

Waiting for Learning: Designing Interactive Educational Materials for Patient Waiting Areas

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ABSTRACT

We describe the research and design of educational media for children in doctor's office waiting areas. Even though technology use for medical purposes has become increasingly prominent for doctors, administration, and patients, research on the use of interactive technology for health education is limited. In this project, we focus on clinics for Sickle Cell Disease treatment. These clinics treat patients of various ages and disease severity, but all patients make frequent, recurring visits for treatments and checkups. We describe our current research to better understand the behaviors and activities of patients as they wait in the clinic, their expectations and understandings of Sickle Cell Disease and its treatment, the educational material currently available, and our preliminary methods for developing interactive technologies for these environments. This research includes observations in pediatric clinic waiting areas, interviews with clinic staff, and preliminary user testing with our interactive designs.

This paper details our observations of waiting areas in two sickle cell clinics. We discuss our findings and their implications for design. We also describe the design of an augmented reality tablet application that we placed in the waiting area for user testing. We use this study to discuss further design iterations and directions for future work.

Categories and Subject Descriptors

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

Keywords

Health, education, interactive media, children, design

1. INTRODUCTION

The use of medical technologies has become increasingly popular both in and out of hospitals for doctors, adminis-

trators, and patients. However, research concerning the use of interactive technology for patient waiting areas is limited, especially with regards to the development of educational tools. We propose to take advantage of the time that patients spend in waiting areas to support health related learning activities using new forms of interactive technology. Our research investigates time that patients spent in waiting areas, the current education material provided in this space, and the design of new technologies to improve this experience for patients and their families. Our focus is on sickle cell treatment clinics in which patients receive blood transfusions and other treatments; here patients wait for treatments to begin and end – providing an opportunity for observations, development, and placement of materials. This paper describes an observation study involving over 500 patients, doctors, nurses, as well as other staff and patient family members. We also describe the initial design of a learning environment for children to learn about sickle cell disease in clinic waiting areas.

2. WAITING ROOMS

Little research has been done to understand the time patients and their families spent in waiting areas. There have been attempts to improve the waiting area experience for patients and their supporters, particularly in regards to design of the space. These efforts tend to focus on patient comfort and convenience through factors such as temperature, seating, coffee, what's on TV, or even wait time (e.g. [14, 9]).

Though there are many opportunities to redesign waiting areas for comfort, safety, and even entertainment, there are also opportunities to redesign the space to encourage learning. Studies have found that traditional educational material in waiting areas is often ineffective and goes unnoticed. Common materials include pamphlets and posters about diseases and disorders. A survey of surgery patients found that 79 percent of people waiting read the posters in the waiting areas, and that the longer people waited the more likely they were to read the posters [21]. However, further investigation found that most patients reported that the posters added anxiety to their visits [22], and that they didn't read or remember what the posters said [21]. Based on findings that suggest patients pay little attention to waiting area notice boards and posters, many conclude that the role of these materials and their presentation should be reevaluated [13, 21, 22].

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3. SICKLE CELL DISEASE

We have selected Sickle Cell Disease as a focus for this work primarily because access to educational resources in the community is limited and patients often come from systematically underserved groups. Sickle cell is a chronic disease that the patients are born with and for which there is no cure. Due to the standard treatment protocols, patient visits also involve substantial amounts of down time as the children wait, allowing greater opportunity for testing and interaction with the material. Sickle Cell Disease, or SCD for short, is an inherited blood disorder in which the red blood cells become hard, sticky, and shaped like sickles. As these irregularly shaped cells move through the blood stream they clog the flow of blood. This can cause pain, strokes, infections, ulcers, internal damage, and anemia, among other symptoms [19].

All of these characteristics stem from an abnormality in the hemoglobin in the red blood cells. The hemoglobin, the part of the cell that delivers oxygen to the body, contain a defect in sickle cell patients. The sickle cell hemoglobin stick together, rather than float freely as they do in normal red blood cells. This causes them to form long chains and forces the red blood cell into non-circular shapes, typically forming something visually similar to a sickle shape. Though there are treatments for SCD, there is no cure. As a result patients with the disorder may practice a variety of different routines to manage their condition – for example, taking vitamins, or penicillin. Patients are also advised to drink plenty of water, to avoid extreme temperature conditions, and to limit stress or exertion. Extreme treatment for SCD can include blood transfusions in which patients visit clinics for many hours at a time [19].

4. RELATED WORK

Technology has come to play an important role in health care by supporting both patients and doctors through on-line communities, management systems, and even treatment options. Although not all study results are positive, technology has generally been shown to positively influence learning, self-care, and skill development as well as strengthen the established medical learning environment [10]. Health knowledge has expanded out of the clinic to the Internet, museums, virtual peers, and even into homes and mobile devices.

