

Hospitalized Children Navigating within a Computer Based Community:
Participants' Perspectives of Starbright World

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Introduction

The use of technology in the delivery of social services is receiving increased attention in social work (e.g., Schopler, Abell, & Galinsky, 1998). Starbright World is a computer based network that links seriously ill, hospitalized children into a fully-navigable interactive community. It presents a virtual reality play space in which children are able to explore and verbally and visually communicate with each other through the use of a representational avatar (i.e., an on-screen character). Starbright World also allows children to interact with each other in real-time via voice and video-conferencing.

We have done both qualitative and quantitative analyses of Starbright World. In a quantitative study, Holden, Bearison, Rode, Rosenberg, and Fishman (in press) assessed the effects of Starbright World in addition to normal pediatric programming in a hospital. Using a repeated measures, single subject design with nine participants (9 to 19 years old), children rated on visual analog scales their (1) pain intensity, (2) pain affect and (3) anxiety (McGrath, 1990; McGrath et al., 1996). Among a total of 702 observations, two of nine participants showed statistically significant effects favoring the use of Starbright World in addition to child-life activities. Using meta-analytic techniques (Onghena, 1994; Onghena & Edgington, 1994) to combine the single subject observations, positive and significant effects on pain intensity and pain affect measures and near significant effects on anxiety measures were found. These findings were taken as preliminary evidence of the use of Starbright World to enhance the quality of life for hospitalized children. The present study reports findings from a qualitative analysis of Starbright World.

Method

The purpose of the present study was to capture children's understanding and utilization of Starbright World from their perspective as participants. Findings are based on two focus groups with six children who had used Starbright World no less than four times and open-ended questionnaires completed

by 37 children at Mount Sinai Medical Center. The focus groups were video taped and transcribed verbatim. Investigators then analyzed the contents to identify common and recurrent themes. The children ranged in age from 7 to 22 years old and were being or had been treated for diseases and medical conditions primarily in the following pediatric divisions: gastroenterology, hematology/oncology, nephrology, and cardiology.

How these children understood the purpose, focus, and impact of Starbright World (and how they voiced their understanding) was considered important because, in several critical respects, they were thought to differ from how designers and producers understand the system. Also, the children's perspectives can help us identify variables for systematic study of the effects of Starbright World which are not readily apparent to those who have not been actively engaged participants. Consequently, participants can offer new ideas for development and ways to modify and adapt Starbright World so as to make it more responsive to its mission. Also, the present findings offer social workers in pediatric health care and those working with the families of seriously ill children an uncommon view of illness, hospitalization as well as attempts to ameliorate some of the associated conditions.

Results

What is Starbright World?

Participants generally understood Starbright World as a method of communicating with others who are in hospitals located in different parts of the country (*"You get to meet kids in different hospitals and even wind up becoming friends with them."*). They generally understood that this is accomplished through a computer, phone lines, and specially created computer environments and that communication can occur either through typing messages on a computer keyboard or one-to-one via microphones, speakers, and video cameras. Boys typically described the system more in terms of its technologies (e.g., *"A bunch of wires that connect and go through a special hookup, through different computers and around the computer"*) while girls focused more on its visual graphic features (e.g., *"...can go through cave, or*

sky world..., can see different things...and you can type or go on video.")

The children generally understood the purpose of Starbright World as providing a way to meet other children who are hospitalized and a way to cope with the boredom of hospital confinement. Consistent with this purpose, there were two aspects of Starbright World that were particularly salient in how children described the system. One was that they could interact with others without having to leave their bed (*"When you are not allowed to get out of your room you have someone to play with," "...you are not allowed to get out of your room and this way you have something to do."*) and the second, that they could communicate with *"...other people who have the same thing as you, and you get to see the things that they like and don't like about it."* Participants particularly valued opportunities to talk to others who were hospitalized for the same reasons that they were. For example, one of the first things that almost all children wanted to know about someone whom they were just meeting on-line was why he or she was in the hospital and whether or not the other's medical condition was similar to their own (*"You get to meet people in different hospitals and you get to see what they have. Like if it's the same or different that what you have"*).

Participants elaborated on the value of interacting with others with similar medical conditions in the following ways:

"It's very important to meet people who have the same thing as you because then you know that you are not the only one who has it, and you don't feel like you are the only one."

"When you have something and you have to come into the hospital, you normally think that you did something wrong. But then you see that other kids have it, you see that you are not the only one who has it and has to deal with it."

