



@neWorld[®]: A Virtual Community for Kids with Cancer

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Abbreviated Abstract

@neWorld[®] is an award-winning educational and social support intervention that uses the Internet as a community-building tool for hospitals and schools. It provides educational continuity for children and adolescents undergoing treatment for cancer and is designed to operate on a small, lightweight laptop featuring a built-in Webcam to facilitate use for both inpatients and outpatients, although it is accessible from any computer. Animated interactive Agents provide online help to the patient, and a proprietary Web-based “mood engine” tailors the look and feel of the site design based on the patient’s health status and mood. Teacher and healthcare provider interfaces enable interaction with the patient and make it possible to download curricula and class content.

Usability testing was completed at the Communications Technology Branch of the National Cancer Institute, and the Website won the World Wide Web Health Award. Efficacy testing in a clinical trial with 38 pediatric cancer patients was completed in 2004 and demonstrated that @neWorld[®] has a positive effect on school achievement and self-esteem and reduces behavioral problems. Hospitals participating in the study include Ronald McDonald Children’s Hospital, Children’s Memorial Hospital, Hope Children’s Hospital, and the University of Wisconsin–Madison Children’s Hospital. Ongoing support for this project is provided by the Leap of Faith Foundation, started by Barbara Rapchak, Founder and CEO of Leap of Faith Technologies.

Primary Investigator

Barbara Rapchak, Leap of Faith Technologies, Inc., 23 Brink Street, Crystal Lake, IL 60014

Phone: (815) 356-1767

Fax: (815) 356-1780

Email: barb@leapoffaith.com

Websites: www.leapoffaith.com; www.awareatwork.com; www.thinkhealth.com;
www.emedonline.com

Research Team & Affiliations

Leap of Faith Technologies, Inc.

Barbara Rapchak, PI and Staff

University of Wisconsin Children’s Hospital, Madison, WI

Hope Children’s Hospital, Oaklawn, IL

Ronald McDonald Children’s Hospital, Maywood, IL

Total Budget

\$1,019,201

Research Objectives

The broad goal of @neWorld[®] is to help adolescent children stay connected to family, classmates, and peers and to remain active participants in their social community. @neWorld[®] is envisioned as a tool that can help children adapt and focus on long-term survival. This long-term view is important because projections are that 1 in 900 young adults will be a cancer survivor.



The study was designed to create and validate a social support intervention that uses the Internet as a community-building tool for hospitals and schools. Our goal is to help adolescent children deal with issues of isolation, fear, anxiety, and decreased self-esteem by providing access to a community of peers and classmates in an environment that encourages communication, education, and self-expression. In this way, the users become the developers and active participants in the information exchange process.

This approach gives us the opportunity to examine and enhance social support, communication, education, and preparation for procedures among children undergoing treatment for cancer. The intended outcome is an improvement in perceived behavioral control, self-esteem, socialization, and understanding of health condition.

Specific aims of the Phase II program were the following:

AIMS

1. Develop *@neWorld*[®] as an Internet-based application that allows children to interact with classmates and participate in classroom activities via email, chat groups, online field trips, an art studio, a music room, and a game room; identify and interact with a community of peers with similar medical conditions; access a dictionary and “pictionary” to get medical information in understandable terms; interact with the medical community online; and interact with family members online.
2. Evaluate acceptability of the program.
3. Evaluate program effects in alleviating psychological distress among a group of pediatric cancer patients
4. Evaluate program effects on self-esteem, coping behaviors, perceived social support, cancer-relevant medical knowledge, and feelings of control over health destiny.
5. Evaluate program effects on performance in school.

Theory/Hypothesis

Children with cancer face myriad psychosocial challenges. Disruption of school and social activities during treatment and recovery are particularly troublesome, leading to a decline in school performance and decreased self-esteem.

Research has shown that interventions that include education, social interaction, and distraction can be powerful tools in helping children cope. This is why the positive outcomes demonstrated by Leap of Faith make *@neWorld*[®] an important and promising tool in pediatric cancer treatment.

Experimental Design

Efficacy testing was conducted in a controlled clinical trial with pediatric cancer patients at any stage of diagnosis or treatment. Hospitals participating in the study included Ronald McDonald Children’s Hospital, Children’s Memorial Hospital, Hope Children’s Hospital, and the University of Wisconsin–Madison (UWM) Children’s Hospital. Subjects at Ronald McDonald and Advocate Hope were assigned to the test condition; subjects at UWM and Children’s Memorial were assigned to the control condition (no use of the *@neWorld*[®] Website). Subjects and parents completed a series of three surveys at baseline, 4 months, and 6 months. Patients were also asked to provide their school information and the name of a teacher to participate in the study. Site visits were made to schools by Leap of Faith’s *@neWorld*[®] project manager to deliver a teacher’s Welcome Kit and the teacher’s baseline survey. Teachers in the test condition were given *@neWorld*[®] accounts and access instructions for using the site. Teachers were mailed followup surveys at 3 and 6 months after baseline.

Final Sample Size & Study Demographics



The sample included 38 pediatric cancer patients, ages 10-15. On average, respondents were 12.9 years old, ranging from age 9 to age 16. The sample was 54% female and 95% non-Hispanic. The majority of the sample was White (84%); another 11% was Black or African American.

Data Collection Methods

Data were collected using periodic surveys. Subjects completed a series of three surveys at baseline, 4 months, and 6 months.

Outcome Measures

General health; self esteem; physical functioning; mental health; coping; loneliness; academic achievement and social competence (measured with the Self-Perception Profile for Children [for children ages 10-13] and the Self-Perception Profile for Adolescents [for children ages 14-15], as well as Furman and Buhrmester's Network of Relationships Inventory, Kidcope, the two-dimensional model of control cognition developed by Weisz and colleagues, and Connell's Multidimensional Measure of Children's Perceptions of Control); and psychological distress and quality of life (measured with the State Trait Anxiety Inventory for Children—State Version, a widely used 20-item survey that measures state anxiety, and the Child Health Rating Inventory, an instrument developed to measure quality of life in children with cancer).

The parent survey used the Child Health Rating Inventory—parent version. This scale has the same items as the child version.

Evaluation Methods

Change scores were compared for those in the experimental and control groups.

Research Results

@neWorld[®] has a positive effect on school achievement and self-esteem and reduces behavioral problems. @neWorld[®] users reported lower distress levels, higher quality of life, and better coping behavior than subjects who did not use @neWorld[®].

Barriers & Solutions

Product(s) Developed from This Research

@neWorld[®]: Internet-based intervention