Technology use has been investigated throughout hospitals to ease patient management issues in areas such as hospital work, patient transfer, patient records, and doctor's charts (e.g. [8, 24]). Recently, there has been a shift towards improving the experience of patients, particularly in terms of educating them about their visit. For example, an information display can give patients the option to view the reason for their visit, their health profile, medications, and information of the staff working on their case [23]. Several studies have involved conversational agents to promote health knowledge and persuade patients to practice healthy behaviors [18] and to provide easy-to-understand discharge information [5]. However, most of these devices tend to discuss clinic visit details such as staff, medications, or test results and not the underlying causes of diseases and their symptoms.

As important as technology has become to hospital care, patients are increasingly reliant on technology when they

are responsible for their own health outside of hospitals and medical offices. One very important use of technology in health is continuous education, awareness, and management while patients are outside of the hospital [7]. Virtual agents, multimodal surfaces, and a variety of other persuasive technologies are also used at home to help patients (e.g. [4, 15, 17, 6]). Many of these systems, such as Chic Clique, Fish N Steps, or Shakra have focused on health and wellness for children and teenagers [20, 11, 1]. Interfaces have become especially common in rehabilitation and therapy for speech [16], autism [3], and diabetes [2, 12]. These are only a few of the many examples of technology in the health realm.

Despite the extensive research on medical technology and educational health materials, none of these materials are designed for waiting areas to the best of our knowledge. Our goal in this work is to begin thinking about patient waiting areas as informal learning environments, much in the way that science museums offer visitors hands-on learning activities. We also attempt to make contributions to the content and form of the health education materials. Many virtual agents and health tracking applications have been developed to help manage health via diet, exercise, or medication adherence; however, none of these applications focus solely on the foundational biology of the body – cell structure, for example – to help patients understand their health. We attempt to go beyond textual descriptions to include interactive experiences with tangible manipulatives and augmented reality systems. These tools magnify characteristic details of the cells and root symptoms of the disease.

5. OBSERVATION & INTERVIEW STUDY

To ground our design work, we were interested in learning more about the education process for children with sickle cell disease. Therefore we interviewed a range of people that the patients with SCD encounter as part of their health care. We also conducted observations of the waiting areas to understand what patients and their families currently do while waiting, what options they have to occupy their time, how long they wait, and other details that may influence the design of material for the environment.

Finally, we collected a range of SCD education materials including pamphlets, books, CD's, and flyers that are handed out by the staff to the patients.

5.1 Participants

We conducted our study at two clinics: a large children's hospital in the Mid-Atlantic, and a small general hospital in the Midwest. During a patient's typical two to five hour long visit at either clinic, they are seen by nurses, physicians, nurse practitioners, social workers, genetic counselors, and psychiatrists. Blood transfusions also take place in both clinics; in either location, the patient is taken to a private area with a bed, seating, and a television. This area is separated by a wall on either side and a curtain at the entrance. Nurses' stations are at the entry of the transfusion center in both locations.

The Midwestern hospital has an SCD clinic with approximately 12 staff and 100 patients. The clinic is run one afternoon every other week. During routine checkups the staff try to limit patient time in the common waiting area and immediately take them to a clinic room. Once assigned a room, the staff rotates to see patients as they wait. The larger Mid-Atlantic clinic employs a 20 person staff and serves over

1,200 sickle cell patients. Here the clinic is run daily during regular business hours. During routine visits at this clinic, patients wait in a large room prior to their appointment, and often return to the waiting area at least once during their appointments. These clinics' locations, sizes, and populations served are quite diverse. These variations provide an interesting contrast for developing a generalizable design directions.

5.2 Methods

The observation portion of this study took place over two years between the two clinics. At the pediatric hematology and oncology clinic in the Mid-Atlantic, we observed over 200 family groups during approximately 38 hours in the main outpatient waiting area. In the Midwest clinic, observations totaled 10 hours between the main waiting area and the area where vitals are taken.

We did not video record or interact with patients or their families while conducting these observations. A researcher collected field notes, wait times, and age and gender estimates for patients and family members. The researcher also noted the behavior and demeanor of visitors as well as their interactions with objects, staff, and other patients.

The observations were interspersed with fourteen staff interviews including three physicians, six nurse practitioners, two social workers, one genetic counselor, and two administrators. These interviews were audio recorded and transcribed for analysis. With the exception of the administrative staff and one physician, all other participants worked almost exclusively with sickle cell patients; one physician was split between SCD and general hematology.

In addition, we interviewed a small number of patients and families to understand what patients take away from current educational materials and their general view on visiting the clinic. Three groups were interviewed: one 17 year old male patient and his mother; a 20 year old female patient; and a father, mother, and their 5 year old son and 7 year old daughter.

For both the family and staff, interviews lasted approximately thirty minutes. The interviews were done individually according to the participant's schedule and generally took place in semi-private locations at the clinics.

