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Reconfiguring the Everyday: Understanding, Designing, and Supporting Chronic Illness Management

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Abstract

Reconfiguring the Everyday: Understanding, Designing, and Supporting Chronic Illness Management

Leslie S. Liu

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From taking medications at the right time to emotionally dealing with their symptoms, patients who have a chronic illness must manage many facets of their illness. Today, patients often utilize different types of general-purpose technologies (e.g., Facebook) to manage their chronic illness. However, many of these technologies were designed with a general user in mind—a user who does not necessarily have the same needs as one who has a chronic illness.

In this dissertation, I discuss how people from three distinct populations—health vloggers with a chronic illness, older adults who have diabetes, and children with a chronic illness—reconfigure the “everyday things” that surround them. In other words, I unpack how artifacts, relationships, roles, and technologies—the things of our daily lives—are deftly reconfigured to support chronic illness management.

In my first study, I examined how adults with one of three chronic illnesses used YouTube to create and upload health video blogs (vlogs) to establish deep and meaningful connections with viewers. Utilizing the video medium, health vloggers shared information and knowledge about their illness with others while also receiving social support from viewers. In my second study, I explored how older adults who have diabetes appropriate opportunistic reminders to help remind them of certain health tasks and overall

health goals. These opportunistic reminders include artifacts, activities, routines, and relationships. In my third study, I examined how children with a chronic illness utilize technologies to maintain a sense of normalcy with their peers. To feel “normal” among their peers, I found that children often appropriated technologies (e.g., such as using Facebook to update their peers about their health without the need to fully engage with them if they do not feel well) to better fit their needs and feelings of having an illness.

Drawing from these discussions, I detail how researchers and other interested parties can design technologies that leverage this appropriation of everyday things for patients’ chronic illness management. Lastly, I expand on how we can further improve current design methodologies when designing *for* and *with* patients who have a chronic illness. In designing technologies for these populations, I suggest designing for reappropriation—supporting appropriation in existing general technologies in addition to newly designed technologies. By designing for reappropriation, we can build upon and embrace the world that those with chronic illnesses have already reconfigured.

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GLOSSARY

COMMENTER: A person who watches a YouTube video *and* comments on the content of the video.

“EVERYDAY THING”: Artifacts, relationships, roles, and technologies that surround one’s daily life.

HEALTH VLOGGER: A person who films and uploads videos about their health to a video-sharing website such as YouTube.

OPPORTUNISTIC REMINDERS: An association between an “everyday thing” and an action or motivation.

TRADITIONAL REMINDERS: Objects that are seen as traditional forms of (digital or paper) reminders such as a calendar.

VIEWER: A person who watches a YouTube video but may or may not comment on the video.

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In 2008, I presented at an undergraduate research symposium. I excitedly emailed my family about my first foray into the research world. My Uncle Steve, who had a PhD, emailed back, telling me:

My first poster presentation was in Chicago around in 1975 and the topic was why birds can fly high ?

We unexpectedly lost my uncle later that year. His passion and drive for life and knowledge have always inspired me. Perhaps, birds can fly high because they learn by example; I hope that I too can fly high through my uncle's example. He never told me whether he had figured out why birds can fly high, but I'd like to think I am getting close to an answer.

DEDICATION

To my parents, Shio-Chuan Wang and Kelvin Shih-Tai Liu,
for their unfaltering love, support, and belief in me.

Chapter 1

INTRODUCTION

People who have a chronic illness must deal with a deluge of information and a plethora of tasks to manage their illness. From taking the appropriate medications at the right time to receiving social support from others, patients often take advantage of the various general-purpose technologies such as Facebook that can help support them in their chronic illness management. However, these technologies do not always support all facets of their chronic illness management accordingly. In this dissertation, I examine how patients from three distinct populations appropriate the “everyday things” in their life—artifacts, relationships, roles, and technologies—to better fit their health needs and how we can design technologies that consider patients’ existing reconfigurations.

1.1 Motivation and Approaches

Chronic illness is defined by the United States National Center for Health Statistics as *a long-term condition that lasts three months or longer, does not resolve spontaneously, is rarely “cured”, and affects a person’s daily living* (National Health Council, 2014; Centers for Disease Control and Prevention, 2009; National Council on Aging, 2015). The CDC suggests that in 2012, about half of the adults in the United States—117 million adults—had one or more chronic illness (Centers for Disease Control and Prevention, 2015). Similarly, approximately 8% of children in the United States between the ages of 5 and 17 were reported to have limited activities due to factors of at least one chronic illness (National Health Council, 2014).

Chronic illness management consists of both self and collaborative management of

the chronic illness. Self-management is described by Lorig and Holman (2003) to be composed of three self-management tasks: (1) medical management—such as medication adherence, (2) role management—such as adapting new meaningful behaviors or life roles, and (3) emotional management—such as managing emotions that can result from having a chronic illness. Social support is also recognized as being an important aspect in chronic illness management (Klasnja et al., 2010; Skeels et al., 2010). On the other hand, work by Von Korff et al. (1997) suggests that healthcare organizations and systems can improve in their collaboration of care with patients. Collaborative management suggests that medical care for patients is enhanced when patients, their families, and healthcare providers have shared goals and a mutual understanding of responsibilities and roles.

Patients must manage several aspects of their health at the same time—from remembering to go to an appointment to emotionally dealing with their condition. Patients often use a variety of general-purpose technologies that can help them in their chronic illness management. For example, Greene et al. (2011) found that people with diabetes frequented Facebook as a way to share personal information, request disease-specific feedback, and receive social support from a community. However, current general-purpose technologies are often designed for the majority—the general user. These technologies sometimes require those who have a unique situation to adapt to a world that is often designed for a general user.

I posit that patients who have a chronic illness *reconfigure* “everyday things”—physical artifacts, relationships, roles, and technology—to better fit their needs within the context of their illness. For example, health vloggers utilized the YouTube platform as a way to receive social support from others by sharing their experience and knowledge from having a chronic illness. By helping others through sharing their stories, patients saw vlogging as self-therapeutic—similar to writing in a journal. Though patients already use “everyday things” in their daily lives, they take further advantage of them to support their chronic illness. In understanding the needs of patients who have a chronic illness, “everyday things” can be utilized in the design of existing and new technologies to better

support patients' reconfigurations of the things that surround them.

1.1.1 Research Questions

By way of examining distinct populations—younger and older adults with chronic illnesses and children with chronic illnesses, in this dissertation, I aim to answer the following research questions.

Research Question 1: How do patients who have a chronic illness appropriate “everyday things”—artifacts, relationships, roles, and technologies—to fit their needs in their chronic illness management?

Research Question 2: How can we design technologies with those needs in mind that can better support patients' chronic illness management?

Research Question 3: How can we further improve and expand on current design methodologies when designing *for* and *with* patients who have a chronic illness?

1.1.2 Dissertation Approaches

To address these research questions, I conducted three studies focused on distinct populations. Below, I describe each of the studies in more detail. From these three studies, I also reflect on some of the methodological challenges in conducting studies with people who have a chronic illness.

Adults with a Chronic Illness. People who have a chronic illness often find it important to share their stories with others. Vlogging is a current phenomenon in the YouTube community where laypeople film and upload videos to share their lives to viewers of YouTube. A subset of these vloggers are what we describe as *health vloggers*—vloggers who share their experiences, journeys, and knowledge about their health to others. The goal of the first study was to examine how adult health vloggers with a chronic illness

utilize video and the YouTube platform. We looked at how health vloggers with HIV, cancer, or diabetes used YouTube as a way to share their experiences, their emotions, and their journey with others, allowing them to connect with their viewers. We found that these videos were a way for health vloggers to establish deep connections with their viewers, creating a sense of social support while also conducting an activity that was seen as self-therapy. The rich affordances of video (for example, being able to see nonverbal and visual cues on a vlogger's face) helped create and maintain a deep connection between the vloggers and the viewers. Comments on the videos were also a way for health vloggers and viewers to maintain that deep connection.

Older Adults with Diabetes. The American Diabetes Association estimates that approximately 25% of older adults in the United States have diabetes (American Diabetes Association, 2014). However, the CDC estimates that only 9.3% of adults with diabetes have *only* diabetes (Centers for Disease Control and Prevention, 2013). For many adults—particularly older adults, diabetes is not the only chronic illness that they must deal with. This finding means that older adults often have a barrage of medications and health tasks that must be completed for their chronic illnesses. The aim of this study was to understand how healthcare organizations can better design their health reminders and notifications to support older adults who have diabetes. We found that many older adults would use traditional ways to remind themselves of when to take medications or to do a health task (e.g., calendar). However, many of them would also use *opportunistic reminders*—reminders that were derived from artifacts, relationships, routines, and activities. These opportunistic reminders were often rooted in the emotional memory of patients such as using an artifact to recall a more difficult time in their life (e.g., a cane helped remind a participant to keep healthy so that she would never need to use it to walk again).

Children with a Chronic Illness. Children with a chronic illness who have to frequent the hospital for various treatments and procedures are removed from familiar environments,

such as their home or school, to stay close to the hospital. Their temporary removal from familiarity can cause patients to feel isolated. Social connectedness with their friends and classmates may help alleviate their feelings of isolation and help make them feel more “normal” like their healthy counterparts. Support and being seen as “normal” by their friends also remind patients of the importance of hope and an optimistic attitude (Woodgate, 1999). In this work, my goal was to understand how children who have a chronic illness stay connected with their peers and how to design technologies that can better support this connectedness. Children who have a chronic illness often use technologies to maintain a sense of normalcy with their peers. However, there are also certain aspects of technologies that do not necessarily fit the needs of these patients.

1.2 Dissertation Overview

In this dissertation, I first situate my work within the context of prior research in the fields of human-computer interaction, health informatics, and medical research in Chapter 2. I then summarize different but specific technologies that support chronic illness management: (1) reflection systems; (2) reminder systems; (3) journaling systems; and (4) communication systems for pediatric patients. I also describe design methods that have been used with patients who have a chronic illness—both adult patients and pediatric patients.

In the following chapters, I expand on three studies, each focusing on a different population: adults with one of three chronic illnesses (Chapter 3), older adults with diabetes (Chapter 4), and children with chronic illnesses (Chapter 5).

In Chapter 3, I highlight how some adults who have a chronic illness turn to a video-sharing platform to connect with others—not only to share information about their personal experience and to gain social support, but as a way to chronicle their own journey.

In Chapter 4, I focus on how older adults with diabetes utilize opportunistic reminders as a way to help them remember daily health tasks. These opportunistic reminders also serve as reminders of their overall health goals.

In Chapter 5, I explicate how children who have a chronic illness use communication technologies to maintain a sense of normalcy or create a “new normal” during their treatment through the perspective of parent proxies and the children themselves.

Following these chapters, in Chapter 6, based on my experiences, I unpack the methodological challenges that can occur when designing and working with populations that are considered vulnerable. I reflect upon these challenges to provide potential workarounds.

In the concluding chapter, I summarize the contributions of this dissertation. I extrapolate on how the contributions of my work go beyond designing systems for just chronic illnesses and how we should *design for appropriation*—supporting appropriation in existing technologies in addition to newly designed technologies.

Chapter 2

LITERATURE REVIEW

2.1 Technologies that Support Chronic Illness Management

With the influx of technology, patients with a chronic illness have an array of technological media at hand. There has been a considerable amount of research that has broadly examined this intersection of technology and chronic illness management—both in terms of informational and emotional management. In this section, I will summarize literature that has illustrated how technologies are designed for patients who have a chronic illness and are being used for chronic illness management.

Researchers have examined the intricacies and complexities of managing a chronic illness as a lifestyle. For patients with a chronic illness, the illness itself is a lifelong, temporal, and continuous act of adjusting one's behavior based on the condition. O'Kane et al. (2013) discussed how a chronic illness can affect a patient from childhood, progressing into their adulthood, and how their concerns surrounding sharing their health information may change as they age. For example, the authors discuss how patients did not realize the relevancy of some of the information (particularly from when they were younger) in their health record and would feel upset that specialists and researchers would see that information as they deemed it private and sensitive. At the same time, more access to new technology has also encouraged patients to share health information online, such as gaining social support through online health communities. Mamykina et al. (2006) used interviews, observations, and a cultural probe to understand how to enhance diabetes self-management. They found that diabetes patients often have a need to: (1) become a detective to understand their own analysis of their condition; (2) flexibly negotiate their actions; and (3) find an importance in motivation.

Chen (2010) also found that each patient has their own way of managing and interpreting their diabetes and calls for designing diabetes management systems that build on a patient's experiential associations. Along the same lines, Park and Chen (2015) found that it was challenging for patients to understand manifestations of their migraines, due to the unpredictable symptoms of the illness. Due to the individualized and intermittent nature of having migraines, the authors suggest that future systems should support sense-making process of their life to help understand certain triggers. Similarly, Owen (2011) suggests that systems must be able to encourage and support patients' sense-making of their condition to mitigate the negative emotional impacts of reflecting on blood glucose levels. Mankoff et al. (2011) further discussed how the complexity of chronic illnesses—such as Lyme disease where there are more than a single explanatory model of a health condition—calls for a better understanding of online health resources.

Building on this previous work, Storni (2013) developed a system called Tag-it-Yourself (TiY) to support patients' detective work. TiY encourages patients to tag and attach media to personally significant events in everyday life that can provide insight into glucose levels. TiY specifically supports the patient's perspective and reaffirms the notion that patients are producers of useful and relevant information and knowledge.

2.1.1 Reflection Systems

Many researchers have advocated for reflection support in technologies. In particular, many health technologies strive to develop systems to support *reflection-in-action* (Schön, 1983). For example, Li et al. (2011) suggest that UbiComp technologies should support and encourage reflection in technologies to allow users to understand the information to make better decisions towards behavior change. For example, Parker (2014) discussed Community Mosaic, a location-specific system that shares photos of food (meals, preparation, food establishments, etc.) to a collective community with the goal of inspiring others to eat more healthy. Community Mosaic helped users motivate others to eat healthily by example. However, the act of sharing photos also helped users reflect and become

more self-aware and conscious of what they were eating. Similarly, Reitberger et al. (2014) designed Nutriflect, a system that visualizes information about a household's food shopping habits, to help users reflect on their food consumption behavior. Studies have also expanded this notion of encouraging reflection into diabetes management technologies. MAHI, developed by Mamykina et al. (2008), helped those who were newly diagnosed with diabetes to reflect on their condition through social interactions. MAHI allowed patients to capture information on their past actions and glucose levels while discussing what the information meant with diabetes educators. The authors found that participants who used MAHI while attending diabetes education classes were more likely to be actively engaged in their care compared to those who were not exposed to MAHI.

Owen et al. (2012) examined patients' self-reflection and how technology can support that as part of the decision making process. For example, the authors found that sometimes when things become routine, simple errors were made (e.g., overdosing on insulin because they did not account for exercise). The authors suggest that on-demand contextual information can help with reflection on patients' actions. On the other hand, it is not always beneficial for patients to reflect on their actions right away. Rennert and Karapanos (2013) developed FaceIt, a lifelogging system that records GPS, heart rate, and visual and audio cues to help those suffering from social anxiety disorder (SAD) reflect later in the day. The authors specifically chose to have users reflect later rather in the moment because symptoms of SAD are highly emotional, and users may have a biased memory on what happened.

2.1.2 *Reminder Systems*

For patients with a chronic illness, there can be a lot going on in their lives. For example, they may have to take a variety of medications at specific times of the day or go to a number of appointments with different specialists. Research on systems that support reminding patients about these various events to better manage their chronic illnesses has often explored how to support patients' reminder strategies at home.

For example, McGee-Lennon et al. (2011) explored reminders for older adults in home care settings and found that a common reminder strategy was to integrate health tasks into routines, to make them easier to remember. However, it is important to note that for older adult participants, simplicity in a design for a general user is not necessarily appropriate for them (Abdul Razak et al., 2013). Similarly, Kendall et al. (2014) found that the close fit between health reminder strategies and daily life was reinforced by the practice of placing physical and visual reminders in salient locations in the home. Moen and Brennan (2005) also found that patients placed health objects, such as medication bottles, in visible spaces, such as the kitchen, to serve as task reminders—for example, to take the medication. Wolters (2014) and Siek et al. (2011) argue for design approaches that leverage domestic routines, artifacts, and activities that already serve as reminder strategies, to reduce the burden of remembering self-management tasks. Such visual and temporal *triggers* have been found to be important features of recalling tasks that have been or need to be completed (Brush et al., 2007). Williamson et al. (2013) examined how older adults felt about linking paper and digital reminder systems (e.g., calendars) with smartpens. They found that older adults liked being able to add annotations to calendar entries because it allowed for customizability and control (for example, underlined reminders could mean that it was a reoccurring event that the digital system could automatically repeat). Strandbygaard et al. (2010) conducted a study where they compared medication adherence for a group of patients who received daily SMS reminders with a group of patients who did not. They found that those who received daily SMS reminders remembered to take 18% more doses of their medication than the group that did not receive reminders. Similarly, Neville et al. (2002) found that participants enjoyed having integrated daily reminders of using an asthma inhaler into lifestyle related text messages about sports, celebrities, and horoscopes through a virtual “friend”.

Barbarin et al. (2015) also examined how time-based objects such as calendars and medication boxes were used in the home for chronic illness management. The authors show how these patients and their families utilize these objects as a way to support

the temporal characteristics of managing a chronic illness. The concept of *information in the world*, that describes the strategy of organizing the environment to reduce the burden of memorizing information, supports contextual approaches to health reminders (Norman, 2013). Similarly, Stawarz et al. (2014) proposed a set of design requirements for smart medication reminder applications. They highlight how important routine can be in medication adherence and suggest elements of a “routine-friendly” app that takes advantages of an already existing routine, rather than trying to remind the patient to create a new one.

2.1.3 Journaling Systems

There has been a large amount of work that has examined blogging—the act of regularly updating a website that focuses on the authors’ own experiences, opinions, etc. For example, Sundar et al. (2006) discussed how seminal work around virtual worlds (Turkle, 1999) and blogging and identities (Nardi et al., 2004b) bleeds over to help understand the motivations and benefits of health blogs. They found that health blogs were mostly written by young (20 to 30 years old) women who revealed personal identifiers more than males, wrote mainly for themselves but were aware of the audience, and welcomed their audience’s feedback. These bloggers also explored multiple identities through blogging. The study found treatments and coping to be the dominant content. Their style was often emotional in nature. Nardi et al. (2004b) discussed five general motivations for blogging: autobiographical narratives, commentary, catharsis, muse, and community forum. Bloggers telling the story of their lives for catharsis can be particularly important for people dealing with a mental illness because telling one’s life story “can renew a sense of meaning and possibility” (Ridgway, 2001).

However, relatively few studies have examined health blogs as an independent genre. Miller and Pole (2010) showed that half of 951 health blogs published between 2007 and 2008 were written by health professionals, one third by patients, and a few by unpaid caregivers. Previous research has shown that cancer patients benefit emotionally by

sharing their experience with other patients through blogs (Chung and Kim, 2007). Many bloggers also explored multiple identities through blogging.

It is unclear how much the results around blogs apply to health blogs on other diseases not necessarily dominated by emotional problems (e.g., diabetes), highly stigmatized (e.g., HIV), or often terminal (e.g., cancer). Though (Ressler et al., 2012) found that blogging about chronic pain and illness helped patients feel less of an isolation because of the online connection, Nardi et al. (2004a) found that bloggers were not interested in “holding any but a minimal conversation” between their readers.

However, results found from work examining blogs may be different for video blogs (or vlogs) due to the affordances of video. Few studies have explicitly examined design issues around vlogging tools specifically for the health domain. Video sharing sites such as YouTube, Vimeo, and DailyMotion are affordable, accessible media production sites where amateur video producers can share their messages with a worldwide audience. People use vlogs for various purposes, ranging from daily personal diaries to informal music learning (Waldron, 2012) to health communication (Fernandez-Luque et al., 2009).

Studies have shown that vlogs are useful in the domain of health. For example, the D/deaf community also used vlogging as an alternative medium for rich communication (Hibbard and Fels, 2011). Vlogs have been shown to become an arena for “truth telling” as seen in self-help groups and political gatherings (Valverde, 2004). Vlogs often carry the forms of personal speaking to invisible listeners, and conducting such an activity can help the speaker feel better (Matthews, 2007). Molyneaux and O’Donnell (2009) found that participants reported high levels of interest in watching user-generated video as a source of awareness and learning around health information. The Kaiser Family Foundation also used vlogs to target young people about the impact of HIV. Young people get to hear first-hand how HIV has affected people their age and how they can prevent or test for HIV (Hoff et al., 2008). While Chou et al. (2011) looked at cancer vlogs on YouTube to understand what made a cancer narrative effective, many of these studies did not explicitly examine the connection between the vlogger and the audience.

Researchers have also employed vlog interventions to study their impact on health outcomes and literacy. One study found high levels of interest in user-generated video for health information gathering (Molyneaux et al., 2011). A randomized controlled trial on a video messaging mobile intervention for smoking cessation showed participants' positive feedback on the social support obtained by the role model video messages. Findings from another study of YouTube videos on inflammatory bowel disease indicated that 83% of their collected videos contained either informational or emotional support, showing the potential use of videos shared online among patients as social support (Frohlich and Zmyslinski-Seelig, 2012).

It is important to mention the presentation of self in this context (Goffman, 1959). If we consider vloggers to be similar to an actor on a stage, and a vlogger's viewers as their audience, the goal of the presentation is acceptance from the audience. Essentially, if the actor has succeeded in the presentation, the audience will see the actor as the actor intended. This idea of self-expression and self-representation is one of the affordances that vlogs offer. However, there has been little work in examining the interaction between the vlogger and the viewers and the affordances that vlogs allow.

These types of public journaling systems have the ability to create a sense of social support for patients and others. According to Thoits (1995), social support is defined as a social "fund" that people draw from when handling stressors. Social support can include help in material aid, behavioral assistance, intimate interaction, feedback, and positive social interaction (Barrera and Ainlay, 1983). Many studies have shown the importance of social support for anyone (Biemans et al., 2009). However, with chronic illnesses, the feelings of isolation can be exacerbated (Charmaz, 1983), and thus social support becomes essential. Cohen et al. (2000) showed that social support promotes health by preventing people from the adverse effects of stress (i.e., through stress buffering). This notion of social support comprises of informational (e.g., strategies and advice), instrumental (e.g., giving a ride, providing food), and emotional support (e.g., sending prayers).

Giving support to others has been shown to help the patients themselves as well;

helping others creates a type of self-therapy. One study looked at elderly patients and found that those who gave informal assistance to others reported enhanced feelings of personal control (Krause et al., 1992). Similarly, another study suggested that women who were abused saw the ability to provide help to others as proof of their own recovery (Henderson, 1995). Schwartz and Sendor (1999) suggested that peer supporters (those who provided support to people with the same disease) were able to reframe their disease experience, resulting in an enhanced perception of quality of life.

Increasingly networked social media environments also provide venues in which social support can easily occur among peers. A systematic review of social media for health communication found the benefits of social media as: (1) increased interaction with others, (2) readily available, tailored, and shared information, (3) increased accessibility and widening access to health information, and (4) peer/social/emotional support (Moorhead et al., 2013). Other studies saw benefits of peer social support in online health communities for specific populations, such as among cancer patients (Fogel et al., 2002), diabetes patients (Huh and Ackerman, 2012), and the adolescent population (Love et al., 2012). Numerous websites such as PatientsLikeMe, CureTogether, and WebMD have also provided online health communities where patients and caregivers can share support with one another.

Researchers observed various effects of informational and emotional support on health and community participation. Welbourne et al. (2009) found that the exchange of emotional support was positively related to the sense of virtual community while observing informational support was negatively related to the sense of virtual community. Wang et al. (2012) found that emotional support in a cancer community played a major role in continued participation of members, while informational support did not. On the other hand, Huh and Ackerman (2012) presented the importance of informational support in online health communities for addressing individualized problems. Similarly, Hartzler and Pratt (2011) found patient expertise to be an essential part of social support (Civan Hartzler et al., 2010). In addition, getting help from peer patient mentors has been clinically proven to be far more effective than clinician mentors (Heisler et al., 2010).

There are also a few video resources for social support that are available to the public^{1,2}. Although these examples are considered health videos, they are curated by an organization, and in some cases, use actors rather than the patients. There has been less work that has focused on health videos that are generated and maintained by patients themselves.

2.1.4 *Communication Systems for Pediatric Patients*

There have been numerous studies that have focused broadly on pediatric patients and the use of technology. Studies have examined how technology—such as a telepresence system or a BlackBerry phone (Fels et al., 2003)—can connect hospitalized children with their classroom or classmates. For example, one study on a remote telepresence system called PEBBLES found that not only did the system help a hemodialysis patient feel more included in the classroom, but helped her classmates become more aware and sensitive to people who are in difficult situations (such as someone with a chronic illness) (Weiss et al., 2001). The increased sensitivity by the classmates helped create a smooth transition when the patient was able to physically attend school again (Fels and Weiss, 2001). Fels et al. (2003) looked at the use of a BlackBerry for children and young people in a hospital. The researchers noted that having an immediate connection to their school through the BlackBerry could cause positive health and well-being outcomes. These studies examined how a pediatric patient might maintain a connection with the classroom as a student attending class, but they did not examine the role of technology in supporting social connections among friends. Hicks et al. (2013) developed Solas, a virtual community that offers communication features such as video links, SMS texting, live chat, and email to help patients keep in touch with others. They found that besides allowing patients to communicate with their family, it was also a source of distraction and entertainment, leading to a positive emotional wellbeing of the patient. Wadley et al. (2014) developed an

¹ <http://www.healthtalkonline.org/>

² http://www.nytimes.com/interactive/2009/09/10/health/Patient_Voices.html

ambient display for hospitalized children that offer a type of constrained communication. However, the authors found that the constraints of the ambient display were not always enough to keep a sustained sense of connection and suggest supplementing the display with voice, video, or text-based communication.

Other studies have focused on helping pediatric patients share their stories with others. For example, Bers et al. (1998) suggest technological *play kits* that help hospitalized pediatric patients leave a trace and signature in the world. They found that others appreciating and recognizing the patient's creations made them feel empowered. Building on that work, Chin and Tsuei (2009) created a narrative sharing system for peer patients that allowed patients to "express their idealized self" through selecting a user name and avatar. Another system, *Coping Cart*, allows patients to watch videos of other patients in similar situations, draw or write stories about their experiences, and play with toy stethoscopes and surgical tools. They found that this mobile multimedia system was useful for patients to see how other patients coped with similar illnesses. Sharing their stories through videos and comic books also helped patients develop a sense of mastery over their illness (Novotney, 2010). Using a virtual community for pediatric patients undergoing kidney dialysis, patients reported feeling closer to other patients after using the system. Patients said that although they knew and recognized other patients when they would see them, they did not actually know their fellow patients, and that the system helped in getting to know their peer patients (Bers et al., 2001). Plaisant et al. (2000) also suggested that using a storytelling robot might help patients meet a therapy goal in rehabilitation. Although these studies examined how patients might share their experiences with other peer patients, they did not study how chronically ill pediatric patients stayed connected with their existing friends.

Besides examining how patients might share experiences with other peer patients, studies have also looked at the interactions between pediatric patients and adults (e.g., clinicians or caregivers). For example, Hourcade et al. (2012) explored a Draw-and-Tell Conversation system on a tablet to encourage children to provide clinicians with

more information on their headaches. The system was able to augment the face-to-face communication between patients and their clinicians. Farnham et al. (2002) developed a novel virtual community for cancer patients (18+ years old) and caregivers to interact with one another and find social support. They found that users particularly liked the ability to broadcast their health updates to friends and families. Mokashi et al. (2013) studied video chat use for children with autism and caregivers and suggest that video-mediated communication could be used between the children and trusted caregivers, such as teachers. Yun (2011) designed and developed a prototype to support pediatric asthma management in the home. Yun found that based on the severity of the asthma in each child, families would appropriate the prototype to manage the symptoms. Packy and Marlon is a video game that was developed by Brown et al. (1997) to encourage, motivate, and build confidence in young children and their self-care with diabetes. To do so, the characters in the video game must avoid certain enemies and engage in behaviors that will help keep the characters healthy. The authors found that those who played the video game had increased communication with their parents about their condition and created more positive health-related behaviors. Similarly, Gerling et al. (2011) developed Cytarius, a game prototype to convey more information about cancer to pediatric patients. Parents of the patients believed that having a game on cancer could help augment their child's understanding of their condition and might be useful in initiating an optimistic and open discussion about dealing with cancer.

Similarly, work by van der Velden and El Emam (2013) examined the usage of social media, such as Facebook, by teenagers with a chronic illness. However, their study focuses on the privacy implications of sharing health information through social media. For example, the authors found that patients often used Facebook as a way to stay updated with their friends, but at the same time, patients would also consciously refrain from sharing anything regarding their health as a way of protecting their privacy with friends who were only acquaintances.

2.2 *Designing with Patients who have a Chronic Illness*

Design methods have long been utilized in research to incorporate users' perspectives and experiences into the design of a technology or system. For example, participatory design (PD)—a method first originating from the Scandinavian workplace—includes theories, practices, and studies that involve the end-user in activities that eventually lead to the design of products (Muller, 2010). This section will focus, in particular, on design studies that have focused on two groups of users: (1) adult patients with a chronic illness, and (2) pediatric patients with a chronic illness.

2.2.1 *Adult Patients*

A subset of health literature has focused on employing design methods with adult patients. For example, Tsianakas et al. (2012) used experience-based co-design (EBCD) as a way to identify and understand the experiences of patients with breast or lung cancer. The authors conducted a large study in which they conducted facilitated co-design workshops with patients and healthcare professionals. Through these workshops, the authors found what patients found important in their care. Most importantly, having these workshops helped both patients and healthcare professionals see the “other side”—for example, the healthcare professionals reported that they felt a greater sense of empowerment to make changes in their care delivery. Andersen (2010) describes a case study of a *participatory patient* who has a heart disease, using a prototype of a personal health record, as a way to bring forth the notion of patients' “dual enactments of participation”. This particular patient was an active participant in his care, and during the co-design sessions, he would encourage for a more active patient in the design (e.g., explicitly asking for more possibilities for a specific function in the system). In this study, Andersen highlights the explicit and implicit ways in which the patient (as a co-designer) helped shape the definition of what an empowered patient does in the system.

Other studies have focused on using design methods as a way to understand the needs

of patients with a chronic illness. For example, Gonzales and Riek (2013) explicate their work with oncologists and newly diagnosed cancer patients to help create patient-centered communication tools that can help both the clinicians and the patients have a more fruitful discussion about their care. They conducted patient design workshops and individual design sessions with oncologists. The authors found that there were conflicts in what type of platform should be used for these tools—for example, the oncologists suggested tablet and mobile platforms while the patients thought large, interactive displays would be easier to use. They also found that both the oncologists and patients agreed that personalized information is important for patients but that there needed to be some level of restriction of information to ensure that the information would not be overwhelming as some discussions for newly diagnosed patients can be very emotional, similar to what Boyd et al. (2012) found in their co-design workshops with breast cancer patients. Skeels et al. (2010) conducted participatory design workshops with patients who have breast cancer. The authors found that the participatory design sessions produced two different types of results: understanding the intricacies of how a social network worked for a breast cancer patient and designs of a technology that would be useful to the patient to overcome any barriers that they might have. The first result of understanding the patient directly informed the designs of technology to better help breast cancer patients collaborate and share information among their social network.

Although the previous studies have focused on participants without physical or cognitive impairments—participants who are able to communicate and express their thoughts about an experience or a design—other studies have examined the challenges in conducting design research with participants who are physically or cognitively impaired. For example, O'Connor et al. (2006) illustrated a case study of conducting participatory design with a participant who is physically limited due to cerebral palsy—for example, the patient is physically unable to speak, so he is often limited to yes or no answers. This can be challenging when conducting a research method such as participatory design which depends on participants to verbally articulate their thoughts. The authors use the notion

of an *exploratory prototype* as a way for the participant to explore a novel space that helps researchers understand what requirements are needed for a technology, but it is not actually part of the design process where the design is being iterated on. The authors found that using an exploratory prototype was indeed able to support participatory design approaches when working with patients with severe disabilities. Wu et al. (2004) conducted design workshops with participants who have anterograde amnesia—a memory deficit that hinders individuals from storing new memories. They present a framework for researchers who are planning to conduct participatory design sessions with participants who may be cognitively impaired. The authors suggest that four steps should be considered: (1) assess each participant; (2) understand the cognitive deficit; (3) choose technique and identify assumptions; and (4) adapt, attempt, and refine approach.

