

# E-Health Communities and Online Self-Help Groups: Applications and Usage

Åsa Smedberg  
*Stockholm University, Sweden*

Medical Information Science  
**REFERENCE**

Managing Director: Lindsay Johnston  
Book Production Manager: Sean Woznicki  
Development Manager: Joel Gamon  
Development Editor: Myla Harty  
Acquisitions Editor: Erika Carter  
Typesetters: Adrienne Freeland  
Print Coordinator: Jamie Snavelly  
Cover Design: Nick Newcomer

Published in the United States of America by  
Medical Information Science Reference (an imprint of IGI Global)  
701 E. Chocolate Avenue  
Hershey PA 17033  
Tel: 717-533-8845  
Fax: 717-533-8661  
E-mail: [cust@igi-global.com](mailto:cust@igi-global.com)  
Web site: <http://www.igi-global.com>

Copyright © 2012 by IGI Global. All rights reserved. No part of this publication may be reproduced, stored or distributed in any form or by any means, electronic or mechanical, including photocopying, without written permission from the publisher. Product or company names used in this set are for identification purposes only. Inclusion of the names of the products or companies does not indicate a claim of ownership by IGI Global of the trademark or registered trademark.

Library of Congress Cataloging-in-Publication Data

E-health communities and online self-help groups: applications and usage /  
Asa Smedberg, editor.  
p. cm.

Includes bibliographical references and index.

ISBN 978-1-60960-866-8 (hardcover) -- ISBN 978-1-60960-868-2 (print & perpetual access) -- ISBN 978-1-60960-867-5 (ebook) 1. Medical informatics. 2. Medicine--Electronic information resources. 3. Self-care, Health. I.

Smedberg, Esa.  
R858.E227 2012  
610.285--dc23

2011020033

British Cataloguing in Publication Data

A Cataloguing in Publication record for this book is available from the British Library.

All work contributed to this book is new, previously-unpublished material. The views expressed in this book are those of the authors, but not necessarily of the publisher.

# Chapter 1

## Virtual Worlds for Children with Medical Conditions: Experiences for Promoting Positive Youth Development

**Marina U. Bers**  
*Tufts University, USA*

**Kathryn A. Cantrell**  
*Tufts University, USA*

### ABSTRACT

*This chapter describes an innovative, technology-based intervention for children with critical medical conditions that utilizes the Zora virtual world. Most specifically, the chapter describes two experiences, one with post-transplant pediatric patients and the other with pediatric cancer patients who participated in Zora. The virtual experience was designed to address issues of school transition and medical adherence, while offering psychosocial support in the context of a virtual community of peers. The design of the Zora virtual world is informed by the Positive Technological Development (PTD) framework which was inspired by Positive Youth Development (PYD). In Zora, users can communicate with each other via real-time chat and participate in open-ended guided activities to create a social network of peers. They can also build the personal and public spaces in the virtual city, create interactive characters and write stories for three-dimensional objects.*

DOI: 10.4018/978-1-60960-866-8.ch001

## SCENARIO

*Peter is a 14-year-old boy. He connects to Zora, a virtual city built and inhabited by 11 to 15 year olds. Peter is happy because he feels that the virtual home he created in Zora is almost finished. He put pictures of his favorite things and people, and wrote stories about his family and friends. Peter decides to go around the virtual city. He quickly navigates through Zora's different public spaces: the Transplant Experience House, the Homework Help Cabin, the Medical Center and the Smart Object House. Upon entering the Smart Object House, a virtual doctor welcomes him. "This is clever!" thinks Peter, "I will program a pill box to tell me when to take my medicine!" The Smart Object House is populated by other smart objects and characters created by youth who have experienced a transplant. At first sight, there is an interactive robot that helps you with medical procedures, alarms that sound when you need to fill a prescription, and a teleportation machine that takes you to the beach when one is tired of the hospital. Peter navigates around the three-dimensional space and encounters many different objects. Peter decides to add a pill box to the Smart Object House that sounds an alarm whenever it is time to take his pills. Peter programs the box to say the color of the pill when it sounds so that it's easier to know which to take. He associates the value "organization" to the pillbox and defines it in the Zora Collaborative Values Dictionary as "it is very important to organize your medicine. That way, you can stay healthy after your transplant." As he is about to leave the Smart Object House, he finds a calendar placed by Elena earlier that week. The calendar lists the many medical-related appointments Elena has scheduled that month. He also sees that Elena has used the Zora Values Dictionary to create a new value, "planning", and linked it to the calendar. As Peter is reading Elena's definition of planning, he recalls that he has an appointment in two weeks, and quickly*

*searches for his own calendar to see if it had been written down.*

This scenario describes an actual engagement by young people participating in a virtual community for post-transplant pediatric patients with a three-dimensional multi-user environment, called Zora. Zora is a virtual world that provides easy-to-use tools for children to design and program their own virtual city and, in the process, learn about school transition and medical adherence, as well as form peer relationships (Bers, 2001; Bers et al, 2010). Children are put in the role of producers, instead of consumers, of information, knowledge, and habits of mind.

This chapter describes an innovative technology-based intervention for children with critical medical conditions. It presents two case studies that show two potential ways of using a virtual world. The first involved a group of post-transplant youth from two different hospitals, who used Zora from their homes to specifically address issues of medical adherence and school transition in the context of a peer-support network. The second case involved a group of youth with cancer, sickle cell, and healthy siblings participating in a summer camp for children with illnesses and their families. They were introduced to the technology while participating in the face-to-face summer experience and then participated in an intervention that used Zora to sustain the friendships and levels of hope attained during camp, once they were back at home.

This chapter focuses on the virtual curriculum that was designed and implemented within the virtual world while offering psychosocial support in the context of a virtual community of peers. Activities, lead by e-mentors, are designed to foster relationships, teach technological skills, and facilitate the formation of a support network of peers and mentors. The chapter presents both case studies, introduces the Zora technology and the virtual curriculum as well as the theoretical framework upon which it was designed, Positive Technological Development.

## INTRODUCTION

As young people discover new ways of using the Internet for social interaction, through social networking sites, multiplayer video games and virtual communities, graphical virtual worlds are emerging as one of the fastest growing on-line environments for youth (Beals & Bers, 2009). For example, the largest virtual world for adults has 13 million registered users, while the largest for children and youth has 90 million users. Furthermore, as of 2008, the Association of Virtual Worlds found that there are over 360 virtual worlds explicitly targeted for this young population (Association of Virtual Worlds, 2008). Within the large presence of virtual worlds, Internet based interventions have been explicitly designed for children facing serious illnesses (Bush & Simonian, 2002). For example, video games (Lieberman, 2001) and virtual reality interventions (Schneider & Workman, 2000), web-based storytelling sites (DeMaso, et al., 1995) and social networking sites (Bush, Huchital, & Simonian, 2002) have been on the rise.

Internet-based psychosocial interventions provide an opportunity to reach children who, due to geographical distance, cannot attend face-to-face meetings. Participation in a peer-based virtual community may engage children in discussion of health related issues, and provides a space to share their needs, feelings and worries. At the same time, a graphical virtual community such as those afforded by virtual worlds, offers different opportunities for participation. Children can choose to express themselves via on-line chat and words, or by drawing and making virtual objects (Bers, 2001). However, when these kinds of psychosocial interventions are put in place, it is not only the technology, but also the social support systems built around the technology and the curriculum mediated by the technology, that can make a difference.

In the past, most young people with a serious medical illness would not survive. Today, advances in medicine make it possible to extend

the length of their lives. However, children are trading a life-limiting disease for invasive follow-up interventions and the hardships of medical adherence associated with difficulties in transitioning back to school and socially engaging with peers (Griffin & Elkin, 2001). Frequent clinic visits, medication intake, and dietary and physical exercise restrictions can be disruptive to the patients' academic and social life (Erikson, 1950; Brem et al., 1988; Rodin & Voshart, 1987; Gerson et al., 2004). Therefore it is crucial that help is provided to address the 'medical, psychosocial, educational, and vocational' needs of the patient at various stages of their lives (Blum et al., 1993). Unfortunately, psycho-social services lag behind medical advances, as it is difficult to run effective programs for patients who are geographically dispersed and small in number.

