Virtual Communities of Care: Online Peer Networks with Post-Organ Transplant Youth

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Abstract: This paper discusses the Virtual Communities of Care Project that uses a 3D virtual environment, Zora, to support a psycho-educational intervention for pediatric post-organ transplant patients. These patients have difficulties in developing a peer network due to chronic illness, and as a result they are often incompliant to medical and other requirements. Our goals are to examine the extent to which we can leverage youth interest in technologies to develop an intervention to support peer network building and medical adherence. During an eight-week intervention, participants engage in weekly online group and individual activities in Zora. We describe here the intervention and preliminary data to illustrate the objectives of this project.

Introduction

Virtual environments present an opportunity to promote the positive development of young people and their communities (Barab et al., 2002; Bers, 2006). Such technologies can support the development of youth with life-long medical risk or chronic illness (Bers et al., 2003), who, due to their condition, may not be able to attend school regularly and have difficulty forming peer relationships. In the past, most young people with serious chronic illness, such as those needing organ transplants, would not survive. Today, advances in medicine make it possible to extend the length of their life. However, psycho-social services lag behind medical advances, and youth who benefit from medical treatment still have difficulties adjusting to lifestyle changes and are often incompliant to medical and dietary restriction (Rosina, Crisp, & Steinbeck, 2003). Consequently, they face medical complications despite surgeries and treatment. Rejection to treatment (e.g., organ rejection) is a big problem that these patients are facing.

The goal of this pilot project is to examine the extent to which we can leverage youth's interests in online technologies to create an intervention to improve the overall well-being and health of these young patients. For this research, we developed a psycho-educational program that engages post-transplant youth to participate in Zora, a 3D multi-user environment (Bers, 2001). The goals are to: (1) facilitate peer networking, (2) encourage medical adherence, and (3) support their adjustment to lifestyle changes. This paper provides an overview of this pilot program; discusses the context of this research, the curriculum and technology used; and presents preliminary data.

Theoretical Frameworks

This research is guided by two theoretical frameworks, *Applied Developmental Science* (ADS; Lerner, 2000) and *Constructionism* (Papert, 1999). ADS focuses on the dynamic relations between individuals and contexts. It integrates developmental research with programs and policies that promote positive development by emphasizing the strengths and assets of young people, instead of focusing on preventing risk-taking behaviors. The strengths and assets are categorized into the "Six C's of *Positive Youth Development*" and they include: Competence (cognitive and behavioral skills), Connection (positive relationships), Character (moral centeredness), Confidence (positive self-worth), Caring (empathy), and Contribution (orientation to civic contribute). While most programs conceived within the ADS model have not attended to the role of new technologies in young people's lives or have limited their use to information delivery, this research extends the framework to examine the extent to which networked technologies could support the development of these assets and promote positive development in youth (Bers, 2006).

This research also draws upon Papert's *Constructionism*. Based on Piaget's *Constructivism* (Papert, 1999; Piaget, 1965), constructionism asserts that people learn better when they engage in personally meaningful projects and sharing them with others. Instead of learning as information transmission, it posits that youth can play an active role in their learning and hence promote their development. Thus, the role of technology and learning is to provide the resources necessary to make good choices and engage in behaviors that would lead to learning and development. Drawing from these two frameworks, the guiding principles of this research are to provide the necessary context and tools to assist youth in forming positive social networks and to encourage them in adhering to medical requirements. These aspects of their lives are imperative in ensuring healthy development and overall well-being.

The Virtual Communities of Learning and Care Project

The NSF funded Virtual Communities of Learning and Care (VCLC) Project is a collaboration between a children's hospital in northeast U.S. and our research team. Working closely with physicians and staff at the hospital (including surgeons, psychiatrists, nurses, social workers, and IT staff), we conceive this as a pilot intervention research looking at the use of 3D virtual environments to promote healthy development in pediatric patients.

Hospital physicians referred 22 patients (13 males) between the ages of 11 and 15 for this study. Using a delayed-treatment methodology, the sample is divided into two groups with one group beginning four months before the second. We provide computers and Internet to those without the necessary equipment, and thus no participants are excluded due to a lack of technology. The environment they log onto is a secured one that only participants and coordinators can access. Online activities are recorded by a log system and reviewed daily to ensure safety. The project design includes communication with clinicians if concerns become apparent in regard to participant interactions or other issues indicative of problems in their well-being; however, no such incidence has occurred.

