Interactive Storytelling Environments: Coping with Cardiac Illness at Boston's Children's Hospital

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ABSTRACT

This paper describes exploration of uses of a computational storytelling environment on the Cardiology Unit of the Children's Hospital in Boston during the summer of 1997. Young cardiac patients ranging from age 7 to 16 used the SAGE environment to tell personal stories and create interactive characters, as a way of coping with cardiac illness, hospitalizations, and invasive medical procedures. This pilot study is part of a larger collaborative effort between Children's Hospital and MERL - A Mitsubishi Electric Research Laboratory to develop a web-based application, the Experience Journal, to assist patients and their families in dealing with serious medical illness. The focus of the paper is on young patients' uses of SAGE, on SAGE's affordances in the context of the hospital, and on design recommendations for the development of future computational play kits. Preliminary analysis of children's stories indicates that children used different modes of interaction—direct, mediated, and differed—depending upon what personae the narrator chooses to take on. These modes seem to vary with the mindset and health condition of the child.

Keywords
Interactive storytelling, authoring environments, cardiology illness, coping strategies, computational play kits, soft interfaces

INTRODUCTION
The work presented here was conducted in the Cardiology Unit of Boston's Children's Hospital with cardiac patients ranging from 7 to 16 years old. Its main purposes were: 1)

to gather stories and pictures to be incorporated in the Experience Journal [1], an intranet site developed at MERL to help patients, hospital professionals, and families to contribute and link narratives related to cardiac illness and medical interventions; 2) to explore the uses and limitations of SAGE [2,], a storytelling construction kit that supports children's creations of their own interactive storytellers and engages them in expressing their feelings in a playful context; and 3) to form design recommendations for future play kits that address emotional needs of young patients and their families, as well as overall design considerations for work with computational tools in hospital environments.

BACKGROUND WORK
Improvements in the management of cardiac disease have enabled children to survive who in the past would have died, however, many of these youngsters continue to experience chronic illness with repeated hospitalizations and opeartions. While existing research addresses the emotional burdens on young patients facing chronic illness [3] and stresses the crucial role of adaptive parent-child relations as a predictor in their well-being, much remains to be done in order to understand the complex relations between life-threatening heart diseases and psychological outcomes [4].

Many interventions have been developed at Children's Hospital to address the needs of patients and their families (e.g. pre-admission hospital preparatory programs, individual physician meetings, books for different ages, psychiatric consulting, etc.). The cornerstone of these

interventions has been to provide children and their parents with important education regarding their illness while allowing their expression of negative emotions. We wanted to explore ways in which the affected patients and their families could develop and maintain a significant role in their own recovery process. Discussion of relevant literature and existing software, on-site hospital observations, and interviews with patients, families, and medical professionals have allowed us to identify a few areas where current interventions could be augmented. Two of these areas will be addressed here:

- The need to provide a forum where families and children can exchange experiences and learn from one another.

- The need to encourage young patients to express and share their feelings through story telling and other forms of symbolic enactment [5].

Narrative or "the story a person tells about her life" can be a helpful therapeutic tool in that it provides a means of dealing with fears and fantasies. For example, myths [6] show us how to live a meaningful life and fairy tales [7] help us develop our inner resources in order to cope with issues in growing up. Research has been done in using narrative with young patients to treat traumatic experiences [8, 9, 10]. Stories serve not only emotional and social functions, but also a cognitive one. Narratives allow us to understand past experiences and organize them in terms of future ones [11].

Work has been done to create interactive storytelling tools that explore: personal family narratives [12], theatrical approaches to human-computer interaction [13], traditional literary problems such as point of view and suspension of disbelief [14], emotionally believable agent-based systems [15], and emergent, dynamic, adaptive story creation [16]. However there have been few attempts to use computational narrative environments for therapeutic purposes.

DESCRIPTION OF THE SAGE ENVIRONMENT

SAGE (Storytelling Agent Generation Environment) is a construction kit that supports children's creation of their own wise storytellers to play with. This environment was developed at the MIT Media Laboratory to address the need for technological environments designed to encourage children's exploration of their inner worlds through the use of personal storytelling [2, 2A].