6. FINDINGS

The Mid-Atlantic clinic averages 9 families entering the waiting area every hour with an average group size of 2.5 people. The average wait time for these families was 32 minutes. In the Midwestern clinic, approximately 8 patients go through the waiting room every hour between noon and 3 P.M. with an average wait time of 13.2 minutes and average group size of 2.36 people.

One of the first things we were interested in is what, if anything, people read while they were waiting. Of the roughly 500 people who were observed, less than 10 read books, magazines, or newspapers; all who did brought their own reading material with them. Over the course of our observations, three separate adults walked to the pamphlet area and looked at the flyers in the stand, and one of them picked up a pamphlet and took it back to his seat. In terms of digital media, one out of every two people used mobile technology while waiting, including cell phones, laptops, handheld gaming devices, or other mobile devices. Mobile technology use was especially common among teenagers and adults. We

only observed four people talking on their phones. TV's, art areas, and toys were popular among younger children and allowed them to play with others as they waited.

We were also interested in the frequency of clinic visits. Typical sickle cell patients visit between once a month to once a year for checkups, with a majority falling in the range of once every 3-6 months.

Every staff member mentioned self-care as their number one priority in patient education; this included information on how to stay healthy using diet and exercise, what to do in the case of SCD pain, and other details on how to manage personal health. Staff members also agreed that the current materials for teaching patients are usually written at the adult level, and used mostly as ways to "help hit high points" during appointments. Staff expected that parents are supporting children by transferring information in a way that suits the family once at home, though they recognize the limitations on parents' time during and after appointments. Most staff also agreed that teaching the patients about the biology of the disease, while interesting, would likely not influence self-care.

However, when discussing with the staff about how to improve patient compliance with health regimes, most suggested that better education and understanding would improve health outcomes and adherence to medications.

"Everybody is pressed for time in the clinic. We may not have time to go over the details, but [the information] can help with compliance and staying healthier."

"You have better compliance when you have better understanding and buy in from patients . . ."

"If you understand why we're concerned, you're more likely to be concerned."

These discussions were interesting contrasts to the staff's strategies on educating their patients, usually focusing on the instructions to stay healthy. Many of the materials found in waiting areas or delivered to the patients were created by the local staff or other physicians and nurses that work with sickle cell patients.

This discrepancy lead to discussions about staff training, specifically in educating patients. Most medical training is centered about the human body and medical care. None of the questioned staff members had ever received formal education training, as this not routinely part of their extensive medical training. When asked how they learned to teach patients, most staff described picking up strategies from their mentors and co-workers.

Based on staff and patient interviews and a review of the available materials, we found that very little information is directed towards the children, especially at a younger age. When one patient was asked when he first learned about sickle cell he said "Never?" and went on to explain that he's always had it, and it was just part of his life knowing how it impacted his behavior. Since this is a disease diagnosed at birth much of the instruction is given to the parents early on. The transition of the information to the child is specific to every physician and family; there is no formal process. When the staff were asked how they begin to direct information to the patient rather than the parents they all explained that they just start talking and distributing materials to the child rather than the parent. There is no shift if types of materials used.

7. IMPLICATIONS FOR WAITING AREA DESIGN

Some key implications from our observations and interviews are discussed below.

DI1.Collaborative There is a requirement that all patients under the age of 18 attend appointments with an adult. Yet, with an average family group size over two, it implies that many patients are attending their appointments with additional family members such as second parents, siblings, or grandparents. This presents an opportunity for collaboration between and within patient groups who share an interest and potential motivation to learn. Moreover, our observations revealed that people in waiting areas frequently interact with one another as they wait. This could provide an opportunity for knowledge exchange and supporting discussions between children and adults.

DI2.Engaging Typical health education materials are neglected by patients and families, nor are they targeted at younger audiences; for our research it is important that our design engages patient groups, especially children. The primary goal of this project is not just to attract people as they wait for appointments but, more importantly, to help them to understand relevant health issues. Ideally education materials will keep people's attention and provide opportunities for discussion.

DI3.Reusability In many cases, patients visit the same clinic repeatedly throughout their lives for routine check-ups. In the sickle cell community repeated visits are very common. Since these patients will be waiting frequently it is important that the material provide multiple opportunities for exploration over the course of months and years. The materials need to draw patients in to explore even after they have been used in multiple prior visits. The design should appeal to audiences of different ages and allow for a variety of different interaction patterns.

DI4.Mobile Devices Another potential aspect of design comes from the prominence of mobile devices. The majority of SCD patients and families spend most of their waiting time on mobile devices; a mode that is common and easily used to create educational experiences and opportunities for local community building. Having an experience that can travel with them as they continue to their appointment or leave the clinic provides additional opportunities for learning and conversation with physicians and staff, even other patients. Mobile devices also support patients in clinics where waiting does not occur in the main area. In the Midwest clinic, for example, the patients spend hours in the exam room waiting, but only a short period in the main area.