There is also a body of research that has described using design methods with more vulnerable populations such as older adults. For example, in order to understand what health metrics older adults wanted to track, Davidson and Jensen (2013) held participatory design sessions and an online activity questionnaire. From both of the design sessions and questionnaires, the authors found that older adults were interested in four particular topics: social interaction tracking, rest tracking, suggestions for local stress relief activities, and suggestions for healthy eating based off what they wanted in their diet.

Other studies have examined how to better design medication management for older adults. Khan et al. (2010) conducted participatory design sessions with older adults and their caregivers to examine better ways to design personal health applications for medication management. From the design sessions and an expert panel of clinicians, the authors found that there were conflicts in what the participants believed was happening and what the clinicians believed was happening. For example, clinicians thought that participants would naturally compare their medication lists with the clinicians' (and bring attention to any discrepancies), but participants thought that it was too much work to reconcile their medication list with the clinicians' list. Along a similar vein, another study also examined the particularities of having a chronic illness and needing support

for medication management (Dalgaard et al., 2013). The authors also found that pervasive healthcare medication management systems should consider heightening the clinicians' awareness of the patient's individual medication overview as a way to share responsibility among the patient and clinician.

Other studies examined how to engage older adults during design sessions such as using games as a way to encourage older adults to be open-minded and playful (Iacono and Marti, 2014; Mayer and Zach, 2013). Other studies have addressed the challenges in designing with older adults with health conditions such as dementia. Lindsay et al. (2012a) thoughtfully described their experiences in designing with dementia patients and address how important the use of empathy was in their study. The authors suggest explicit scaffolding for researchers who would like to engage dementia patients in their research. Another study highlighted the fact that it is difficult for researchers and older adults with dementia to truly be "equal" participants (Hendriks et al., 2014)—the authors provocatively stated that although researchers may learn a lot from older adults with dementia, it may not be the same for the inverse. However, similar to the work by Lindsay et al. (2012a), the authors also recognized that it is important to be cognizant of "minimal utterances" and how researchers sometimes extrapolate participant statements to larger proportions, even when the participant did not necessarily mean that.

2.2.2 *Pediatric Patients*

Beyond the scope of this literature review, there is a vast amount of work that has examined designing with healthy children. Seminal work on cooperative inquiry on co-designing with children has often served as the fundamental basis of many design studies with children (Druin, 2002). However, these methods are often used with healthy children. Participatory design sessions can be more challenging when participants are children, particularly children who are undergoing intensive treatment.

Some work has specifically examined challenges in conducting design research with children who have a chronic health condition. For example, Hornof (2009) details a

field-based participant observation study on designing with children with severe motor impairments. He suggests that typical design research activities need to be reconstructed for children with severe motor impairments. It is imperative for researchers to learn how to hear “I’m done.” He also suggests researchers should interact with as many different caregivers as possible in order to understand the holistic experience of the child. Lindberg et al. (2014) examined the ethics of conducting participatory design with children who are in vulnerable situations such as those who are undergoing cancer treatment. The authors suggest the concept of *Ethics in Design* that focuses on shifting the notion of reactive ethics to building the ethics into the design process upfront.

Ruland et al. (2008) conducted various participatory design sessions to design SISOM, a novel interactive communication tool that helps “give a voice” to children with cancer on their symptoms and problems during treatment. However, healthy children were recruited to be informants or partners in the actual participatory design sessions due to the time and energy that a PD session may require. The authors conducted usability tests with both healthy children and children with cancer throughout the development process. Through this process, the authors were able to see how having children (both healthy and chronically ill) as design partners worked. In another study, Lindberg (2013) conducted various design workshops for children with cancer between the ages of 11 to 13 years old. She suggested that children partner up with an adult during design sessions because of the sensitive nature of the illness and the physical limitations that it can impose. In one case, a child who was still going through cancer treatment did not have enough energy to draw as part of the design exercise. Instead, the adult was able to help the child draw so that the child could still participate. Similarly, Høiseth et al. (2013) conducted a workshop with pediatric health experts to determine various design considerations for developing a technology to motivate and support medical adherence for toddlers. The authors suggested that systems should: (1) provide treatment-relevant play activities; (2) support social/family-centered activities; (3) use stories that confirm togetherness; (4) use repetitive elements; (5) use elements that have potential as meaningful rewards; (6) mix

reality and fantasy; (7) provide practical and informative information. In another study trying to understand the emotions of children with diabetes, the authors asked children to create various mockups of potential systems but found it difficult to analyze the emotions of children with diabetes when the systems were often unrealistic or fantastical. Despite this initial barrier in the analysis, the authors found that they could analyze the unspoken and implicit emotions—emotions portrayed through the design of the mockups—to understand how children with diabetes might feel about their condition (Glasemann and Kanstrup, 2011).

Similarly, Tsvyatkova and Storni (2014) suggested using *design probes* as a way to elicit design data from children with Type 1 diabetes in the privacy of their own homes. Using materials such as disposable cameras, modeling clay to create a super hero figurine, a recipe book for children to fill out, etc., the design probes allowed authors to get a sense of the child's everyday activities in a non-clinical environment. This helped the authors also develop a perspective and language for the design of an eBook for newly diagnosed patients and their families. Robertson and Balaam (2013) found that their initial participatory design workshops with children who were in the hospital were not fruitful in the elicitation of ideas. Instead, they extrapolated design stories based on formative interviews and observations and had patients discuss the stories. They reflected that it was difficult because of the transitive nature of patients—many patients that were initially working with them would go home, and there would be a new set of patients.

Chapter 3

HEALTH VLOGGERS

3.1 Introduction

The first video on Lily's YouTube channel showed her joking about wearing a "*beautiful [neck] brace*" due to lesions on her spine because of her breast cancer. Sixty-three videos and 10 months later, the last video uploaded showed a solemn man, Lily's husband:

This update is long and coming. I apologize for its tardiness. Some of you may know, some of you may not know yet. Lily passed last Saturday. She lost the battle...She fought hard—sometimes it's just too hard. She was surrounded by family when she went. Forgive me, this is a little hard. She wanted me to remind everybody: don't take labels, be yourself, make a difference in the world. So, I'm going to sign off with what she said—I hope you take it to heart—be good human beings. Farewell.

Although it had only been 7 days since his wife had passed away and it was visibly difficult for him to speak about it, Lily's husband still needed to update his wife's viewers, treating them as if they actually knew her and were her friends. It was clear that Lily felt a strong connection with those who watched her videos (her videos had a total of 11,806 views)—she even wanted her husband to remind her viewers to be themselves. Many of the comments that were left by viewers were comments of condolences but also about how inspirational Lily was during her journey.

Many people like Lily opt to share their story with the public through social networking websites and blogs. Over the years, traditional text-based blogs have evolved to support

various presentation forms—art blogs, photoblogs, sketch blogs, audio blogs, and video blogs (vlogs, in short).

Vlogs have been widely used for e-learning (Trier, 2011), citizen journalism (Markham, 2010), product marketing (Hoffman and Fodor, 2010), and daily interaction with family and friends (Lange, 2007b). Another emerging area is health vlogs, in which individuals with health conditions share their stories with others. Sharing personal experiences with others has been proven to be helpful for peer-support, especially for those who have chronic illness (Brubaker et al., 2010). The connection between the vlogger and the viewers is critical in health vlogs as past literature has shown that social support or connections with others work as self-therapy (Tan, 2008).

Despite the apparent advantages in further developing health vlogs, research has not yet explored in depth how patients appropriate these video-sharing platforms as part of their illness management (Ohno-Machado, 2012) in order to connect with others and to receive and provide social support. Patients not only utilize the video medium but also the commenting features of video-sharing communities. There is a large impact of these patient-initiated health vlogs and commenting features of a video-sharing community as tools for social support, especially the relationship among viewers and vloggers.

In this chapter, I describe how health vloggers appropriated videos, comments on the videos, and the YouTube platform as a way to create deep and meaningful connections with their viewers—providing support to others who might be going through similar situations while also receiving social support from viewers. I then explicate how “broadcast” technologies—technologies that typically do not have an equal amount of interaction between people—can better support the connections between health vloggers and their viewers.

3.2 Methods

To examine health vloggers who posted a series of health vlogs, rather than a standalone vlog, my colleagues and I studied health vlogs on three chronic diseases that require self-

	HIV	Diabetes	Cancer
Sex	12M	9M/3F	8M/4F
Age (Median)	27 (21/51)	33 (15/75)	38 (25/49)
Videos per person (Min/Max)	46.5 (2/150)	14 (2/1027)	23 (6/197)
Views per person (Min/Max)	37,180 (273/370,444)	5,441.5 (570/313,235)	14,808 (258/341,788)
Subscribers (Min/Max)	232.5 (1/1457)	21 (4/405)	22.5 (1/505)

Table 3.1: Descriptive data of each category of vloggers

management activities over time: HIV (human immunodeficiency virus), diabetes, and cancer, though cancer is not always considered a chronic disease. We chose these three diseases because they have a high prevalence in the world for us to be able to collect a reasonable amount of data, differ in ways in which self-management strategies are formed and maintained, and have different levels of social stigma (e.g., HIV may have a higher level of social stigma than cancer).

We considered all forms of diabetes, and we did not distinguish cancer types. Specifically, YouTube was selected as the video platform because of its worldwide and enormous usage (over 1 billion users). Because YouTube did not have a specific health category, we utilized YouTube’s search mechanism by using the keywords <disease name> blog to get the search results. We received 2500, 2090, and 12900 search results for diabetes, HIV, and cancer, respectively. We narrowed down the list to a set of vloggers who fit into the following inclusion criteria:

1. The vlog title contained words that were directly related to diabetes, HIV, or cancer (e.g., “insulin”, “chemotherapy”, etc.)

2. The vlogger either verbally in the video or in the written description confirmed that he or she was diagnosed with the illness
3. The vlogger was the diagnosed patient him/herself and not an institution or organization. This criteria was set because many videos uploaded by an institution are professionally edited, but I was more interested in looking at amateur vloggers.

We reached data saturation after 36 vloggers (the first 12 vloggers for each disease). For each vlogger, we analyzed their first and last health vlog posted, resulting in a total of 72 vlogs. Certain characteristics of the vloggers (e.g., all HIV vloggers were gay males) were a result of the selection process (see Table 3.1 for more information on each disease vlog group). We then transcribed each vlog with timecodes, captured representative images for each scene change, recorded the textual description of the vlog and comments posted to each vlog. I have changed the names of the vloggers throughout this chapter.

Specifically focusing on 9 unique users (2 videos per user) in order to first get a baseline understanding of the vloggers, we developed descriptive codes for the dataset. The resulting descriptive codes focused on the following attributes: basic information about the vlog (title, post date, vlog length, caption), demographical information about the author, medical information about the author (disease timeline, emotional stage), visual information (video editing, scripted, location), and other information that describes the different styles of authors' performance and attitude, as well as the way stories are presented (attitude, message of the video, intended audience, purpose).

Next, we used open coding to analyze the rest of the dataset (54 more videos, resulting in a total of 72 videos including the first 18 that was used to develop the coding scheme). We also analyzed a total of 21 comments from three different vlogs (one video each from the HIV, diabetes, and cancer vlogs) using open coding to develop a different coding scheme that was used specifically for comments. The total number of comments coded was 1,274 comments. Through our analysis, we identified relevant themes that emerged

from both the descriptive codes and the open coding schemes. We then performed an affinity diagram with the codes of the vlogs and comments.

3.3 *Establishing Connections*

In this section, I describe how vloggers used vlogs as a medium to connect with their viewers as a form of self-therapy while helping others. I first discuss different genres that vloggers devised to convey specialized messages to the viewers. I then discuss how video affords richer viewer connection than text-based media. Lastly, I discuss various methods that vloggers used to explicitly interact with viewers.

3.3.1 Health Vlogging Genres

Vloggers produced different genres of vlogs, depending on the stage they were in, their illness trajectory, the chronic illness they were suffering from, and their purpose for vlogging. The different genres, discussed below, reflected the messages vloggers wanted to convey and how they wanted to present their messages to the viewers.

Teaching. In teaching vlogs, vloggers attempt to educate viewers with information about their illness and management strategies. Vloggers typically created teaching vlogs with content highlighting their own knowledge and experience. Teaching vlogs allowed vloggers to cast themselves as an expert to viewers in what they do.

More of the diabetes vlogs in our study were for the purpose of teaching (42%), compared to vlogs for the other illnesses—HIV (13%) and cancer (17%). For diabetes management, self-education is critical. Because diabetes is a chronic illness that can be managed through diet and personal lifestyle, many diabetes vloggers offered suggestions to viewers. Examples included eating certain types of food, such as cinnamon (DIB12a) or a particular brand of pasta (DIB8b), or advocating for a lifestyle change, such as a vegan lifestyle (DIB9a). Thus, one would expect that many diabetes vloggers would attempt to teach strategies and solutions that others could use. In one case, a type 1 diabetes patient

(DIB5a) was educating himself to become a diabetic coach, and he used vlogs to gain experience in teaching others.

In teaching videos, vloggers shared information on characterizing their illness and strategies to manage the illness. For example, Anthony wanted to distinguish between Type 1 and Type 2 diabetes, by giving an overview of the differences:

When people talk about diabetes, they're almost always thinking that it's diabetes Type 2... For me, I'm Type 1 so... we just don't produce insulin...But for Type 2 diabetics, they could have complete insulin resistance, so that's a whole other thing. (DIB5b)

We observed frequent *show-and-tell* behavior throughout the teaching videos, which is difficult to convey through text-based blogs. For example, vloggers demonstrated how a device worked, how to cook low-carb meals (DIB4a, DIB7a), or how to replace gauze on open wounds (CAN12a). One diabetes vlogger explained that he had a heart monitoring device and said, "*I have electrodes attached to my chest*" (DIB4b) before showing how the heart monitor device worked. John showed how he got blood tests done (HIV4a). Vloggers also used hand descriptions to show the size of a swollen testicle using their index finger and thumb (CAN6a) or where and how long in length the stitches were (CAN4b). In another example, one cancer patient talked about what one might expect when conducting intravenous (IV) therapy by showing himself in the hospital:

They need to warm [my arm] up so the veins pop up more and they can insert the IV easily. (CAN9a)

Vloggers also used a mixture of different types of media to present informational material. Some used video recordings while others used text along with still images. Others would draw a picture by hand. As shown in Figure 3.1, Sue created a scenario and rendered it on a still image, which was then inserted into her vlog as teaching material (DIB1b).

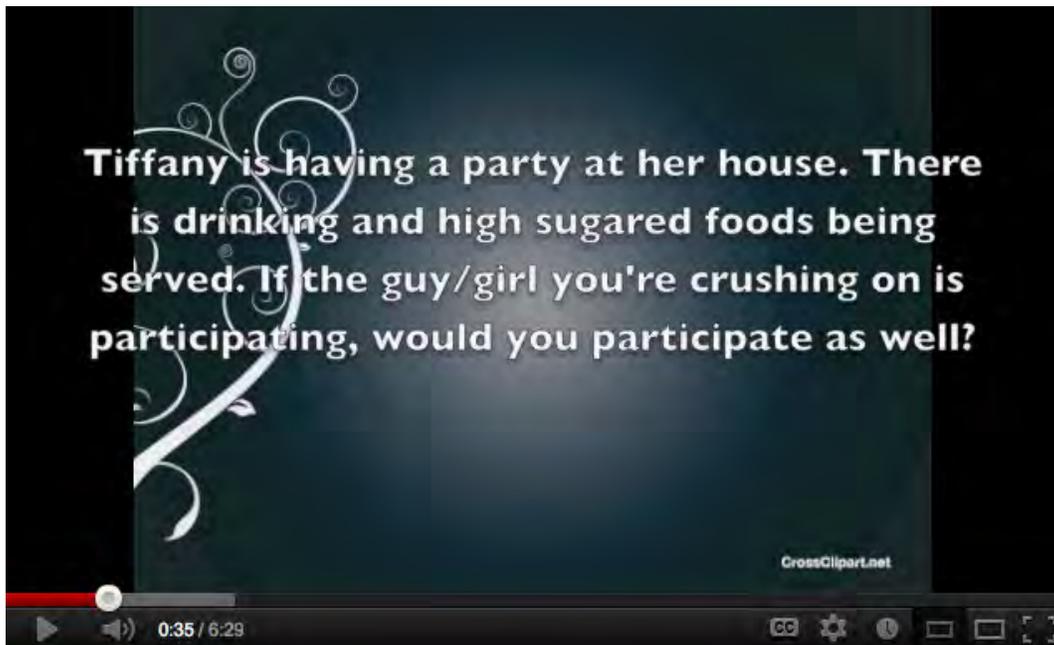


Figure 3.1: A fictional scenario was used by a diabetes vlogger to teach viewers about everyday diabetes management.

Similarly, Figure 3.2 shows another vlogger explaining how uterine cancer affects pregnancy by drawing a diagram on paper (CAN7a). She drew a uterus and indicated where her cancer resided to explain the challenges of becoming pregnant while having uterine cancer. To this video, one commenter showed gratitude, stating that the information provided in the video was useful:

Thank you for the great information you are giving us. I have found it very helpful. My step daughter who is 17 years old is going through this now.
(Comment, CAN7a)

Personal Journals. One of the most common genres of videos was a personal journal. In this genre, vloggers gave updates on their current emotional and physical status or experiences during major stages in their illness trajectories. According to Raun (2012), by sharing such day-to-day changes, vloggers can create a sense of connection with others



Figure 3.2: A cancer vlogger drew a picture to show and explain how uterine cancer affected pregnancy.

and reflect upon themselves, working as a therapeutic activity.

Many vloggers included current updates to their treatment and shared their thoughts and feelings, akin to a written diary. Through these updates, vloggers made personal records of what they had accomplished and what future events were left on their treatment plan. Commenters also left highly emphatic words for vloggers. For instance, after a breast mastectomy surgery, one cancer vlogger shared her status that her surgery went well (CAN4). She then shared the emotional struggles she had to go through, emphasizing her divorced situation and issues around caring for a child while being sick, weeping as she shared the information. A commenter then left a message of encouragement to the vlogger:

=) you are so strong keep up the good work I LOVE YOU (Comment, CAN4a)

The vlogger responded back:

Thank you sweetie. And for all your encouraging words throughout this frightening journey. And,.... I love you more! ;) (CAN4a)

Some vloggers explicitly mentioned that the goal of their vlog was to serve like a journal (CAN1a, CAN8a). Other vloggers not only gave updates on their disease, but also on their personal lives. However, HIV and cancer vlogs had different focuses within journaling. HIV vlogs tended to focus on self-reflection, which allowed the vloggers to reflect on their disease as they shared both their past experiences around diagnosis and their social relationships. On the other hand, most of cancer vlogs focused on updating about vloggers' physical and mental well-being statuses. Cancer vloggers stated they wanted to create a "*personal record*" while easily giving updates to their loved ones. In one case, Andy, a diabetes vlogger explained that his video was to update his viewers about the results of his daughter's diabetes test as negative (DIB10b). Other vloggers updated their medication practices. Nick updated his viewers about his experience with a new medication:

Today's the first day I took the medication, and it's Complera....I'm very nauseous...pain in my chest...stomach is a little hurting. (HIV8a)

Sharing such day-to-day experience provides viewers with information about the medication while also building personal connections with consistent followers.

HIV vloggers, compared to other vloggers, tended to be more reflective, sharing their revelations and acceptance of having HIV. Matthew reflected on why he might have contracted HIV: "*I love people more than myself—that's probably one of the reasons I got HIV.*" (HIV1a).

In one case, Blake stated that he was struggling with accepting HIV in his life. He also said that he felt that everyone was constantly judging him, even strangers. Finally, he came to an epiphany on living with HIV and shared it with the viewers:

[HIV] was owning me. It was taking over...I was so tired of it wearing me down. And I say 'was' because I had this epiphany. I was just like...don't let it own me, own it. How do I do that? Hmm. Personalize it maybe? Own it. Meaning, it's yours. HIV—the Human Immunodeficiency Virus or BIV—the Blake Immunodeficiency Virus. That's when it hit me; I don't have HIV. I have BIV! Own it, bitch! (HIV10b)

Viewers for Blake's video commented that it inspired them greatly, thanking him. Steven, another HIV vlogger, began reading a letter he wrote to HIV:

I can only blame me, not you, for coming into my life. Since our relationship began, I focused on what I lost, and neglected to see what you've actually given me—my life... (HIV6b)

Through this letter, Steven was able to share how he integrated HIV as part of his life with his viewers. His interesting approach on speaking directly to HIV, as if it were a person, triggered thanks from the viewers, and many agreed with his thoughts.

Other vloggers also reflected on their past diagnosis experience as well as various struggles around social stigma, social life, dealing with pain, dealing with the work place, and emotionally staying strong. For instance, Alex reflected on the emotional struggles going through reoccurring cancer:

It's going to be a hard waiting period. It's all about ups and downs, really, isn't it? You just get over one thing, then you find out you got a tumor, then you get told you're going to have it removed, then you get told a procedure of how it's going to happen, then you get told were going to check if you got another one. It's a bit shit really, isn't it? (CAN6b)

While Alex had focused on letting out his emotional struggles of dealing with the uncertainty of having cancer, Fiona shared the positive things that have come out of her having diabetes:

I can focus on some of the positive things that have come out of [having diabetes]. Positive #1: it's taught me to be more organized because I have to plan more. Positive #2: it's taught me a lot more about nutrition and how the body works to control blood sugar. It's made me appreciate a lot more how important it is to take care of your health. Positive #3: more health checks. (DIB11b)

Many personal journals used a stylistic format of a talking head, only featuring the author and their head. This style follows the idea of virtual social proxemics (Olson and Olson, 2000) and other work that has shown that the size of the image often affects the interaction of a videoconference (Grayson and Coventry, 1998). Yet, unlike remote videoconferencing, vlogs are one-sided. Vloggers are not able to get immediate feedback from their audience.

Vloggers discussed how they were feeling, current updates, or past experiences using this style. Many would also share past experiences with the audience. In one example, an HIV vlogger explained his initial experience after his diagnosis:

There were times in my life I got really involved in drinking, and I just wanted to forget about life. I wanted it to end. (HIV1b)

Often, vloggers would also take the opportunity to plead for viewers to take action. In the case of HIV, Dan begged viewers to get tested if they had not already and to be safe and protected. He repeatedly said, *"It's not worth your life...yes, I'll live to a ripe old age, but how long will I live? I don't know"* (HIV7a). A cancer vlogger shared her past experience before getting diagnosed with uterine cancer, explaining some of the symptoms that showed up. She urged viewers that if they were experiencing any of these symptoms to *"please go see a doctor to make sure you're fine and that this is not happening to you"* (CAN7a). From these pleas, vloggers are able to show their concern and care for viewers, thus potentially increasing the connection between the vlogger and the viewers.

Self-Documentaries. Vlogs have the ability to capture situated, in-the-moment information that traditional text blogs cannot. Vloggers took advantage of this capability and allowed their viewers a glimpse into their highly situated experiences.

For instance, Sam, audio-recorded a confirmed diagnosis with his doctor, providing subtitles against a black screen. Although the viewers could not see the video of what was happening, the audio, together with the subtitles, intensified the delivery of what happened inside the clinic.

Beyond clinics, vloggers took the camera with them as they participated in various events. Jen had her husband film her during a triathlon (CAN3b). Another vlogger filmed his time at an AIDS conference (HIV9b). One vlogger brought his camera with him as he finished a military-like 5K run (HIV12b). Bringing the camera and allowing the viewers to get a peek into their lives, regardless of whether the content was directly related to the illness or not, allows moments of connectedness between the vlogger and the viewers.

Video Compilations. Vloggers also used creative ways to inspire and encourage their viewers by compiling video portraits of people sending positive messages. Although they were patients, the vloggers in these genres were not the main information givers of the vlogs, but rather, information gatherers.

Video compilations helped create a sense of community with those who are going through the same illness. For example, one diabetes vlogger uploaded a video that simply contained messages from people who attended a diabetes conference, saying their name, how long they have had diabetes, and *“you can do this!”* or *“I’m Type Awesome!”* (DIB3a). As written in the caption of the vlog, the purpose of this vlog was to give support to those struggling with living with diabetes.

In another vlog, Nicole started off by dancing and then explained that her friend’s daughter who had Type 1 diabetes was about to get glasses, but was worried that people might make fun of her for wearing glasses and an insulin pump. Nicole said to the camera, *“So this video is for her, and I have a few friends that want to help me...c’mon guys!”* (DIB3b)

and showed a slideshow of both photos and video clips of more than 50 people who were wearing both insulin pumps and glasses.

Some vloggers brought their viewers back into their vlogs for further inspiration for others. For example, Sam compiled videos sent from other viewers into a series. He introduced the series by saying:

Several people have emailed me because the blog has touched people in so many different ways, so I'm providing an opportunity for people to tell their stories... how they became positive. (HIV5b)

Here, the vlogger actively engaged his viewers through his vlogs, which in turn connected him with his viewers.

3.3.2 *The Affordances of Video*

Vlogs allowed for a form of presentation that traditional text blogs do not allow. Vloggers used cameras to film themselves talking, show their cats, capture real-time moments, use animations, demonstrate how to do things, or make picture slide shows. This high level of customization enabled vloggers to take control of their vlogs' presentation and content, which is a means for self-expression (Tremayne, 2006). In the following section, I discuss several affordances of video, including *non-verbal cues*, *other actors*, and *context filming* as ways vloggers took control of their vlog presentation.

Non-verbal Cues. Nonverbal cues are typically visual cues without words. We observed vloggers trying to build personal connections and rapport with viewers through their nonverbal cues, such as pausing, crying, or giving facial expressions.

Subtle but powerful pauses in speaking can create a range of emotions that vloggers and viewers can share. Jen, who wanted to express how much compassion she had for another cancer survivor's video, looked directly into the camera and paused for ten seconds, occasionally sniffing to hold back tears and said, "*I feel closer to you now that*

I know your family history” (CAN3a). Similarly, Felicia, another breast cancer survivor continuously suppressed her tears as she shared her update:

As much as I don’t want to deal with that, I understand that I have to because it is part of my journey. <pauses, sniffs, sighs> But, um, I’m really, really grateful <sniffs, looks down, pauses> that the surgery was a success <clears throat>. I’m really grateful that I am cancer free. (CAN4b)

Blake wanted to share his emotional state at the time of diagnosis as HIV positive with his viewers (HIV10a). He paused, glanced, gave emotional expressions, and eventually sobbed as he recounted his story (Figure 3.3), which helped create a personal connection that would have been hard to do with traditional text-blogs.



Figure 3.3: Blake (HIV10a) wiped away tears as he shared his experiences and thoughts about being newly diagnosed with HIV.

The vloggers also used humorous expressions to build rapport with the viewers. John wanted to show how regular blood work for HIV patients is done. He asked the nurse

to explain the purpose of blood work, blood containers, and then the needle, to which he changed the camera angle to show his face humorously frowning (HIV4a). Eric, a cancer vlogger, adjusted his webcam while making a silly face at the camera (CAN2a).

Most importantly, for highly stigmatized diseases such as HIV, disclosing one's face, name, and family history in front of a worldwide audience can be quite intimidating. Yet, the vloggers used this disclosure to create intense and personal connections with the viewers.

Other Actors. Another unique component we saw from vlogs was incorporating more than one actor in the scene. These actors included significant others (CAN3b, HIV7b), pets (CAN2b, CAN3a), or health care providers (CAN6b) who provided further context about the vloggers and their situation.

Other actors participated in vlogs to send messages for the vloggers when the vlogger was not available (CAN1b, CAN3b), broadcasted events in the moment as vloggers participated in those events (CAN3b, HIV4a), or became the ambiance of the video that added meaning to the message being delivered to the viewers (HIV7b, DIB7b).

For instance, the goal of Dan's vlog was to deliver a teaching message on what to do after having unprotected sex with someone who is HIV positive. In this video, Dan's partner, who is HIV negative, was sitting beside him. The caption of the video says:

If you think you may have been exposed to HIV or a condom has broken or if you are having unprotected sex, please watch this as this video was done by my partner who is HIV negative and I thank him for his courage...he is amazing. (HIV7b)

Having an HIV negative person disclose their face with an HIV positive partner can be a highly stigmatized activity. This strengthened Dan's delivered message of safe sex.

In Sam's video, his doctor was present, though only through voice. As a form of self-documentary, Sam captured the moment of being diagnosed, shocked by his doctor's

words that Sam had a large viral load (HIV5a).

Doctor: "It's a positive viral load...you expected that."

Sam: "I did?"

Doctor: "So...your viral load right is like, a 5,517,000."

Sam: "5 million? Oh my god. Wow, okay. I was hoping for, like, 12." (HIV5a)

The next scene shows Sam's concerned face outside the hospital, telling the camera that he is now flying home to tell his parents about the diagnosis. In the vlogs, Sam showed himself as being nervous but at the same time, trying hard to stay calm and positive.

Using the voice exchange with his physician in the video, the emotional progress, and externalization of his inside voices, Sam was able to capture his fear, anger, sadness, and surprise in that moment. In response to Sam's video, one commenter shared his experience of being diagnosed, comparing his own viral load to Sam's:

Thx for sharing your video. i just found out a month ago of my status with a 1 million VL [viral load]. 3 weeks later I was put on hiv medication. only on meds for 9 days now. hopefully the medication is working for mine. *hugs*
(Comment, HIV5a)

Another commenter thanked Sam for his video, stating that he was inspirational:

Omg, you're so inspirational. Please do update us on your condition. Thanks for this (Comment, HIV5a)

Context Filming. Videos have a great ability to capture *in-the-moment* without needing to describe them in text. The most frequent background in vlogs was the vloggers' rooms, especially the back wall behind the vloggers' talking head. In this case, viewers would then focus on the message being delivered by the vlogger. However, once vloggers began to push the boundaries of where the vlog was filmed as well what their appearance was,

richer context began to add onto the vlogs. Furthermore, they began adding rich context to augment and intensify their messages to viewers.

For instance, Ted filmed his first vlog at home in his room, but his last video titled, “My HIV Life ‘Obstacles’ ”, showed himself in front of a red brick wall (see Figure 3.4). He explained that the red bricks were a symbol of strength because they stayed the same throughout any obstacle:

I actually did this setting behind a brick—you can see the brick wall behind me 'cause bricks are symbols of, like, strength. You know, they're very strong throughout the weather, the erosion, everything, and they stay the same. They have a lot of strength throughout the obstacles they face and all that stuff. I think, I want everybody to...just be strong brick houses, and do your thing, and don't let nothing shake you 'cause you stronger than that. That's what I want this video to be about. (HIV3b)

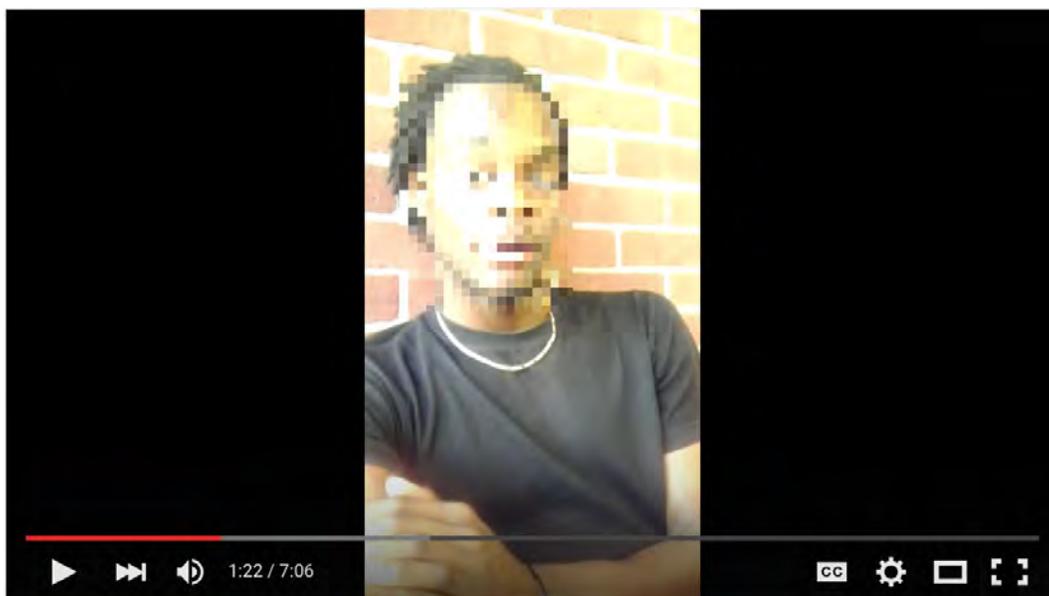


Figure 3.4: Ted consciously chose to film with a brick wall as his background to remind his viewers that bricks are a symbol of strength.

