

Project Number: LDH-PW20

PATIENT RECOVERY AND EMPATHY THROUGH VIDEO ILLNESS NARRATIVE

A Major Qualifying Project Report

Submitted to the Faculty

Of the

WORCESTER POLYTECHNIC INSTITUTE

In partial fulfillment of the requirements for the

Degree of Bachelor of Science

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Date: April 29, 2010

Approved:

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“It has always seemed to me that there is a kind of quiet heroism that comes from meeting these problems and the sentiments they provoke, of getting through each day, of living through the long course with grace and spirit and even humor; sick persons and their families understand the courage, even if most others do not.”

-Arthur Kleinman, *The Illness Narratives*

Abstract

Anthropologists believe that patients can emotionally recover from illness-related events when they write about them in a causally and temporally coherent story, also known as an “illness narrative.” By constructing this account and sharing it with others, patients gain the empathy of a “listening community” and often learn to respond differently to similar events in the future. Over seven months, I compiled an extensive literature review on general and illness narrative theory and then used this information to co-construct a video-based illness narrative with Dawn, a 19-year-old Type I diabetic.

Acknowledgements

I worked with several people over the past seven months whose overwhelming generosity, advice, and general enthusiasm not only made this project a success, but also made this experience as a whole very enjoyable.

I would like to thank the following people for their encouragement and contributions:

- Professor Lorraine Higgins, my advisor, for her support, patience, and academic advice both as my major and project advisor
- Alyssa Bisson, my sister, for taking time away from her nursing studies to discuss a topic that is so personal, so difficult to talk about—her illness—and for opening up and sharing that experience with others—but also, for inspiring me every day to dream and live beyond my limitations. You are truly my hero.
- Talene O'Brien, Katharine Winner, Becky Damon, Hannah Dubois, and Andrea Fine, my sister's good friends from school, for all of your help and support to both me and my sister throughout the production of her video illness narrative. I cannot express to you in words how much your generosity, kindness, and acceptance has meant to me.
- Jim Monaco of the WPI ATC, for helping me with all of the many, many technical problems I encountered with video editing.

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Introduction

As scientists improve screening and diagnostic technology in medicine, some physicians may be inclined to rely on less face-to-face doctor-patient communication to diagnose or treat a patient's illness. Diagnosing a patient based on a list of symptoms and a series of tests may seem faster and more efficient than relying on a patient's account of the illness. However, anthropologists have found that poor doctor patient communication may cause patients to feel unfulfilled because they feel doctors ignore the story of their illness, or their "illness narrative." Although technology offers quantifiable data, doctors must communicate effectively with their patients to deliver satisfactory care.

According to illness narratologist, Elliot Mishler, for over thirty years anthropologists have urged doctors to consult a patient's "illness narrative." Illness narratives are oral or written coherent stories of illness experiences that are authored by the patient or others around him. When a doctor allows a patient to share and develop his story, both parties increase their understanding of what has happened to the patient and their role in the patient's illness experience.

But more than just improving the doctor-patient relationship, illness narratives can benefit patients themselves. Patients can carry on emotionally when they tell their stories because they build coherence between illness-related events and identify the cause-and-effect relationships that connect them. I have chosen to focus on this application of illness narrative in this project.

Although anthropologists have compiled research to support doctor and patient use of illness narrative, these narratives have yet to gain popularity within the medical world. Many doctors resist illness narratives because they learn a clinical philosophy that promotes "elitism" in medical school and teaches them to separate a patient's personal life from his medical record; as a result, some doctors consider patient narratives inappropriate for doctor-patient discussion. If

only clinicians realized that co-constructing an illness narrative with a patient benefits the patient and the doctor and sometimes the overall level of patient care, then perhaps they would accept them within the medical world. Additionally, people might consider writing illness narratives outside of the medical encounter to communicate better with loved ones and make meaning out of traumatic experiences.