Thus, there is a need to find other vehicles through which to provide the needed supports. This is the driving force at the core of the Zora virtual world project described in this chapter. The first pilot has been running for the last five years with youth transplant recipients aged 11-15 first at Children's Hospital Boston, and then extending it to Tufts Medical Center (Bers, 2009; Bers et al, 2010). The second project was a pilot run for campers aged 13-16 who attended Camp For All in Burton, Texas. The campers, members of the oncology/hematology week at camp, experienced either cancer, a blood disorder, or were siblings (Cantrell & Bers, 2010).

The focus of this chapter is the on-line Zora curriculum used in both interventions, the resulting experiences, and the theoretical framework that informed the development of the virtual curriculum. It is our goal that, by providing a theoretical foundation that presents the key elements for running successful interventions in virtual worlds for children with medical conditions, others might be able to adapt our work to the needs of the specific pediatric populations they serve. While we used the Zora virtual world, other virtual environments that afford similar kinds of experiences might be used.

The chapter will follow the subsequent structure while presenting virtual worlds for children with medical conditions:

1. The Zora Virtual World will introduce the program.
2. Theoretical Background will describe the concepts informing the virtual world.
3. Case Studies will provide two examples of virtual worlds for children with medical conditions
4. Curriculum will describe the e-curriculum utilized within the case studies
5. Future Research Directions will highlight considerations for potential studies.
6. Conclusion will sum up the chapter and explore future research directions.

## **THE ZORA VIRTUAL WORLD**

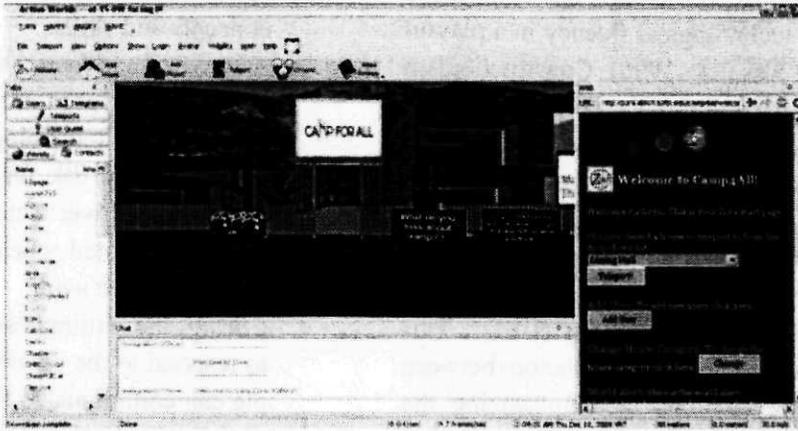
*Zora* is a 3D virtual environment that provides easy-to-use authoring tools to create and inhabit a virtual city or summer camp (see Figure 1). Users interact and communicate with each other in real time through a chat system, as well as in asynchronous ways through message boards. Users are graphically represented as avatars. They can populate the virtual world with their own creations by designing 3D graphical objects, interactive characters, personal and public spaces. They can create stories for each of the objects as well as personal or moral values that highlight the special meaning children assign to their objects and characters. *Zora* provides easy to use authoring tools for young users to create their own objects, but the focus is not only on the aesthetics of 3D objects, but also on the meanings assigned to them. Thus the design elements of *Zora* are contained within a design framework that encourages users to create stories and values for every object they make in the world, models of identification (such as heroes and villains) for their avatar profiles,

and a collective values dictionary for the resulting virtual community.

Upon logging into *Zora* for the first time, users encounter an initial blank 3D world. Their task is to create the virtual world's public and private spaces and populate the world with interactive objects (e.g., objects that can hold "conversations" with visitors). While using building tools in *Zora* to construct personally meaning projects, users learn basic computer programming principles as well as gain technological fluency (Barron, Martin, & Roberts, 2006). The underlying assumption is that young people learn best by making, creating, designing and programming their own projects (Papert, 1980; Resnick, Bruckman, & Martin, 1996). *Zora* allows youth to participate in the virtual community not only by engaging in discussions and arguments, but also by designing and making new objects and new places within the virtual city, to explore psychosocial issues associated with illness. Youth engage in chatting as well as doing, discussing as well as creating, thinking as well as producing (Bers, 2008). The overarching goal of *Zora* is to provide a safe space for youth to explore issues of identity in hope to promote positive youth development while using technology in positive ways (Bers, 2006; Lerner et al., 2005).

The first version of *Zora* was developed in 1999 using the Microsoft Virtual Worlds development platform (Bers, 2001b). The current version of *Zora* used in the studies described in this chapter has been revised and developed using the ActiveWorlds platform (Bers, 2007; Satoh, McVey, Grogan, & Bers, 2006). This platform for developing educational multi-user environments is widely used by educational research projects such as Quest Atlantis (Barab et al., 2005) and River City (Nelson, Ketelhut, Clarke, Bowman, & Dede, 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

*Figure 1. Image of Zora virtual world including chat bar (bottom), navigation screen (middle) and welcome screen (right)*



secured and password protected world in which only youth with a particular educational program or intervention, can view and access the world and contribute to it. The design of the Zora virtual world is informed by the Positive Technological Development (PTD) framework. Thus, it supports the implementation of a virtual curriculum that takes advantage of the many features of Zora that are well-aligned with the theoretical model. The next section presents the PTD framework and the theories that informed it.

## **BACKGROUND**

The Positive Technological Development framework (PTD) guides the design of the curriculum implemented in the Zora virtual world. PTD examines the developmental tasks of a child growing up in our digital era, and provides a model for developing and evaluating technology-rich youth programs (Bers, 2008). From a theoretical perspective, PTD is an interdisciplinary approach that integrates ideas from the fields of computer-mediated communication, computer-supported collaborative learning, and constructionist learning with technology, with research in applied development science and positive youth develop-

ment. In brief, PTD focuses on two related aspects: (1) the design and evaluation of technology-based psycho-educational programs and experiences aimed at helping young people use technology in positive ways, and (2) the trajectory that leads youth to use technology to learn new things, to express themselves in creative ways, to communicate and take care of themselves and others, and to contribute to society, while developing their own sense of identity grounded on personal and moral values.

Two bodies of work have influenced the PTD framework:

**Constructionism:** Developed by the pioneer in the field of computers and education, Seymour Papert, Constructionism is rooted in Piaget's work and advances the idea that children learn better when they can use computers to create their own meaningful projects by exploring (computational) materials and developing their own (computational) theories. The main tenet is that computers can serve as "objects to think with" when children are given the opportunity and the tools to make their own projects, thus creating their own content. Following Piaget, Constructionism might best be defined as a constructivist philosophy for educational technologies. The claim is that by engaging in the process of creating virtual objects

to share and reflect upon, children are more likely to construct internal knowledge, and at the same time, develop technological fluency in a playful way (Kafai & Resnick, 1996). Constructionism has influenced the design of the Zora virtual world by providing an environment, a virtual city, that children can create. They can make their own virtual rooms, their own interactive objects and characters, and write stories and values to define them.

**Positive Youth Development (PYD):** This research focuses on the dynamic relations between individuals and contexts by emphasizing the strengths and assets of young people, instead of focusing on diminishing or preventing risk-taking behaviors (Lerner et al, 2000; Damon, 2004; King & Furrow, 2004; Larson, 2000; Theokas & Lerner, 2006; Scales, Benson, & Mannes, 2007). The use of the term “positive” connotes the promotion of valued characteristics and activities (i.e., developmental assets) that would lead a young person toward a good developmental trajectory (i.e. development toward improvement of one’s self and society). Lerner et al. (2005) frame the various developmental assets into a model of six “C’s”, competence, confidence, character, connection, caring, and contribution, conceived as pathways to promote thriving and healthy communities. PYD has influenced the design of Zora by including on-line activities that promote the six C’s.