Background transitions in vlogs also helped vloggers effectively convey context. Paul started his cancer vlog by describing his synovial sarcoma and history with the hospital waiting room as his background. As he progressed through the hospital visit, the backgrounds changed from the waiting room to the hospital room, where he was getting his chemotherapy, and then back home. During this transition, he walked his viewers through his medical history, current status, and remaining treatments to be done. In the vlog, he gave small show-and-tell examples. For instance, he explained the specifics behind how the warm blanket around his arm allowed for easier IV insertion and then showed his viewers his arm with the IV inserted (Figure 3.5). Such show-and-tell examples, tied with a hospital setting as a background, was Paul's choice to deliver his context more effectively to his viewers. As he noted, *"Once they call me in, I'm just going to go over the different things that they do in the chemo room"* (CAN9a).



Figure 3.5: While he was in the hospital, Paul (CAN9a) outlined what they were doing to him during chemotherapy (inserting an IV into his arm) and the reasons as to why there was a warm towel around his arm.

Vloggers also captured their vulnerable appearance to inspire others and to help them learn. Ely, a brain tumor patient, filmed himself in a vulnerable state, while lying in a hospital bed with a nasal cannula and wires around him. He then stated, *“I wanted to take my experience as a photo journalist to help people learn from my tragedy”* (CAN11a). Similarly, Tom presented himself as vulnerable and not willing to live, filming himself in bed 7 days after his diagnosis of HIV. He repeatedly stated, *“I refuse to participate in this world”* (HIV2a). In contrast, a year after the initial vlog, he posted a photo slideshow as part of his HIV vlog series, where he was standing in front of the White House holding up a picket saying, *“I am HIV+”* along with pictures of him and many supporters smiling. He had become an HIV activist a year after he uploaded his first vlog. Tom also confirmed his purpose of posting health vlogs as supporting his peers—for those who *“might have been going through the same thing that [he has] been going through”*.

One of the critical elements in peer patient support is sharing emotional experience situated in context (Kurtz, 1997). Through health vlogs, vloggers brought an intense personal connection to the viewers, through nonverbal cues and enriched context of major illness events using other actors and background context. Accordingly, health vlogs are particularly useful for peer patient support. At the same time, not only peer patients but any individual interested in the health problem, such as undiagnosed patients or care providers, could learn about the disease from health vlogs more thoroughly than through traditional text-based blogs.

3.3.3 Requesting Viewer Interaction

In contrast to the implicit methods for vloggers to establish viewer connection that I just described, in this section I describe explicit methods used to request viewer interaction and build a connection with viewers.

Vloggers also sought viewer interaction by verbally responding to comments or certain groups of viewers. In one example, Roger used his vlog to address his reaction to a certain group of his viewers:

All of you HIV denialists that keep hitting me up and keep leaving comments on my channel...stating that I am misinformed, informing me how HIV is nothing but some kind of scam that was cooked up by the government and Illuminati...I appreciate what you guys are doing, but I will frankly have to say, carry that bullshit to someone else's page...I don't want to hear that! (HIV11b)

Other vloggers solicited viewers' interactions by requesting comments or questions. Anthony ended his video with the following message to explicitly request interaction: *"If you have any comments or questions, go ahead and shoot it back to me, and I'd be more than happy to answer that"* (DIB5a).

Another vlogger encouraged his viewers to help guide the direction of future videos by saying, *"If you see this, comment on it. I'll try to add more as I go on"* (CAN5a). Others asked the viewers to correct them if they gave out incorrect information, using the viewers as gatekeepers. For example, Anthony said, *"Questions, comments—you want to call me out on something? Maybe I got something wrong? Maybe I got lots of things wrong"* (DIB5b).

These types of interaction requests were fairly common for many of the vloggers, but some tried to engage their viewers in a unique way to spark further interaction. Carl, a diabetes vlogger uploaded a vlog about a prize giveaway:

Just leave a comment on this post that includes the words, *Bacon Wrap My Pump*, and you can be one of six lucky winners of this sweet bacon skin for your Medtronic insulin pump! (DIB6b)

Some vloggers provided a way for viewers to communicate by providing external links such as to their Facebook, Twitter, email, website, and even a phone number. Steven, for instance, wrote his phone number and email address on a piece of paper and showed it to the camera, telling the viewers to contact him if they need help (HIV6a).

3.3.4 *Self-Therapy*

These results show that health vloggers use a variety of implicit and explicit ways to create a connection with their viewers. This vlogger-viewer connection is critical in one of two main motivations in health vlogging: self-therapy.

Many vloggers stated that they created vlogs for their own benefits. Some mentioned that vlogging was something their psychiatrist recommended, while others just hoped that it would help them in some way. Nonetheless, the self-therapeutic aspect of health vlogs was not confined to helping oneself. As vloggers mentioned in their vlogs, having the added benefit of helping others while helping themselves gave vlogging a greater purpose than a means to indulge in narcissism (Griffith and Papacharissi, 2009). For instance, one cancer vlogger commented that her main vlogging purpose was to record her journal. However, she also said, *“walk this journey with me”* and wished that other cancer patients could take something from her vlogs and apply it to their own lives (CAN4a). One cancer vlogger also said that he wanted to share with those who wanted to know what it was like to go through cancer treatment. Although there was usually no validation that their vlogs had helped anyone, knowing that there was the potential helped many vloggers.

Particularly for the vloggers with diabetes or HIV where the illnesses were dependent on self-management strategies, creating vlogs helped hold the vloggers accountable for their actions. If vloggers stated a plan of action or even suggested their viewers to act upon a plan, vloggers would then be expected to follow suit:

If I have to actually propose my diabetic frustrations and problems to others, I should theoretically be able to have it in better check. (DIB5a)

Similarly, Matthew was able to reflect on himself as he looked back into his past, contrasting the past with his present status. Such self-reflection could encourage not only himself, but also the viewers who might be going through similar situations:

The first five years was a living hell. I remember being very self destructive

with alcohol, sometimes with drugs, and just hurting myself more, because I felt like if I was going to die, I might as well give up. It was a rough time. But as you can see, 9 years down the road, I'm still sexier than ever, still muscular, but I can tell you it wasn't easy. (HIV1a)

3.3.5 *Helping Others: Dealing with the Invisible Audience*

Many vloggers also stated in their vlogs and captions that their main purpose was to help others by inspiring them and teaching them with the expertise they gained over many years. From our findings, I discuss altruistic motivations that played into teaching and personal journal vlogs. Many explained that they wanted to share their experiences with those who were recently diagnosed or were struggling with their illness because vloggers did not receive the right kinds of help when they needed them.

However, the interpretation of “helping others” varied. In personal journal vlogs, some vloggers believed that speaking freely to the camera about what was on their mind would be helpful to others. As shown in the teaching vlogs, others took an educational route by including tangible strategies and solutions that could be useful to viewers.

Although vloggers explicitly mentioned helping others as one reason for creating vlogs, we did not find much evidence that they received confirmation from their viewers saying that it was helpful, unless viewers contacted vloggers through comments or private messages. This notion of an invisible audience, where vloggers do not have any knowledge of their viewers, was observed throughout many of the vlogs. For example, Dan, an HIV vlogger said:

[If] one person listens, and one person doesn't catch this chronic illness...I'll never meet you—whoever you are—then, I'll sleep better tonight. (HIV7a)

For vloggers, presenting one's struggle during illness management was a common approach that many HIV and cancer vloggers used to inspire others. They contrasted the worst moments—either captured through video in the moment or as they recalled the

memories and talked about those moments with tears—with an often improved current situation. In this way, vloggers demonstrated that other patients at their worst moments could see a more positive future for themselves, as described by Ely:

I want to do a documentary. I want to share my experience with the world, hope that other people can understand and learn from what I've gone through and what I'm going through. (CAN11b)

For vloggers, simply believing that they helped others gave them a sense of peace, perhaps, serving as self-therapy too. At the same time, as I discussed in *requesting viewer interaction*, some vloggers attempted to gain explicit feedback from their viewers. Although some viewers did comment on the videos, many of them were silent—simply following the vloggers' stories without interacting with them. The attempt to explicitly connect with viewers may have been vloggers' struggle to grasp their invisible audience into companions, whom vloggers can consider as partners of social support.

3.4 Health Vlogs as a Platform

3.4.1 A Platform for Sharing

Health vlogs and their commenting features provided a platform for commenters and vloggers to share their personal experiences, knowledge, and advice around the topic presented from the vlogs. We observed both commenters and vloggers thanking, challenging, or adding on top of the shared expertise using the comments. Commenters and vloggers also exchanged questions and answers to gain further contextualized information from one another.

Sharing Information, Knowledge, and Advice. Commenters and vloggers shared their knowledge around the disease, treatment information, advice, resources, and personal experience. In his vlog, Sam had stated that his viral load was 5.5 million at the time

of his diagnosis. One commenter responded to this information by questioning Sam's health while comparing Sam's viral load to his, which had only been 410 for the two years he had been HIV positive. Another commenter stepped in and clarified that the original commenter may have a unique condition. Here, the second commenter provided his knowledge around a unique genetic condition that prevents HIV from becoming AIDS. He further advised the first commenter to monitor his viral load carefully:

If your viral load has held steady at 410 without meds, you are probably a rare individual known as an -HIV controller-, someone with a genetic makeup that allows you to prevent HIV from becoming AIDS. Just make sure to get tested every few months to be sure your viral load isn't increasing. If it does increase radically to a dangerous level, you need to start taking meds. (Comment, HIV5a)

Commenters would ask for more detailed information regarding the content of the vlogs. For example, one commenter asked for more information on Sue's diabetes vlog. The commenter geared the question towards Sue, but other commenters would also step in to provide information:

I am 12 and I have a pink Animas pump! I switched about 2 months ago and I love it ^_^ Also what is a combo bolus? I woz playing around with my pump and relized this. What is it? (Comment, DIB1a)

In response to this commenter's question, another commenter responded with detailed instructions:

Your DEC [diabetes educator] should have helped educate you (or Animas Tech Support should have) on what a Combo Bolus is. you should also have received a large manual with your pump when it arrived, read it from front to back, then read it again. Combo can be used for foods that do not immediately

affect your blood sugar (foods low on the glycemic index). combo's let you deliver a certain amount of insulin right away and a percentage of the total bolus over a chosen period of time later. (Comment, DIB1a)

Such information sharing also happened in the cancer vlogs. Vloggers would also contribute to sharing information in the comments. In one cancer vlog, the commenters on those vlogs comprised of those who were going through similar stages of testicular cancer. This time, the vlogger shared with the commenters on what to be careful of post-surgery:

My oncologist advised against working out heavily... can make things spread faster and further. gentle exercise is fine tho (CAN10b)

Commenters further provided resources that were useful for vloggers and commenters such as links to related informational videos (HIV11b) or ways to connect with other related societies such as the Leukemia and Lymphoma Society (CAN5b).

Sharing Personal Experiences. A unique type of help that peer patients can provide to one another is sharing their personal experiences. For example, one commenter showed appreciation for Stuart's shared experience. Furthermore, commenters in Stuart's vlog shared their own experiences of being diagnosed with and treating testicular cancer. The commenter thanked Stuart for sharing his experience with seeing a doctor because the commenter felt that he could finally understand what his brother might be going through:

Thank you so much for posting this inspirational video. My brother has recently had his operation to remove the offending testicle and has had a Chest X-Ray (clear) and a CT scan which were waiting the results for. I was so worried and concerned because like you, he didn't tell me or my parents until relatively late (after the op) but your explanation of how you felt and what

you were going through has really helped me understand things better. Thank you. (Comment, CAN10a)

Other commenters shared their own personal experiences, which collectively further helped both vloggers and commenters understand the process of being diagnosed with testicular cancer and how it felt like to go through treatments and surgery:

I think a LOT of us who have had testicular cancer put off going and seeing a doctor...It took me a solid 6 months after noticing a small lump to go see a doc. I really do hope you can go see someone soon though about it. You're not an idiot for not going to see your GP yet...Wishing you the best. (Comment, CAN10a)

3.4.2 *A Platform for Emotional Support*

Compared to informational support as described in the previous section, many commenters and vloggers would provide words and encouragements that would support each other emotionally throughout the difficult times that people often have when dealing with a chronic illness.

Commenters Supporting Vloggers. Commenters asked vloggers for updates and sent prayers and empathy. Sometimes, survivors of the same disease would leave encouraging comments for the vloggers. Vloggers showed gratitude to thank the support that commenters were giving them.

For instance, Felicia did not post vlogs for many months which led commenters to leave messages, asking for updates:

I hope you're doing better and can post a video soon. We are all praying for you! You're going to do fine, you seem like such a strong, wonderful woman. We are all learning so much from following your journey. God bless you, I respect the way you're handling this very much! (Comment, CAN4b)

Commenters would often check on vloggers to see how they were doing—this type of interaction between the commenters and vloggers showed that commenters were beyond just viewers of the vlog. The commenters established a certain connection with the vlogger—enough to follow the vlogger and to check in with the vlogger to keep up with how they were doing with their illness:

my man. you need to be strong, love your first 2 videos, please make a new one soon, make a video about you, you are a great person (Comment, HIV5a)

Most importantly, fellow patients, caregivers, or anyone who also went through similar situations provided positive personal experiences that helped encourage the vlogger. For example, one commenter spoke about how he was cancer-free for years even after multiple clinicians told him that he would not survive past 5 years:

I was diagnosed with NHL in Dec 1986 w/o much hope of surviving-- 2 doctors said 6mos to 1 yr, the Oncologist said up to 5. Surgery on Dec 26th, out of the hospital on New Years day. Chemo for 4 months (great weight loss program), and have been cancer free since then. God/Prayers and Attitude is the key. (Comment, CAN5a)

Another commenter who had HIV commented about how she was able to live a healthy life despite her condition, providing tips and suggestions on how to deal with the illness:

Hi [Sam] I'm Sarah and I'm HIV+ just stay strong ad take your meds I'm 26 will be 27 in october and born with it and have a beautiful family so you can still live a healthy life. I'm on Atripla (Comment, HIV5a)

In return, vloggers would also show gratitude to the commenters, showing that the vloggers indeed felt supported and hopeful from commenters' encouraging words:

Thank you! That makes me feel so good to read, you have no idea. Thank you so much! I only hope that I can provide that same support in return (HIV10)

Vloggers Supporting Commenters. Comments to the vloggers, stating that the vlogger inspired and helped them, were strong signs that the vlogs provided support to the commenters. Many comments stated that the vlog was their inspiration and how helpful it was, regardless of the disease. For example, one comment on an HIV vlog said:

You're such an inspiration to HIV pos+ and HIV neg- people alike (Comment, HIV10b)

Similarly, commenters would also remind vloggers about how useful their vlogs were:

[Nicole], you will undoubtedly save lives by posting this personal cancer journey. Hope all is well with you. (Comment, CAN7a)

The content of one vlog was a message to a young girl who was self-conscious about wearing a diabetes pump and glasses, thinking that she wouldn't be considered pretty. The message was a compilation of various people with a diabetes pump and glasses to show that they were beautiful regardless. One commenter thanked the vlogger, saying:

It made me smile and shed a few happy tears. I have been type 1 diabetic for about 10 years, have had glasses for almost one year, and no pump yet, but that is my goal!! Thanks for posting this not only for that beautiful little girl, but all the other beautiful diabetics out there!! Thanks for making my day <3 (Comment, DIB3b)

Vlogs were more than just a source of inspiration. They presented potential implications for public health, and commenters would recognize these implications:

You're very brave and it's so nice to see the message you're sending to people to practice safe sex. (Comment, HIV5a)

They were also an encouraging experience for the vloggers themselves, especially knowing that commenters were gaining support from the vlogs. For example, one vlogger said:

WOW thank you so much it really means a lot to me when someone can take something from this and learn from it (HIV12)

Both the vloggers and commenters exchanged highly mutual and dynamic support. Both vloggers and commenters were seen as helpful in encouraging and supporting one another.

3.4.3 *A Platform for Moving Beyond the Social Circle*

Vlogs played a role as a platform in which commenters and vloggers could continue to build connections using their shared interests (e.g., religion, disease experience, location, etc.). Beyond just interacting over the commenting feature, vloggers and commenters made personal connections, reciprocated help and encouragement, and expanded the social worlds in which vloggers can participate in. As with any online social network application, some commenters disagreed with the video content or intentionally left hate comments. However, vloggers and commenters alike would come together to form a territory against these hate comments as a community, moving beyond the traditional sense of a *social circle*.

Building Personal Connections. Commenters expressed sensing personal connections with health vloggers, regardless of whether the commenters had the same disease or not. Many of the commenters found the vloggers' stories and experiences to be inspiring which prompted commenters to become followers or even Internet friends (friendship established and maintained through virtual means). For example, one HIV commenter said that the vlog made them want to become friends with the vlogger:

So when I saw your videos, I had to subscribe to you and I want to be friends with you !!! (Comment, HIV11a)

In another case, the connection between the vloggers and their followers became apparent when a cancer vlogger's husband uploaded a final video to inform the viewers that the vlogger had passed away. Many of the vlogger's commenters expressed their sorrow:

I am so so sorry. i have been following [Lucy's] journey and have been thinking about her so often, and praying for her. I will continue to pray for her and her family. thank you for letting us know. My heart goes out to you and the rest of [Lucy's] family at this most difficult time. she was amazing; her outlook was always so upbeat; just a pure heart. (Comment, CAN1b)

Similarly, vloggers also felt the same connection with their viewers. One HIV vlogger (HIV6) provided his phone number and email at the end of his vlog and offered support to any viewers who were struggling with HIV (see Figure 3.6).

Not only did many commenters consider themselves followers of the vlogger and their journey, many of them saw the vlogger as their Internet friend as well. For example, one commenter commended Lucy's personality, saying:

That is such sad news,[Lucy] really touched my heart, she talked in such loving terms of you, her son, and her family. She was a SPECIAL lady, and i only know her from her videos on here. (Comment, CAN1b)

For commenters who were going through the same disease, especially for those who had a relatively hard time finding others in similar situations, health vlogs became places where they could relate to and get support from:

Thank you so much! There's hardly anyone out there who is a teen who had diabetes and talks about it :D im 13 and im a type 1 :) (Comment, DIB11a)

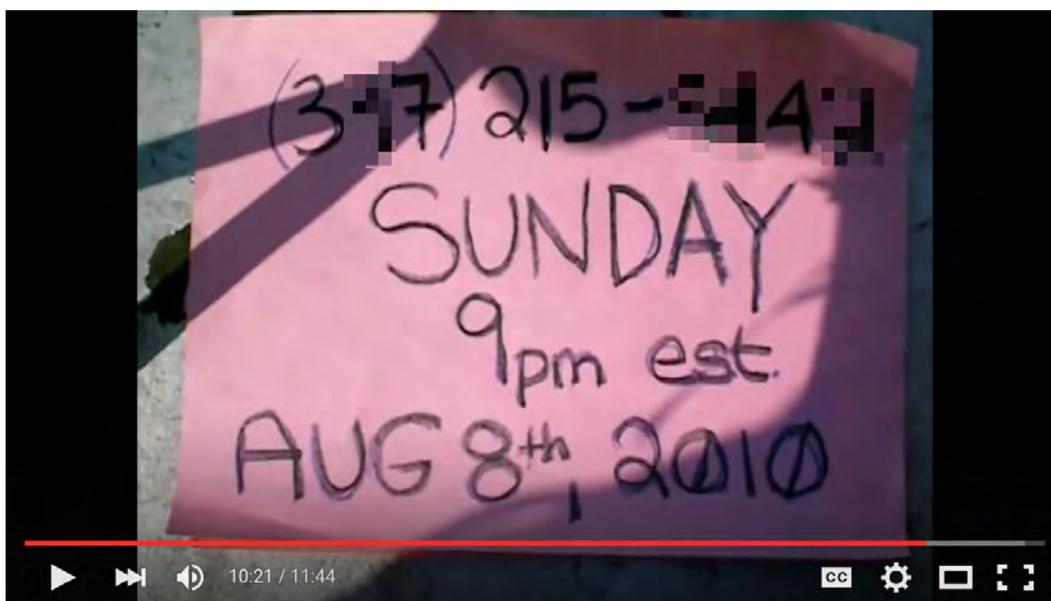


Figure 3.6: An HIV vlogger provided his contact information at the end of his vlog so his viewers could reach out to him if they were was struggling with living with HIV.

Even those who stumbled onto the vlog by chance, regardless of whether they had the same disease or not, felt a personal connection with the vloggers. Roger's vlog helped change one commenter's view on their life, saying:

Ok so I'm just up late at night and came across your video. I had no interest in it but my heart just said watch it and now i am on video like 4 and i want to thank u for changing my life in 15 min. (Comment, HIV11a)

Many commenters expressed how relatable the vlogger and their experience was, even if their diseases were not always the same one. Regardless of the disease, commenters felt a strong connection to the vlogger:

I just wanted to comment again. I have had health issues (nothing like Cancer) but, just that makes me able to relate to you. It's nice to know that you do get sad and you don't pretend to be something you aren't. Like you said, you're

only going to get stronger from this experience. You are inspiring so many people by blogging. Stay strong, and know you are indeed helping others!!!
(Comment, CAN4b)

Because of the personal connections they felt, commenters also offered help or more tangible forms of support, such as spreading the word about the vloggers' videos. For example, commenters would reach out to offer more advice or to provide more details to the vloggers:

if you're willing to chat about this I'd be happy to catch you up with what I've been through and my own research and give you the run down in a way where you know (Comment, HIV11b)

Commenters further suggested sustained relationships with vloggers either by following the vlog or exchanging emails (HIV5a). One commenter suggested meeting in person, offering to introduce him to people that could benefit from having the vlogger as a mentor:

My Friend, You rock! I wish you to come to Toronto and meet me. I have connections to a group that you can be a mentor for. (Comment, HIV10a)

Commenters also stated when they found the vlog content useful by saying they would subscribe to the vlogger. This showed empathy and gave vloggers the emotional support that they often needed: *"you are great in all aspects you just got a new subscriber"* (Comment, HIV3a).

Sparking Community Building. Commenters not only attempted to build personal relationships with the vlogger, but also among other commenters. They would ask for each other's email addresses, updates, thanked each other, and shared concerns. Commenters showed a sense of community building around the vlog. Commenters would sometimes have a conversation in the comments of a vlog:

Commenter 1: I'll start chemo in a week :(

Commenter 2 (in response to Commenter 1; one month later): How is it going?

Commenter 1 (three months later): Hi there, sorry for the late reply! I have already finished chemo...my 1st one was 3 weeks ago. Im fine, get tired easily but my hair is growing back :O

Commenter 3 (in response to Commenter 1): Live strong :) (CAN10a)

In the exchange shown above, over many months, commenters asked and shared updates. Another commenter came in and asked a question about the specific procedure of prostate cancer surgeries, and a number of commenters answered the question. The exchange here resembled that of a community forum, where community members ask questions, share their experience, and exchange support. Though previous research has found that many YouTube content creators see YouTube as a community itself, the research has often focused on the content creators as one whole community rather than a community around a specific content creator. The support exchanged in comments of the health vlogs were not just between vloggers and commenters but also among commenters as well:

Please, if anybody needs answers or just needs to talk about this, I am all here. Lets fight this together and make other people check themselves, since [testicular cancer] is much easier to fight when found out earlier. I wish the best to all of you! (Comment, HIV10b)

Commenters would even discuss, in the absence of the vlogger, the status of how the vlogger was doing. To a commenter's question of asking how a vlogger was doing, a commenter said that she found the vlogger on Facebook:

[Felicia] looks very well- happy on her face book page. Her last name is [anonymized], was starting to wonder if she was doing ok. Glad to see she is well (Comment, CAN4b)

The fact that commenters were sharing vloggers' health statuses without the vlogger always present showed that the health vlog was not simply a place for commenting about the vlog itself. Rather, it was an anchor that the vlogger provided, by which commenters could connect, share information, and support one another.

Interacting Beyond a Binary World. The interactions among vloggers and commenters involved places beyond YouTube, such as other organizations and social networking websites. Health vlogs also involved commenters from the vloggers' real life family and friends, which made the health vlogs not only a virtual social place but rather, a place that included social connections between both a vlogger's offline and online worlds, beyond simply YouTube.

For instance, a commenter suggested Marcus to post his videos on TuDiabetes (DIB7), a social network site for "*people touched by diabetes*"¹. Commenters on a cancer vlog shared website addresses that provided information for cancer patients. Commenters asked whether vloggers had a Twitter account and notified that they had retweeted the video. One health vlogger was asked to be on a radio show:

Hello I am a radio show host for [anonymized] radio. We are doing a show about getting tested for HIV awareness, would you be interested in sharing your story? Please feel free to email me at [email] or inbox me for my number.
(Comment, HIV5a)

Not only did various online worlds collide within health vlogs, but vloggers' family and friends from real life also became part of the conversations in the health vlogs. A commenter, supposedly a close friend from real life, commented a supportive comment at James:

Commenter: [James], you know I love you. You're a precious gem, and I'll always be in your corner.

¹ <http://www.tudiabetes.org/>

James: [Commenter], how are you I miss you man how are you?

Commenter: I'm well, and I miss you, too! *HUG* (HIV12a)

Vlogs also became places for socializing and social networks among friends of friends. For example, one commenter stated, "*Subscribed! Thanks for sharing your story! A friend of Kengi is a friend of mine!*" (Comment, HIV11a). Health vlogs, together with commenting features, presented itself as a dynamic social place where vloggers and commenters shared informational and emotional support. They were also places where various social worlds collided, allowing vloggers and commenters to interact beyond only their offline world and YouTube.

Forming Territories Against Hate. Hate comments working against the positive atmosphere of the vlog were often either collectively voted to be removed or flagged as spam by the author or YouTube. HIV vlogs had 94 hate comments (out of 1,104 total), whereas diabetes and cancer vlogs had none that were coded as hate comments. Instead, diabetes and cancer vlogs sometimes had comments that were not necessarily supportive of the video content. For instance, on a vlog that was about a pink lemonade recipe, one commenter replied, "*that is the grossest thing i've seen all day*" (Comment, DIB7a).

For HIV vlogs, commenters disapproving video content or the vlogger mainly mentioned disagreements towards vloggers' sex lives, sexuality, life style, religious beliefs, or whether to take drugs despite side effects. For example, one commenter disapproved of the sexuality of the vlogger and said:

I praise your efforts, your kindness and sincerity - however homosexuality is a forbidden in the Holy Bible (Sodom and Gomorrah same story in the Quran), so is alcohol and so is pre-martial sex only difference is you chose to ignore it- In addition God in Islam is infinitely merciful and forgives all sins except one associating partners with him- not the same in the Bible! (Comment, HIV10a)

Other comments were disapproving in very hostile tones. For example, one commenter said, *“Let all faggots die from HIV - it’s their destiny!”* (Comment, HIV6b).

The hate comments and comments disapproving vloggers’ life styles were not left unhandled. Vloggers and other commenters defended vloggers by either debating with disapproving messages or sending supportive messages, urging vloggers to ignore hate comments. In a way, the vloggers and their supporting commenters formed a sense of protection against the hate comments. For instance, vloggers would defend themselves against hate comments, either by removing the comments or responding to the comments:

If you are not HIV+ nor are you a doctor, then there is no grounds for you to debate anything that I say, or do on MY video’s. When you have walked in my shoes, and lived through MY experiences, then you may speak to me. When you have watched HIV+ people eat up the crap that HIV dissidents spew, and die from not seeking medical treatment, then you can debate me! (HIV11)

In Roger’s comment above, he mentioned that the commenter cannot *“do [anything] on MY video”*. This phrase highlights a territory that the vlogger is building against hate commenters—that the video and the community surrounding the vlog was *“his”*. Similarly, other commenters drove away hate commenters or urged vloggers to ignore hate comments. One commenter asked those who were writing hate comments on a diabetes vlog:

I would be mean [in response to the hate comments], but that is just wrong. So I will say this nicely. If you don’t want to watch this then why did you click it. If you didn’t like it then don’t comment. (Comment, DIB6b)

Similarly, another commenter left a message to an HIV vlogger who was getting hate comments from others. The commenter said:

Thank you for posting this video. I am so sorry that you are going through this. It is tough to talk about. Pay no attention to the haters. You are very brave for putting this video out. God Bless you. May we find a cure for this horrible disease. (Comment, HIV10a)

The interactions between the vloggers and commenters were seen as moving beyond the traditional definition of a social circle. They were able to build personal connections with one another, offering support and help, blending various social worlds—both on-line and offline worlds, and creating a community among each other, often warding off negative comments from others.

3.5 The Design of “Broadcast” Technologies

Patients who utilize *broadcast* technologies—technologies that typically do not have an equal amount of interaction between stakeholders—can experience various advantages and challenges in their attempts to share information to the appropriate audience and interact and connect with their viewers.

3.5.1 Personalized Presentation and Message Delivery

Augmenting metadata. Health vloggers used nonverbal cues to enable intense personal connection with their viewers and used various genres to convey their messages more effectively. Current vlogging systems underexplore using vloggers’ nonverbal cues as information resources or giving vloggers the ability to tailor presentation and deliver of vlogs. Health vlogging systems have the potential to use new signal processing techniques to record metadata about the frequency and quality of nonverbal cues (e.g., Byun et al., 2011). Machine learning techniques could be used to determine metadata features automatically. Using this metadata, systems could inform vloggers about their use of nonverbal cues and their potential impact on viewers’ interpretation of the vlog. Systems could also suggest vlogs based on this metadata to viewers who are looking for

intense personal connection more so than informational content. However, with current technologies, searching for content and style is much easier to do in text than in video.

Vlogs present additional meta-data to inform metrics for similarity and complementarity that are otherwise missing in text blogs. One representative example includes demographical information. In text-based online social networks, extracting demographical information often meets challenges, since it depends on the poster to disclose any demographical information about themselves. However, in vlogs, which often exposes the vlogger's face, we can extract race, age, gender using existing image and video processing technology (Chen et al., 2013; Yeasin et al., 2006). Also, systems can capture constantly changing emotions expressed in vloggers' faces (Sanchez-Cortes et al., 2013), which again can be used to suggest new vlogs that viewers can watch so that they realize they are not the only ones who might be going through hard, emotional processes (such as crying in front of camera after chemotherapy). We can also learn from prior work in gesture for understanding communication cues of the vlogger (Quek et al., 2002).

Currently, the quality of presentation depends on the vloggers' technical knowledge and software. Health vlogging systems can provide users with templates to help users create various genres and style of presentation. For instance, for vloggers who want to teach disease management strategies, the wizard can provide templates to use images, pointers, and screen shots. The wizard can also provide ideas for presenting and delivering messages using examples from other vloggers. Health vlogging systems can also support the creation of vlogs through mobile devices, letting users create and upload videos in the moment.

Mitigate Challenges in Using Vlogging Tools. Health vloggers should not have to worry about using advanced third-party editing tools to effectively convey their messages. Easy-to-use editing tools integrated into the health vlogging systems can help peer patients easily exchange experience and knowledge. To further facilitate social support among chronic illness patients, we should improve the ability to organize vlogs to allow viewers

to browse health vlogs easily, according to their stage of the disease as well as their information and emotional needs. Health vlogs should help patients, who have similar interests, connect with each other both online and locally, and these vlogs should help facilitate prolonged conversations.

3.5.2 Supporting Distinct Disease Characteristics

Differing Content. Vloggers used different genres depending on the stage of the disease and emotional state. In turn, these genres created different kinds of interaction. Diabetes vlogs used graphic tools to present workable self-care strategies, whereas vloggers attempting to inspire the newly diagnosed used nonverbal cues, such as crying or sharing raw footage of the time of the diagnosis.

