HEMONAUTS: INITIAL IMPLEMENTATION OF DIGITAL GAMES TO INCREASE STEM LEARNING AMONG CHRONICALLY ILL CHILDREN

Initial Implementation of Digital Games to Increase STEM Learning Among Chronically Ill Children

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Abstract

This study reports on findings from the first phase of the *Hemonauts* project, a suite of interactive digital games, designed in collaboration with software developers at Thrust Interactive, which were intended to increase Science, Technology, Engineering and Mathematics (STEM) content knowledge and promote healthy lifestyle choices in chronically ill children. Chronically ill children are at risk of falling behind in school due to frequent absences and disease implications, potentially resulting in additional psychological complications and long-term setbacks. *Hemonauts* seeks to leverages childhood diseases as an entry point to exploit the target population's innate interest in anatomy and physiology. We created and tested a suite of three game prototypes to engage children in challenges related to Sickle Cell Anemia. Participants were middle school students and pediatric patients with Sickle Cell Anemia. They expressed that the game was captivating and highly needed and patients with Sickle Cell Anemia demonstrated high levels of interest-driven engagement with content relevant to their diagnosis. However, at this stage, they did not demonstrate increases in STEM content knowledge and more generally, we found that patients expressed an alarmingly low level of disease literacy.

Introduction

This study reports on findings from the first phase of the *Hemonauts* project, a suite of interactive digital games to serve chronically ill, frequently hospitalized, students in grades five through eight and their support networks. The aims are to increase STEM content knowledge through gameplay; increase knowledge of and intent to persist in STEM careers; and increase disease literacy to improve patient self-advocacy, treatment compliance, and to promote healthy lifestyle choices.

While there are health-based apps on the market that promote disease management, there are few games offered to children with chronic diseases such as Sickle Cell Disease (SCA), Asthma, and Diabetes. *Hemonauts* leverages these childhood diseases as an entry point to exploit the target population's innate interest in anatomy and physiology, leading to not only a greater understanding of patients' diseases but also an increase in STEM knowledge through newly designed, adaptive math and science challenges and virtual interactions with STEM professionals.

Chronically ill children and their families are a new, and promising, audience for targeted STEM education efforts. Health-related issues can cause frequent school absences, cognitive disabilities, and social and act as emotional stressors for chronically ill children. Yet, due to their disease, these children, their family members, and caretakers are eager for information about how the body, and more specifically, their disease, works. There are many challenges in health literacy (Wolf et al. 2009) and these challenges are more complex with regards to children's health (DeWalt & Hink, 2009) where parents are intermediaries and children's literacy rates are typically lower than adults.

This pilot study was building upon previous work conducting STEM education with children who have Sickle Cell Anemia (SCA). We sought to understand if we could leverage the interest of children in their own experiences, helping them establish their disease and their body as and interest area to encourages them to seek out more learning experiences. The goals were to improve health literacy and STEM learning. The innovation in this approach was to better understand whether chronic illness, which is generally considered a deficit learning challenge, could be leveraged into a learning asset, as a motivation to learn.

In this initial implementation we sought to (1) undertake the process of design, going from a low to high fidelity prototype while gathering formative feedback to improve the games; (2) to evaluate aspects ranging from usability, to social sharing, game experience and learning. Because we were using a thematic game about disease, rather than children's interest, humor, or "fun" topics we hoped to answer a more general question about engagement with informal learning: *Can something personally negative serve as the catalyst for learning the same way that positive and playful experiences do?*

Our interdisciplinary team, comprised of software developers from Thrust Interactive (thrustinteractive.com) and academic researchers from Georgia Institute of Technology and Emory University's College of Medicine, created and tested a suite of mini-games to engage children in challenges related to SCA. Chronically ill student players expressed that the game was captivating and highly needed and demonstrated an interest in using the game to learn and to teach others; however, they did not demonstrate increases in STEM content knowledge and in general expressed an alarmingly low level of disease literacy.

Background

It is estimated that up to 20% of the school-age population have a chronic medical illness or disabling condition (Kilewar, 1997). Chronic illness has been defined as, "a disorder with a protracted course that can be fatal or associated with a relatively normal life span despite impaired physical or mental functioning. Such an illness frequently shows a period of acute exacerbations requiring intensive medical attention" (Mattsson, 1972). Chronic illness is treatable, yet not curable, and requires management for long periods of time. We contend that chronically ill children are an *underserved*, *under-represented* and *educationally disadvantaged* population with regards to education. In addition to the child's medical illness, they are also at risk for psychological problems (Kilewar, 1997). One of the most common psychological problem areas is educational difficulties or academic and learning problems due to regular school absences for medical reasons. Also, complications from disease can result in learning disabilities or educational delays. We see an opportunity to leverage this disadvantage, a chronic and debilitating illness, into a learning opportunity, providing motivation to learn in a personally meaningful content area about the systematic and scientific processes of ones disease, which may spark an overall interest in math and science. Additionally, because of chronic illness, hospitalized children are a captive audience for informal learning using the math and science behind their disease.

Chronically Ill Children's' Education

Pediatricians and pediatric health care providers place a large emphasis on patient education when caring for chronically ill children. Multiple studies have established that effective patient education leads to significant improvements in clinical outcomes among chronically ill children (Brink, Miller & Moltz, 2002; Kahana, Drotar & Frazier, 2008). A key aspect of patient education involves teaching patients about their disease pathophysiology, in which they learn, in a step-by-step fashion, the complex nature of how the underlying causes of their disease ultimately cause their symptoms, from the microscopic to macroscopic scale. Interestingly, learning about the pathophysiology of one's own chronic disease is a form of complex systems learning (Papathanassoglou, Bozas, & Giannakopoulou, 2008). For example, children with sickle cell disease are taught not only about their expected symptoms such as arm/leg pain and difficulty breathing, but also the underlying mechanisms that sickle cell disease is caused by one small genetic mutation in their DNA, which leads to an abnormal hemoglobin molecule that has a propensity to pathologically polymerize into long chains in their red blood cells under certain conditions (dehydration, high temperatures, low oxygen). When this occurs, during a fever or when a patient doesn't drink enough water, the mutated sickled hemoglobin polymerization increases, causing the red cells to stiffen and leading to painful physical symptoms.