As a double-major in Professional Writing and Biology, I initially became interested in illness narratives because they bring together knowledge from both fields; moreover, constructing one would give me an informative, yet creative project. Perhaps, more importantly though, I was driven by my sister's struggle with Diabetes Type I since the age of twelve and epilepsy since the age of 15, to become involved with biology in the first place, and it continues to fuel my passion for the field and the hope that it offers today. I wanted to tell her story.

I began this project by developing a foundation of research in illness narrative theory through exploring medical and health communication journals and conducting other internet and library searches. Although I initially gathered literature that described and supported illness narrative use, in order to understand how people benefit from story-telling in general, I temporarily refocused my research to general narrative theory.

I found several books and articles on narratology and incorporated them into my research. Once I had researched and developed a section on narrative theory, I applied this particularly to "illness narrative." Over four months, I had compiled enough research to write an extensive literature review on written illness narrative which explored the types, the benefits and the critiques of patient-written illness narratives.

While I constructed this review, my adviser and I questioned how and if a *video* illness narrative could help a patient to redefine meaning in his life after crisis and how and whether those close to a patient might benefit after seeing her story. According to rhetorician W.J.T. Mitchell, multimodal platforms, like video, more intensely engage an audience than purely print platforms, because people form stronger associations through visual representations. In order to build upon previous research on written illness narrative research, I decided to investigate the benefits of a video illness narrative by developing a methodology based on several previous written illness narrative studies and one video illness narrative study. I wanted to determine how a video illness narrative might alter a patient's interpretation of his illness experience, how a video illness narrative might affect a patient's "listening community," what obstacles might one encounter during the process of constructing a video illness narrative, and whether a video illness narrative could benefit a patient.

Over a two-week period, I visited my sister, a 19-year-old Type 1 Diabetic, three times to collect her explanatory model of her illness and to guide her through the process of drafting her story and then embellishing and revising it in video format. Throughout this applied portion of my project, Dawn and I kept separate journals to record the benefits, obstacles, and resources that we encountered during the process of creating a video illness narrative. See Appendix G and Appendix H for records of my journal entries and Dawn's journal entries. We used Adobe Premiere Pro to tell her story. See Appendix B for full specifications of this editing software. I also collected information on how creating a video illness narrative affected Dawn's initial interpretation of her illness experience and how the views of her "listening community"—her mother and a friend might have changed after watching her video narrative.

In this report, I review the literature on general narrative and illness narrative theory, detail my method of constructing the video and studying its impact, and I report on what I learned in the process. I have also attached a copy of the video's rough cut.

I hope that people who view Dawn's video illness narrative realize the potential of having patients tell their story—through writing or film. Videos like this might help patients develop understanding of their illness and its effects, their role in managing it, and what they might do as they struggle with it. It also might develop empathy for the daily struggles that diabetics endure. Potentially such narratives, if distributed widely, might rally for additional diabetic funding and research in a time when scientists are so close to finding a cure.

Narrative Theory

Narrative is an Important Part of Being Human

Narratologist, Roland Barthes, states that first and foremost, narrative is a human activity. From the advent of mankind, narrative pervaded society in the form of drawings, dance and oral stories (Barthes). Humans assign meaning to everyday life events in order to sort through and learn from confusing events. People connect advantageous and detrimental events together in meaningful ways in their life narrative. By presenting life events through narrative, we can remember, reflect on and accept what has happened to us.

What is narrative?

Anthropologists define narrative as a recollection of events bound by an underlying or collaborative meaning (Bruner). Scholars discovered evidence of visual and oral narrative before the invention of a linguistic system. In fact, Bruner claims that narrative belongs to different specific genres, such as theatre, painting, prose, or dance (Bruner, 14).

Anthropologists vary in their detailed narrative definitions, but here I will consider the basic requirements of narrative. First, all narratives require some kind of change in the central character and second, the change of state must be revealed through time and logical connections—it must make sense to others.