DI5.Detailed Biological Explanations While clinic staff have reported that they do not emphasize the biological details of the disease with patients, they do believe that this information would help with medication compliance and good health practices. It is difficult for staff to find the time to go into such detail during appointments, so if we can find a way to share that information at any time it may show some benefit. If the material explains the fundamental concept of the disease, then we might further explain why taking medications or other treatments correct or change those issues to improve health; for example, if we detail cell structure in sickle red blood cells and show its resulting effects on the body's blood flow, we can also detail the effects of medication on that structure and its corrections to the blood flow.

Ideally these explanations will help patients understand why they need to adhere to medical routines and result in better overall health.

8. DESIGN OVERVIEW

8.1 Implementation

We created a Sickle Cell Station consisting of three main features: a mobile application, a tangible blood vessel, and an information poster. These three features were designed to cover the implications listed in the previous section. Here we discuss the development and preliminary analysis of the mobile application and supporting poster.

For our initial iteration we focused on the basic principles underlying sickle cell disease including the difference in hemo-globin and the difference in blood flow with sickle cells. Materials used in this round of testing consisted of a tablet computer app, a physical blood cell model, and the poster. Each part of the design can be used independently, but they also reinforce one another conceptually.

We designed each component to support group interaction and collaboration. The tablet, tangible cells, and poster can all be shared by multiple users at once. In addition, the design anticipates that users will work with multiple components to explore the demonstrated phenomena.

Mobility is a more complex design issue for the station. Since we are trying to educate patients as they wait, we aim to provide an experience that patients will want to take advantage of during their visit to a clinic. For this reason, much of the station is not mobile; creating an experience that can only happen at the clinic and that patients will ideally look forward to. However, given the sporadic nature of some wait sessions (for example, being called to the clinic for vitals) we take advantage of the ubiquity of mobile devices so that patients can do some activities away from the waiting area, perhaps when they leave the clinic, or as they wait in an exam room. A tablet application provides a system that users can take with them, but also can be elaborated on at the local clinic station.

We attempted to make the exhibit engaging by creating an inviting design and demonstrating concepts without excessive amounts of information. We expect this allows users opportunities to notice and question details and encourage further investigation across the different materials at the sickle cell station.

Biological explanations are provided across the design. Hemo-globin and its impact on cell structure are highlighted on all branches of the station textually, physically, and visually. We anticipate that additions to the tablet application will give users an opportunity for deeper exploration as patients and their families become motivated to learn more.

8.1.1 Tangible Cells

We begin the design with the fundamental issue of sickle cell disease – the internal workings of hemoglobin. This is the key element for defining sickle cell disease so we use all three parts of the station to highlight the differences between normal and sickle hemoglobin. Hemoglobin floats freely in normal red blood cells but in sickle cells molecules bind with one another and form stiff chains. We use two tangible red blood cells (one normal and one sickle) made of fabric. The tangible normal cell is stuffed with beans, while the sickle cell is stuffed with beans as well as stiff strings of beads to

replicate the hemoglobin structures of each cell respectively. Both cells are made from the same circle pattern measuring approximately six inches in diameter. However, when the sickle cell circle is filled with stiff rows of beads the shape becomes a longer narrower sickle shape approximately ten inches long; the strategy used to create the tangible cells was intended to replicate the natural process of cell sickling in the body. With only the tangible cells the user can feel the chains of hemoglobin in the sickle cell, while also being able to feel the loose hemoglobin of the normal cell. By itself, the tangible cell allows patients to begin understanding the mechanism behind SCD. These cells highlight biological details in a tangible form and also provide an inviting material to encourage its use.

8.1.2 Cell X-ray

We use a tablet application to generate an augmented reality of the hemoglobin over the tangible cells. This tangible representation is reinforced by the augmented reality view that visually shows both types of hemoglobin in its respective structures. On top of each cell is a tag for the augmented reality software to recognize the three dimensional orientation for image projection. The X-ray mode

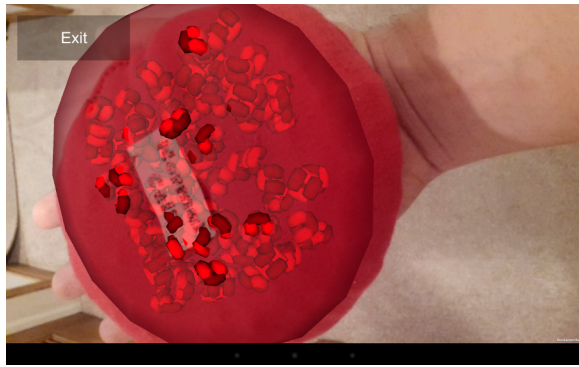


Figure 1: Screenshot of the X-ray augmented reality tablet application, displaying hemoglobin structure overlaying the camera image of the tangible normal red blood cell.