Chronic diseases affect all members of the child's family who have the potential to become a secondary audience for informal STEM learning efforts. The patient's siblings, who also spend a great deal of time in hospitals and doctor's offices with their family, can be learning partners and game users with their chronically ill sibling (Goszer Tritt & Esses, 1988). We propose that using their child's disease pathophysiology can increase a whole family's general scientific literacy and their understanding of their child's disease. By engaging parent and siblings with our learning experiences, families have the opportunity to continue the conversations and learning at home.

Health Literacy

Promoting health literacy has been identified as a successful method for improving health outcomes among children (DeWalt & Hink, 2009) and in the transition of care that begins in early adolescents with chronic illnesses (Carden, Newlin, Smith, & Sisler, 2016). In a literature review, Wolf et al. (2009) identified that the need for greater health literacy was well documented, but the tools to improve such literacy were unclear. They found that most research to improve health literacy was focused on reading literacy and encouraged the use of simple language and design choices to limit the cognitive load. Rothman et. al (2009) utilized a more comprehensive approach with an intense, personalized, Diabetes management program for low-literacy patients. This intervention showed promising results with the study group reporting better health outcomes than the control group.

Games for Children's Health

Previous serious games research, in relationship to childhood illnesses, have sought to effect behavior change and improve children's compliance in managing their illness (Kato et al., 2008; Thompson et al., 2008). In the game Packy & Marlon, Brown et al. (1997) found that the game was effective at improving the children's' ability to manage their diabetes. The game in and of itself was not teaching new information to the children, but it did improve their communication with friends and family about their disease. The children were positioned as experts in the domain of their illness in these interactions. This improved their understanding of their disease and improved their health behaviors. Many of these games have auxiliary learning outcomes, but learning is not the primary goal, nor is the learning structured in a systematic way to meet larger learning goals for STEM education.

Learning Motivation and Islands of Expertise

Currently, the field of informal learning focuses on interest driven topics that are personally meaningful for learners in traditional settings such as museums, after school activities, and software. We see many positive learning experiences, for example learning with dinosaurs (Palmquist & Crowley, 2007) or cooking (Clegg, Gardner, & Kolodner, 2010). Crowley and Jacobs identify these deep content areas that children develop as islands of expertise. They have observed that islands of expertise develop through a fundamentally social process where children and family negotiate a co-construction of the child's interest and abilities. As the child becomes an expert in a domain, or island, that topic becomes a platform for developing learning habits and for conversations that can address both general and abstract model of the world that might not be possible without the rich content knowledge. But what happens when your audience is deeply engaged with their own crisis? We sought to develop a suite of learning experiences that are adaptable to these adverse, but personally meaningful experiences to help answer these questions and build learning theory.

Previous Work

Our project was building upon an outreach component of research on SCA which proposed an educational enrichment program in collaboration with a children's hospital. In this project undergraduate students iteratively designed, developed and deployed interactive science and math learning activities for chronically-ill hospitalized children, where the child's own disease was used as the springboard and hook for learning. This program included a STEM curriculum and the undergraduate students were able to integrate relevant concepts into teaching patients, emphasizing that medicine is interdisciplinary and involves biology, physics, chemistry, and math. During that pilot program, approximately 36 patients for 40 total hours were taught, in the patient's hospital room or in the hematology clinic while receiving a blood transfusion. As part of this program we observed two primary contributors to the successful engagement of children with the STEM content. First, the undergraduate students were enthusiastic teachers in the hospital environment. These students are well informed about diseases and STEM content and they are a near-peer age group to the hospitalized patients. Second, we observed that the children's interest in their own illness helped to build interest in the STEM content related to their disease. While this program is continuing, the primary challenges are scalability and consistency of student led teaching.

Methods

We conducted two types of game testing sessions with children. The first was prototype testing sessions in two 5th grade classrooms of a public school. The second prototype testing session was with patients who have SCA at a children's hospital.

Prototype Testing with Middle School Children

Our initial round of user testing involved approximately sixty 5th grade elementary school children.

Testing took place in two 45-minute science classes with approximately 33 students in each class (some students may have been absent on the day of testing). Across the two classes there was an even distribution of male and female students. These children were selected because they were a diverse population, that were within the age range of our target demographic. We obtained IRB approval from our institutions for a waiver of parental consent because the activity was similar to classroom activities. We asked the children if they wanted to participate in the study, and all of them gave verbal consent. One of the researchers has an ongoing, working relationship with the teacher and the school where she regularly conducts educational activities similar the activities we conducted.

To structure their play experience, student participants in each class were split into three small groups of ten players, which rotated between the three different gameplay stations. At each station, participants engaged with a game prototype for 10 – 15 minutes of play facilitated by researchers. The play sessions were then followed by a ten-minute discussion in the small groups where students shared general impressions and feedback on the game before moving on to the next station with their peers. Testing concluded after three rounds of both play and discussion with breaks for moving from one game to the next.

At this stage in the iterative development process the three *Hemonauts* mini-games ranged from a fully digital prototype of the game, *Cell Counter*, a paper prototype simulating the mechanics of a second game, *Vein Navigator*, as well as a functional prototype of the *Body Balance* game in the form of a tabletop board game. The meta concept of the three games is that the player is piloting a microscopic robot (a nanobot) that is placed into the body to perform tasks.

The initial meta-concept was a collaborative design effort between the professional game designers, SCA experts, and educational technology experts to find a unifying theme to bring together many of the learning activities developed in the previous work described above. Our constraints were to find a concept that would allow us to magnify the interworking of the of function in the human blood stream and something that would help to distance the player from the dark prognosis of SCA. In this stage we were in part testing young people's reaction to this meta-concept.

When testing the fully digital *Cell Counter* game, students played in groups of two or three on one of four Apple iPad's with researchers by their side to help or answer questions. In *Cell Counter*, players have a bird's eye view of their nanobot passing through a series of veins filled with red blood cells, white blood cells, and platelets. The game mechanic (i.e., the action undertaken by the player) is to pause their ship at specific targets and collect blood samples that will be visually analyzed to determine the total cell count. This play experience not only introduces basic concepts related to hematology (e.g., veins, red and white blood cells, platelets) but also introduces the mathematical concept of ratios (e.g., a patient's blood volume to cell count). This game visually translates the mathematical concept of ratios to the patient's common experience of blood sampling (complete blood count), which is an important indicator for those with SCA.

