Designing a Mobile Makerspace for Children's Hospital Patients:

Enhancing Patients' Agency and Identity in Learning

By

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To Robert "Bob" Calfee, my mentor who is smiling from above.

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CHAPTER I

INTRODUCTION

This study focuses on the out-of-school learning of preadolescent and adolescent

youth in a rather unusual and unconventional out-of school setting, a children's hospital. I have

been pursuing a new patient learning experience that allows children to change the organization

of their setting in ways that emphasize and enhance their own self-agency in learning. I have

designed mobile Makerspaces, mobile maker environments that provide a variety of physical and

digital materials that children can explore in their hospital rooms. Children are invited to use

these materials and devices to pose and solve personally meaningful problems by deploying an

array of human, material, and environmental resources around them to drive their own learning.

Patients often do not feel in control of what happens to them in the hospital, but this mobile

maker environment encourages hospitalized patients to change the circumstances of being

sequestered in the room. The intent is to provide children at the hospital with creative outlets and

learning opportunities, and also to encourage social interchange with others and improve patient

health care by increasing physical mobility.

In my research I focused on a group of female patients (ages ranging from 8

to 18 years old) who have Cystic Fibrosis (CF). CF is a chronic, life-threatening disease

manifested by generalized dysfunction of the exocrine glands, which produce excessively

viscous mucus secretions. The pancreas and lungs are the main organs involved. Fourteen-year-

old patient Hayley aptly describes CF as, "…a lung disease, basically that means that you have

mucus in your lungs. I describe it as 'nasty snot.' I have to do extra stuff to get it out" (Hayley,

10/2014, Interview). Patients with CF are required to repeatedly spend periods of several days or weeks at the hospital isolated in their rooms undergoing treatment, which are colloquially referred to by both patients and staff as "tune-ups." The purpose of these tune-ups is to boost the patient's lung function via a series of mechanical and chemical treatments. Treatment is mainly palliative, aimed at slowing or preventing some of the secondary effects of the disease, and includes: replacement of pancreatic enzymes and nutritional supplementation, antibiotics, chest physiotherapy, postural drainage and nebulization, and lung transplantation in some cases (Glasscoe, 1997, 2007). During those treatment periods, days go by really slowly for the children. They are at risk for infection from other children with CF or cross-contamination during a stay, so roaming the hospital is simply not an option. Hospitalized children, such as those with CF, also struggle with a number of issues that may impact their learning, including: the interruption of their everyday routines and activities, including school; a diminished sense of agency over their immediate and long-term goals; isolation from their peers; and anxieties about their future. For patients with CF, these issues are faced with a heightened sense of gravity due to the fact that the median survival rate in the United States is only 37.5 years (http://www.nationaljewish.org).

Illness tends to focus patients and families on short-term health crises rather than on preparing for the distant future. But as these patients are youngsters, education and learning are still important, even though these goals are often shunted aside to deal with more pressing health matters. Since patients with chronic illnesses spend a significant amount of time in the hospital, they rely upon hospital school services to provide comprehensive academic support. Unfortunately, hospital school services are not always up to addressing the patient's learning needs due to limited resources in hospital settings and limited support from a patient's local

school district. Every hospital with a school program will face some of the same challenges. For example, every hospital school program struggles with complying with state laws and working with the requirements of school districts. Furthermore, since every class tends to proceed at its own rate through school material, it may be impossible for the hospital school program staff to know what assignments to provide for patients when a district fails to provide lesson plans or assignments. Due to the complications that these challenges present, academic performance and learning are not always perceived as priorities for hospitalized children. With medical care taking center stage, children often lose interest in learning that is typically provided in pre-canned formats from the hospital school program. For this reason, there is an immediate need for a way to immerse patients in more authentic learning activities that stimulate their interest in learning while being hospitalized.

In this research I take a broad view of learning that emphasizes the role of children's personal agency in orchestrating their own learning and in identity formation as a critical long-term consequence. Personal agency and identity are intimately related. Personal agency refers to one's capability to originate and direct actions for given purposes and is influenced by belief in one's effectiveness in performing specific tasks, which is termed self-efficacy (Zimmerman & Cleary, 2006). Identities are important foundations from which people create new activities, new worlds, and new ways of being (Holland, Lachicotte, Skinner, & Cain, 1998). Holland, et al. (1998) describe how identities are shaped within "figured worlds" that are "socially and culturally constructed realms of interpretation in which particular characters and actors are recognized, significance is assigned to certain acts, and particular outcomes are valued over others" (p. 52). Figured worlds are places where people come together to construct joint meanings and activities (Boaeler & Greeno, 2000). As explained by Urietta (2007), "Through

participation in figured worlds, people can reconceptualize who they are, or shift in who they understand themselves to be, as individuals or as members of collectives. Through this figuring, individuals also come to understand their ability to craft their future participation, or agency, in and across figured worlds" (p.120). Within figured worlds, identity is constructed as individuals both act with agency in authoring themselves and are acted upon by social others as they are positioned (Nasir & Cooks, 2009). Simply put, just as one's sense of agency affects identity, so too does identity affect agency, because one's identity includes the mental representation of possible potential actions.

Although identity and self-efficacy are often treated in the literature as personal qualities or accomplishments, they are, in fact, at least in part the products of one's experiences, and therefore, are learned. Learning is the mechanism that creates identity and, in turn, identity and self-efficacy shape and constrain future learning. When learning is broadly construed to include all of the settings that an individual crosses in life, several questions arise that are related to possible interdependencies between settings. For example, what kinds of resources do learners seek out, and how might we conceptualize such processes of self-initiated learning (Barron, 2006)? The view of learning that I am pursuing in this study is a broad one, consistent with the way people make sense out of the experiences they encounter in their everyday lives. In school, curriculum developers and teachers deliver material in packaged sequences, but when people go about learning things as part of their everyday practice, learning takes on a more socially distributed character (Lave & Wenger, 1991; Hutchins, 1995).

Research on learning out of school has been especially useful in driving greater attention to the nature of systems within which learning occurs. As Hutchins (2006) points out, these systems are deeply multimodal and are composed of a complex network of relationships

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among resources. In Hutchins' view, cognitive processes are properly conceived not as residing within individuals, but as distributed across an overarching system of interaction, a system that includes tools, activity systems, spatial organization, established roles, norms and rules, and other people. Cognition resides within and is emergent from the entire system, rather than the person. Therefore, this is a non-psychological (or perhaps a-psychological) account in which the individual is not particularly prominent—the individual is immersed within the system that supports the solution of problems, like docking a ship or flying an airplane.

Lave and Wenger (1991) acknowledge the complexity of learning contexts, but provide an alternative framing in which neither the individual nor the context is portrayed as the primary locus of learning; both are fully present in the theory. Lave and Wenger describe learning as engagement in ongoing social practices that take place within continually evolving contexts. Learning entails becoming a more central participant within such a context. This means assuming the roles and identities that the context affords, while at the same time catalyzing change in the context. Participants and the overarching context continually change, renew, and transform each other.

Consistent with this theoretical foundation, newer research has been exploring a connected learning model that tracks continuities and changes in people's participation as they move across contexts and time (Ito et al., 2013). Work within this new tradition is oriented not only toward describing learning, but also enhancing it, by capitalizing on and enhancing potential connections among settings, especially for non-dominant youth. According to Ito et al., "Connected learning is socially embedded, interest-driven, and oriented toward expanding educational, economic or political opportunity" (p.6). As Ito et al. explain, "It is not simply a

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'technique' for improving individual educational outcomes, but rather seeks to build communities and collective capacities for learning and opportunity" (p. 8).

As I will explain, learning in the hospital shares many of the distributed features of learning in out of school learning settings and also highlights how personal motives, goals, and self-efficacy play a central, rather than a peripheral role in learning. My focus is on enhancing patients' sense of agency and identity, rather than narrowly focusing on their learning of any specific conceptual content. I hope to provoke their sense of curiosity, encourage them to set up and pursue personal goals via invention, and inspire them to feel more agentive in taking charge of their learning process. It would also be valuable if patients began to connect a growing sense of competence with the broad fields of invention and technology. Advances in technologies that are increasingly available have raised two important educational challenges that are secondary considerations in this work: (1) How to keep patients connected to and participating in a rapidly changing world that is technologically advanced; and (2) How to introduce a future horizon in which these patients see themselves as potentially playing a role within the next generation of computer scientists, inventors, and technology specialists (Barron, Martin, & Roberts, 2004). For example, Barron, Martin, & Roberts (2004) argue for the importance of these goals for all students: "...there is a need to prepare all students to capitalize on new technologies and a critical need to increase the diversity of the membership of professions that contribute the most to innovation" (p. 76). The intent, therefore, of my research with CF patients was not to immerse them in a program of workforce development, but, more modestly, to help them enhance and expand their "figured worlds" to include the possibility of a future in which they can use and invent technologies to solve problems, invent, and connect with others.

In this study, I presented eight hospital patients with a mobile Makerspace intended to support their personal efforts in devising and implementing design and invention projects with a range of digital devices. The hospital appears to be an unusually impoverished setting for fostering learning. Yet the patients with whom I worked have collectively spent months of their lives as participants in hospital settings. All of them are balancing the tasks of learning to be CF patients with the task of learning to become young adolescents, who also have lives outside the hospital. My conjecture was that, within the hospital, it might be possible to support children in becoming increasingly inventive and proactive in marshaling resources for their own learning. Accordingly, this study was guided by two research questions:

(1) How do patients recruit and negotiate resources — conceptual, material, and social — to pursue personal goals with the mobile Makerspace?

(2) How do patients both adapt the mobile Makerspace into existing hospital routines and, conversely, coopt it to transform and even disrupt hospital routines, roles, and expectations?

CHAPTER II

COPING WITH A CHRONIC ILLNESS

The term chronic illness refers to disease categories for which there are no cures, and

therefore are ineradicable and usually progressive (Royer, 1998). Chronic diseases differ from

acute diseases in ways that are especially consequential for children's learning. For example, as

explained by Holman & Lorig (1992), "…acute diseases usually result from identifiable, abrupt

and potentially reversible specific events. By contrast, initiating events for most chronic diseases

are obscure. The disease processes appear to emerge over time from protracted interaction

among environment, genetic and behavioral risk factors. Once established, chronic disease may

be further altered by interactions among the disease process and its consequences" (p. 306).

Table 1 enumerates some of the distinctions between chronic and acute diseases.

Table 1

Comparative characteristics of acute and chronic illnesses (Holman & Lorig, 1992)

	Acute disease	Chronic Disease/Illness
Onset	Abrupt	Commonly gradual
Duration	Limited	Lengthy; indefinite
Cause	Usually single cause	Multivariate causation of both disease and illness, changing over time
Diagnosis and prognosis	Commonly accurate	Diagnosis often uncertain; prognosis obscure
Technological intervention	Usually effective (laboratory testing, imaging, medication, surgery)	Commonly indecisive; adverse effects frequent
Outcome	Cure likely with return to normal health	No cure; management over time necessary
Uncertainty	Minimal	Pervasive
Knowledge	Profession knowledgeable; laity inexperienced	Profession and laity partially and reciprocally knowledgeable

Representations of chronic illnesses are influenced by social and personal contexts, including the structure of the medical care system (in this case, the hospital). For children who have a chronic illness, there are many events and influences that make the hospital a potentially stressful place to cope with a chronic illness (Eiser, 1985; Rudolph, Denning, & Weisz, 1995; Schmidt, 1992; Saile & Schmidt, 1990; Smorti & Tani, 1990 as cited in Schmidt, 1997, p. 124.) These include, for example: separation from the mother, the father, and siblings; fantasies and unrealistic anxieties that are not specifically related to hospitals but may be initiated by the strange situation (Smorti & Tani, 1990, in Schmidt, 1997); deprivation of social contact and the inability to pursue age-characteristic social goals (e.g., to find acceptance among peers, to be attractive, to date); threats to independence, privacy, autonomy, and control; pain and other complications of the illness; stressful medical procedures; and fears of disablement and death.

In the next section, I describe a day in the life of a typical CF patient undergoing treatment in the hospital, as portrayed through interviews and journal entries kept by one of my participants, Christy. Although this story was recounted by a particular 18-year-old, it nonetheless serves to highlight what hospital life is like for patients of this age and, more specifically, how isolation in the hospitalization destroys patients' sense of agency, which in turn translates into a loss of self or identity for the patient.

A "Day in my Life" by Christy

Christy begins by describing how Cystic Fibrosis affects her life in general. She reports that she tries to maintain a normal teenage identity to the extent that she can, and even feels that her disease may make her more compassionate in her everyday relationships. Nonetheless, the disease often cuts her off from everyday life, and she is continually reminded that her time may be short. Christy says:

I try to be a normal teenager and hang out with my friends and go to school every day. I'm really smart and I love school, so it's hard for me to miss so much, though I always make great grades. It's hard to do everything I want to do. I'm not involved in many extracurricular activities because I don't have time and when I miss a lot for being sick, it's hard to be a part of something. I'm in art club and graphic design leadership. My daily routine is so tiring. Most of the time I go through the motions, not really paying attention. It's so stressful to constantly be worried about your health, but I try to be upbeat about it. No point in wasting your life being sad. I am more compassionate because I understand what it's like to be unhealthy and alienated from your peers because you're different. In the hospital I put on a brave face and I cut up and laugh, but a lot of the times I'm sad. Sad that I have CF, sad that I'm alone, sad that I see the dates changing and it feels like life is passing me by. I do (almost) everything that's expected of me in here and just go through with my day. It's hard being out of school, and everything I have to do is annoying and tiring, but I do it. Because in the end, if I don't, I'll die. And I don't want to die. So I try to keep myself healthy (Christy, 2/2015, Interview).

As this citation demonstrates, Christy feels that her life is restricted by CF. Medical appointments, home administration of IV antibiotics, and other treatment requirements result in excessive absences from school for children with CF, like Christy. Sometimes, children like Christy anticipate social rejection due to misconceptions among peers regarding illness and its contagiousness (Sexson & Madan-Swain, 1993; Shaw & McCabe, 2007). Peer rejection may also result in increased school absenteeism, which further complicates the problem (Shaw, 2008). Moreover, frequent absences from school and other activities disrupt friendship formations, reduce opportunity for social support, and make children with chronic illness

increasingly vulnerable to other life stressors or secondary illnesses (Shiu, 2001). Charmaz (1991) points out that coping with a chronic illness is not simply a matter of knowing how to deal with illness as an additional complication in life; instead, this kind of illness changes one's life qualitatively: "No longer can people add illness to the structure of their lives; instead they must reconstruct their lives upon illness. Hence, they cannot simply add regimes, rest periods, timeouts, and so forth to work, school, leisure, and family activities. The requirements of illness and health come first and now define their pursuits" (p. 76).

When there is a sufficient change in frequency or severity of symptoms in comparison to her usual or baseline symptoms, Christy is admitted to the hospital for two weeks of treatments or "tune-ups" to boost her lung function. However, Christy dreads those two weeks of treatments, as the isolation of hospitalization adds to her depression. Christy says:

> I do get depressed a lot when I think about my life with CF. Why can't I be normal? Why does no one else in my family have it? Why am I alone? Why does bad stuff always happen to me? It gets me down. In the hospital I get what I call the "hospital blues." I'm lonely and I have almost no control and I'm stuck inside a tiny room with my only interaction being with people who are paid to talk to me. It kind of sucks. You wouldn't believe the boredom in here. You eventually start going crazy (Christy, 2/2015, Interview).

Anxiety and depression appear to be more common in patients with CF than in the general population (Cruz et al. 2009). Treatments can take two to four hours per day, making it difficult to balance the things patients want to do and also how they manage their disease (http://www.cff.org). Christy describes what a typical day at the hospital is like:

Typical day at the hospital. Wake up for morning breathing treatments and taking meds.

Doctor visit first thing every morning to check in. Cefepime started at 6 am, then

Benadryl, Atarax, and Tylenol, Vancomycin started at 7, run over 2 hours, then 500 mL

saline bolus to flush kidneys. Repeat at 2PM and 10PM. Tobramycin at 5PM. After being

hooked up at 10PM, when antibiotics are finished, normal saline run through the night at

low speed. Breathing treatments 4 times a day (albuterol, vest-30 minutes, then

Pulmozyme for first and last treatment). Eat breakfast, take enzymes. Keep occupied with

TV or Internet or stuff from Child Life until lunch, with more enzymes. More activities,

then dinner, with more enzymes. Chatting with nurses and therapists help pass the

time…. especially the witty, sarcastic, funny ones. Then activities until I fall asleep. I

have a hard time sleeping with everything, so it's usually a long night. Once a week I get

PFT's done and my port re-accessed to prevent infection. Sometimes I have to have an

NG tube with Golytely, also. Just depends. Physical therapy a couple times a week,

walking around the pod or in the gym on the 6th floor. Sometimes I have visitors, but

usually I'm by myself (Christy, 2/2015, Interview).

This excerpt provides only a glimpse of what a day looks like for Christy. Table 2 provides a

more detailed timeline, summarized from Christy's journal, of one typical day in her life from

morning (12:15AM) until night (11:45PM).

Table 2

"Day in My Life" (Christy, 2/2015, Journal)

Time	Description
12:15AM	I'm being hooked up to my I.V. pump. I named him Fred ☺ I'm getting Vancomycin. It's a really strong antibiotic. It will run for 2 hours and then normal saline will follow to flush the line.

3:15AM	Nurse Rachel comes in to change fluid bag for normal saline bolus, 500 ml at 150 ml/hour. Boluses are to flush my kidneys to avoid infection or kidney failure.
5:15AM	Rachel comes in to draw blood for morning labs. Afterwards, starts Cefepime, another antibiotic, to run at 150 ml/hour. It will run for 20 minutes, followed by saline flush.
6:10AM	Unhooked from pump, and given Heperine through the port to prevent blood clots and seal the line.
7:10AM	Woken by Dr. Ulbrich, listened to lungs, talked about hypertonic saline, and left at 7:14 to finish rounds.
7:15AM	Nurse Cathy gives me premeds to prevent an allergic reaction to Vancomycin. Benadryl, Tylenol and Atarax. Sets normal saline to run until Vancomycin is given. Checks skin and pulses and leaves at 7:19.
7:30AM	Back to sleep after playing on my phone for a few minutes.
8:06AM	Cathy starts Vancomycin.
8:34AM	Waken by respiratory therapist Matthew. Take 2 puffs of albuterol then start the vest. Takes 30 minutes. Then inhale Pulmozyme through nebulizer.
8:55AM	Doctors interrupt treatment. They listen to my lungs and say I sound good. Cynthia is changing my premeds for Vancomycin. For 1 dose. 25mg Atarax + 500mg instead of 50mg Benadryl, 10mg Atarax, and 500mg Tylenol. If reaction occurs, 50mg IV Benadryl to be given. PFTs on Thursday. Left at 9:02. I'm very upset.
9:19AM	RT Matthew leaves after treatment is finished. Watched Netflix during treatment & talked about stocks and food.
9:35AM	Morning meds- Bactrim (2 pills, antibiotic), Omeprazol, Colace (2 gelcaps), Vitamin D (4 tablets), Chewable CF Vitamins (2 tablets), Fluticasone Nasal Spray (Spray each nostril).
10:31AM	Housekeeping comes to clean room and take out trash.
10:37AM	Ordered breakfast (Bagel, grapes, Sprite, and ice water).
10:46AM	Unhooked from pump and hep-locked.
10:48AM	Vital signs checked.
10:54AM	Weighed.
10:59AM	Debbie from physical therapy is taking me to walk around the pod. Must wear paper gown over clothes, gloves, and mask.
11:30AM	Finished walk. 37 laps in 22 minutes with breaks to chat with nurses.
11:32AM	Taking Creon (enzymes) before I eat to digest my food. Ate all my breakfast.
12:42PM	Another breathing treatment with Matthew. No Pulmozyme this time. Matthew told cow jokes the whole time. Hilarious! Finished at 1:18PM.
1:22PM	Took more Creon to eat a Poptart.
1:58PM	Hooked up to Cefepime.
2:20PM	Tarri from Art Therapy comes to paint and talk. She teaches me a little bit about oil paints. Leaves at 2:45 for meeting.
2:48PM	500ml saline bolus and Colace given.
4:00PM	Student nurse check vitals and pulses. Chatted a bit and answered patient survey. Left at 4:10 after giving premeds.
4:12PM	Respiratory therapist Debrah comes to give me treatment. Albuterol 2 puffs, then vest for 30 minutes. No Pulmozyme. Talked about art.

4:30PM	Vancomycin started.
4:52PM	I.V. Benadryl given over 5 minutes to stop reaction. Flush with normal saline 3 minutes.
5:00PM	Vancomycin restarted. No reaction.
5:25PM	Ordered dinner (Steak, loaded baked potato, vanilla milkshake, grapes).
5:53PM	Food is delivered.
5:55PM	Enzymes taken and eating dinner. Finished at 6:30PM.
6:48PM	Taking a nap.
7:58PM	RT Donna woke me up to do last treatment of the day. Finished at 8:36PM.
8:39PM	Introduced to night shift nurse Rachel, first time ever having her. Pain scale, listened to chest & belly, talked about medicine schedule. Left at 8:45PM.
8:49PM	Vitals taken by care partner Trai. Left at 8:56.
9:10PM	I'm sitting here by myself crying in the dark. I feel so alone and sad. I'm lonely. I haven't had a visitor the whole time I've been here. Everyone who said they would visit made up excuses or just keep putting it off…Is there something wrong with me? I hate being alone. Starting to cough again. I can't even cry without my stupid lungs betraying me…
9:28PM	Dumped a full can of sprite all over my bed and the floor…of course. Everything sucks. Today is horrible.
9:35PM	Trai came in to help clean up my mess and housekeeping is coming to mop the floor. I feel like a nuisance. I think the worst thing about being in the hospital is the loss of independence. You can't even do the simplest tasks for yourself. Hungry? Someone has to get and make your food for you. Thirsty? Gotta ask someone to get you a drink. Room dirty? Housekeeping cleans it. Bored? Someone gets you something. Clothes dirty? Wait till someone can wash them for you. Need meds? Nurse has to get them. Docs have to order it. Can't just take it. Need a shower? Have to ask and wait for an aqua guard. Hooked up during PT? They don't even let you push your own pole. Want to go somewhere? I grab my keys and go. Wanna walk? I take my happy ass outside and walk. I don't like losing my independence.
9:45PM	Unhooked and Hep-locked. Next meds at 10 and 11.
9:52PM	House keeping is here to mop my floors. Maybe I can keep my drink upright this time.
10:15PM	Mom texted. Make a Wish sent the flight itinerary. We go to Hawaii March 16-22. Cheers me up a little.
10:29PM	Colace, Bactrim, Singulair, Vitamin D, omeprazole, CF Vitamins, and hooked up to Cefapime.
11:08PM	Tobramycin started.
11:33PM	Vancomycin premeds taken 50mg P.O. Benadryl 10mg Atarax, 500mg Tylenol.
11:45PM	Still pretty sad. Not crying anymore, just kind of disconnected. Starting to not care. Sorry this is starting to suck. It's been a bad day. Maybe I'll try again tomorrow.

As these journal entries reveal, Christy and other CF patients experience their hospital life as isolating and regimented. When they are hospitalized, patients feel subject to the schedules and whims of interlocking teams of professionals. Charmaz (1991) explains, "The more dependent ill people become upon the health care system, the more likely losses of self accrue. For these people at this point, the medical care system takes on static, monolithic qualities. They depend upon the system for care — perhaps even for their own survival — but the system only provides care in narrow, rigid categories. Autonomy and independence dissolve at this point" (p.263).

Hospital Services to Cope with a Chronic Illness

To address the psychosocial concerns that accompany hospitalization and other health care experiences, like those illustrated in the example of CF patient Christy, most pediatric hospitals offer Child Life services. Using play and self-expression as primary tools, child life interventions attempt to facilitate coping and adjustment with hospital stays. Play and age-appropriate communication may be used to promote optimal development, present information, plan and rehearse useful coping strategies for medical events or procedures, work through feelings about past or impending experiences, and establish therapeutic relationships with children and parents to support family involvement in each child's care, with continuity across the care continuum (Council, C. L., 2006).

Child Life specialists focus primarily on the present, that is, on the time a child spends in the hospital. Hospital school services, on the other hand, work in addition to and alongside a successful Child Life program. Their emphasis is to aid in satisfying the child's (and the parents') need for the possibility of a future outside of the hospital (Oberstein, 2012). "Learning takes on a very different meaning when a child is hospitalized. Going to school in the hospital

can be a link to the past and the future. It reassures a child that his parents, his home, school, and the hospital staff all work together and believe in getting well" (Plank, Caughey, & Lipson, 1959, p.47). For that reason, hospital schools are special in that they serve "to emphasize the healthy part of a child during his/her confinement" (Wilson, 1979 as cited in Weiner, Hoffman, & Rosen, 2009). Unfortunately, academic performance and learning are not always perceived as priorities for hospitalized children. Once a child is deemed eligible for school services in a hospital environment, the amount of time he or she spends with a teacher is varied, is usually inadequate for making sustained progress, and often lacks continuity (Oberstein, 2012). Moreover, a child with chronic illness may lack motivation for academic and school-related activities for a number of reasons. For example, disease symptoms or side effects of treatment regimens can induce fatigue, lethargy, irritability, or other physiological states that reduce motivation. Being disconnected from peers may further cause children to lose interest and motivation for schoolwork (Shaw & McCabe, 2006).

Given the challenges that these particular hospital services face in addressing the psychosocial concerns of patients, I propose a new patient learning experience unlike other services currently provided by the hospital: a mobile Makerspace. The idea of a mobile Makerspace resonates with Schmidt's (1997) suggestion that the hospital may become a potentially compensatory and positive place, by offering opportunities for social experiences with other children and adults, promoting a new identity and providing intellectual stimulation. Fortuitously, in the context of pursuing this study, I also noticed that the mobile Makerspace has the unexpected yet highly beneficial potential to improve patients' physical health (e.g., increased mobility). This provides the opportunity to expand on a more general conception of learning as it bridges the gap between what we call physical therapy and what we call learning. I

employ the term "Maker Therapy" to communicate my interest in motivating patients to be more physically active in their design and making process while at the same time striving to enhance their sense of agency and identity. If one can get children actively engaged and orchestrated in their own learning, there is something about that setting that tells us about the power of how people learn, and about settings in which learning is not simply delivered in pre-canned formats.