SAGE was conceived to help children "play out" what is happening in their lives by telling and listening to stories. In order to encourage children's emotional engagement, the assistant of the sage storytellers is embodied in an interactive stuffed animal — a *soft interface*. With SAGE, children become the designers as well as users of their creations. Thus, SAGE supports two modes of interaction. In the first mode, children share their personal stories with a wise sage, and its rabbit assistant, who "listen" and then offer a relevant tale in response. In the second mode, children can add to the collection of wise sages by

designing their own storyteller for themselves and others to interact with.

In order to support children in creating their own characters, a visual programming language was developed to design and program: (1) the scripts that are used by the storyteller, (2) the conversational structure or flow of the interaction, (3) the body behaviors of the interactive toy, which behaves as the pet assistant of the storyteller, and (4) the database of tales that are offered in response by the character. SAGE also has multimedia capabilities allowing children to record their own stories and to draw their own characters.

Development of SAGE was guided by the educational philosophy of constructionism [17, 18], according to which people learn best when engaged in creating some tangible object that they can reflect upon and share with others. In light of this approach, SAGE focuses on creating stories and storytellers as "evocative objects" [19] that invite reflection about the child's inner world.

SAGE seeks cognitive and emotional engagement. Hence, the decision to embed the assistant of the sage storytellers in a programmable interactive stuffed animal — a soft interface [21] (see figure 1). Winnicott [20] introduced the term "transitional object" to refer to the first "not-me" object perceived by infants to give warmth, have texture, or move about "as if" endowed with a life of its own — while remaining resilient and responsive. Quintessential examples are the blanket, stuffed doll or teddy bear that many young children like to carry around. In SAGE the rabbit assistant plays the role of a transitional object.

The stuffed animal is capable of some of the types of nonverbal behaviors that humans use to indicate engagement and which are commonly found in conversational narratives between people [22]. In interaction mode, children can watch the stuffed rabbit move as they converse with it. In design mode, children can decide on the toy's communicative behaviors as well as the different personalities it might have.

Figure 1: Interactive programmable stuffed rabbit

Previous work showed that children engaged readily with SAGE [2, 21]. Children created storytellers as projections of fears, feelings, interests, and role-models. Their experiences were supported by an iterative design process that enabled children to *decenter* [23] and *debug* their characters after observing other people's interactions with them.

Our current effort aims to observe how patients with serious cardiac illness might appropriate the tool. Erich Lindemann, former Chief of Psychiatry at Massachusetts General Hospital, describes such patients as "young people who suddenly have become quite a bit older; they are facing possible death, or serious limitations in their lives; and they will naturally stop and think about life, rather than just live it from day to day" [24]. We wanted to offer SAGE to young patients in life-threatening situations as a means for exploring issues that worry them.

SETTING THE STAGE AT THE HOSPITAL

We hoped that eventually a culture would develop around the SAGE technology involving nurses, doctors, parents, and patients. We also saw possibilities for adapting SAGE to the Experience Journal and future efforts to develop software play kits. With these ideas in mind, we agreed on a work procedure that would not interfere with medical routines and adjusted the technology to fit the needs of the hospital setting. Preparations were guided by DeMaso and Gonzalez-Heydrich (psychiatrists), Donegan (child life specialist), and Lualdi (social worker). We mounted the computer and rabbit onto a wheeled cart so the setup would

be mobile, safe, and properly wired. Later, we conducted sessions with SAGE at each child's bedside.

To engage the young patients, we created a character who could tell stories relevant to the medical environment. As a first example, we made "Mrs. Needle". This cartoon-type character allows for symbolic enactment of fears children have of needles. She uses humor as a way to break the ice and engage children in an interaction. Later, different children created new characters, such as "Sadly Alone" and "Mr. Tape", and hospital professionals built their own, such as "Mr. Squeeze".

SESSIONS WITH SAGE

We wanted to deepen our understandings of how young cardiac patients might work with SAGE and how SAGE could fit into a very different environment from the one it was conceived for originally. We worked with eight children ranging from 7 to 16. We explained the project to all children and their parents. Written consent was obtained from the parents to use their children's contributions.

Here we describe children's uses of SAGE and propose a framework for interpreting their stories. (The children's names have been changed in order to ensure privacy.) We then discuss SAGE's affordances for the hospital environment and make design recommendations for evolving SAGE, the Experience Journal, and play kits that may be developed in the future.