Two cardboard mock-ups of the second game, *Vein Navigator* were used to guide students through a representation of the gameplay experience that was then being developed for the iPad. A side scrolling "endless runner" style game, *Vein Navigator* was demonstrated using a long horizontal cardboard and game board with a strip of red crafting felt representing the side cutaway view of a human vein. Players pushed small felt-backed cardboard ships along the surface of the game board and the friction of the rough fabric texture was used to explain the fact that the speed at which blood flows is based on its thickness and "stickyness" or viscosity. Game pieces scattered throughout the vein, some which were without felt backing and slid more quickly, represented different kinds of beverages which could speed up or slow down the player's progress based on how effective they were at aiding hydration.

Our third mini game, was originally conceived as a design activity to see if the meta concept involving a narrative of a *Body Balance* including collecting cards and points would be a motivator for the students and did not follow the nanobot narrative. Gameplay involved seven rounds of play, representing seven days of the week. Students chose between cards featuring randomized pairings of physical activities, both active and sedentary, alongside food and beverages with various levels of nutrition. Overall health or "balance" between calories and hydration versus levels of physical activity would change day to day based on the student's choice of card.

Pilot Implementation

Building upon findings from the initial prototype testing we develop digital prototypes of all three games. An evaluation of the suite of these high-fidelity games was conducted with 20 pediatric sickle cell patients aged 8-12 from a children's hospital in the form of play test sessions. The children were randomly selected from pediatric sickle cell patients in the hospital's blood and disorder center All the participants parents were given IRB approved Parental Permission Form, completed and signed by the children's parents. Prior to the study, children completed Child/Minor Agreement Forms to participate in the research study. The study was conducted at the hospital over two weeks. Each child participated in a 1-hour session. Upon completion, the children were compensated with a $25 Visa gift card. The aim of the playtest sessions was to gather data to evaluate the game mechanics and the children's conceptual understandings of the games so as to inform future improvements of the games.

The suite of games were introduced to the participants and they were asked to interact with the game on the iPad while using a think-aloud method in which participants speak aloud while playing (Nielsen, Clemmensen, & Yssing, 2002). Researchers observed the activity and recorded observations on how the participant engaged with the games and reacted to them. This allowed researchers to gather qualitative data to evaluate design implications of playing the game; this data was not analyzed for generalizable findings but was used to understand where the design was breaking down and what mechanics were successful in the games.

After the participant had finished playing all three games, a thirty to sixty-minute semi-structured interview was conducted by the researchers in which participants reflected on their experience and understanding of the games. The interviews were audio recorded, transcribed, and the resulting qualitative data was imported into a qualitative data analysis software and analyzed to reveal patterns and themes.

Two researchers worked collaboratively side by side to generate a codebook based on reviewing the data generated by the twenty participant interviews. Codes were created to capture content related to all of the structured questions covered in the interview guide as well general themes that emerged naturally from the interviews. Parent codes were generated in association with both the general topics of the questions posed and to themes and then child codes were generated to capture a greater level of detail with regards to the subjects covered both in questions regarding STEM content and the participants subjective responses (See Table 1). The codebook was revised in three phases. Phase one, one researcher coded a set of 3 interviews and the second researcher then took a code application test. Discrepancies were then discussed and the codes were refined to clarify the researchers' understanding. This was repeated two more times until the researchers reached an interrater reliability of 94% correlation. The code application test results are reported using Cohen's kappa statistic (Cohen 1960). Sage suggest that inter-rater reliability should approach .90 (Miles & Huberman, 1994). With a score of 94%, there is strong confidence in agreement of these codes.

Pilot Intervention Description of Digital Game

The three games were again part of overarching narrative that introduced players to the "Hemonauts," microscopic robots that players could pilot through the human body to complete tasks in support of the body's overall health. The three games were *Cell Counter* (Figures 1a-c2), *Vein Navigator* (Figure 23), and *Body Balance* (Figure 34).

Cell Counter, was very similar to the game prototype tested initially in the classroom and described in the prototype methods section. Players look at their nanaobot from above as they navigate through the veins to collect blood samples. Based upon feedback we slowed down the game and added in boxes for the player to fill in the equations used to calculate ratios on the final game screen (see Figure 12cC).

In *Vein Navigator*, players raced their nanobot through a cross section of a vein. In keeping with a quintessential "side-scroller" genre of video game, players had to carefully avoid vein walls and choose to pick up "bonuses" representing beverages that could affect the speed at which they moved. Sugary beverages (e.g., juice and soda) lead to dehydration and increased blood viscosity and vasoconstriction, which slowed down the player's robot. Conversely, drinking water would speed up the robot through vasodilation and decreased viscosity of the blood. This game supports a player's understanding of day-to-day healthy lifestyle choices, while also introducing the disease-concepts of hydration, dehydration, and blood viscosity all of which are factors which can contribute to an SCA pain crisis (Figure 2).

Body Balance, the digital game, again moves away from the nanobot function and challenges players to progress through 7 rounds (days) of a card-style game. Players choose cards representing daily diet and activity choices in an effort to balance hydration and calorie intake and output as seen in two fill meters: representing calories in vs. energy expended and hydration gained vs lost. Players try to balance sedentary choices (e.g., watching TV) with physically active choices (e.g., biking and walking) while selecting from a variety of foods and beverages (e.g., water and apples, donuts, and milk, hamburgers and soda, etc.). This game directly promotes healthy lifestyle choices and mimics the day-to-day decisions of our target population (Figure 3).

Findings

Findings from Prototype Activities in Classrooms

The prototype testing provided feedback from the target age group on functionality and game design.