PTD borrows the six C’s and makes them relevant in our digital world. However, instead of emphasizing only developmental assets, since PTD is about informing interventions, it focuses on positive behaviors supported by the technology and how those behaviors can in turn promote the six C’s. For example:

- A sense of *competence* in the technological domain is displayed by the ability to use the computer to *create content* using programming languages or computer applications, to debug projects and problem-solve.

Engaging in content creation behaviors promotes, in turn, the development of new concepts and skills.

- A sense of *confidence* in oneself as someone who can act, and learn to act, successfully in a technology-rich world, who knows how to ask for help and who has perseverance over technical difficulties, is further promoted when one uses technology in *creative ways*.
- *Caring*, the willingness to use technology to respond to the others, assumes that people can communicate through the technology. For example, social media promotes new ways of *communication*.
- *Connection*, the capacity to establish and maintain positive bonds and relationships through technology, promotes and supports *collaboration*.
- An orientation to *contribute* to society by using and inventing technologies to solve social problems engages in *community-building*.
- A sense of *character*, a moral compass that guides the use of technology in responsible ways, is built upon having *choice of conduct* in the digital world. In turn, being exposed to choosing our behavior and facing consequences has an impact in the development of character.

Youth programs that are informed by the PTD framework are focused not only on promoting development, but also on choosing technologies and pedagogical approaches that engage children in positive behaviors, such as content creation, creativity, communication, collaboration, community building, and choices of conduct (Bers, in press). The following sections will describe how the virtual curriculum used in the psychosocial interventions with both pediatric cancer and post-transplant patients address each of these aspects.

## **CASE STUDIES**

The PTD theoretical framework and the Zora virtual curriculum were utilized in two different interventions for youth with medical conditions. The next sections will describe each of them by using guidelines identified by previous work as key aspects to consider when developing virtual worlds interventions and educational programs for youth (Bers et al., 2010)

### **Post-Transplant Pediatric Patients**

*The goals of the pilot study with post-transplant pediatric patients were:*

1. Facilitate peer networking building amongst same age pediatric post-transplant patients.
2. Encourage medical adherence through on-line activities and a virtual environment that foster discussion, sharing of experience and informal content delivery.
3. Support post-transplant patient's psychosocial adjustment to school transition and lifestyle changes by creating a community.

This research project was in collaboration with pediatric psychiatrists and medical staff in the pediatric transplant program at Boston Children's Hospital and the Tufts Floating Hospital for Children and lasted for 12 months. Post-transplant patients were first referred to the project by doctors based on their age (11-15) and health status. Those eligible patients and their families were then contacted and invited to participate in the project. Most participants used Zora from their homes (all over New England, and some other further states in the US) and at times, during hospitalizations (Bers et al., 2007; Bers et al, 2010; Bers et al, 2010a).

Seventy-five patients were originally contacted through phone calls and mailings; 38 verbally agreed to participate and 35 returned the necessary consent and assent forms. Of these 35, we could not provide Internet to 3 due to their remote loca-

tions. Thus we worked with a total group of 32. Of the 32 patients, three never logged in into Zora, so our user group was composed of 29 children, however 32 returned questionnaires. Fifty-five percent of the participants were females and the average age at the start of the program was 13.7 years. Participants engaged in weekly online activities for the duration of the study. While they were free to log on at any time, the group activities followed a semi-structured curriculum aimed at sparking conversations about transplant experiences by encouraging them to create virtual spaces such as a Health Museum and a Pharmacy. An example of the e-curriculum is explored in the curriculum section of this chapter.

During 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" (Bers et al., 2010).

During the course of the study, three individuals underwent cardiac re-transplantation. Their participation from the hospital both before and after the transplant added an extra dimension to the virtual group discussions. It also provided an opportunity for some of the participants to meet for the first time face to face.

During interviews, users reported positively about their experience with the project, especially about being able to meet other children who had received a transplant as made evident by a feedback from a participant:

*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.*

Preliminary analysis of the data collected from the questionnaires reveal little change in the participants' medical adherence over the course of the Zora intervention primarily due to the fact that the participants were already exhibiting satisfactory level of adherence prior to participation in the project. However, it became clear that patients with high severity in their illness were the ones who used Zora the most and that participating in Zora helped in ameliorating children's fear of follow-up clinic visits. Based on log analysis and quantitative responses to questionnaires, we have also observed positive impact in terms of peer networking. For example, a social worker described Zora as providing "something that none of [the patient's] Doctors or medical professionals could- a connection to other kids who knew exactly how he was feeling and experience the unpleasant things that go along with transplant each and every day".

The following paragraphs describe specific aspects of the virtual intervention:

### Mentoring Model

The facilitator was a child development doctoral student with experience in child health and a clear agenda in terms of the research and learning goals of the project. The facilitator coordinated weekly Zora on-line activities but spent most of her time, helping participants with the technical aspect of the program, from installing it to supporting creative uses. Although the goal was for the facilitator to progressively move towards getting the partici-

pants to help each other, this happened very slowly as children were on different schedules (Cantrell, Fischer, Bouzaher, & Bers, 2010). Our mentoring model was composed of a facilitator and several mentors, older teenagers who had had a transplant were identified as potential mentors for the Zora community and were invited to join. For example, when participants discussed on-line their worries about going to college and not having their mothers around to help them to remember to take their medications, we asked one of the mentors, a college student with a transplant, to come on-line to talk about his own experience. The long terms plan is to have the participants, as they become older, to assume the role of mentors.

### Diversity

The diversity among this project's participants is found in terms of the type of organ they received, the types of medical situations that lead them to require an organ transplant, the time since transplant, and the severity of their condition. There were 13 participants from the heart transplant program, 3 from liver, and 6 from renal. Diversity is also present based on their location: 12 participants were from Massachusetts, 1 from Florida, 1 from Maine, 3 from New Hampshire, 2 from New York, and 3 from Rhode Island. They all had in common that they underwent the transplant procedure and received post-transplant follow-up treatment at Children's Hospital Boston. Regardless of their original ailment or organ received, they all share the experience of going through organ transplantation and thus were all committed to a life-long regimen of medications and follow-up invasive interventions.

### Project Scale

Although 32 post-transplant patients with Internet access signed consent forms, only twenty-one used Zora (logged in more than twice) and half of them participated on a regular basis (N=11).

Although at the beginning of the project, scale was not an issue and children were happy to meet for the first time other post-transplant children, as the project evolved, children wanted to have more participants, as it was difficult to have synchronous activities and conversations. Throughout the study, we had to hold our weekly online meetings at two different times to accommodate different participants' schedules. In addition, the voluntary nature of the project meant that we could not enforce regular attendance. Thus there might be as few as one or two participants attending planned activities. However, participants would be online at other times to work on individual projects. Due to the "constant on" nature of this project, participants were welcomed to sign on at any time; however, our data showed that in many cases, a participant who logs on and finds that only one or two other members are on would sign off. This may be due to the lack of a minimum critical mass to sustain participants' engagement. Other researchers (e.g., Markus, 1987; Preece, 2000) have shared similar experiences for the need to have a minimum critical mass when building a social network or a virtual community. To increase the probability of having a minimum critical mass to sustain a discourse we are increasing the overall user or participant pool by bringing on board a new site, Tufts Floating Hospital for Children.

### Types of Contacts with Participants

Besides regular online contact with the regular participants, we have made home visits to a few local participants' homes to gain an understanding of the environment and context in which Zora was being used. We also arranged to meet some patients at the time of their regular hospital's clinical visits or while they were hospitalized for treatment. However, depending on the time since transplant, the frequency of the participants' routine visits to the hospital varied; therefore we could not arrange to meet every participant and

their family. For those participants whom we could not visit either at home or at the hospital, interviews were conducted over the phone. In addition, users created a monthly newsletter, *Transplant Times*, which reported on some of the key activities that took place on Zora. The newsletter was printed and mailed to all participants, their families and hospital staff. At the end of the year, we organized a Zora group who would represent the virtual community of transplant patients at the hospital's annual fund raising walk. Five of the participants and their families joined for the walk which gave us, and them, the chance to meet other face-to-face.

