

# Use of a Computer-Based Application in a Pediatric Hemodialysis Unit: A Pilot Study

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## ABSTRACT

This report describes preliminary efforts to implement a computer-based application, called Zora, in a pediatric hemodialysis unit. The feasibility and safety of establishing a virtual community in the hemodialysis unit are explored. Zora allows users to design and inhabit a graphical virtual city where they create characters, stories and spaces while communicating in real-time. Over a 5-month period, 7 hemodialysis patients and 4 unit staff found Zora enjoyable and safe. The results support the premise that computational environments may offer an opportunity for pediatric patients and their caregivers to participate in virtual communities that promote coping with chronic physical illnesses. *J. Am. Acad. Child Adolesc. Psychiatry*, 2003, 42(4):493–496. **Key Words:** computer, hemodialysis, intervention, pediatric, renal disease, safety, virtual community.

Although successful kidney transplantation provides the optimal mode of renal replacement therapy, an organ may not be available. For nearly 50% of children with end-stage renal disease (ESRD), chronic hemodialysis in a medical facility is the necessary bridge to sustain life until transplantation (Weiss, 1995). Studies have found evidence of psychological resiliency, but also significant constraints on patients facing hemodialysis (Brownbridge and Fielding, 1994; Garralda et al., 1988; Rosenkranz et al., 1992). The treatment often significantly disrupts the social and academic experiences of children.

While children facing hemodialysis might gain support from each other, several factors hinder the formation of mutually supportive communities among patients. While the treatment generally occurs thrice weekly for 3 to 4 hours per session, patients are on different dialysis schedules and often have no chance to interact. Although patients may spend hours together in the same room, they are often

unable to communicate with each other in a private way. Dialysis ties them to unmovable beds that are too far apart physically to allow social conversations.

Virtual environments represent an innovative technique to respond to the social isolation faced by patients with ESRD (DeMaso et al., 2000; Gonzalez-Heydrich et al., 1998). In the design of an effective intervention for medical crises, Shapiro and Koocher (1996) outlined the importance of the expression of emotion, working on relationships, examination of meaning, involvement in meaningful activity, and seeking others with similar experiences.

Zora is a virtual environment designed by Bers to engage children in all these key activities. It is a three-dimensional graphical computer environment in which users create a virtual city and populate it by designing spaces, objects, and interactive characters, and at the same time, converse and interact with other users (Bers, 2001; Bers et al., 2001). This study is unique in its use of a computer application to engage both patients and staff in the creation of a virtual community-support network. This report describes the initial efforts to implement Zora in a pediatric hemodialysis unit. The results are meant to guide ongoing work in developing technological supports for families facing pediatric illnesses (Bers et al., 2002).

## METHOD

### Procedure

The Zora environment was installed on three networked bedside computers in a seven-bed hemodialysis unit. Zora was accessible to patients, as well as unit and research staff. Appropriate human studies permission was obtained. An agreement to respect a code of con-

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duct in using Zora and the Internet was signed by the patients and their parents.

In the first month of the study, Zora was introduced and demonstrated to the unit's patients and staff in an effort to build interest. In the second month, the research staff worked on a one-to-one basis with the patients and taught them how to use Zora to readily express themselves through their creations. Once patients became familiar with the technology, they used Zora independently over a 3-month period. On certain days the research staff logged on remotely from outside the unit.

### Participants

The hemodialysis unit at Children's Hospital Boston generally has an average of 7 children and 15 adolescents undergoing hemodialysis at any given time. From this group, the dialysis staff identified 18 of their patients with ESRD who expressed interest in trying out "cool computer software." After one demonstration, 11 of these patients declined to participate because of changes in their medical condition, feeling tired during dialysis, and/or lack of interest in computers. A total of four girls and three boys participated in the pilot study. The mean age was 15.0 years ( $SD = 4.3$ ); four were white, one was Latino, one was Chinese American, and one was African American. Zora was used an average of six 1-hour sessions.