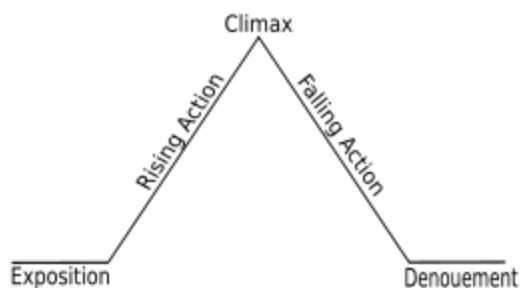
German narratologist, Wolf Schmid, believes that narrative must contain at least one “change of state” that connects a character’s beginning and end state through temporal and causal coherence (Schmid). Williams claims, like Bruner, that temporal coherence refers to events that proceed in a way that maintains narrative meaning, but isn’t necessarily chronological; whereas causal coherence refers to the cause-and-effect reasoning between successive events (Williams).

Bruner further explains why temporal coherence doesn't simply mean chronological events; it would prevent important narrative events like flashbacks and flash-forwards, "William Labov, one of the greatest students of narrative, also regards temporal sequence as essential to narrative, but he locates this temporality in the meaning-preserving sequence of clauses in narrative discourse itself... For there are many conventions for expressing the sequence durativity of narrative even in discourse, like flashbacks and flash-forwards, temporal synecdoche, and so on" (Bruner, 6). For example, if a character is fervently pro-life, the narrative might flash years back to her emotionally-draining miscarriage; this would add another dimension to the narrative meaning.

Causal coherence is disrupted if improbable events occur. Causal coherence is interrupted when a character acts against his "intentional state," or his beliefs, values and experiences (Bruner, 7). Bruner states that a story retains "narrative truth" based on the plausibility of events that occur within the narrative world (Bruner, 13).

Traditional Structure of Narrative Plot

Traditionally, basic narrative plot begins with exposition, leads into rising action, reaches the



story's peak at the climax, and then relents into falling action and the conclusion. Each feature of this basic structure functions differently in a narrative plot. Although an element of plot structure might dominate over others, a trace of each portion

Figure 1: Basic Outline of a Narrative Plot or Storyline

http://1.bp.blogspot.com/_jmFY0F1bHnY/Sj952BoDxqI/AAAAAAAAAJ0/6F_y3BfyB_E/s400/800px-Freytags_pyramid.svg.png

can be found in every traditional narrative. For example, it a story can be primarily composed of

rising action, that builds and builds throughout the course of the narrative until it reaches the climax, and then relents into very little falling action before quickly rushing through to the conclusion. The basic structure outline of a plot is illustrated in Figure 1 (A. Charters and S. Charters).

The Exposition, or Setting of a Story

A story's exposition develops setting details like information about past events or present circumstances that allow a reader to comprehend a story's plot and narrative meaning. Few events occur in the exposition and those that do provide a background for subsequent events.

Rising Action

Narrative exposition leads into a succession of events, the "rising action," where one event leads into another to form a causally coherent timeline. Each event exacerbates the next, until the sequence culminates into the story's climax.

Climax

Rising action events build upon each other until they reach a certain threshold, and the plot's climax, or the plot's most significant conflict, unfolds. Bruner claims that conflict occurs through a "breach of canonicity," and therefore gives a piece its purpose. He claims that, "not every sequence of events recounted constitutes a narrative, even when it is diachronic, particular, and organized around intentional states. Some happenings do not warrant telling about and accounts of them are said to be 'pointless'" (Bruner, 11). For example, cookbooks and product directions are certainly useful, but do not form narrative because there is no breach of canonicity. Readers invest a great deal of emotion into a plot's climax because it is the major turning point in a narrative; they are brought back down from the whirlwind of activity in the falling action.

Falling Action

Readers recover from a plot's climax as characters enter the "falling action." These sequential events equilibrate a plot's action as the plot reaches its conclusion, or resolution of the story.

Oftentimes, the falling action involves a character making amends or fixing problems that arose during the plot's climax.

Patients get caught up in the conflict of their illness, and they need some way to enter the falling action, so they can cope with their disease and find resolution.