CHAPTER III

MOBILE MAKERSPACE DESIGN & IMPLEMENTATION

A Makerspace is a physical location where people gather to share resources and

knowledge, work on projects, network, and build. One key demand of a Makerspace is that it

exists as a physical location where participants have opportunity for hands-on work (Educause,

2013). However, safety concerns and cross contamination issues that arise in a hospital make it

impossible for many children with chronic illnesses to leave their rooms to participate in spaces

like these. For those reasons, I have designed mobile Makerspaces that can be brought into

patients' rooms and left there for use throughout the entire duration of the patient's treatment.

The design of the mobile Makerspace went through three phases of development and

each phase was informed by design-based research methodologies along with empirical study

with users (Figure 1). According to Cobb, Confrey, diSessa, Lehrer, & Schauble (2002), "design

experiments entail both 'engineering' particular forms of learning and systematically studying

those forms of learning within the context defined by the means of supporting them" (p. 9).

Penuel, Fishman, Cheng & Sabelli (2011) highlight four key elements of design based

implementation research (p. 1): (1) focus on persistent problems of practice from multiple

stakeholders' perspectives; (2) commitment to iterative, collaborative design; (3) concern with

developing theory related to both classroom learning and implementation through systematic

inquiry; and (4) a concern with developing capacity for sustaining change in systems. Because

this work takes place in naturalistic contexts and involves the systematic revision and study of

theoretically inspired aspects of the learning environment, this research can offer insights into

why and *how* a particular intervention works (Barab, 2005).

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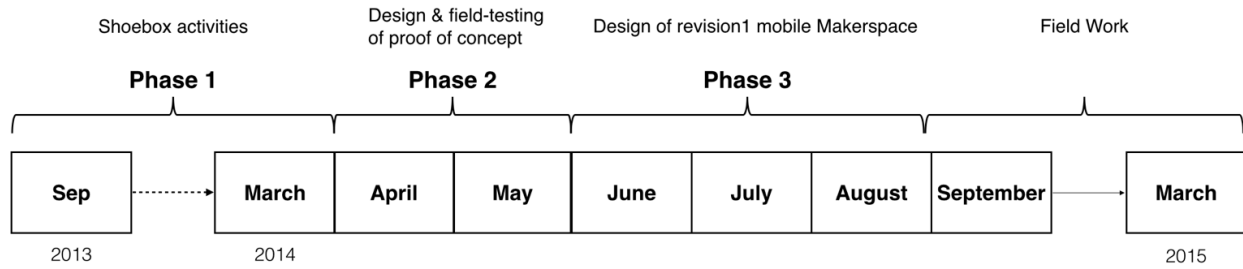
Figure 1. Phases of Design

Phase 1: "Shoebox" Activities

In September 2013 I was introduced to Josh, a bright and aspiring high school senior whose goal was to become an engineer. Unfortunately, Josh had been diagnosed with Leukemia and was undergoing treatment in the children's hospital. To support Josh's engineering aspirations, I provided Josh with a "Mystery Box" that held a variety of digital and physical materials, such as an Arduino microcontroller, LEDs, a string, a plastic cup, an eraser and LEGO™s. I then suggested that Josh use these materials to design and make anything he could imagine. Just overnight, Josh designed and built a night-light for nurses. The purpose of the light was to illuminate a patient's bathroom, thus allowing nurses to determine if any trash needed to be disposed of without turning on a bright light and waking the patient (Figure 2). Like an engineer, Josh saw a problem and came up with a remedy using the materials at hand.
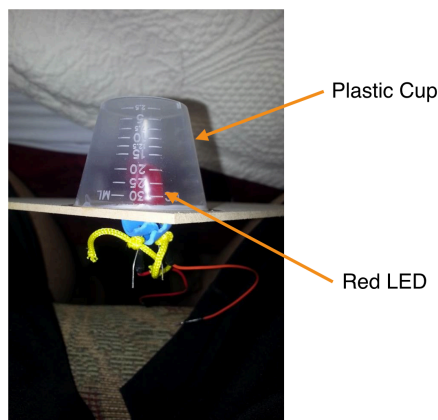
Figure 2. Nurse Night Light

This experience with Josh inspired me to engage with other children at the hospital, using additional tangible learning tools such as littleBits and Squishy Circuits. The results were multiple demonstrations of children enjoying their learning and coming up with creative DIY (Do It Yourself) solutions. I noticed that the children's creations fell into four general categories, including room decorations, privacy-maintaining devices, gadgets that depicted a patient's mood or state of well-being, and contraptions intended to scare or prank adults, especially nurses. Table 3 briefly describes some examples of projects that children made.

Table 3

Categories of children's creations

Category	Problem identified by patients	Solution to problem (Invention)	Description
Decorating patient's room	A patient's room in a hospital is generic, dull, and boring.	Rotating Suncatcher (Figure 3)	While in the hospital, children, families, and loved ones take a lot of time and effort to make the patient's room bright, colorful, and simply more enjoyable. To this effect, 13-year-old patient, Kristina, along with the help of her grandmother, created a rotating sun catcher using littleBits (Bdeir, 2009) and a variety of physical materials found around the hospital. Kristina's grandmother helped to scavenge these physical materials (e.g. crystal, metal string wire, heart-shaped wrapping paper, juice box) from around the hospital. Designing and making the suncatcher allowed Kristina and her grandmother to bond and spend quality time together. It also gave Kristina a sense of pride and peace admiring her creation.
Solving privacy issues	Nurses knocking on patient's doors at night disturbing their sleep.	"Manna's Magic Bell" (Figure 4)	While in the hospital, nurses generally knock on patient's doors, waking up children and disturbing their sleep. In response, 16-year-old patient Lauren created a device that she called "Manna's Magic Bell," that is placed outside the

			patient's door. When the nurse wants to enter the room at night she can press a button on the device, which causes a colorful light to flash inside the patient's room. Parents, who are usually in the room when their child is sleeping at night, would know that someone outside wants to enter. The parent then quietly opens the door for the nurse, preventing the nurse from knocking on the door multiple times.
Depicting mood	Repeated questions asked to patients about their state of health and well-being.	Wearable Mood Necklace (Figure 5)	Some patients get really annoyed when people at the hospital constantly ask them, multiple times a day: "How are you feeling?" and "Are you okay?" Instead of repeatedly replying to those questions, 13-year-old patient Taylor, along with the help of his parents and grandparents, created a wearable "mood necklace" using Squishy circuits (Johnson & Thomas, 2010). Instead of having to reply to those questions, Taylor employed a system of lights to convey how he felt. For example, a green light from his necklace signified that he was in a good mood, and a red light meant that he was not in a good mood.
Pranking nurses	Lack of playful social interaction	Dangerous Snake (Figure 6)	Pranking or scaring nurses is a popular pastime for children in the hospital, partly because it is just fun to scare adults and partly because it may express resistance to being continually controlled by the priorities and schedules of the medical staff and routines. Thirteen-year-old Mandy created a rotating snake that appeared to be coming out of its den ready to strike anyone near its vicinity. She also created a large "Beware of Snake" sign to warn (and provoke) people. Her snake scared a lot of unsuspecting nurses and, more importantly, created a lot of laughter and joy for everyone in the hospital.
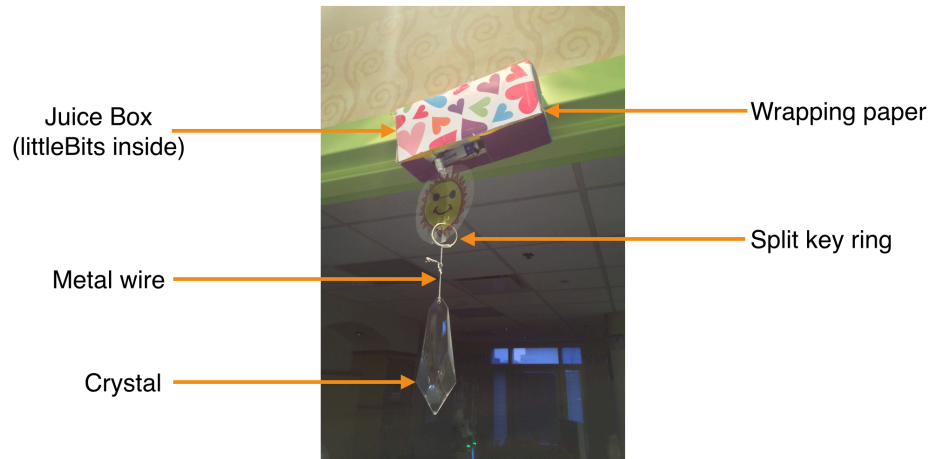
Figure 3. Rotating Suncatcher
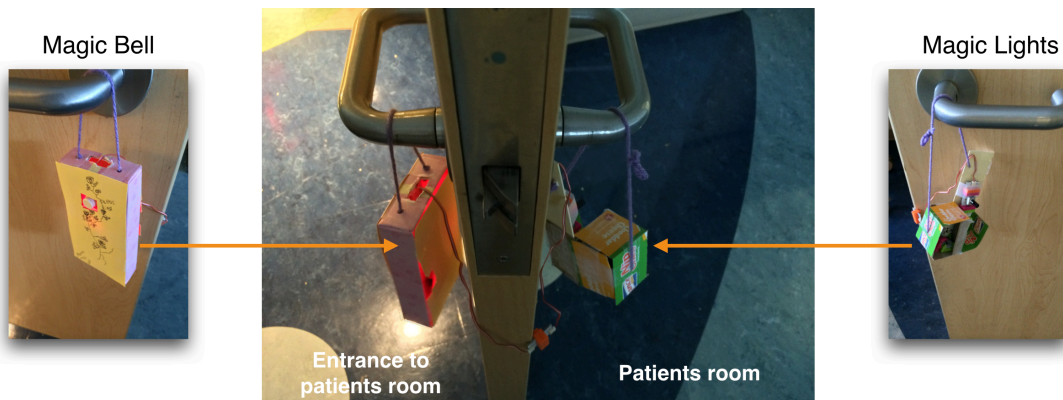
Figure 4. "Manna's Magic Bell"

Figure 5. Mood Necklace
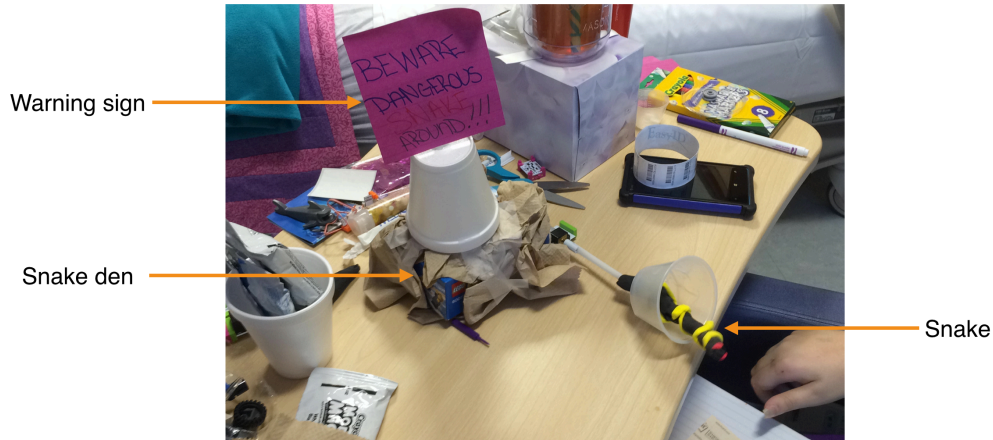
Figure 6. Dangerous Snake

As I thought about these experiences, I began to consider, "Imagine if there were a space that could provide children with creative outlets and learning opportunities." Since many of the children with whom I worked were isolated in their rooms, I envisioned the space as a mobile Makerspace — that is, I would bring the learning space into the patient's room. I decided to talk to patients about this idea and get their feedback about how such a mobile space should look and function to support learning. Patients suggested that the mobile Makerspace: (1) be colorful and bright, (2) be engaging, (3) serve as their own workspace and, (4) encourage collaboration.

Phase 2: Proof of Concept

Based on patients' feedback, I designed a proof of concept prototype (Figure 7) in April 2014. I tested the proof of concept with a group of 20 third and fourth graders during an after school session in May 2014. I bought a steel cart and incorporated various features to it, such as: cubbies that could store a variety of items (e.g., physical and digital materials, books); strips of multi-colored LEDS attached to the inside of the cart that could be controlled by a remote control to make the cart colorful; a flat Plexiglas surface above the cart that could serve as a workspace to design and make; and an area that could be allocated for a 3D-printer. The primary goal of

field-testing this prototype was to give me a sense of how children interacted with the cart and to help me determine ways that I could improve on the overall look and design of the cart.

Figure 7. Proof of concept prototype

Phase 3: Mobile Makerspace Design

Soon after field-testing, I decided to meet with a professor at the Business School who had years of extensive design experience to help me transform the proof of concept prototype to a mobile Makerspace that could be used by children at the hospital. After months of design thinking and prototyping, we came up with the first revision of the mobile Makerspace (Figure 8).

Dell XPS Portable All-in-One Desktop with Touch

Dell Tablet

Work Surface

3D-Printer

HDPE Sheets (sides/back)

3D-Printing Supplies

Locking-Wheels

Multicolored drawers designated for:
1. Fujifilm Instant Camera & Film
2. Polaroid Cube Video-camera
3. Basis Peak Wearable Fitness Tracker
4. iPod
5. Journal Book
6. Writing materials

littleBits stored in SmartJars

LED lights lining the inner walls of the cart.

Figure 8. Revision 1 mobile Makerspace design

I have attempted to design these mobile Makerspaces as more than just physical environments in order to address the broader goal of therapeutic environments. As Sternberg (2009) explains, "Most hospitals today instill fear, but they don't inspire hope. More than anything, a person who is ill needs an environment that fosters calm and comfort as a means to healing. The spaces around us can and should do this" (p. 166). These mobile maker environments are designed to encourage social interchange, increase physical mobility, and positively affect mood for children who have chronic illnesses. The design features of these mobile Makerspaces resonate with an argument put forward by Ulrich (1991), who suggested that to support coping with stress and promote wellness of patients, health-care environments need to be designed to foster a sense of control, provide access to social support and positive distractions, and ensure a lack of exposure to negative distractions.

I will now explain the various features of this mobile Makerspace design and how it addresses patients suggestions — (1) be colorful and bright, (2) be engaging, (3) serve as their own workspace, and (4) encourage collaboration.

Colorful and bright. The lack of color and stimulation in a patient's room can significantly impact a child's mood and emotion. As Sternberg (2009) explains, "The notion that color can affect mood is not new. Colors on the walls around us, in the clothing we wear, in all the objects we see, as well as the various wavelengths in ambient light—all can influence our emotions." To make the mobile Makerspace colorful and bright, I attached strips of multicolored LED strips to the inner walls of the cart. The lights could be controlled either by a remote control (in the initial prototype) or a dial (in the revised prototype constructed during December 2014) so that children could pick and choose their favorite colors and customize the color of the cart according to their mood and emotion. I also attached opaque off-White HDPE (High Density Polyethylene) sheets to three sides of the cart so that the cart would emanate a soft glow whenever the lights are turned on. To add more color to the cart, I incorporated multicolored storage bins for the first revision. For the second revision (constructed in December 2014), I incorporated two LED light boxes with illuminated bases and red colored mini storage chests to experiment with a more transparent theme. To add an additional pop of color, I stored the littleBits modules in different colored Smart Jars, which are modular storage jars that stow securely on a pegboard. Smart Jars are colorful and eye-catching, and also practical for organizing different colored littleBits modules (power, input, output, extensions). Making the mobile Makerspace colorful, bright, and playful serves as a "positive distraction" (Ulrich, 1991) in the sense that it helps shift the patient's thoughts from the isolation of hospitalization and their illness. A lack of stimulation or distraction can be a threat to health and well-being for children

with chronic illnesses. Ulrich (1991) explains, "…when there is a lack of external positive stimulation or distractions, patients may focus to a greater degree on their own worries or stressful thoughts, which can further increase stress."

Engaging. Being isolated in a hospital for several days or weeks at a stretch can be depressing. Using play and self-expression as primary tools, Child Life interventions attempt to facilitate coping and adjustment with hospital stays. However, services provided by Child Life services tend to be modular and short-term. For example, art and craft activities are employed to engage patients, but they do not pose greater depth of challenge or build learning over time, nor do they provide much of a sense of long-term possibility related to the patient's future. To design a mobile Makerspace that could be playful and engaging while transcending the isolation in the hospital, I aimed to trigger a more enduring interest by engaging patients in their own learning. Ainley (2012) elaborates on the relation between interest and engagement by using a "hook and switch" metaphor—when an activity (or condition, specific situation, learning environment) triggers interest, specific features of the activity snare or hook the student, drawing the person in for deeper engagement (the hook metaphor). The opportunity to engage switches open connections between the person's existing personal interests and opportunities to express those interests (switch metaphor). The mobile Makerspace draws patients to engage with the variety of physical and digital materials (hook metaphor), while the activities and challenges accompanying the cart invite patients to pose and solve meaningful problems by deploying an array of human, material, and environmental resources around them to drive their own learning (switch metaphor).

Serve as a workspace. Many patients suggested that the mobile Makerspace should serve as a workspace. As 13-year-old Cystic Fibrosis patient Kristina explained to me, "If the mobile Makerspace serves as a workbench, it would allow me to leave my bed, move around, and feel that I have my very own working spot" (Kristina, 2/2014, Interview). Accordingly, the top surface of the mobile Makerspace is designed to serve as a workbench, which we encourage the children to utilize in the execution of their designs and creations. It is especially important for children with CF to move around physically. Rachel, mother to 14-year-old CF patient Ariel, explained, "They need the exercise. The more they move around, the more the mucus in their lungs will move around. Sitting in their beds is not good for their muscle tone, but is also bad for their lungs. They need to keep that stuff moving so that they can cough the mucus up more easily" (Rachel, 9/2014, Interview). The mobile workspace serves as an anchor for children's invention activities. They move repeatedly from bed to the workspace; many move around the room (or move by proxy around the hospital by sending their relatives on scavenging trips) to seek cereal boxes, string, and other materials that can be incorporated into their inventions.

Collaboration. The social context of the hospital makes coping with a chronic illness difficult and stressful. Being disconnected from peers can cause patients to feel isolated and depressed, feelings that are counterproductive to their treatments and the overall process of getting healthy. Many patients and parents I spoke to wanted a space that would allow them to communicate with other kids around the hospital. Autumn, mother to 15-year-old Cystic Fibrosis patient Kelsey, explained to me that virtual collaboration among patients would make the patients "feel not so alone" (Autumn, 10/2014, Interview). She continued to say, "Many of the kids in the hospital are teenagers, and they get tired of being with their parents for two weeks. So they want someone different to talk to. Someone more of their age level." To foster collaboration

among patients, I equipped the mobile Makerspaces with large, touchscreen Dell tablets that included Skype, a free communication software that supports instant messaging and voice- and video-calls to fellow Skype users on the Internet. Using Skype, patients could now virtually collaborate with other patients who had their own mobile Makerspace. Virtually collaborating on projects provides users with opportunities to make a new friend — a relationship that could extend beyond the hospital stay. Virtual collaboration among patients forestalls isolation, provides openings to talk to others who are going through the same health and life issues, and offers an escape from the dull drill of hospital life.

A design challenge with respect to the mobile Makerspace involves sanitization. The mobile Makerspace needed to be sanitized to prevent cross contamination when taken into another patient's room. Sanitization of the Makerspace was my responsibility. As per hospital infection control guidelines, the mobile Makerspace needed to be entirely wiped down after leaving a patient's room. The wipe-down process involved everything on the cart, including cords, computer parts, littleBits pieces, drawers, tablet screens, and containers. Any porous materials that cannot be easily cleaned, such as Play Dough or paper, must be discarded. Future designs of the mobile Makerspaces should address ways of making sanitization more efficient and pathogen-free. One possibility is using UVC disinfection devices that are specifically designed to deactivate bacteria, viruses, and fungi in spaces that require frequent wipe-downs.

The Makerspace as Part of a Distributed Learning Environment

Hutchins (2006) explains that a change in the physical environment often provokes changes in interactive processes that may also generate a new cognitive ability in the interactive cognitive system. The mobile Makerspace is designed in an attempt to meet the concerns of supporting identity and self-efficacy for patients in a way that acknowledges the distributed

character of learning, especially in everyday environments that are not specifically tailored for teaching. The mobile Makerspace encourages patients to orchestrate people, materials, information in symbolic forms, ideas, etc., to solve problems that they have identified. As they generate and revise problems and solutions, patients increasingly assert control over their environment—that is, they create cultural arrangements to take control of their environment. As I will explain, I have observed patients deploying an impressive array of human and material resources, distributed across contexts, both within the patient's room and across the hospital. The mobile Makerspace supports the emergence of a complex social and technical system in which learning is distributed across multiple subsystems, including some or all of the following: (1) the patient, (2) the patient's room, including its layout and its contents, (3) the children's hospital, and (4) the world outside the hospital.

The first subsystem is the patient, who identifies and solves meaningful problems by deploying an array of human, material, and environmental resources around her to drive her own learning. For the patient, the cognitive process of identifying and solving problems is distributed: (1) through time (earlier stays in the hospital influence problem identification and solving); (2) within the hospital context (e.g., treatments/services rendered by health care providers, isolation of hospitalization); (3) among people (e.g., relationships with hospital staff, such as doctors, nurses, respiratory therapists, and family members); and (4) outside the hospital (e.g., family members bringing in materials from home).

The second subsystem is the patient's room. As I previously explained, patients with CF typically are isolated in their rooms. The Makerspace becomes a catalyst that transforms the patient's room into a site for learning where people and materials flow in and out and new social ties are established and maintained through interactions and exchanges of ideas. Learning

involves negotiating the physical space of the room by disciplining materials (materials in the mobile Makerspace, repurposing found objects within the room) and recruiting members who enter the space (e.g., health-care providers, visitors) or reside in the space (e.g., family members).

The third subsystem is the children's hospital. With the help of the mobile Makerspace, the children's hospital becomes a context where learning happens, shaped by both the affordances and constraints of the hospital setting. The children's hospital itself provides a physical structure, a social structure, and a time structure within which new learning opportunities can arise. For example, the kind of daily rhythm of treatments and interactions determines when the child can work on the Makerspace. Additionally, these same rhythms of treatments and interactions also bring people into the patient's purview who might not otherwise come into contact with her.

The fourth and final subsystem is the world outside the children's hospital. The hospital is located within the framework of the larger setting of the patient's wider world. Visitors (including myself) help establish contact with that world through the Makerspace activities. Materials and ideas flow in and out of the hospital, carried by parents and other visitors.

CHAPTER IV

METHOD

This study took place in a 271-bed children's hospital in the mid-south. Fieldwork spanned the course of six months from September 2014 to February 2015. Eight female children with Cystic Fibrosis between the ages of 7-17 years of age participated in the study. Two of the eight children were repeat visitors to the hospital. Table 4 summarizes important details about the participants.

Table 4

Participant information

Patient	Age	Number of days worked with patient	Notes
Ariel	14	3 (first visit); 9 (second visit)	The first time I was introduced to Ariel was during the final three days of her treatment. For Ariel's second treatment visit (which occurred just three months later), I spent nine days with her. Ariel's mother, Rachel (an English teacher for high school seniors at a public school in Dickson County, Tennessee), stayed with Ariel throughout the two weeks of treatment. During stays at the hospital, Rachel values the time she spends with Ariel. As Rachel explains, "Ariel and I both value the quiet time we have together while we are in the hospital because our everyday lives are so busy with treatments, school, life, etc., that we don't get as much of this downtime at home" (Rachel, 9/2014, Interview). Ariel received visits from both school and Camp Rainbow friends and family members at least three to four afternoons a week, and almost always on weekends.
Lori	17	9	I was introduced to Lori the day she was admitted into the hospital and spent a total of nine days with her. During two weeks of treatment, Lori spent most of her

			time by herself, with her mother spending the occasional night at the hospital. When Lori was younger, her mother, Michelle (a preschool special education teacher for public schools), would spend every night with her daughter; but as Lori has grown older, Michelle has not spent every night at the hospital. As Michelle explained, "She (Lori) gets tired of me being there all the time" (Michelle, 10/2014, Interview). During those two weeks of treatment Lori received visitors, such as friends from her local church and members of her basketball team, during the afternoon, and on the weekends her entire family came to visit.
Kelsey	15	9	I spent a total of nine days with Kelsey, including the first day she was admitted to the hospital. Kelsey's mother, Autumn, spent the entire duration of this treatment period with her daughter. Since Kelsey and her mother lived two hours away in Kentucky, they did not get any visitors, other than the occasional visit from Kelsey's father, who is a coal miner. Kelsey explained, "Normally during the hospital I miss home a lot and the days go by really slowly. I get really homesick some visits. But the nurses are really nice and sometimes help the day pass by. During the hospital visits it's just mom and me twelve to fourteen days, so we lay in my bed and watch movies or just talk about things back home. My mom and I always find something to entertain us. My dad is normally the only one to visit, and he works 24/7 so the whole two weeks is pretty much 'Mommy-and-me' time" (Kelsey, 11/2014, Interview).
Wesley	16	3 (first visit); 3 (second visit)	I was first introduced to Wesley while I was working with Kelsey, although at that time I only spent a few days with Wesley. For Wesley's second treatment visit, I spent the final three days of her treatment with her. During both visits Wesley spent her entire treatments by herself with the occasional visit from her grandmother, who would spend the night. Wesley explained, "I've been coming to the hospital since I was born…most of the people know me by name. Like, even the people who bring up food know me" (Wesley, 10/2014, Interview).
Hayley	11	3	I was introduced to Hayley during her final three days of treatment. During two weeks of treatment, Hayley's grandparents stayed with her. In addition, her parents took turns spending the night a few days a week. Hayley's mother, Jennifer, explained, "This is Hayley's

			seventh admission. Hayley lost a brother when she was two-and-a-half. He was five months old and also had CF. He never came home from Vanderbilt. I guess you could say his situation was more severe. So he was here at Vanderbilt for five months. This is Hayley's seventh admission to do a tune-up. It's been a year and two months since Hayley was last admitted. So in our world that seems terrible, but we are hearing that's really good in the CF world" (Jennifer, 11/2014, Interview). During two weeks of treatment, Hayley had a lot of visits from her aunts, uncles, and friends from school.
Kristina	14	10	I spent a total of nine days with Kristina, including the day she was admitted. During two weeks of treatment, Kristina was primarily by herself, as her mother had to work during the day. During the weekends, Kristina had friends from school visit her. Kristina explained, "It's hard when I go in the hospital for two weeks; I miss dance and my sister. She does come and visit me, but I don't get to see her every day. My mom stays with me most of the nights and my dad stays with me some of the nights. I just prefer my mom over my dad. I have been coming to the children's hospital since I was four. Life in the hospital is kinda like a normal day, except that you're stuck in a room and hooked up to an I.V. pole 24/7. I still have to do school and I still can dance, but not full out. The activities at the hospital I am not able to do, because I am not allowed to go out of my room because I can get sick, or worse, give germs to other people with Cystic Fibrosis. But I am allowed to have visitors come see me" (Kristina, 1/2015, Interview).
Molly	8	3	I was introduced to Molly during the final two days of Molly's first treatment at the children's hospital. Molly's mother, Hillary, and grandmother spent the entire two weeks with Molly. The only visits Molly received were from family members during the last week of her treatment. Hillary explained, "Molly was diagnosed with CF at three years old. Prior to that she was very sick, and her pediatrician either wasn't aware of symptoms of CF or just thought I was being paranoid. Once we were diagnosed, she was admitted to a children's hospital in Knoxville, Tennessee for almost three weeks. Having no right medicines or treatments for three years has already caused damage to her lungs. The right lung already has scarring to it from the

			infections that were never treated the right way. Our lives were forever changed! Molly has to go in for tune-ups every four to seven months" (Hillary, 1/2015, Interview).
Christy	18	3	I spent the first three days of treatment with Christy. A sudden winter storm prevented me from seeing Christy the rest of her time at the hospital. During those two weeks of treatment, Christy was by herself, with occasional visitors during the weekend. Christy said, "I typically go in the hospital two to three times a year. In the hospital I get what I call the 'hospital blues.' I'm lonely and I have almost no control and I'm stuck inside a tiny room with my only interaction being with people who are paid to talk to me. It kind of sucks. You wouldn't believe the boredom in here. You eventually start going crazy." (Christy, 2/2015, Interview).