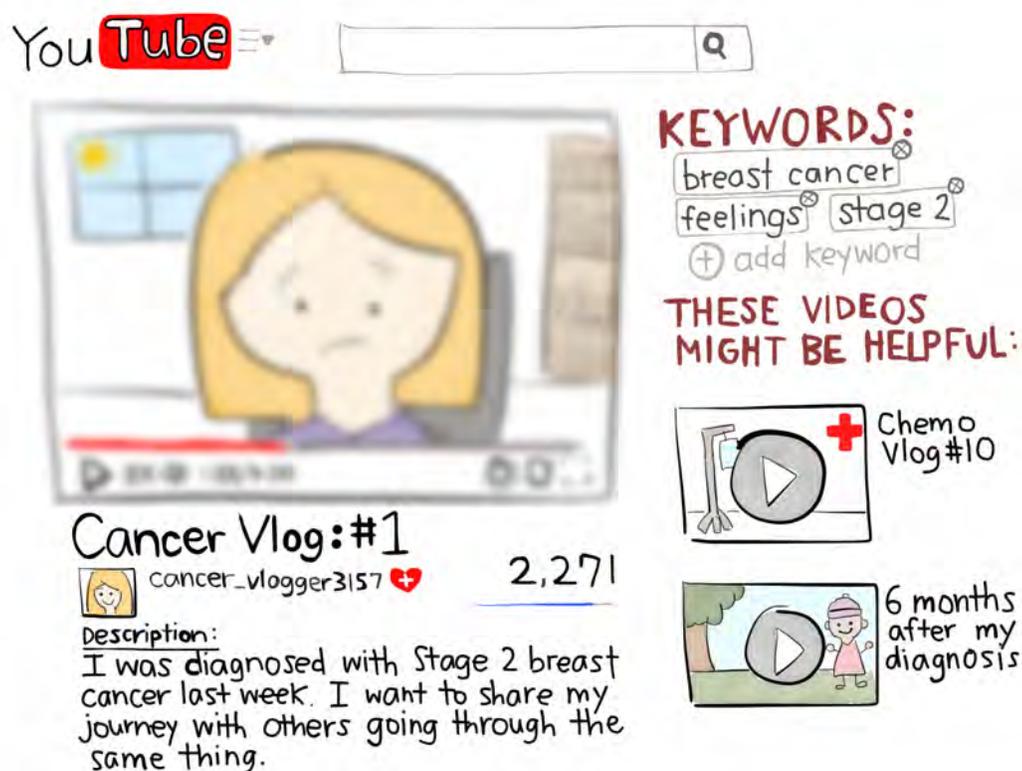


Figure 3.7: Keywords related to the video topic, illness, or the stage that the vlogger is can help viewers find relevant videos on similar topics.

Providing additional information or resources to viewers is not something that is as well supported by current vlogging systems. YouTube allows the vlogger to write a description below the video, but information can sometimes get lost if there is too much of it. To address this problem, health vlogging systems could create a sidebar by the vlog where vloggers can add information at specific timestamps. The information could be about chapters in their teaching messages, stages of illness trajectory, their personal history, resources they might have mentioned, or points of nonverbal cues that viewers can use either to skim what the vlog is about or to “fast-forward” to the moment of their interest. This feature provides more related content to the viewer. It also allows the viewer to search for or scan and choose what segments of the video they are interested in, instead of having to watch the entire video. Currently, YouTube offers recommended videos on the sidebar, but the algorithm in understanding why these videos are recommended are not known to the general population. Videos could have certain keywords based on the topic or illness and based on these keywords, relevant videos can be suggested that match keywords. This would make it easier to find relevant videos for viewers who are looking for information on a specific illness (see Figure 3.7).

Social Stigma. Because of YouTube’s open and public nature as well as the identifying characteristics of video and audio, vloggers must be willing to make a public disclosure. HIV vloggers in our study intentionally disclosed their diagnosis to the worldwide audience as a tool to overcome social stigma. However, all the HIV vloggers we studied were gay males, implying that the stigmatization of the disease still prevents some from vlogging about their disease thereby limiting the amount of self-therapy they can receive by using this helpful media.

The age of the HIV patients also ranged from teenagers to young adults to middle-aged adults. Patients may need guidance in their individual personal growth. They might also struggle with being young and not having resources and support due to its stigmatized aspect of the disease. HIV patients in those situations can greatly benefit from

having matched personal mentors, as previously explored in online health community and clinical settings (Hallett et al., 2007; Heisler et al., 2010), and as many of our vloggers and commenters offered to do.

Health vlogging systems could allow vloggers to customize the level of disclosure. YouTube currently offers an option called Xtranormal Movie Maker² which allows the vlogger to “set up [a] scene, type in [a] script, and animate it instantly.” This feature lets the vlogger share their story and experience without having to fully disclose their face, voice or name. Yet, we did not observe any of the vloggers in our study using this feature. Furthermore, the system allows vloggers to generate a “mask” to hide facial features or to upload only voice with photo slideshows or even blank screen with titles. Similarly, replacing oneself with avatars can allow vloggers to incorporate gestures and body movements while retaining anonymity, as previous work has shown to be successful (Kennaway et al., 2007). Systems could further utilize this feature to allow vloggers to restrict personal information and encourage those who are wary to share their experiences.

Self-Monitoring. We found that one of the motivations for vlogging was to journal their experience. Not only was journaling helpful for the vlogger, it also benefited others. The metadata produced, such as the emotional changes, could help one to monitor how vloggers have changed over time. One HIV vlogger was first seen in bed, with depressive characteristics. Gradually, the videos showed him becoming an HIV activist. The metadata capturing various things like facial expressions or whether it is a video collage or a self-portrait can potentially inform the changes of the person’s status. This metadata can also be used to inform the vlogger on their own changes over time. Vloggers can also manually inform at what point the videos were in their story. For example, Figure 3.8 presents “Chapters” of the vlogger’s story to the viewer. It selectively chooses the videos from that specific time point of the vlogger’s journey.

² http://www.youtube.com/create_detail/Xtranormal



Figure 3.8: The “Chapters” section in a YouTube channel could highlight how the vlogger has changed throughout their journey.

3.5.3 Sustainable Connections

In online communities, members have sustained relationships and reciprocity in sharing experiences and information. However, we saw little of such vlogger-viewer interaction happening in YouTube. The only viewer interaction mechanisms that YouTube support are commenting and voting features. Because the current organization allows for vloggers to interact with a general audience, vloggers can be attacked by harsh comments (Lange, 2007a). This also does not promote long-term connections with viewers. Health vlogging systems should be able to facilitate sustained viewer engagement and community. A variety of modalities could help accomplish this goal. Integrating asynchronous video-based communication systems, such as VideoPal (Inkpen et al., 2012), into health vlogging

systems could help sustain viewer connection and generate a sense of community. Viewers could leave comments inside particular segments of the vlog. Viewers could also utilize video as a way to communicate back to the vlogger. For example, viewers could leave video comments rather than text comments to convey non-verbal gestures and emotions that are harder to convey through text (see Figure 3.9).

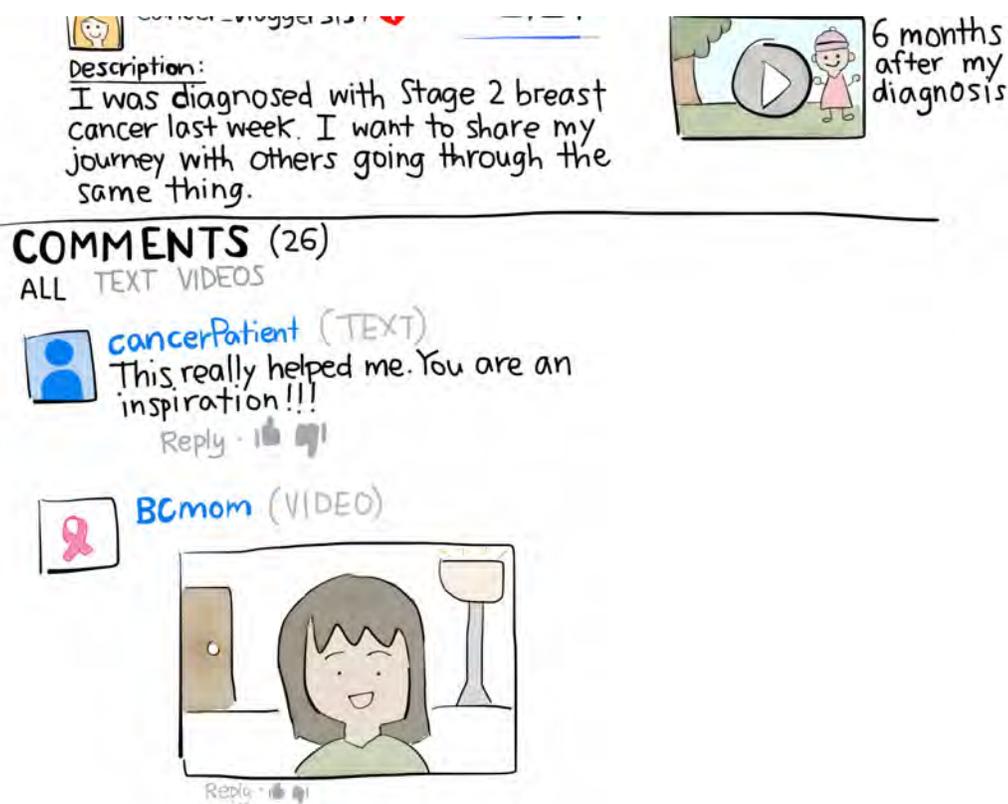


Figure 3.9: Allowing viewers to leave video comments instead of only text comments can convey emotions and non-verbal gestures.

Systems can record information about participants in these comments to profile users, which then can be used to suggest viewers and vloggers into vlogs or topic based communities within the health vlogging tools. The system can further support local meet ups, virtual gatherings, and suggestions of advocacy and fundraising events.

Online health communities can also incorporate health vlogs as a new avenue with

which patients can share their experience and receive and give social support in unique ways. However, whether the semi-anonymous culture of online health communities and openness of health vlogs will mesh is yet to be seen.

We also observed vloggers and commenters coming back to the same vlog and commenting after being away for months. Going through surgery and recovering can take months—incorporating such distinct lifestyles instead of more frequent, daily engagement with social network services can be important. For instance, health vloggers can have the option to incorporate automatically generated information on certain surgery procedures for their viewers while the vlogger is away. If the vlogger is scheduled to have a breast implant at a certain date, the system will inform the audience average time of recovery for breast implant patients and what help mechanisms can be helpful for the patient. The audience of the health vlog can provide the appropriate support and help for the vlogger as well.

3.5.4 Vlogs as Part of the Chronic Illness Management Routine

Vlogs can be further integrated as part of the chronic illness management routine. For instance, tools that are part of the chronic illness management (e.g., insulin pumps) can interact with video blogging tools to record patients' interactions with the pump, which can later be presented to the health vlog viewers. However, once the video data are captured, how the data can be filtered and used for vlogging should be considered.

We envision that an ideal vlogging tool would incorporate certain stages of the chronic illness that vloggers or viewers are currently in to bring related vlogs and recruit users who can create a helpful community together. Considering the slow progression of a chronic illness, there is a large potential for vlogs to take part in the community building process.

Education and Outreach. An increasing number of organizations are taking advantage of Internet access and wide use of video-based patient testimonials (Norman and Yip,

2012). Currently, the patient testimonials that organizations distribute to their audience and user-generated health vlogs are not closely connected. Linking both user-generated health vlogs with official, publicly available patient testimonials can be useful for the purpose of outreach and education, combined with related links, demonstrations, and various ways to inspire others. The rich, contextual cues that patients show in their show-and-tell videos allowed one commenter who is a caregiver to understand what her stepdaughter was going through. Using meta-data to aggregate sources for caregivers presents another opportunity for vlogs.

Studies have shown the great potential new technologies can have towards the rise of citizen-consumerism (Clarke et al., 2007) and to give voices to marginalized groups (Rakow and Navarro, 1993). Health vlogs can help further empower people, especially those with stigmatized diseases, as we saw from our HIV vloggers' active efforts to reach out to those who might be in similar situations. Studies show that creative activities can contribute to improving such isolated illness experiences (Stuckey and Nobel, 2010). Utilizing existing research practices around crowd creativity (Nickerson and Monroy-Herna, 2010; Yu and Nickerson, 2011)—collaborative drawings, sketches (Obrenovic and Martens, 2011) and projects to produce games—can help patients manage challenges in dealing with unanticipated illness experiences.

3.6 Summary

Health vlogs allow individuals with chronic illnesses to share their experience, knowledge, and stories with others. Connections among patients, such as those between vloggers and their viewers, have shown to be a form of social support and are self-therapeutic for health vloggers. However, little has been done in trying to sustain and strengthen health vloggers' connections with their viewers.

In this chapter, I described a study that examined how health vloggers—adults who have a chronic illness and posted a series of video blogs to YouTube on their illness—appropriated videos, comments, and the YouTube platform itself to establish deep and

intense connections with others. We looked at how health vloggers attempted to connect with their viewers as a form of self-therapy and social support. Our results showed that health vloggers use the uniqueness of video and the commenting features of YouTube as a way to create rich and strong connections. Vloggers also used specific genres and other explicit methods to communicate personalized messages and connect with their viewers. Viewers were able to see the emotional aspects of the vlogger's lives through videos and their interactions through comments. Vloggers appropriated an "everyday thing"—the YouTube technology—as a way to convey information and knowledge and to receive and provide social support. The deep connections between vloggers and viewers were strengthened by the emotional weight that the videos and comments held.

The findings from this study helps researchers understand how emerging social media can deliver new types of support mechanisms to patient self-management. With improvements on the social-technical design of vlogging tools, health vlogs bring a new avenue through which patients can share experiences, encourage, educate, and support one another in unique ways.

Chapter 4

OLDER ADULTS WITH DIABETES

4.1 Introduction

Patients with chronic illnesses have a multitude of information such as medications, lifestyles, and emotions that they must manage on a daily basis (Lorig and Holman, 2003). Patients must remember their follow-up appointments, daily medication regimens, and their recommended physical activities. Adding to the already extensive amount of information that patients must remember, the Center for Disease Control (CDC) estimates that 1 in 4 patients with a chronic condition have multiple chronic conditions (Centers for Disease Control and Prevention, 2014). With this deluge of health information and actions that they must remember to do to stay healthy, patients have found various strategies to help in keeping track of health activities and information. For example, calendars have traditionally been used as a way to remind people of their schedules and events. Now, smart phones provide the ability for real-time reminders and easy access. These reminders have been shown to be valuable for patients who have chronic illnesses. For example, patients with diabetes can be prescribed a large quantity of medications that must be taken at specific times. Having time-sensitive reminders can improve medication adherence. Being able to keep track of what needs to be done can also reduce the stress and anxiety of needing to remember the information themselves. Though the CDC suggests that Type II diabetes can be managed well by having a healthy diet, staying active, and working with a health professional, challenges still remain in helping patients remember to take appropriate medications, attend follow-up clinic visits, and make healthy lifestyle choices.

We found that patients often reconfigured “everyday things”—physical artifacts, activities, relationships, and routines into the form of reminders. Though these objects and

activities were not always consciously set as explicit reminders, the act of seeing these appropriated objects or doing the routines helped trigger certain associations that acted as *opportunistic reminders*. These opportunistic reminders often went beyond just reminding patients to do certain events; rather, they served as reminders of their health condition, their overall health goals, and the future health state they want to be in.

4.2 Methods

Gender	Age	Race	Education Level
Female	69	White/Caucasian	More than 4 year degree
Female	83	Black/African-American	More than 4 year degree
Female	85	Black/African-American	More than 4 year degree
Male	88	White/Caucasian	Some high school
Female	67	Black/African-American	4 year degree
Male	78	Asian	4 year degree
Female	88	White/Caucasian	Some high school
Male	58	Black/African-American	Some college
Male	83	White/Caucasian	More than 4 year degree
Male	65	Black/African-American	Some college
Female	75	Hispanic	High school/GED
Female	83	White/Caucasian	High school/GED
Male	53	White/Caucasian	Some college

Table 4.1: Demographics of diabetes participants

Participatory Design (PD) is a methodology and theory that emphasizes direct and active engagement of users in the design process. Users are engaged as peer collaborators with designers, fostering a process of mutual learning. My colleagues and I conducted two design workshops with the same group of participants, one week apart. The design

workshops helped us understand the patients' perspective on their condition and the problems and solutions for health self-management that have personal significance to patients and that stem from their experiences and expertise with diabetes.

The workshops were held in a conference room at a large healthcare organization. In between the two design workshops, we asked participants to complete an optional "cultural probe"-inspired activity (Gaver et al., 1999). Participants were asked to (1) take photos of what they deemed a good reminder and describe why and what it was, (2) describe reminders that they provided other people and what it was for. These were meant to encourage patients to reflect on the content of the first design workshop. It was also a method in gaining a deeper insight into their home life. Participants then shared their cultural probes in the second design workshop with other participants.

13 older adults (six male) with diabetes Type 1 or Type 2 were recruited from the Group Health Cooperative¹. Eleven of these participants had participated in the first two phases of a longitudinal study, during which they were interviewed in their homes about their health goals, tasks, and self-management strategies. There was a large effort to recruit as many participants as possible back for the design sessions so that we could analyze their design work in the context of data from their in-depth interviews. Ages ranged from 53 to 88 years old (median=78), and race and education were diverse, representing the Pacific Northwest region (Table 4.1).

We conducted a structured, iterative qualitative analysis of the workshop session transcripts, design activities, homework worksheets, and photographs. We used open coding to first analyze one workshop. We then iterated on the coding scheme as I found common and emergent themes. The iteratively developed coding scheme included codes for values (e.g., privacy, trust, and convenience) and self-management concepts (i.e., accountability, decision-making, and patient-provider relationships). We then used the scheme to code the rest of the workshops and the data from the cultural probe activity

¹ Group Health is a non-profit healthcare organization based in Seattle, Washington

(photos and written descriptions).

4.3 Adults with Diabetes: Finding Reminders in the World

I first describe how participants managed their condition with traditional reminders (e.g., calendars and signs)—artifacts solely designed to serve as memory aids. I then discuss a definition and description of the *opportunistic reminders*—reminders that participants think of to not only remind them in the traditional sense (e.g., appointments), but to evoke feelings and thoughts of both past events and future states.

4.3.1 Traditional Reminders

People often rely on traditional forms of reminders to remember actions or events that are coming up. Below, we discuss two forms of traditional reminders that patients spoke about: calendars and phone calls.

Calendars: Physical and Digital. Calendars are one of the most traditional forms of reminders. As other research has highlighted that calendars are often a central organizer (Eschler et al., 2015; Klasnja et al., 2010; Moen and Brennan, 2005; Plaisant et al., 2006), not surprisingly, almost all of the participants mentioned using a physical calendar as a way to track their appointments and activities.

Many participants also spoke about using multiple calendars. For example, one participant explained:

One of the main reminders...is my calendar, one upstairs and one downstairs. So if I have calls come in when I was downstairs, I put it down here [on the downstairs calendar] and then try to rewrite another one on the same [upstairs] calendar. Normally, if I see something missing on [one calendar], I go down there and then I see one or the other will have that recording. (P7)

Other participants utilized this method as well—many of them kept calendars in particular areas that they frequented. Participants discussed that having multiple calendars allowed them to confirm various appointments and events. Writing it down also reinforced the date of the event in their mind. As one patient described:

I write everything on [my calendar]...if I'm going to meet a friend for coffee on Thursday, I write it down. You know, everything. So phone calls—I can't say that I would never forget anything, but the phone calls are kind of redundant, because I write all my appointments down. (P11)

Similarly, participants spoke about using digital calendars—calendars on their smartphones or computer. However, many participants mentioned the inconveniences of using digital calendars. For example, one participant talked about using multiple calendars:

I do have my phone calendar, and then I have just a regular daytimer like everybody. But sometimes they don't coincide, so that's a chore to keep that up. I wish they had a better way to keep them updated. (P1)

However, participants still touted the benefits of using a calendar—both physical and digital, saying *"I can relax knowing what is scheduled and can plan my day, weeks, monthly activities"* (P3).

Although many participants enjoyed using digital calendars, participants discussed the many advantages of using physical calendars. In particular, being able to write and use various colors was seen as an extremely useful benefit. Participants spoke about being able to immediately know the information from a glance. For example, one participant explained her detailed method of color-coding her appointments:

I work with three calendars...and what I do is I use colors, because I'm on a number of boards and I go to a lot of meetings and come up here a lot, so I use a different color. Like the color for medical is yellow, and I have these little tiny

stickers: doctor, dentist, etc...I circle it with whatever color is associated with what I'm doing. And that way I see it. (P2)

Participants were often able to find ways to personalize their schedules, knowing what cue (e.g., colors) would catch their attention.

Phone Calls. Participants often relied on phone calls from their clinics to give them advanced notice about their appointments. One participant told us that, *“a phone call from the provider would help the frequent[ly] forgetful patients for remembering [the] next appointment schedule”* (P4). Providing information on only the next upcoming appointment helped patients who might have a large amount of information to remember.

Calendars were used in conjunction with the phone call—phone calls were a way to re-confirm the information that was written on the calendar, such as the date, time, and location of the appointment.

4.3.2 *Opportunistic Reminders*

Participants explicated how they appropriated “everyday things”—artifacts, routines, activities, and relationships—into forms of reminders. Differing from a traditional reminder, these *opportunistic reminders* were not always conscious reminders, but rather an association between an “everyday thing” and an action or motivation. At times, the “everyday thing” would trigger a reminder to do an action, which in turn reminded the participant of their overarching health goal. Other times, the “everyday thing” would speak to the motivation and health goal first which helped enforce and encourage the action. The opportunistic reminders would not only remind a participant to do an action (e.g., take your medication) but of why they should do said action (e.g., so you can run around with your grandchildren).

Below, we illustrate these opportunistic reminders in relation to “everyday things”—artifacts, routines, activities, and relationships that comprise our participants’ lives. Many

of the motivations behind opportunistic reminders stem from an encompassing health goal of *taking care of one's health*.

Artifacts. Physical artifacts served as a useful way to remind participants both of the actions that they still had to do and of the various states of their health.



Figure 4.1: The quantity of medications reminded a participant of how much poor health can cost.

When asked to take a photograph of a reminder, one participant took a picture of around 20 medication bottles on a table (Figure 4.1). He explained that:

Whenever I look at them I'm reminded of how much poor health can cost you...they all add up, and so they remind me to try to watch my weight and watch what I eat so hopefully keep my problems under control, hypertension and diabetes and also my chemotherapy drugs. (P8)

The participant also described how *“improving your health can improve your finances and free up money for other things”*. To him, the numerous medication bottles were not only a reminder of his current health status but that he also had to take care of his health to keep costs down. Although seeing the medication bottles is a helpful trigger in reminding one to take medication, in this case, the participant used the medication bottles (and the quantity of them) to represent the cost of his health care and the state of his current health.



Figure 4.2: The cane on the left side of the picture represented the participant’s past condition and how she never wanted to be in that position ever again.

Participants often ruminated on the meaning and placement of physical artifacts. In a similar example, another participant depicted how she thoughtfully placed a cane next to the table where she kept her medications (Figure 4.2). She said that:

So I took a picture of...my cane to remind me of my condition before I started taking my blood sugars really serious, the condition I was in, to remind me “You don’t want to go back there.” (P5)

The physical presence of the cane and the fact that it was always in her peripheral vision when she needed to take her medications reminded the participant of her past state of health. Though the cane itself can be construed to resemble a negative memory (a difficult time in her life), she still found it a motivating and encouraging reminder to take care of her health.

Participants found encouragement through other physical reminders. One participant discussed how she had polymyalgia rheumatic (PMR) and how that pain would often disrupt her sleep. She would track “*red dot days*”, explaining that:

I have PMR and it keeps me awake at night with pain and everything, so we’ve got one calendar, if I sleep through the night and no pain, we put red dots on it. (P7)

Seeing the red dot stickers on her calendar provided the participant with comfort. The artifacts (the red dot stickers) were able to trigger her retrospective memory (her experience of sleep), leading her to feel comfort. Even if she had a night with more pain, the stickers showed evidence that there were actually painless nights and stood for the encouragement that there would be fewer painful nights ahead.

The previous examples highlight how goals (e.g., being healthy and lowering the cost of poor health) are brought forth as a *side effect* of a previously established routine. In other words, the primary, initial impetus for the routine is to take his required medication. Yet, in thinking about the number of medications he must take, he is able to reflect on the fact that poor health is costly, and improving his health can save money. There were other cases where participants created purposeful strategies to help them remember information. For example, one participant spoke about how he asked his provider to give him a call before his appointment because:

[I] ask whoever the provider is to give me a call. My phone system records digitally...to tell me what I’m supposed to do, and it blinks it for me...So every time

it blinks, it gives me an idea, “Oh, somebody’s called,”—whatever it is...that makes me—well, gives me assurance that, “Ah, that’s what I’m supposed to do.” And I usually leave it on the phone recording just to double-check because...you may not necessarily remember exactly what time to be [there].
(P6)

Another participant told us that:

I put my syringes in...the little box with my insulin bottle. And this is how I remember to take my insulin: I put two in there...if only one is in there, I took my insulin that morning. (P5)

In both these cases, the participants had thoughtfully created strategies in helping them remember certain information. The answering machine was left blinking when there was important information regarding the next appointment. The answering machine provided a reminder to the participant of (1) the logistical information needed to get to an appointment and (2) the fact there was an upcoming event because of the blinking. In the case of the number of syringes, the participant consciously thought about how showing the number of syringes left in the box would help remind her of whether she had taken her medications, needed to take her medications, or needed to refill the box for the next day. These artifacts were not a result of an already established routine but rather a thoughtful strategy to remind them of important information.

Routines. Routines, often motivated by a passage of time, are embedded in one’s life. They are a series of activities or actions that are done regularly and can often form into habits. Participants described how certain routines encouraged them to do certain activities. Often, participants would start off with a certain, specific motive in mind. However, as time went on, routines would help broaden the motives into overall health goals and motivations.



Figure 4.3: One participant's reminder was her dog. The routine of walking her dog helped her stay active and exercise.

One participant provided a photograph of her dog as her reminder (Figure 4.3). When asked to describe the reminder and why it was helpful, she said that:

I need to walk to add to my regular exercise classes. It gives me extra exercise by walking my dog. She reminds me to please go on a walk. I would probably not think of walking without her as a reminder. She is my shadow. (P1)

This participant did not develop a routine of simply walking but rather a routine of walking the dog. This routine served as a reminder for her to stay active (a side effect of the established routine). Without her dog barking and growling at her for its daily walk, the participant would not take the initiative to go on a walk. The routine of needing to walk her dog every day became a form of exercise. At the same time, that specific routine turned into a reminder of her health and how she now needed to exercise in order to stay

healthy.

Another participant talked about how she had a set routine before bed, saying that:

I usually have a cup of tea or something in the kitchen, so on the television [in the kitchen], I put a little small sign in red saying “Meds.” So if I picked the cup up and looked at the screen, I would see the sign. (P2)

She also described how she would put a sign on the bathroom mirror as another reminder when she brushed her teeth. This participant had developed a set of evening routines that she would do everyday. She took advantage of these routines by creating safety nets—preemptively putting up reminder signs at the places she knew she would definitely be, just in case she had not taken her medications yet. Unlike the other participants, she did not reappropriate her routines into a reminder. Rather, she utilized these routines as a way to give herself reminder messages “from the past”. Putting up signs has been shown to be one of the most effective reminder strategies (Reason, 2002). It is important to note that though this could be considered more of a traditional reminder, reminders are still highly dependent on routines. Utilizing these routines can be a useful way to capture a patient’s attention. Similarly, another patient described how he utilized a car sun visor organizer to put reminders and health information in the sun visor. He discussed that it was useful because:

That’s probably the most...visual reminder, because it’s right there. I have to sit in the same seat when I’m driving. It’s within my field of view. (P18)

He took advantage of the fact that he was “stuck” in the same spot whenever he was driving and used that as a place to remind him about his health information.

Patients heavily discussed how the act of taking medications became a routine for them (e.g., “some of the pills, I take at a prescribed time of the day...before bed, in the morning, blah, blah blah” (P11)). Though this was not a routine that reminded them specifically of

their health goals, it was still part of their overall health management. Patients brought up the notion of remembering *if* the routine was done correctly. For example, one patient described how because of three different health conditions that he has, he must take a large amount of pills. He brought up the concern that:

So anyway, my problem is remembering whether I took certain pills or not. And I don't want to take something twice that I shouldn't. As well as not take something that I should. (P11)

He suggested a technology that could not only help him in remembering to take his medications but also provide him with a confirmation that it was taken or not taken.

Activities. Differing from routines, activities are discrete events that could be part of a routine (series of activities) or a stand-alone event. Participants often described activities that served as a reminder of their health goals.

Some participants outlined activities and hobbies that they enjoyed doing. For example, one participant spoke about her favorite hobby was sewing:

You sit and knit, and it is so relaxing. Good for you and your whole body. Working on the [sewing] machine with a quilt pattern does the same thing. (P7)

The participant found that doing the activities she enjoyed, in particular sewing and knitting, helped her relax. She stressed the importance of the activity as a way to help her whole body and thus, her overall health. However, for this participant, she also had issues with one of her hands and was waiting to complete surgery on that hand. She mentioned that it was sometimes frustrating that she could not sew due to the pain. She told us that as a substitution of her sewing hobby, she would “*go out and smell the flowers and take it easy*” and “*to stop and take a deep breath, slow down*” (P7). The participant felt that slowing down and not focusing on what she could not do was useful for her emotionally and



Figure 4.4: The flowers in one participant's garden served as a reminder to go outside and take it easy.

mentally. Smelling the flowers was an activity that would help her relax and remember that she should take it easy. It was a reminder to her that she needed to take a deep breath and slow down (see Figure 4.4). Similarly, she stated that she was currently off limits from sewing, which was *"driving me crazy, so I got to remember 'I'll get back to it, just relax.'"*—to her, the flowers were a symbol that she would eventually be able to start sewing again.

Along the same line, another participant highlighted how he enjoyed looking outside and enjoying the day. He showed us a photo of his outside yard and described that:

Being able to look outside and enjoy the day..One [photo] was at night, and one was at day time, just a reminder to myself—[I] get a chance to see another day. (P16)

Another participant highlighted that he was able to *"do what I want to do, when I want to do it"* (P4). He spoke about how he enjoyed gardening and spending time with his

neighbors. He explained that:

The thing I do is I get in the car and go to the beach. I have a beach property and we go there, mow the lawn and so on. And that's how I keep healthy. (P4)

Spending time at his beach property and doing outdoor activities was not only a way for him to keep him active and healthy. The participant re-created a meaning and a reminder of keeping healthy with these activities. Although he enjoyed going to the beach and mowing the lawn, these leisure activities also became a form of exercise for him and a reminder to keep healthy.

Though many participants discussed hobbies or activities that were for pleasure, other participants recalled activities that highlighted the more negative aspects of their condition. For example, one participant explained how the activity of cooking was not easy. To him, cooking was a reminder of the complexity of his condition, a *"moving target"*:

I'm not alone. I'm married too. But when you try to eat something where two people cannot eat the same thing, that means you have to do your own menu preparations and not to burden the other half so that you just do basically your own cooking for whatever you need. And that becomes an exercise too. And a lot of times just one night, I'm thinking a sandwich or [sic] sauté something...very simple. Trying to have a complete meal, including dessert, is not very convenient, especially when you're trying to cook something you know you can't eat that in one setting. So that means leftover[s]. (P6)

He noted that it was difficult to figure out the perfect balance between the food he was consuming and his insulin levels. For the participant, not only did he have to consider the actual food he was consuming but he also had to think about whether he was preparing too much. Though this was not a reminder of his health goal, cooking reminded him of his condition and the complexities that were part of it. These complexities served as reminders that can help motivate patients to be effective self-managers of their condition.

In another case, the same participant discussed the importance of sleeping and napping. He admitted that:

I think the sleep [sic] is very important. I do not sleep—or take a nap, I should say during the...day so far. I'm 79, but I have not reached that point. But I'm beginning to feel that sometimes a nap is helpful, if not necessary...with the idea that your body is deteriorating by the days. (P6)

Although the participant did not actually do the activity (i.e., taking a nap), he felt that napping was still an important activity to be aware of. The participant reappropriated the goal of napping—instead of napping just to rest, it stood as a reminder of him being aware that he was getting older and that he needed to take care of his health.