Conclusion

The conclusion of a story ties all narrative events together with collective meaning to provide closure for the characters and reader. However, a story's conclusion doesn't necessarily have to be happy, although many are; an ending must only fully develop the narrative's meaning and purpose.

Narrative Plots

Literary critic, Christopher Booker, named seven basic plot-themes that can categorize every storyline ever written. Booker names the seven plots—"overcoming the monster," "rags to riches," "the quest," "voyage and return," "comedy," "tragedy," "and "rebirth"—and divides each into five stages.

1. Overcoming the Monster

The Overcoming the Monster plot follows a hero who confronts a fearsome monster that threatens a community and slays him, against all odds. In the first stage, the hero hears of the monster's existence through word of mouth or media. The monster destroys and threatens the community until the hero receives "the call" to travel and destroy the beast (Booker, 48). After the ready and determined hero receives "the call," he prepares for his

journey by collecting items and advice from others. After the hero prepares for battle, he confronts the monster at his lair and realizes that defeating the monster will be more difficult than he originally anticipated. As the battle begins, the monster dominates over the hero and proves his strength until it seems the hero will fail. When the plot enters the “Nightmare Stage,” the hero seems to be within the grasp of death. At the last second, he gains the upper hand and triggers a dramatic reversal of events (Booker). Against all odds, the hero makes his “thrilling escape from death” by slaying the monster. The hero returns to the community to share the good news and is rewarded with a prize or the hand of a “Princess” in marriage (Booker, 49).

2. Rags to Riches

The hero in Rags to Riches usually begins as a lowly character, unnoticed by others. Oftentimes, self-indulged dark figures that are both older than the hero and the hero’s age, prevent the hero from realizing his potential for greatness. The dark figures make the hero’s situation worse by teasing him and taking advantage of his unfortunate state. The hero is relieved when he receives “call” to the outside world and can temporarily escape his home life. When the hero first ventures into the outside world, he succeeds at any task he befalls. The hero is devastated when he must return to his former life. The “dark figures” return in full-force to make the hero miserable by negating any happiness he found in the outside world. The hero meets his “central crisis” and nearly relinquishes to his former life. When the hero enters the “Independence and Final Ordeal” stage, he unexpectedly gets caught up in a series of events that reveal his inner qualities and potential. The revitalized hero confronts the dark figures and leaves victorious, free from his previously destitute life. The hero often meets his/her “Prince” or Princess,” receives

treasure, or even rights to a kingdom. Most importantly, the hero discovers their true self, their “perfect self,” and who they always could have been (Booker, 66).

3. The Quest

Booker’s Quest plot begins with a hero beckoned embark on an arduous journey that promises self-renewal or self-discovery. After the hero prepares for his journey, he departs from his community. On his way to self-renewal, the hero is tested by obstacles, monsters, and temptations. Against all odds, the hero conquers each task that is set before him and eventually sees his goal or destination in the distance. Before he can reach his destination, he confronts and defeats a final set of obstacles, nearly meeting his demise. The hero returns to his community, as a “new self,” and is often rewarded with treasure or rights to the kingdom. Upon return, the hero shares tales of his journey and what he learned along the way (Booker).

Illness narratologist, Arthur Frank, adapts the Quest plot for illness experiences by expanding it to include the physical and emotional journeys of patients. Frank, like Booker, encourages patients to share what they have learned with others, “The quest narrative tells self-consciously of being transformed; undergoing transformation is a significant dimension of the storyteller’s responsibility” (Frank, *Wounded Storyteller* 118).

4. Voyage and Return

Voyage and Return” begins with a hero that is pre-dispositioned for a journey because he is bored of his current environment, curious about other environments, or other reasons. When the hero enters the new world, he is amazed by its opportunities and differences,

but keeps a place in his heart for “home.” Unfortunately, the new world loses its appeal when the hero encounters its challenges and trials. A cloud of darkness sweeps over the new world, no longer bright and friendly, and nearly consumes and destroys the hero. The hero narrowly escapes his enemy or problems by returning to his old world, his “home.” When the hero returns home he shares what he has learned and how he has changed, if he has learned anything or changed at all (Booker).