The amount of time spent with each patient varied, for multiple reasons. First, I was allowed to work with patients only when a hospital schoolteacher was present at the hospital to ensure that all research protocol was adhered to. Hospital schoolteachers were present in the hospital five days a week (Monday through Friday) from 8:30AM until 5:00PM. Second, some of the children's health deteriorated during the hospital visit, resulting in gaps of several days when visitors could not be welcomed. Third, presence of visitors or necessity of hospital treatments occasionally pre-empted scheduled sessions with patients. And finally, because of the multiple rounds of treatments and medications that they endure, CF patients are prone to fatigue, often at unpredictable times. For that reason it was important not to overexert the patients too much with extended sessions. As Rachel, mother to 15-year-old CF patient Ariel, explained, "These CF patients get tired a lot more easily than most kids, and it's very important that they rest while they are in the hospital. Rest is healing, and CF kids need a lot of that! They just simply can't pay attention for long periods" (Rachel, 12/2014, Interview).

Procedure

I rely on the hospital schoolteacher to nominate patients for participation with the mobile Makerspace. The schoolteacher selects from among a pool of patients who are already receiving hospital school services. She considers the patient's current state of health and whether the patient's family is present at the time to sign consent forms. If these considerations are met, she informs those patients and families of my research project to gauge their initial interest in participation. After talking to multiple patients, the hospital schoolteacher compiles a list of patients who would be good candidates for potential participation in my research study. Once I receive this list, I introduce myself to the patient and her family and I explain the idea of the mobile Makerspace.

I give myself only ninety seconds to introduce the idea of the mobile Makerspace. I consider my introduction to serve the same function as a movie trailer. A good movie trailer, around ninety seconds long, captures the viewers' attention and leaves them wanting more, while not giving too much away. What follows is an example of my introductory speech:

Hi! How are you? Is this a good time? I heard about you from the hospital schoolteacher. She said you would be a great person I could work with. The reason I am here is because I have designed this super cool space, which is a colorful, bright, and playful cart. For example, if you want the cart to be blue, you just have to press a button on a remote control and the cart will magically transform to blue. If you want the cart to be red, you just have to press another button on the remote and the cart will be red in color. If you want the cart to flash different colors like a disco, all you have to do is press another button on the remote. You can change the color of the cart according to your preference. This is your cart! The cart also has a large touchscreen tablet. You can surf the internet,

watch TV and movies, and listen to music. It's your personal home theater. The cart also has different cubbies, which have a lot of fun materials that you can use to design and invent anything that you want. For example, just the other day I worked with a girl who has CF. Do you know what she designed? Well she said every time she was in the bathroom "pooping," she could never hear the nurses knock on the door when they entered. She got really annoyed when nurses suddenly popped up in the room after she got out from the bathroom. So she designed a doorbell to protect her privacy. Another kid that I worked with designed a Mood Necklace. Do you know why? He was tired of people asking him, like, forty times a day, "How are you feeling?" "How are you doing?" So do you know what he did? He designed a Mood Necklace to let people know how he feels. For example, a green light from his necklace would mean, "I am in a good mood and you can talk to me." A red light from his necklace would mean, "I am not in a good mood, and please don't talk to me." Have you felt that way? I'm sure you have! And do you know what the coolest part of the cart is? A 3D-printer! Do you know what a 3D-printer is? Well, say you want to build your own iPhone case — you can do that! You want to create your own bracelet, or earrings, or glasses — you can do that as well! You can make almost anything you can imagine using the 3D-printer! It's so cool! The kids I have worked with at the hospital love it! So, do you want to check out this space? I can bring it into your room and explain it to you in more detail.

As I worked with patients during my initial "shoebox" studies from September 2013 through March 2014, I noticed that that my very first meeting with a patient determined whether or not they wanted to work with me. On a daily basis, patients may see nurses, respiratory therapists, doctors, and physical therapists. Patients cannot say "no" to doctors, nurses,

respiratory therapists, or physical therapists, as medical treatment is a necessity. However, patients can choose to say "no" to working with me. Christy, an 18-year-old CF patient with whom I worked, explained why she agreed to work with the Makerspace, and with me:

> The reason I said "yes" about the Makerspace was because you made it seem fun. If you had been boring and spoken in monotone and just said "I have a cart with a tablet. Do you want it?" I probably would have said no. It's all about the attitude you have upon us first seeing you. If we see someone who doesn't seem excited to do the job they're doing, or who are too stiff like they need to loosen up, we are not going to be happy or have the curiosity to explore more. I know I can just write you off if your first impression is terrible. You seemed genuinely excited and happy to be working here and helping kids with this cart. Your attitude was contagious and made me really happy. You seemed so excited to be doing your job and introducing the Makerspace. If you hadn't been so excited about it and bouncing all over the place I don't think I would have been that excited about it (Christy, 2/2015, Interview).

If the patient and family tell me that they would like to learn more about the mobile Makerspace, I head to the hospital schoolroom to retrieve the mobile Makerspace and consent forms to take to the patient's room. Prior to entering the patient's room, all staff, including me, must don PPE (Personal Protective Equipment), including gloves, gowns, and masks, because of infection control precautions. Faculty, staff, and health care workers perform hand hygiene and don gown and gloves upon room entry; later, gown and gloves are removed upon exiting the room, and hand hygiene is performed once again. Figure 9 shows a picture of me wearing PPE in a patient's room.

Figure 9. PPE (Personal protective equipment) — Gloves, gowns, and masks

After the introduction, I explain the consent forms in detail and answer any questions that may arise. Once consent forms are signed by both the patient and by an adult family member, I spend the next hour setting up the Makerspace and explaining its features and the accompanying project activities.

Plugging in the Mobile Makerspace (10 minutes)

I first ask the patient where she would like to place the mobile Makerspace, given that the Makerspace needs to be plugged into an outlet in order to power the 3D-printer, the LED lights in the cart, and the tablets. It must also be placed in a location that does not impede the movement of the patient or health care providers, such as nurses, doctors, and respiratory therapists. Four areas where the mobile Makerspace are usually placed include: opposite the desk area, against the large window overlooking the city, next to the bed, and against the wall perpendicular to the couch. After finding a suitable location in the room, I show the patient how she can control the color of the cart, using either a remote (Revision 1 cart) or a dial (Revision 2 cart).

Running the 3D-printer (20 minutes)

After allowing the patient to explore different colors on the cart, I introduce the patient to the 3D-printer. I tell the patient, "Together, we are going to print out a custom bracelet with your name on it. I want you to design the bracelet using software on the Dell tablet and print it out yourself using the 3D-printer. I will help by giving you step-by-step instructions." This hands-on experience helps the patient to understand how to operate the Dell tablet and the 3D-printer, and, equally importantly, gets them excited about their own plans for making devices. Printing a bracelet takes around thirty minutes; during those thirty minutes, I introduce other materials on the cart and project activities.

Playing with littleBits (15 minutes)

Once the printer starts running, I remove the littleBits from the Smart Jars and place them on the work surface of the Makerspace. I explain, "LittleBits snap or connect together with magnets. You can design and invent anything you can imagine!" In ten to fifteen seconds I create a simple circuit to make a buzzer by connecting a power module to an input module (push button) to an output module (buzzer). I ask the patient to press the push button and see what happens. Because the patient does not know I have created a buzzer, she is usually surprised when a loud "BZZZZZZZZ" noise like the sound of a thousand charging bumblebees emanates out from the buzzer. The patient's eyes light up and I usually see a big smile on her face. It is important to create a circuit quickly to show the patient how easy it is to do. Then I explain the littleBits: "littleBits are grouped into four different categories, which are color-coded. Power modules, which are blue, always come first and are needed in every circuit and at the start of all your creations. Input modules, which are pink, accept an input from you and the environment, and send signals to the output modules, which are green. These output modules do something —

light, buzz, move, and the like." After this brief introduction, the patient and I create some sample circuits. After five minutes of playing around with the circuits and answering patient questions, I invite the patient to experiment with all the other inputs and outputs once I leave. It is important to give the patient space and time to explore the littleBits and, more importantly, to let her know that she is more than capable and competent to explore the littleBits by herself.

Introduce the Website (5 minutes)

Following this introduction, I show the patient the Project M@CH website (http://www.projectmach.com), which displays what other children in the hospital have designed and made with the littleBits and other materials found around the hospital. When a patient comes up with their own creation, I showcase their work on the website, in addition to social media such as Twitter and Instagram. Showcasing patients' work via the website and social media validates patients' individual learning and encourages them to take pride in their creativity. I spend five minutes explaining to the patient how creative these featured children were when I asked them to "let their imagination go wild."

Introduce the Activities (5 minutes)

After describing what other children in the hospital have created, I ask the patient to use the materials provided by the mobile Makerspace to come up with a design and creation that is personally meaningful to her, and that perhaps she could even use during her current hospital stay. I explain that she is allowed to collaborate with anyone she chooses, including her family, friends, nurses, respiratory therapists, or other health-care providers. Second, to support her design, I tell her that she can use the 3D-printer, incorporate materials from around her room, or ask for help in getting materials outside her room. For example, if she needs some art and craft materials, she can ask people from Child Life, family and friends, or nurses and health-care

providers to help acquire them. As an equally important part of the mobile Makerspace experience, I also ask the patient to create a visual journal in order to document her design and making process by taking pictures or videos during each step of the way, using the instant camera and video camera provided for patients' use in the mobile Makerspace. I let the patient know that the journal should tell me a story about her design process.

During these final instructions, the 3D-printer completes the printing of the bracelet, which I give to the patient. As further incentive, I tell the patient that once she completes her project successfully, she can use the 3D-printer to design and make practically anything she wants.

CHAPTER V

DATA SOURCES & ANALYSIS

During the course of this study, the patients were asked to collaborate with me in the process of documenting their work in order to share the task of data collection. This way, the entire process of design, from problem posing through final product creation and use, could be documented as thoroughly as possible. Because many patients worked on their designs during hours when I could not be present, I asked the patients to assist me in the documentation, and many of the children seemed to enjoy this process almost as much as the design process itself. As I will explain in more detail, several of the patients generated elaborate, illustrated journals in their roles as participating "researchers." As previously mentioned, the amount of time I spent with each patient varied considerably. Moreover, the forms of data varied somewhat as the study progressed. These changes often resulted from either attempts to resolve problems with the data collection methods I was pursuing, or from my observations of new and promising issues that seemed worth addressing further. I next explain the sources of data and the rationale for selecting those data sources.

Researcher-collected Data

I conducted informal and unstructured running interviews with patients and their families while present during the design process. During those interviews, I asked participants to tell me about the patient's background and hospital history, how design ideas were first identified and refined, how and why design iterations were conducted, and how patients tried out their creations.

From earlier studies conducted between September 2013 and March 2014, I observed that many children with chronic illnesses seemed to be uncomfortable being videotaped. Many patients reported that they have a negative view of their appearance while they are hospitalized. As one patient explained, "I don't look my best while in the hospital. That camera makes me feel very self-conscious about my appearance" (Lauren, 10/2013, Interview). Therefore, rather than using a standalone camera, I decided to use my iPhone to make video recording feel less intrusive. Many patients were a lot more comfortable with the iPhone, perhaps because they are so familiar with mobile devices as a part of their everyday lives. However, after a couple of months of video recording using the iPhone, I noted two problems with this form of data collection. First, it was difficult to acquire a panoramic view of the patient's room to capture whole-room interactions. Second, there were still some patients and health care providers, such as nurses and respiratory therapists, who felt self-conscious while being interviewed or observed with the iPhone.

To address these challenges, I started using a Polaroid® Cube HD Action Camera to record videos. At just 35mm, this tiny camera supports HD video, has a built-in 124° wide-angle lens, and uses a battery that records up to ninety minutes of footage at a time. Patients, families, and health-care providers found the tiny camera to be unobtrusive, as it blended seamlessly into the patient's room. To complement these video recordings, I used an audio recording application on my iPad to record patient interactions when the use of video recordings was not appropriate. For example, there were often occasions when patients were not well and did not feel they looked good enough to be on camera, or times when patients had to undergo treatments with nurses and respiratory therapists. Finally, I compiled field notes to record observations, interviews, encounters, impressions, and insights as they occurred with patients.

Patient-collected Data

Because of the time constraints in my face-to-face work with patients, I had to depend on patients becoming collaborators in the data collection process. Patients were provided with Fujifilm or Polaroid instant cameras, Dell tablets, and a Polaroid Cube video camera, and were asked to help document their design and making processes by creating a visual journal. Children seemed to enjoy using the camera to construct a record of their problem solving process. As one of the patients said, "The camera is amazing! I love the cameras. They're memories I'll always have and they're great memories" (Kelsey, 09/2014, Interview). Patients were invited to use the cameras to record themselves talking about the steps they took in coming up with their design or to record their interactions and collaborations with other people (e.g., hospital staff, family) during their design and making process. In addition to taking videos, the Dell tablets were used by some patients to research ideas via the Internet, to design CAD (Computer Aided Design) models for the 3D-printer, or to facilitate virtual collaboration among patients. Other types of data sources included patient-generated artifacts such as design journals, repurposed materials, and final design products. In January 2015, I updated the IRB document to allow patients to use wearable devices to capture health and fitness data. The data from the wearable was designed to have constant Bluetooth connection with an iPod touch in order to enable transfer of data from the wearable, such as data regarding physical mobility (steps taken) to an application on the iPod touch. I began to collect this data after observing that patients using the mobile Makerspace seemed to become much more active and mobile. Rather than merely lying in bed and watching television or playing with their electronic devices, the patients seemed more likely to be up and around the room once introduced to the mobile Makerspace. Nurses noted that increased activity could be an important unforeseen contributor to patient health and well-being, so it seemed

important to try to establish whether patients' activity levels were in fact increasing when the mobile Makerspace was present.

Table 5 summarizes the amount of data collected by both patients and me. The table describes the total number of minutes of video and audio recording and the total number of photographs taken by patients and the researcher, respectively.

Table 5

Amount of data collected

Patient Name	Researcher			Patient	
	Minutes of video taken	Minutes of audio taken	Number of pictures taken	Minutes of video taken	Number of pictures taken
Ariel*	25	196	17	0	30
Lori	12	165	71	0.5	24
Kelsey	0^+	60	50	21	36
Wesley*	167	360	30	16	10
Hayley	30	290	30	0	15
Kristina	838	926	60	8	10
Molly	97	309	17	27	13
Christy	0^+	90	27	10	44

* Multiple visits

+ Patient chose not to be video recorded

Timeline Notational System

To encapsulate the approximate duration of time that each patient devoted to her mobile Makerspace project, I created a notational system in the form of an annotated timeline. Figure 10 shows an example timeline. The purpose of the notational system is to summarize the evolution of design and also to explain the data sources that underlie that reconstruction of the timeline. First, the course of each patient's design process was roughly segmented into episodes that, based

on the available evidence, represent successive points when a patient's design process took an important turn. For example, an episode might mark a step of progress in constructing the original design. Alternatively, it might denote a turning point, when the original design was revised or reconceived. Once major episodes were identified, I described them in the following notational scheme. Each episode is represented by a circle and labeled with the day (days labeled successively) in the design process when the episode occurred. So, for example, if two separate episodes occurred on the same day, they would be located at the same point in the timeline (one directly above the other) and labeled with the same number. Color of each circle denotes the evidence base for its description. If a circle is white, the episode was reconstructed from secondhand accounts provided by someone other than me or my recording devices, such as the patient herself, a family member, or a member of the hospital staff. These sources included retrospective accounts, interviews, and patient-created records, such as journal entries supplemented by photos or video "documentaries." Circles that are colored black represent episodes when I was directly present, when I was working from personally collected, unedited video and/or audio recordings and photos, or, in many cases, both.
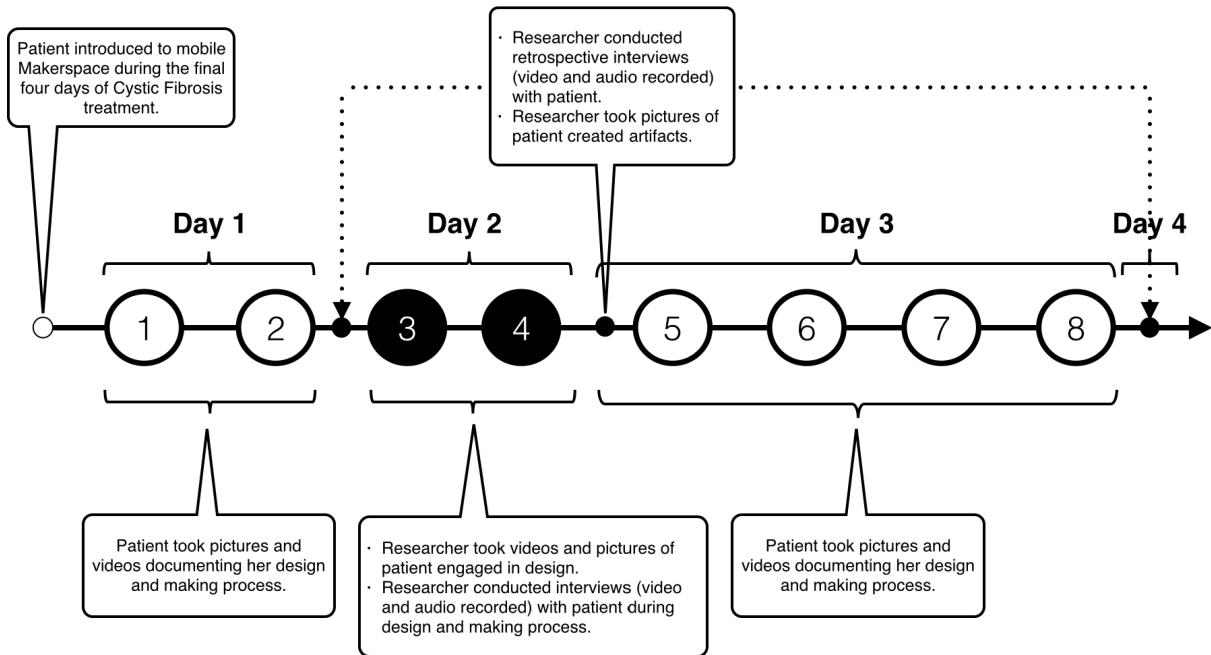
Figure 10. Example of timeline notational system

In the following section I am going to describe a series of five case studies. The rationale for selecting five case studies from the larger pool of participants was to highlight the fact that each child had an important and somewhat different way of mobilizing the issues of people, ideas, and materials in order to orchestrate their design and making process. The purpose of the case studies is twofold: to summarize the course of design for each of the patients, and, in addition, to emphasize important commonalities and contrasts in the way each patient constructed the design process by negotiating the affordances and constraints of other participants, design materials and tools, and ideas.

CHAPTER VI

CASE 1, RECRUITING A DESIGN TEAM: LORI

The focus of the first case is Lori, a 17-year-old CF patient. This case, which spanned the entire duration of her in-hospital treatment, highlights how Lori played a central role in recruiting and orchestrating a variety of people, such as family members and hospital staff, into her design and making process. For Lori, social interaction seemed to be of primary importance in her design; she was not a solitary problem solver. Instead, Lori drew in a host of participants, leading to a design process that, in many ways, seems even more distributed than some of the others that I observed. Although this case focuses on Lori, it begins with a description of another girl, Ariel, who is Lori's 15-year-old cousin. It is important to take a moment to go back to discuss Ariel because Lori's work with the mobile Makerspace was significantly influenced by interactions at the hospital with Ariel, who also has CF. I will first provide a little history of Lori's experience with Ariel, as Ariel helped shape Lori's design processes and creative thought.

I first met Ariel and her mother, Rachel, in September 2014 near the end of Ariel's two weeks of CF treatment. At the time, the mobile Makerspace was in the final stages of approval and review from the children's hospital. Until this approval came, I was unable to take the mobile Makerspace into patients' rooms, and in the interim, I was continuing to work with patients on carry-in shoebox activities. Rachel seemed excited about the shoebox activities, which she considered to be completely unlike the other types of hands-on activities offered by the children's hospital and the projects that she and Ariel bring from home. During hospital stays, Rachel brings craft projects such as origami, beading, and friendship bracelets. When

visits are not planned in advance — for example, a visit from a member of the hospital staff for stomach issues or because of sickness or low PFT's (Pulmonary Functions Test) — Rachel urges Ariel to take advantage of the arts and craft projects that are offered by Child Life. However, as Ariel has become older, she has lost interest in these activities. Rachel explained, "Her interests have changed a bit. She now likes to spend more time on social media, computer games, and journaling" (Rachel, 9/2014, Interview).

Hoping to provide a more engaging and stimulating experience, I provided Ariel with a shoebox that contained a variety of physical and digital materials. I asked Ariel to use these materials to design and make anything she could imagine, I told her she was allowed to collaborate with anyone she chose and to find materials around the hospital to support her design. After providing some basic littleBits tutorials and sharing examples of what other children had made, I told Ariel and Rachel that I would come back the next day.

Timeline/Data Sources

I introduced Ariel to the shoebox activities a few days prior to her being discharged from the hospital. When I first presented Ariel with the activities, she was not feeling well because of a recurrence of a lung infection. Due to Ariel's illness, I was unable to spend any time with her during the first two days beyond providing a brief explanation of the activity. My data sources during those two days were primarily recreated by Ariel's mother, Rachel, who provided me with retrospective accounts of the evolution of Ariel's design process. Two days after I introduced Ariel to the activities, Ariel was feeling much better and was accepting visitors. When I came to check up on Ariel, she was in the process of finalizing her design. I was able to take videos and pictures of Ariel completing her design and conduct brief interviews with Ariel and others who were involved in the design process, including her mother and her cousin, Lori.
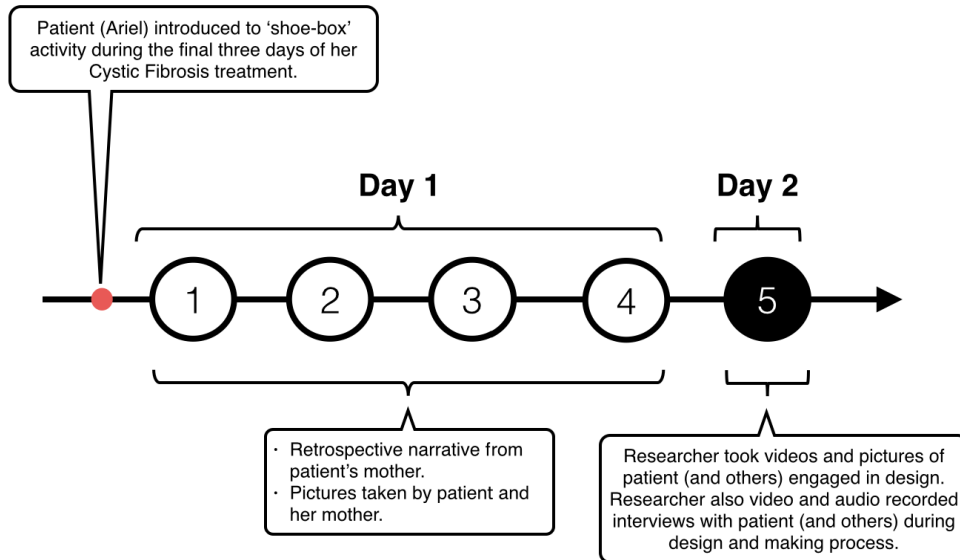
Figure 11. Timeline notational system: Ariel

I introduced Lori to the mobile Makerspace the first day that she was admitted to the

hospital for treatment. As seen from the timeline, Lori spent a lot of her time feeling unwell

during the entire duration of her hospitalization. Lori preferred to work on her designs in the

afternoons, which happened to be very convenient for me in that it allowed me to carefully

observe her design sessions. Lori's mother, Michelle, explained, "Lori enjoyed staying up late

and talking and goofing off with the night nurses. During the afternoon, she was mostly alone, so

working on the mobile Makerspace kept her busy" (Michelle, 10/2014, Interview). Lori was not

comfortable with formal, on-camera interviews, so my data mainly came from video recordings

and pictures of Lori and others present as they engaged in the design and making process.
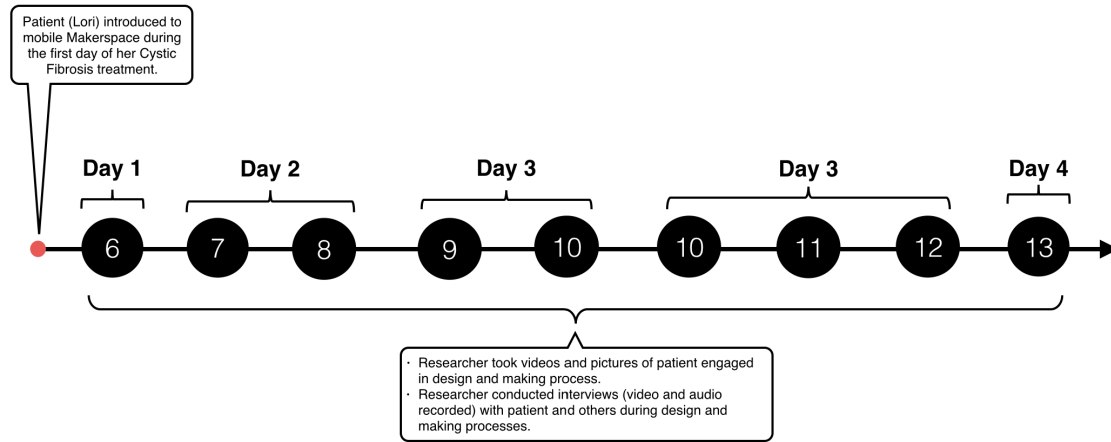
Figure 12. Timeline notational system: Lori

Episode 1

After I first met Ariel and left her with the shoebox materials, Ariel asked her mother to join her in exploring the littleBits kit. As Ariel was playing around with the modules, she became interested in the DC (direct current) motor module. Ariel found a standard syringe needle in the storage drawer of her room and attached it to the shaft of the DC motor. Ariel then connected the DC motor module to the power module and turned on the circuit. She showed her mother the rotating needle and asked whether they could use the contraption for some application. In this case, Ariel produced an effect that she found interesting (i.e., the rotating DC motor shaft), and only subsequently began to consider a potential application. Rachel could not think of an application for the rotating needle, and actually thought, "It looked a little cruel and scary" (Rachel, 9/2014, Interview). After several minutes of brainstorming, an idea came to Ariel. Ariel loved putting mascara on her eyes but faced problems in distributing it evenly. Ariel decided to create a mascara applicator to apply the mascara more evenly. After retrieving her mascara brush, Ariel used the white tape provided in the shoebox to attach the mascara brush to the shaft of the DC motor. She then connected a push-button module to the DC motor module so that pressing the push button would cause both the shaft of the DC motor and the mascara brush that

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was connected to it to rotate. Ariel's thought was that the rotation of the mascara brush would more evenly apply mascara to the user's eyelashes. However, as Ariel and Rachel tested out the mascara applicator with each other, they ran into a stability problem (Figure 13). As Rachel explained, "The mascara applicator was a bit clumsy, and the applicator wand of her mascara seemed a bit heavy for the rotator device" (Rachel, 9/2014, Interview).