Cell Counter was the only digital prototype. Students expressed excitement about this game and the general prospect of using digital technology although when playing some struggled to pilot the onscreen nanobots using the game's touch screen controls, which lead to crashing their nanobot into the vein walls, ending the game quickly. Although feedback was generally positive, the students requested that the speed of the game be slowed down to allow them to easily control the ship, minimizing the discouraging feedback from collisions which caused the screen to shake upon impact. We also noted that shorter and better instructions were needed for students to understand game play and STEM content more quickly and with less assistance. (Figure 2a).

Vein Navigator was prototyped using a a 30-inch long by 8 inch game board physical prototype where the side-scrolling path of the vein was represented on a 30 inch long by 8 inch foamcore game board illustratingillustrated. printed with the outline of the vein walls. Students navigated by pushing small cardboard ships left to right through the vein where game pieces representing different beverages were placed for them to "pick up" on their journey. Although this prototype was a preview of the digital game experience, our playtesting demonstrated that the students had previous game play knowledge to draw on and that the concept of a side-scrolling game was easy for them to conceptualize regardless of the content. Competition was a significant motivator, as was social play. Students enjoyed physically interacting with the tangible prototype but offered feedback on the graphics which represented the beverage choices as different colored batteries or fuel cells assigned the properties of different drinks. Based on the feedback revisions were made to introduced more literal representations of different drinks to make the connection between various beverages, levels of hydration and blood flow more explicit for young players.

Body Balance was played as a tabletop game with a board featuring an outline of the body and various card choices representing activities and dietary choices scored with simple positive and negative number values representing calories lost and gained and hydration lost and gained based on different combinations of food and beverage with different activities in these prototype sessions. . Their score was represented by game pieces placed on a hydration and a calorie scale where and the pieces were moved up and down to represent changes in calories and hydration. The values of each scale could be "balanced" when the game piece was within a certain number range, or either one or both the hydration and calorie scales could become "imbalanced" with too high or low of a value. The interest players showed in picking cards demonstrated that students (even these without disease) had an interest in their bodies. They liked the meta view of the body and could relate to their choices to the consequences demonstrated through game play. The students were receptive to the overall concept of Body Balance, quickly grasping the concept of how choices of both activity and diet could impact overall health of the body As a result of this initial testing phase we chose to build a digital version to better refine the relationship between the body/health knowledge and the game experience.

Findings from Pilot Implementation in Hospitals

Based upon these findings we refined and developed digital versions of these three games and piloted these In addition to building the games we sought to assess learning and motivation, and to evaluate the potential for learning about STEM content in the context of the body. Piloting the three aforementioned prototypes, we conducted play testing and interviews with pediatric SCA patients. Researchers conducted nineteen sessions with the 20 children (in one session siblings participated together), which ranged from approximately twenty to forty-five minutes, across two locations of the Children's Healthcare of Atlanta.

While the general feedback from our pilot test was positive regarding user experience and usefulness of the app, the games were successful at delivering health educational (e.g., effects of exercise and nutrition) and unsuccessful in communicating higher-level STEM content.

Overall experience.

Participants described the overall experience as positive, they were able to quickly understand how the games operated and noted elements of traditional digital game play and content that was related to Sickle Cell Anemia. There were few cases were the participant asked the researcher to explain how the game was played, and in those cases, participants were given simple instructions, as a friend might offer when sharing a new game. All of the participants demonstrated a recognition that the game was "educational" and related to human bodies. For most participants the educational nature of the game was complimented as a positive aspect of the game, although one participant did share that learning games were not to her taste, noting, "I don't play those type of games." Approximately 50% of the participants described the game as if it were taking place in their body. Sometimes this embodiment of the game mechanics was made clear with descriptions about interactions in specific games. For example, one participant told us, "The *Cell Counter* one [game] is to count the cells by scanning yourself." And when asked how they would describe the games as a whole, participants often talked about how the games related to their own bodies. The goal was, as one participants described, "To have to take care of your body. It was about your cells and stuff."

Prior Experience with Games.

19 of 20 participants described having previously played some form of digital game, whether on a tablet or smartphone, a console system or computer and as a group they demonstrated a high level of fluency with digital game play, quickly grasping the physical controls and mechanics of the *Hemonauts* games. 16 out of 20 participants said they played games on tablets or smartphones regularly but play preferences also varied throughout the group with several students saying that they preferred playground games or board games to digital games. Several reported playing primarily on phones and a few described playing primarily on consoles such as the PS4 and Xbox. (See Table 3).

Hemonauts Gaming Experience.

During play testing, participants were able to readily grasp how to operate the games and recognized familiar game mechanics as well as that the games contained SCA-related themes. Overall, participants expressed that the games were "fun," intuitive, and easy to manipulate toward an understood goal.

However, we discovered that the timing of the *Cell Counter* game was still too quick and that several players needed to stop and restart the game. Most participants did not read directions and instead started, stopped, and then restarted the games after gaining a basic understanding of game play. Because the STEM content was integrated into the directions, the participants missed opportunities for learning the content. For the *Cell Counter* game, some understanding was necessary to play, so players later took time to read.

While participants understood the *Vein Navigator* game, many did not grasp how it was contextualized in the body. However, because game play was based upon a traditional side navigator game, players were able to pick up and play the game without first reading instructions or understanding the context. Some users were confused about the effects of beverage choices (e.g., milk or water icons) and while most of these participants knew that there were “good” and “bad” things to pick up they were primarily operating upon their prior knowledge about side navigator games, rather than knowledge based on SCA content.

The *Body Balance* game was perhaps the easiest for players to understand, as its mechanic of choosing between different food and activity choices required little explanation and leveraged basic knowledge about diet and exercise. While the game did not involve the microscopic view of the body featured in *Cell Counter* and *Vein Navigator*, an outline of a body was featured alongside the food and activity cards and students were able to make the association between the body, the health levels represented on screen, and in-game choices.

Sharing the Game.