5. Comedy

Booker defines the Comedy plot broadly because it encompasses a variety of different stories and divides it into four stages (Booker).

At the beginning of a “Classical comedy,” character misunderstandings cause mass confusion within a community. As a result, the characters ignore each other and prevent others from seeing their true identities which increases tension within the community.

The story’s antagonist takes advantage of the chaos by furthering it for his own benefit and preventing the hero and heroine from coming together (Booker).

The confusion heightens into a “nightmarish tangle” and tests the true identities of community members. When the true identity of the story’s antagonist is unveiled, the community, particularly the hero and heroine, can realize they are meant to be together and are left well and happy (Booker).

6. Tragedy

The “Tragedy” plot opens with an unsatisfied hero in pursuit of an object he believes will bring him happiness. The hero initially progresses quickly towards his object of pursuit.

Unfortunately, things soon turn bad and the hero makes a deal with a “shadow figure,” because he believes it is the only way to achieve his goal. Not surprisingly, the hero meets his demise when his evil agreement backfires on him and everything he had achieved is gradually destroyed (Booker).

7. Rebirth

In the “Rebirth” plot, the hero is trapped within a shadow of unhappiness and darkness. Eventually, the hero meets another character or encounters a turn of events that improve his situation to the point it seems he might escape the “dark cloud” (Booker).

All hope of redemption is shattered when the darkness returns in full-force and forces the hero into a dark reclusion. The hero nearly succumbs to his trouble but forces himself to continue by barely tolerating his surroundings. After what seems like forever, the heroine rescues the hero (or vice versa) and they live on peacefully in a newfound state of happiness (Booker).

The Ideal Plot

Although many narratives follow the same plot-theme, they are made unique by Bruner’s “particulars,” such as setting, characters, and objects (Bruner, 6).

Narratologist, N. J. Lowe, established that an ideal plot must execute “transparency,”

“economy,” and “amplitude” effectively (Lowe).

Economy

Every piece of information or action in a classical plot somehow effects its development. When readers find out that a character doesn’t like blue, the character’s subsequent actions are

perceived differently, even if only in the slightest. Lowe explains that the “function” of each information piece increases based on how much it affects the plot. “Economy” refers to a piece’s function-to-content ratio. Narratologists argue that ideal plots have very high function-to-content ratios, or are very “economic” (Lowe).

Perhaps, economic plots are so effective because they are structured similarly to the way that we store memories. According to Hampl, we only remember images and events that are important, even if we don’t immediately know why we considered them worth remembering (Hampl).

Narrative is more powerful when each piece has a function, and so is memory because each event is remembered for its importance.

Amplitude

Every plot contains minimally consequential events and events of greater consequence, known as “moves.” The “amplitude” of a plot refers to its number of moves: the type of genre of the piece, the density of the narrative, and the actual moves themselves. Lowe claims that the ideal plot contains the greatest amount of moves possible without clouding or confusing meaning (Lowe).

The genre of a piece often dictates the maximum number of moves its plot can contain. For example, a novel can feature an almost infinite number of moves, if the author lengthens its plotline. However, a film is limited by a general running time and forces the director to cut superfluous moves that obscure the plot’s meaning (Lowe).

Narrative density relates a plot’s speed to its number of moves. If the narrative is very fast-paced then it can include several more moves than a narrative that is advancing slowly. Plot amplitude measures the number of comprehensible moves and the cognitive capacity a reader must use to understand them (Lowe).

Transparency

The ideal plot is believable. Lowe argues that an author must eliminate any trace the way the story was constructed within the narrative to fully immerse his reader in the “narrative world.” For example, films are less powerful if the equipment used to create them can be seen because they prevent the audience from fully immersing in the film’s narrative world. All events or “moves,” must be triggered by probable causation so they are likely to occur in the “narrative world,” in quite the same way certain events are likely to follow others in reality. When authors use words that refer to the reader or the author, readers are reminded that what they are reading did not actually happen and a reader’s ability to merge his own reality with that of the narrative is reduced (Lowe).