For some participants, doing a particular hobby acted as a *forgetting mechanism*—a reminder to forget—for the negative aspects of their health. Instead of the activity helping them remember to do an action or their health goal, conducting the activity helped them refocus their thoughts on something else. For example, as I mentioned previously, one participant's favorite hobby was sewing. She often had pain from PMR that would disrupt her sleep. She explained that:

When I'm in a lot of pain and I get up and walk and everything, I can go to my sewing machine and start quilting. And I told my doctor the last time, "It's got to be in my head, I know." But he says that I'm concentrating so much on quilting that the pain goes away. Then I can get back to sleep. So I think you have to have a hobby or something to keep going. (P7)

Quilting acted as a forgetting mechanism for this participant. It helped her forget about the pain that she was in. This forgetting mechanism in turn helped her pain go away, allowed her to sleep better, and have more "*red dot days*".

Relationships. For many participants, their relationships with others and themselves represented forms of motivational reminders. While family members helped in providing informational reminders such as the date of an upcoming appointment, participants mostly spoke about how they appropriated their relationships into reminders of encouragement.



Figure 4.5: To one participant, the relationship with her family reminded her of their constant support and encouragement.

One participant provided a photograph of her husband and daughter (Figure 4.5) and said:

I got a picture of my husband and my daughter that lives next door, and they're the ones that got me through my stroke years ago by encouraging me and helping me. (P7)

Even though the participant also said that, "*[my daughter] lives next door, checks in to see*

if we have everything we need and everything is lined up", she emphasized the encouragement and support that her family provided her. The picture of her family was not only a reminder of her past health status but also the fact that through their encouragement and help, she was able to get past her stroke.

Participants also provided their own family members with reminders of motivation and encouragement. One participant told an evocative story of reminding her granddaughter, who was going through chemotherapy, that she would get through the treatment. The participant said:

[My granddaughter] asked me if she was going to be alright. I reminded her that this was probably the hardest thing she would go through in her life. That after each chemotherapy treatment, even though it's really hard, she is closer to being well...while this is not going to be easy, she was strong and had to believe she was going to be well. Also to know that [her family] are all with her every step of the way. (P5)

To this participant, this was a reminder to her granddaughter to stay strong and that she would get through this difficult health situation. Though this was not a reminder of the participant's own health, it serves as an example of a motivating and encouraging health reminder.

Similarly, participants spoke strongly about reconciling their relationships with themselves as a way to remember accountability and as a general reminder of their overall health. When asked what was a reminder for them, one participant provided us with a picture of herself (see Figure 4.6). She proudly told us that:

I took a selfie to remind me that I'm responsible for remembering...I am responsible for the life I want. [The] selfie reminds me just like He-man, I have the power. (P5)

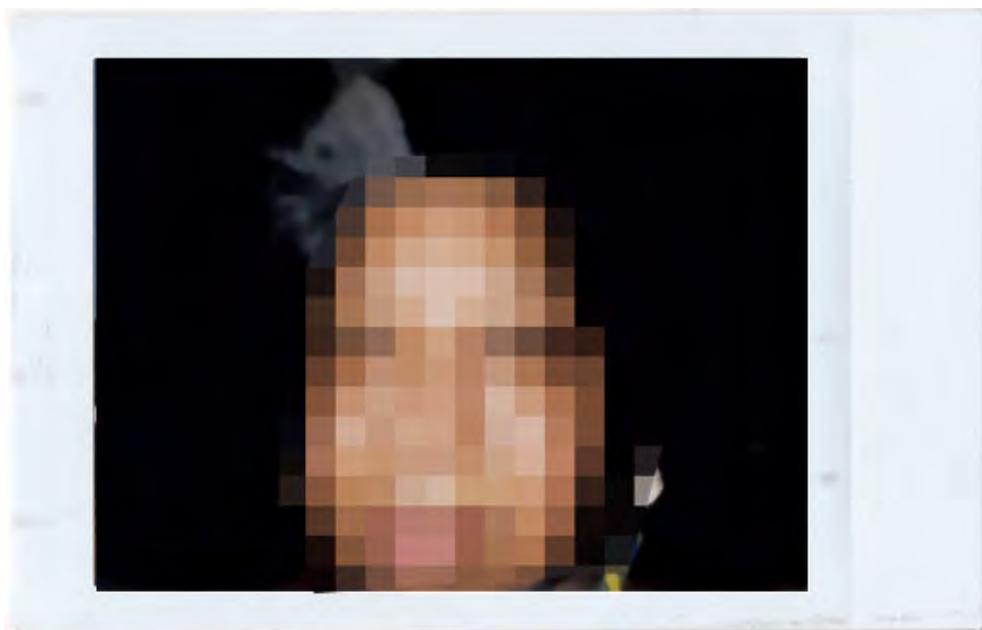


Figure 4.6: This was a selfie taken by a participant who said this picture was a reminder that she was the person responsible for her health.

Similarly, another participant told us that it was his past self that served as a reminder. He said:

I took a picture of myself, and it's about five years ago...I look healthier. That [picture] sits in the living room behind the lamp, so when I come in, I look at that, and say, "Okay, try to get back to that". (P16)

For that participant, the healthier past him served as an inspiration of his health goal—that he eventually wanted to get back to that healthier state. When asked to describe how a magical genie might grant them a wish, one participant explained that at first, his wish was for the magical genie to take away 30 pounds, but as he thought about it:

My response...is how do I maintain [this weight]? And then I was just struck at the idea that it really wasn't a good wish to ask for [simply losing 30 pounds]

to begin with, because what I should have wished for is to develop the habits or have the habits granted to me to establish that to begin with. (P18)

To this participant, he realized how he and his actions were actually the factors in changing his behavior. Participants often spoke about their overall health goals and that the path to a healthier lifestyle stemmed from ultimately, themselves.

4.4 *The Design of Everyday Reminder Technologies*

My findings have shown that patients often appropriate “everyday things” into *opportunistic reminders* as a way to remind them of actions that need to be done and of their overall health goals. Even without pervasive technologies built to remind patients of activities to help their chronic illness management, participants were remarkably deft at using the things around them to live a life with chronic conditions.

Below, I expand on this notion of opportunistic reminders and describe design implications for technologies that can utilize the emotional weight attached to these “everyday things”. Instead of designing products anew, I suggest that future technologies should essentially interlock with the inert artifacts, routines, and activities around us, empowering patients to create an environment where the things around them allow them to manage their lives without disruption or coldness and to remind and encourage patients in leading a healthy lifestyle.

4.4.1 Keeping Reminders Meaningful

Participants often mentioned the notion of routines—for example, getting a cup of tea before bed and turning on the television. As described in this chapter, one participant used the traditional form of reminders (Post-its as signs) but in a preemptive manner by putting them where she knew she would go based on her routine. Participants also delineated that these opportunistic reminders had emotional meanings attached that helped motivate and encourage them. For example, the routine of walking the dog everyday helped

one participant get regular exercise. Ubiquitous computing technologies can expand on the utilization of routines in the home with smart-home sensors and ambient devices. However, these technologies must be designed in a way that retains the meaningfulness of these opportunistic reminders after a long period of time.

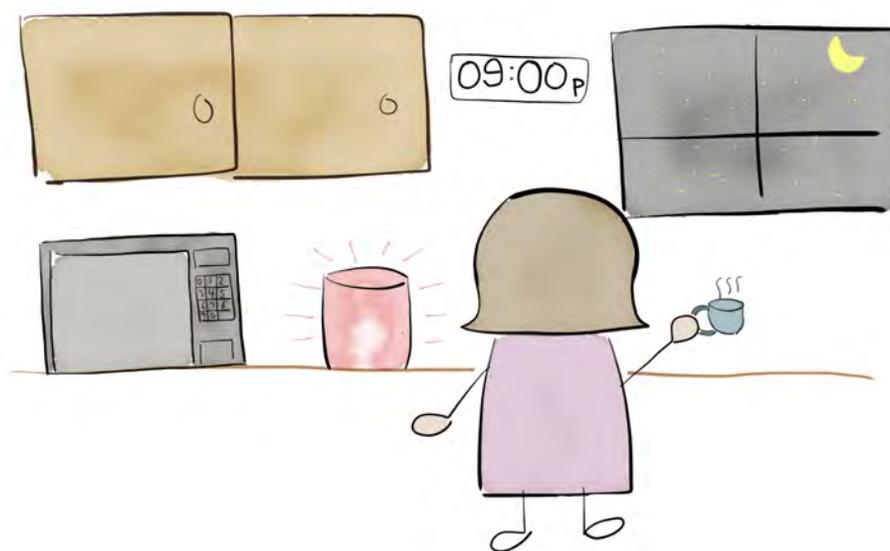


Figure 4.7: Sensors can learn a patient's typical routine and have an ambient display gently remind patients of certain tasks.

For example, current smart-home sensors are able to tell where a person is in their home (e.g., in the living room). Many of them are also able to determine whether someone is at home or is away, such as the Nest (a learning thermostat) that will automatically lower the temperature if it does not detect a person walking by. Similarly, these types of smart-home sensors can also learn a patient's typical routine around the house. For example, it could learn that some time between 9:00pm to 9:45pm, the patient typically walks into the kitchen and opens a cupboard to take out a mug for tea. Knowing that the patient is supposed to take their evening medication around that time, the sensors can send a signal to an ambient device that is placed in front of that particular cupboard to catch the patient's attention (see Figure 4.7). Placing various ambient devices in "high-traffic" areas

increases the conspicuousness (Reason, 2002) of the reminder, ensuring that the patient will see it.

At the same time, technologies that are utilizing patients' routines should be wary of over-stimulating a patient. Therefore, ambient devices could provide a good balance of gently reminding patients that something still needs to be done while also being conspicuous enough for them to notice it. For example, the ambient device could glow certain colors—each color standing for a particular reminder (e.g., purple for a reminder to take their medications). Having latent displays has an added advantage of protecting the patient's privacy—only the patient knows to interpret the signal as a health reminder, in contrast to explicit health reminders that are easily interpreted by others, such as leaving a medicine bottle out in the open.

Similarly, one participant spoke about how he used his car visor as a place to put reminders. He took advantage of the fact that he was essentially stuck in the same place for a prolonged period of time. Technologies can also take advantage of these situations—providing reminders while the patient is doing something else. Using an ambient display can catch a patient's attention while still remaining mostly in the peripheral vision, ensuring that the patient is not distracted while doing something else important (e.g., driving). Another patient suggested that not only could a technology help in reminding information (e.g., taking medication), but also in conducting healthy activities such as eating at a regular time. He emphasized how much time he spends in the car daily, and having a technology that “kills two birds with one stone” would be useful.

Although it is useful to attach an emotional meaning to the routine, as many of our participants noted, devices that are meant to act as regular reminders can sometimes decouple these emotional meanings with the routine. By thoughtfully embedding ambient reminders into personally significant routines, health reminders can become meaningfully associated with healthy routines and retain their poignancy over time.

4.4.2 *Providing the Bigger Picture*

Many patients indicated that sometimes it was difficult to truly know whether they were on the right track or doing the right things for their health at all times. If patients do not understand why they are doing a certain action, such as taking a certain medication, it can be discouraging and potentially detrimental to their health. A high-level visualization system that uses information from an Internet of Things system can help patients gauge a big picture of their overall health.

For example, a weight sensor can be put on the dresser where medication bottles are kept. Each time the weight sensor detects that the bottles are taken off the table, the sensor sends information to a central hub to indicate that the patient has taken their medication. Similarly, a sensor on the bed can determine whether a patient is moving around a lot (perhaps due to pain from PMR) at night (Waltisberg et al., 2014). In the morning, the patient can confirm whether or not they had pain at night. This information can then be used in a way to visualize their overall health and how they are doing.

The information from an Internet of Things system can be visualized in a high-level manner, similar to the flower and garden visualization of UbiFit (Consolvo et al., 2004). The visualization should be personalized and relatable to the patient's goals. For example, one participant had stated that one of his goals was to become healthier to save money on the costs of medications. A high-level visualization could show a piggy bank and the number of coins in the piggy bank. If the patient goes out for a walk or goes to a healthy restaurant, more coins are added into the piggy bank to show how he is saving money when his health improves. One group of patients came up with a technology that visualized a road map—a map that contained short- and long-term goals. They suggested that this would help patients in knowing how they were doing. Technologies that offer these types of visualizations can also include helpful tips, suggestions, and encouragement to get to the next goal. Personalized visualizations can keep patients engaged in their health (see Figure 4.8).

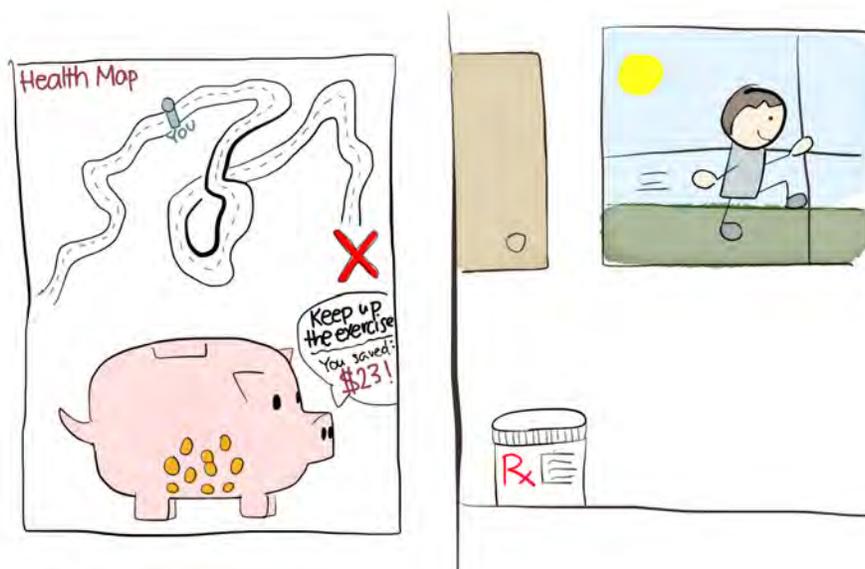


Figure 4.8: A visualization can provide the participant with information on how to reach their goals. These visualizations should be personalized to the patient's health goals.

4.4.3 Supporting Reflection in Reminders

Reflection has shown to be an important aspect in health management (Mamykina et al., 2008). Patients need support for reflecting on their actions and its influence on their own management of their disease.

Technologies should be designed to support users in reflecting on what their own actions are and how the technology might be influencing those particular actions. Similarly, supporting reflection in reminder technologies can create more motivations for the patient.

Technologies can support reflection in different ways. A traditional way to support reflection about the patients' activities is to manually prompt them and ask them to think about a rhetorical question. Akin to the questions that were asked in the cultural probes, questions can encourage reflecting on their activities. For example, one of the activities in the cultural probe was to take a photograph of a reminder that was helpful. Participants

were then able to reflect on what they deemed a reminder (e.g., flowers, dog, cane, etc.) and how those cues or objects were related to their overall health goal or their health.

Using location-based information, technologies can encourage reflection by patients based on where they are. For example, if a patient is at the park, the technology can prompt the patient to think about why they are at the park (perhaps it is to walk their dog) and how those actions affect their overall health. At the same time, technologies should be cognizant in balancing the framing of these questions—in other words, framing these reflective questions in a more positive light, such as encouraging patients to reflect on how their actions positively affect their health, may be more welcoming for patients. For example, if technologies chastise patients for conducting an unhealthy action (e.g., going to McDonald's), this action could make the patient feel defensive and discourage them from participating in reflection. However, as the purpose of reflection is to encourage patients to think about how their goals and certain cues (actions or objects) might influence each other in both positive and negative ways, technologies should still bring up negative influences.

4.4.4 *Cognitive “Underload”*

Patients with chronic illnesses must keep track of a lot of information—taking medications, attending appointments, keeping a healthy lifestyle, etc. Remembering all this information can create cognitive overload for patients. Technologies can help reduce this cognitive overload by providing suggestions to remove the mental effort that is needed to manage the complexities of their condition; in other words, technologies can help support cognitive “underload” instead.

One patient had discussed the complexity of his condition, saying that it was difficult to know what to cook. Smart kitchens (Chi et al., 2007) have the ability to provide feedback to cooks about the nutritional information and cooking activities. In addition to patients' manually entering what they have in their pantry and refrigerator, current technologies could suggest healthy options based on the food that the patient already has. These

prompts could help reduce the amount of time and effort it takes for a patient to think about what to cook and what kind of food will help manage his condition (e.g., less carbohydrates).

Other participants discussed how doing certain activities helped them deal with various emotions. One participant explained how sewing would help her relax. Technologies can help patients deal with negative emotions, such as anxiety, frustration, or stress, by learning and suggesting activities that patients enjoy doing. Coupling questions on patients' current moods and existing technologies, such as the galvanic skin response, technologies can offer suggestions that may help the patient deal with negative emotions. For example, though one participant enjoyed sewing, sometimes she was not capable of sewing because of her hand pain and went outside to smell the flowers instead. If the technology senses that she is starting to feel stressed, it can suggest an option based off what she has done before (e.g., "You might enjoy a small walk around the park."). These types of prompts reduce the cognitive overload for patients in figuring out what activities could counter their emotions while still providing suggestions that are inspired by what patients already enjoy doing.

4.4.5 Supporting the Continuity of Reminders

I have highlighted design implications for when a patient is at home or in a familiar environment where they have established routines and artifacts that act as reminders. However, an important consideration for technologies is to provide continuous reminders even when patients are not in a familiar environment, such as when they go on vacation.

When patients are removed from their familiar environments and routines, such as when they go on vacation, the lack of routine makes it harder for them to maintain their standard healthy actions. For example, patients might not remember to take their daily walk. This omission could be because patients are not near the "everyday things" that provide these opportunistic reminders. For example, one participant had mentioned how the routine of walking her dog everyday helped her remember to walk and exercise;

however, if she was on vacation without her dog, she might not have that reminder.

Technologies can help patients feel “at home” by providing images or projections of certain objects. As one participant told us, seeing her cane near her insulin syringes encouraged her to take care of her health so that she would not fall back into an unhealthy lifestyle where she needed the cane to walk. As it is less practical to carry a cane (that is not used) around during a vacation, technologies that project the image of the cane near her insulin syringes could provide the same affect to remind her that even though she’s on vacation, she should still be taking her medications and exercising regularly.

Another participant mentioned how her routine of walking her dog helped her remember to get continuous exercise. She even stated that she was unlikely remember to walk without her dog. If she is somewhere without her dog, it is likely that she would not remember to exercise and go for walks. Similar to projections, technologies can offer a type of hologram of her dog barking that can help remind her to go for walks (see Figure 4.9).

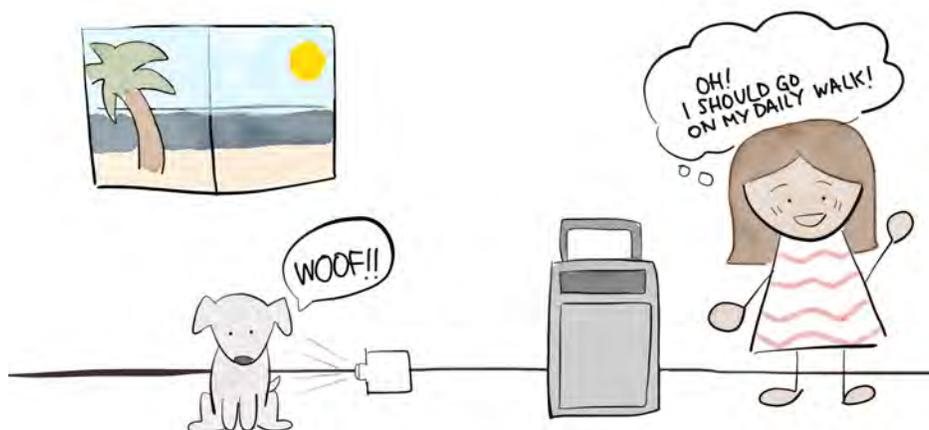


Figure 4.9: Technologies can support the continuity of reminders even when patients are not at home.

For example, one patient mentioned that it was difficult to remember the timing of his medication when he would travel overseas because of the time zone differences (P6).

Technologies can help the patient adjust to the new time zone a few days before they leave by scaffolding the times needed to take the medications. Technologies can remind patients to take medications at certain times by providing informational projections, such as saying “It’s time to take your medications now!” with the current time in the new time zone. For patients taking time-sensitive medications, this can be very useful in knowing exactly when to take the medications regardless of the time zone.

It is important to consider how we can design technologies that are not bound by a location (e.g., home). Supporting the continuity of reminders is an important factor in helping remind patients of their healthy lifestyle that they usually lead at home.

4.5 Summary

The complexity of diabetes requires patients to remember a large amount of information to stay healthy. Patients must remember to take a number of medications—some which are time-sensitive. They must also attend various follow-up appointments with their health providers, remember to follow a healthy diet, and stay active. Patients with a chronic condition are also likely to have multiple conditions. This complex health situation creates a large amount of information that patients must manage just to stay healthy.

Although research has examined the use of traditional reminders, such as calendars and phones, little work has delved into how patients might appropriate the “everyday things” already present in their lives as a way to remember the health information. In this chapter, I presented the notion of *opportunistic reminders*—appropriations of “everyday things” such as physical artifacts, routines, activities, and relationships—and how these opportunistic reminders can serve as not only a way to remind patients of particular health actions that must be done but also of the complexity of their condition and their overall health goals. Similar to the group of health vloggers that I examined, the “everyday things” that participants reconfigured and reappropriated carried a great deal of emotional weight. The emotional aspect of the “everyday things” resonated with participants, triggering them to remember and reflect on their health tasks and goals. For example, the cane that

was used as motivation to not go back to an unhealthier past self was not effective as a standalone object, but rather the fact that seeing the cane resonated with the participant emotionally.

In taking advantage of these appropriations, technologies can provide patients with contextually sensitive reminders that help them manage and reflect on their condition, health actions, and their overall health goals. These personalized reminders can help reduce the burden for patients who are already managing a copious amount of information and tasks.

Chapter 5

CHILDREN WITH CHRONIC ILLNESSES

5.1 Introduction

For children who are diagnosed with a chronic illness, growing up can be harder than their healthy peers. These patients face numerous challenges in staying connected with their social circle. Regardless of whether the patient is confined to a hospital room or is simply missing a few days a week from school to receive treatments, they may feel isolated because of their temporary removal from familiarity. They may also feel as if they are no longer who they used to be because of changes in their physical appearance.

With the ubiquity of technology, patients are likely to use some communication technology to keep in touch with their friends while they are in the hospital or at home. The prevalence of technology can be particularly high with children. In a 2013 report on teenagers and technology, the Pew Research Center found that 78% of teenagers in the United States have their own cell phone (Madden et al., 2013). Studies have focused on healthy children and how they use various ways of communicating, such as teenagers and video chat (Buhler et al., 2013) or looking at how children communicate with remote family members (Ames et al., 2010). Few studies have examined how children with chronic illnesses communicate with healthy peers.

I conducted a qualitative study that consisted: first, 22 interviews among 15 healthcare professionals and 7 parents of pediatric patients with a chronic illness, and second, six design sessions with children who have a chronic illness. I found that due to the uncommon nature of having a chronic illness, patients use and want a wide variety of technologies in an attempt to maintain normalcy with their peers. At the same time, patients recognize that they are not the same as their healthy peers and try to meld their *new normal* with their

previous identity. Although numerous studies have found that pediatric patients seek to be seen as normal by their friends and peers during their illness, I focus specifically on *the role of technology* in their endeavor for maintaining normalcy and how these technologies are appropriated to help maintain that normalcy. Pediatric patients may have vastly different needs and experiences when using a communication technology than their healthy counterparts. I found that along with using different technologies to maintain normalcy, patients also appropriated the technology to fit their current needs and feelings of having an illness (for example, using Skype as a way to still participate in a special event). I also designed *with* patients in order to understand what they were looking for in a technology.

5.2 Methods

5.2.1 Interviews with Proxies

To understand how chronically ill pediatric patients are staying connected with their peers, I interviewed parents and clinicians of children with a chronic illness who might be physically away from home or school for a long period of time, such as those with cancer or those who need kidney transplants. This allowed me to obtain a more in-depth perspective on how these patients stayed connected with their friends. I conducted semi-structured interviews with 22 participants—clinicians and parents of children who have a chronic illness. Fifteen of these participants were healthcare professionals including physicians, registered nurses, clinical social workers, and a Child Life Specialist (see Table 5.1) from hematology/oncology, nephrology, and general pediatrics departments. These were healthcare professionals at large Children’s Hospitals throughout the United States and interacted with an average of 30 patients per week. Interview questions and topics included methods that pediatric patients use to stay connected to their friends during hospitalization, challenges for patients to stay connected with their friends, and thoughts about connecting patients to peer patients. Interviews lasted 30 to 60 minutes. I chose to interview healthcare professionals because they see a large number of children with

Role	Department	Experience (Years)
Child Life Specialist	Child Life	4
Nurse Practitioner	Hematology / Oncology	21
Fellow (MD)	Hematology / Oncology	4
Nurse	Nephrology	36
Nurse	Nephrology	9.5
Nurse	Hematology / Oncology	4.5
Fellow (MD)	Hematology / Oncology	5
Nurse	Nephrology	6
Nurse Practitioner	Hematology / Oncology	32
Physician	Nephrology	8
Social Worker	Nephrology	10
Nurse	Hematology / Oncology	7
Social Worker	Nephrology	20
Resident (MD)	General Pediatrics	3 months
Social Worker	Hematology / Oncology	10

Table 5.1: Demographics of interviewed healthcare professionals

a chronic illness and can reflect upon patterns that they have observed with a variety of pediatric patients.

The remaining seven participants were parents of chronically ill pediatric patients from North America and Europe. I chose to interview parents because they are able to articulate, reflect upon, and generalize on their children's experiences more easily than young children. These parents felt confident that they had a good understanding of how their child felt during treatment and the types of technologies their child used. Because I wanted to reduce the burden for sick children, I did not have them participate in the interviews. Due to the sensitive situations that these children are going through, it was

Gender	Age	Location	Condition
Male	5	United Kingdom	Acute Lymphoblastic Leukemia (ALL)
Male	10	United States	T-cell Non-Hodgkin's Lymphoma
Female	15	United States	Osteosarcoma
Female	10	United States	Aplastic Anemia
Female	7	United States	Leukemia
Female	14	United States	Acute Lymphoblastic Leukemia (ALL)
Female	17	United States	Osteosarcoma

Table 5.2: Demographics of patients, provided by their parents

important to gain an understanding of the key issues before interacting directly with the children.

Parents were from the United States and the United Kingdom. Out of the seven parents, six were parents of children with various types of cancer and one was a parent of a child with a blood disorder (aplastic anemia) that required constant blood transfusions. Patients ranged from 5 to 17 years old, with a median age of 10 years old (see Table 5.2). Interviews were conducted in person or through Skype. Interview questions included ways that their child stayed in touch with friends, positive and negative experiences related to staying in touch with friends, and thoughts about connecting their child with peer patients. Interviews lasted 45 to 60 minutes.

I coded transcribed interviews looking for emergent themes, following a grounded theory approach (Strauss and Corbin, 1994) by using axial and open coding, affinity diagrams, and stopping upon data saturation when themes no longer presented new theories.

Gender	Age	Condition(s)
Male	11	Acute Lymphoblastic Leukemia
Female	9	Kidney Disease
Male	8	Undiagnosed
Male	10	End Stage Renal Disease (ESRD)
Female	10	End Stage Renal Disease (ESRD); Leukemia
Female	5	End Stage Renal Disease (ESRD)

Table 5.3: Demographics of design participants

5.2.2 Design Sessions

Following the interviews, the next step was to understand how the design of technologies could support normalcy and how to help patients stay connected to friends. Inspired by Druin’s approach to participatory design (PD) from her cooperative inquiry framework (Druin, 1999), I first held weekly open participatory design sessions over a couple of months. These sessions were held at a conference room in the Pediatric Clinical Research Center at Seattle Children’s Hospital. The “open” aspect of the sessions meant that any patient could stop by the scheduled time—this was done to encourage new patients to join at any time, without requiring prior knowledge to participate.

However, I found that recruitment was difficult for this population for a variety of reasons. I expand on the methodological challenges and reflect on these challenges in Chapter 7 (Methodological Challenges and Reflections). Due to the challenges from recruitment, I decided to modify the design sessions from group sessions to individual one-on-one sessions.

Patients were recruited through word of mouth and recruitment flyers posted in two different clinics: (1) the hematology/oncology department and (2) the nephrology department. I asked clinicians to hand out flyers to patients that they thought might be interested in participating. In particular, I was able to speak to interested patients and families about

the design sessions in more detail after the clinician had introduced the concept of the design sessions to them. Six patients were recruited from Seattle Children’s Hospital (see Table 5.3 for more detailed information on participants). Patients’ ages ranged from 5 to 11 years old (mean=8.8 years old). Four patients had kidney disease (those with end stage renal disease were ones who required kidney dialysis multiple times a week); two patients had leukemia (one patient had both end stage renal disease and leukemia); one patient was undiagnosed.

Participant	Character Description
Charlie	7-year-old girl with leukemia
Rachel	9-year-old girl with cancer
Jimmy	10-year-old Jeb (Minecraft creator) who is very sick
Edwin	7-year-old Babidu who is getting a transplant
Kelly	31-year-old physician
Lacey	5-year-old stuffed dog

Table 5.4: Characters created by participants

For individual design sessions, I scheduled an appropriate time with patients and their families where I could go in and design with them. For some patients, I was able to run the design session right after their clinic appointment. For others—particularly the patients who were undergoing dialysis, which mean that they could not move from their chair for approximately 3 hours—I conducted the design session during their treatment. Patients were asked to create a character (Grundy et al., 2012) who had to be in the hospital for a specific reason (see Table 5.4). Upon creation, we referred back to the character during the design sessions. Two patients conducted a second, iterative design session, but the other five sessions were standalone design sessions as patients were unable to participate again because of either health reasons (e.g., not feeling well enough) or due to location (e.g., patients returned home and lived more than a couple of hours away). Sessions were

audio-recorded and transcribed. Analysis followed a grounded theory approach, where I used open coding to group relevant themes.

5.3 Normalcy

In this section, I describe a key theme that emerged from my interviews—how pediatric patients utilize different technologies in an attempt to maintain normalcy by staying in touch with their peers (Figure 5.1). I also discuss ways that patients begin creating a *new normal* that integrates their pre-diagnosis lives with their lives after diagnosis.

In describing my results, I refer to healthcare professionals with the label: hcp and parents with the label: pcg. All names used are pseudonyms.



Figure 5.1: (a) Cancer patient playing games; (b) Cancer patient Skyping on a laptop while using Facebook on her iPad; (c) Aplastic anemia patient (rightmost) listening to her iPod while friends are visiting.

5.3.1 Interfering with Normalcy

While undergoing treatment, pediatric patients must deal with numerous hurdles that challenge the normalcy of their lives. Based on the narratives from the healthcare providers and parents I interviewed, I outline various obstacles that can cause patients to feel different than their healthy friends.

Struggling with Health Aspects. At a time when children and teenagers are constantly developing, chronically ill patients often have to deal with the extra burden of physical changes from their illness. For example, medications can cause many side effects—for example, patients can be struggling with acne, a bloated face, or weight gain. Having surgery may leave scars, and chemotherapy often causes patients to lose their hair. Many patients are forced to realize that their appearance is no longer what it was prior to their diagnosis. Not only are patients aware of changes in their appearance, but it may be equally obvious to strangers as well. Having a recognizable physical change (e.g., baldness) essentially advertises their illness to the rest of the world.

Besides physical changes, patients sometimes have other issues related to their illness that contributes to a lack of normalcy. Side effects from having the illness or going through treatments often hinders patients' lives, leaving them unable to participate in certain events or causing them to become self-conscious about things out of their control. Physical limitations could also hinder their ability to use certain technology, thus potentially limiting their capacity to stay connected with friends, such as having physical limitations with using touchscreen devices. Medications or treatments could leave patients feeling exhausted. Many clinicians and parents mentioned that during certain treatment times (e.g., chemotherapy), patients would be so tired that they would sleep for a week, not want to see any friends or family, and not talk to anyone.