Some stories

Lisa (16) created a character (herself) called "Sadly Alone." The character asks the user, "Are you feeling sad?" and then tells a story. Lisa worked on her story with a close family member. Lisa was gravely ill when working with SAGE.

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My name is Lisa, and I have a problem.
I'm 16 years old and I have a real bad
heart problem and I am getting ready to
have a heart transplant really soon but
the hardest thing is my mother [is very
sick] And I have a little brother, so
it's so hard to leave them alone   so I
just stay strong and do what I have to
do  and if you ever have this kind of
problem just stay strong for your family
and think of me. (*) Lisa *
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Samuel (13) is an outpatient who visits the hospital regularly in order to receive treatments. He wrote three stories and then put them together under the same title.

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The heart transplant dictionary
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At first I felt very sick and I had to
go into the Emergency room. First I had
an IV which I never had before which I
was pretty scared about and then I had a
blood test on my arm and I never had one
of those either which I was very scared
about too but the IV was much scarier
because I didn't know how much it was
going to hurt. And another scary part
was a lot of different doctors coming in
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all the time and that made me nervous because it made me think that there was something very wrong with me [...] but then I got better and I got to go home and I thought that everything will be OK but then I got sick again and I had to go back to the hospital and then they realized that I had to have a heart transplant.

After my heart transplant I was very sick because my body was rejecting my heart and it made me feel very sick and I had to go in for medicine and get biopsies twice a week where they go through a vein in your neck with a needle and they thread a catheter through and then they scrape a little piece of the heart tissue to see if you have any rejection. Rejection is when your white blood cells do not recognize your heart and think it is some bad virus or disease because it is not your original heart and your white blood cells try to attack your heart. So I kept having rejection [...] so they sent me to [another hospital] to go on a experimental drug [...] and felt better and the new drug is working very well and now I have no heart rejection at all [...]

The following examples are from saved logs of interactions that patients had with different characters, some already existing and others created by the children. Interaction between CHILD and SAGE happens through the keyboard: typing input and text-to-speech or recorded output.

This is a log of an interaction between Damian (16) and the rabbit, best friend of "Mrs. Needle."

SAGE: Hi, what is your name?
CHILD: Damian
SAGE: Welcome, Damian. I am Bunny, the best friend of Mrs. Needle. She hides in the computer because she is a little shy. She thinks that all the kids hate her. So she asked me to talk on her behalf. Is that OK with you?
CHILD: yes
SAGE: Wonderful, wonderful, Damian! Mrs. Needle is worried because kids scream when they see her. But, have you met Mrs. Needle before?
CHILD: I guess yes
SAGE: Well, Mrs. Needle is my best friend and she hides in the computer. Tell me, Damian, how old are you?
CHILD: 16
SAGE: Wauh, Damian, you are older than me. I wonder if you are you scared of needles as I am ? I hate them, all except my friend Mrs. Needle. What about you?

CHILD: They are all right
SAGE: As I was telling you, Damian, I am Mrs. Needle's best friend and she asked me to find out why children hate her so much. She thinks that it is because she stings, but she is not sure. What do you think?
CHILD: yes   no kid is excited to get any needles
SAGE: I see Damian ... what else can you tell me about this?
CHILD: the kids are afraid of it because it hurts and they don't like it to hurt and I guess that is it
SAGE: Well, Damian, let me see if I understand. I am sure that Mrs. Needle is very happy to hear what you have to say. Yes no kid is excited to get any needles the kids am afraid of it because it hurts and they don't like it to hurt and you guess that is it. Am I right?
CHILD: yes
SAGE: Guess what, Damian? Mrs. Needle has a story for you. She is shy but she loves to tell stories. She always says that they have power...Listen to her...
SAGE: They built me to sting, but that is not all I do. If you were a flower I could water you without hurting you. But you are not, and I am not a water pot. My nose is like a hose or like a straw and my belly has goodies than can help you to heal. When my belly is empty, the goodies are yours and you can feel better. But sometimes it is the other way around. My belly starts completely empty, and then it becomes full with your goodies. You can think of me as a someone that only stings, but I also do good. The problem is that this is not always immediately obvious.
SAGE: I loved Mrs. Needle's story, but how about you? Does it somehow relate to what you told me before, Damian?
CHILD: yes it does
SAGE: I see, Damian, please explain me the connection. I don't get it.
CHILD: the children don't realize that the stuff can help them, the medicine
SAGE: I see, Damian, you got the power of the story. I am sure my friend Mrs. Needle will be very happy. I wish that you will always have the courage to keep telling and listening to stories. I hope to see you soon....Bye !