This pilot project uses a virtual environment, Zora, to assist young patients in developing a peer support network and foster medical adherence. Developed as an Identity Construction Environment, Zora provides tools to design and inhibit a virtual city (Bers et al., 2001). Participants populate the virtual city by making interactive creations, including 3D objects, characters, message boards, and signs. Each creation consists of various properties, including a description, value designations and definitions, and narratives to help express meaning and personal stories. Zora also provides a real-time chat for participants to communicate while navigating throughout the virtual world. The environment is designed to provide both synchronous and asynchronous modes of communication in order to accommodate different personalities as well as afford them a chance to self-reflect upon their narratives, values, and stories. This type of self-reflection is an important process in healthy youth development (Eccles, 1999).

Over a period of eight months (or four months for group 2), participants logged onto Zora at any time they wish to explore the virtual city and to populate it with personally meaningful images and objects along with narratives and value designations. Participants also take part in weekly one-hour group activities that range from icebreakers to discussions about dietary requirements and medicines. Group activities are designed to foster collaborations among participants to promote community building in Zora. For example, participants collaboratively built a Halloween house consisting of favorite stories and images from each participant. Other examples include a Zora restaurant, pharmacy, Zora zoo, etc. It is clear from the beginning that, while the virtual environment affords tools for participants to express themselves individually, group activities successfully bring the community together.

Another example is the monthly newsletter, *Transplant Times*, written by participants about their experience. It is printed and distributed to families and physicians as a way to share their experience. This allows participants to collaborate online to create a product that is shared to others outside of the virtual city. Participants choose a monthly theme and topics to write about; they collaborate and share responsibilities such as graphic design, writing, and editing. Through the newsletter, participants share their experience with their family and physicians and it becomes a permanent artifact of their activities. The intention of this newsletter is to illustrate to them that knowledge, relationships, and connections built in Zora can be carried beyond the virtual realm and impact their life.

In addition to building a network, activities are also intended to promote certain assets in participants in hope to increase medical adherence and quality of life. One of Zora's features is that participants are given the tools, not the content, to learn about specific issues (i.e., medical adherence in this case), in ways that are meaningful to them. So instead of planting a "Health Museum" that is dense with information, participants are asked to research about their own or other's transplant stories and build 3D objects and narratives to communicate their ideas and make their own museum. This approach is aligned with the *Constructionist* approach to learning. Finally, physicians and nurses at the hospital periodically attend group sessions to interact with their patients via the Zora system.

Data Collection

Data collection includes three activities. An online log provides qualitative data (activities and coding of 3D creations) and quantitative data (e.g., log-on frequency and number of objects created). Participants completed questionnaires addressing research questions such as changes in coping strategies, medical adherence, the six Cs of Positive Youth Development, and attitudes about technologies. In addition, home-visits are conducted to get a picture of the home context in which they log onto Zora and feedback about their experience.

Preliminary Results

This paper primarily draws on qualitative and descriptive data from the Zora log and anecdotal accounts from Group 1 phase of the study to provide an overview of the project. Participants logged onto the system on average 2.6 hours per week. They took on different roles in the virtual city; some participants tended to decorate and build objects while others focused on sharing stories and chatting. Over the first four months, they created 1,375 objects, ranging from self-portrait pictures to objects representing discussion about health, transplants, and medicine.

The project has been successful in fostering narrative sharing. For example, a participant wrote this story on one of the 3D objects in his virtual house: "I received my liver on [date]. I was only [age] at the time. I received the message while attending a Halloween Party, and me and my family took a jet out to [city]. The donator was a baby girl, named [name], who died of SIDS or sudden infant death syndrome." Besides building Zora creations, participants have also shown interest in the newsletter. Topics have included: featured citizens and houses, tips and tricks for remembering medication, citizens' artwork, and websites for kids. Interview responses have shown that the newsletter is a motivating factor for participants to continue their active participation. For instance, one participant stated, "It was exciting to see my drawings printed. I will do more next time." Physicians and families have also responded positively about the newsletter as a way to get a sense of what participants are doing online. Although we do not experimentally control for the effect of the newsletters, responses have supported our hypothesis that the newsletter helps connect participants' online activities with their real-life experience.

During one-on-one interviews, participants commented positively about the project in regard to their adherence and personal development. In particular, participants discussed how, prior to meeting others in Zora, they felt isolated because other peers "don't really get the seriousness of the matter" and "no one really understands."

Implications and Next Steps

The Virtual Communities of Learning and Care project is a pilot program to examine the extent to which we can leverage youth's interests in technologies to develop interventions to promote positive youth development. This project showed that new technologies can augment psycho-therapeutic services available to post-transplant pediatric patients to help them build stronger peer networks and develop motivation for medical adherence.

Preliminary data, e.g. interview responses and activity logs, identified several components that are central to this project's success. Connecting participants' online experience with real-life (i.e., the newsletter) was critical to our primary objective of motivating them in making positive life decisions (i.e., medical adherence) through their online experience. Future work may look at multi-hospital programs to connect patients from different geographic regions, as well as including patients from different medical units rather than focusing on post transplant patients.

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