Figure 13. Rachel and Ariel testing out the mascara applicator

My conjecture is that Ariel constructed this device primarily by means of analogical thinking — that is, the practical tool that most resembled the rotating needle was a mascara wand, so Ariel tried to apply what she learned in making the needle rotate towards making a mascara wand that would work in a similar way. The failure of this first iteration seemed to generate information about the constraints of the materials. For example, this trial resulted in Ariel learning that components that are too heavy cannot be successfully moved by the motor. After failing in her attempts to make the mascara applicator more stable, Ariel eventually abandoned the idea.

Next, Ariel began to explore other modules in the littleBits kit. The goal she set for herself was to make a button-operated buzzer. The purpose of this buzzer was merely to annoy people in a playful manner and to get their attention. As Rachel explained, "Ariel had a great time annoying all of us with the buzzer whenever she wanted anyone's attention!" (Rachel, 9/2014, Interview).

Episode 2

Soon after the buzzer contraption was completed, Ariel received a visit from her cousin Lori, who also has CF and is the main focus of this case (Figure 14).

Figure 14. Lori and Ariel

During the visit, every time Lori spoke, Ariel pressed her buzzer device, presumably to interrupt and annoy Lori, but also perhaps to invite questions from Lori about the invention that Ariel had constructed. When Lori asked Ariel about the device, Ariel recounted the history of creating both the buzzer and the mascara applicator that preceded it. Then Ariel invited Lori to explore the littleBits with her, to see if they might come up with some ideas that they could make together. According to Rachel, this type of engagement between Lori and Ariel was different from the interactions that she had observed during previous hospital visits. Usually when Lori visited Ariel, they passed the time by watching movies, listening to music, or talking, but mostly spent

their time on social media. However, Rachel reported that this engagement with the littleBits

(i.e., designing and making) was altogether different as it allowed Ariel and Rachel to be more

active and exploratory rather than remaining sedentary. After playing with the different littleBits

modules, Ariel and Lori decided to go online to find ideas for their potential creation. On

YouTube, Lori found a DIY lamp project that she particularly liked. Ariel agreed that it would be

a good project to work on, and Lori invited Rachel to help them in designing the lamp.

Episode 3

Ariel, Lori, and Rachel brainstormed a design plan for constructing the table lamp.

Together they decided that the lamp would require three core components: a base, a lampshade,

and a frame to hold the lampshade. After agreeing on this design, Ariel, Lori, and Rachel began

to search around the room for materials that could be used to design these three components

(Figure 15). Rachel described their "foraging" activities:

> We foraged around the room for materials. Ariel had received a gift from her cousin, a
>
> "tower of snacks" that amounted to various snacks packed into boxes that decreased in
>
> size. They experimented with different sized boxes until we found the right one for the
>
> base. The girls also played around with various items for something to use as the lamp
>
> frame. They tried straws, pens, tongue depressors, etc. before finally deciding that a
>
> magic marker worked best (Rachel, 9/2014, Interview).

Figure 15. Variety of materials stored above the desk

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Having a wide variety of materials available gave Ariel and Lori the ability to pick and choose different items and then use them to troubleshoot a number of designs. For example, they determined that the box that would serve as the base for the table lamp had to be the right size to enclose the different littleBits components inside. Ariel explained, "We had to troubleshoot a few times because we had a box that wasn't the right size. It was too tall or too small, so we did a little troubleshooting and finally came up with the right combination of stuff." Ariel and Lori also struggled to find the right item to use as a lampshade. The girls initially tried to use a Styrofoam cup for the shade, since it seemed to fit properly over the magic marker that they had planned to use to frame or support the lampshade. However, a lampshade needed to be translucent in order to allow light to pass through, but the Styrofoam cup was opaque and would therefore block out all the light from the light source. Once they discovered this limitation, Ariel and Lori abandoned the Styrofoam cup design and turned instead to a variety of cups found around the room, but still found no satisfactory solutions. Fortunately, an unexpected breakthrough in the design occurred when Ariel asked her mother Rachel to bring her some juice from the snack room. Rachel explained:

> It wasn't until Ariel asked me to get her some apple juice from the patient nourishment room that inspiration struck. I think it was Lori who realized that the apple juice cup would make a perfect lampshade. Once they experimented with the juice cup and decided it would work, one of the girls decided to color it to look like stained glass. Lori used colored Sharpies to decorate the lampshade, and, voila! It was a pure coincidence that we stumbled upon the juice cup idea (Rachel, 2/2014, Interview).

Episode 4

Once Ariel and Lori had successfully located materials for all three of the main lamp components, Lori suggested that they divide the labor so that they could share equally in the process of creating the actual device. Lori liked playing the role of leader. According to Rachel, "This is usually the case when Ariel and Lori are together, because Lori is older and tends to be more take-charge than Ariel." Lori assigned a specific design role to each girl: she would decorate the juice cup to look like a stained glass lampshade, while Ariel would be responsible for assembling the littleBits components that would make the lamp work (Figure 16), since Ariel had more expertise with the littleBits kit from her history with designing the mascara applicator and the buzzing contraption. Ariel created a circuit in which the light source for the table lamp (in this case, an LED module) could be turned on via two input modules, namely, a pressure sensor and a dimmer switch. Ariel described her circuit, saying, "You can turn it on using the dimmer to make it brighter. Or, if you have your drink and take your medicine at bedtime, you can set your drink down on it [the pressure sensor] and it turns the light on."

Figure 16. Ariel assembling the littleBits components for the table lamp

Episode 5

When Ariel and Lori had both finished their assigned tasks, Ariel invited her mother Rachel to join the two cousins in assembling all of the different components in order to finalize the creation of their table lamp (Figure 17).

Figure 17. Final assembly of the completed table lamp

Rachel commented on the fact that designing and creating the table lamp had seemed to visibly improve both Ariel's mood and well-being. The challenge of the table lamp project had given Ariel something to think about and had provided her with an escape from the constant drudgery of the hospital room. This was especially true after Ariel invited Lori to get involved in the creation of the lamp, as the project challenged the girls to stay "on their toes," instead of just "vegging out," as child patients of chronic illness are prone to do in the hospital.

Just a few weeks after Ariel was discharged from the hospital, Lori was admitted into the hospital for two weeks of "tune-ups." Upon hearing that Lori was in the hospital, I decided to pay her a visit. Lori was surprised to see me, since she rarely gets any visitors at all. During my visit, I asked Lori about what she had planned for the next two weeks, to which she responded:

The next two weeks is pretty boring. I try to stay sane in here by watching television,

playing games, and having conversations with the staff members. Sometimes I feel like I

am going crazy in here because I am stuck in one room. I even get depressed because I

have to stare at the same four walls for two weeks. I get irritated too, because I don't like

to be inside all the time (Lori, 9/2014, Interview).

I then asked Lori if she would be interested in being the first patient to use the mobile

Makerspace. She responded with an enthusiastic "Yes!" Lori's mother, Michelle, who was in the

room as well, was equally excited about this opportunity, because Lori "does not like to engage

with people she does not know and rarely gets involved with activities the hospital offers, like

the arts and crafts activities provided by Child Life" (Michelle, 9/2014, Interview). Lori agreed,

"I don't really like doing any of those things. It all seems so boring."

In what follows, I explain Lori's design and making process using the mobile

Makerspace to which she was introduced on the first day I met her.

Episode 6

When I saw Lori the following day after introducing the mobile Makerspace, she

emphatically said, "I came up with an idea!" In response, Lori's mother, Michelle, proudly said,

"She come up with the idea all by herself!" Just as I was about to ask Lori to explain her idea in

more detail, Lori's favorite respiratory therapist, Heather, came into the room to perform Lori's

second breathing treatment of the day. Upon seeing Heather, Lori excitedly told her that she had

a "really cool" idea that she had come up with. Lori explained to both Heather and me that after

coming out of the bathroom the previous day, she was surprised to find a nurse in her room. The

nurse's unexpected presence in the room annoyed Lori, because she had been unable to hear the

nurse knock on the door while she was in the bathroom. According to Lori, this type of

disturbance was not limited to a one-time occurrence; to the contrary, interruptions like this frequently happened during every hospital admission. Patients like Lori view their hospital room as a private space, even though the doors do not have any locks. Teenagers, especially, defend the right to view their room as a private space, in spite of the fact that patient rooms are constantly invaded by caregivers, trash collectors, and food bringers. Truth be told, patients actually have no privacy at all. As a solution to this privacy problem, Lori had been inspired with the idea of creating a doorbell for her room that would alert her to the presence of visitors who might enter, particularly the nurses. Lori said, "I came up with an idea of a doorbell so that I could hear people knock on the door every time I'm in the bathroom pooping." Lori's doorbell device would empower her to take more control over a valued aspect of her life, i.e., the privacy that was so consistently violated in the hospital. This violation is especially annoying for a teenager like Lori, who prizes privacy while at the same time characteristically asserting newfound independence and sense of self during those formative years.

Episode 7

Thanks to her previous design and making experiences with her cousin Ariel, Lori was able to use the littleBits modules from the mobile Makerspace to quickly assemble a circuit to create a working prototype of her doorbell. Lori connected a power source module to a push button module and mounted them on a plate, and this was in turn connected to a buzzer module which would be placed inside the room via an extension wire. With a simple push of the button, the doorbell would be triggered and the buzzer would sound. What follows is a transcript of a conversation between Lori and Heather, in which Lori explains her proof of concept and the design's functionality.

Heather: Is this the doorbell?

Lori: Yes.

Heather: I'm so excited!

[Lori takes the prototype and goes to the door.] (Figure 18)

Lori: This is going to be outside of the door [indicates the power module and push button module] and this [the buzzer module connected to the push button via an extension wire] is going to come through and sit right here, and then…. [Lori presses the push button and a loud sound goes off from the buzzer.]

Heather: Wow!!!

Lori: So when you come in, you can ring my doorbell. When I'm pooping and people come in, I don't know when they are coming in. So they can ring this – DING, DING! – and I can yell, "POOPING!"

Figure 18. Lori explaining her prototype to her nurse Heather

Episode 8

After demonstrating her prototype to Heather, Lori asked her mother, Michelle, to help her search for a box that would be the right size to house the doorbell circuit. However, their initial attempts to find the perfect box proved to be unsuccessful. Feeling unwell, Lori decided to take a break from her box hunt for the day, and decided to postpone continuing in the search until the following day. While Lori napped, Michelle decided to head to the hospital laundry room to wash and dry Lori's clothes. As Michelle readied Lori's clothes for the washer, she stumbled upon a Snuggle fabric softener box that someone had left behind in the laundry room. Michelle quickly realized that this box was actually the perfect size for housing Lori's littleBits circuit (Figure 19).

Figure 19. Michelle holding a Snuggle fabric softener box

Episode 9

The following day, Lori and Michelle got back to work on the doorbell creation by attempting to assemble the littleBits circuit inside the Snuggle box that Michelle had found in the hospital laundry room. Michelle decided to take charge of the task of housing the circuit in the box. She started by cutting a small hole on the front of the box through which the push button

module could protrude. However, when she placed the circuit inside the box, she realized that the box was actually much larger than the circuit, which caused the circuit to move around in the empty space and therefore prevented the push button module from sticking out of the cut hole. To prevent this unwanted movement of the circuit, Lori and Michelle together decided to fill up the extra space in the Snuggle box with small washcloths found in the bathroom. As Lori and Michelle stuffed the washcloths into the box, the weight of the box drastically increased, and they began to realize that the box would not be able to hang outside the door without falling down. Eventually, Lori and Michelle decided to remove the washcloths from the box and attempted to brainstorm other possible materials with which to fill the space in the box, including newspaper, scrap paper, or construction paper. As in this particular instance, Lori and Michelle frequently seemed to converge on a plausible solution to a problem (i.e., finding the right size box and filling up space with washcloths), only to later find that the solution under consideration simply presented additional problems, which, in turn, demanded solutions of their own.

Episode 10

After several unsuccessful attempts to fill the empty space inside the Snuggle box, Lori decided to turn her attention instead towards decorating the box. Lori decided to decorate her box using Mod Podge, a craft material, as she had been working with this material the previous evening on an unrelated project. Just as Lori was about to begin, she noticed two student nurses casually chatting outside her room and decided to invite them inside to help her decorate the box. This invitation to the nurses seems to be part of Lori's general style of involving people (from her mother to even these casual passersby) in her design team. The two nurses readily agreed to help, and Lori began to instruct them on her method of decorating the box, which involved

tearing colored construction paper into small pieces, and then using the Mod Podge liquid to

adhere the torn pieces of paper onto the box surface (Figure 20).

Figure 20. Two student nurses helping Lori decorate the doorbell

Episode 11

While Lori and the student nurses were busy at work decorating the doorbell, I remained

in the room and continued to video record the entire process. At this point, Michelle decided to

leave the room to get juice for Lori and me. As soon as I finished drinking the juice, Michelle

approached me and took the empty juice bottle away from me. Michelle had suddenly stumbled

upon a rather ingenious solution to the problem posed by the extra space inside the Snuggle box.

Rather than packing the box with a malleable material (e.g., a washcloth, construction paper,

etc.), Michelle suggested attaching the littleBits circuit to the surface of the juice bottle and then

securely positioning the bottle inside the box (Figure 21).

Figure 21. Michelle attaching the littleBits to the flat surface of the juice bottle

Michelle hypothesized that using the juice bottle to fill the empty space would serve as a clean and simple way to secure the circuit inside the box while at the same time preventing the box from being so heavy that it would end up falling off the door. Michelle used two hair elastic bands she had found lying around the room to attach the plate-mounted circuit to the flat surface of the juice bottle. She then waited for Lori and the student nurses to finish decorating the Snuggle box so that she could place the circuit attached to the juice bottle inside. This episode provides a good example of how the large design team that Lori recruited managed to proceed without interfering with each other's work. In particular, although the group often agreed about problems that needed to be solved, individuals were considered free to work independently on different parts of the project (e.g., Michelle solved the stability problem while Lori and the nurses continued to work on the decorative aspects of the invention). After Lori and the student nurses completed the decoration of the box, Michelle successfully placed the circuit mounted on the juice bottle inside the box (Figure 22).

Figure 22. Juice bottle with littleBits attached placed inside the decorated box

Episode 12

After completing the decoration of the Snuggle box and successfully placing the littleBits

circuit inside, Lori and Michelle began to consider how to attach the completed doorbell to the

outside of the door. One of the student nurses suggested that Lori use tape to stick the box to the

surface of the glass window adjacent to the door of her room. Lori attached strips of rolled tape

to the back of the box and asked Michelle to firmly secure the doorbell outside the room while

she used additional tape to adhere the buzzer just inside the door (Figure 23).

Figure 23. Assembled doorbell placed outside the door

Once the doorbell was in place, Lori then instructed Michelle to press the push button, which

resulted in a loud buzzing sound inside the room. As the next step in this initial testing process,

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Lori shut herself in her bathroom and asked the student nurse to press the doorbell multiple times to see if Lori would be able to hear the sound of the buzzer from inside the bathroom. After thirty seconds, Lori came out of the bathroom and excitedly announced that she had heard the buzzing sounds "loud and clear."

However, this excitement did not last long, when a mere fifteen minutes later the doorbell came crashing down after another nurse pressed the doorbell to enter the room. This malfunction was a direct result of the failure of the tape to firmly attach the box to the glass surface. This is another example of trial-and-error with materials, resulting in further discovery about the properties of the materials that made them problematic (i.e., the tape seal was not strong). Disappointed that the box did not remain in place, Lori and Michelle began to brainstorm other ideas for more securely attaching the box to the glass.

Episode 13

Michelle decided to look for materials available outside the hospital to help keep the doorbell firmly in its place. The following day Michelle returned to the hospital with a bag of items and Lori's younger sister, Emma, who was particularly excited to be at the hospital since "…she had heard and seen so much cool stuff Lori was up to" (Emma, 9/2014, Interview). Among the items that Michelle had gathered were 3M Command strips (adhesive mounting supplies that can firmly hold heavy items) that could be used to hang the doorbell without fear of it falling. Lori's excitement about the project returned once she saw the potential of this possible solution, and she asked her sister Emma to attach the 3M Command strips to the box. Michelle joined Emma outside the room as they fixed the box to the glass surface while Lori reattached the buzzer to the wall inside the room (Figure 24). To everyone's delight, they were then able to successfully test out the doorbell, and Lori immediately celebrated by giving high fives to

everyone around. When a doctor happened to pass by, Lori asked him to press the button on the box. The doctor hesitated, playfully expressing fear that he might receive a shock, assuming it might be a prank device. After Lori spent a few minutes explaining her doorbell to the doctor, he pressed the button and smiled, saying, "We need this on every patient's door!" Realizing that other people might also be apprehensive about pressing an unfamiliar button, Lori created a sign above her doorbell that said "Ring My Doorbell" so that anyone who saw the device would know that it was a doorbell designed to be used to enter the patient's room.

Figure 24. Michelle and Emma fixing and testing the doorbell outside while Lori is inside

Discussion

This case highlights how Lori both recruited and orchestrated a variety of people into her design and making process. While the idea of designing a doorbell remained prominent throughout the duration of her treatment, the social context within Lori's room changed periodically. Lori took a directing role, while all the other people on her team (e.g., her mother, sister, and nurses) revolved around her, helping to raise possibilities, solve parts of the problem,

divide simple labor (e.g., decorating), and bring materials and partial solutions into the room. Lori directed in the sense of suggesting roles for the other participants, but she did not apparently feel a strong need to be the one to come up with solutions to the design problems that arose. But these same people also played an important role in entertaining Lori and keeping her engaged in problem solving. A prime example of this is Lori's recruitment of the student nurses, standing outside the room, to help in decorating her doorbell. Thus Lori did not invent purely for the purpose of inventing; rather, for her, invention seemed to be a social activity that provided a forum for audience and communal participation.

Due to the multiple participants, materials and ideas flowed both into and out of Lori's room. As a result, the hospital room did not remain a sequestered space. Instead, people — even those whose presence would not ordinarily be sanctioned — came in and out. Materials, such as juice bottles, Snuggle boxes, and mounting strips also came in and became transformed as people take them up to fit design goals. Ideas popped up and were incorporated or abandoned in a rather catch-as-catch-can style. Although this process may not seem very systematic, it has the advantage that materials and ideas co-determine each other during each stage in the process. By that I mean that sometimes Lori was able to see the affordances of stuff (e.g., a box that can serve to hold components), and those affordances inspired ideas for designs. At other times, Lori had driving ideas, and those allowed her to see potential materials in a different light (e.g., she wanted to fill a box, and washcloths are good for stuffing). So in Lori's design process, it is not as simple as saying that first people have ideas and then they look for ways of achieving them. Sometimes what happens is that people notice what you can do with stuff, and what they notice in turn generates potential ideas that drive or even redirect subsequent phases of design.

CHAPTER VII

CASE 2, ENGINEERING TAKEN SERIOUSLY: KELSEY

This case introduces Kelsey, a 15-year-old CF patient who was diagnosed with the

disease when she was just five-years-old. For Kelsey, time spent in the hospital passes at a

painfully slow rate. She explains:

Normally during the hospital I miss home a lot and the days go by really slowly. I get

really homesick some visits. But the nurses are really nice, and sometimes help the day

pass by. During the hospital visits it's just mom and me for twelve to fourteen days, so we

lay in my bed and watch movies or just talk about things back home. My mom and I

always find something to entertain us. My dad is normally the only one to visit, and he

works 24/7, so the whole two weeks is pretty much "mommy and me" time (Kelsey,

10/2014, Interview).

I was introduced to Kelsey and her mother, Autumn, the day Kelsey was admitted to

the hospital. This case, which spanned the entire duration of treatment, highlights how Kelsey

followed a more systematic and engineering approach. In contrast to Lori (Case study #1),

Kelsey carefully planned and systematically executed her design while working mainly by

herself and only resorting to help from her mother when problems arose, carefully documenting

her whole process in a journal (Figure 25). Her documentation was more meticulous than that of

Lori and was notated in the form of a journal rather than in a series of "storyboards." Kelsey

explained her reasoning for choosing to work by herself: "Whenever I'm by myself I can collect

all my thoughts and focus on the topic. Whenever all my thoughts are together I feel like I'm

more productive. All of my school projects I do, I do them alone because I'm a perfectionist and I want everything to be perfect in my eyes. And whenever I'm alone I can make sure it is perfect in my eyes. Of course with Mom's opinion."
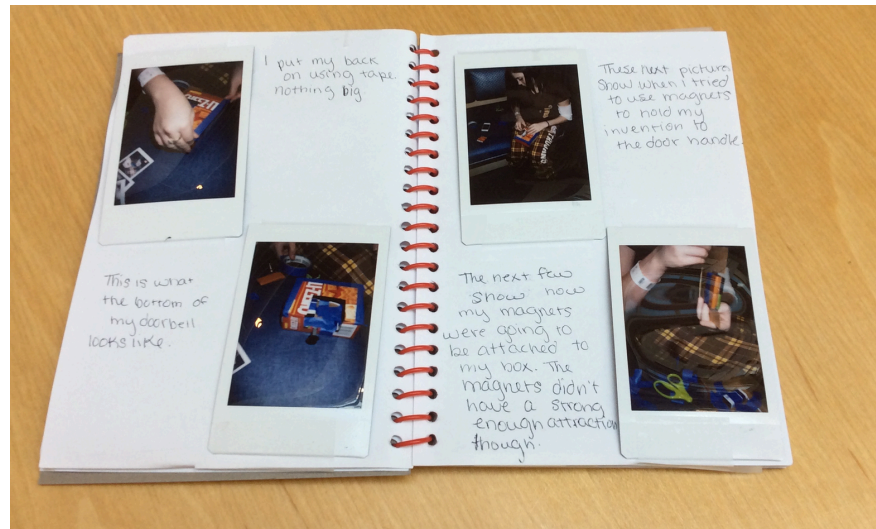
Figure 25. Snapshot of a part of Kelsey's design journal

Timeline /Data Sources

I introduced Kelsey to the mobile Makerspace during her first day of admission to the hospital. As seen from the timeline, all the data was collected directly by Kelsey. There are two reasons for this type of data collection. The first reason relates to the fact that Kelsey valued her privacy and preferred not to encounter distractions during her designing. She said, "I can think better whenever I'm by myself." Kelsey created detailed, step-by-step, instructional, illustrated design journals that documented her design and making process. In addition, Kelsey made videos to accompany her design journals so that she could have another creative means of explaining her design and making process. The second reason for Kelsey's self-collected data stems from the fact that, unlike Lori, Kelsey worked on her designs during different times of the day, mainly in the evening. Kelsey explained, "Whenever I'm alone at night, I can think things through. I'm a night owl." Kelsey worked on the mobile Makerspace with her mother, Autumn, at times in

between respiratory treatments during the day, and more often at night after the day's last treatment. Kelsey described her daily routine when the mobile Makerspace was in her room:

Every morning I would get up, order breakfast, then take a shower. When I got out of the shower, I would eat until the respiratory therapist got there for my treatment. For a few hours, Mom and me would just relax and put on our makeup. Then about 12:00PM we would eat lunch. After lunch, we would work with the [mobile Makerspace] cart a little until respiratory got there for treatment. Then we would watch TV for a little while, or I would nap. Then we would eat dinner and wait on respiratory. After respiratory, I would work with the cart some more. Then we would have a late night snack and wait for the last respiratory treatment. Then I would try and sleep; if I couldn't sleep, I would use the cart and listen to music (Kelsey, 10/2014, Video Journal).
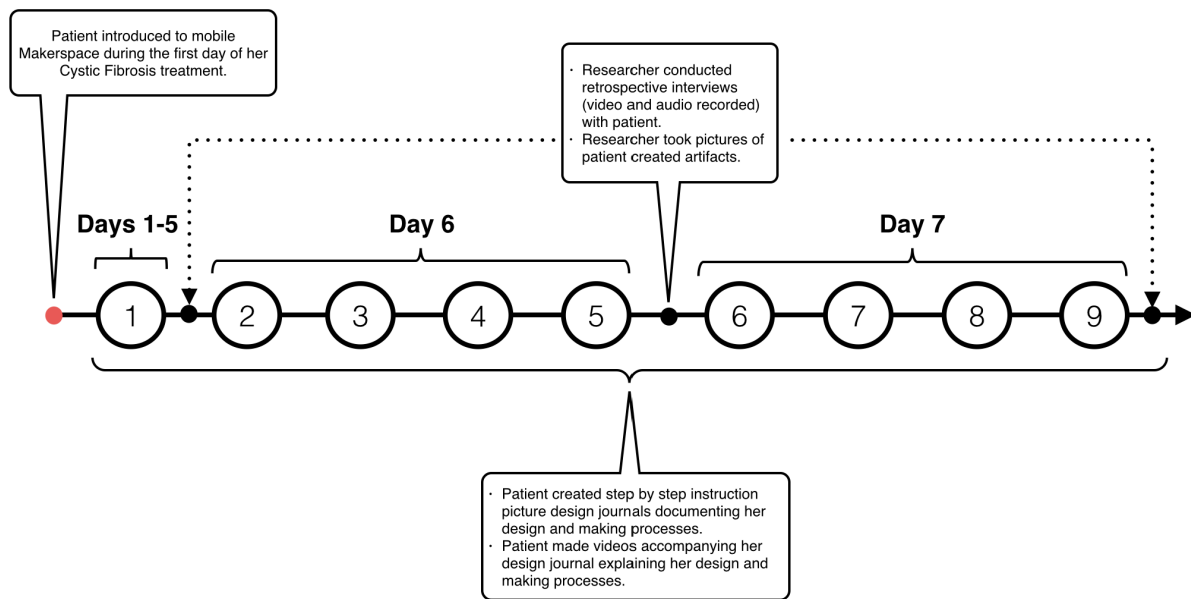
Figure 26. Timeline notational system: Kelsey

Episode 1

As soon as Kelsey received the mobile Makerspace, she began to explore the littleBits kit, creating different configurations of circuits by systematically exploring practically every possible input-output configuration. Her systematicity contrasts sharply with the trial-and-error style that Lori employed for exploring these materials. As Kelsey explained, "To explore all of the parts of the cart, I pulled everything out and put it on the work space. I tested every one of the parts to see what they did." As Kelsey systematically explored the littleBits circuits, she concurrently began to make note of personal problems that she faced in the hospital that might potentially be addressed with the use of the mobile Makerspace. Rather than just messing with the materials however it occurred best to her, Kelsey explicitly worked to make connections between problems that might be solved and goals that the circuits could help her accomplish. Kelsey often brainstormed her ideas with her mother to get her feedback, as she considers her mother to be very creative and usually collaborates with her during other design activities such as school projects.