### Assessment

Data collection included automatically generated logs that provided qualitative and quantitative data of user's online activities, self-report instruments and semi-structured interviews, as well as spontaneous feedback. We collected three sets of data: (1) data pertaining to Zora use and participant feedback through semi-structured face to face or telephone interviews, as well as Zora logs, and home visits to check for fidelity in the way the system was used by the patients and the ways it was intended to be used; (2) data pertaining to the positive development of youth through the use of technology collected through questionnaires; and (3) data about patient's medical adherence and medical history provided by parents, medical staff and children's themselves.

### Access Environment

The participants were expected to log online from their computers in their homes. Since not every family had access to a computer suitable for using Zora, we provided computers to three families and also Internet service to one family. During hospitalizations, patients were able to participate from the hospital.

## Institutional Context of Usage

Participants were requested to sign a Code of Conduct which outlines some basic rules of Internet behavior (such as not disclosing personal information online) prior to logging into Zora for the first time. This was requested by the hospital IRB to ensure the safety of the participants. The initial items on the Code of Conduct signed by the participants are created by the researchers but once on Zora, we encouraged discussions about appropriate and inappropriate behavior on Zora (such as resolving issues of participants building on top of, or within someone else's "property" without notification). Once consensus was reached as a community, new items were added to the Code in the Zora world. The institutional complexity of hospitals and the interdisciplinarity of this work makes it difficult to be in full control of crafting an innovative educational intervention that, although might not meet the scientific review criteria of the medical field in terms of statistical significance of results, shows clear qualitative signs of having a positive impact

## Pediatric Cancer Patients

This pilot study was done with a group of campers at a pediatric campsite called Camp For All in Burton, Texas (Cantrell & Bers, 2010). Zora was introduced to 40 campers with cancer (16), blood disorders (6), and their siblings (18). The four goals for the pilot study were to determine if:

1. Zora could sustain the campers' hopefulness after their week of camp.
2. Zora could sustain the campers' sense of connectedness after their week of camp.
3. Zora could foster positive technological development.
4. Zora could be successfully integrated into pediatric recreation programming.

Zora was utilized as a tool for remaining connected; in addition to this, the program offered an e-curriculum exploring concepts of hopefulness, social connectedness, and positive technological development. Although the virtual world was open for 6 months following the closing of camp, the e-curriculum was administered for 6 weeks. Participants were allowed to access the virtual world 24/7 but the group curricular activities occurred bi-weekly (to accommodate participants' schedules) and lasted an hour. The curriculum is explained further in the curriculum section.

Forty campers signed assent forms and completed the baseline data collection sequence. Twenty-three participants were females and 17 were males. Eighty percent of the participants were returning campers. The ethnicity of the sample was 45% European American, 30% Hispanic American, and 25% African American. Of the 40 who agreed to participate, 26 used Zora as a tool for maintaining contacts and supporting friendships and 10 regularly came online to complete curriculum. The ten individuals who participated the Zora curriculum came online twice a week to discuss issues of hopefulness, social connectedness, and positive technological development.

This Zora virtual world was designed to mirror the actual physical campsite. When it was first constructed, it included all the buildings you would see at camp such as the dining hall and the cabins. Additionally, it contained a virtual lake and areas for the various activities offered at camp such as a ropes course and horses. After introduced to the campers, the participants worked to make the space personalized by adding pictures to the buildings and sharing stories about each of the activities. Ultimately, the virtual camp was designed to look like the physical space but the campers worked to make it reflect the culture.

Overall, the virtual community resembling camp created over 2240 objects, 1788 lines of chat, over 24 stories, 16 values, and 2 interactive characters over the course of 6 months. During the bi-weekly curriculum times, participants worked

together to create objects that represented hope, friendship, and camp. For example, campers constructed a Hope Hut, a building that held all their hopeful memories related to illness. One camper who had recently ended treatment for liver cancer created a virtual talking organ: the liver said, "I am hope because I am healthier now." Another camper who had a negative experience with Hurricane Katrina posted this story within the Hope Hut:

*Hope is light at the end of the storm like when I lost my house in Hurricane Katrina and that was really hard because I had to move to Texas but now I love it in Texas so it became a blessing!*

Campers also constructed buildings that reflected their favorite moments from camp. For example, a Ropes Shack was constructed to hold all the campers' memories from the ropes course. One of the campers explained why the Ropes Shack should be added to the virtual world by saying, "people can go in there when they are down and remember when they were flying and their friends cheered for them."

Data analysis revealed that Zora may contribute to sustaining social connectedness and positive technological development. The mean positive technological development increase ( $M=2.13$ ,  $SD=4.55$ ,  $N=40$ ) demonstrates significance ( $t=-2.95$ ,  $p<.005$ ) and the mean social connectedness increase ( $M=1.08$ ,  $SD=2.27$ ,  $N=40$ ) is also significant ( $t=-2.99$ ,  $p<.005$ ). Despite this, there was no significant change in campers' hopefulness after using the program (Cantrell & Bers, 2010). These findings were seen across the population, not within the curriculum cohort; thus, it cannot be confirmed that the curriculum impacted the campers' scores.

Overall campers demonstrated a positive reaction to the program. In interviews, 94% of participants stated that Zora should be used again in the coming summers. Safety was consistently cited as a priority for the population and as a rea-

son for using Zora instead of other online social networking sites; for example, one camper said, "Safety is really important to my parents cause there's lots of crazy people on the Internet and stuff so this will be a way that we can talk and stay in touch but without the dangers."

### Mentoring Model

The facilitator was a certified child life specialist with expertise in child development and pediatric psychology. The facilitator was also a former employee of the pediatric camp facility, making communication with the campsite more accessible. Once the campers arrived home, the facilitator spent much of the week on the phone with families as they began installing the program. After most families had installed the program, the facilitator set up weekly meeting times for the participants. Because of scheduling conflicts, the facilitator met campers online twice a week for hour-long sessions that engaged participants in discussions about hopefulness, social connectedness, and positive technological development. The mentoring model was comprised of one facilitator and "camp leaders." The camp leaders were campers that expressed an interest in assisting the facilitator with weekly curricular goals. These campers helped other participants with the technical steps involved in constructing curricular objects within the virtual world.

### Diversity

In order to participate in the study, campers were in the age range of 13-17 (the developmental stage the program targets) and receive permission from their camp director (some were omitted by the directors due to behavioral concerns). Of the 120 camp attendees, 45 were eligible for inclusion in the study and 40 assented, resulting in a participation rate of 89%. Forty campers between the ages of 13 and 17 enrolled in the project at Camp For All, 22 from Children's Hospital at Scott and

White (Temple, Texas) and 18 from University of Texas Medical Branch Children's Hospital (Galveston, Texas). Twenty-three participants were females and 17 were males. Eighty percent of participants were returning campers, meaning that they had attended camp before. The ethnicity of the sample was 45% European American, 30% Hispanic American, and 25% African American. Of the participants, 45% were siblings, 40% had been diagnosed with cancer, and 15% were being treated for a blood disorder.

### Project Scale

Although 40 campers signed consent forms, only nineteen used Zora and 10 participated weekly, completing the entire curriculum. Interestingly, the 10 campers who came on regularly were not friends at camp; through Zora Camp4All, a new community was created. Additionally, unlike the experience with patients who had received transplants, many campers did come online during non-designated curriculum times. For example, there were two campers who met online every night around midnight and used Zora Camp4All as a chatting tool. Typically, the campers who came online after hours were not members of the 10 who demonstrated consistency within the curriculum.

### Types of Contacts with Participants

In addition to the designated curriculum times, the facilitator spent many hours emailing and calling families. Because the participants were located across the country, there was not the ability to visit family homes to aid in technical troubleshooting; instead, all of this had to be completed over the phone. E-mail became the most reliable tool for communicating with the families and updates came nearly daily. In addition to logistical and scheduling emails, the facilitator also updated families on the curricular activities completed online. For the interviews, all were completed over the phone as it was not feasible to schedule face-to-face interviews.