Based upon previous success with games related to childhood diabetes (Brown, 1997) we were interested in understanding if a game about SCA would be something that the participants would share with their friends and family. When asked if they would recommend the games to others, most participants were enthusiastic about playing the games with friends or family members. They thought that a game about SCA would be a positive way to engage their friends in conversations about their disease. For example, in an interview with one patient, a 13 year old male:

> Patient: *Yes, I would [play the games with friends]. [The games could] teach them a little bit about [my disease] ‘cause …my friends aren’t that smart.*
>
> Interviewer: *What would this teach them?*
>
> Patient: *Homeostasis and Sickle Cell and your red blood cells and white blood cells.*
>
> Interviewer: *Do you ever talk to your friends about Sickle Cell?*
>
> Patient: *No, I keep it a secret*.
>
> Interviewer: *So, if you played this game with your friends, would you talk about Sickle Cell?*
>
> Patient: *Yeah. I’d tell them a little about it.*

Similarly, others told us they tried to not talk about their disease because other kids did not understand why they were sick or could not play sports at times. All but two participants thought that sharing information about their disease with these games would be helpful, and that if other children understood they would be more supportive. One participant explained that playing the game with peers would be good,

> “Cause sometimes when I’m at school I don’t feel good, like I feel sick, and I don’t have just keep on explaining myself like everything that’s going on with me and my body. Like if I tell one friend and they just realize how sick I can get they can just tell a teacher that I’m not feeling that good that day or they can just tell a teacher to call my parents to help or ask them to come pick me up because I’m not able to do any of my work at school.” (female, age 14)

One participants told us a story about why she felt positive about sharing the games with peers.

Previously she had been picked on in school because of issues around SCA. When her best friend told her classmates about her SCA, the classmates asked her for more information about SCA, apologized and stopped picking on her.

Learning in the games

During the interviews, most participants mentioned liking the educational aspects of the games and noted that they saw the connection to their disease. For example, when asked if they had learned anything about SCA from playing the game, several players noted lessons about the effects of nutrition and expressed a desire to learn how nutrition might help them manage their pain crises. As one play tester expressed, "Don't overdo it. Drink more water. And the calories you burn, try to maintain it. Like keep it balanced…. Don't [get] dehydrated… just keep going, checking, do research on what's going on in your body. You're not a doctor… so just do your research and maybe try to find more games about Sickle Cell" (female, age 13).

Although players could identify that the game was educational, not all were as confident when asked to describe *what* they learned from the games. Only the *Body Balance* game appeared to deliver the intended educational content with all participants, who describing having learned "That you need to stay hydrated and eat and drink healthy foods and drinks, and don't eat unhealthy food or drinks…" (female, age 11). While the importance of hydration and avoiding sugary beverages was also mentioned independent of eating choices, it was often still spoken of in connection with the *Body Balance* game and not with the more relevant *Vein Navigator* game which focused on drinking alone. Often participants had a hard time understanding and recalling the goal of the *Vein Navigator* game, explaining "The *Vein Navigator*, I didn't really understand that one." Or mischaracterizing the game as having been, as one participant, explained, "…about like finding all the veins."

Some students correctly identified that the *Vein Navigator* and *Body Balance* games shared themes related to diet and hydration and responded positively. When describing her favorite game, one female participant, age 13, shared that she "…loved the *Body Balance*. It was *Body Balance* and *Vein Navigator*. I loved those two the most because it's like telling you what's going on inside of a body in a game, the body of the game. It's very creative, because it's like helping you. Like this is what I should start doing. This is what I shouldn't do. Then with the *Body Balance*, it's making you choose like, "Should I really choose this?" or, "Should I stop doing this?" However, for other players, this connection was not as clear and a few described the *Vein Navigator* and *Cell Counter* games as connected, perhaps because of their visual similarities, despite the fact they address different learning content. As one participant (female, age 12) put it "…the first one [*Cell Counter*] and the third one [*Body Balance*] were mostly related because it was mostly focused on keeping your body hydrated." This accurately describes the goal of the *Body Balance* game but misidentifies the idea behind the *Vein Navigator* game as that of the *Cell Counter* game.

The concept covered by the *Cell Counter* game was often recalled only partially, and it was often described as a game focused on "counting" or "scanning" blood cells rather than counting blood cells *and* liquid. Participants didn't remember that counting the number of cells repeatedly was for purposes of determining a ratio of cells to liquid and to later arrive at an average. Instead, participants understood simply that "You have to count how many red blood cells the patient has" (female, age 11) or that the goal of the game was, to "Find all the blood cells and scan them" (female, age 11). Only one participant recalled the fact that the scanning in the *Cell Counter* game was used to measure more than just blood cells, explaining "The *Cell Counter* one is to count the cells and something by scanning yourself and collecting the water on yourself…" (female, age 13).

Further, some players expressed incorrect learned concepts. For example, one player said, "Well you have a lot of white blood cells that stop the red blood cells from flowing through [the veins]." In other cases, participants had difficulty articulating their ideas. One thirteen-year old female player vaguely revealed that the new thing they learned about SCA was that "it could do different things in the body. Stuff I didn't know about…I did not know about blood clots." And when pressed could not explain how they learned about blood clots, what blood clots did or how they formed.

General knowledge and feelings regarding SCA.

Most strikingly, many patients demonstrated a large deficit in knowledge of SCA physiology and disease management. While they understood that their blood cells were different, specifically that they "look like a moon" or were shaped, "like a crescent…or a C", players' vocabulary (i.e. disease fluency) and understanding of concepts related to the vascular system were very limited. Often in explaining the disease they referenced their experience of treatment or symptoms, but struggled to describe mechanics of it:

> Interviewer: *Why don't you tell me what you know about sickle cell?*
>
> Participant: *Well I know that that keeps me in here Monday and Wednesday. Sometimes Tuesday. They just give me blood. Sometimes they take it away and I come back up here Wednesday. They stick me then they give me blood and I just watch TV."*
>
> Interviewer: So sickle cell to you is something that makes you come back here?
>
> Participant: *Yes.*
>
> Interviewer: *Come back to the hospital and they do stuff related to your blood?*
>
> Participant: *Yes*
>
> Interviewer: *Ok. So do you know how it affects the body?*
>
> Participant: *No*. (Male, age 10).

Only a few players seemed confident when describing the science of their disease. Most could only name the effects of the disease, such as lethargy, a pain crisis brought on by exercising too rigorously: "It kind of holds a grudge on you 'cause it keeps you from doing things that you actually want to do like a normal kid would do that doesn't have sickle cell… It keeps me from running a lot. I don't get to run. Sometimes my knee starts to hurt from running a lot so it keeps me from running" one 12 year old girl explained. By and large, many patients expressed feelings of loneliness and embarrassment, unable to explain their disease.