Based on unit staff requests, three nurses and the child life specialist were also trained to use Zora. They used Zora an average of four 20-minute sessions.

### The Zora Computer Environment

Zora is a three-dimensional graphical multiuser computer environment that uses a city metaphor to place children in the role of city

designers and inhabitants (Bers, 2001). The name was chosen from a story describing an invisible city 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" (Calvino, 1972). In the computational Zora, children create a virtual city and populate it by designing rooms, creating characters, adding objects, and writing stories. Children are represented by pictures or cartoon characters called avatars. Children can visit each other's rooms and can communicate in real-time through their avatars via text or gestures. They can also communicate through messages left on "bulletin boards" within the city. Zora has a virtual "City Hall" where the avatars can gather to decide the city's social organization (Fig. 1).

### Measures

Four ratings of "satisfaction and safety" of the Zora environment were obtained in semistructured interviews (Beardslee et al., 1992; DeMaso et al., 2000) with patients and staff at the end of the study: (1) Did you feel Zora is safe? (2) Do you feel Zora is fun or enjoyable? (3) How satisfied are you with Zora? (4) Do you feel Zora was hurtful at all? The ratings were determined by using a 7-point scale anchored at one end by "1 = not at all" and at the other end by "7 = a great deal." Open-ended questions regarding satisfaction and safety, as well as suggestions for improving Zora, were included.

### Data Analysis

An ethnographic approach was used to explore Zora's utilization (Geertz, 1973). Observations of online and face-to-face interaction, and analysis of the system logs that recorded, with date and time, everything participants said or did online were reviewed. Descriptive statistics were calculated for the rating scales.



**Fig. 1** On the left, the three-dimensional personal Zora home built by an adolescent. On the right, the Zora authoring tools. On the bottom, the chat space for users to communicate in real-time and the graphical avatar with the posing gestures.

## RESULTS

### Description of Use

Zora provided both synchronous and asynchronous ways of communicating and sharing experiences. Online patient conversations tended not to be about hemodialysis, but more about favorite activities or mutual interests. The patients designed 16 virtual places including their own personal homes as well as common spaces such as "Renal Rap," which was described as "a virtual space for dialysis patients to get together to do fun things." The staff created three places, including the "Temple of Feeling Better," which was a "place to tell each other ways to cope with hard things."

The patients described Zora as a good way to communicate privately with each other while undergoing the public event of hemodialysis. "I could use Zora to talk to other kids who were at a distance.... Others could not eavesdrop.... I felt more comfortable discussing things... without being heard," said one adolescent.

Zora helped some patients voice personal concerns without the burdens of face-to-face or real-time conversation. For example, an adolescent complained about an increase in hemodialysis time by writing on Zora's community bulletin board, "I believe that my time on dialysis is too long.... Most patients are on for only 3½ hours.... Maybe you can pull some strings and get it cut back...." When the staff read this, it became a starting point that eventually helped him to speak directly with his physician.

### Satisfaction and Safety

The overall patient satisfaction was high (mean = 5.3, SD = 1.3), as was their enjoyment (mean = 5.7, SD = 1.6) in using Zora. One patient summed it up saying, "It was nice to have something fun to do that could keep my mind off dialysis and that was not schoolwork." The patient safety rating was high (mean = 5.9, SD = 1.8), and the patient rating of harm was low (mean = 1.4, SD = 1.1). Patient and staff ratings of safety do not rate safety per se; rather, they reflect perceptions about safety in their own experience with Zora, in which no adverse events occurred. Another patient stated, "It might be unsafe if you put things in your room that younger kids shouldn't see.... But that's the point with having the city hall, where we set the rules for Zora... it's safe for kids."

The hemodialysis staff ratings of satisfaction (mean = 6.5, SD = 0.5) and safety (mean = 5.6, SD = 1.4) were high. The level of harm (mean = 1.0, SD = 0.0) was low.