After playing with "Mrs. Needle", Damian decided to create his own character called "Mr. Tape." He created the conversational structure[1], the scripts that "Mr. Tape" says,

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[1] A diagram of the conversational structure is displayed in a window area where children can design the flow of the

and also the stories that he tells. After, he interacted with the character and invited other people in the Cardiac Unit to play with him. This is a saved log of Damian's interaction.

SAGE: Hi my name is Mr. Tape. What is yours?
CHILD: Damian
SAGE: Well hello, Damian, my name is Mr. Tape. I am very sticky, as you probably may know, a lot of children don't like tape because when you have to take it off it hurts. Some kids like me to put me anywhere, like the face, hands, just for fun. Do you like tape?
CHILD: no
SAGE: I am sorry, why don't you like me. Does it hurt you?
CHILD: sometimes, yes
SAGE: Well, I am good for taping things up that are broken and I come in different kinds. I try to do the best I can with making things back to normal. So, Damian, how old are you ?
CHILD: 16
SAGE: You are lucky to be able to live that long. My life expectancy is only two to three years. Some people use me up fast and sometimes I am forgotten in the junk drawer. I get pretty lonely in there. Would you like to hear my story?
CHILD: yes
SAGE: When I am used as medical tape I am the number 1 user for nurses and doctors. I go on IVs and wrap things up. I am good to write on for the nurses to put on IV medication. You can use me just about everything in the hospital but I am not very sticky for heavier objects. I could be colored on and used for decorations for kids that are very bored. Some people just throw me around and drop me which hurts my feelings, I can't pick them up and drop them, but I thank them for using me as their number one choice. Well it was nice talking to you, maybe you will talk to me again and listen to my story. Bye

Interpretative framework

As a means of understanding the coherence in children's interactions with SAGE, we drafted an interpretative framework that groups the creations (stories and storytellers) into three categories according to narrative function. These modes correspond to ways of using SAGE. We call them "direct," "mediated," and "differed." We used some classic questions from literary studies to guide our reading: "Who is saying what to whom?" and "What persona does the narrator choose to take on?". Answering these questions led us to focus on interesting characteristics

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conversation between the storyteller (computer or toy) and subsequent users [2, 21].

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of the children's creations, such as: the role of the child as a designer (as expressed through the chosen narrative voice), the audience for whom the message (story or storyteller) is intended, and the persona used in the narrative. These characteristics seem to vary with the mindset and health condition of the child.

Some of the children employed the **direct mode**, using the first-person voice and telling stories from personal experience or creating storytellers who are clear representations of themselves. The narrator chooses to behave as an author or spokesperson and sends a message to an audience which is the world. Within this mode we identified two different approaches, which we call "expressive" and "informational." In the expressive approach, children who need or want to tell their own personal life stories open up to others about their inner feelings. In the informational approach, children give factual accounts of their illnesses and medical interventions. For example, Lisa's approach was expressive; she called her storyteller "Sadly alone" and told a very personal and sad story. Samuel used SAGE in a strictly informational way. He called his story "The heart transplant dictionary" and frequently used medical names and facts. Both children had serious health problems. However, by the time he worked with SAGE, Samuel had already overcome the worst of his illness and was an outpatient visiting the hospital periodically, while Lisa was an inpatient in very serious condition.

Some of the children employed the **mediated mode**, using SAGE to express their feelings indirectly. They may choose to interact with an already existing character who does not ask direct personal questions, or to add stories to this character's database. Children may behave as actors or performers and may use the second-person voice in their stories. The children we worked with who adopted this mode were sick but their condition was not, at the time, life-threatening. They were willing to enter into a fantasy world that allowed them to play with different aspects of their illness, without approaching the issues directly.

Some of the children employed the **differed mode**, using SAGE to its maximum potential by situating themselves in the role of a playwright or choreographer of the interaction. They created a character who may have represented themselves in a symbolic way. The audience was the whole world and the children were conscious of how audiences might react to their storytellers. The children we worked with who adopted this mode were about to go home and often chose to give a humorous profile to their characters.