> Interviewer: *Okay. What do you know about Sickle Cell? Like if you were to tell a friend of the family. They're like, "What is that? What do you have?"*

Participant: *I wouldn't really know. I would go to my Grandma.*

Interviewer: *Okay*.

Participant: *I just know that our cells are different. They're crescent and not round is all I know.*

Interviewer: *Okay. So, what affect does it have on your body to have Sickle Cell?*

Participant: *I don't know.* (Female, age 13)

In connection to this finding, and in answers to our prompt to gauge patient interest in sharing the game with friends, players frequently remarked that the game would help explain their disease experience to peers and seemed enthusiastic about the idea of others better understanding their experience. As one patient put it "I could explain it to them like they don't understand, well, like, there is this game you can play to try and understand and figure out what it is" (female, age 13).

Discussion

Our initial motivation in developing this project was to develop a learning environment for chronically ill children that would be engaging and support children's health literacy and learning about STEM disciplines. Our first goals were to address the games' usability and if participants learned from the games. We specifically tried to address the question, can something personally negative serve as the catalyst for learning the same way that positive and playful experiences do? Two aspects of learning with the game that emerged as promising opportunities were the embodied experience of the participants in the game and the social development that the games offered.

While participants we able to play the games, there were some usability issues. Unsurprisingly players did not read directions. While we had tried to make the text short and easy to read, we recognize that it is unlikely players will read unless it becomes more integrated into the game play. However, the game mechanics, particularly within the *Body Balance* game, did support health literacy and most players felt they learned something about balancing food and beverage intake and exercise and exertion that might help them avoid a pain crisis. In contrast the lack of reading and the lack of, or awkward, integration of STEM content into the game play of the other two games left us with little evidence of learning STEM content. Overall the games were fun and playable, and improvements in health literacy were noticed, however it was our assessment that the learning goals needed to be better aligned and then integrated into the game mechanics.

In answering the initial question, *Can something personally negative serve as the catalyst for learning the same way that positive and playful experiences do?* We identify that the participants eagerness to share and play the games with friends and family suggest it can. This is similar to Brown et al. (1997) research on games about childhood diabetes, in that this type of shared gaming experience can become a collaborative learning experiences because of the dialogue it starts and the ways that these discussions align the patient as "experts" in conversations around their medical condition. We had expected that "expert" role would be something that the participants already had to some degree. However, while participants showed a strong interest in learning about SCA and their bodies, their lack of understanding about SCA and their body suggest that their chronic illness is not currently an *island of expertise*.

Instead our findings indicate that the need for disease literacy among this age group is much more critical than we anticipated. This game was, in all but one case, was the only informal learning experience about SCA, outside of direct instruction from healthcare providers, that participants could recall. So while participants enjoyed the game, this was their first opportunity to build an interest with informal or playful learning about SCA. However, the strong interest they had in the games about SCA demonstrated to us promise in leveraging their disease, a typically negative experience, into an asset for motivating learning.

The meta concept of the game was designed to suggest that players were controlling a nanobot and exploring a body, yet many players understood themselves as the owners of the body being explored. We had anticipated they would play as the robot, not as the body. This raises some interesting issues. There is a growing recognition that the body plays a significant part in reasoning and thinking across disciplines and an embodied learning seems to be natural fit with learning about the body. However, the embodied talk of the participants was also concerning. We had hoped to create some distance between the body and the player because of the negative consequences of chronic childhood illnesses. This poses a challenge in design that should be explored further.

While we anticipated that participants might like to share the game with friends and family with chronic illnesses, the social and emotional aspects of their disease were surprising. SCA has unique properties in that the children do not look ill even when in great pain. A pain crisis has little external identifiers and this seems to cause some social and additional emotional discomfort for the participants. The participants saw promise in sharing this game not only to help others learn and have fun, but also as a social lubricant to improve others empathy and reaction to their illness. And while health literacy generally addresses issues around physiology, these emotional issues, and tools to navigate them, seem just as critical for improving children's lives.

Conclusions and Future Work

We concluded from this initial implementation that children with SCA lacked comprehensive knowledge about SCA, but were motivated to share the games with peers. This suggest that we could best serve our target population by (1) Understanding the mode of delivery of educational content that leads to desired outcomes and (2) Ffocusing on children's knowledge about their disease rather than STEM concepts, to empower the students to engage in diseased-based dialogue with family and friends. To address issues related to mode of delivery and to increase reading and the desire to learn through play we anticipate several studies with future iterations of the games. We anticipate testing integration of a graphic novel with the game, testing options for audio or text, and specific game design that will offer learning remediation through narrative branching. Narrative branching can be used to identify misconceptions and direct players towards better understanding of STEM concepts. For example, Players might choose between three options that would represent the correct path and two paths that might be taken if the player has misconceptions about the STEM content. If they choose a path based upon misconception we would allow for productive failure with a non-player character assisting in problem-solving then directing them towards the correct path with remediation.

While our initial goals with this project did not include measuring health literacy, findings indicated that most players improved their health literacy. A greater focus on health literacy through gaming could help us in identifying methods for supporting children as they make the transition away from parental responsibility for their health compliance.