Figure 2: Image of the X-ray app in use from the tablet application, displaying augmented reality image of hemoglobin structure over the tangible sickle cell.

uses the Vuforia augmented reality software development kit (SDK) and its extension to the Unity game engine, allowing easy deployment to both the Android and iOS operating systems. The Vuforia extensions are used to track the physical red blood cell model in 3D space once it is in view of the tablet's camera. This information is then used to render a semi-transparent virtual model of the cell (see Figures 1 & 2). The virtual model shows the interior composition on top of the camera's image, making the physical cell appear transparent when viewed on the tablet. This is akin to an X-ray effect: when a user looks at the physical cell he/she only sees its exterior, but when viewed through the tablet, additional details of the interior of the cell are now visible. This application runs in real-time – as the user pans and tilts the camera, or moves it closer or farther, the virtual model follows and allows the user to explore the cell from multiple angles and zoom levels.

To assist in tracking, Vuforia requires a unique tag to be placed on each physical object. In the case of our cells, we created labels for "Normal" and "Sickle" cells, placed in the center of the object for both tracking purposes as well as cell identification for the user. This provides the app with an estimate of the space in the image that the physical object occupies. The 3D representation of these cells is modeled using Blender, an open source 3D animation software package. This included specifying properties such as the textures, transparencies, colors, and interior contents. These models were then imported into the Unity engine for rendering. In reality, the hemoglobin in normal red blood cells have some freedom of movement. To create a more realistic image, we added C# code to define the rules for movement (rotation, velocity, and containment) of the hemoglobin in the blood cells.

8.1.3 Blood Flow Animation

Another key difference for sickle cell patients is blood flow. The shape of sickle cells causes various issues in the blood stream, primarily obstructions. A video shows a dynamic illustration of normal blood flow and compares it with one of a sickle cell patient.

The blood flow animation visualizes the movement of cells in a small section of the human circulatory system (Fig. 3). It includes several branches of blood vessels, with a cut-away view so that differences between sickle and blood cells are visible. The main concepts for this model are: normal and sickle cells have different shapes, and sickle cells (due to their shape) have more difficulty moving through constricted spaces slowing or blocking the smaller branches of the vessel. The animation was again developed using Blender. 3D models were built for individual blood cells, including both normal and sickle red blood cells, platelets, and white blood cells, as well as the vessel itself. Next, each cell type was defined as a particle system set to flow through the vessel. The sickle cells were configured to have higher resistance in the narrower portions of the vessel. An animation of the normal blood flow and the sickle cell flow were then created and added to the app. Lastly, a simple user interface was assembled to combine the two components in a single unified app. To rapidly prototype the UI, we used MIT App Inventor (<http://appinventor.mit.edu/>) to build an interface that allows for selection of the two components and handling the playing of the blood flow animations.

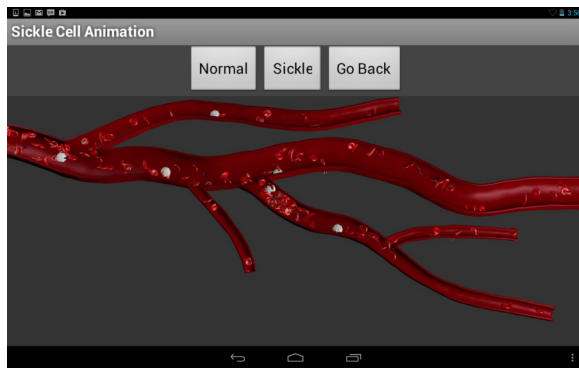


Figure 3: Screenshot of the sickle cell blood flow animation from the tablet application.

8.1.4 Information Poster

The station also includes an information poster measuring six feet by three feet (Figure 4). The poster illustrates a large blood vessel, and defines some basic principles and characteristics of the human circulatory system and issues related to sickle cell disease, including four types of blood cells, the shape and stiffness of sickle cells, and the cause of pain from sickle cells. This information is intended to build the understanding of blood by complementing the tangible and virtual materials and provide a written version of the information we are trying to share. For consistency, the image of the blood vessel is generated from the same Blender model used in the video application discussed in the previous section.

This poster contains text descriptions of sickle cell disease, the effects on the red blood cells and their hemoglobin, and short detail on treatments. It should be noted that this information is not described in either of the tablet applications.

9. USER TESTING

We conducted preliminary user testing on the base functions of the sickle cell station. Primarily we wanted to evaluate how people used the blood flow application, the X-ray application, and the poster.