One of the problems that Kelsey noticed in the hospital involved the fact that she had frequently observed nurses struggling to knock on patients' doors with one hand while holding a tray in the other. She had also seen how the nurses would flip on the lights upon entering a patient's room at night when they needed to check the readings on a patient's I.V. monitor, invariably awakening the sleeping people inside. Kelsey explained, "For a couple of days I just pointed out problems I noticed everyday. I noticed that the nurses tried to knock on the door even when their hands were full, and I noticed that it was hard for them to see at night. I started to think of a nightlight and a doorbell." Once again, Kelsey's logical, systematic approach characterized by identifying and cataloguing problems starkly contrasts with a patient like Ariel

(Case study #1), who instead tended to observe the interesting effects that she could create with the littleBits (like the revolving wand) and then, by association, tried to consider what practical applications these effects might address.

Episode 2

Kelsey decided to first tackle the problem of the nightly interruptions from the lights in her room getting switched on by nurses by designing an invention she later decided to call a "nightline." The inspiration for this device stemmed from years of personal experience of being disturbed at night by the nurses when they entered the room to check the readings on her I.V. monitor. A CF patient's I.V. medications ("meds") are administered on a strict schedule, usually every four, six, or twelve hours, for example. Because this schedule continues around the clock, the nurses must administer a patient's medicines even in the middle of the night. Kelsey chose to call her invention a "nightline" because she envisioned it serving as a nightlight in the form of a long, electroluminescent wire that would wrap around and thereby illuminate the I.V. pole. In the dark, this electroluminescent light found among the various modules of the littleBits kit glows a soft blue along the entire length of its almost four foot long wire. Kelsey explained, "It's a 'nightline' because my actual nightlight is a line, kind of like a wire, and it's got lights all through it, and it connects to a switch and a battery. And anytime I need it on, I just turn a little knob and it comes on. It's bright blue…it's really pretty."

Kelsey determined that her nightline invention could actually serve a dual purpose beneficial to both nurses and patients. For example, if a patient dropped something in her room at night, she could use the nightline to find the object, rather than turning on the room light and waking up anyone else who might be sleeping. Without this invention, if the patient were connected to the I.V. pole, she would need to first unplug the pole from the wall, walk to the

light switch toting the I.V. pole along with her, and turn on the light and find the missing object. After switching off the room light, the patient would need to walk back to the bed, plug the I.V. pole back into the wall, and then get back into bed. Kelsey further described her remedy for this cumbersome process:

> The nightline isn't necessarily just made for the nurses, but also like, the patients, because you know, at night, you have your parents sleeping over here in the corner, and you are sleeping over here, and say you drop something on the floor…you don't want to get up and turn on all these lights and wake your parents up. If you are hooked onto an I.V. pole, you know, you don't want to unplug it, take it all away over there to turn on the light, and bring it all the way back to get back into bed. And then you have to find whatever you are getting and then go back. It's just a lot easier if you can just reach above you and switch on the light. That way you can see whatever you have dropped. (Kelsey, 10/2014, Video Journal).

Episode 3

Kelsey asked her mother, Autumn, to help her execute her plan in order to create the nightline. This process did not take long for the two of them to accomplish. Kelsey explained:

> It didn't take too long to make my nightlight. I have had the cart a week-and-a-half, almost two weeks, and every day I learn something new. Because I get these littleBits out, and I learn the different things it can do. It's just that you can't learn everything in one day, you can learn all kinds of different stuff you can do, and within about a day I knew what I wanted to make: a nightlight. I just didn't know how I was going to make it. So for a couple of days I played around with the littleBits, figured out which sensors were which, which ones were better for my invention, and I woke up one day and started

working on it. And I knew by that night I would have it done (Kelsey, 10/2014, Video Journal).

Kelsey considered herself to be a perfectionist: she liked to be methodical, organized, and precise. As Kelsey and her mother worked on creating the nightline, she also decided to create a book that documented her design and making process. During each stage of designing and making, Kelsey took photographs and wrote a few sentences about each picture. She intended for the book not only to document her own thought process, but also to serve as a descriptive means of informing other children around the hospital about her experience with the mobile Makerspace, anticipating the likelihood that they too might want to replicate the designs she had created. Kelsey truly believed that people would enjoy her book of inventions. "It's just so they can get new ideas, change things up, and make them how they want." She continued, "I really thought the instructions were important, because somebody could read them and get different ideas, and maybe improve the invention. So I thought it would be really neat to make sure all my instructions were wrote down and see if there was anything I could improve on, and how to make my invention better."

Episode 4

Initially, Kelsey decided to use small, individual LED modules to construct her nightline. However, "They weren't bright enough to be a nightlight." When the main lights in the hospital room were turned off, the light emanating from the small LED lights lit up only a very small portion of the I.V. pole. The light was not bright enough to allow the nurses to check the readings on the I.V. monitor, or to potentially help a patient see what she might have dropped on the floor at night. So Kelsey decided to use the electroluminescent light wire from the littleBits to light up the I.V. pole, wrapping the light wire all the way around the I.V. pole and thereby

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allowing light to be dispersed over a broader area. However, turning on the completed circuit by connecting only the light wire directly to the power module (which uses a nine -volt battery to supply electricity to the littleBits) and then leaving the light wire on throughout the day would cause the power module battery to drain rapidly. Kelsey was already aware of this potential limitation because during her first week of exploring the littleBits circuits, she had inadvertently attached an LED wire directly to a power module and turned on the circuit and then left it on throughout the night. The following morning, the battery was dead and the LED would not turn on. For that reason, for her nightline invention, Kelsey decided to look for an input module to allow her to turn the LED light wire on only when it was required.

As a first step, Kelsey connected the LED light wire to a push-button module, but immediately realized that when she pushed the button "the light only stayed on as long as the button was being pushed." She faced similar problems when attempting to use other input modules, including pressure, sound, and motion sensors. Kelsey complained, "The problem that I had was what button to use. The sound sensor didn't let the light stay on long enough…the motion sensor didn't make it stay on long enough…even the push button and the pressure sensor didn't keep it on long enough."

Having reached an apparent impasse in identifying an appropriate input module for her nightlight, Kelsey turned to her mother for help. Autumn noticed a dimmer switch in the littleBits kit and suggested that Kelsey try using it as a possible solution. The dimmer switch allows the user to control their creations with a simple knob, so Autumn thought that this method might provide more versatility to Kelsey's invention since it would allow the patient to more easily adjust the brightness of the LED light wire at night. This way, the nightline could be set to a level of brightness that would be visible to a nurse upon entering a patient's room, but it would

not be so bright that it caused a disturbance to the patient's ability to sleep. Moreover, if necessary, the nurse could also use the dimmer switch to adjust the brightness of the nightline to see the I.V. monitor readings more clearly. Likewise, if a patient dropped something on the floor, she could also adjust the brightness of the LED light wire to locate the object.

Episode 5

Kelsey found all of the materials that she needed to design and create her nightline within the mobile Makerspace and her hospital room. According to Kelsey, the nightline "wasn't that hard to make." She explained:

> I just had this box right there – that teal box – I had that laying around in my room, and there was tape and Velcro on the [mobile Makerspace] cart. So I took my littleBits and connected them together, took one of these batteries and hooked it to that, and before I put it in my box I made sure it worked. And then I taped the box closed and used Velcro to hold it on to the [I.V.] pole (Kelsey, 10/2015, Video Journal).

The execution of Kelsey's nightline creation showcased her skillful and methodical approach to the entire design process, similar to that of an engineer. After first assembling the nightline circuit and placing it inside the box found in her room, Kelsey cut two small slits in the back of the box, explaining, "I did this so I could put Velcro through them [the slits] to hold my invention to my I.V. pole." Next, Kelsey cut pieces of blue tape to use to attach the littleBits circuit securely to the inside of the box so that the modules would not fall apart. This solution differs from Lori's in interesting ways, in that rather than trying to stuff the empty space inside the box with extra material like Lori did (e.g., using washcloths to fill the box for her doorbell), Kelsey mounted the littleBits circuit directly to the side of the box using tape. At this point in the process, Kelsey left the top lid of the box open to allow the long LED light wire to pass through.

Once the assembly of this circuit-housing box was complete, Kelsey attached the box to the top

of her I.V. pole using the Velcro strips. Next, Kelsey enlisted her mother Autumn's aide in

winding the LED light wire around the entire length of the I.V. pole while Kelsey taped it into

place (Figure 27). To test out the design, Autumn pretended to be one of the nurses and switched

off the main light in the room, while Kelsey role-played by lying in her bed, adjusting the

brightness of the LED light wire with the dimmer switch. Still playing the role of nurse, Autumn

was able to enter the room and maneuver her way to the I.V. pole without turning on the bright

overhead light and waking up the "patient," played by Kelsey. After a successful first user

testing, Kelsey and Autumn decided to put nightline to use for the first time that night. Kelsey

said, "I was really excited, like, I couldn't wait for it to get night-time just to use it."
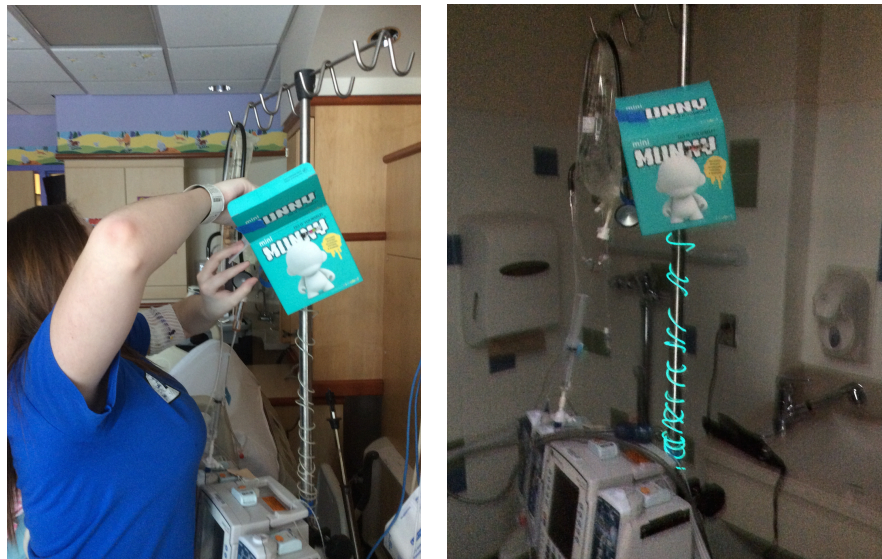

Figure 27. Kelsey assembling and testing her nightline

Episode 6

Kelsey's second design idea resulted in the creation of a doorbell, which she decided to

call "TAP" (Touch And Press). Like Lori, who had also designed a doorbell, Kelsey actually

found the inspiration for this device while she was in the bathroom. CF patients spend a lot of

time in the bathroom because of pancreatic insufficiency (i.e., their bodies don't digest food well, especially fats, because of this insufficiency that causes gastrointestinal issues such as diarrhea, stomach cramps, and constipation). Both girls shared the primary goal of preserving privacy with the creation of their doorbell invention, as they were uncomfortable with people coming into their rooms while they were in the bathroom. However, Kelsey took this idea one step further by recognizing the potential usefulness of her doorbell for nurses by devising a dual-functionality for her device as both a doorbell and as a way to easily open the door to enter the patient's room without having to knock. Kelsey had observed that nurses often struggled to knock on and open the door to a patient's room while carrying items, and she considered her doorbell to be an ergonomic way to address this challenge. Kelsey decided to attach a pressure sensor module to the door handle, which in turn was connected to a buzzer module from the littleBits kit. Using this system, the nurses could trigger this buzzer by pressing the doorbell as they opened the door and alerted the patient to their presence in the room. Kelsey explained her idea:

> I kinda made my doorbell just to help patients know that someone is coming in. My inspiration was the other day I was in the bathroom and I was taking a shower, and my respiratory therapist came in and I had no clue they were in here, and so if I had my doorbell up, you know, I would have been able to hear it go off when they came in. But it's something that can help both nurses and the patients. Also if the nurses, their hands are full, they only have one hand or if they have stuff on both of their hands, they don't have to knock. They can just push on the door and make a noise. And for the patients, if they are busy doing something and they can't get to the door on time and they don't hear somebody knock, they will know somebody is coming in when the buzzer goes off (Kelsey, 10/2014, Video Journal).

Episode 7

Kelsey found the process of designing and making her doorbell to be considerably less difficult than that of making her nightline. She said:

> The second invention was easier because I wasn't worried about messing up. I was just
>
> having fun and getting excited for someone to test my invention. It didn't take me long to
>
> make my invention. I kinda knew what I wanted to make when I started to look at the
>
> pieces. It took about a day to complete the whole invention and write about it (Kelsey,
>
> 10/2014, Video Journal).

With the approach to her first invention, Kelsey had strived to be perfect and methodical. For the second invention, she focused instead on just "having fun."

Kelsey had already predetermined what materials she would need for the execution of her second invention. Kelsey explained:

> For my second invention, I used a buzzer, a V9 battery, a presser sensor, tape, a Cheez-it
>
> box, and double sided tape. I chose my materials by thinking of what would best fit the
>
> objects I was sticking my designs to. The batteries were the only things I didn't have in
>
> my room. Everything else I found around my room (Kelsey, 10/2014, Video Journal)..

This is another example of Kelsey's systematic design approach. Unlike some of the other patients, who seemed at times to accidentally stumble upon the materials they chose to incorporate into their designs as they went along, Kelsey pursued a process that followed her strategy of careful planning which helped her to identify critical components even before beginning to make the invention. For example, Kelsey recalled that the AAA batteries she had used during the prior week in her nightline creation had eventually died due to overuse, and that her mother Autumn had tried unsuccessfully to find more batteries around the hospital. So

Kelsey asked me to supply her with extra batteries that I was able to acquire from a local store so that she would be able to then start work on the construction of her doorbell project.

Episode 8

Kelsey found an empty Cheez-it box in her hospital room and realized that it was the right size and strength for housing the littleBits modules for her doorbell design. Kelsey gathered all of the materials that she would need to begin the design process and carefully organized them into different categories (e.g., circuits, adhesives and mounting materials, cutting tools) on the surface of the mobile Makerspace. Kelsey explained, "To build my inventions, I sat down with all the materials and thought of the best way to put it all together. I ran all my ideas by my mom first to see what she thought before getting started."

Episode 9

At first, Kelsey decided to try using Play Dough to hold the littleBits firmly inside the Cheez-It box. However, she soon realized that the littleBits circuit did not work when it was in contact with the Play Dough, because Play Dough actually conducts electricity. Kelsey confirmed, "The Play Dough made the battery for the littleBits lose energy." Kelsey then decided to remove the Play Dough and use blue tape as an alternative adhesive to attach the littleBits circuit securely to the inside of the box. Next, Kelsey began to work on a way to attach the box now housing the littleBits to the front of the door to her room, taking special care to make sure that pressure sensor module from the littleBits circuit would lie directly over the handle of the door. To address this challenge, Kelsey and Autumn experimented with different positions for the location of the device on the surface of the door, only to later realize that slight modifications to the box would be needed first. They determined that a small slit on the underside of the box would need to be made so that the pressure sensor module would protrude out of this opening,

allowing for direct contact of the sensor with the door handle. Kelsey said, "I cut a square out of one of the sides so the pressure sensor will fit the hospital doors perfectly."

After this minor revision was complete, Kelsey then returned to work on attaching the box to the door handle. Realizing that the door handle was metallic, Kelsey first attempted to use magnetic, wooden Tegu blocks, left in the mobile Makerspace as play items, to join the box to the door handle. Kelsey took four small Tegu blocks and stuck them to each other using blue tape, and then used double-sided tape to attach the back sides of the blocks to the box. However, when she then tried to attach the box to the door handle using these magnets, Kelsey observed that the magnets did not successfully keep the box in place on the door handle, so she ultimately resorted to using just the double-sided tape. She said, "The magnets didn't have a strong enough attraction. Since the magnets didn't work, I tried double sided tape."

With the box firmly attached to the door handle, Kelsey asked her mother to exit the room and test out the doorbell. Autumn made sure to press the pressure sensor and use it to open the door several times, both to test out the stability of the design and to make sure that the sound of the doorbell would be audible to Kelsey from inside the bathroom (Figure 28). Excited that the doorbell worked, Kelsey called her nurse to come give the new doorbell a trial run. She later described the scene, saying, "I used my nurse, Heather, to test out my designs. She was excited to try them and was astonished that I made inventions while in the hospital. She loved both designs, and I also used the 3D-printer to make her a bracelet which she also loved."

Figure 28: Kelsey testing her second invention, TAP (Touch And Press)

Discussion

The problems that Kelsey seeks to solve while using the mobile Makerspace are similar to those issues previously noticed by Lori (Case study #1), namely, problems related to preserving patient privacy. However, Kelsey's design process proves to be quite different from that of Lori. Unlike Lori, Kelsey does not deploy an army of interested others in her service, but instead prefers to work either alone or with her mother, and favors spending time working on her designs between respiratory treatments or even late at night. Kelsey seems to engage in design for its own sake, rather than primarily as a catalyst for social interaction. In addition, the solutions that Kelsey proposes to the problems she faces in the hospital are more commonly inspired by the systematic exploration of the materials available at hand than by fortuitous trial-and-error discoveries or analogical noticings. For example, when Lori designed her doorbell, she did not spend any time planning ahead for the kinds of materials she would need, instead satisfying herself in the moment with materials that "could work" and making alterations if these

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materials did not complement the design. In contrast to this primarily trial-and-error design

method, when Kelsey designed both her doorbell and her nightline, she came up with a well

thought-out plan for the kinds of materials she expected to need. Kelsey explained, "I chose my

materials by thinking of what would best fit the objects I was sticking my designs to." She

elaborated further:

> To build my inventions I sat down with all the material and thought of the best way to put
>
> it all together. I ran all my ideas by my mom first to see what she thought. Once I knew
>
> what I wanted to make and what I needed, the two inventions were simple to make. I ran
>
> into a few problems, but once I solved them the design was a breeze (Kelsey, 10/2014,
>
> Interview).

Consistent with this methodical approach to her design process, Kelsey seemed to be

almost as interested in the meticulous documentation of her design process as she was in the

design process itself. Kelsey was extremely proud of the two journals that she had created to

document the design and creation process of her nightline and TAP doorbell inventions. These

design journals are intended for an audience that Kelsey clearly anticipates — other young

patients in the hospital who might also potentially have the opportunity to use the mobile

Makerspace. Kelsey made it very clear that she was eager for me to share these journals with

other children, and remarked:

> I think that other people would enjoy my invention because this way they have a book of
>
> instructions for it, so if they wanted they can go through my instructions and improve on
>
> the ideas and change them and find other ways to make a doorbell or nightline. Not
>
> everyone is going to use a Cheez-It box or a pressure sensor. It was just how I made it,
>
> and then if somebody has got the instructions for it, then they can change it up and make

it their own. But I really think others will enjoy my doorbell and nightline, and my book of instructions. It's just so they can get new ideas, change things up, and make them how they want. But if they get the chance to make a doorbell, then I would like to see it and know their ideas. […] I would advise that anyone in the hospital wanting to make an invention shouldn't be scared to mess up. They'll learn what works and what doesn't. Take a risk on all your ideas (Kelsey, 10/2014, Interview).

After the thrill of the excitement from her two successful creation experiences with the mobile Makerspace, Kelsey also admitted that she was disappointed by the fact that her two weeks in the hospital were soon coming to an end. She told me, "Designing stuff in the hospital really expanded my knowledge and expanded my expectations of myself. I felt like I wasn't sick anymore once I wasn't in bed all the time. I had something to do." Kelsey also explained how using the mobile Makerspace was unlike projects she did at school:

The difference between this project and projects for school is this one is kinda fun and it's not like you have a due date for it. You can just go day by day, put little pieces together, come up with ideas. Because, you know, you are in the hospital because you are sick, so it's not like you have to hurry up and put all your medicines aside to do this project. I thought it was really cool just to relax and work on these…I felt like working (Kelsey, 10/2014, Interview).

CHAPTER VIII

CASE 3, THE ROLE OF COMMUNICATION IN DESIGN: HAYLEY

The focus of the next case, which spanned only four days, is Hayley, an 11-year-old

CF patient. This case highlights the pivotal role of communication in design. Hayley was first

diagnosed with CF when she was just two years old. Sadly, her younger brother passed away

because of CF at only five months of age. As her mother, Jennifer, explained,

> He never came home from the hospital. I guess you could say his situation was more
>
> severe. So he was here at the hospital for five months. This is Hayley's seventh
>
> admission to do a tune-up. It's been a year and two months since Hayley was last
>
> admitted. So in our world that seems terrible, but we are hearing that's really good in the
>
> CF world (Jennifer, 11/2014, Interview).

Hayley referred to her CF as "nasty snot," saying, "I have to do extra stuff to get it out" (Hayley,

11/2014, Interview). Like most CF patients, Hayley does not enjoy being at the hospital. She

elaborated, "It's not fun being hooked up to a cord all the time, because in the middle of the

night when you have to use the bathroom, you have to drag it along with you. It's not fun!"

Being sequestered during hospitalization is especially challenging for young patients like

Hayley. Jennifer explained:

> Hayley can't leave the room. We can come and go – we can go downstairs and get her
>
> things, we can leave – but Hayley can't leave the hospital room. So we have to find
>
> things to entertain her within the room. We have grandparents that come and stay with
>
> her. We have parents that take turns, we have aunts and uncles that come and visit and

lots of friends. Anybody can come and see Hayley, but she can't go out. So getting to go

to physical therapy for thirty minutes is like a fun field trip out of the room. If you are

stuck in a room for two weeks, that would be the highlight of your day! (Jennifer,

11/2014, Interview).

Indeed, Hayley excitedly agreed that stepping outside the room for physical therapy is, in her

words, "Fun!!!! The best part of the day."

Timeline/Data Sources

I introduced Hayley to the mobile Makerspace during the final four days of her treatment.

Hayley was not interested in documenting her design and making processes by herself because

she found the task to be too cumbersome and boring. Instead, Hayley asked me to help her create

a short movie that would explain the evolution of her design. As Hayley explained to me, "You

would be the 'cameraman' and I would be the actor and director in the movie." Serving as the

cameraman, I was able to take videos and pictures of Hayley's design sessions, which primarily

occurred in the afternoons. Types of data included video- and audio-recorded interviews with

Hayley during on-going design sessions, as well as additional videos and pictures documenting

Hayley while at work during her design and problem-solving experiences, in the presence of

both family members (e.g., her mother and grandmother) and/or a variety of healthcare providers

(e.g., nurses and respiratory therapists).