Illness Narrative

The “illness narrative,” an application of general narrative, temporally and causally ties together a series of illness-related events. Freshwater and Holloway assert that temporal and causal coherence allow patients to reflect on past, present, and future events in illness narratives, which encourages a patient’s recovery, but patients aren’t the only authors of such narratives and others may benefit as well (Freshwater and Holloway).

Here I consider point of view in the three main types of illness narratives—oral, written and visual.

Oral Illness Narrative

Clark and Mishler establish oral illness narrative as the informal sharing of personal or patient stories through conversation (Clark and Mishler). People tell these narratives through casual interactions in several different environments. This type of illness narrative is further classified. Patients can discuss events with their doctors or their family and close friends, doctors can share patient stories with other doctors, and ill people can empathize with fellow-sufferers at support groups.

First, some clinicians encourage patients to share illness through oral narrative (Clark and Mishler). Some doctors allow patients to form their own recollections of events rather than using the traditional Question-and-Answer interview. Moreover, patients can explain illness-related occurrence or symptom with friends or family through informal, daily discourse to seek empathy from those they are closest to. Though the medical world, as a whole, refuses to endorse illness narrative as a standard tool for the doctor-patient interview, Cheryl Mattingly discovered that clinicians naturally use illness narrative in casual discourse with other professionals in the work setting. Clinicians often discuss patient experiences with each other and suggest treatment plans

that would better suit a patient's lifestyle. Interestingly, clinicians incorporate personal patient characteristics and facts about patient home-life to form an accurate diagnosis (Mattingly).

Finally, support groups provide platforms which elicit patient-sharing of illness narratives as a coping mechanism. Members share stories to develop a deeper empathy with others that have experienced similar situations. Each person retells an illness experience and allows others in the support to react and build off of that story to share their own.

Written Illness Narrative

Some patients prefer to write illness narratives because they can actively refer back to and alter them according to personal change over time and through experience. Patients can transcribe their narrative in a diary format or as a collective reflection years after the illness experience. They use these for self-recovery and to share these personal reflections with loved-ones to gain physical and emotional understanding from those they are close to. When writers publish these accounts, they allow others to relate to and learn from the writer's recollection.

For example, in the book, *What Happened to You?* edited by Lois Keith, disabled women share illness narratives about their own experiences. Each short illness narrative is written by a different woman with a different struggle, ranging from cancer to mental illness. Keith, who has also experienced illness, explains that the book is intended for her self-recovery and for any woman who has struggled in life. When the book was written, she was dealing with a physical disability herself and felt that she might be comforted by reading the illness narratives of women that "share many of the same experiences of exclusion and prejudice because of the barriers we all faced" (Keith, 5). Soon though, Keith discovered that the book wasn't only for her, but for all woman who realize "how fragile our grasp of independence can be and how we have to fight to define it for ourselves; how difficult things can be for those of us who are not 5 feet 6 inches tall,

thin and blonde, with complete working parts; how tough and isolating it is to live with pain or illness; how easy it is for us to accept other people's view of ourselves as second-class citizens, and why we must fight to reject such definitions" (Keith, 5). *What Happened to You?* exemplifies an illness narrative written by the patient, or patients in this case, to be published for himself, others, or both.

Nurses and other health practitioners also write illness narratives. Christensen and Egerod have researched illness narratives written by a clinician or family member for a patient. Usually clinicians or family members write a narrative for the patient when he is too ill to witness or record the events himself. Patients can later use these recollections to create coherent narrative between events they might otherwise have not remembered.

Narratologists and other researchers, like Migliore, listen to patients orally recount illness experiences and record the dialogue as they speak, providing prompts when necessary to foster a naturally-flowing discourse. Sometimes the researcher will search the narrative for subconscious patient motives or masked emotions to identify a misdiagnosis and assign a more appropriate treatment plan (Migliore).