Missing Out. As expected, patients often miss out on activities due to the health aspects of their chronic illness. For example, they miss out on special events, such as birthday parties, graduations, or weddings. Some also stop attending school regularly and miss out on school events.

Besides not participating in events, patients also miss out on social interactions with friends. Many of their social interactions prior to being diagnosed happened during school. However, without being in that environment, patients miss out on building and growing their relationships with friends. Healthcare professionals and parents both

stated that friends would often move on and form new friendships, especially the younger children.

Fitting In. Because of the diagnosis and treatment that patients have to go through, they often have to balance their old identity before being diagnosed with their new identity after being diagnosed. For many, this balance is challenging because they feel they are now outsiders of their previous social circles. For example, one oncology nurse explained how there was a patient who was very studious, but because chemotherapy can cause issues in memory, the patient felt she was no longer as smart as her friends (hcp9). Healthcare professionals and parents alike also spoke about how patients tried to keep up with the news of their sports teams, but that it was difficult for them knowing that they could no longer participate (hcp9, pcg3, pcg6).

Patients often had to adjust to being recognized as “the sick kid”. When patients were well enough to return to school, many students immediately recognized the patients. One parent said that her seven-year-old daughter became shyer after being diagnosed with cancer. This shyness resulted from everyone, including people that she did not know, recognizing her (pcg5). Additionally, sometimes being recognized as “the sick kid” caused jealous peers to post negative comments about patients. A 17-year old patient being treated for cancer had the opportunity to meet an NFL player. Her peers wrote negative comments directed to her on Twitter, accusing her of having cancer for attention:

“Maybe you’re doing this for attention” and “oh, this is all I need to do to get to meet [NFL player]”, and things like that... (pcg7)

Her mother recognized that these were most likely not her daughter’s friends, but rather classmates who seemed ignorant about having such an illness.

Although this struggle in balancing an identity seemed to be less of an issue for younger children who had been in treatment since they were very young (before really forming a previous identity), they still had to eventually deal with the realization that they were

different than their healthy friends. Many of them assumed that the hospitalizations, procedures, and medications were all part of a normal routine that everyone had to go through.

The mother of Jeffrey, a five-year old patient who had been in treatment since he was two years old, spoke about when Jeffrey began realizing that he was different:

We go fortnightly to his hospital to have chemotherapy administered, and he got in the car the other day, cried and said, "All my friends have popsicles and a DVD to watch this afternoon as a treat. But I have to miss out. I'm not like my friends. I'm different to everybody." He's realizing he misses treats and fun things at school and parties. It's starting to really bug him. (pcg1)

After Jeffrey started interacting with healthy peers at school, he began realizing that his friends did not have to go through the same things that he did and that he was actually missing out on things his friends were doing. His mother explained how the older he became, the more difficult it was to get him to adhere to medications because he began to correlate the side effects of taking the medication (e.g., feeling really weak) to missing out on events with his friends.

One healthcare professional explained that younger children who have not had a chance to form a previous identity prior to being "the sick kid" might have trouble developing the appropriate coping mechanisms:

As you grow up and you start to determine how different you are from society, that is isolating. And some kids...have a hard time learning the coping skills that they need to establish friendships and relationships, see themselves as normal, and worthy of friendships. (hcp8)

Feeling Rejected. Aside from the lack of normalcy that the illness creates, patients also have to deal with a fear of rejection where they fear that if they miss school or events,

their friends will eventually forget them and leave them out. A cancer nurse explained that even children as young as preschoolers and kindergarteners ask about their friends:

They talk a lot about their friends, about being missed, about being left out. They talk about, "Does anyone know I'm not showing up for school?" (hcp2)

These fears were not limited to young children. Even adolescent patients expressed similar fears. The same cancer nurse said that there was another adolescent patient who had friends who were going back to school who said:

"Now I'm going to have to do this on my own." And I [nurse] said, "Well, you will still stay in touch with them." And she said, "Yeah, but they'll be in school and they'll be working. And they'll have their own lives, and they're going to leave me behind." (hcp2)

Although the healthcare professional said that she had met the patient's friends and did not believe that the friends would leave the patient behind, the patient feared the possibility of that happening.

Beyond the fear of rejection, patients also had a perception of rejection where they believed that their friends no longer cared about them. One healthcare professional stated that for some patients, *"I think they feel that when they're not there, their friends forget about them"* (hcp2). It is difficult for patients to understand that there might be external factors inhibiting their friends from contacting or visiting them, such as their friends worrying that a visit would be a burden. Similarly, for many children, it is difficult to visit their friend without someone driving them to the hospital. A Child Life Specialist talked about how sometimes patients have friends who fall off their support system *"which makes them sad because they realize, 'Oh, I thought this person was a better friend' "* (hcp1).

In addition, some patients agonize over rejection when friends do not respond or reach out for long periods of time. Various technologies can make it easy for friends to

stay connected virtually, which may lead to them not physically coming to visit. One healthcare professional described a situation in which an acute myeloid leukemia patient had been in the hospital for months and no friends had visited her or texted her. The healthcare professional said:

Her mom actually came to me...and was like, “This is a really hard day. It has been months that no one’s returning her Facebook thing she sent out.” She had posted something on YouTube...and no one had really responded. (hcp7)

Although her friends did not explicitly make it clear that they were leaving her out, the fact that they did not make an effort to respond to her made the patient feel like her friends had abandoned her. A cancer nurse explained potential reasons as to why friends may no longer reach out to patients:

The cancer makes it really difficult because [patients] can’t go do things...They can’t participate in things, so then the friends often stop calling them, and they don’t reach out because they’re a little shy...But now, because they cannot accept invitations to things as often and because they’re not going to school as often, they—people just move on. (hcp9)

Lacking Control. Patients have to surrender to the fact that having a chronic illness means that many of the things that happen to them are out of their control. For example, if a patient has low blood counts, they may have to stay overnight at the hospital even if they are feeling fine. One nurse described the patient’s lack of control as:

Sometimes the body’s just not functioning the way it should be. So they’re feeling well, but they have to be stuck there [in the hospital]. (hcp12)

Patients were aware of their lack of control in these situations, which caused even more annoyance and frustration. One father explained how his daughter would feel unhappy

and frustrated about the situation and “*sometimes she’ll verbalize it. You know, ‘I didn’t choose to have this cancer’ is a term that she’ll use*” (pcg6).

Some patients took this lack of control and tried to turn it around. A social worker described a situation where the patient’s friends were not reaching out:

This one patient, she pushed people away. And so in some ways, it looks like the peers held back first, but really, she became bristly because...you know, taking control of the situation by becoming bristly. (hcp13)

In this case, the patient took control by making it seem like she had chosen not to interact with her friends rather than the other way around.

5.3.2 *Maintaining Normalcy*

Patients were extremely cognizant that they were not the same as their healthy peers. Below, I delineate various methods that patients used to try and maintain normalcy in their lives.

Staying Connected. Not surprisingly, patients stayed connected with their friends through a variety of technologies. All of the healthcare professionals and parents mentioned some kind of communication technology that the patients used. Most of them recognized that texting and social networking sites—such as Facebook and Twitter—were the most prevalent ways of staying connected. Technology also allowed rapid response times from friends and allowed multiple conversations simultaneously. According to most healthcare professionals and parents, email was not a very popular tool because it was seen as a more formal way for communicating with relatives or for school purposes.

Typical communication methods—such as texting, email, and social networking sites—are beneficial because they are prevalent for the general population. Patients can use these tools and easily correspond with their healthy friends because they are already using them.

At times, which friends stay connected to patients depends on which have access to that technology (hcp11). One parent explained this by saying:

Some kids have better resources to technology...So who she's just communicating with may just be who has FaceTime or has all the things that she has. You just talk to who's there sometimes. (pcg3)

Feeling Present without Being Present. Because of their hospitalization or their compromised immune systems, patients are not always able to be physically present. At times, patients simply want to be with their friends and do everyday activities such as playing games. Other times, patients have to miss out on special or momentous events. In these situations, they often take advantage of various technologies, such as the rich affordances of video chat.

One parent recounted how her daughter was able to work around the limitations of Minecraft, a game that she would often play with her friend. The patient would FaceTime her friend while they were playing, but they would not spend most of the time speaking directly to each other. The patient left her iPod in her peripheral view so that she could still see her friend while playing her game (pcg4). The parent explained that:

They can both be in the same place in Minecraft, but they can't hear each other, so if they're on FaceTime, they can talk, "Hey, I'm in this part of the castle" or..."Come here and get something." There's no voice part [in Minecraft], so they do that part on FaceTime. (pcg4)

In one case, a patient had to miss her sister's wedding due to treatment. Although she was only able to participate in part of the wedding through Skype, the patient acknowledged the hard work and effort of the healthcare professionals who had set it up for her. The patient told them that it was better than not being able to see or participate in anything (hcp1).

Another patient had to miss out on her eighth grade graduation because she was hospitalized. The school put a laptop that was running Skype on a chair. The patient was able to watch and listen to the ceremony and speeches while she was in the hospital. Her father recounted:

It was like she attended the ceremony...and then after, people were coming up to the laptop saying "Hi Elizabeth," and talking to her, and her talking back.
(pcg6)

Even times when patients would video chat to participate virtually in an event, they would still dress up as if they were physically attending. For example, Elizabeth's father was very surprised that she had dressed up when Skyping into the eighth grade graduation ceremony (pcg6). Another patient was involved in a school club, but since she was not able to attend to school, it was very difficult for her to be part of the club election. Instead, she dressed up and Skyped her election speech to the club (hcp1).

Another patient would Skype into her classroom any time she could. The healthcare professional said:

It was just like she was there. She would get up in the morning, shower, brush her teeth, and brush her hair and put on nice clothes 'cause she knew she was going to be Skyping just like she would go to school...it wasn't like, "Oh, I'm not going to school and I'm just staying home, so it doesn't really matter. I can stay in sweats on the couch all day." She actually felt like she had to get up and get ready to go to school. (hcp2)

Not only did keeping this routine gave the patient structure, mimicking her daily routine at home, it allowed for an easier transition when she began to attend school again, and brought back a sense of normalcy where she felt like she was actually attending school.

Participants also illustrated how often, part of playing together was seeing and being with their friends. They expressed how they would like to see others when they were playing together, even when they were not physically together. For example, Edwin's character played Minecraft with his friends, but he noted that something his character did not like about playing Minecraft was that:

[The character feels] sad and depressed 'cause he doesn't get to hang out with his friends [in person]. (P4)

Participants also commented that they wanted to see family members along with their friends. For example, Kelly said that she wanted to be able to play Uno with her friends and family, but in particular, she wanted to see her brother and play Uno with him since that was something they would do together. Similarly, Edwin also delineated that he did not just miss his friends but he wanted to see and be around his big brother. He mentioned that they did not actually do anything special together, but rather he simply wanted to be around his big brother.

Rachel told a story about her character feeling like she was missing out on school events because she was in the hospital—in particular, Rachel brought up a story about missing out on her best friend's birthday event at school, where there were cupcakes for everyone. She explained that although she felt sad that she couldn't be there physically, the class sent pictures of videos of the class singing Happy Birthday to her best friend that made her feel as if she was physically there. Even though Rachel was not able to interact in real time with her classmates, watching the videos and seeing the photos still made her feel like she was participating because she could see what happened at the birthday event.

Another participant, Charlie, explained that for him personally, he did not want to talk to his friends about the medical aspects of his cancer. He said that:

They're too far away. They're on the other side of the mountains. (P1)

For Charlie, if he was going to discuss his cancer with his friends, he would rather it be done face-to-face than through a technology such as Facebook. To Charlie, face-to-face was more personal than a technology.

Although participants wanted to be able to see their friends when doing activities with them, some parents were still wary about the potential of their child interacting with a stranger. For example, although Edwin said that he wanted to be able to see his friends when playing games with them, he said that his mother would probably not allow that. Even when we designed an imaginary technology that would only allow his friends or whoever he wanted to play games with him, he lamented that:

You don't know what could happen because a random person could join the game...[maybe] they hacked it and went on, and they're playing [the game] and my friend as well. (P4)

Conversation Topics. When talking with their friends, patients often talked about topics that did not revolve around their illness such as typical life topics, depending on the age of the patient.

Younger patients usually do not sit and simply talk to friends, but instead conduct show-and-tells or play. For example, the mother of a five-year-old patient explained how the patient showed his friend things over video chat:

They like to show each other stuff, and he'll go get things...They showed each other their baby brothers...It encourages him to get up and move around...or go and get things to show his friends...Toys and books and DVDs—things that he's been bought. (pcg1)

The affordances of video and the mobility of many devices allows younger patients to feel as if they are face-to-face with their friends. One nurse explained that she would see young patients use video chat to play Barbies with their friends and family (hcp12). This

follows work that has shown that younger children enjoy showing things through video chat while they play (Yarosh et al., 2010).

Other patients talk about various games, such as Minecraft (pcg4) or building LEGOs online (pcg2). As patients got older, conversations shifted towards adolescent topics and staying updated with what was going on in their social circles outside of the hospital. Patients would discuss school, celebrities, bands, and sports (pcg4, pcg5, pcg6). They would also talk about parties that were happening (hcp14), who was dating who (hcp8, pcg6), other friends, and prom (hcp14).

Although patients would talk to their friends about typical life topics, as well as staying updated with the current gossip, some of them were cautious to create a balance between staying in the loop without knowing too much in fear that they would feel left out. As one mother explained:

For the most part, she'll ask them questions like, "What's happening with soccer? Has soccer started yet?"...She still has an interest in what's happening, but she's very careful to not ask too much to where she starts to feel sad because she's missing it. So it's a fine line of keeping communication yet staying at a distance because it's hard to be away. (pcg3)

Patients would also take advantage of the asynchronous properties of various technologies such as SMS or Facebook. This allows patients to step back if they begin feeling sad about missing out on things without feeling pressured to constantly stay engaged in the conversation.

Playing Together. Unsurprisingly, many participants noted that doing activities together was something that their characters wanted to do with their friends. For example, Kelly enjoyed playing the card game, Uno—even to a point where she asked me to first play Uno with her before we started the design session. For Kelly's character, the character also wanted to be able to play Uno with their friends and relatives when they were in

the hospital. Kelly also expressed that the character also wanted to play Uno with the physicians and nurses at the hospital when they were at home. Lacey, a 5-year-old patient with kidney disease, described how her character—a stuffed animal named Snuggles—enjoyed playing hide and seek with his friends. However, she described Snuggles as feeling sad sometimes because *“he wants to play with them but he can’t”* (P6).

For Edwin, his character liked talking about and playing video games such as Minecraft and Plants vs. Zombies with his friends. He described the benefits of online and offline characteristics of video games:

Online [games] makes it so that you can all play together. Like, oh, you can play with your friends and all, but offline, you can play by yourself or with people around you. (P4)

In another session, Edwin created a maze in Minecraft and explained how Minecraft could be a platform for him to be able to hang out with his friends even when he was not at school. He said:

I’m building a competition first for me and my friends...so [the maze] is a cool way for me and my friends to hang out...Well, I hang out with [my friends] at school. That’s the only time I get to be with them [physically]. (P4)

However, Edwin discussed the restrictions of playing an online and open video game such as Minecraft. He explained that both he and his character could not play Minecraft in an online mode because:

My mom won’t let me [play online] at all. She thinks strangers are just going to pop up on my screen and then start playing, and then probably destroy everything, and then I have to start it all over. (P4)

Although there were benefits that Edwin saw in playing Minecraft with his friends online—especially when he could not be with his friends physically, his mother restricted that option for him due to privacy and online safety concerns.

Charlie described how his character liked playing dolls with her friends—her favorite ones being Polly Pockets and Bratz. He expressed how his character wished she could play Polly Pockets and Bratz with her friends more, particularly when she was in the hospital. However, if special people or events happened at the hospital, such as being able to play with a service dog, he told us that his character would not always tell her friends because that was something special just for her. Similar to his character, Charlie also discussed his own personal preferences when it came to sharing information with his friends. For example, he used Facebook as a way to connect with some friends and said:

[The fact that my friends and I are not old enough to use Facebook] is what makes it fun. Once I get old enough, then [using Facebook] is not going to be as fun. (P1)

For Charlie, he also enjoyed parts of doing *special* activities—something that he did not want to necessarily share with his friends. Although he illustrated that his character wanted to be able to play and speak with their friends more often, he was wary in what they spoke about or did. His character wanted to be able to do and talk about fun things with friends rather than the medical issues.

Validating Feelings. Patients often express fears about their illness. Sometimes they articulate to healthcare professionals and their parents how awful they feel or that perhaps having this illness was of their own doing. Healthcare professionals and their healthy friends were able to validate patients' feelings as well as ensure that although this was something they had to go through, this was not by their own choice. However, patients had to deal with the paradox of wanting to be seen as normal by their peers but needing the social support and validation that only a peer group can provide.

One patient, who needed a kidney transplant, actively chose to isolate himself from his family and friends. He told the hospital staff that he wanted to be alone and that nobody understood what he was going through. However, a surgeon, who he held in high esteem talked with him:

Yes, [the patient] needed a transplant—but he didn't get to choose if he got a transplant; it was done to him. We had the surgeon come back and sit down with him and just hear him out. He was a totally different kid after that point. (hcp8)

Having someone that the patient held in high esteem listen to him, assure him, and validate that what he was going through was not his fault and that it was normal to have these feelings made the patient open up again. He was then able to interact with his friends and family without feeling like he needed to pretend to be strong and upbeat.

A cancer social worker explained that when patients share their fears, healthcare professionals normalize those feelings:

We validate where they're coming from and how they can overcome it: "You're not your cancer. Your cancer is part of your experience, but that doesn't define who you are. You're still the person that you are." (hcp15)

A general pediatrician recounted when an eight-year-old cystic fibrosis patient would wait by the door every day for visitors, but because she was on contact precaution¹, it was difficult for visitors to come by and visit. The patient eventually broke down, thinking that she was very different. The healthcare professional explained:

¹ Contact precaution is used by clinicians when something can be transmitted easily by contacting the patient directly or other objects around the patient. Clinicians and any visitors are required to wear a gown and gloves when entering a patient's room.

We try to make it very clear to her that “this doesn’t make you a worse person. This isn’t your fault.” It’s making her realize that [her friends] are not here not because they don’t like [her], but because they can’t. It’s just hard to [physically] come to [her]. (hcp14)

At the same time, it can be difficult for patients to accept validation from healthcare professionals or their parents. One mother of a patient who lost her hair explained that her daughter felt better when her friends or strangers validated her, even if her parents or her healthcare team said the same thing:

To lose [her hair] that she was always guaranteed to get a compliment on really devastated her. She was like, “Forget about cancer. I’m going to go bald?”—I can tell her a million times that she’s beautiful. Her dad, the doctors, the nurses [but she won’t believe it] until [her] peers and even people that didn’t have to stop for a second to say something nice do. (pcg3)

Some patients might have felt that it was part of a parent’s or a healthcare team’s job to compliment or validate them. However, when the validation came from others who did not “need” to do so, the patient would begin to believe those compliments. Patients also utilized social media, such as Facebook, Twitter, and Instagram for validation. Posting a picture or a status update generated many positive and encouraging comments from acquaintances that might have otherwise never contacted them (pcg3).

Protection. Many participants spoke about how the character that they created would speak or not speak to friends about certain topics. Often, this was to protect themselves but it was also to protect their friends as well. Many participants expressed that their characters wanted to spend their limited time with their friends talking about things that they liked, rather than the hospital and their conditions.

For example, Charlie explained how his character did not want to talk to their friends about chemotherapy. When asked about what topics his character did not want to talk

about with their friends, he said, “*Chemo...cause it’s weird [to talk about]*” (P1). He suggested that friends should talk more about fun stuff because often they might not understand the medical parts.

Similarly, Edwin explained that his character did not talk to his friends about his condition or why he was in the hospital because, “*Because he doesn’t get time to, and he’s all alone*” (P4). He expanded that when his character could see his friends, he would rather talk about fun things that they enjoy such as video games.

Rachel described how her character really wanted to speak to her best friend about being in the hospital, but she also did not want to because she was afraid that her friend would be sad and start crying. For Rachel, her character wanted to protect her best friend from feeling sad, and so she made the decision to not talk about her health condition with her best friend. Rachel also illustrated how her character had to wear a mask and specifically asked her friend to keep it a secret because she still had to go to school. She was worried that her classmates would make fun of her for wearing a mask and see her as a sick child who was not like the rest of them. Rachel’s character wanted to protect both her friend from not feeling sad and to also protect herself from being made fun of by her classmates.

5.3.3 *Creating a New Normal*

Although patients strived for normalcy, they also knew that they still had an illness and therefore, by the nature of having it, could not lead the same lives as their healthy peers. In this section, I talk about various methods that many patients go through to *create a new normal*.

Connecting to Peer Patients. Although patients were often stuck at home, in clinic, or in the hospital, they had the opportunity to meet others who were going through similar situations. One physician explained how being treated for similar illnesses can create strong bonds, even resulting in a case where two patients on the same ward got married

to each other. He explained the reason behind such a strong connection is because:

[Patients] understand each other, they can empathize with each other and there's no secrets because they know all the ins and outs of what it means to be a chronically ill patient. They've found someone who can look past the tubes and the hoses and embarrassing things that happen. (hcp3)

While their healthy friends might not be able to fully comprehend or know exactly what it is like to go through treatment, other patients do. The common ground that the experiences provide is something that patients would not be able to have with anyone who was not chronically ill as well.

Being able to connect with those who already went through what they are currently going through was very valuable for patients. In many cases, older patients were able to calm younger patients down and show them that it was not as bad as they thought. For example, one mother explained that her daughter, Anna, had a mentor who she met while in the hospital, and she helped Anna learn to take medication.

When it was time to learn how to take medication and she couldn't learn how to swallow pills...we'd FaceTime [her mentor] and she was able to give Anna some ideas on how to take the pill so that she wouldn't have to taste this yucky medicine. It didn't matter what Mom and Dad said, but having it come from another kid was pretty instrumental for her. (pcg5)

Patients were not only able to learn from other patients but help those who are not as far along in the treatment process. While, at times, patients can provide support to other patients, those experiences can also be a double-edged sword. Some patients would rather not associate with peer patients simply because doing so reminds them of their illness and that they are different than their healthy friends—another stark reminder that they are not “normal”. Healthcare professionals sometimes recommend that patients attend a cancer

camp, where many pediatric cancer patients can gather to connect with one another, over the summer. However, one cancer nurse said:

I've had some kids go, "Why would I want to go to Cancer Camp? I got cancer enough. I want to go to school. I want to go to my Boy Scout Camp." (hcp2)

In these cases, the patients have no desire to create a new normal, but instead, attempt to maintain their previous lives. These patients do not want to be reminded of their illness—something that is too often present in their daily experiences.

It was not just the patients who had apprehensions about interacting with peer patients. Parents were also concerned about the constant reminder to their child. One mother explicitly stated that she would prefer her daughter not talk about her illness with other peer patients because:

I don't really want her to talk about her sickness 'cause I just want her to be a normal kid. I'll deal with that medical part. She just needs to be a kid. (pcg4)

Educating Healthy Peers. Often, healthy peers do not understand the gravity of a patient's illness—they just know that the patient cannot attend certain events or that they look different. One social worker explained that it had been very helpful for patients to do some kind of education within their school to tell their classmates that:

"Hey this is what I've got, this is why I've got it, this is what it looks like for me" ...it may not be the whole 7th grade, but these twenty kids know a little bit better what she's experiencing. (hcp13)

Another nurse explained that another form of education is to have their friends physically visit them at the hospital. She said that, "*then their friend sees what a hospital looks like; what a clinic looks like; what it means to have a port access and get chemotherapy*" (hcp9).

Although healthcare professionals encourage this type of education between patients and their healthy peers, none of the parents that I interviewed mentioned their child explaining more to their friends. There could be multiple reasons for this. Patients may have wanted to maintain normalcy with their friends and bringing up such issues may have reminded their friends that the patient is not well. Similarly, although one nurse suggested that seeing the hospital physically would be a useful learning experience, it can also be very difficult for patients' friends to actually come to the hospital.

Managing Reactions. Patients had to balance other people's expectations of how they saw them, particularly because their physical appearances often changed vastly from before they were diagnosed. Instead of showing up one day at school looking very different than before, patients sometimes managed those reactions by using certain technologies.

For instance, Lucy, a 15-year old osteosarcoma patient who had long, dark red hair, was very self-conscious about losing her hair. Every time they drove home, if she did not have her wig on, she would begin panicking. She would run into the house and put on her makeup and wig before she saw anybody because *"she wanted the world to still see her as her"* (pcg3). However, she slowly started posting pictures of herself with less makeup and without her wig on Facebook. Her mother explained that:

I think, just slowly putting pictures of herself...putting that out there, and then getting some really positive feedback to now. Like yesterday, she finally just put a full collage of herself on Facebook, which is just of her doing different things, all without her wig and without makeup and getting feedback from people like, "You're really brave for that." (pcg3)

Some patients used Facebook as a way to asynchronously manage real-time reactions. Lucy was able to acclimate others to her new appearance. Once she was ready to go back to school or go home, she would not have to deal with other people's shock of her drastic change in appearance. Not only did Facebook help in mediating reactions

asynchronously, it also allowed others to validate and commend Lucy for her strength in dealing with cancer. The positive comments that Lucy received encouraged her to post even more pictures, thus constantly readjusting her appearance in other's minds.

However, there were also other patients who feared what their friends would think, so they chose not to share their appearance with their friends. In one instance, there was a cancer patient who had to have both her legs amputated because of an infection. Every time she would go home for a brief visit, she would tell the clinicians that she saw her relatives, but that she did not want her friends to see her without her legs. The nurse expressed that going home permanently will be very difficult for her:

The little bit of connection that she's done [in the past 14 months she's been in the hospital] has been texting, and so [her friends] have not seen her and they've not had to deal with the fact that she's in a wheelchair and doesn't have legs. (hcp2)

Although using SMS is beneficial because it requires minimal effort on the patient's side and provides asynchronous access, in many cases it is still primarily a one-to-one interaction. Therefore, if patients use SMS to share their appearance, they may have to deal with multiple conversations and multiple reactions, which is different from Lucy's case where she just posted it on Facebook.

5.4 The Design of Peer-to-Peer Technologies

Patients try to maintain normalcy by doing things they would normally do—including communicating with friends using whatever technology their friends use. When designing for this population it is important to remember that it might be difficult to gain critical mass if it is a novel system that their friends do not have easy access to. Indeed, patients that I designed with mentioned how important it was to interact with their peers, and the technologies that they designed were often built on top of current technologies.

When the patient...	Text	Video	SNS
<i>does not feel well enough to engage in the conversation</i>	X		X
<i>does not have enough energy to update individuals</i>			X
<i>wants to be “there” with friends</i>		X	
<i>wants to play games with friends</i>	X	X	X
<i>wants support and validation from peers</i>	X	X	X
<i>is worried about other’s reactions</i>	X		X
<i>wants to educate healthy peers</i>		X	X
<i>wants to find and meet peer patients</i>			X
<i>wants to connect with peer patients they have already met</i>	X	X	X

Table 5.5: Different technologies that can help maintain normalcy

I outline how and when existing technologies might be leveraged to assist chronically ill patients. However, novel applications can also be built on top of existing platforms that are already being used (e.g., Facebook). Systems can also be adapted to better support a blend of asynchronous and synchronous communication, thereby helping reduce the rigidity of current technologies. I also examine the various needs as well as challenges for patients and identified benefits and drawbacks of existing technologies to support children with chronic illnesses (summarized in Table 5.5).

5.4.1 Health Limitations

When the patient does not feel well enough to engage in conversation (e.g., those who are going through intensive treatment), texting and social networking sites can be a good solution. For example, from our results, many clinicians and parents mentioned times where because of the treatment, patients felt “crappy” and did not want to talk to their friends in their tired state. These asynchronous technologies allow patients to control when they want to interact with their friends, without feeling pressured to be connected

constantly. It allows the patient to remain connected and up-to-date with what their friends are doing, but on the patient's own schedule. In contrast, synchronous technologies, such as phone or video calls, might not work as well because patients might feel obligated to engage in the conversation, even if they do not feel well enough to do so.

When the patient does not have enough energy to update individuals, social networking sites (e.g., Facebook or Twitter) allow the patient to update everyone at once, relieving the burden of many individual conversations. We found that many patients were not only feeling bad after their treatment, but were also so completely exhausted that they would often go for a week without talking with their friends. Social networking systems also allow others to comment on the patient's status updates, which can engage others in keeping the patient's social network informed (Skeels et al., 2010). Social networking apps, such as Instagram or Snapchat, that focus on sharing photos to a large audience can allow patients to share richer contexts through photos, rather than textual status updates. However, this type of interaction can be difficult for younger patients who do not necessarily have access to social networking sites. Parents could also be concerned about privacy or safety with social networking sites that have more public postings (e.g., Twitter). However, blogs like CaringBridge that are meant for parents and caregivers can help with safety and privacy issues. These sites can provide status updates to the public, taking away some of the responsibility of keeping everyone updated from the patient. An aggregation of all social networks can help a patient keep their social circle easily informed, along with a blog-style update from the parents (see Figure 5.2). In contrast to social networking sites, texting and many synchronous technologies are more likely to be one-on-one interactions, requiring patients to update friends individually.

5.4.2 *Being Present*

When the patient wants to be "there" during an event or activity, they could take advantage of a rich medium, such as synchronous video, that can help patients to feel as if they are interacting with their friends face-to-face. Patients can see friends' faces, reactions,

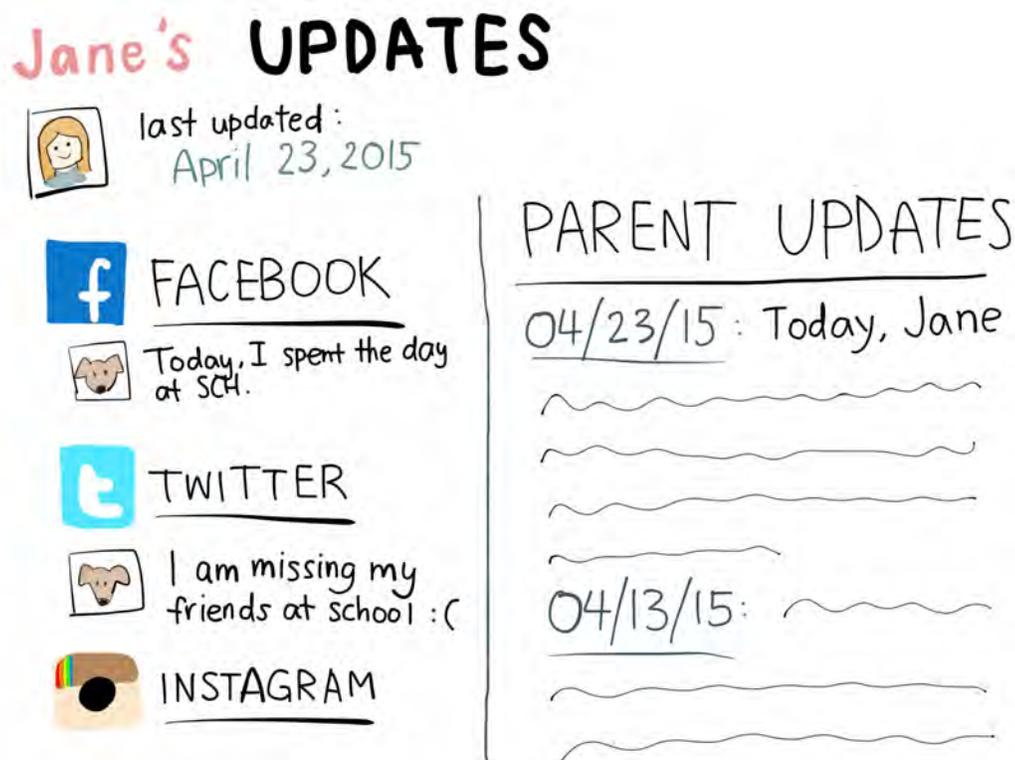


Figure 5.2: An aggregation of a patient's social media, along with updates written by the parents can help the patient's social circle get updates from one place.

and gestures that do not come across well in other technologies. For example, one parent described how his daughter utilized Skype to be part of her graduation ceremony, even though she was not able to physically attend. Similarly, patients can use video to virtually attend classes, enabling them to continue daily social interactions with classmates. Other synchronous technologies may also be useful but less valuable for patients to feel "present" if the communication is through text.