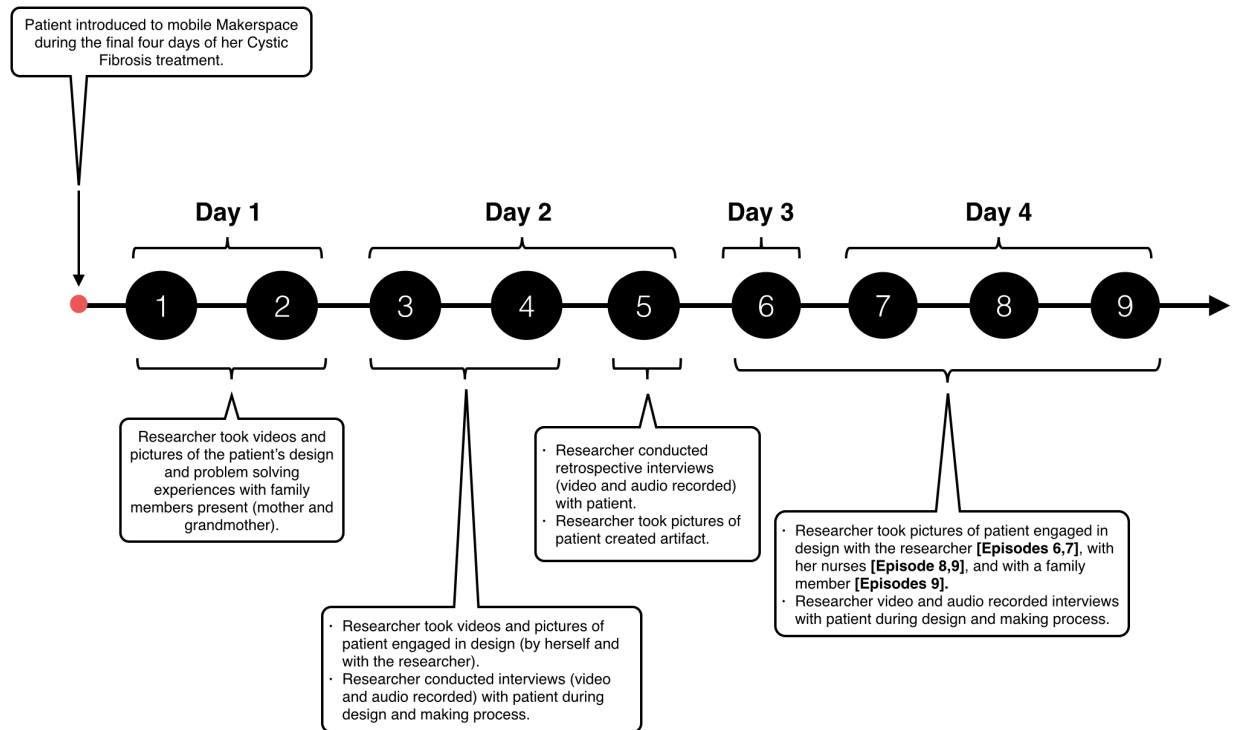*Figure 29*. Timeline notational system: Hayley

Episode 1

Just as Hayley was about to start exploring the mobile Makerspace, a respiratory therapist

entered her room to provide routine treatment. Hayley decided to play around with the littleBits

to keep herself entertained while she was undergoing her airway treatment (Figure 30).

Figure 30. Hayley playing around with littleBits during airway treatment

After one of the littleBits modules in particular caught Hayley's eye, I explained to her that the

remote trigger module she had spotted actually allows the user to make use of a common remote

control device to trigger the littleBits circuit remotely. Upon hearing this explanation, Hayley

immediately looked at her mother and exclaimed, "I have an idea!!!" Hayley realized that she

could use the littleBits and the remote control to create a device to alert the nurses to her beeping

I.V. pole in a quicker and more effective way than the mere use of her bedside call button. The

following excerpt recounts the conversation that followed (Videorecord, 11/2014):

> Hayley: I don't want to listen to this thing [the I.V. monitor] going off all the time, and
>
> when my door is closed, it makes it really hard for them [the nurses] to hear this going
>
> off. It wakes me up and I have to hit the nurse button, tell them my I.V. is beeping, then it
>
> takes, like, five minutes for them to come in, switch it off, and then it takes another thirty
>
> minutes to get back to sleep. That happens around two or three times a night, and it's not
>
> very fun.
>
> Jennifer: So your goal is for this [the littleBits alert device] to what?
>
> Hayley: Is for it [the littleBits alert device] to work and to be outside the door, so
>
> whenever this [the I.V. monitor] goes off, I can go like this [press the remote control to
>
> trigger a buzzing sound from the littleBits alert device] for the nurses to know that my
>
> I.V. is going off and for them to change it.

After explaining her idea to her mother, Hayley quickly assembled a littleBits circuit that

included a power module, followed by the remote trigger (input) and a buzzer (output). Once

Hayley's airway treatment was completed by her respiratory therapist, she quickly got out of her

bed to test out her design. Since she was still wearing the treatment vest and was attached to the

I.V. pole, Hayley asked her mother to go outside the room in order to give her instructions on

where to place the littleBits circuit. Hayley carefully directed her mother, "It's going to be right here, so sit it right here [on the outside of the glass window beside her room door]" (Figure 31). While Jennifer held the littleBits in place on the surface of the glass, Hayley pressed the button on the remote from inside the room, which caused the buzzer within the circuit that Jennifer was holding to make a loud buzzing sound. Jennifer began to laugh as she heard the sound, while Hayley shrieked and jumped, yelling, "Oh my God! It works!"

Figure 31. Hayley providing her mother, Jennifer, with instructions

Next, Hayley asked her mother to come back inside the room and return the littleBits creation to her since she already had another idea in mind for her newly-minted device. Hayley wanted to attach an LED wire to her design so that this way she could use both sound and light to attract the nurses' attention. Quickly attaching the LED wire to the littleBits device, Hayley once again asked her mother to go outside the room and position the creation on the glass window. Once Hayley determined that her mother had placed the device in the right location, she pressed the button on the remote control. Immediately, the LED wire lit up, accompanied by the loud sound from the buzzer. Jennifer opened her mouth wide with shock, while Hayley began to jump up and down, shouting, "Yayyyy!!!" Jennifer encouraged Hayley to press the button again. Each

time Hayley pressed the button, the littleBits device would light up and emit the buzzing sound, causing quite an exciting scene outside the room for the many people passing by. With a laugh, Jennifer responded to the curious onlookers, "Sorry we are disturbing everyone while making noises!" Hayley yelled to a family passing by, "Sorry! We are doing an experiment!"

Episode 2

Soon after she tested out her new creation, Hayley's grandmother walked into the hospital room to take Jennifer's place as the adult responsible for staying with Hayley through the night. Jennifer excitedly told her mother, "You have to see what Hayley made!" and took the littleBits creation from Hayley to show her mother how it worked (Figure 32). The following excerpt describes the conversation between all three family members about Hayley's new alert device for her I.V. monitor.

Jennifer: Keep in mind this [the littleBits alert device] would be in a box outside the door [Jennifer holds the littleBits creation outside the glass]. It's dark in the room and her I.V. is done. Rather than waking everybody up, hitting the red button, and saying, "My I.V. is beeping," she does this….

[Jennifer looks at Hayley.] [Grandmother looks at Hayley.] [Hayley presses the button on the remote.] [The light and sound go off on the alert device.] [Grandmother turns to look at the littleBits alert device that Jennifer is holding outside the door.]

Jennifer: It [the littleBits alert device] lets her nurse know the I.V. is going off.

Grandmother: Oh, cool!

Jennifer: Her I.V. is going off, without having to wake the parents and wake the child.

Grandmother: How cute!

Figure 32. Jennifer explaining Hayley's design prototype to her mother

Episode 3

The following afternoon, I came back to see Hayley, who told me that she could not find

a box the right size in which to enclose her littleBits creation. Jennifer had previously suggested

the use of a box to contain the alert device in the appropriate position on the glass window

outside of the room door, but the only boxes available in her room were either too big or too

small. Given that Hayley could not find an adequate box from among the boxes in her hospital

room, she had requested earlier in the day that Child Life services provide her with a box.

Unfortunately, the box that they supplied was very thin and light-weight, and therefore was not

strong enough to sustain the weight of the littleBits. Unhappy with her inability to find a box

close at hand, Hayley decided to create her own custom box with the 3D-printer available for use

in the mobile Makerspace. I asked Hayley why she wanted to use the 3D-printer to produce a

suitable container. She responded,

> If we use paper, it wouldn't be stable. And this [showing a bracelet that I had previously
>
> created for her during the initial activities that I conduct to introduce the mobile

Makerspace to all patients] is, like, really, like, thick and hard to bend (Figure 33). With

paper, it's so easy it could fall and rip. Well, the paper right now is very thin. And, like,

the weight of the circuits and all that, is very, very, very…well, I guess it's medium-ish

weight; it's not heavy, but it's not light…and yeah…we just need it stronger (Hayley,

10/2014, Interview).

Figure 33. Hayley showing off her bracelet created from the 3D-printer

Episode 4

Since Hayley wanted to use the 3D-printer to support her design, I asked her to first

design a prototype or model to demonstrate what she envisioned for her box. Uncertain of what I

had meant by this request, I clarified for Hayley that in order to print out a box using the 3D-

printer, we would need to use software to create it, which would first require us to know the

exact dimensions of the box she had in mind to house her littleBits creation. I asked Hayley if

she could use physical materials to create this model of her box. I explained that once she

prototyped a box that satisfactorily fit the dimensions of her littleBits device, we could then use

those same dimensions to create a model using the 3D-printer software on the Dell tablet. To

create her box prototype, Hayley requested thick construction paper and a measuring tape. By the

time these materials were gathered, it was late in the day, and Hayley needed to rest. Before

taking my leave, I told Hayley that I would come back the next day to see the progress of her

prototype. In the interim, Hayley used the measuring tape to measure out the length, width, and

thickness of her littleBits creation, and then cut one of the rectangular sheets of construction

paper to fit those dimensions.

Episode 5

When I saw Hayley the following day, she greeted me with a big smile, and said, "I

completed the box!" Showing me the finished box prototype, Hayley explained, "This is the

design I wanted the box to look like. I wanted to have a hole in here for a light to come out of it.

I wanted another hole right here for where the stuff [the littleBits alert device] can lay in the box,

and for it not to fall out. And so here is my design for the box." As Figure 34 illustrates, Hayley

had drawn a black, rectangular outline on the back of the box to show an opening inside of which

the littleBits device would be placed. In the front of the box, she created a small hole to allow the

light from the LED wire to stick out.
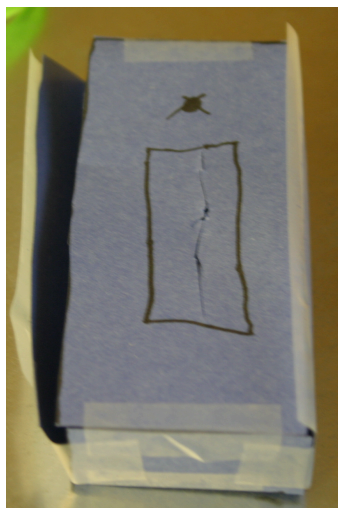
Back   Front

Figure 34. Back and front of paper box prototype

Episode 6

With the paper version of the box model now complete, Hayley and I began to design the final-form box using a 3D-modeling software program called Tinkercad. Tinkercad is a free, easy-to-learn, online application that anyone can use to create and print 3D models. Once we completed our box design with the help of Tinkercad, we transferred the completed design file to the 3D-printer. Since this version of the box would take a little more than three hours to print, and it was already late in the afternoon (around 4:00PM), I told Hayley that I would come back first thing in the morning to run the 3D-printer. Before I left, Hayley asked me if she could use the 3D-printer later on to create a tag with the word "nurse" on it. She planned to attach this tag to the completed box to let nurses know that the device she had created was specifically intended for them.

Episode 7

The following morning at around 10:30AM, I was back at the hospital to run the 3D-print job and thereby create the rectangular box for Hayley's littleBits device (Figure 35). While the box was printing, I periodically came into Hayley's room to check on the status of the box, which was finally completed at around 1:30PM. Hayley excitedly removed the finished box from the printer and placed it on the surface of the mobile Makerspace. She then picked up her littleBits creation and placed it inside the opening on the back of the box. Unfortunately, the box turned out to be a little too small to fit the entire littleBits creation. However, since Hayley was going to be discharged from the hospital the next day, we did not have time to make a revised version of the box. Designing and printing out a new box would once again take several hours to print, so Hayley and I had to come up with an innovative solution to modify the box so that the littleBits materials could better fit inside.
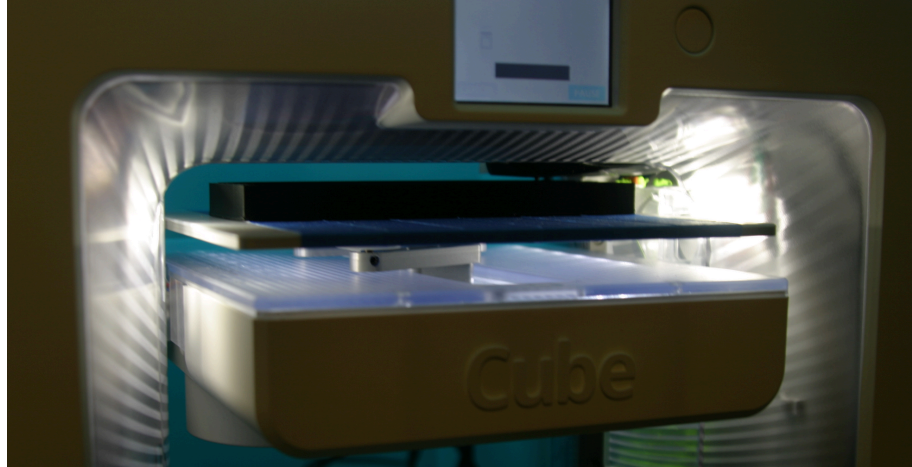
Figure 35. 3D-printer creating the box

I asked Hayley what she thought we should do to resolve the current problem with the box design. Hayley responded, "We need something to balance it," meaning that the wire from the littleBits power cable that connected to the battery needed to be aligned so as not to protrude out from the box. If the littleBits creation did not fit completely inside the box, then the wire from the power module would "lift up," causing this module to detach from the remote trigger input module. But Hayley came up with a clever solution using Play Dough found in one of the storage drawers of the mobile Makerspace, proposing that the entire opening of the box be filled with Play Dough and that the littleBits creation be positioned on top. That way, the entire circuit would be on a level surface, thus preventing the detachment of the power module cable wire.

Hayley emptied out the Play Dough from its containers and used it to fill the open space of the box all the way to the top. She then carefully pushed the littleBits creation into the Play Dough surface, which also served as an adhesive that would allow all of the parts to stay together should the device be inverted. However, after Hayley turned on the power switch in the littleBits circuit, no light came on. Then I remembered from the earlier incident with Kelsey (from Case study #2) that Play Dough actually conducts electricity. I told Hayley about Kelsey's experience and then advised her to try using sticky tack instead, as sticky tack acts as an insulator and

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therefore would not disrupt the littleBits circuit. Since we had access to a very limited amount of sticky tack, I suggested putting a thin layer of the sticky tack over the Play Dough and then replacing the littleBits device on top. After following these instructions, Hayley once again tried power switch — and this time, the light came on (Figure 36). It worked! Hayley then quickly took the remote control and pressed a button to test out the completed device, successfully activating both the sound of the buzzer and a flash of the LED light.
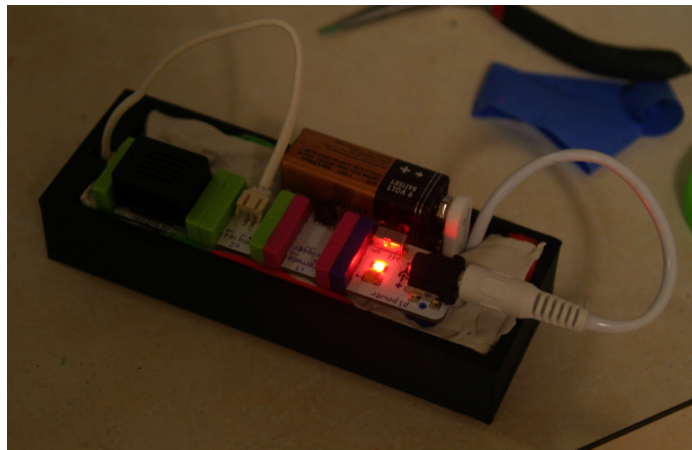
Figure 36. Hayley's completed design

Episode 8

Pleased that the littleBits creation now aligned with the box, Hayley set about finalizing all of the finishing touches of the design. As she was working, a nurse came in to check on Hayley's I.V. pole and asked Hayley what she was working on. The following excerpt is from a conversation between Hayley, her nurse, and myself (Videorecord, 11/2014).

Hayley: That sound [the I.V. monitor] gets really annoying. After about two minutes, if the nurse doesn't hurry to the room, it's very annoying. And there is a silence button, but that silence button only lasts for thirty seconds.

Nurse: But we are not supposed to touch the silence button.

Hayley: Exactly. And that is why we are creating this thing [the littleBits alert device]. Because this [the I.V. monitor beeping] is annoying to us, and the nurses are so used to it that they just like silencing it out [the nurse laughs nodding his head]. So this new noise [from the littleBits alert device] is going to get on their nerves.

Nurse: I think we don't silence it out. The problem is, we will have a problem understanding what that is [the littleBits alert device].

Hayley: Well, this noise [from the littleBits alert device] means that this [the I.V. monitor] is beeping and that it needs to be taken care of right away. Because in the middle of the night, when you are sleeping, it will wake me up and my mom up. So then it takes two minutes to thirty minutes for them to get in here to make that stop, and then it takes you another ten minutes to get back to sleep.

Gokul: So, why does it take so long for the nurse to get here?

Nurse: Well, maybe we are in another room with patients.

Gokul: So when Hayley presses the silence button, who does that alert?

Nurse: That alerts the nurses' station. And the receptionist pages us out.

Hayley: And when sometimes they are in another room, they don't hear it.

Nurse: We do listen to those alarms, but you would need to let your nurse know what that alarm [the littleBits alert device] is.

Hayley: And in the middle of the night, I have to wake up and say my I.V. is beeping. And basically with this [the littleBits alert device], we are trying to do the same thing, but not have them wake us up to talk to them about what the problem is. So like, when this [the littleBits alert device] goes off, it means specifically that there is an I.V. beeping.

Nurse: You might need to educate the nurse on that.

Hayley: You understand it!

Nurse: I know, you educated me now.

Hayley: So whenever they hear this [the littleBits alert device], the nurse would know my I.V. is going off.

In this excerpt, Hayley explains the concept behind her invention and answers the nurse's questions. This problem of I.V. monitors beeping at night when medicine runs out is extremely common. As Hayley told me, "Although we can push the silence button on the machine, we can't turn off the machine, so we have to wait on the nurses. The nurses have a lot of patients, so it sometimes takes them a little while to get to one patient." The noise from the I.V. monitor tends to annoy the patient and disturb their sleep. The nurse in the conversation above disagrees at first with Hayley with the idea that nurses "silence" out the alerts they receive, reminding her that the nurses are assigned to care for multiple patients every night, so it can sometimes take a while for them to get to each patient's room. The nurse also informs Hayley of the need to "educate" other nurses about the purpose of her littleBits device. Since a children's hospital is always full of noises, the sound of the littleBits buzzer could be confusing or misleading for nurses who do not know what that noise is. This conversation between the nurse and Hayley challenged Hayley to explain and justify her creation to an actual user (i.e., her nurse). Furthermore, Hayley's nurse's legitimate concerns also inspired a minor design revision. Since it would be impossible to explain her device to every nurse passing by, Hayley used a silver marker to create a note on the surface of the box that read, "My I.V. is beeping" (Figure 37). In doing so, she thought that the noise and light emanating from the littleBits device would draw the nurse's attention to the label, notifying them that it was time to change her I.V. medication.

Figure 37. Hayley labeled her device using a silver marker and 3D-printed tag

Episode 9

After finishing the final design of her littleBits alert device, Hayley recruited her aunt to help position the completed device on the glass window outside of her hospital room door. Hayley pressed the button on the remote control, and to her delight and satisfaction, the LED light flashed and the buzzer sounded. After successfully testing out the device, Hayley called her main nurse to get final approval for the use of her new creation. Hayley demonstrated the littleBits device for the nurse, who responded, "That is cool! Then we will know when we're outside your room and the door is closed that your I.V. is beeping." Confirming that she approved of the use of Hayley's invention, the nurse looked at Hayley and said, "You can use it during your stay."

Discussion

This case highlights Hayley's growing understanding of the importance of communicating the purpose and operation of her design to her "clients" (i.e., the nurses). As Hayley navigated the design process, she quickly realized that the purpose of her design was not as transparent to others as it was to her. The initial impetus for her design sprang from her

annoyance at having to constantly deal with noisy interruptions caused by her I.V. monitor. In response to this particular predicament, Hayley in turn came up with a device intended to annoy the nurses, and, at the same time, to grab their attention so that they would come to her room as quickly as possible to resolve the I.V. monitor issue. However, Hayley soon realized that she would need to further "educate" her clients in the hospital in order to better communicate the functionality of the design so that, rather than simply annoying (or even alarming) her nurses, it would actually serve the more practical purpose of helping the nurses prevent the equally annoying disruptions that Hayley faced with her noisy I.V. monitor. The conversation between Hayley and her nurse is especially important because it provided Hayley with her first true forum to explain her creation to an actual user (i.e., her nurse) and, in turn, this interaction inspired Hayley with the idea of labeling the device so as to communicate her design effectively and without ambiguity. As a result, Hayley felt comfortable leaving her littleBits device, positioned and ready for use outside her door, knowing full well that other nurses would be able to clearly understand its uses and meaning.

CHAPTER IX

CASE 4, DISSEMINATION OF DESIGN IDEAS ACROSS ENVIRONMENTS: MOLLY

The focus of the next case, which spanned only three days, is Molly, an 8-year-old CF patient. This case highlights how ideas can disseminate both within the hospital (e.g., design ideas shared between patients) and beyond the hospital into the outside world (e.g., designs that can be applied to the patient's life outside of the hospital). Molly was first diagnosed with CF when she was just three years old. Molly's mother, Hillary, explained,

> "Having no right medicines or treatments for three years has already caused damage to her lungs. The right lung already has scarring to it from the infections that were never treated the right way. Our lives were forever changed! Molly has to go in for tune-ups every four to seven months" (Hillary, 2/2015, Interview).

Soon after I introduced the mobile Makerspace to Molly, a respiratory therapist came into the room to do a hypertonic saline treatment for Molly. Since I was not familiar with this particular therapist, I quickly described the mobile Makerspace to her and explained the kinds of activities in which Molly would be engaged. After hearing my explanation, the respiratory therapist expressed excitement and said, "Two weeks in this jail cell, they start going bonkers. It is hard on them. Parents can come and go; the kids are stuck here…it's rough. You know, we try to make it as good for them as we can, but it's just hard…I would go crazy" (Natasha, 2/2015, Interview). Before leaving, I asked the respiratory therapist if she would brainstorm project ideas with Molly and, if possible, take videos of their interaction. Since hypertonic saline treatments take around twenty minutes to complete, this allows time for the respiratory therapist to interact

with the patient on projects and tasks while at the same time keeping herself occupied in a meaningful way, rather than just sitting still on a chair next to the bed, watching the patient undergo treatment. I repeatedly observed that the patients and the hospital staff tended to interact together with the mobile Makerspace materials during moments like these when the staff member was present for an extended time (e.g., during a treatment) and not otherwise actively occupied. Hospital stays typically feature many such "empty" interludes, when patients' ongoing activity is interrupted, leaving both patients and caregivers together in close proximity for an extended period of time. During these periods, patients and staff seemed to turn to the Makerspace as a resource for framing and shaping their social interaction.

Timeline/Data Sources

I introduced Molly to the mobile Makerspace during the final three days of her treatment. As with 15-year-old patient Kelsey (Case study #2), most of Molly's designing and making happened in the evening, a schedule that unfortunately prevented me from directly observing her design sessions. Also like Kelsey, Molly created videos that included step-by-step instructions detailing how to recreate her design. To better understand her thought processes, I was later able to video- and audio-record interviews with Molly and her family members. Other types of data included videos taken by Molly's respiratory therapist, who recorded Molly exploring the littleBits kits and coming up with ideas as she completed her respiratory treatment. Of particularly notable importance is the fact that, in this case, I was also able to capture a video of the first virtual collaboration between two patients in a hospital: the collaboration between Molly and 17-year-old patient Lori (Case study #1) via the use of two mobile Makerspaces.
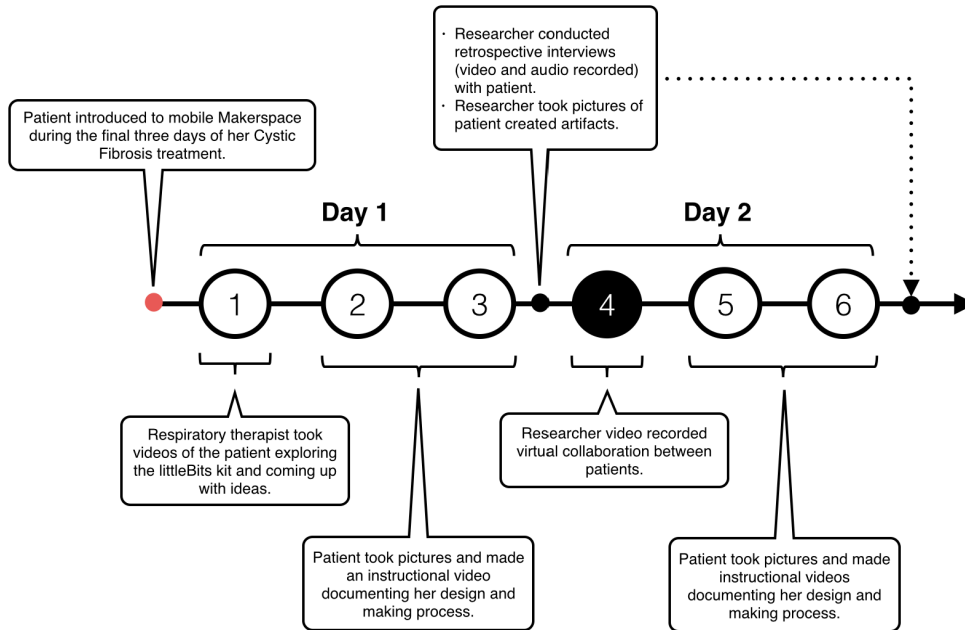
Figure 38. Timeline notational system: Molly

Episode 1

As Molly underwent her routine hypertonic saline treatment, she began to play around with different configurations of littleBits modules, exploring a variety of input and output configurations. While Molly fiddled and worked with the littleBits, the respiratory therapist became curious and began to engage with Molly in her exploration, posing questions to her such as, "What part is that?" "What does it do?" and "How does it work?" (Figure 39).

Figure 39. Respiratory therapist engaging with Molly in her design and making process during breathing treatment

The following excerpt describes one such interaction between Molly and her respiratory therapist. In this particular scene, Molly is attaching a light sensor to a buzzer module while the respiratory therapist engages with Molly by posing questions, assisting with testing of the device, and all the while ensuring that Molly was properly performing her breathing treatments (Videorecord, 2/2015).

Respiratory Therapist (RT): Which piece are you using?

[Molly shows the RT the light sensor.]

RT: Ok, we will turn the light on [turns the light on and off]. So you have the sound effects on the light sensor.

[Molly nods.]

RT: So when the light goes on and off, you can choose whether to get the sound effects to go on and off when your light is on and off. Nice! Stick that on real good. Push it real hard [fixing Molly's nebulizer].