### Assessment

Data collection for this study was conducted in two phases. The first phase was at camp, face-to-face while the campers were introduced to the program. The second phase of data collection occurred over the phone after 6-weeks of program usage. Data collection included semi-structured interviews, 3 questionnaires to assess hopefulness (Hind's HSA), social connectedness (Lee's SCS-R) and positive technological development (Bers' PTDQ), and automatically generated logs that provided qualitative and quantitative data of user's online activities. We collected four sets of data: (1) data assessing the affect Zora had on the campers' sense of hopefulness after use; (2) data pertaining to the affect Zora had on the campers' sense of social connectedness after use; (3) data assessing the affect Zora had on the campers' positive technological development after usage; and (4) data assessing the feasibility of incorporating technology in recreational programming.

### Access Environment

An installation CD was provided to every participant that assented, so they could take Zora home with them. Additionally, the two participating hospitals installed the program on hospital computers to account for families without computers. During the study, all 40 participants indicated that they had computer access at home. Of the 40 that assented, 36 are recorded as having logged in at least once.

### Institutional Context of Usage

Participants were requested to sign a Code of Conduct which outlines some basic rules of Internet behavior (such as not disclosing personal information online) prior to logging into Zora for the first time. The Code of Conduct for this study mirrored many of the ethical codes established at Camp For All. Because Zora was a tool for continuing the camp community, the campsite

requested that the code would hold the campers to the same expectations and continue to emphasize inclusivity and compassion. The facilitator also established a strong rapport with the camp director and the hospital staff who were immediately notified if the facilitator became uncomfortable with any online behavior.

## THE CURRICULUM

Although both case studies presented above involved two different populations of youth with medical conditions, both followed the PTD framework that guide the design of the program and both used Zora for children to engage in the following activities:

1. *Content creation* by designing a virtual city with personal homes and public spaces, interactive storytellers and objects. The Zora authoring tools foster *competence* in the development of computer literacy and technological fluency.
2. *Creativity* by utilizing different media to express ideas in virtual spaces and solving technical problems. By using the Zora tools in creative ways, children develop a sense of *confidence* in their learning potential.
3. *Collaboration* tools to promote *caring* about others by engaging in shared projects and providing support and guidance to each other in the learning community.
4. *Communication* mechanisms via both synchronous and asynchronous exchanges that promote a sense of *connection* between peers or with adults
5. *Community-building* virtual spaces and tools that enable the formation of a social support network that can bridge, in some cases, to face to face exchanges. This promotes *contribution*, to make a better learning environment, community, and society.

6. *Choice of conduct* by engaging youth in the creation of a collaborative values dictionary that guides actions in the virtual world and the design of narrative-based models of identification, such as heroes and villains, that provoke examination of values. Combined, these Zora features enable users to explore *character traits* and their ethical and moral dimensions while assuming a responsible use of technology in the virtual city.

Next, this chapter will take a closer look at the curriculum within the Zora intervention for post-transplant youth. The following sections describe each of the on-line activities contained within the curriculum that emphasized school transition and medical adherence. Since Zora was explicitly informed by PTD, there is an alignment between the affordances of the technology and the positive behaviors it supports.

## Overview

The Zora curriculum was comprised of six objectives that mirrored the six C's of positive technological development. Throughout the virtual meetings, participants were encouraged to complete the objectives within the curriculum. Because the participants came into the project with various technological skill-sets, it was not required that the youth complete the computational knowledge objectives in sequential order or in a certain period of time. Instead, the curriculum followed a loose structure and sequence to encourage and accommodate differentiated levels of instruction and previous expertise. E-mentors, child development students with studies in child life, facilitated the on-line activities and kept track of the youth's progress through the curriculum. When a child came online, e-mentors were able to assist her on an individual basis, knowing the learning objective matched to her progress. Table 1 briefly describes each of the six objectives within the curriculum.

## Participation

This section chronicles the six objectives within the curriculum, highlighting the theoretical background informing the prompt given to the child and also providing examples of participation and objects constructed by the youth. Each of the case studies followed the curriculum at their own pace.

### Objective 1: Content Creation (Competence)

#### Construct a Virtual Object That Represents a Struggle You Face While at School

The first objective in the curriculum addresses school transition through the positive technological development term *content creation* and promotes technical proficiency within Zora. Because

it was essential that the youth become comfortable with the various elements of the Zora virtual world in order to utilize the technology appropriately and with confidence, this first objective is embedded within the youths' introduction to the program. Participants were encouraged to learn about the technology by constructing their personal homes, decorating it with pictures, and writing stories about their interests. After, they were asked to join the virtual group in the Zora School where the community worked on individual objects representing school-related struggles. During these sessions, participants engaged in conversations that expressed many school transition issues such as strategies for homework completion, concentration struggles, stage fright, and bullying.

*Jill was one of the younger participants within the Zora virtual world and had recently received a*

Table 1. Curriculum chart

Objective	Positive Technological Development	Positive Youth Development	Prompt given to child	Relevance
One	Content Creation	Competence	Construct a virtual object that represents a struggle you face while at school.	Poursanidou (2007) explains how crucial communication with educators and families is. Objective 1 promotes communication about school issues.
Two	Creativity	Confidence	Construct a virtual object that represents a solution to your school struggle.	Objective 2 promotes initiative and problem solving related to school transition.
Three	Collaboration	Caring	Interview another participant about their school struggles and school solutions objects.	Objective 3 promotes awareness of the many school transition concerns (Poursanidou, 2003).
Four	Communication	Connection	Make and program an interactive character that represents someone who has helped you through your transplant experience.	Objective 4 promotes communication about the importance of proper medical care and its continuation through adherence.
Five	Community Building	Contribution	Participate in the virtual scavenger hunt and reflect on the community within Zora. How has it helped you?	Objective 5 encourages reflection on the community comprised of fellow transplant recipients.
Six	Choice of Conduct	Character	Construct an innovative virtual object that will help you manage your medical routine. Add a value for this object and define it.	Objective 6 encourages independent consideration of adherence and creative problem solving related to medical regime. It also promotes adherence responsibility (Shaw et al., 2003).

*heart transplant. During a conversation on Zora about school, Jill vocalized a concern about bullies. She explained that there was a reputed group of bullies at her school and was scared that they would antagonize her once she returned from the hospital. Fortunately, her school had recently become aware of the students in question and implemented a "bully awareness" program that taught the student body various ways to prevent bullying. Jill's conversation on Zora motivated her to create a sign that described her fear of bullies. She also built a virtual interactive sign that when clicked on, opened up to a list of ways to prevent bullying. (Figure 2)*

**Objective 2: Creativity (Confidence)**

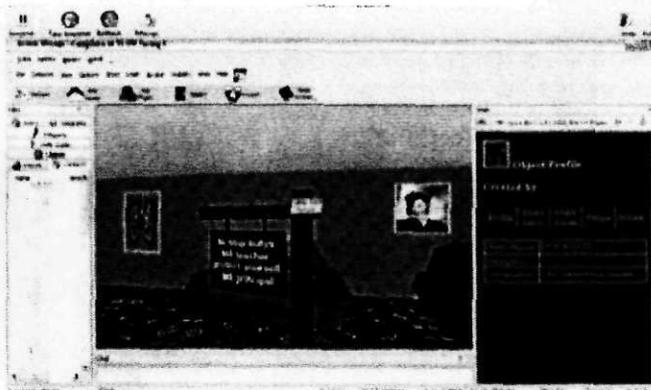
**Construct an Object That Represents a Solution to Your School Struggle**

The second objective in the curriculum also focused on promoting technological proficiency within the program. By having the participants utilize the same skills they developed during the first objective, such as object creation, the second objective provided opportunities for the participants to enhance their *confidence* within Zora; they could learn to use new tools within the program to express their *creativity*. During the second objective the facilitators noted a broader range of objects being constructed and

an increased level of vocal participation from the youth. The sessions that related to the second objective encouraged participants to consider solutions to their school transition issues, promoting communication, cited as an important aspect of a successful school transition (Poursanidou, 2003; Anthony et al., 2009; Burton et al., 2009). Participants engaged in conversations about how to talk to parents, educators, and healthcare providers about their concerns with school. After construction, the Zora School transformed into a museum of various objects expressing concerns and solutions related to education.

