic: “*We don’t talk about medicine very much...I didn’t read any of them [about adherence strategies] on Zora nor do I really care...I knew these things already.*” Of note, factual information regarding transplantation seems well understood by nearly all participants suggesting that the curriculum needed to go beyond presenting factual information.

## Discussion

This study supports the feasibility and safety of a virtual community for recipients of solid organ transplants. This is the first report of a virtual “support” group in pediatric solid organ transplant patients. The high utilization rate of Zora combined with the lack of worrisome interactions argues for the use of a computer interface as an adjunct in promoting social interaction between pediatric patients with significant physical illnesses. This intervention appears to offer alternative ways to reduce the social isolation that may be experienced by the adolescents who feel isolated and overwhelmed by their chronic physical condition.

When the developmental importance of adolescent peer interaction is considered, it is apparent that interventions that promote social support hold significant promise in helping adolescents cope with the demands of transplantation. For most transplant programs, attempts to promote interactions between patients are limited by the small patient numbers, geographic distances, and the daily routines of most adolescents let alone medical interventions that may intrude. Interactions with others facing the same problem generally are difficult at best, if not impossible. A virtual community may overcome the geographic barriers of the traditional “support group.”

Internet-based psychosocial interventions have the potential to provide a wonderful opportunity to reach physically ill adolescents who, because of geographic distance, cannot attend face-to-face meetings. Participation in a peer-based virtual community offers these adolescents the opportunity for the discussion of health-related issues that are important to them and can provide them a space to share their needs, feelings, and worries. The use of a graphical virtual community offers innovative and engaging opportunities to engage with adolescents facing similar issues. Further larger studies of these interventions are warranted to further understand their impact not only on social

support, but also on the critical problem of treatment adherence. This intervention did not show improvement on medical adherence as all of the participants were already compliant with their treatments. Future studies will look at engaging a larger and more diverse population of transplant patients to observe change over time.

### Limitations

This study was limited by the small sample size and lack of a comparison group, which limits the generalizations that can be made for a broader population of transplant patients and other physical conditions. Not all of the participants who agreed to be part of the program participated regularly and further reduced the community size. Only 41% of eligible patients enrolled in the study. While the reasons are not fully understood, it is possible that those that declined may have more difficulties with treatment adherence.

### Clinical implications

As adolescents today become surrounded more and more by computer technology, there is a tremendous opening for health care providers to use this fact to find new and innovative ways to engage adolescents with physical illnesses. Virtual environments that promote psychosocial development have significant potential to provide adolescents with the opportunity to meet, talk, and share experiences with others who are facing the same issues. As adolescents increasingly use the Internet for all sorts of purposes ranging from schoolwork to shopping to dating, the health care community can leverage this potential use by crafting Internet-based psychosocial interventions that promote wellness and resiliency.

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