[Molly removes the buzzer and attaches a motor.]

RT: What does that one do? Do you know? What part it is?

[Molly shows the part, then takes another module, output fan, and attaches it to the motor.]

RT: Is that a fan? It is a fan!

[Molly gives the RT the fan.]

RT: Nice!!!! There's the fan. Hey! Put that to your light sensor — the fan — and when we turn the lights off, the fan will come on.

After an additional five minutes of playing with the light sensor, Molly decided to

create a circuit with a pushbutton and a buzzer. The respiratory therapist proposed a

variety of potential ways to use Molly's invention (Videorecord, 2/2015).

Molly: I invented a doorbell!

RT: A doorbell! Congratulations on your great invention of the doorbell. I really

like the doorbell.

[Hearing the buzzing noise, another staff member stops by and pops her head

inside.]

Molly: They probably heard the noise!

RT: They came to play with the contraption here. That is really creative! I wonder

if they will allow you to put it outside your door, and everyone who comes in

could ring your doorbell.

Molly: I need a box then!

Episode 2

After coming up with the idea of designing a doorbell, Molly began to search for an

appropriate box in which to enclose her littleBits circuit. "It took a long time to find the box,"

said Molly (Molly, 2/2015, Interview). She opened all of the storage drawers, searched inside the

bathroom, and stood on a chair to see if her mother and grandmother had stored any boxes on the

shelves over the desk. No luck; there was no box to be found. Just as Molly was about to take a

nap, she saw a Kleenex tissue box next to her bed. Quickly, she grabbed the tissue box and

removed all of the tissue paper. Molly then took her littleBits creation and carefully placed it

inside of the tissue box through the top opening of the box, where the tissue comes out.

However, as soon as Molly lifted the box to stand it straight on one end, the littleBits moved and

fell apart. To keep the littleBits creation intact, Molly first removed the littleBits from the box and began to position one stack of tissue paper on each side of the box to keep the littleBits in place. Molly said, "I took all the tissues out and put all the tissues on the side of it so it [i.e., the littleBits circuit] wouldn't be leaning on top, and then I put the little thing [the littleBits] in here. That's why I need tissues…to keep it straight!" Molly's idea of using tissue paper as a means of keeping the littleBits stable worked perfectly. She further tested out the successful stabilization of the littleBits circuit within the box by flipping the box vertically and horizontally.

Episode 3

Finally satisfied with her design, Molly began to decorate her tissue box. "I started decorating it with two pieces of tissue paper, but it got tored off, and then I put stickers on it." Molly had initially hoped to wrap the entire box with a thin layer of tissue paper, but unfortunately the thin paper kept tearing, forcing Molly to abandon that idea and instead decorate her box with Disney stickers which she had received from the art therapist earlier in the day. Once Molly finished decorating her box (Figure 40), she attached two strips of the double-sided tape found in the mobile Makerspace drawers to the back of the box and took her finished creation to the door entrance. As she was not allowed to step outside her room, she asked a nurse standing outside to help her stick the box to the front of the door.
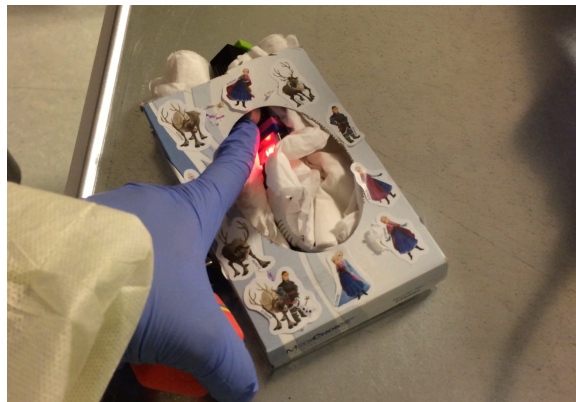

Figure 40. Molly's decorated doorbell

Designing a doorbell had inspired Molly. Her grandmother later told me, "You know what she [Molly] said she wanted to do after that [creating the doorbell]? She said, 'I can make arms and legs for little kids that didn't have any.' So Molly's going to be an engineer!" (Grandmother, 2/2015, Interview). Molly confirmed, saying, "I want to when I grow up!" Her grandmother explained to me, "It gave her some ideas." She confessed, "When you first brought that [mobile Makerspace] in, I was quite skeptical. She was seven years old, but I was surprised how into it she got."

Episode 4

The following day, when I saw that Molly had designed a doorbell, an idea suddenly popped into my head. Seventeen-year-old patient Lori, who had also designed a doorbell (refer to case study #1), was back in the hospital and currently had a second, revised mobile Makerspace in her room. I thought that it would be a great idea for Molly and Lori to communicate with each other via Skype using the Dell tablets provided by the two mobile Makerspaces so that they could better explain their ideas to each other. After a virtual introduction, both Lori and Molly discussed how they had each designed their doorbell and some of the challenges they had faced in the process, in addition to brainstorming ideas for possible future projects. Figure 41 shows both patients virtually collaborating with each other. This resulted in the first case of virtual collaboration between two patients with chronic illnesses isolated in their hospital rooms.
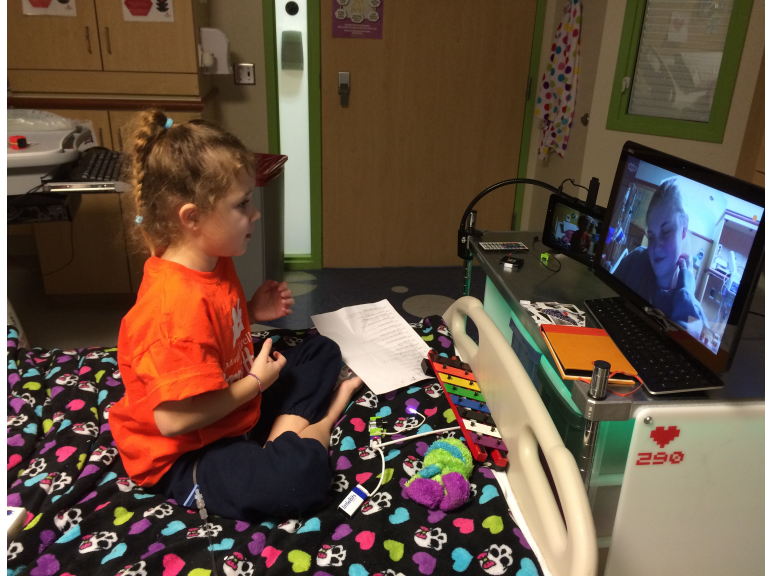
Figure 41. Virtual collaboration between Molly and Lori

Episode 5

Inspired by the experience of her virtual collaboration with Lori, Molly quickly determined that she did not want to stop with just the creation of a doorbell. She sat down with her mother for several minutes to brainstorm new ideas. Eventually, Molly identified a recurring problem that she faced, telling her mother, "I can never see my pills at night at home!" To resolve this issue, Molly decided to create a night light for her pill cup (Figure 42). CF patients like Molly take multiple pills during the day that help enable proper digestion, both at the hospital and at home. At home, when Molly wants to have a bedtime snack, she is forced to turn on the room light to see the many pills that she must take along with her food. Every time she turns on the light, the pet dogs that sleep in the room with her wake up and start barking. Using a small, lighted pill cup rather than turning on the main room light, Molly could avoid disturbing the sleeping dogs, and likewise the peace of the home. Hillary, Molly's mother, explained this in more detail:

Molly's body doesn't digest food because this mucus in the body has blocked her

pancreas, so every time she eats she has to take enzymes to digest her food! They only

last an hour! She has to take four of them. As she gets older, she will intake more food, so

she will have to take more pills to digest the food right way. So at night if she wanted a

bedtime snack, we had to turn the lights on so she could see where her pills were and

always woke up the dogs at home. Now this way she could take her meds without

disturbing anyone (Hillary, 2/2015, Interview).
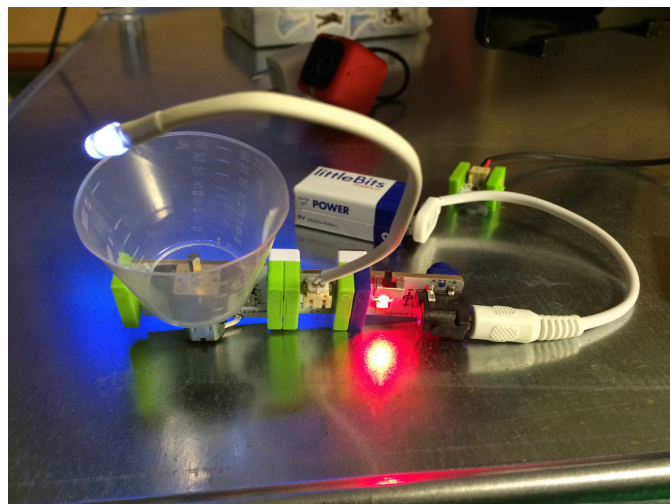
Figure 42. Molly's pill cup night light

Using the Polaroid Cube video camera, Molly created a small instructional movie to

document how she came up with her design (Molly, 2/2015, Videorecord) (Figure 43).

Picture 1. We always have to start with the blue piece [the power module].

Picture 2. And now I am going to take this [the motor] and stick it on there [the power

module].

Picture 3. And now I am going to take this [the LED wire] and stick it on there [the

motor] too. Why do we need a light though? And why do I need a pill case?

Picture 4. And now I am taking the pill case and putting it on top of this [the motor shaft].

Picture 5. I am going to curve it [the LED wire] a little bit. Now it's curved. Why do I need it curved though? Maybe for something cool? We will see.

Picture 6. Now I am going to put it on [turn on the power]. Now guess what it will do? Why would you need a pill case and a light? Weird! But watch this! It's a thing so you can see your pills at night.
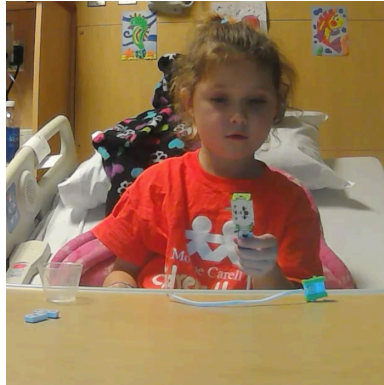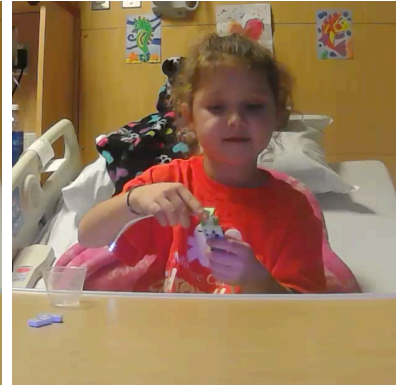
| Picture 1 | Picture 2 | Picture 3 |

| Picture 4 | Picture 5 | Picture 6 |
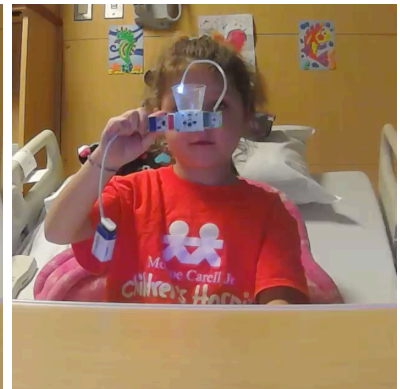
Figure 43. Molly's instructions explaining assembly of her pill cup night light

Episode 6

The following day, I came back to check up on Molly's progress. As soon as I entered the room, I was scared by a sudden, loud buzzing noise. The source of this alarming sound turned out to be none other than a prank device created by Molly, as shown in Figure 44.

Figure 44. Molly's prank device placed outside her door above the hand hygiene station

Molly had attached her device outside the door on the glass window above the hand hygiene

station. As soon as an unsuspecting victim (such as myself) entered her hospital room, Molly

would "prank" or scare them by pressing a button on a hand-held remote control, which would

then trigger a noise to sound from her device in the box on the door. To make this contraption,

Molly had repurposed and redesigned her original doorbell design by making a small change the

night before: she had replaced the push button from her first design with a remote trigger, which

could now activate the device with the press of a button. Molly had been inspired to transform

her doorbell design into a prank device by her recent conversation with Lori during their virtual

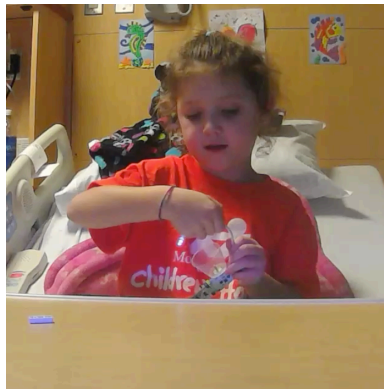collaboration session. Lori had told Molly about a prank device that she was creating using the

littleBits and other materials from the mobile Makerspace, an idea that Molly found to be

particularly appealing. When asked why she wanted to create a device to prank people, Molly

simply replied, "I never have. I always wanted to!" When I asked Molly how many nurses she

had scared and how they had reacted to her device, she said, "I scared four of them! They

jumped up!" Molly had another idea to scare nurses using her prank device. She said, "I can ask the nurse to give me a tissue, and then I could press a button to scare her!" Molly's mother, Hillary, responded, "If she had the cart from the day we got here, there is no telling what she would do. She would have booby-trapped everything in here."

Mischievous devices intended to surprise the staff show up in the creations of several of the patients. Perhaps this particular type of design is so popular because it provides patients with a safe but satisfying outlet for pushing back against their hyper-controlled, hyper-scheduled hospital existence. Although patients express a great deal of affection for the hospital staff, they also inevitably become disgruntled with the many ways in which the staff control and constrain their existence, from enforcing rules about restricting patients' mobility and visitors to implementing a schedule of treatment that disrupts patients' chosen activities and even their rest.

Discussion

This case highlights how ideas can disseminate both within the context of the hospital and far beyond the confines of the hospital. A wide variety of people – including fellow patients, family members, and hospital staff – play an important role in inspiring Molly's design and making process. For example, when Molly interacted with the mobile Makerspace for the first time, her respiratory therapist engaged with her during breathing treatments while she explored the littleBits kit by posing meaningful questions, helping with user testing, and even suggesting a potential design idea (i.e., the doorbell). Molly's interaction with Lori during their virtual collaboration via the two mobile Makerspaces also played a vital part in Molly's creative process, as it allowed Molly not only to talk about her invention with another patient and to see that there were other patients like herself who were also designing and making things during long hospital stays, but more importantly still, this social context provided her with a rich source

of potential design ideas and inspiration for both future projects (i.e., the prank device) and even project revision and repurposing.

This type of people-propelled idea dissemination laid the foundation for Molly's subsequent design ideas by igniting a creative spark that transcended the boundaries of the rigid hospital setting. Spurred by a growing inner confidence cultivated by her design experiences within a strong and varied social support system, Molly became the first patient who decided to create a device that could be used at home, as opposed to only at the hospital: the light for her pill cup. This would suggest that patients' making activities may ultimately have an even longer lasting importance to them than just the time that they spend using the mobile Makerspace while they are hospitalized.

CHAPTER X

CASE 5, PURSUING ARTISTIC EXPRESSION: KRISTINA

The focus of the next case is Kristina, a 14-year-old CF patient who spent many days at

the hospital by herself. My first encounter with Kristina was in February of 2014 (see shoebox

activities, page 19), when she designed and built a rotating suncatcher. Kristina has been coming

to the hospital since she was four years old. During hospital admissions, Kristina's mother,

Sandra, stays with her daughter most nights, although her father also takes turns by staying other

nights. Since Kristina's parents work during the day to maintain their health insurance coverage,

Kristina spends many days in the hospital by herself and often keeps herself occupied by

working on a variety of artistic projects that feed her creative interests. Kristina says:

> When I go into the hospital I have more time to focus and do more art work. As much as
>
> I love dance, I need a break. I even bring some of my arts supplies from home! To me
>
> arts and crafts are fun and relaxing. It's fun when other people do it with you, but most of
>
> the time I do it by myself. One, to be relaxed, but also because it's one of the things I'm in
>
> control of. (Kristina, 2/2015, Interview)

This case highlights how patients, like Kristina, choose to focus their efforts on the pursuit of

outlets for artistic expression and creativity rather than functionality.

Timeline/Data Sources

I introduced Kristina to the mobile Makerspace during the first day of her admission, late

on a Friday afternoon. After introducing Kristina to the mobile Makerspace, I told her I would be

back on the following Monday to see if she had come up with any ideas. The timeline for this

very brief case spanned only an hour-and-a-half on that Monday afternoon. During that time I was able to observe Kristina as she constructed her design, and I documented her design process with video and audio-recording interviews.
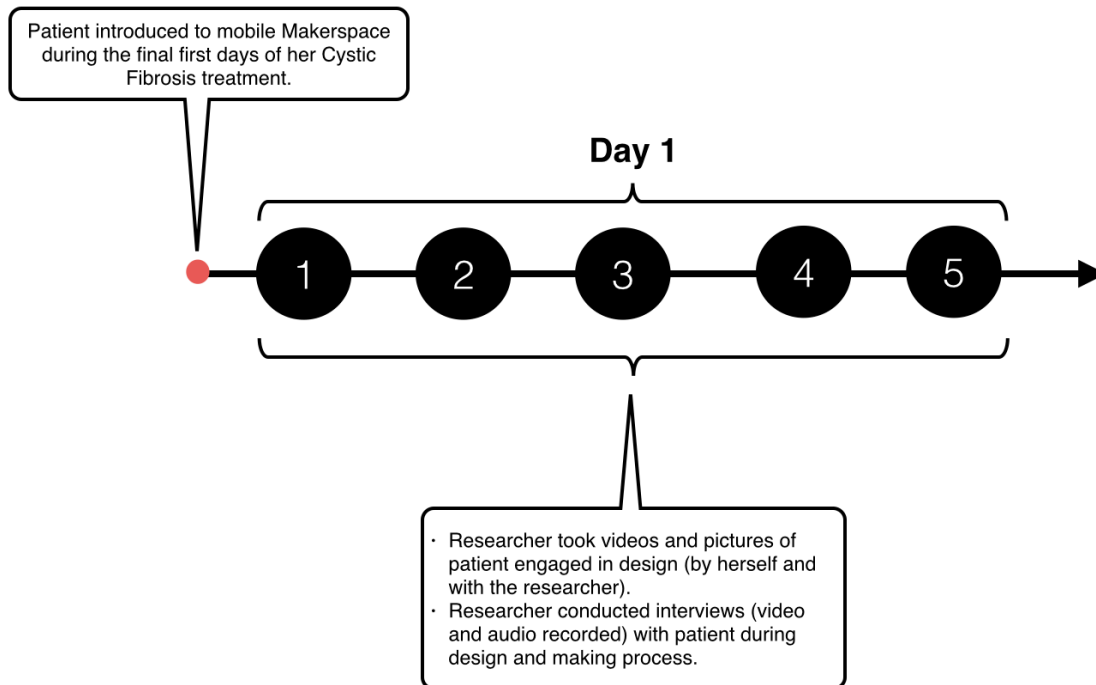
Figure 45. Timeline notation system: Kristina

Episode 1

Upon seeing me the following Monday, Kristina excitedly yelled, "I came up with an idea!" (Kristina, 2/2015, Interview). Over the weekend Kristina had been visited by friends who had asked her about the stars on the ceiling, and in particular, whether or not they glowed in the dark. Kristina explained, "There are stars on the ceiling. Everyone asks me if the stars on the ceiling glow in the dark. I am always, like, 'They do not glow in the dark.'" Every patient's room in the hospital has stars on the ceiling (Figure 46). Years ago, the stars used to glow at night, as they had been painted with a special glow-in-the-dark material. However, as years passed the stars faded and no longer glowed in the dark. So Kristina came up with an idea. She decided to

create a device that she called "Stars in a Jar" that she would use to project stars on the ceiling and walls at night.

Figure 46. Stars on the ceiling of patients' rooms

Episode 2

Kristina had already considered the kinds of materials that she would need for this project: "I needed a transparent jar, construction paper, scissors, and a marker." Kristina had all of these materials in the room except for the transparent jar. Kristina asked me to find a mason jar from the playroom, but unfortunately I discovered that there were no available jars there. Unfazed by this news, Kristina decided to use one of the Smart Jars that stored the littleBits.

Episode 3

As the next step in her design process, Kristina took some yellow construction paper and began to draw multiple stars on it with a black marker. After drawing the stars, she carefully cut each one out with scissors. However, one of the challenges that Kristina faced was that "either the stars would be either too small or too big. And [she] had to restart." Another challenge Kristina faced was that of cutting the paper to the exact height of the Smart Jar, and also sizing the width of the paper to fit precisely around the jar. Kristina explained, "I had to measure it [the

construction paper] because I still wanted to be able to open the top and shut it so I could turn on and off the light [i.e., from the littleBits]. So I had to cut it just right, so that was kind of tricky." Once Kristina wrapped the Smart Jar with the construction paper decorated with star-shaped holes (Figure 47), she began to assemble the littleBits circuit.

Figure 47. Kristina drawing stars on yellow construction paper with a black marker, cutting the stars with a pair of scissors and then wrapping the Smart Jar with the construction paper filled with star holes

Episode 4

Kristina connected a bright LED light to the littleBits power source and placed it inside the Smart Jar. Since her hospital room was bright from the light streaming in through the windows, Kristina took the prototype into the bathroom, closed the door, and turned off the bathroom light. Soon after, Kristina came out, saying, "A couple of the stars were coming out, but not as much as I wanted. How do I get the stars on the ceiling?" The problem Kristina faced was that she had covered only the side of the Smart Jar with construction paper, but not the lid. Consequently, none of the stars were projected onto the ceiling. Realizing this mistake, Kristina quickly got back to work. She measured the diameter of the lid and cut out a circle of that same diameter with the yellow construction paper. On the circular paper, Kristina once again drew stars and carefully cut them out using a pair of scissors. Then, she glued this paper onto the lid of the Smart Jar and took it back into the bathroom to test out. After testing, she exited the bathroom saying, "The light is enough, but I want more." Kristina realized that the problem

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stemmed from the fact that the light from the bright LED was not strong enough to clearly project the stars onto the walls and ceiling.

Episode 5

To make the light brighter, Kristina decided to attach another light source, a long LED light, to the littleBits circuit to "give it extra;" that is, to increase the intensity of the light inside the Smart Jar (Figure 48). After connecting the modules together, Kristina returned to the bathroom for one more trial run, and this time she came back out with a triumphant smile saying, "It works!"

Figure 48. Testing out the "Stars in the Jar" in the bathroom

Discussion

Kristina's case emphasizes the fact that she is most attracted to inventions that are primarily artistic and self-expressive in nature, rather than strictly utilitarian. In previous cases, we have seen the value that youngsters place on the attractiveness of their inventions (e.g., they decorate them with stickers and Modge Podge), but these enhancements are not usually fundamental for the functionality of their designs. In contrast, Kristina's creations are primarily intended to be artistic. Other researchers who study children's engineering projects, such as

Resnick (1990), Buechley & Eisenberg (2008), and Peppler (2013), have also emphasized the importance of providing design outlets for youngsters whose main interests are in artistic expression. Peppler (2013) uses the term "interest-driven arts learning" to refer to the idea of engaging young people in artistic creativity by using the power of new technologies. Peppler suggests a four part framework that might be used for thinking about what students can gain from interest-driven arts learning, namely: technical, critical, creative, and ethical practices.

In Kristina's case, she employed several participatory competencies while pursuing her artistic goals. For example, Kristina engaged in technical practices by learning basic programming skills (i.e., assembling littleBits modules) to create a light that could be turned on using a switch, in addition to learning how to debug when the light from the circuit was not bright enough to illuminate the stars and project them onto the walls and ceilings as she had originally imagined. Kristina also engaged in critical and analytical thinking by identifying a problem (i.e., the stars on the ceiling no longer glowing in the dark), generating and evaluating options (i.e., finding the appropriate materials to simulate an effect similar to that of the original stars), and coming up with and implementing a solution (i.e., her "Stars in a Jar" creation). Furthermore, Kristina engaged in creative practices by practically applying her artistic abilities in each step of the execution of her design project, including the precise cutting of the stars, and the careful alignment and positioning of those same stars on the Smart Jar to produce the desired illuminating effect. To maximize her creative potential, Kristina made use of additional art and craft materials that she brought from home to complement the materials provided by the mobile Makerspace. Kristina says, "When I bring my craft supplies from my house, I feel like I have more options to choose from" (Kristina, 2/2015, Interview). Thus, the mobile Makerspace lent itself well to patients like Kristina, who tend to focus on the aesthetics of design.

CHAPTER XI

MAKER MENTALITIES

One of the major findings from the case studies was that children adopted a highly varied

set of positions with respect to design and making. I call these "Maker Mentalities" because they

seem to be predominant orientations toward design. This is important, as my observations of the

patients highlighted in the five case studies strongly suggest that it would be a mistake to expect

every child to see the Makerspace primarily as a repository of classical engineering problems

needing to be solved. Children approach the Makerspace by negotiating a complex social

network and technical system of people/machines/material/environmental affordances to assume

control of their own learning. As I have argued, this is important for patients because isolation in

the hospital destroys their sense of agency, which in turn translates into a loss of self or identity

for the patient. The Makerspace diverts the patient's thoughts from the isolation of

hospitalization and their illness by enhancing their own self-agency in learning. Learning for the

patients involves disciplining materials (e.g., materials in the mobile Makerspace, repurposing

objects found within and outside the room) and recruiting people who enter the space (e.g.,

health-care providers, visitors) or reside temporarily in the space (e.g., family members). Of

course, it is important to point out that many, perhaps even most children sustain multiple

motives, although some appear to be canonical examples of particular kinds of Maker

Mentalities. I will describe each of the major Maker Mentalities that I have observed, explaining

how each connects with the ideas of personal agency and identity that I raised earlier in the

introduction.

Seventeen-year-old Lori (Case study #1) is the canonical example of the "posse" leader who designs within a rich social network that she deputizes and maintains. Lori recruits and orchestrates a variety of people in her design and making process, including her mother, sister, and nurses. In this way, Lori's personal identity shifts from that of an isolated self to being a part of a larger community in which she has a directing role. These co-participants both entertain her and keep her engaged in problem-solving. Lori does not invent purely for the purpose of inventing; rather, for her, invention seems to be a social activity that provides a forum for both an audience and communal participation. This type of Maker mentality (a "posse" leader) works well when plans for the contraptions are a little more open-ended and are hence open to flexible adaptation if new ideas about the design or materials are introduced in a way that disrupts the ongoing activity (or, in Lori's case, provides a way out of a cul de sac in the design).