Although video is a rich communication medium, it is still limited in how well it can support some activities. Currently, most of these systems have been designed to support conversations (i.e., a talking head format where both sides just show the person's head) and the mobility of these systems can also create barriers. For patients who really want to

have a strong sense of “being there” it will be important to explore systems that can better support shared experiences so patients feel like they are actually participating (Inkpen et al., 2013). Asynchronous technologies, such as texting or Facebook, can give quick updates to patients in the moment, but are not as immersive as video communication, potentially making the patient feel more like a bystander than being present.

5.4.3 *Integrating Peers*

When the patient wants to play games with friends, especially synchronous games, using technologies such as text (mainly, synchronous texting systems such as instant messaging) or video can help patients play games with friends even when they are physically separated. For example, one patient from our findings used FaceTime as a way to see and talk to her friend while playing a game that did not support talking. She appropriated a video communication technology to help her feel as if she was sitting next to her friend, playing the game. Other parents mentioned that they would like it if applications such as Skype supported different games while still being able to see the other person. One recurring theme with patients was how they wanted to be able to look at their peers while playing different games. This type of synchronous video communication would work well for patients who are not self-conscious about their appearance and who would like to feel as if they were present with their friends. For patients who might be less willing to share their appearance or simply do not feel like it, using synchronous texting systems such as instant messaging may work well. For patients who might be concerned with strangers in an online game, overlaying games with a video-conferencing system that is restrictive such as Skype can allow them to play games with their friends without worrying about strangers jumping in (see Figure 5.3). Alternatively, patients and their friends could play a wide variety of asynchronous games. For example, Facebook supports different social games, such as Words with Friends, Candy Crush Saga, or Farmville. These games do not require both players to be playing at the same time. This type of game can work well for patients who do not want to feel pressured to play games with their friends when they do

not have enough energy to play.

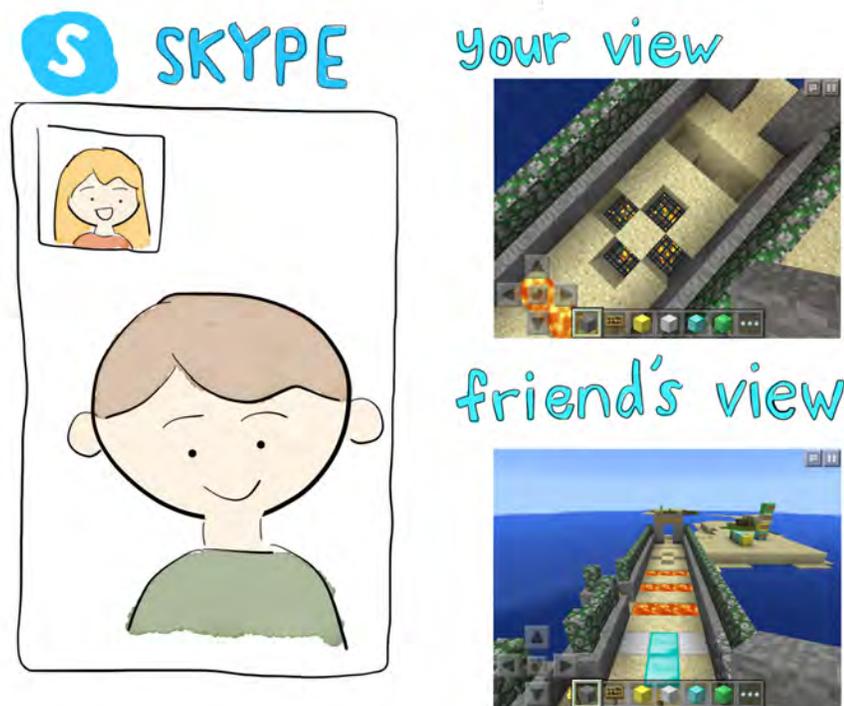


Figure 5.3: Overlaying games with a restrictive video-conferencing system can allow patients to play games together without worrying about strangers.

When the patient wants to receive support and validation from peers, depending on the individual, potentially any type of communication tool could work well, however, social networking sites like Facebook, Twitter, YouTube, and Instagram have the ability to reach a wide audience of their socially connected peers. Patients can receive support and validation as well as generate positive feedback from acquaintances or people who are not comfortable enough to reach out directly. However, because social networking sites can produce fleeting interactions, patients might feel that the support and validation they receive from this medium is superficial. Similar to the example of the patient who received jealous comments directed to her through Twitter, these social networking sites can sometimes be public, potentially garnering negative feedback from strangers, which

can be detrimental to a patient.

When the patient is worried about other's reactions to their different appearance, video communication could accentuate these concerns. Patients who have lost their hair or have gained weight may feel self-conscious about communicating through this medium.

In contrast, asynchronous or non-video tools can be useful for patients who are worried about other people's reactions. For patients who are not ready to show their friends their physical changes (e.g., losing their hair), texting or sending audio messages can be a good way to stay connected with friends while still maintaining some control over what type of information is being shared. Additionally, social networking sites have the potential to encourage patients to be more open with others, such as posting a photo without any hair, without the awkwardness that might come with a synchronous interaction. Social networking sites can also generate a lot of positive feedback that can help the patient come to terms with these changes. In our results, one parent described how her daughter received positive reactions after posting a picture of herself without hair, which encouraged her to continue posting such pictures.

When the patient wants to educate friends and classmates, various technologies can help others see what the patient has to go through. For example, asynchronous technologies such as websites, blogs, video blogs (vlogs), and social networking sites can allow for in-depth explanations on the illness or the procedures and treatments that a patient is undergoing. Videoconferencing tools can also be a way to educate others to see what it is really like. For example, many clinicians suggested ideas where patients can "bring" his or her whole class to the hospital via video and educate them on what it is like to be hospitalized and the different treatments that the patient has to go through.

5.4.4 Connecting with Peer Patients

When the patient wants to find and meet distant peer patients, social networking sites can be very helpful. Social networking sites, such as Facebook, have many groups where patients with similar illnesses converge to share their experiences with one another. Pa-



Figure 5.4: A system that searches through different social networking sites can help patients meet other patients.

tients can find other peer patients through other sites such as Twitter or Instagram by using various hashtags. Having a system that can search various social networking sites using hashtags can also help patients get in touch with other patients who may be in similar situations (Figure 5.4). Using other types of technologies, such as synchronous technologies or other asynchronous technologies like texting, seems to be too personal for patients who want to first establish a relationship with other peer patients.

When the patient wants to connect with peer patients they have already met, although any type of technology can connect patients, certain technologies could encourage a common ground when establishing their friendship. For example, many parents and healthcare professionals commented that it was difficult for some patients to connect with other peer patients in the same clinic because they did not know if they shared any of the same interests and were often too shy to find out. By utilizing social networking sites, patients might be able to discover things they have in common with other patients, aside

from their illness.

5.5 Summary

Children with a chronic illness lead very different lives than their healthy friends. Treatments, side effects, and changes in appearance can all cause chronically ill pediatric patients to feel different. The results from my work show that children with a chronic illness reconfigure various technologies to maintain normalcy in a life that can be very different than their life before diagnosis. Even when designing with children who have a chronic illness, many of them spoke about technologies that would help them to continue doing specific activities that they would do with their friends. At the same time, these patients must also balance integrating a new type of “normal” with their previous before-diagnosis identity. The use of “everyday things”, in particular technologies and the roles that patients take, are in part due to the emotional weight of the “everyday thing”. They are not simply objects, technologies, or “thing”, but rather, there are certain emotional components attached to these things that prompt the patient to reappropriate them. For example, when one patient reappropriated Facebook as a way to manage the reaction of her peers to not deal with real-time reactions about her changing physical appearance, the emotional encouragement and support that she received was the reason why she reappropriated the technology.

I presented opportunities for peer-to-peer technologies to help patients connect with others and feel a sense of normalcy, as well as point out considerations to take into account when designing for this population. Although chronically ill patients might not always feel “normal”, by designing with children who have a chronic illness, we can design technologies that can help them maintain a sense of normalcy while embracing their “new normal”.

Chapter 6

METHODOLOGICAL CHALLENGES AND REFLECTIONS

6.1 Introduction

Research has shown that to design new technologies for a group of people, an important aspect is involving said people in the design process. However, designing with certain populations—for example, children or older adults with a chronic illness—can be challenging, with various issues that may come up, such as recruiting participants (Foss et al., 2013) or respecting a child’s autonomy in the process (Thomas and O’Kane, 1998).

Designing with distinct populations, particularly those who have a chronic illness, includes a series of issues that are not commonly present when working with healthy groups. For example, children who have a chronic illness often have individualized physical limitations that restrict their movement or ability to work with certain materials or supplies. These types of issues, along with logistical issues such as recruiting participants or finding the appropriate location to conduct design sessions at, hinder potential design research that has the ability to help these children who have a chronic illness. The American Academy of Pediatrics suggests that ten to twenty million children and adolescents are living with a chronic illness (American Academy of Pediatrics, 2015). Of those chronic illnesses, some interfere heavily with a patient’s everyday life. For example, chemotherapy treatment for cancer is extremely disruptive to a patient because patients spend large amounts of time in a hospital or clinic and because of the overwhelming side effects from those treatments. Following their treatment, patients also suffer from a variety of side effects from excruciating pain to weight gain to hair loss. Similarly, a child living with chronic kidney disease must go into a dialysis unit multiple times a week to get dialysis (to filter out waste and extra fluid in the body). The dialysis process takes a few hours to

complete, and patients are unable to move during this process. These illnesses often impede the child's ability to attend school on a regular basis. The prevalence of these chronic illnesses can be high—an estimated 16,000 new diagnoses of pediatric cancer were made in 2014 (National Cancer Institute, 2015) and an estimated 18 to 100 per million of the age-related population (4-19 years old) have chronic kidney disease (Harambat et al., 2011). During the design sessions, there may be ethical issues that arise as well. For example, the below scenario is an excerpt of a memo written after conducting a design session with Kelly, a child with kidney disease who needed kidney dialysis three times a week:

[Kelly] seemed to have a hard time creating fictional characters that were supposed to be her character's friends. We decided to step in a little and probed her about this, asking her questions like, "How about one of your friends at home?" She ended up telling us that, "I don't have any friends at home. My best friend is Mommy." Her mother nodded in agreement, saying that Kelly is constantly at the hospital, and she doesn't have many chances to socialize with others. Hearing that, I was not sure how to react. To be honest, it was heart breaking to hear her say that. How does one continue? Should I have asked her more about it? Is that even ethically right?

There are also different issues that can come up when designing with older adults who have diabetes. For example, they may have mobility issues in physically getting to the design workshops. Similarly, some older adults may also have physical limitations that can hinder their ability to participate in crafts (such as using scissors or drawing with pens).

In this chapter, I explicate and reflect upon different methodological challenges that can arise when designing with these specific populations—children with a chronic illness and older adults who have diabetes. These design sessions and workshops were done either at Seattle Children's Hospital (with children with a chronic illness) or at a Group Health clinic (with older adults who have diabetes). I also suggest solutions or workarounds, but

many of these concerns will need to be developed in situ and iteratively. As designers and researchers, we often insert our own preconceived notions of the world into the design of a technology—it could be what we ourselves experienced before (our version of a childhood) or what we expect others to experience. Thus, it is important when designing a technology for a specific population to involve them in the design process (Druin, 2002). The goal of this work is to edify researchers of the challenges they can expect to face when conducting design sessions with distinct populations such as children with a chronic illness or older adults with diabetes. By reflecting on my own experiences conducting such research, this chapter also provides insights on how to potentially address these obstacles.

6.2 Logistics

As with any type of research that asks participants to take time out of their day, there can be many logistic issues that arise. This can be magnified when one is working with populations that are dealing with health conditions.

6.2.1 Working with the Ethics Committee

Controversial studies such as the Tuskegee syphilis experiment (Thomas and Quinn, 1991) or the Monster Study¹ (Reynolds, 2003) have highlighted the need for a committee to review study designs to ensure that the *four principles* (Beauchamp and Childress, 2008) (autonomy, beneficence, non-maleficence, and justice) are upheld. However, because medical studies can be invasive, such as testing an experimental drug, or bring up sensitive topics, biomedical ethics committees in particular are stringent when reviewing study designs.

¹ The Monster Study was a linguistic/stuttering experiment performed on 22 orphan children, giving positive speech therapy (e.g., praising them) to half of the children and negative speech therapy to the other half (e.g., telling them they were stutterers). The children who received negative speech therapy resulted in not only negative psychological effects, but also some having speech impairments for the rest of their lives.

This cautious attitude can be particularly challenging for HCI researchers. When using methods that are novel to the medical sciences research community, the ethics committee requires large amounts of information to fully understand the study design. I had to justify the reasons for choosing various methodologies, even though in HCI, these methodologies are quite pervasive such as participatory design or various design research methods. It is often ingrained in the hospital ethics committee that “research” is “medical science research” (e.g., taking blood samples, etc.) that could potentially harm the patient. For example, for the application to Group Health, I had to explain extensively what a design workshop would consist of (e.g., the types of activities, what types of materials would be used in the activities, etc) because they had never heard of that type of research.

When coupled with conducting research with more distinct populations, such as children who have an illness, hospitals’ ethics committees are extremely wary with any type of research. For example, the university ethics committee was nervous about the basic concept of user research—such as whether providing compensation for the patients in our study would be coercive to children.

In my experience, I had to juggle both the hospital and university ethics committees. While the hospital ethics committee asked for clarification on certain issues because they had never encountered this type of study, the university ethics committee was even more tedious. The university filed my application for Human Subjects Review under the “Biomedical” committee when the study was more suited for the “Social and Behavioral” committee. Being reviewed in the “Biomedical” committee meant that we had to provide extra details in the justification of our methodology, the proposed participant population, and the collected data, as well as provide unnecessary and inappropriate information on the type of medical equipment we would use. We were also collaborating with Microsoft Research—an industry lab that has worked on a multitude of user study research projects within the university. However, because the “Biomedical” committee did not often encounter these university-industry collaborations, it took the committee over two weeks just to approve this external collaboration.

Given these challenges, it is important to develop an understanding of how the review process works at a specific institution. Doing so should help to reduce problems and confusions after the application has been submitted. In addition, some ethics review board committees offer consulting services, where a research team meets with a member of the review board to discuss the study and obtain advice on how to frame the study and approach the review process. It is important for researchers to add in buffer time to their study timeline in the chance that the ethics review board is wary about the study design.

6.2.2 Location

With any type of patient-informed design session or workshop, it is imperative to consider how the location of the sessions are held can affect either the session itself or participation within the session. The design sessions should be held at a place where the participant feels comfortable, and if possible, friendly and inviting. Holding the sessions in an easily accessible and familiar location is important to help participants feel at ease.

For example, a good place to hold design sessions with children was at the Ronald McDonald House (RMH). RMH is a charity house in walking distance to the hospital that provides living spaces for patients and their families who do not live near the hospital, but need to be close by for extended periods of time. Ideally, I would have liked to conduct the sessions at the RMH because the location would allow patients to feel removed from the confines of the hospital and hopefully allow patients to think imaginatively and comfortable. Holding sessions at the RMH could also pique the interest of patients and families who were walking by but may not have heard about the study through the traditional means of recruitment.

However, after speaking with the RMH staff, they informed me that conducting such research would not be possible at the location. Appropriate locations, such as the RMH, often have *research fatigue*, where many researchers and projects either request help (in recruiting patients or conducting actual research) or request to use their space. The RMH made it clear that their first priority was to protect the patients and their families through

an email that said:

To keep this feeling like a home, we thought it would be best to not allow [research projects] onsite.

Patients are bombarded with various types of ongoing research projects when they visit the clinic or when they are in the hospital as well, and understandably, the Ronald McDonald House did not want patients to feel pressured or uncomfortable when they were at home away from home.

Because the RMH was not available as a location for the sessions, the next best location that would be familiar to patients and would minimize travel time would be at Seattle Children's Hospital. I held open sessions weekly in a conference room at the research center of the hospital. Unfortunately, holding open sessions at the hospital proved to be difficult as well. Patients were often hesitant about coming back to the hospital just to participate in a research study. Patients already spend a considerable amount of time in the hospital, and they were unwilling to spend any free time there as well. Many of the patients who were already in the hospital that day were those who had appointments or who had finished treatments and were often too exhausted to participate in a two-hour long design session.

Because recruiting a group was so difficult for this project, I also gave patients the option of conducting individual design sessions. This option allowed more flexibility, and I was then able to meet at a convenient location for the patient. However, I was careful about conducting design sessions with patients who have been admitted to the hospital (also known as inpatients). Many inpatients suffer from severe illnesses and need continuous monitoring throughout the day. Patients can be physically limited (e.g., cannot hold a pencil), exhausted, or just not feeling well from their treatment. There is also a need to consider infection control in the inpatient setting. Many patients are immunocompromised and sharing or bringing in materials that other patients have already used could be dangerous. Privacy concerns also present an issue particularly if patients are sharing

a room with another patient. Depending on the patient, some are unable to move for a period of time because of their treatment. Dialysis patients, for example, are confined to a chair for a few hours. The hemodialysis machines (a machine that removes the waste from the blood and essentially filters the clean blood back to the body) often block patients from seeing or interacting with each other. For example, we conducted design sessions with Kelly during her dialysis treatment. She had a blood pressure cuff attached to her arm and also was connected to a hemodialysis. This setting meant that she had a limited range of motion (see Figure 6.1). Because I knew that she could not move around a lot during the design session, I were able to ensure that our design activities did not require her to be on the move.



Figure 6.1: Kelly, a dialysis patient, was not able to move around during the design session because she was connected to her hemodialysis machine (in the back).

Identifying a safe and convenient location for patients should be considered early in the planning process. Understanding the limitations previously mentioned ahead of time will help to minimize their impact and reduce wasted efforts. At times, however, the

most appropriate location is not available. Researchers should weigh the tradeoffs of less desirable locations to determine where would be the best compromise.

However, for older adults who have diabetes, holding the workshops in a clinic was important because it was a familiar place, easily accessible, and safe to participants. The workshops were held in different clinic locations—Seattle, WA and Tacoma, WA—of the Group Health Cooperative to minimize traveling for the participants. Originally, the workshops held in Tacoma, WA were scheduled for after-clinic hours for participants who might be busy during the day. However, due to security concerns and that the clinic was in a high crime neighborhood, the workshops were changed to Saturday afternoons at another clinic in a safer neighborhood.

6.2.3 *Scheduling*

When conducting workshops that have two sessions each, it can be difficult to retain participants (e.g., participants may attend one session but not the following session). However, older adults with diabetes often did not have issues in scheduling workshops. Out of the 15 total participants, only two did not attend the second session—in one case, one participant had told us prior to participating that she was not available for the second session.

However, for children with a chronic illness, they often have a vast number of appointments or treatments that come up, not to mention the unpredictability of the disease itself. This situation leads to challenges in determining a time when the patient is available and feels well enough to participate.

More challenges arise when schedules change quickly. A child may suddenly be admitted into the hospital where they may no longer be available to participate, physically able to participate, or feel well enough to participate. For example, I had planned to meet a patient for her routinely scheduled dialysis time. However, when we got there, the patient's mother told us that they had switched their dialysis to an earlier time. She was very apologetic, but admitted that it had been a "crazy" day for her and the patient, and

it had completely slipped her mind to let us know beforehand. It is difficult to rely on the parent or caregiver to give advanced notice because they are often too preoccupied with everything else going on. Although researchers can ask clinicians to keep them updated, clinicians are also likely to be occupied with other medical situations that are happening.

Even if the parent or caregiver is able to give advanced notice, there are times when it is out of their control. In one case, I had scheduled a design session conveniently before a participant had to go into a sleep clinic for a study. However, the patient and his mother had to drive 60 miles to get to the sleep clinic from their hometown. Although they left four hours before their scheduled appointment, the traffic was so horrible that they spent 3.5 hours driving, leaving only 20 minutes before their sleep study appointment and not enough time to complete a design session. Although the mother had let me know in advance that they might be late, I ended up needing to reschedule the design session.

The length of the design session with a child who has a chronic illness is also an important factor to consider. Children with a chronic illness often have back-to-back appointments, tire easily, or are suddenly not feeling well in the middle of the session. For example, one participant declared that he would only participate in the session for exactly 45 minutes. He asked a clinician to help him set up an iPad timer in front of him so that he could constantly monitor the time. In this case, I had to tweak the design session plan to make certain that the more pertinent parts of the session were still conducted, forgoing the parts that were less so.

Regardless of how well one plans, these difficulties are bound to happen when working with many populations. Therefore, it is key to ensure the research team is flexible and agile to adapt to the changing needs of their subjects. In addition, rescheduling will undoubtedly lead to delays in project completion, and therefore it is important to have realistic timelines and build extra time into the project.

6.2.4 *Dynamics of Sessions and Workshops*

Although previous research has strongly encouraged design sessions to happen at a group level (Muller, 2010) because each individual has their own experience and knowledge to share and reflect upon, it is not always possible with particular populations. Finding an agreed time that works for all participants can be very hard because there are often various appointments that the participant must also go to. Some patients are also immunocompromised where they cannot go to a session with other patients.

In my experience, I first started with group design sessions for children who have a chronic illness, but it was difficult to gather enough children in a group. At times, patients would express interest by calling beforehand but would ultimately choose to not participate because that day, they were not feeling well enough to interact with others. I adjusted the design sessions and began conducting individual design sessions that were more flexible. The individual sessions were more fruitful, as it was easier for patients to participate if I could go to a specific location and a certain time that worked for them—patients would not have to travel specifically for the session. Individual sessions can also help patients feel more comfortable. For example, I was conducting a design session with Rosie. She was clearly shy and apprehensive speaking to me at first, making sure that she was always faced forward and not looking at me even when she was speaking. However, as the session progressed, she became more and more comfortable. She would turn around and face me, sometimes getting wrapped up in the story that she was telling.

Choosing to conduct group design sessions or individual design sessions depends on multiple factors such as the chronic illness itself or the location of where the sessions are held. For example, it may be easier to gather a group of children with diabetes together than it is to gather a group of children with cancer. As other research has shown, latching on to an established program, such as after-school programs or clubs, can be useful in conducting group design sessions because the participants are already physically collocated (Foss et al., 2013). However, children who have a chronic illness are

often not able to attend school and are unable to participate in these social groups.

It was logistically easier to schedule older adults who have diabetes than children with a chronic illness. For one, though it can be difficult for them, many of the older adults had their own ways of transportation (i.e., driving to the session). For older adults with diabetes, having the group dynamic was more valuable in the design workshop than conducting individual design sessions because a lot of the group discussions came from multiple participants speaking about their own experiences. It was also beneficial for our participants because they were able to meet other peer patients who were going through similar experiences (and sometimes shared clever solutions to problems that others were also dealing with). It was helpful for participants to be able to see that they were not alone in this—that there were others who were experiencing similar things.

As with any decision in the study design, researchers must consider potential tradeoffs. In my experience with designing with children, I had to give up the group dynamic and group interaction that comes from group sessions in order to recruit participants. However, I was able to utilize the group dynamic in the design workshops with older adults who have diabetes.

6.3 Partnerships Between Clinicians and HCI Researchers

Because these participants are still under care at the hospital, it is important to gain support of various hospital departments, particularly in terms of recruitment or even having their patients participate. For example, some departments are more protective over their patients and can turn away researchers because their patients are already inundated with various research projects. If the researchers are not already part of the hospital (e.g., a researcher or clinician at the hospital) or are new to the hospital, it can be a challenge to request other clinicians to assist in recruitment or mentioning the research to patients and their families. Therefore, having a champion (Lorenzi and Riley, 2000) will help other clinicians accept such a project and in recruitment.

Partnering with clinicians and the healthcare organization was helpful in recruiting

older adult participants. In these design workshops, I worked with Group Health's staff and clinicians to recruit older adults who were patients in their clinics. Working with Group Health gave me credibility when I spoke to participants and also provided trust between the research team and the participants. I was also able to take advantage of the organization's resources, such as being able to run design workshops in an outpatient clinic over the weekend (where typically only the emergency room and pharmacy are open).

I was able to work closely with a pediatric nephrologist at Seattle Children's Hospital. He would first talk to the patients and their families to introduce me and to briefly talk about the project. This helped in establishing trust from the patients and their families' side—their physician *knows and advocates* about the project. It also helped in acceptance and trust from other clinicians such as nurses. I was able to go into the dialysis unit, for example, regardless of whether the nephrologist was there or not, and the on-call clinicians would recognize us (or if they did not, as long as we mentioned the nephrologist, they did not mind us being there as he had already primed the other clinicians about the project).

As a researcher who was constantly at Seattle Children's, I was provided with a badge, issued by the hospital. This allowed me access around the hospital, such as being able to go into the dialysis unit during the weekend, instead of being a visitor, which requires an employee chaperone at all times. This made my design sessions even more flexible. For example, I was able to conduct a design session with one patient and her mother immediately after her follow-up appointment at an empty table in the cafeteria. This would have been difficult without a badge because I would have needed a hospital employee to accompany me for an hour without scheduling it beforehand.

Having access to clinicians (physicians or nurses) is important for both the participants as well as the researchers. If patient-specific care questions come up, researchers would have a way to address these needs. In addition, researchers themselves might have questions that require medical knowledge to answer. For example, a participant might describe a condition or intervention that the researcher does not understand and having

the medical context will be important. In addition, having an understanding of the medical issues that the participant is facing can help the researchers find additional context and insight into the research findings. Finally, this relationship can also provide some emotional support as well because clinicians will have advice in dealing with emotionally difficult situations.

In addition, many clinicians are unaware of HCI methods and best practices. Though many are interested in developing novel tools to help their patients, they do not know how to effectively design an intervention that has the potential to benefit their patients. Therefore, creating meaningful relationships between clinicians and those familiar with HCI methods have the potential to develop into fruitful multi-disciplinary teams.

6.4 *Holistic View of Patients*

Patients who have a chronic illness receive treatment for just one of their multiple problems at any time. For example, a child in the dialysis unit is there for kidney dialysis. However, they are likely to have other medical problems that they are dealing including psychosocial problems and dysfunction. Similarly, it is common for many older adults with diabetes to have a number of co-morbidities (e.g, hypertension, cardiovascular disease, etc.). It is essential when conducting research with this population to remember to step back and look at the holistic view of the patient.

6.4.1 Stepping Back From a Disease Focus

In a design session, it is easy to focus the session around a specific disease. However, many times, patients have other co-morbidities, physical limitations from their illness, or developmental issues.

For example, I conducted a design session with Edwin who was undergoing kidney dialysis, but he also had Asperger's syndrome—before the first session began, his mother took me aside to give me tips on how to interact with the patient (e.g., he preferred smaller groups of people, limit my questions, etc.). It was important to have that information as

background for when the session began because I was able to then tailor the session making him more comfortable.

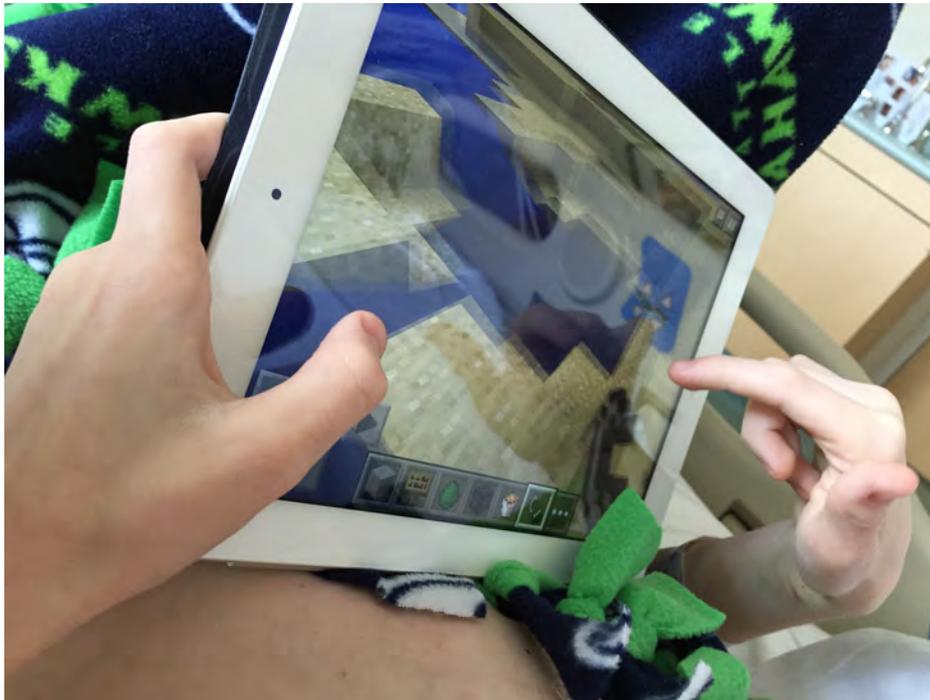


Figure 6.2: Using mediums that participants are interested in can keep patients engaged in the session.

One method in keeping participants engaged is to utilize mediums that they are interested in—Edwin had emphatically expressed how much he loved to play Minecraft (Figure 6.2). He was also the type of participant who would not participate if he did not feel like it. For example, as I entered his room for the second session, he was not in a good mood—his mother told me that he had just gotten a kidney transplant and was recovering from surgery, but the surgical wound was not healing properly and so it was hurting him. He was yelling at his nurse and told two other clinicians that they needed to “*get out of my room now!*” because he had never seen them before and that there were too many people in the room. He seemed unwilling to participate, but when I mentioned that I had brought

Minecraft, his mood boosted, and he was happy to use the Creative mode² as a medium to participate. Compared to the first session where we used markers and paper, he was more engaged in the second session because we were utilizing something that he enjoyed.

Similarly, each age group is at different developmental stages. Working with a 7-year old can be vastly different than working with a 12-year old. In my design sessions with children, I tried to keep the session age and gender neutral, meaning the content that I asked for (and the methods that I had participants use) were not too “baby-like” (e.g., using drawing as a method) but were also not too difficult for younger children to understand (e.g., forming questions in a simple manner). In addition, variability within the population is inevitable. Some patients who have chronic illness might have developmental delay, where their developmental age is less than their chronological age. Therefore even though a patient is 12 years old, they might actually function more like a 6 year old, and the research methods need to be flexible enough to accommodate this variability. Finally, some patients are developmentally precocious, perhaps as a result of their disease, and prefer to engage at a level beyond what one would normally expect for his or her age.

With older adults, it is also easy to focus solely on their diabetes condition. Although the goal of the project was to understand the ways in how health reminders and notifications could be better designed for the management of their diabetes, many older adults who have diabetes also have co-morbidities. More so, their conditions are only a subset of who they are as a person. Similar to the example of Edwin, researchers can take advantage of the various likes and dislikes of the participants in order to encourage engagement in the design session.

It is important as researchers not to assume or project our own feelings onto the participant. This is particularly true for participants from specific populations, especially those who are struggling with health issues. We forget that many of us have not experienced

² Creative mode is a mode in Minecraft that allows players to have unlimited resources, and it is very difficult for players to die; essentially, players can construct anything in Creative mode.

what the child is experiencing with their health condition, and thus, end up projecting how we would expect a child to feel. For example, we may expect that a child in the hospital would feel sad about their situation and inadvertently bias the discussion towards why they might be feeling sad.

6.4.2 *Protection of Participants*

As researchers, we must also be mindful that patients can be experiencing difficult and emotional situations. At times, for example, children's lives may lack a sense of normalcy compared to their healthy friends at school. While the goal of our research is to understand their experiences in order to better design technologies for them, it is important to create a comfortable environment for the patient and to recognize when a sensitive topic comes up and when to back down from that.

For example, in one design session, Charlie—a very cheerful participant—began talking about his friends and family who lived 800 miles away. He spoke about not being able to see them constantly because he had to live nearby the hospital for his chemotherapy treatment. As Charlie was talking about not seeing his friends, he stopped smiling and began to look sadder as he continued. I noticed that his father, who was sitting on the side, also took notice of Charlie's sudden change in mood. I decided that, though it would be interesting to hear more, I would not pursue the topic further because it seemed to affect Charlie in a detrimental way.