The nurses found that Zora did not interfere with their medical routine. On the contrary, they enjoyed seeing their patients using Zora. One nurse said, "I noticed that kids could say things in the computer that they might not say face to face.... Zora was a safe place and way for patients to get their feelings out...."

## DISCUSSION

The findings support the premise that a computer-based intervention theoretically derived from preventive intervention, medical crisis counseling, and narrative therapy (DeMaso et al., 2000) may be not only safe and feasible, but also potentially beneficial to both patients and staff in a pediatric health care setting. Zora had high satisfaction and safety ratings along with very low ratings of harmfulness. The volunteer involvement of the hemodialysis staff suggests that the computer is a potential medium for facilitating new kinds of therapeutic interactions between patients and caregivers.

Zora was previously pilot-tested with similar-aged physically healthy children (Bers, 2001). In comparison with these children, patients on dialysis appeared to make more use of fantasy (i.e., using cartoon characters for their avatar while the healthy children used their own identity). Hemodialysis patients preferred not to encounter any renal illness content in the application, instead wanting Zora to be a place to escape from dialysis. This contrasted with unit staff, who saw Zora as a medium to educate patients about their illness. These observations outline a critical need to incorporate the coping style of the specific target population in further intervention design.

### Limitations

The small sample size limits conclusions regarding the feasibility and safety of this application as well as an understanding of its potential use in a broader user community. The multiuser and open-ended nature of Zora and the fact that it runs on the Internet where patients could find inappropriate content raises important safety and confidentiality concerns. While these concerns were not borne out in this study, this may have been related to the small sample, unit staff participation, research team supervision, and Zora's code of conduct. Further program implementation to a wider community will need to be mindful of these concerns.

Slightly more than 60% of the patients declined to participate in this study after one demonstration of the appli-

cation. The majority of patients declining attributed this to the direct medical effects of their renal illness and dialysis as opposed to either complex user training needs and/or concerns about safety and confidentiality. Nevertheless, the impact of illness severity on usability and feasibility is another important consideration in further application design.

#### Clinical Implications

More and more hospitals are acquiring the means to connect to the Internet. Computational environments open up new possibilities for integrated mental and physical health care. As suggested by this study, the use of a computer intervention has the potential to be feasible and safe in the context of a hospital setting. Introducing a fun, self-exploratory, and community-building computer activity may have several positive benefits. Patients may use their extensive time involved in medical procedures in an innovative way to express themselves and explore aspects of their identity that may enhance adaptation to physical illness. They may be able to interact with others in a similar situation in a private way while at the same time expressing emotion, working on relationships, and being involved in a meaningful activity (Shapiro and Koocher, 1996). Computational environments may offer an opportunity for targeted pediatric populations and their caregivers to

participate in virtual communities that promote adaptive coping with physical illness.

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**Employment Barriers Among Welfare Recipients and Applicants With Chronically Ill Children.** Lauren A. Smith, MD, MPH, Diana Romero, PhD, MA, Pamela R. Wood, MD, Nina S. Wampler, DSc, MPH, Wendy Chavkin, MD, MPH, Paul H. Wise, MD, MPH

*Objectives:* This study evaluated the association of chronic child illness with parental employment among individuals who have had contact with the welfare system. *Methods:* Parents of children with chronic illnesses were interviewed. *Results:* Current and former welfare recipients and welfare applicants were more likely than those with no contact with the welfare system to report that their children's illnesses adversely affected their employment. Logistic regression analyses showed that current and former receipt of welfare, pending welfare application, and high rates of child health care use were predictors of unemployment. *Conclusions:* Welfare recipients and applicants with chronically ill children face substantial barriers to employment, including high child health care use rates and missed work. The welfare reform reauthorization scheduled to occur later in 2002 should address the implications of chronic child illness for parental employment. *Am J Public Health* 2002;92:1453–1457. Copyright 2002 by the American Public Health Association.