*Diane was out of school for five months while she underwent a bone marrow transplant at the age of 13. While the surgery was successful and she has since been in remission, her time away from school was a struggle for her when she returned. During her second week back at school, Diane was asked to give a presentation about the transplant she received. She recalled that the presentation was frightening and that she could barely get any words out because of her stage fright. When asked to program an object that represented a school struggle, Diane immediately expressed how presenting in front of a class made her feel. When she joined us on line for Objective 2, she constructed an object that provided tips for others in Zora on how to get over stage fright. The virtual object she created was a picture of a man*

Figure 2. Bully object



on stage and listed practicing, deep breathing, and talking slowly as tricks for becoming more comfortable in front of the class. (Figure 3)

### Objective 3: Collaboration (Caring)

#### Interview Another Participant about Their School Struggle and School Solution Objects

While a sense of community is promoted within Zora, early on in the experience most of the conversations within the virtual world were initiated by the participating children but directed toward the facilitators. Rarely did participants chat with one another. The third objective was aimed at building a stronger sense of community by promoting *collaboration* between the participants, and enhancing *caring* within the group. For the third objective, participants were asked to interview each other on-line about the school struggle and solution objects they had created. While conducting these interviews, participants were able to learn more about the wide range of topics related to school transition (Poursanidou, 2003). They were also able to start communicating with each other in a direct way, without the need of e-mentor's intervention. Once the dyads had completed the objective, each individual reported to the group what they had discovered, continuing the conversation on a larger scale.

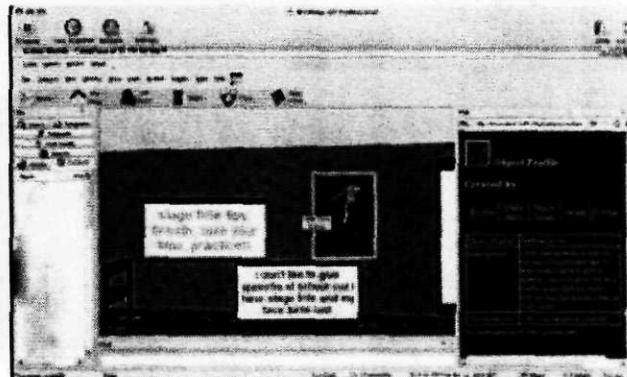
Tanner was one of the older participants in the Zora project. During his time within the virtual world, he often acted as an informal mentor, helping the other participants with the technical elements behind their constructions. During objectives 1 and 2, Tanner expressed having difficulties concentrating in school after his heart transplant. During the group conversation, Tanner was surprised by the response he received from the other participants. His role shifted as the other youth, mostly the younger ones, gave him advice on how to stay awake in class.

### Objective 4: Communication (Connection)

#### Construct and Program an Interactive Character That Represents Someone Who Has Helped You through Your Transplant Experience

The fourth objective extended technical confidence by introducing a new programming skill-set, the programming of an interactive character. Additionally this objective provided an opportunity to enhance *communication*. While the prompt was technically sophisticated, it also asked the participants to think about and share about someone they value. Utilizing *communication* in various forms, this objective promoted *connection*. The interactive character had to be programmed

Figure 3. Stage fright object



to carry out a dialogue that expressed how the individual was helpful. Participants were able to place the character wherever they liked within the world. After multiple participants had built their characters, the group toured the world, searching for one another's characters and engaging in conversations with them.

*Mary was 10 when she had her lung transplant. During the experience, her parents used the metaphor of a butterfly to emphasize how much healthier she would feel after her transformation. Since that time, the butterfly has turned into her favorite image. When giving the prompt for the fourth objective, facilitators expected to see characters inspired by parents, doctors, and child life specialists. Instead, Mary, the first participant to complete the objective, constructed a butterfly named Flutter. When asked how the character helped her through her transplant experience, Mary's answer was simple: Flutter means hope. (Figure 4)*

### **Objective 5: Community-Building (Contribution)**

#### **Follow the Scavenger Hunt and Reflect on the Community within Zora: How Has it Helped You?**

The fifth objective was designed to promote reflection about time spent on Zora. Recalling how the group had developed throughout the project promoted further *community-building*. Likewise, the group format of the scavenger hunt promoted *contribution* and collaboration. Together, the group chatted about how each participant had contributed to the Zora family. The scavenger hunt was a collection of riddles throughout the virtual world asking the participants to leave behind an object at each stop. After the objective's completion, there were dozens of objects throughout the virtual world reflective of the Zora community. This objective, like many of the others, worked to promote communication and expression within the participants; in this manner, the youth gained

skills that could later be accessed at school and at the hospital.

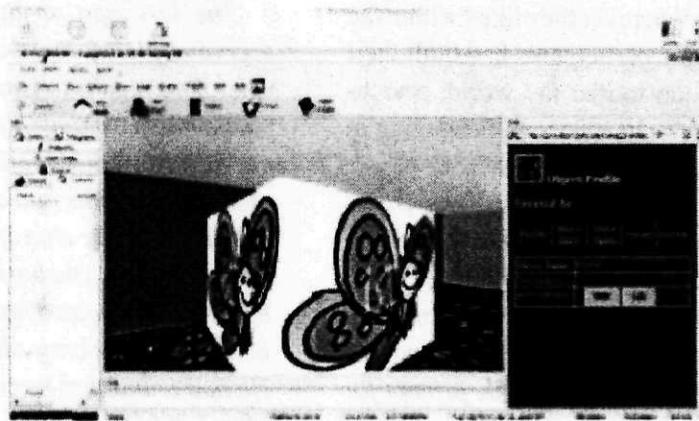
*The last sign on the scavenger read, "can everyone please build an object that represents what Zora means to you?" One of our most loyal participants, Johnny, had a difficult time throughout the program initiating conversation with the other participants and coming out of his shell. In fact, most of his chat had been directed toward the facilitators. During his time with the program, he frequently voiced how difficult it had been for him to make friends since his heart transplant. He had found that he couldn't relate to his peers after going through so many health challenges. To the facilitators' surprise, the object he chose to build at the end of the scavenger hunt was a dedication to the friends he had made on Zora. The object's description said, "Zora is about friendship." (Figure 5)*

### **Objective 6: Choice of Conduct (Character)**

#### **Construct an Innovative Object That Will Help You Manage Your Medical Routine: Add a Value and Indicate if it's a Hero or a Villain**

The last objective of the project addressed the topic of medical adherence by asking participants to construct an innovative virtual object to assist with their medical routine. The prompt asked the youth to categorize the object as either a hero or a villain; also, they were encouraged to give the object a value that represented how it was constructive. This examination of values, provoked by the participant's *choice of conduct*, promoted *character*. In the Zora Smart Shop, participants were asked to gather and discuss innovative objects that aid in managing medical routines. During the conversation, facilitators promoted simple strategies for adherence; likewise, the group discussed the long-term responsibilities of adherence including adapting a medical regime to college-life (Shaw et al., 2003). Participants recalled pill-boxes, calendars, and phones with

Figure 4. "Flutter" interactive character



alarms. Facilitators then asked the participants to create their own innovative, futuristic object to help with medical adherence; there were no limits to their creation.