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Tables

Table 1

Parent Code:	Subcode	Description	Example Quote
First Impression of Game		Comment that the game was enjoyable, fun or not very good.	“It was more fun than I expected.”
Game is Educational		Comment that the game was educational in some general way	“People could learn things from playing this.”
Motivation to Share with Others		Comment that they would or would not share with their friends and why.	“I might show them what is in there and tell them about it if they don’t know, like tell them the details of what sickle cell disease is”
Learned Specifically:	Body Balance, Hydration, About the body, Sickle Cell	Comment on content learned from playing the games.	“I learned about platelets in the vein game.”
Prior Knowledge:	Vein, Artery, Capillary, Average, Ratio, Volume, Sickle Cell	Comments on what they already know or what they don't know about these specific topics.	"I know about how platelets go to a cut in your skin and form a scab" or "I don't know what an artery is."
General Impression		Comments on meta game or specific game; suggestions or qualities.	"I like how everything is related to the body?" or "I like the game with the ship."
Personal Disease Experience		Talk about how SCA effects them on a personal level.	"It keeps me from running a lot. Sometimes my knee starts to hurt"

Interview Codes

Figures

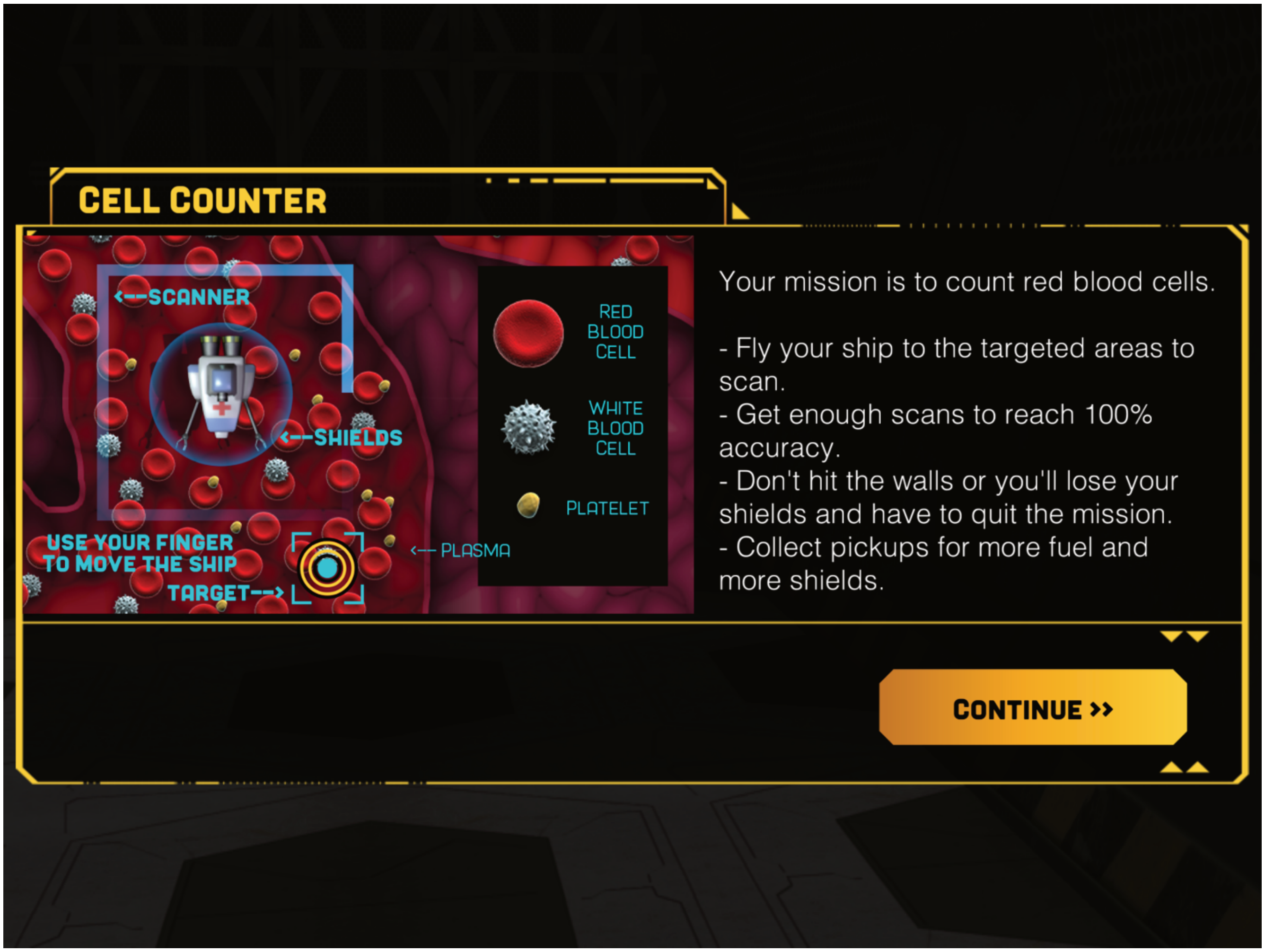

Figure 1a. A Cell Counter instruction screen.

Figure 1b. Cell Counter gameplay

Figure 12c. The Cell Counter results screen during initial prototyping (above) and after our first round of playtests when it was changed to require input from the player in an effort to encourage more engagement with math content.