Writers, reporters, and those more distant from the doctor-patient relationship, can also write fictional or non-fictional illness narratives. *The Spirit Catches You and You Fall Down*, written by Anne Fadiman, exemplifies this in an illness narrative about a young epileptic Hmong girl, Lia Lee. Fadiman records the Lee family's struggle with the disease and refusal to comply with American treatment for cultural reasons (Fadiman).

Visual Illness Narrative

Although visual illness narratives have not received much attention, mediums like film and photographs might foster a stronger path to recovery. Since the proliferation of technology, new media forms have shaped the American definition of literacy, making it difficult for those unfamiliar with film and computers to progress in society. According to Selfe and Hawisher, today's generation forms life meaning "not only with words, but also with digitized bits of video, sound, photographs, still images,...and animations" because they grew up with new media forms as a commonplace way to communicate with others (Selfe and Hawisher, 183). Therefore, visual illness narrative might be especially helpful for young people who have known how to use technology, like film, their whole lives.

Film provides a multimodal medium that immerses an audience because it contains audio and visual elements which stimulate two sensory systems—sound and sight (Benjamin). Patients could use film and photography to document the before and after states of illness to compare where they were physically and possibly emotionally in the midst of illness, and where they are now, free or recovering from illness. They might also benefit from sharing their visual illness narratives with others in order to bring them into their illness experiences.

Anthropologists agree that pictures are much more powerful than written or oral communication. People are affected by pictures because we carry with us the aura and characteristics of the real-life objects or people pictured, with their replicated presence. As a result, pictures often change the way a person thinks about an event or emotion; W.J.T Mitchell believes that, "Images are not just passive entities that coexist with their human hosts, any more than the microorganisms that dwell in our intestines. They change the way we think and see and dream. They refunction our memories and imaginations bringing new criteria and new desires into the world" (W.J.T.

Mitchell, 92). Patients could capitalize on this power by creating a visual illness narrative that positively reshapes their memory of and change the values they associate with traumatic events. Pictures are also powerful because the direct representation of events through visual information evokes intense emotions in viewers, which cannot be accomplished orally or by written form. People commonly apply words like, “love and hate, affection and fear, forms of overestimation such as worship, adoration, and veneration and of devaluation or underestimation—horror, disgust, abomination...” to pictures that they like or are disgusted with, but much less often use the same extremity of words to describe a written piece (W.J.T. Mitchell, 93).

Patients could also benefit from visual illness narrative by using the natural meaning of pictures to assign illness-related meaning to their own photographs or film segments. People actively assign meaning to pictures by choosing which to keep or reproduce and which to destroy (W.J.T. Mitchell). When patients create their own visual illness narrative, they decide which photographs or segments are integral to the meaning of their illness-related experiences and make sense in their life narrative. As a result, patients might find visual illness narrative easily more meaningful because each picture harbors personal meaning because they have chosen each individually.

Medical school teachers have used visual media in the classroom since the 1970s, by incorporating instructional videos in interpersonal skills courses (IPS) (Cohen et al.). However, according to Bruner, many instructional videos aren't actually narratives at all because there is no breach of canonicity.

Although the use of visual illness narrative hasn't been discussed as much as oral and written illness narrative, it has existed in society since the birth of photography and film through TV shows and movies. Many TV shows already use video illness narrative to raise awareness for

particular diseases or life-problems and to develop public empathy for the ill. One popular show, “True Life,” follows the lives of a few individuals that have a certain disease to show viewers how the disease affects a person’s daily life. In the episode, “True Life: I Have Obsessive Compulsive Disorder,” True Life follows three young adults affected by different forms of OCD to show problems in their daily life and the path they take to try and cure these problems (True Life). As a result, each story forms its own narrative, by beginning with a set of problems at the show’s beginning and attempting to reach some sort of resolution at the end.