Ong [25] quotes Henry James in saying that "an author makes his reader very much as he makes his character." This describes what children did using SAGE. They made characters as well as stories, but they also made their own imagined audiences. For example, Damian was very concerned, during the creation of Mr. Tape, about what "the other kids" would think while playing with the character. He was worried that they would get afraid of real tape or get ideas about things that might not really happen to them.

He would carefully edit his story and dialogs — not from a literary perspective, but from an awareness of the implications and effects that his character might engender in the recipient of the message. In this context, the digital domain can offer more than printed media. Although there is a long literary tradition, as shown by Ong, in fictionalizing audience, interactive media offer the possibility, after one has created a character (and audience), to try it out. As previous work with SAGE suggested [2], the fact of actually trying out the character with the audience, in an iterative design process, helps children *decenter*, put themselves in someone else's place, and get a little closer to the audience.

SAGE'S AFFORDANCES

A few features would need further consideration if the tool were to be developed for use in hospital environments. Here we are especially concerned with young children as users.

- **Support different styles of storytelling**: The children were able to use SAGE in many different ways. They moved with ease between modalities (draw the character, record stories, write stories, create conversations, create stories, interact with the characters, have other people interact with the characters). Children need to be able to choose from a set of computer-based storytelling experiences based on the desired level of personal engagement (from personal stories to fictional stories), as well as on readiness for self-reflection.

- **The importance of voice**: Children generally liked to hear their stories read by the different text-to-speech voices in the computer. Moreso than in previous work with SAGE, young patients in the hospital enjoyed recording the stories in their own voice. Children engaged in the direct mode wanted human voices, while children engaged in the differed mode tended to prefer "funny computer voices." The recording and replay of a child's own voice needs to be better integrated in future versions of SAGE.

- **Software limitations**: The conversational structure of the tool, while important, is too complex for the current use. In order to create a conversational structure, the child needs to know some basic programming, which may require a lengthy learning curve. In the hospital, time for play is unpredictable, so it is impossible to plan a session in which a child would have some time to learn the tool and some time to actually use it in a meaningful way. To solve this problem without taking the possibility for children to design their own storyteller dialogs, we created a conversational template that children could easily change without worrying about the underlying programming.

- **A steep learning curve**: At the moment, SAGE's interface is not intuitive. It requires a knowledgeable person to first work with the children and show them what they can do and how. At the hospital, is not easy

to establish times for learning a new tool. However, what we saw at first as a problem — the need for a human mediator as part of the interface — turned out to be a positive aspect of the interactions.

- **Hardware limitations**: SAGE's big computer and rabbit (with its delicate devices that must be plugged in at all times) proved too cumbersome to be easily moved around the unit to different patients' rooms. The tool setup required for each session consumed part of the time available for working with the children.

In summary, while SAGE enabled children to express emotions in different ways, it is still a prototype that requires future work on both the hardware and software.

LESSONS ABOUT THE HOSPITAL SETTING

In this section, we address issues affecting the use of technological / educational tools in hospital settings.

- **Researchers' emotional shock**: Interdisciplinary teams are needed in order to produce computational multimedia environments. Team members necessarily have different backgrounds and skills, and in our case varying exposure to severely ill children. Adjusting to the grave realities of some of the children's' situations required support from all involved.

- **Scheduling complexities**: So many interdependent procedures occur during a hospital stay that it is hard to find or guarantee time for an extra activity such as working with a computational tool like SAGE. Sessions can be very short or very long, and often there is no opportunity for follow-up. Visitors and medical professionals may arrive at the bedside at any time, and children may go home earlier than expected.

- **Children as design partners**: The children we worked with often knew a lot about their illnesses and needs. They told us about their situations and decided when or when not to engage in and sustain SAGE activities. We hope to include children, as well as their caregivers, in making decisions about future play kits.

- **Computers in public spaces**: When we were not using the computer it stayed in the unit's playroom, where patients and families spend free time. Most of these people are naive computer users. They inadvertently found ways of messing up the organization of system files, the SAGE application, and children's creations. We didn't want to lock or isolate the computer, since we want to create a culture around the technology. However some sort of protected system is needed — ideally, one that does not require people to remember a password.