Similar to guidelines outlined by Hornof (2009) in working with children with severe motor disabilities where he emphasizes that it is important to learn how to hear "I'm done", researchers who are designing with distinct populations who have a chronic illness must be cognizant and know when to back down from a sensitive topic. Not only do researchers have to be aware of when to back down from a sensitive topic, participants are not always feeling their very best. At times, I had to stop a design session to protect the participant's health. For example, I was conducting a design session in the hospital with a child who was having problems with her kidney. In the middle of the design session, she suddenly

began to cry and told me that she wanted her mother because she was not feeling very well. I immediately texted her mother to let her know what was happening. Once her mother was back in the room, we discussed that it would be best to stop the design session and to try again another time.

There are also physical difficulties that participants may be undergoing. For example, Pamela, an older adult who had diabetes, also had PMR (polymyalgia rheumatica) which caused extreme pain in her legs—often disrupting her sleep at night. During one workshop, she suddenly stood up during the group discussion—she had pain from her PMR, and she needed to stand up to move around. Though it was clear that Pamela was in a large amount of pain, she did not want to leave the workshop. However, I was very cognizant that she was feeling this way and made it clear to her that we could find a clinician or call someone if she needed us to.

6.5 *Dealing with Mortality and Morbidity*

Participants with a chronic illness can be dealing with an illness that is life-long (but with proper management, they can lead fairly normal lives) to an illness that is terminal. Being aware of the morbidity and mortality of these illnesses is especially pertinent in group and individual situations.

Although our design workshops with older adults were targeted specifically to those who have diabetes, some of the participants had more severe chronic illnesses as well—for example, one participant mentioned that he had to have a variety of treatments such as chemotherapy. Because the research study was not focused on his management of that particular disease, I did not know his prognosis. Thus, patients can come in with different severities of prognoses. For example, pediatric patients with high-risk neuroblastoma have an estimated 40-50% five-year survival rate. If a patient is able to participate in a few group sessions but passes away later, this can be emotionally traumatic for both the other participants and researchers.

In this case, such ethical questions can arise: should group design sessions only include

participants with less severe morbidities? Should the participants be primed before a session (for example, during informed consent or assent) that this could happen to another participant?

In particular, parents of pediatric patients can also be wary to have their child interact with someone whose illness has a poorer prognosis than their child. For example, in studies from the previous chapters, I interviewed a parent who said that her preference was that her child not interact with another patient who has a more severe prognosis, even if that other patient was the same age as her child. She explained:

It would honestly be hard for [name] to connect with another 10-year-old with neuroblastoma or something that has a really poor prognosis. Then what if something happens to that kid, and how do you deal with that?

Not only is this a difficult emotional experience for the patient, but the parent now shoulders the responsibility of explaining (or reminding) to their child of the child's own mortality. Similarly, parents may not wish to bring up the topic of death with a young child. While this topic may not have a "right" answer, as researchers, we can provide transparency to the participants and their families by first bringing it up to the parent or caregiver during the informed consent process.

6.6 *Continuity of Design*

Literature has suggested that design research should be an iterative process with continual participation to unpack invisible and tacit knowledge that did not come up in the beginning (Spinuzzi, 2005). Depending on the chronic illness, this can be challenging, in particular if the chronic illness is causing patients to go in and out of treatment. Some of the children with a chronic illness with whom I worked with did not live near Seattle Children's Hospital, and many of them leave the hospital area to go home for an extended period of time. For example, in one of my design sessions, I found out after the first session that the participant only comes to the hospital every 6 months for a follow-up

appointment (and has to take a plane to visit the hospital). Also, some patients could develop physical limitations that prevent or interfere with future sessions.

Researchers then must consider the continuity of the sessions—what is the best way for participants to have continual participation (if they want to) without needing to be there physically?

6.6.1 *Group Workshops*

Scaffolding the design sessions are especially pertinent in group settings. Patients are leaving the hospital to go home while other patients are entering the hospital to begin treatment. Design workshops should not require a patient who is joining a session for the first time to have prior knowledge of previous sessions to fully engage and participate. This could not only impede the flow of the design session but discourage new participants from engaging in future sessions.

Researchers can create modular design activities to ensure that those who are joining in a design session for the first time will not feel lost or need prior knowledge. Researchers can also ask participants to help in combining all of the modules from previous design activities to help create a cohesive design or technology. Even if participants have not participated in all of the sessions, it can help patients feel included and help them see the end result.

In one design workshop with older adults, two participants did not come for the first half of the workshop. However, the workshops were designed so that they could still participate even though they had missed half of the workshop. Both of the late participants were still engaged in the group discussions and contributed heavily to the discussion. Adult participants often have a more difficult time when asked to use their creativity and imagination. They may need more probing or time to be able to think creatively. This could be because of the constraints of “reality” and the social perception that adults should not think like children. For example, as part of our design workshops with older adults, one activity asked participants to invent a magical system that could

help them with reminding them about their health information. Many of the participants expressed uncertainty in approaching the activity. Out of 14 older adult participants, only one came up with a system that did not exist—the remaining 14 participants discussed systems and routines that they were already using. This shows how grounded in reality adults participants may be. One successful workaround to the notion of concrete thinking is using video prompts that illustrate a particular scenario with an *invisible design* (Lindsay et al., 2012b).

There can also be a gap of time between design sessions. Though it was not a large gap, in my design workshops with older adults, we had a week gap in between the sessions. However, to encourage reflection on the design workshop, I provided participants with a *cultural probe inspired* bag. The bag included two worksheets that asked participants to describe and reflect upon a health reminder that they had received recently and how it was useful to them. I also included a Polaroid instant camera for participants and asked them to take photos of reminders. At the second design workshop, participants described their photos to the group. Participants enjoyed the activity, and the act of taking a photo helped in reflecting on their own health and the reminders that help them manage their health. Having “homework” activities can prompt participants to think about the session topic even if there is a gap in time. The activities that were provided to the participants were thoughtfully constructed to ensure that it would not take a lot of time to complete and were enjoyable to do as well.

These activities worked well for older adults as many of the participants joked that they had not done homework in years. However, researchers may have to consider how to create “homework” activities for children without mimicking actual homework too closely. Children may be unwilling to participate if they feel that it is another required assignment.

6.6.2 *Individual Sessions*

It can be difficult to schedule group sessions for patients who are constantly going to various appointments. To be flexible, individual, one-on-one sessions can be a better choice. However, one of the appeals of design research is the iterative process. While being cognizant of the need for flexibility and without losing the iterative aspect of design sessions, individual design sessions must be able to still incorporate group feedback into these sessions.

For example, at the end of our design session (after a participant has thought of and explained a new design), I asked participants to look through a stack of other designs created by other participants, to give feedback and comments on each design, and to imagine if one design could fit together with their own. This created a sense of group feedback. However, many of the pediatric participants were very focused on their own design and were less interested in giving feedback on other's. It is important for researchers to come up with creative ways to elicit group feedback individually.

6.7 *Children as Participants: Concrete Thinking*

Anecdotally, many children are quick to jump into a fantasy world with little hesitation. This could be because, compared to many adults, children may feel less pressured to think the "correct way". Similarly, other research has suggested that this could perhaps be because quantitatively, children have fewer experiences than adults, and thus, their thoughts are be less grounded in reality (Vygotsky, 2004). However, I found that many participants struggled when I asked them to imagine a character and describe how the character felt. Some participants would describe a real person (e.g., someone famous) or describe themselves, where the character had the same age and name as the participant. After some of the sessions, some of the participants voiced that it would have been easier if we had asked them to just describe themselves and how they felt.

This is different to most of the literature in child design research, which recommends re-

searchers to employ a number of methods that encourage and spark imagination amongst their participants. Grundy et al. (2012) suggest that using characters (fictitious personalities that have certain characteristics relative to a scenario) can help distance the child from the character themselves. Lindberg (2013) also echoes this sentiment when conducting workshops with children with cancer, suggesting that it is important for participants to distance themselves from their creations through proxies.

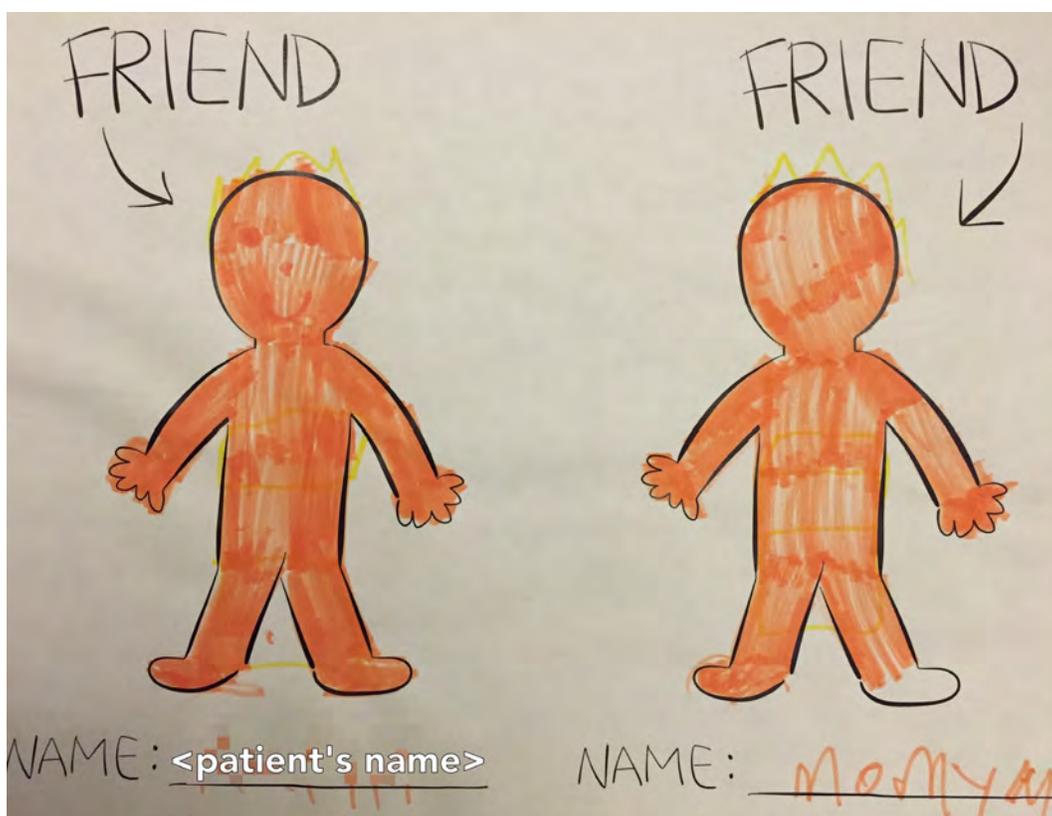


Figure 6.3: When creating her character's friends, Kelly used herself and her mother as inspiration.

Many of my participants are dealing with chronic illnesses where they undergo intense treatments (e.g., chemotherapy). Similarly, many of our participants must come into the hospital a few days a week for dialysis for long periods of time (e.g., months). For example, Kelly had been in and out of the hospital for the majority of her life. During one of my

design sessions with her, I asked her to first create a fictional character that had certain likes and personality attributes. At first, she decided to name her character, Mommy and said that the character was her mother. After some suggestions that the character could have another name besides Mommy, she decided that the character's name was the same name as her favorite physician and even asked her mother how old the physician was. When I asked her to explain why her character was in the hospital, she clarified that: *"He's not in the hospital [for treatment]"* (P5), but rather because he worked there as a doctor. When I asked her what her character did at the hospital, she answered, *"[He] goes to clinic"*. In our design session, I also asked Kelly to create a few friends for the character. The friends that she created were named Kelly and Mommy (see Figure 6.3). For Kelly, it was difficult for her to imagine a character beyond her own reality.

Many of the characteristics that participants would describe about their character paralleled their own life and characteristics. For example, when Rachel was describing her character—whose name was the same as her own middle name—she described something that her character liked, but answered with *"Well, I like—"* (P2) and immediately clamped her hands over her mouth. She quickly corrected herself, saying, *"[Character name] likes..."*. When I asked Charlie (P1), a participant with leukemia, why his character was in the hospital, he responded with, *"She can have the same thing as me—I don't know how to spell it. I'll do my best. Leu...kemia"*. Charlie also described that his character's best friend was, *"Her friend, Mariah—that's my friend's sister"*.

Another example of when the participant showed more concrete thinking was my design session with Jimmy (P3). At the time of the session, his parents were still trying to receive a proper diagnosis for his condition. This meant that Jimmy was out of school many times a week to run various types of tests at different hospitals and clinics. When first asked to think of a character and a character's name, Jimmy (who profusely told us beforehand that he loved the game, Minecraft) said his character's name was Jeb, the name of one of the Minecraft creators. Although he did not link the characters to his actual life as Kelly did, he still used a real person as inspiration for his character.

One potential reason for the concrete thinking in our participants is due to their chronic illness, which might have forced them to grow up faster than their healthy counterparts (Evans and Radford, 1995). Other research has also found that many survivors of pediatric cancer felt that they had no choice but to grow up faster than their friends during their treatment (Lozowski, 1991). The fact that many participants are constantly in the hospital and are constantly exposed to the realities of life (i.e., life and death) might suggest that the “premature aging of [the participants] becomes more apparent” (Travis, 1976).

Though my sample size is relatively small and thus hard to determine whether *premature aging* correlates with concrete thinking, this could be a potential avenue for future research in examining the differences of conducting design sessions with children who have a chronic illness and healthy children. Researchers may find that some of their participants have a more concrete view of the world and that a *one-size-fits-all* activity will not always work. If this is the case, researchers can try to adapt the activity to fit the way participants think. For example, because Jimmy excitedly told me stories about Minecraft and how much he enjoyed playing the game, one potential solution to spark his creativity is to utilize Minecraft as a medium in the design activity, rather than using pen and paper.

6.8 Children as Participants: Parental and Familial Challenges

Parents and caregivers are an important component to consider when conducting design research with children. Parents can both encourage or impede the session—for example, they will speak on behalf of the child, but the child clearly feels more open and comfortable if the parent is part of the conversation.

In one case, we had one mother who would constantly speak on behalf of her child. Rosie’s mother would first speak for her because Rosie seemed apprehensive at first, constantly looking to her mother before answering or for confirmation. However, as the design session progressed, Rosie became more comfortable speaking to us and did not need her mother to speak for her. Unfortunately, in this case, Rosie’s mother would still answer for Rosie, even when Rosie was clearly comfortable answering herself. While that

was one case where the parent was impeding the session by speaking for the child instead of letting the child speak themselves, there are also cases where the parent can encourage the design session.

The challenging issue for researchers lies in how to avoid barriers that arise with parents' involvement but at the same time, respect their requests. For example, it might be best for parents to not be involved in a design session in order to avoid any potential barriers. At the same time, this is not always what the parents want—they may want to be there physically and monitor what the discussion is as they feel the need to stay and protect their child from potential harm or pain. Previous research in designing with children has encouraged researchers to try to avoid having parents involved because of these potential barriers (Jokovic et al., 2004).

However, it is very difficult to separate parents from their children during a session. Similarly, patients are not always comfortable without their parents nearby. Another important point to consider is the role of the parent as a protector. Parents may feel a need to protect their children from perceived harm, but often, the need to protect their children from harm is heightened when their child is going through a chronic illness. Since their children are already sick, parents can feel as if they do not have full control over the wellbeing of their children. At times, parents can act to try and regain control in other areas of their child's life to prevent any additional pain or suffering. As a result, parents might still need to be involved in research to ensure their child stays safe. When designing with children with a chronic illness, researchers must consider these tradeoffs and the need to develop tools and methods to try and overcome any potential barriers the parents' presence might present.

At the same time, researchers should not always consider the parents' involvement as an impediment. We have seen patients who felt more comfortable having their parent there as a safety net in case they were not sure of the answer. Such as the case with Kelly, who said her mother was her best friend, involving the parent in the design session could result in a richer understanding of the patient's experiences. In another design session,

Jimmy would answer questions very concretely. He was getting frustrated when I asked him to think creatively. At that point, I was not sure what to do—push him a little bit more (because in some previous situations, he simply needed a bit of prompting) or to stop. However, his mother could tell and would step in to rephrase our question or talk to him in a way that he would understand without biasing him in any way.

While past research (Jokovic et al., 2004) has argued that direct, unencumbered interaction with children leads to the best design insights, researchers should consider to not automatically seek to exclude parents from their studies with children, especially in the case of children who have a chronic illness. They may consider the benefits of having parents participate in or assist with patient-informed design sessions. Parents can sometimes serve as useful proxies for their children, perhaps giving a different but useful viewpoint on the technology needs or opportunities for their children. For example, in my previous study of current communication practices of inpatients, I relied on parent and clinician testimonials but nonetheless yielded rich results that have directly informed these design sessions (Liu et al., 2015).

Besides parents and caregivers, the inclusion of siblings in sessions should be considered. Siblings can offer a different perspective, and research has shown that many siblings are worried about the patient (Menke, 1987). At the same time, other research has suggested that siblings can feel jealous or neglected by their parents (Peck, 1979); therefore, including patients' siblings can lead to problematic sibling dynamics. However, the inclusion of siblings has the possibility to actually make the patient more comfortable because there are now familiar faces that are participating as well. In respecting the patient's autonomy, researchers can ask the patient if they prefer having their sibling participate in the design session or not.

6.9 Concluding Design Sessions

An aspect to consider when working with children with a chronic illness is the conclusion of the design sessions. Working closely with patients long term can result in an expectation

that the researchers will come back to “visit” them. Naturally, after spending time together, researchers often become part of a patient’s social support circle. For example, after a month of not seeing Kelly in the dialysis unit, when I came back, her mother had joked, “I thought you had forgotten about us!”.

Akin to providing technology as part of a study (resulting in the participant potentially getting use to having the technology) and then taking it away at the end of the study, researchers must consider the potential consequences that happen due to concluding the study and whether it would be detrimental for the patient if the researchers stopped the sessions.

Researchers should think about ways to mitigate these consequences and be transparent with the patient and their families. In my design workshops with older adults, I had clearly stated that there were only two workshops in total. Although many of the participants lamented that they would have loved to continue the workshops, they were also aware that it would not be possible to continue.

6.10 Self-Care as a Researcher

Working with particular populations can sometimes be emotionally draining or difficult as a researcher. Acknowledging and realizing how important to consider *self-care* is essential when working with distinct populations (Verdezoto et al., 2014). For example, memoing (Birks et al., 2008) is a useful tool, both in gaining research insight but also in reflecting as a researcher. In a similar vein, it is useful for a researcher to share how they are feeling with others (e.g., colleagues, mentors). In addition, there is also a chance that some participants may have a terminal illness and pass away. Researchers often spend a considerable amount of time with participants and naturally develop a bond and relationship with those participants. It is important to recognize that there are times when we might need to step back from our research in order to take care of our own emotional wellbeing.

6.11 Summary

Patient-informed design has great potential to improve the lives of patients who have chronic illnesses and those around them. By collaborating closely with such patients, the hope is to design digital artifacts that carefully consider and mitigate the unique challenges their conditions bring.

Based on my experiences designing with different populations of patients, I outlined the methodological challenges that I faced and reflected on these challenges. For some challenges, I suggested solutions or workarounds, but many of these concerns will need to be developed in situ and iteratively. By reflecting on and making these challenges explicit, we can increase awareness of such challenges and to enable researchers to proactively plan ahead and come up with creative ways to address these issues.

Chapter 7

CONCLUSION

In the concluding chapter, I first summarize the findings from previous chapters and the contributions of each study. I also discuss the limitations of my studies and speak to opportunities for future work.

7.1 An Overview of Findings

I conducted three studies that examined how patients who have a chronic illness reconfigure “everyday things.” I define “everyday things” as the artifacts, relationships, roles, and technologies that exist in our daily lives and environments.

In my first study, I looked at how health vloggers—adults who have a chronic illness who utilize YouTube, a video-sharing platform—share their experiences, emotions, and knowledge about their chronic illness with others. By appropriating the videos, comments, and YouTube platform, health vloggers were able to establish a deep connection with their viewers through the rich medium of video and gain social support while also providing support for those who were viewing the videos. Similarly, comments left by viewers emphasized the multi-directional support (viewers provided support to vloggers, vloggers provided support to viewers, and viewers provided support to other viewers).

In my second study, I unpacked how older adults with diabetes appropriate opportunistic reminders—existing artifacts, routines, activities, and relationships—to serve as a way to remind patients of specific health actions and tasks. These opportunistic reminders also helped remind patients of the complexity of their condition and their overall health goals.

In my third study, I examined the role of communication technology in maintaining

a sense of normalcy for children who have a chronic illness. Children appropriated and wanted technologies that would help them feel and do “normal” activities with their peers. However, at the same time, children with a chronic illness also recognized that having a chronic illness meant that they were not the same as their healthy peers and often tried to meld their “new identity” with their previous, pre-diagnosis identity.

Through these studies, I found that a large reason for why these reappropriations by patients were successful was because of the emotional meaning that often came hand in hand with “everyday things”. When coupled with emotional weight and meanings, these “everyday things” were able to be reappropriated in a way that supported patients’ chronic illness management.

7.2 Contributions

7.2.1 Going Beyond Chronic Illness: Designing for Reappropriation

From my three studies, I have shown how though “everyday things” already exist in patients’ daily lives, they take advantage of these “everyday things” by reconfiguring them to help support their chronic illness.

Although YouTube was not designed specifically for information gathering on chronic illnesses, health vloggers and viewers found ways to do so by providing resources to others through websites or other health vloggers. For health vloggers, the act of sharing their feelings or experiences (through uploading a video) was therapeutic and cathartic (Nardi et al., 2004b) for the vloggers, akin to writing in a journal. However, sharing their stories had multiple benefits—namely, it supported viewers by providing them with advice, suggestions, and information on what to anticipate next. Both health vloggers and viewers reconfigured videos into something that supported their chronic illness management.

Older adults who have diabetes did not necessarily reconfigure one specific technology as the health vloggers did. Rather, they appropriated artifacts, routines, activities, and relationships that served as opportunistic reminders. Opportunistic reminders helped

them remember certain health tasks such as exercising daily or their overall health goal (e.g., taking better care of their health so medication and overall healthcare costs are lowered). These opportunistic reminders also held great emotional meaning for our participants—such as a past photo motivating a participant to try and go back to a healthier version of himself.

Children who have a chronic illness reconfigured “everyday things” to maintain and create a sense of normalcy among their peers. For example, they often used social media (e.g., Facebook, Instagram, etc.) as a way to gain support from their peers. At times, patients reveled in receiving support (a “like” or comment) from acquaintances more so than their close friends; the semi-impersonal nature of Facebook meant that an acquaintance did not have to take the time to comment or like their status, and when they did, patients felt encouraged. Some patients reconfigured their role as a patient into one that helped others who were not as far in the treatment process as they were. They took their knowledge and role as a “patient” to become a peer mentor.

Because people who have a chronic illness utilize “everyday things” that already exist, we must also consider the *reasons* for appropriation in the first place and to find ways to integrate emotional meanings that are often a part of the “everyday thing” into a design. For example, one participant explained how she appropriated her walking cane—defunct for the purpose of aiding her to walk but still purposeful in reminding her that she must take care of her health to ensure that she would never go back to needing her cane to walk.

Although *new* technologies must still be designed to fit the users’ needs, I postulate that we should expand on the design process itself—*designing for reappropriation*—where researchers should plan for the occurrence of reappropriation within different groups. Dix (2007) suggests that when designing new technologies, technologies should allow and support appropriation by its users. Expanding on that notion, I suggest that *existing* technologies should also consider designs for reappropriation. One solution could be overlaying designs onto a general template based on the needs of different groups. Designing for reappropriation is a useful consideration beyond designing technologies

specifically for patients who have chronic illnesses. However, we must still consider how to design for reappropriation without losing the “everyday-ness” of the reappropriated “everyday things”.

7.2.2 *Methodological Considerations*

From my experiences in working with distinct populations, I made methodological contributions by reflecting on the challenges that often arise when working with these populations. Though these experiences were specific to my situation, being exposed to potential challenges and potential workarounds allows researchers to first reflect on challenges in conducting research with distinct populations without needing to go through the potentially difficult experience. These methodological considerations can be used by both HCI and health researchers when designing with and for distinct patient populations. For example, I illustrated how patients, in particular children who are constantly in the hospital for treatment, may be more concrete thinkers than imaginative thinkers. This finding is different than prior research which often suggests that researchers who work with children should use imaginative methods—such as using character proxies—as a way to create distance between the child’s actual situation and the character. Although I was unable to provide a definitive solution, being aware of this potential situation is useful for researchers in planning ahead to minimize future obstacles.

However, working directly with distinct populations with a chronic illness (for example, children who have a chronic illness) can pose a number of challenges. Thus far, there has been little to guide researchers on what one might expect and how to deal with problems when conducting such work. Through my experiences, I give researchers a glimpse into the subtle and complex challenges inherent in a chronic illness, but in dealing with the processes and actors that surround them. For example, researchers must deftly juggle numerous institutions (hospitals, ethics committees, charity houses) and their procedures (e.g., scheduling).

Perhaps more important, however, is that researchers must be willing to adapt and

change as researchers to respect these patients whose challenges often dwarf our own. This willingness to change and adapt entails not only the possibility of changing one's design approach and research tools but to change one's willingness to rethink how to interact with distinct patients with a chronic illness (e.g., exercises that are less "creative" and more "concrete"). Although each site will require different adaptations, my experiences and reflections should prove helpful to anyone conducting research with distinct populations experiencing particular, unique hardships.

7.3 *Limitations and Tradeoffs*

As with any study, certain limitations will undoubtedly arise. In this section, I describe the limitations and tradeoffs of my work. Although some of these limitations could not be predicted, it is important as a researcher to acknowledge how these limitations and tradeoffs could have affected the data or analysis.

7.3.1 Health Vloggers

In my chapter about health vloggers, I analyzed two videos per health vlogger: the first uploaded video and most recently uploaded video. This was done to gain an insight into their journey. However, analyzing the first uploaded video and the most recently uploaded video did not guarantee that we would be able to gauge the changes that occurred throughout their journey—for example, there could only be a difference of a few months in between the first uploaded and most recently uploaded videos.

Because we analyzed publicly available videos, we did not speak to health vloggers directly. The information presented through their videos, video description (as part of YouTube), and comments were the only means of understanding their experiences. We were unable to probe further—for example, some health vloggers stopped uploading videos, but we did not know why they stopped. Similarly, when analyzing comments, we were unable to follow up with commenters/viewers as well. YouTube also upgraded their commenting API, which meant that some comments were lost within the upgrade.

Although we could see in the comments dataset that a user was replying to a comment, we were not able to see what the comment was.

7.3.2 *Older Adults with Diabetes*

In my chapter on older adults with diabetes, I described design workshops with 13 older adults. We had a small sample size which may not be representative of the older adults with diabetes population. Because we had a small sample of participants, there was also the potential for selection bias for people who are willing to participate in research.

7.3.3 *Children with Chronic Illnesses*

In my chapter on designing with children who have a chronic illness, I presented results from interviews with patient proxies—parents and clinicians of children who have a chronic illness. Following these interviews, I conducted individual design sessions with children who have a chronic illness. Interviewing patient proxies offered the advantages of a more reflective perspective and a large breadth of experiences. Parents were able to articulate their children’s experiences and reflect on them, and because clinicians see a large number of patients throughout the day, they were able to provide a wide variety of experiences.

For the design sessions with children, I was forced to change the design sessions from a group setting to an individual setting because of recruiting and logistical issues (in which I explicate further in Chapter 6). The feedback nature of a group setting was not present in the design sessions.

Designing with children one-on-one can have potential effects on the study. For example, the children may have felt pressured to answer questions or design technologies in the way I wanted. Because it was often just myself and the child, some were shy or reluctant to answer at first, resulting in limited answers.

7.4 Future Work

Though I have examined in detail how different groups of patients appropriate “everyday things” to fit their health needs, a wide area of future work is still open that needs to be examined in more detail. In this section, I outline potential areas of future research.

7.4.1 In-Depth Understanding of Health Vloggers

As I mentioned in the Limitations and Tradeoffs section, one avenue of future research would be to directly interview health vloggers on their experiences with sharing their story publicly and their connections with an “invisible” audience. Through interviewing health vloggers (and health vloggers who may have stopped vlogging for certain reasons), we would be able to get a deeper sense of how the connections between the health vlogger and their viewers are established and maintained. For example, perhaps health vloggers and their viewers have other means of staying connected such as Twitter that were not explicitly obvious in their vlogs. Probing these means of connections outside of the vlogs would allow us to further understand how these connections are created and maintained. Furthermore, we would be able to understand how to better design video-sharing platforms to encourage sustained connections for the vloggers and viewers.

7.4.2 Prototyping “Reminders in the World” Technologies

As shown in my study with older adults who have diabetes, participants often took advantage of existing “everyday things” to find “reminders in their world”. By prototyping different types of ubiquitous technologies, we can evaluate the kinds of technologies that utilize participants’ reappropriations. For example, by using location-based information, we can create an application that prompts reflection by having the participant reflect and think about their current action, their current location, and how those are associated with their health. Evaluating a prototype will also help refine and reiterate these technologies to ensure that the patients’ perspectives are matched in the design. We can also build

prototypes that build on the emotional connection that “everyday things” often have to understand how we can utilize and build upon these emotional connections in designs.

7.4.3 Reappropriating “Different” Platforms for the Design Process and Deployment

In designing with children who have a chronic illness, I noticed that Minecraft was a potentially engaging platform that could be used to design with children. In my experience, the participant that used Minecraft as a design platform opened up considerably and was excited to design with me. Not only was the participant interested in the platform itself, Minecraft’s sandbox characteristics made creating and designing new technologies easy for the participant. Utilizing Minecraft as a design platform could create new methodologies that encourage children to be more engaged in the design process. We can also examine whether Minecraft’s collaborative environment could serve as a method in gaining group feedback remotely.

Considering designing for reappropriation, we can also design “overlays” for current technologies that help children with a chronic illness participate in activities that they would normally do with their peers. Many of the participants that I designed with mentioned and designed technologies that would allow them to do activities with their friends. However, it was also important to them that they were able to interact with their friends when doing the activities together. For example, having an overlay of Minecraft or another game onto Skype would allow children to speak to each other while playing a game. This feature could make the child who is not at home or school feel more involved and connected with their peers. Deploying and evaluating the reappropriated technology would help us understand how we can design better ways for children who have a chronic illness to interact and conduct activities with their peers.

7.4.4 Integrating Emotional Meaning into “Everyday Things”

An important concept that has been present throughout my studies is how the reappropriation of “everyday things” is successful in part because of the emotional meaning and

weight that it holds. An object is just an object, but when there is an emotional component attached to it, participants find more meaning and work hard to reappropriate the “everyday thing” to support their chronic illness management. Another reason that reappropriations of “everyday things” are successful can be because of their “everyday-ness” and the fact that it is not necessarily a special, specific “thing”. Therefore, it is important that the “everyday-ness” of these “everyday things” is not lost during the reappropriation as well. Future work should investigate methods in utilizing the “everyday-ness” and the emotional meanings of these “everyday things” without losing or desensitizing users to it. Conducting field deployments to evaluate the best methods in how emotional meanings and “everyday-ness” can be embedded will help in understanding how we can build technologies that support the emotional and “everyday-ness” of reappropriations.

7.5 Concluding Remarks

I have shown how people who have a chronic illness—both adults and children—reappropriate various “everyday things” that already exist in their lives. Be it physical artifacts, relationships, roles, or current technology, it is important to recognize how the design of general technologies may not always fit the needs of certain users. Significantly, my three studies concretely illustrate that people who have chronic illnesses find ingenious strategies to manage their chronic illness in ways that better fit their needs.

Designing for reappropriation has the potential to reduce the barriers and challenges that people who have a chronic illness may face. This perspective into design argues that “everyday things” hold important emotional meanings (e.g., the cane that represented the unhealthy version of herself). The most helpful “everyday things” are not neutral “things” that help people manage chronic illness; rather, they are valuable things which have deep meanings for patients, supporting them in their chronic illness management. This is not to say that we, as researchers, have nothing left to do to improve the lives of those with chronic illness. Indeed, as I have shown, patients work hard to reconfigure their world to better support their chronic illness. Rather, we should see these examples of

reconfiguration as inspiration to foster and cultivate the reconfiguration of the world that these forerunners have done. The key to supporting chronic illness management is to build upon and embrace the world that those with chronic illness have already reconfigured.

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