9.1 Methods

Preliminary testing took place in the Mid-Atlantic clinic waiting area. Two flyers were posted in the waiting area to recruit participants on the day of testing: one outside the main entry door and the other on the back of the information poster in the testing area. The researcher also approached patient groups as they waited. We were not limiting users to sickle cell patients for testing since the material is designed for the general waiting area population.

A child-height table was set up in the back of the large waiting room. We spread the poster facing the rear wall of the room to create a barrier between the main area and the video recorded test area. We created this wall for two reasons: to ensure privacy during testing and consent-required video recording; and to make sure that the patients viewed the poster for the first time during testing. A video recorder was set up on a tripod focused on the table with the tangible cell models and tablet, which also meant it would capture and users' hand interactions. An additional audio recorder

was placed on the table for a secondary audio stream to validate transcriptions.

The groups were taken to the testing area and consented to video and audio recordings of their interactions with the station. They were then told the purpose of the testing and asked to use the material for as long or as little time as they would like. The researcher waited within view of the testing area and recorded notable interactions and conversations during testing. Following participants' use they were asked a few questions about their experience pertaining to usability and understanding of the materials.

9.2 Participants

In total six patient groups were recruited for testing. A patient group is defined as at least one parent and one child age 5-18 years. Each group consisted of a parent-child pair. However, in one instance the mother was called to the desk, so the child mostly participated alone. In another instance, the child was called up and the mother participated for the remaining time. Since these are common scenarios in the user population in the waiting area, we did not remove these sessions from our data set.

The children's ages ranged from 5 to 14 years, with an average of 7.7 years old. Four of the children were male, two were female. Five of the children participated with a female parent or guardian while one attended with a male parent. Three of the groups were African American, one group was Middle Eastern, and two groups were Caucasian.

Of the six groups, one of the children had heard of sickle cell before. Four of the adults had heard of the disease, but did not know much about it; one parent's knowledge is unknown. One mother of a sickle cell patient claimed to be an expert; her son had been to hospitals outside of the city for special programs and the Ronald McDonald program, among others; it should be noted that this mother was participating in the study with a different child.

9.3 Results

At this point in our design process we are interested in participants experience with usability and material engagement.

9.3.1 Usability

The groups had positive feedback about the station, saying the applications and poster were "cool" and they had "never seen anything like this". Every group managed to use both tablet applications independently, and only one technical error was uncovered during testing, discussed in detail later in this section. The tangible cells were used by multiple groups to feel the difference between the cells; one in a parents' explanation of why sickle cells get stuck. Three of the groups read some of the poster together, and compared the applications to the informative text. At least two groups referred to the images for identification and definitions of video details.

However, some groups had problems understanding the flow of the station as a whole. Half of the groups appeared to read the poster; this was determined by reading aloud or looking at the poster for more than a few seconds. As they approached the exhibit four of the groups immediately picked up the tablet before looking at the poster. However, the design of the station assumes that the information on the poster has been read prior. This was confusing for



Sickle Cell Disease

is a disorder in the blood that makes red blood cells become shaped like sickles instead of doughnuts

Blood

is a fluid that delivers necessary nutrients and oxygen to the cells in the body through blood vessels. It is made of cells that float in a thick liquid called plasma. Plasma is mostly water.

Why are sickle cells sickle shaped?

Some people inherit a different type of hemoglobin from both parents. This special hemoglobin forms long strands and causes the red blood cells to stretch into a sickle shape.