"To me it was important because you know you are not the only one who has the same thing."

"It's very important for them to talk to somebody who has the same thing, so that they can talk to each other and see what they are doing to the other person, to compare what's happening to them to what is happening to the other person...you compare the hospitals, like what they are doing to the other person"

to what they are doing to you, like giving them medicine and treatments and everything. I had a Broviac and some of the kids who had the same chemo or radiation had different PICC's and everything else, and you would ask them why do you have this instead of this and they would say my doctor told me this was better and you would say my doctor thought this was better, and so you would have two different opinions...but then you just learn to trust the doctor that you have, not that they have...they [the doctor] might have gone to a different school and was taught a different way, and people who are different might be better with one way than the other way."

"At first it was very important that you meet people with the same problem, but after a while you get used to having your problem and its just fun to meet people in general and see what they have."

Some of the children spoke about meeting others who had more serious medical conditions than they did: *"As you are talking with other kids on the computer you find out that some of the other kids have other things that are more severe than what you have, that are more dangerous to be inside the hospital than what you are in for, which only takes a week or two, they might be living in the hospital."*

"It is scary because here you are talking to another person that is almost dying, and it is scary because you really don't know what to talk about, because they are not in school, they are not doing any sort of hobbies or anything, they are resting and there is really nothing that you can do."

Participants generally were comforted by learning that there were children across the country that had conditions similar to their own; that they were not at fault for being sick and hospitalized; and that they were able to compare the kinds of treatment and medical procedures they had received with those that others had received. Aside from their illnesses and treatments, the children said that they mostly talked with others about "school stuff" and hobbies.

Participants had very definite ideas about when they did not want to participate on Starbright World. This often were times when they were depressed or in pain: *"You just kind of get depressed after a while because you are still in the hospital and you just want to go home to see your friends and get back to the stuff you are used to doing so I just said, 'No. I don't want to do Starbright tonight' or something."*

“Right after you just get out of surgery, you just want to relax, get back to your normal life, well not really normal, but to get stronger, and Starbright isn't really going to help you any. You are just going to sit there and watch the avatars go by.” “If you are in pain, you just want to rest and sleep. You do not feel like talking to anyone.” “Most of the time when you have pain, you are very grouchy and are like 'get out of my way, I don't want to talk to you.' You are very irritable so in a way it's not good to go on Starbright then because you can get mad at the person for no reason and they don't know why they are being yelled at by you. You might say something you didn't want to say and would regret it.”

Other participants, mostly younger ones, spoke about the benefits of using Starbright World when depressed or in pain. *“When I was in the hospital, I had back pain and it didn't hurt as much when I was on Starbright.” “It gets me happy when I can use the computer in the hospital.” “When I was going to have surgery, it distracted me and sometimes you forgot about what is going to happen to you.”*

Suggestions for improving Starbright World

Participants expressed concern about three general areas of Starbright World: 1) the quality of the games available, 2) not consistently having other participants on-line, and 3) the role of child life specialists when using Starbright World..

Regarding the quality of the games available, they said, *“They only have two games to play...one takes a really long time, and the other one, most people don't have a clue how to play it, so you are kind of stuck between a really long game or a game you don't know how to play. It would be better if they had games that everyone knew how to play or if they had short games.”*

Regarding not having other participants on-line, they said, *“Not all the time there were people on it, maybe they could set a time when people could go on it.” “You might be waiting to go to bed at eight o'clock, and someone would be sitting there at six o'clock, saying, O.K. it's six, where is everybody.” “...because of the different time zones, conversations were cut short because you had to go off and they were just getting on.” “Lots of times there's just no one else there except other kids in your hospital.”*

Participants generally understood the role of the child life staff as helping them learn how to use

the system, and fixing “glitches” that occurred in the system. *“If there is something wrong with the computer, if there is a glitch or something, they are right there to help you to see what's wrong, but in a way it would be better if they were outside of the room so that you can talk face to face with just the other person.”* Although this view of the role of child life was basically accurate, they also were present to monitor the contents of participants’ discourse for inappropriate messages that might upset participants. This was indirectly acknowledged by some participants:

“Sometimes it's better to have them there, but other times it isn't, it depends, like my first time it would be better if someone was there but once you get used to it you really don't need them.” “...because you don't want to talk when the grownup is around because then the grownup will want to start a conversation with them, and you are really on the computer just with you and someone else, not with someone watching you and what you are doing.” “...there is normally a child life in the room with them also, and then they will get into a conversation [with each other] and then you are just left listening.” “You can accidentally get distracted by them and start talking to them and you forget about the person you are supposed to be on with, but most of the time they don't do that.”