*During the sixth objective, creations ranged from robots to time machines to virtual alarms. One participant, Dan, decided to be more literal with his response to the prompt. "My innovative object that helps me is my new kidney," Dan explained during the conversation. While other participants were constructing machines, Dan built in the virtual world the kidney he had recently received. Dan explained, "My kidney helps me remember why I have to take my medicine because it keeps my body going." (Figure 6)*

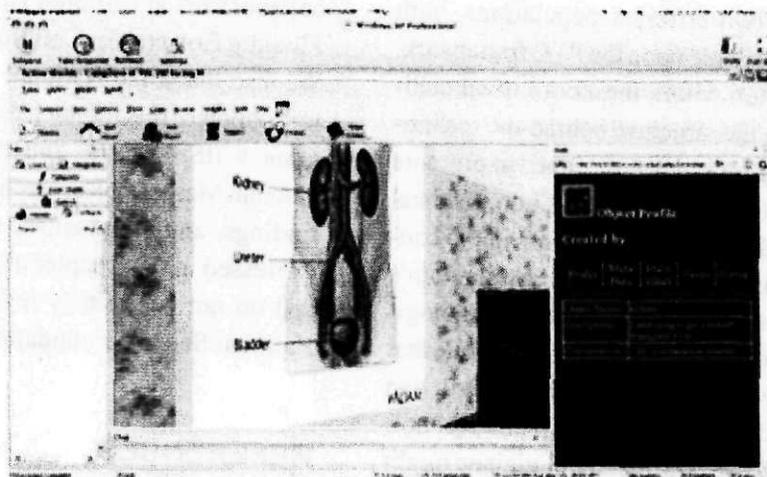
## FUTURE RESEARCH DIRECTIONS

The facilitation of psychosocial programming through virtual communities can be a challenge. In order to maintain the virtual world, collaboration between healthcare professionals, families, researchers, and the youth must be consistent and frequent. Due to this limitation, the virtual format for psychosocial curriculum can seem less than feasible; despite this, both case studies demonstrate that there is a population of youth embracing the technology. Additionally, the portability of the format provides an additional outlet for educating youth when distance and medical isolation are factors.

Figure 5. Friendship object



Figure 6. Innovative object



The case study chronicling the program for post-transplant youth saw about 11 devoted participants. Similarly, the program for youth with cancer had 10 participants who religiously contributed to the curricular activities. This rate, approximately 25% of the assenting population, may seem small; despite this, those that did consistently use the program excelled in the virtual world, devoting hours to constructing objects and personal cabins. For many youth, this alternative form of socialization may be more comforting than face-to-face conversation. Additionally, the ability to not just chat but also construct objects together might be more appealing for some youth. For these populations, the virtual form of intervention may be ideal in the face of illness.

Considering these factors, more strides need to be made in the field of technologically based interventions. The case studies presented in the chapter involve a small sample of participants and both were conducted over the span of a year. Increasing the sample size and maintaining the project for an extended amount of time would not only validate data analysis but also provide an example of how much work is required to keep a virtual intervention running continuously.

In addition to larger sample sizes and longer timeframes, virtual interventions for youth with

illnesses need a strong advocate within healthcare. Conducting these projects from within hospital walls provides immediate access to participants and a consistent face behind the technology. Knowing that the tool would be a strong resource in programming for youth with chronic illnesses, interdisciplinary collaboration with the clinical teams caring for the participants is imperative.

## CONCLUSION

This chapter conveys the prevalence of virtual worlds in the lives of young people and presents two case studies of programs that used the Zora virtual world with children with medical conditions. Zora was designed and implemented to be used by researchers and practitioners developing psycho-educational interventions. However, in order to have successful experiences, the virtual world by itself is not enough. It is important to have a theoretical framework, in this case Positive Technological Development, that guides the design of the technology, the development of the virtual curriculum, the type of participation, mentoring approach and activities to happen on-line. While the projects presented in these case

studies engage two different populations, both were strongly designed upon the PTD framework.

The curriculum within the Zora virtual community acted as the structure behind the technological intervention and was designed to promote positive adaptation to school transition, medical adherence and a sense of hopefulness in the context of a community of peers. The curriculum's skeleton was the six C's of positive technological development, the theoretical framework that simultaneously informs community growth and technological skill development. While technology continues to develop, more clinicians might have the opportunity to facilitate interventions online. Because these population's experience the chronic stress of illness and the risk factors associated with it, a foundation of accountability for online curriculum is needed to maintain safety and promote success in this setting.

We live in a society where concepts of self and community are constantly changing. This context makes it challenging for young people to construct a sense of self and grow into positive contributors to civil society. This becomes even more challenging for youth suffering from a severe medical condition that requires invasive medical interventions. Today, the current advances in medicine make it possible not only to extend their length of life, but also their quality. However, life style changes and compliance to demanding medication regiments and dietary restrictions are needed. As shown in this chapter, new technologies, such as virtual worlds can help young patients to tackle this challenge by integrating already existing face-to-face psycho-educational programs with virtual environment and by allowing them to participate in novel virtual interventions.

## ACKNOWLEDGMENT

We thank Clement Chau, Laura Beals, Amy Fischer, and Keiko Satoh, from the DevTech research group at Tufts University, as well as our

collaborators at Children Hospital Boston, Tufts Floating Hospital for Children, and Camp For All. We also thank the National Science Foundation for support of this research through an NSF Career grant # IIS-0447166 and the Deborah Munroe Noonan Memorial Research Fund. Any opinions, findings, and conclusions or recommendations expressed in this chapter are those of the authors and do not necessarily reflect the views of the National Science Foundation.

## REFERENCES

- Barab, S. A., Thomas, M., Dodge, T., Carteaux, R., & Tuzun, H. (2005). Making learning fun: Quest Atlantis, a game without guns. *Educational Technology Research and Development, 53*(1), 86–108. doi:10.1007/BF02504859
- Beals, L., & Bers, M. U. (2008). A developmental lens for designing virtual worlds for children and youth. *International Journal of Learning and Media, 1*(1), 51–65. doi:10.1162/ijlm.2009.0001
- Berquist, R. K., Berquist, W. E., Esquivel, C. O., Cox, K. L., Wayman, K. I., & Litt, I. F. (2008). Non-adherence to post-transplant care: Prevalence, risk factors and outcomes in adolescent liver transplant recipients. *Pediatric Transplantation, 12*(2), 192–200. doi:10.1111/j.1399-3046.2007.00809.x
- Bers, M., Beals, L., Chau, C., Satoh, K., Blume, B., DeMaso, D., & Gonzalez-Heydrich, J. (2010). Use of a virtual community as a psychosocial support system in pediatric transplantation. *Pediatric Transplantation, 14*, 261–267. doi:10.1111/j.1399-3046.2010.01271.x
- Bers, M. U. (2001). Identity construction environments: Developing personal and moral values through the design of a virtual city. *Journal of the Learning Sciences, 10*, 365–415. doi:10.1207/S15327809JLS1004new\_1