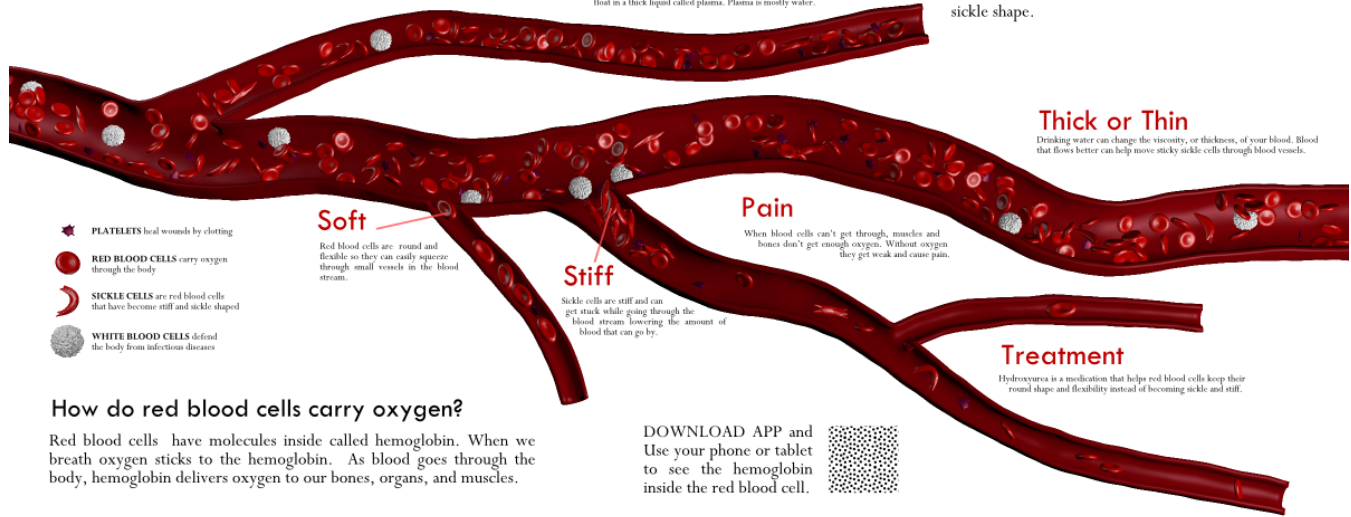


Figure 4: Informative poster.

many users as they attempted to use the X-ray application wondered what the “popcorns” in the cells were.

Holding the tablet computer camera steady above the AR tag also proved difficult for some users. One had trouble figuring out how to point the camera at the cells, even after given instructions; the camera would not focus on the tag resulting in no change to the application image.

One unexpected issue was discovered when one group used the tablet sitting down. Typically the application has been used while standing above a table – placing the tablet about ten inches away from the screen, and allowing the entire cell and its interior features to be visible. When the group used it while seated the tablet was approximately three inches above the cell, displaying a zoomed-in version of the hemoglobin to be displayed. While functional, this viewing distance focuses closely on the hemoglobin, but does not show the bigger picture of the cell, and makes the comparison of the hemoglobin structure less obvious. The mother in this group also pointed this out as a difficulty in getting the camera to focus on the label at such a close distance. The group never figured out to hold the tablet at a further distance during their testing, but still had meaningful conversation about the differences between the cells.

The tags on the tangible cells are written in QR type font for recognition; this makes it a bit difficult for the human eye to read. One mother asked her daughter to read it, but she couldn't make out the words. One young child pointed the tablet X-ray app at the poster after viewing the cells, implying that he expected a similar augmented reality of the blood vessel image, demonstrating his understanding of the tablet for augmented reality application. Unfortunately, this is a feature we designed the video application for in future iterations, but have yet to implement.

Otherwise, there were few technical issues with the usability of the systems. The design of the interfaces are attractive

and interesting to the users, but the tasks are not clear and require additional instruction or a design with clearer use implications.

9.3.2 Engagement

The participants used the material for an average of 6.9 minutes (SD=0.12), with only one group using it for less than five minutes, and the longest lasting nearly eleven minutes.

Our first measure of engagement looked at the amount of discussion happening within groups. Four of the groups that worked in pairs had conversations about the material. We define these conversations as direct back-and-forth questioning or clarification between the parent and child.

Almost every user group alternated between the two tangible cells, the two videos, and the augmented reality feature (X-ray) comparing as they discussed the differences between them. For example, while using the X-ray application a mother asked her child “See the difference? Between the normal and the sickle cell one?...” as the child moved the camera from the sickle cell to the normal cell and back again. “One is jumbled up together, and this one is spread apart and moving” the child responded as they continued to look between the two. Similar instances occurred repeatedly with the video application, observing the blood clot caused by the sickle cells. “Its like they're trapped. Its like there's a door or something” pointing at the sickle cell video after having gone back and forth between the two. One girl held the tangible sickle cell and said “this one looks like a banana.” The daughter went on to point out the stiff thread of beads in the sickle cell asking “Wait. What's this?” The mom explains, “That makes it have the [sickle] shape”. The daughter then picks up the normal cell and says “this doesn't have it.” In all three design aspects with comparable conditions the users noted and discussed differences.

We also used cross-references between the materials to measure engagement. That is, any time that one of the three parts of the station (tangible cells, virtual models, or poster) are used to support another; for example, if the patient is reading the poster and refers to the tangible cells to emphasize hemoglobin structure. We found cross-referencing to be common among the four families working in pairs. One mother read through the first part of the poster with her daughter asking her to read aloud specific parts. The mother then held the tangible normal cell and asked her child “this is like the blood you have; it’s shaped like this. You can see it in the drawing... Do you see any that are shaped like this [sickle cell]?” The daughter then walked to the poster and pointed out several of the sickle cells. In another group, while watching the sickle video, one child asks “why are they getting stuck?” and the parent responds, picking up the tangible cell by the point on top “well these sickle cells are stiffer”. They then switched to the normal cell video and continue their discussion comparing the normal cells to marbles in a tube.

Although the material highlights sickle cell disease, we were pleased to see other patients make the information relevant for themselves. Both the video and poster started conversations within groups that seemed relevant to the child, even if they didn’t suffer from SCD. One example, a mother called her son over “...that’s a vein filled with blood cells”. The boy followed with “like my blood cells?... that [shows] my blood pressure.” In another instance, a father pointed out all the features that were relevant to his son who was currently undergoing chemotherapy, “See.. those are the white blood cells - the ones you’re low on from the chemo.” Many foundational concepts relating to the human body can be described using the same materials.