Some participants felt that having child life staff in their rooms with them affected the quality of the interactions they had with others on-line. For example, *“you wouldn't say something insulting or really personal. You try to keep it on the surface.” “Like, you wouldn't get specific, you would ask certain things like 'why are you in the hospital, and they would say, 'well I'm getting chemo,' and then you would say, 'why are you getting chemo?' and they might feel kind of shy and might not want to explain it to you because they might be kind of embarrassed. It makes them get quieter because there is an adult in the room.”* Many participants concluded that it would be better not to have child life staff present with them in their rooms once they had learned how to use the system.

Other suggestions for improving Starbright World included:

- Make the environments easier to navigate. Several younger participants complained that, *“You can't go into the castle in the sky,”* and *“You can't catch the cow*

that flies in the sky because it goes too fast.” One eight year old participant suggested having *“buttons to push like easy, hard, and normal so to let the computer know how I like it.”*

- More than half of the participants said that they wanted more games in Starbright World, particularly *Ninetendo* and sports games that can be played interactively with other participants on-line. Many complained that the present games should be shorter and “easier to play.”
- Allow the system to have the capability of letting children bring from homes their own computer games that could be loaded into the system so that they could play with others on-line. A participant explained that he is already able to do this from his home using a modem connection between his and a friend’s computer.
- Many participants said that it was difficult or *“frustrating”* to use the computer mouse and suggested replacing it with a joystick. Others advised novices on the system to use the directional keys instead of the mouse.
- Many participants complained about having to identify other participants via the avatars. *“I would make the characters appear bigger and brighter. Also, at the bottom of the screen I would let some kind of signal appear to let you know if someone is even out there.”* *“What I hated was the fact that it was so hard to find the people.”* *“It was hard to control your movement and hard to find people.”*
- Several suggested providing an instruction booklet, when parts of the system were too complex to simply “learn by doing.”
- One participant suggested that they have adults on-line who, when they were children, had similar medical conditions and procedures as he did. *“I think adults are good, because they could have had their operation when they were younger and then you can see how it is when you get older.”*

- Several adolescent participants spoke about the value of having relevant, easy to understand, medical information available to children as part of Starbright World. One suggested it be called "*Information World*" in which participants would be able to click on medical terms and get an "*easier*" definition, correct pronunciation, with an option to see a picture. She went on to say that, "*The doctor's use such big words, the right words, that you don't even understand. I've asked them what they mean. They give you the answer, but they give you the scientific answer and you still have no clue what they are talking about.*" Another participant suggested that, "*Maybe you can put the pamphlets [about different medical conditions] on Starbright, and it would have easier words that you would understand, or if there was a longer word that you didn't know, there could be a definition next to it, and you have the pronunciation keys. You could have all kinds of conditions on it and then you could click on the one you wanted and you would get a pamphlet on it. There could be an option if you want to see a picture or if you don't want to see, like click on if you would like to see or just keep going if sometimes it's scary to see a picture of a thing that you know is inside of you.*"
- Several participants discussed the idea of having a census directory of other children in hospitals across the country who could be contacted on-line: "*You could have a phone hooked up to Starbright, and you can get phone numbers and call whoever you want, and next time they come in, you will always have their phone number, and you can always call them instead if they are not on at that time.*" "*Yea, like a phone book. Have a built in phone book inside the computer, that if you wanted to talk to a certain person, it would show their age, what they have, and where they are located, and if they are in or not.*"
- Many participants talked about the need to be able to be in video and, at the same time, to be in different Starbright World environments as they can do in "text block."

"Text-block is better because you can read everything that everyone writes." " It's hard work, but it's better because you can talk to two people or more than that at the same time ." "Because [on text block] you can go anywhere and still talk, on video you need to be near that person." Technologies are already in place on the World Wide Webs that allow avatars in various virtual realities to directly communicate with one another in "chat modes." Their speech appears in cartoon like balloons directly above each speaking avatar. Having such a system in Starbright World would substantially facilitate initial engagements among participants.