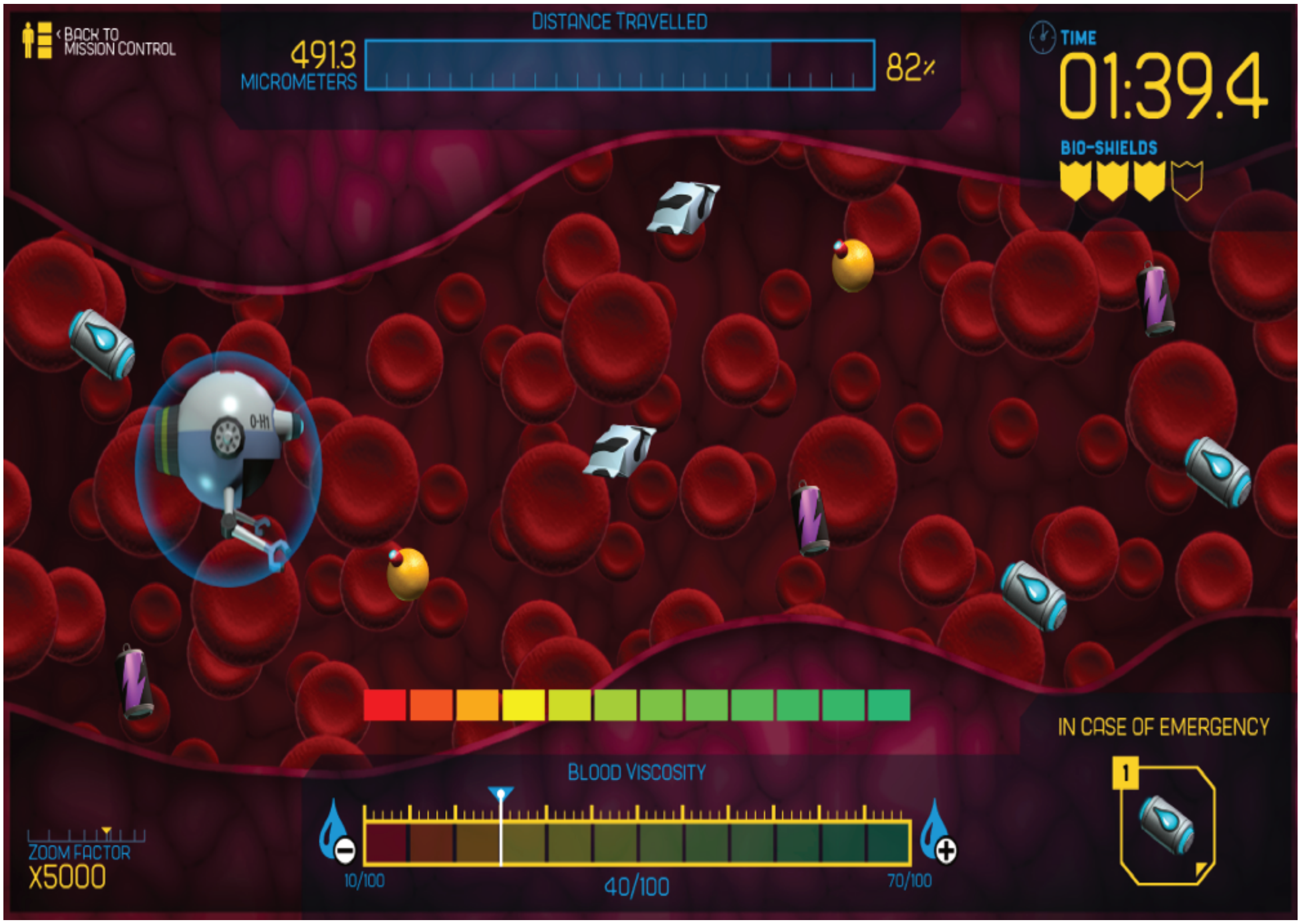

Figure 2. Vein Navigator gameplay

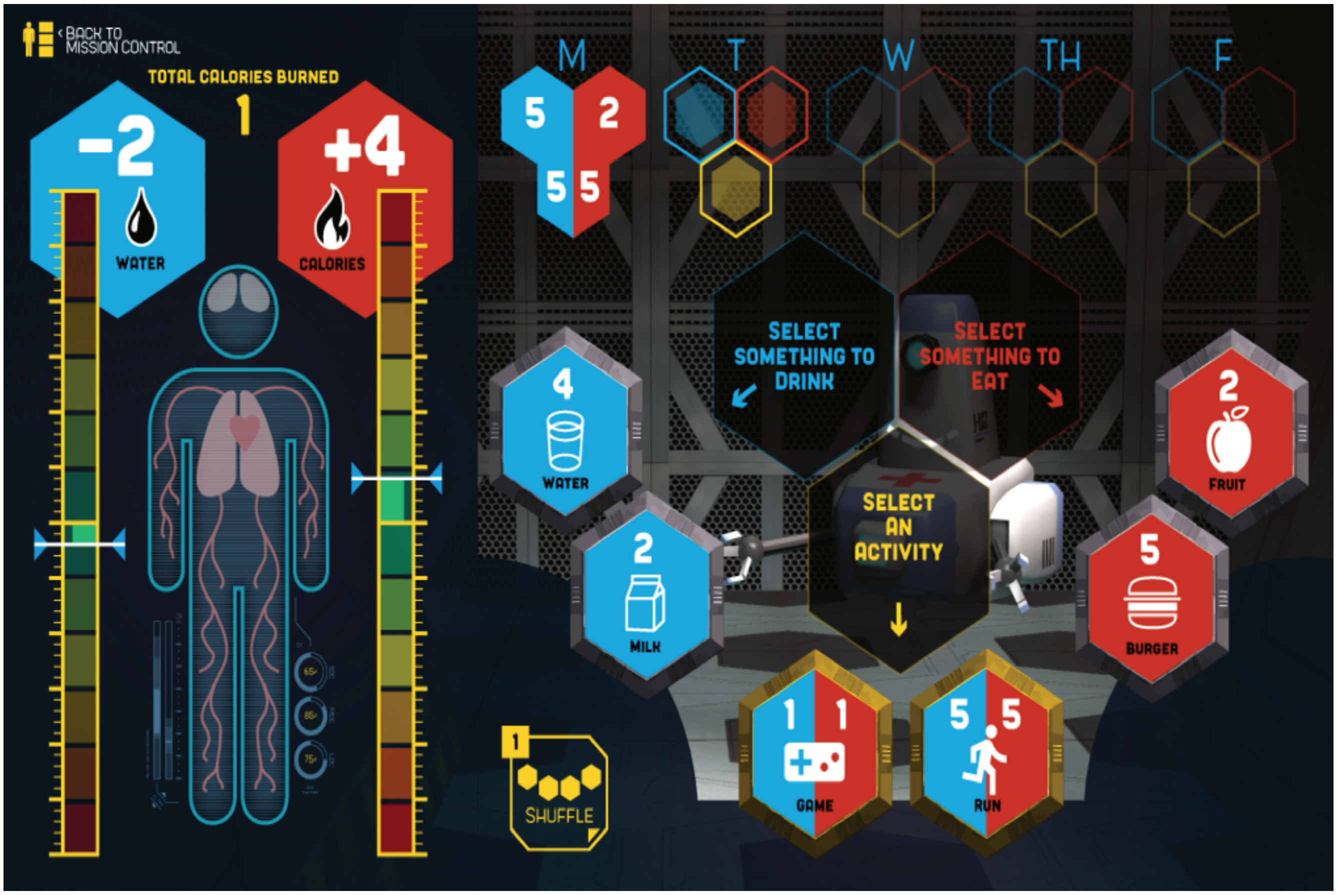

Figure 3. Body Balance gameplay