- Bers, M. U. (2006). The role of new technologies to foster positive youth development. [Mahwah, NJ: Lawrence Erlbaum Associates.]. *Applied Developmental Science*, 10(4), 200–219. doi:10.1207/s1532480xads1004\_4
- Bers, M. U. (2007). Positive technological development: Working with computers, children, and the Internet. *MassPsych*, 51(1), 5-7, 18-19.
- Bers, M. U. (2008). Civic engagement and the internet: Developing technologically-rich educational programs to promote civic participation online and offline. In Bennett, L. (Ed.), *Volume on digital media and civic engagement* (pp. 139–160). Cambridge, MA: MIT Press.
- Bers, M. U. (2009). New media for new organs: A virtual community for pediatric post-transplant patients. *Convergence (London)*, 15(4), 462–469. doi:10.1177/1354856509342344
- Blum, R., Garell, D., & Hadgman, C. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *The Journal of Adolescent Health*, 14, 570–576. doi:10.1016/1054-139X(93)90143-D
- Brem, A., Brem, F., McGrath, M., & Spirito, A. (1988). Psychosocial characteristics and coping skills in children maintained on chronic dialysis. *Pediatric Nephrology (Berlin, Germany)*, 2(4), 460–465. doi:10.1007/BF00853442
- Bunzel, B., & Laederach-Hofmann, K. (2000). Solid organ transplantation: Are there predictors for post transplant noncompliance? A literature overview. *Transplantation*, 70, 711–716. doi:10.1097/00007890-200009150-00001
- Burton, J. H., Marshall, J. M., Munro, P., Moule, W., Snell, G. I., & Westall, G. P. (2009). Rehabilitation and transition after lung transplantation in children. *Transplantation Proceedings*, 41, 296–299. doi:10.1016/j.transproceed.2008.10.047
- Bush, J., Huchital, J., & Simonian, S. (2002). An introduction to program and research initiatives of the Starbright foundation. *Children's Health Care*, 31(1), 1–10. doi:10.1207/S15326888CHC3101\_1
- Bush, J., & Simonian, S. (2002). Program and research initiatives of the Starbright foundation. *Children's Health Care*, 31(1), 1–10. doi:10.1207/S15326888CHC3101\_1
- Cantrell, K., & Bers, M. (2010). Zora Camp4All: A virtual community to augment the hopefulness of pediatric camping. *Child Life Focus*, 28(3).
- Cantrell, K., Fischer, A., Bouzaher, A., & Bers, M. (2010). The role of e-mentorship in a virtual world for youth transplant recipients. *Journal of Pediatric Oncology Nursing*, 27(6), 344–355. doi:10.1177/1043454210372617
- Damon, W. (2004). What is positive youth development? *The Annals of the American Academy of Political and Social Science*, 591(1), 13–24. doi:10.1177/0002716203260092
- DeMaso, D., Twente, A., Spratt, E., & O'Brien, P. (1995). The impact of psychological functioning, medical severity, and family functioning in pediatric heart transplantation. *The Journal of Heart and Lung Transplantation*, 14, 1102–1108.
- Erikson, E. (1950). *Childhood and society*. New York, NY: W.W. Norton.
- Gerson, A., Furth, S., Neu, A., & Fivush, B. (2004). Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. *Pediatric Transplantation*, 8, 543–550. doi:10.1111/j.1399-3046.2004.00215.x
- Griffin, K. J., & Elkin, T. D. (2001). Non-adherence in pediatric transplantation: A review of the existing literature. *Pediatric Transplantation*, 4, 246–249. doi:10.1034/j.1399-3046.2001.005004246.x

- Kafai, Y., & Resnick, M. (Eds.). (1996). *Constructionism in practice: Designing, thinking, and learning in a digital world*. Mahwah, NJ: Lawrence Erlbaum.
- King, P. E., & Furrow, J. L. (2004). Religion as a resource for positive youth development: Religion, social capital, and moral outcomes. *Developmental Psychology, 40*, 703–714. doi:10.1037/0012-1649.40.5.703
- Larson, R. W. (2000). Toward a psychology of positive youth development. *The American Psychologist, 55*, 170–183. doi:10.1037/0003-066X.55.1.170
- Lerner, R., Fischer, C., & Weinberg, R. (2000). Toward a science for and of the people: Promoting civil society through the application of developmental science. *Child Development, 71*, 11–20. doi:10.1111/1467-8624.00113
- Lerner, R., Lerner, J., Almerigi, J., Theokas, C., Phelps, E., & Gestsdottir, S. (2005). Positive youth development, participation in community youth development programs, and community contributions of fifth-grade adolescents: Findings from the first wave of the 4-H study of positive youth development. *The Journal of Early Adolescence, 25*(1), 17–71. doi:10.1177/0272431604272461
- Lieberman, D. A. (2001). Management of chronic pediatric diseases with interactive health games: Theory and research findings. *The Journal of Ambulatory Care Management, 24*(1), 26–38.
- Nelson, B., Ketelhut, D. J., Clarke, J., Bowman, C., & Dede, C. (2005). Design-based research strategies for developing a scientific inquiry curriculum in a multi-user virtual environment. *Educational Technology, 45*(1), 21–27.
- Papert, S. (1980). *Mindstorms: Children, computers and powerful ideas*. New York, NY: Basic Books.
- Penkower, L., Dew, M. A., Ellis, D., Sereika, S. M., Kitutu, J. M., & Sharpiro, R. (2003). Psychological distress and adherence to the medical regimen among adolescent renal transplant recipients. *American Journal of Transplantation, 3*, 1418–1425. doi:10.1046/j.1600-6135.2003.00226.x
- Poursanidou, K., Garner, P., Watson, A., & Stephenson, R. (2003). Difficulties and support at school for children following renal transplantation: A case study. *Support for Learning, 18*(4), 170–176. doi:10.1046/j.0268-2141.2003.00303.x
- Preece, J. (2000). *Online communities: Designing usability, supporting sociability*. Chichester, UK: Wiley.
- Resnick, M., Bruckman, A., & Martin, F. (1996). Pianos not stereos: Creating computational construction kits. *Interaction, 3*(5), 40–50. doi:10.1145/234757.234762
- Rodin, G., & Voshart, K. (1987). Depressive symptoms and functional impairment in the medically ill. *General Hospital Psychiatry, 9*(4), 251–258. doi:10.1016/0163-8343(87)90080-6
- Satoh, K., McVey, M., Grogan, D., & Bers, M. (2006). *Zora: Implementing virtual communities of learning and care (VCLC)*. Presentation at the New Media Consortium's, Regional Conference at San Antonio TX.
- Scales, P., Benson, P., & Mannes, M. (2006). The contribution to adolescent well-being made by nonfamily adults: An examination of developmental assets as contexts and processes. *Journal of Community Psychology, 34*, 401–413. doi:10.1002/jcop.20106
- Schneider, S. M., & Workman, M. L. (2000). Virtual reality as a distraction intervention for older children receiving chemotherapy. *Pediatric Nursing, 26*, 593.

Shaw, R. J., Palmer, L., Blasey, C., & Sarwal, M. (2003). A typology of non-adherence in pediatric renal transplant recipients. *Pediatric Transplantation, 7*, 489–493. doi:10.1046/j.1397-3142.2003.00117.x

Shaw, S. R., & McCabe, P. C. (2008). Hospital-to-school transition for children with chronic illness: meeting the new challenges of an evolving health care system. *Psychology in the Schools, 45*(1), 74–87. doi:10.1002/pits.20280

Shemesh, A., Lurie, S., & Stuber, M. (2000). A pilot study of posttraumatic stress and non-adherence in pediatric liver transplant recipients. *Pediatrics, 105*, 1–7. doi:10.1542/peds.105.2.e29

Stilley, C. S., Lawrence, K., Bender, A., Olshansky, E., Webber, S. A., & Dew, M. A. (2006). Maturity and adherence in adolescent and young adult heart recipients. *Pediatric Transplantation, 10*, 323–330. doi:10.1111/j.1399-3046.2005.00473.x

Theokas, C., & Lerner, R. (2006). Promoting positive development in adolescence: The role of ecological assets in families, schools, and neighborhoods. *Applied Developmental Science, 10*(2), 61–74. doi:10.1207/s1532480xads1002\_2

## **ADDITIONAL READING**

Bennett, W. L. (Ed.). (2008). *Civic Life Online: Learning how digital media can engage youth*. Cambridge, MA: The MIT Press.

Ching, C. C., & Foley, B. J. (Eds.). (2009). *Technology, Learning, and Identity: Research on the Development and Exploration of Selves in a Digital World*. Cambridge University Press.

Khine, M., & Saleh, I. (Eds.). (2010). *New Science of Learning: Cognition, Computers, and Collaboration in Education*. New York: Springer Publishing Company.

Papert, S. (1980). *Mondstorms: children, computers and powerful ideas*. New York: Basic Books.

## **KEY TERMS AND DEFINITIONS**

**Constructionism:** Learning theory which claims that learning can happen most effectively when people are also active in making tangible objects in the real world.

**E-Curriculum:** Curriculum designed and facilitated virtually.

**Positive Youth Development (PYD):** Summarizes the intentional efforts of other youth, adults, communities, government agencies, and schools to provide opportunities for youth to enhance their strengths, promoting positive development.

**Positive Technological Development (PTD):** A research model that details the overall impact of a technology on youth and their development.