RECOMMENDATIONS FOR FUTURE PLAY KITS

Severely ill children have different emotional and physical needs than healthy kids. They often get tired easily and may feel uncomfortable, helpless, or anxious. Some children, especially those in a recovery stage, need to walk, practice good posture, and do breathing exercises. Play kits should help in the physical and emotional recovery processes by

empowering children, entertaining and relaxing them. The technology needs to be secure and flexible enough to allow children who are distracted and sick to play in fantasy worlds. Here we outline some recommendations for future play kits and other computer-based environments, such as our Experience Journal, for use in a hospital setting.

- **Mobility / portability**: In a hospital, ubiquitous computing becomes a must. Technologies must be portable and mobile, perhaps even wearable. This is essential to the success of a long-term project.

- **Mediation of a trained person**: At the hospital, a good computational interface may not suffice on its own. A person may need to guide and often type for patient/users (it is hard to type while wearing an IV). Both the Experience Journal and SAGE require a human gate-keeper to ensure that children will not encounter stressful contents that they may not be prepared to deal with.

- **Leaving traces and being heard**: Technological environments can help sick children to leave their trace and their signature in the world. Play kits are places for them to say "I did this" and for others to recognize and appreciate their creations. This can be very empowering in hospital environments, where children often feel disempowered. It is equally important for them to know that people who are import to them will listen and respond.

- **The potential healing power of narrative**: Although sick children are often provided with entertainment software, it is important to design play kits that allow children to explore their inner worlds. In a hospital environment, work with play kits can complement the work of psychiatrists, psychologists, and child life specialists.

- **Collaborative play**: Play kits can encourage the participation of visiting friends and family members. Through shared creative activity, participants can learn to cope with long stays at the hospital and build trust.

- **Supporting interruptions**: Play kits need to support activity in both small and large chunks of time, and should have an automatic saving function. Such a feature ensures that children's work is safely kept, but also prevents felt "tragedies" when interruptions occur.

- **Flexible input modalities**: Children in the hospital sometimes need to exercise their bodies as well as their minds and emotions. Furthermore, children may have health limitations that impinge on their abilities to use common interface devices such as keyboard-and-mouse. Experiments with multimodal interface technologies, such as pen-based input and speech and gesture recognition, may yield useful combinations for sick children.

ETHICAL QUESTIONS IN THE WORK

The dictionary defines deontology as "the theory or study of moral obligation." It is a word that we do not use very often. However, it is always present when thinking about uses of technology in a real-world environment. Especially in a place like a hospital, where we constantly deal with life and death issues, we need to think about how our interventions affect a situation.

Often, when developing new technologies, we create prototypes and test them in the real world. These prototypes often crash and are not yet ready to be used in a reliable way. This is well known by the first users of the prototype, and if work gets erased or ill-saved, that is part of the "contract." There is always a second chance for the user to re-do his or her work and, in testing situations, there is no major emotional involvement.

However, working with a prototype with children who are sick presents a very different challenge. These users may not have a second chance, either because it is not always sure how long they will stay in the hospital or because they may die. They understand that they are working with a prototype, but nevertheless their stories and contributions are deeply meaningful for them. In many cases, testing the tool is their unique last chance to leave a trace of their existence in the world. Designers and facilitators of the technology need to take extra care in making sure that things done once will remain. The deontological question should always be in mind.

FUTURE WORK

It takes time to create a culture around a technology. We hope to keep the effort going, to ensure a smooth transition until the Experience Journal and other play kits are ready to be used at the hospital. At the present time, we are designing a transition period, the purpose of which it is to provide the hospital community with different options to keep alive the culture around narratives from personal experience that we started with SAGE. For example, Donegan and Lualdi are creating an extensive library of hospital-oriented characters for children to interact with. We are also using "low-tech" avenues to compensate for the lack of mobility / flexibility of our existing prototypes. We created special envelopes that families can take home with them and use in case they do not have Internet connection but still want to contribute to the Experience Journal.

Concurrently, we have started evolving the SAGE environment into a marionette-style play kit, anchored in puppet shows often used in health-care settings. This scenario assumes that the tool has a "low threshold" for kids who do not feel up to working with the computer and the keyboard, and a "high ceiling" for those who want to use all the computer's potential and may want to enter the world of programming.

ACKNOWLEDGMENTS

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