The expert mother said she had never been shown the inside of the cells before, elaborating that “There’s a lot of information out there [about sickle cell disease]. But you have to go digging for it yourself. It’s a lot footwork...” She had previously taken her son across to a neighboring city just to see a hospital exhibit on Sickle Cell. She continued to stress her enthusiasm for an exhibit so convenient for patients, especially using non-printed materials.

When asked about the cell structures in the follow up interview, one child described the hemoglobin as “all jumbled up... I thought it looked a lot like popcorn so I just kept thinking of that. These popcorns [in the sickle cell] are stuck together, like.. ‘I can’t let you go!’” Although this patient did not identify the hemoglobin by name, she showed an understanding of the basic cell structure which is the design’s primary goal.

We found the conversations among participant groups to show an understanding of the content, and, moreover, often created meaningful ties to their own health care. Many collaborative conversations and inquiries were initiated from the materials, and users bridged highlights from each material to others to better understand or describe concepts of cell structure and blood flow. This evidence suggests the material provides an engaging experience for the users.

10. DISCUSSION

Although technology has become an everyday part of health care at home and in hospitals, the focus is almost exclusively relegated to the management of records or health regimens. Chronic diseases that begin at birth pose an interest-

ing problem for patients since there is no initial lesson; it’s just a part of who they are. Our initial interviews suggest that current materials need reworking, especially if they intend to be used by children. Most information is either shared orally by a physician or given in writing using language geared to an adult audience; both are strategies that require parental involvement and may not be most engaging for children. In addition, the level of involvement of parents varies from family to family, again suggesting that children can benefit from materials that are more engaging and age appropriate to support direct and independent education if parental support is less available.

Our observations suggest that waiting areas are valuable settings for patient and family learning experiences. SCD patients and their families spend an average of 13 to 30 minutes in waiting areas before their appointments; some of this time could be spent learning about SCD in an engaging and interactive way. Family support in these environments is also noteworthy. Many families come together with the patients for various reasons, opening the possibility for collaborative learning experiences, much like those experiences shared by families in interactive museum exhibits. Physician interviews highlight expectations of knowledge sharing in the family, though our interviews suggest that this may not be a realistic expectation in all cases. The preliminary part of their time at the clinic provides an occasion to be free of other obligations and focus on working with their child to learn about relevant health issues.

Although we cannot draw any conclusions with such a small sample size, the results are promising for the design and purpose of our research. Based on the user testing we will reiterate our designs to include more information and instruction directly in the tablet applications. The material seemed engaging for our participant groups with relatively lengthy use times and meaningful conversation. The combination of materials allowed users to compare across different media and types of experiences, bridging the knowledge highlighted in each. Some patients even took the opportunity to relate the material to more personal situations. We hope this work will benefit not only the population of children with sickle cell and their support networks, but also become transferrable to other disease populations that face many of the same practices and issues for their own waiting area education designs.

We also hope that the design of the materials will help patients to understand the importance and purpose of medications and good health habits.

11. FUTURE WORK

This project will continue to explore options for SCD providers to take advantage of the unique qualities of waiting areas, such as time, family support, and an abundance of mobile devices to create interesting and engaging tools for education and even health management. We plan to collect additional interviews directed towards patients’ personal experiences with education including how and what information they receive from their doctors, the clinic, family or friends, and personal research. These interviews will also expand on the family relationship to education.

We have developed additional interactive material for the station, including a tangible blood vessel model measuring approximately eight feet long, which demonstrates many of the same characteristics as the blood flow videos. Tangible

white blood cells, red blood cells, platelets, and sickle cells are poured down the vessel replicating blood flow. A series of sensors along the vessel track the amount of oxygen delivered by the blood flow and reflect resulting oxygen levels in muscles using a light system. An in-depth user study is being conducted to evaluate the usability and understanding of the station as a whole and the materials individually. Naturalistic observations are also being collected to test the station's real world applicability in both clinics. During this process we are also conducting pre-test and post-test evaluations to elaborate on the children's and families' knowledge change after use of the material.

Future iterations of the design include improvements to both the app and the tangible blood vessel to demonstrate the effects of hydroxyurea, a common sickle cell medication, and hydration levels. In addition, we plan to continue all previously described testing in the Midwestern clinic to compare with the shorter wait periods and private wait locations.

As mentioned in the discussion, we hope to continue this work to better understand compliance issues with health care, but this is a long term project goal. Though a difficult process, long term follow ups with the help of the staff and medical records should help shed light on any behavior changes, as well as interviews with patients about their personal habits and understandings.

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