In contrast, 15-year-old Kelsey (Case study #2) is the canonical example of a "classical engineer" who designs with a systematic plan in mind. Unlike Lori, whose personal identity seems to shift as the invention process proceeds, Kelsey's personal identity remains constant throughout. From the beginning to end of the process, Kelsey continues to be methodical, systematic, and organized. Unlike Lori, Kelsey does not deploy an army of interested others in her service. Rather than appearing to be distributed in nature, her learning seems to be more tightly controlled. Although she accepts ideas and advice from others, especially her mother, she is the person who ultimately evaluates her designs and makes the decisions about how to proceed. Indeed, Kelsey seems to be engaged in design for its own sake, rather than primarily as a catalyst for social interaction. Consistent with her methodical approach, Kelsey seems to be as interested in meticulously documenting her design process as she is in designing. This

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"engineering" type of Maker Mentality works well for patients who have a fixed plan of action in their mind.

Eleven-year-old Hayley (Case study #3) is a designer who places importance on communicating the purpose and operation of a design to "clients" (in this case, nurses). For Hayley, the roles of people and materials are equally important, but the communicative aspect of design takes forefront because Hayley is genuinely interested in her design's practical utility for others. As Hayley proceeds, she realizes that the functionality of her design is not as transparent to others as it is to her, and she converses with hospital staff to improve on her design and to communicate its purpose effectively and without ambiguity. This type of orientation seems to emerge when the purposes of the invention are not self-evident to the intended users. This situation requires participants to emphasize communicating design intent to clients, a matter that may take as much thought and invention as the actual design and construction of the contraption in question.

Eight-year-old Molly (Case study #4) is the example of a designer who gets inspired by others' creations, which, in turn, fuel her own imagination and curiosity. Molly's imagination is initially fueled by ideas inspired by others, such as Lori, which eventually expand to include devices that transcend hospital boundaries (e.g., the pill cup light she created for use at home). As Molly invents, her ideas begin to disseminate beyond the confines of the hospital to address the bigger task of solving problems in the outside world, suggesting that patients' making activities may have lasting importance to them even beyond the time when they are hospitalized. Interestingly enough, I actually noticed that, with time and experience, Molly's personal identity eventually shifted from that of a follower (who seeks inspiration from others) to that of a leader (who makes decisions independently). This type of Maker Mentality may characterize younger

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participants, who initially need help or a creative spark in coming up with ideas. The more general insight that this offers designers of future versions of the Makerspace is that providing participants with ideas from others may allow some participants to enter the process of invention by "editing" the invention of another person to make it their own. Over time, as their confidence grows, these makers may increasingly exercise their own creativity.

Fourteen-year-old Kristina (Case study #5) is the canonical example of a designer whose invention emphasizes "artistic expressiveness" rather than functionality. She prefers to focus on creating artistic contraptions (e.g., "Stars in a Jar") rather than devices that solve practical problems. Kristina's identity is that of an artist, with a strong background in both dance (she performs in competitions as part of a dance team) and media creation (she has her own YouTube channel on which she posts videos that she creates about CF). To support Kristina's artistic interests while in the hospital, Kristina's mother, Sandra, keeps Kristina occupied by "…using crafts as a way to keep Kristina entertained in the hospital" (Sandra, 2/2015, Interview). In pursuing her agenda of self-expression, Kristina consistently works independently (similar to 15-year-old Kelsey, mentioned above) rather than incorporating dispersive ideas and feedback from a variety of individuals. It may be particularly challenging for people, especially young people, to negotiate a complex design when they must simultaneously manage and respond to the input of other individuals, and artistic expression may sometimes be an agenda that is particularly difficult for youngsters to pursue collaboratively.

As my participant pool included only eight individuals (of which five are highlighted here), there may well be additional kinds of Maker Mentalities that I have not yet observed. The takeaway seems to be that, to be successful, mobile Makerspaces should be designed to support variability in both goals and approaches. This is very consistent with what we know about

successful permanent Makerspaces. People do everything in these spaces, from weaving to spot welding, and they also seem to pursue a wide range of objectives, including "fix-it" jobs, invention, artistic expression, and, of course, talking and interacting with other makers and designers as part of a collaborative community that shares a common identity. Successful mobile Makerspaces should likewise provide an array of useful tools and lots of opportunities for interchange with other people, who are pursuing their own projects and ideas, while not limiting the users with "pre-canned" projects or problems to solve.

CHAPTER XII

CROSS-CUTTING THEMES

Having described the design process for each of the children who participated in my study, I next turn to some important themes that I observed across all five cases. The first theme concerns a secondary kind of design in which many of the participants became deeply engaged, namely, a variety of creative ways to document the design process for subsequent makers. The second theme concerns the increase in physical activity that health-care providers noticed among patients as they used the mobile Makerspace. The third theme concerns issues specific to the hospital context that affect patients' design progress. The fourth theme involves a crucial phase of idea generation, in which participants seem to spend time simply fiddling around with materials. Finally, the fifth theme concerns the ways in which the mobile Makerspace provokes and sustains patient interest, even providing them with an incentive to come back to the hospital.

Documentation as a Secondary Form of Invention

As explained previously, because of the time constraints in my face-to-face work with patients, I had to depend on the patients themselves to become active collaborators in the data collection process. Patients were provided with documentation tools such as a Fujifilm or Polaroid instant camera, Dell tablets, and a Polaroid Cube video camera to help document their design and making processes by creating a visual journal. The exact process in which documentation was generated and organized was left to patients' discretion. As it happened, patients invented three different formats for documenting their design and making processes:

(1) journals; (2) storyboards; (3) and video documentaries (some recorded by me at the patient's request, and some recorded by the patient herself).

As described in case study #3, Kelsey created a detailed picture design journal similar to an engineering design journal. Kelsey took photographs of each step of her design process and wrote accompanying notations for each picture. Her intention was to generate a set of illustrative instructions that others could potentially follow. In addition, the picture journal provided her with another opportunity for self-expression and identity. Kelsey explained her journal as follows:

> I think that other people would enjoy my invention because they have a book of
> instructions for it, so if they wanted, they can go through my instructions and improve on
> the ideas and change them and find other ways to make a doorbell or nightline. Not
> everyone is going to make a Cheez-It box or a pressure sensor. It was just how I made it,
> and then if somebody has got the instructions for it, then they can change it up and make
> it their own. But I really think others will enjoy my doorbell and nightline, and my book
> of instructions. It's just so they can get new ideas, change things up and make them how
> they want. But if they get the chance to make a doorbell, then I would like to see it and
> know their ideas (Kelsey, 10/2014, Interview).

Kelsey created her picture journal primarily to inspire the imagination of other patients in the hospital. She hoped that the journal would inspire other patients to tackle the same design problems in alternative ways, rather than constraining them to rigidly following her instructions.

A second genre of documentation is Lori's storyboard, in which the mobile Makerspace itself became a canvass for documenting her design process (Figure 49). She accomplished this by taping photographs that she took with the instant camera onto the back of

the cart. She then used a washable marker to write a brief explanation below each picture. Lori decided to use hashtags (the use of the "#" symbol before a word or phrase) to explain each picture. Hashtags are a type of label or metadata tag, used on social network and micro blogging services that make it easier for users to find messages with a specific theme or content. Lori was inspired to use this hashtag storyboard system based on her frequent usage of social media, such as Instagram, which emphasizes hashtags. Thus, the Makerspace became not only a space to design and build, but also a mobile advertisement of her design process that conveyed the story to others who might be interested in the Makerspace.

Figure 49. Lori working on her "storyboard"

A third format for documentation was video documentaries of the design process. For example, 8-year-old Molly used the Polaroid Cube video camera to document how she came up with her design. Her videos incorporated detailed instructions accompanied by additional commentary. Documentaries like these provided a new medium for expression, but they usually tended to be embraced by patients who were not particularly self-conscious about their appearance on-camera. As mentioned previously, many of these young girls often felt self-

conscious about their appearance while they were ill. For instance, 14-year-old Hayley was not keen on creating a design journal or self-documented videos of herself working on her project. Instead, Hayley asked me to record videos of her at specified intervals as she worked on her project. Hayley informed me that she would play the role of both actor and director, while I would be the cameraman, following her instructions. Hayley intended to create a film that highlighted the progression of her design, bringing into light the important design shifts in her project. During those intervals, Hayley provided a running narrative of what was happening at that time and what would happen next. After creating multiple episodes, Hayley asked me to edit the videos taken by me to create a short film of her project evolution. I also noticed that nurses and respiratory therapists were willing to play the role of cameraman and take videos of patients' design and making process. For example, Molly's respiratory therapist recorded videos of Molly fiddling with her littleBits while she was undergoing breathing treatments. However, this kind of documentation, which relies heavily on the participation of others, depends on the social circle surrounding the patient and their willingness to be involved in the patient's design and making process.

I originally requested patient assistance with documentation to surmount some of the difficulties of collecting data in a hospital setting. However, it was surprising to me that patients ended up devoting so much time, thought, and care to these records of their design process. Allowing for variability in terms of the different methods of documentation paid off in relation to the patient's investment in this work. Patients' journals and documentaries suggested that they were genuinely invested in the hypothetical future audience of potential readers/listeners, whether they regarded that audience primarily as appreciative "consumers" of the design, as other inventors, or simply as admirers.

Increasing Patient Mobility

As the mobile Makerspace was brought into the rooms of more patients, I began to receive feedback from health-care providers that they were noticing an increase in patient activity. Physical therapists and nurses reported that they were observing that patients were spending more time out of bed. If this were true, it would potentially be an unintended benefit, because inactivity, especially for CF patients, can further endanger health. To better understand how the mobile Makerspace might be impacting patient's mobility, I asked patients to use wearables (i.e., the Basis Peak Fitness & Sleep Tracker) to track their total number of steps per day. Basis (http://www.basis.com), an Intel company, is a leader in wearable device technologies for fitness, sleep, and wellness applications. The Basis Peak provides 24/7 heart rate monitoring, including during exercise, without the need for a chest strap. I provided the patients with a Basis Peak watch in addition to an iPod touch. The Basis Peak is designed to have constant Bluetooth connection with the iPod touch in order to enable transfer of data from the watch to the application on the iPod touch.

Mobility tracking was implemented only near the end of the study, as there were delays in receiving permission from the University Institutional Review Board. However, I was able to obtain quantitative data that spanned nine days for Kristina, the patient in case study #5. Figure 50 displays the total number of steps that Kristina took each day as she worked on her project. She explained:

> I did a project called "Stars in a Jar" using littleBits. With having a project to work on, it made me feel more active, and the Makerspace just made it two times better. My nurses and friends visiting thought that the Makerspace was really cool. They would always ask me about the Makerspace and the project I was working on, and it always made me want

to get up and explain and show them. I also had this watch on. One day I took a total of 2000 steps, all because of the Makerspace (Kristina, 1/2015, Interview).
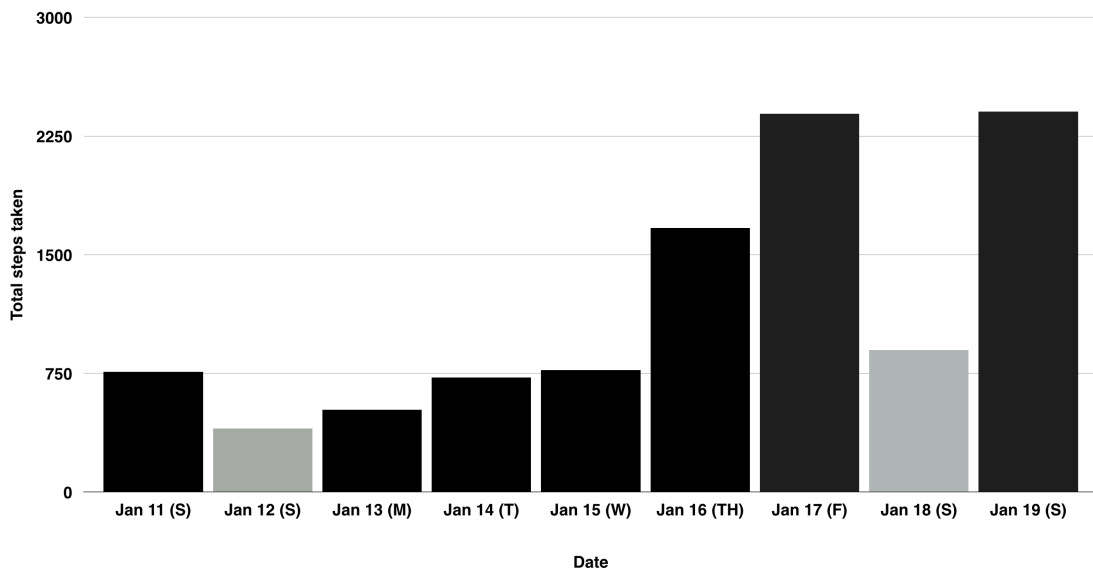
Figure 50. Patient mobility data

On January 12, Kristina did not use the mobile Makerspace, as she was feeling unwell. That day serves as a baseline against which to compare days when she was in fact able to use the Makerspace. The data revealed that the number of steps increased daily, except for January 18, when she once again fell ill. Why did the number of steps increase? Conversations with Kristina suggest two reasons. First, after completing one project, she decided to tackle more complex projects that required more time and, one might assume, more moving around. Second, Kristina started to invite more people into her room to describe the projects she was working on and also to recruit them into her design and making process. This triggered a chain reaction: the nurses and respiratory therapists who worked with the patient in turn let other health-care providers know what was going on. Soon, other people in the hospital began to drop by Kristina's room to check out the Makerspace and the projects she was working on. This attention cemented the patient's commitment to design, and a positive cycle seemed to emerge.

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Duration and Complexity of Projects

Some of the projects that patients worked on were long-term, whereas others were completed relatively quickly. For example, Kristina preferred short-term projects that could be completed readily. In contrast, the majority of the patients with whom I worked preferred to work on long-term projects that spanned several days. There are multiple reasons for this preference. For example, as CF patient Ariel's mother Rachel explained earlier, "CF patients get tired a lot more easily than most kids, and it's very important that they rest while they are in the hospital. Rest is healing, and CF kids need a lot of that! They just simply can't pay attention for long periods" (Rachel, 12/2014, Interview). Because of multiple treatments combined with the effects of medications, many CF patients have difficulty focusing on projects for many hours at a time. Consequently, they tend to space their projects out over the course of their treatment. According to Rachel, medications have had a direct influence on her daughter's attention span. She claimed:

> I also have a theory about CF children and their meds. I'm no expert, of course, but I truly believe that all of their meds affect their attention spans. All of the CF kids in our family have at least some degree of Attention Deficit Disorder. Ariel and Lori are both diagnosed ADD. They can't take ADD meds because they take away their appetites and affect their physical growth. They just simply can't pay attention for long periods (Rachel, 9/2014, Interview).

Multiple treatments throughout the course of the day also tend to interrupt patients' design work. Many CF patients have weak immune systems and therefore often fall ill so that they are not able to complete their projects in a brief time.

In addition to their physical limitations, some patients simply like to involve other people in their project. Two weeks of isolation can be extremely hard on patients, as they tend to feel over-controlled and under-in-charge. Spacing a project out over the entire duration of treatment gives children the opportunity to recruit a network of people/machines/materials/environmental affordances in order to assume control of their own learning in an elective learning situation. Deploying both people and physical materials provides the patient with a renewed sense of control over their environment, empowering the child in the hospital to pursue new ideas with confidence.

Finally, some patients just like to take their own time, enjoying the fact that there is no deadline in terms of project completion, in so long as they finish their creation prior to being discharged. As 15-year-old CF patient Kelsey explained:

> The difference between this project and projects for school is this one is kinda fun and it's not like you have a due date for it. You can just go day by day, put little pieces together, come up with ideas. Because you know you are in the hospital because you are sick, so it's not like you have to hurry up and put all your medicines aside to do this project. I thought it was really cool just to relax and work on these…I felt like working. (Kelsey, 10/2014, Interview).

The Importance of Fiddling with Stuff

As described in 18-year-old Christy's journal in Chapter 2, patients spend a lot of time with their nurses and respiratory therapists undergoing multiple breathing treatments. Christy explains:

> I get four breathing treatments a day in the hospital. A respiratory therapist comes in the morning to start your treatment and take care of you. I do two puffs of albuterol inhaler

through a spacer, the vest for thirty minutes. In the morning and at night I also get a

nebulized medication called Pulmozyme It takes four to five minutes. The whole cycle

takes about forty to forty-five minutes. While doing my treatments, I play on my phone

or work on an art project to pass time. Sometimes I watch TV, but the machine is loud, so

it's hard to hear. After every ten minutes they want you to cough to try to expel the

mucus from your lungs (Christy, 2/2015, Journal).

Christy's journal conveys how regimented this life seems to be in the hospital, where the patient

is subject to the schedules and whims of interlocking teams of professionals. After months of

working with these patients, I noticed that CF patients spend the time during breathing

treatments fiddling around in a general way with the materials available in the mobile

Makerspace, such as the littleBits. Although this kind of tinkering might seem undirected, it

actually seemed to help patients begin to achieve a broader sense of what was available in the

Makerspace and what one might do with those materials. This observation is consistent with

research from the related field of scientific reasoning, in which researchers also report that

youngsters almost always engage in a period of trial-and-error fiddling with materials and their

effects before they settle down to more systematic experimentation (Kuhn, 1989). As 15-year-old

CF patient Kelsey explained:

Whenever I'm doing treatments I get bored. To pass time I check social media and that

gets boring too. So whenever I'm doing treatment I played around with the littleBits, it

was a form of entertainment. Also as I messed with the littleBits I was thinking of things

I wanted to create. Also my RT's are interested in the littleBits and what they do. They

like to get involved with creating. I ask them their opinions on creations because they

may have different ideas than I do (Kelsey, 10/2014, Interview).

Breathing treatments proved to be important times for exploring and coming up with design ideas. During these recurrent cycles of activity, patients often collaboratively brainstormed ideas and received feedback from the respiratory therapists. These observations of patients apparently "fiddling" in an undirected way confirm once again that it may be unproductive to analyze children's engineering purely as a process of cognitive problem-solving. From this perspective, patients' trial-and-error exploration may look unsystematic and nonstrategic. Yet upon closer inspection, these periods actually play an important role in patients' problem solving. They provide opportunities for patients to explore the properties and boundary conditions of materials in order to both understand at a basic level how to make the materials function as intended and to think in an uncommitted, open-ended way about how the materials might contribute to potential project ideas.

Provoking and Sustaining Interest

Interacting with the mobile Makerspace sustained patients' interest during hospitalization. As 15-year-old CF patient Kelsey explained:

Designing stuff really expanded my knowledge and expanded my expectations of myself. I felt like I wasn't sick anymore once I wasn't in bed all the time. I had something to do. The camera is amazing! I love the cameras. They're memories I'll always have and they're great memories. I think all patients should get a chance to use the mobile Makerspace. Not only the patients who can't leave their room, but also the ones who can. Just because the hospital lets them leave their rooms doesn't mean we shouldn't share. The mobile Makerspace really makes you think and gets your creativity going. You aren't given instructions and you have to think for yourself. Make the question easier to understand. The volunteers stay for 30 minutes or so; then they're gone. But the mobile Makerspace is

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there for days and you don't have people looking over your shoulder. You can just think

for yourself and experiment. The parents would enjoy the Makerspace, too, because of

the Intel devices. Both of my parents used the tablets more than I did. They enjoyed

getting on the Internet and using Cubify. The parents enjoy it just as the patients do.

(Kelsey, 10/2014, Interview).

Use of the Makerspace sustained patients' interest long after they were discharged from

the hospital. For example, patients Ariel and Lori, who came back to the hospital for another

round of treatments, were both eager to use the Makerspace once again. The second time around,

Lori came up with a device to prank her nurses using littleBits and other materials found around

her room and the hospital. Even patients' families were excited about the Makerspace. Ariel's

mother Rachel explained:

The mobile Makerspace gave Ariel something novel to do in the hospital, and the 3D-

printer also fascinated us. We remembered the fun we had with the Makerspace during

the previous visit, and it made the hours seem to pass more quickly. With the tablets, the

littleBits, and the printer, there's plenty to keep us entertained. Parents, like me,

appreciate any help in keeping our kids happy and entertained, and we like to see our kids

learning instead of just "vegging out" with TV or video games (Rachel, 12/2014,

Interview).

The Makerspace and related activities were not simply a novelty; instead, they had a more lasting

impact. Both children and families communicated that they were excited for the next visit to the

hospital, a truly surprising statement given that hospital visits to most people are more dreadful

than exciting.

These cross-cutting issues — patients becoming deeply engaged in documenting their

design process for subsequent makers; increase in physical activity that health-care providers observed among patients as they used the mobile Makerspace; issues specific to the hospital context that affect patients' design progress; patients spending time simply fiddling around with materials during idea generation; and ways in which the mobile Makerspace provokes and sustains patient interest, even providing them with an incentive to come back to the hospital — emerged repeatedly across the cases. These themes once again suggest the need for a broader view of children's learning and the need to take into account the variability of children's design approaches when designing future Makerspaces for children's hospitals.

CHAPTER XIII

CONCLUSION

My study was guided by two research questions:

(1) How do patients recruit and negotiate resources — conceptual, material, and social — to pursue personal goals with the Makerspace?

(2) How do patients both adapt the Makerspace into existing hospital routines and, conversely, coopt it to transform and even disrupt hospital routines, roles, and expectations?

With respect to the first question, I found that patients recruited and negotiated a wide range of resources (conceptual, material, and social) for the purpose of pursuing their personal goals in the execution of their design and making process with the Makerspace. Patients working with the Makerspace adopted a varied set of orientations, or "Maker Mentalities," toward design and making. These Maker Mentalities were characterized by different motives and processes, such as whether patients preferred to include other people in the design process or whether they preferred to pursue a solitary vision, and whether their engineering approaches were predominantly systematic or instead tended to capitalize on fortuitous, trial-and-error discoveries.

Designers of future mobile Makerspaces need to keep this variability of Maker Mentalities in mind. There is no one "typical" patient Makerspace user. For example, it is critical to provide for a range of accessibility, so that even patients who are new to the mobile Makerspace can easily access the materials to successfully engage in design projects, while patients with more experience with the mobile Makerspace should be sufficiently challenged in

order to sustain their interest in continued use of the mobile Makerspace. Above all, my results suggest the importance of expecting that users will invent a variety of ways of participating with the mobile Makerspace and ensuring that the mobile Makerspace learning environment invites and supports that variability. Regimented, prescriptive experiences that presume that users will have a particular way of doing things may not take optimal advantage of a child's preferred ways of learning in contexts like these. For many children, experiences that allow them to easily incorporate other individuals' ideas are especially attractive. Thus, mobile Makerspaces need to support artistic and expressive projects, as well as practical designs to solve everyday problems, in addition to creating outlets that support and encourage patients to communicate and learn from each other (e.g., social media outlets).

In response to the second question that drove my research, I found that patients flexibly adapted the Makerspace into existing hospital routines. For example, they took the opportunity to explore the Makerspace materials during their multiple daily treatments, brainstorming ideas and discussing design progress with their respiratory therapists. Children took advantage of the regular flow of people through the hospital — doctors, nurses, therapists, visitors, hallway traffic — to seek feedback about their designs, and sometimes just to get positive attention. Hospital routines inspired many of the designs that the children created, such as the nightline creation that employed electroluminescent lights to guide nurses (Case study #2). Conversely, patients also coopted the Makerspace to transform and even disrupt their regular hospital routines, roles, and expectations. For example, children used their inventions to push back on privacy invasions, to improve the quality of their hospital stay experience, to "leave" the room virtually when hospital rules forbid them from interacting with other patients, and even to prank nurses. Resistance to authority is a persistent developmental theme for young adolescents, and given the rigid rules

and compliance expectations that the hospital enforces on CF patients, it is no surprise that designs were especially popular that, in one way or another, expressed a gentle (although not hostile) resistance to these expectations and demands. Children coopted the mobile Makerspace to their overarching goal of learning how to find a better balance between their lives as young adolescents and their lives as young patients subject to the constraints of life in the hospital.

Future Research

Assembling even one mobile Makerspace is moderately expensive. Addressing the needs of multiple patients in a children's hospital with a variety of chronic illnesses will of course require several mobile Makerspaces. Therefore, a considerable challenge for a viable scaling strategy is ensuring that individual mobile Makerspaces are not cost prohibitive. As children's hospitals vary in terms of their size, their patient demographic, and the types of services that they provide, the total number of mobile Makerspaces will vary from hospital to hospital. Further research and experience in multiple children's hospitals should better reveal how many Makerspaces are required to effectively cater to patients needs.

In this study, a small, homogeneous group of children participated. In the United States alone, there are nearly 7,000 rare diseases (http://www.rarediseases.org). As the type of treatments available within a children's hospital to combat these diseases varies this will give rise to a wider range of design issues for the mobile Makerspace. For example, a mobile Makerspace environment might need to be designed differently for a child with an end-stage disease than for child with a long-term chronic illness, who nonetheless looks forward to an extended future life.

A research question that has been particularly captivating to me is that of how to best maximize professional development for those individuals who will introduce the mobile

Makerspace to patients and guide their beginning experiences in design. It is critical to bear in mind that the mobile Makerspace has extremely minimal impact on a patient without the inclusion of the right human guide, and I feel (and many patients affirmed) that my role was vital in the patients' mobile Makerspace experience. I not only engaged the patient in the design and making process, but more importantly, I fostered personal relationships with patients and their families. I strongly believe that the mobile Makerspace is more than just a cart; it is an immersive learning experience that is conceived in a fundamentally social context. At this point, little is known about the personal qualities, motivations, or training that make individuals potentially good candidates for the role of a Makerspace guide or "coach." No doubt this question of how to address professional development with relation to the mobile Makerspace will turn out to be as complex a question as the questions currently being explored about teaching in classroom contexts. As knowledge of and experience with informal learning settings grow, research will need to focus more seriously on the broader roles of teaching in these contexts, including what it takes to prepare the individuals who choose to take on those roles.

In general, research is necessary to determine the programmatic viability of the mobile Makerspace approach across a more varied array of hospital settings. At this point, we do not know what kinds of implementation models children's hospitals may become interested in adopting, the protocols and procedures that need to be followed for different populations of patients across these settings, the typical range and nature of staff support and training, and the variety of outcomes that may emerge as patients engage in design and making and, perhaps, increasingly take leadership of projects like these into the patient community.

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