- Of course, there were many participants who liked Starbright World just the way it was and did not want to see anything about it changed: *"I would not change anything about Starbright World."* *"New programs would be great but change it, never!"* *"Nothing needs to be changed. It's fun and it's perfect."*

Conclusions

On-line activities. While participants generally enjoyed opportunities to communicate with others on-line, it was clear that they wanted and expected more activities with which they could interactively engage others and which could serve to initiate, maintain and substantiate their discourse. The form of such activities was generally and enthusiastically expressed as different kinds of games. There was little enthusiasm, however, for the two games presently in the system and a sense of frustration about using the building environment because it was difficult to use and not interactive. In this regard, the idea of being able to load onto the system participants' own computer games is compelling and suggests opportunities to incorporate both commercially available games as well as specially designed games into Starbright World.

Information seeking. While Starbright World was generally conceived as a form of behavioral distraction and computerized entertainment to help hospitalized children cope with their confinement and

illness and treatment concerns, participants talked about the value of information seeking and sharing illness related information on Starbright World as another mode of coping and adjustment. This was directly reflected in their concern about wanting to know whether or not other participants on-line had the same medical condition as they did. It also was reflected in several ideas about providing medical information on-line so that participants could access relevant information at their own pace and level of comprehension. This kind of information seeking is a common mode of adjusting to chronic conditions of illness and treatment and it would be worthwhile to consider how Starbright World can serve participants' natural and spontaneous needs to struggle to understand and make sense of their conditions. Also, the idea of occasionally having people on-line who have successfully recovered from their medical condition and who now have a perspective different then when they were in the immediate grasp of illness and treatment is an intriguing one and might have more value than simply having media and sports celebrities on-line as visitors to Starbright World.

Child life specialists. Whether or not to maintain current practice of having a child life person present when participants use Starbright World is an issue that needs to be addressed relative to the myriad responsibilities that they assume, the promise of having more computers available on site, and with more and more children thereby having opportunities to simultaneously use the system. Depending on the age of a participant, child life specialists at Mount Sinai report that it takes two to four sessions on line with participants for them to master the system and be able to use it on their own. Other activities that involve child life management of Starbright World include, a) identifying participants appropriate for participation, b) securing informed consent, c) identifying times when participants are available to participate, d) transporting the units to participants' rooms and activating the system for them, and e) assessing, planning, and implementing variable levels of training and support among different participants.

However, there also is the issue of whether participants can be "trusted" to participate on their

own without being monitored by adults once they have mastered the mechanics of using the system. This issue is significant given present findings that participants often chose to discuss illness related concerns and events with others on-line and sometimes felt stymied from doing so by the presence of child life people. This issue takes on further meaning in the current climate of informed consent and recognition that we cannot and ought not “protect” children by withholding medically relevant information from them. The role of child life specialists in the rooms with participants continues to be an area of further consideration as well as the roles of child life interns and hospital volunteers who can provide simpler levels of participant support.

Empirical variables. The present findings suggest several empirical variables to test the impact of Starbright World that augment the present empirical concerns with reductions in perceived pain, anxiety, and length of hospitalization. One variable concerns participants’ causal attributions about the nature of their illness. It is likely that as participants engage others on-line and come to appreciate the diversity of participants who have similar conditions as their own, they will be less likely to self-blame and attribute their illness to pernicious events for which they (or their parents) somehow were responsible. Similarly, active and continuing engagement with Starbright World should improve participants’ self-esteem and help to restore greater balance among domains of self identity (e.g., appearance, academic achievement, physical prowess, etc.). Given participants’ interests in talking about their medical conditions with others on-line, measures can be obtained of changes in their concern and understanding of their illness and treatments as a function of participating in Starbright World. There is today a substantial literature in pediatric psychology of empirical findings based on each of these variables. Given the communicative intent of Starbright World, studies also would benefit from substantial findings regarding the development of children’s and adolescents’ discourse processes, particularly those dealing with computers as a mode of discourse.

Many of the suggestions raised by the participants about the utilization of Starbright World have

been incorporated in more recent upgraded versions of the system. In this regard, we view our research as formative in kind providing continuing findings that can be incorporated into the ongoing design and development of Starbright World.

Finally, the present study demonstrates how the suggestion often heard in social work literature--to combine qualitative and quantitative research--can be implemented. For a relatively small investment, we were able to combine formative research that facilitated system development with summative research that gave us an early indication of the effectiveness of the intervention.

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