Likewise, several movies also use video illness narrative to show fictional or non-fictional stories about a person’s struggle with illness and how it has affected his life and the lives of those close to him. Famous examples of movie illness narratives are Steel Magnolias, which follows the life of a Type I Diabetic who dies during the birth of her second child, and A Beautiful Mind, which follows the life of the brilliant economist John Nash, who battles schizophrenia with the help of his wife through a life-long emotionally-draining struggle and wins the Nobel Prize in Economics in 1994.

Purposes of Illness Narratives

As suggested above, these different forms of illness narratives can serve different purposes.

Below, I discuss four ways that people benefit from forming illness narratives.

1. To improve communication between doctor and patient

Narratologists began to promote illness narratives for patient-therapy to doctors twenty-five to thirty years ago. Over the years, Kleinman has urged doctors to consider using anthropologically-based narrative tools, but most doctors still don’t seriously consider a patient’s narrative when they assign treatment plans or communicate with a patient (Kleinman, Medical Anthropology) (Mishler, Patient Stories). Rather, Clark and Mishler claim that the current

doctor/patient conversation is structured to start with a physician’s question, and is followed by a patient response. The patient often tries to respond by framing his answer with circumstantial details, which doctors see as non-relevant, to create a coherent narrative of his experience. Unfortunately, the doctor usually interrupts his patient with his next question (Clark and Mishler).

Doctors learn to downplay the personal life or emotions of a patient early on, even though doctor/patient protocol prompts them to emphasize a patient’s social history or demographic information. Up until recently, medical students were taught to diagnosis a patient based on his concrete symptoms, the quantifiable “data,” and to disregard the mental and emotional aspects of a patient because they are unreliable and lack methodology. In the medical field, they took these lessons with them. Doctors identified, and perhaps still identify, a patient based on their symptoms; doctors viewed their patients as specimens, problems that need to be solved—an answer that is yet to be found (Clark and Mishler).

Even though doctor/patient empathy has been given more attention since the 1970’s, research still shows that many physicians cannot gauge patient emotion and satisfaction. Hall et al. sent out 261 questionnaires to diabetic patients asking about the quality and outcome of a recent office visit. Doctors were able to predict patient emotion, but often severely underestimated the satisfaction of their patients. Although this suggests that doctors are not ignoring patient dissatisfaction, they may be responding to patients in ways that foster a negative atmosphere (Hall et al.).

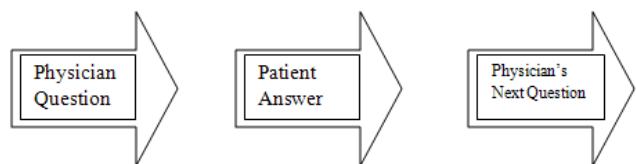


Figure 2: Flow chart of typical structure of doctor/patient discourse

Skultans argues that ineffective doctor/patient discourse partially causes unsubstantial doctor empathy (Skultans). Doctors begin to distance themselves emotionally from the patient as soon as they begin the diagnosis. Mishler claims that the format of “Question and Answer” interviewing within the medical field is an abnormal form of discourse because it is distinctly different from natural discourse that people use to create coherence through narrative. As a result, doctors are unable to use the natural context of everyday discourse to infer what life events may be related to patient symptoms. If a doctor uses the “Question-and-Answer” styled interview, he must fill in the gaps between questions because they lack natural context, “Question and answer settings are stripped of their natural social context and thus the researcher must be able to ‘fill in the missing pieces,’ or what would have been said in conversation” (Mishler, Research Interviewing 3). Doctors often make inaccurate cultural assumptions and incorrectly fill in natural context, because they are not trained in anthropology (Mishler, Research Interviewing).

Frank also criticizes the “Question and Answer” format because it deprives the patient of control over his illness. Doctors are allowed to control what questions are asked and when an answer is sufficient, preventing patients from deciding what topics are discussed and for how long (Frank, Standpoint of Storyteller).

Although many patients still complain about poor doctor/patient communication, clinicians and medical schools have responded to the “direct concerns of medical academicians” by incorporating interpersonal and communication skills courses into medical school curriculums since 1977 (Cohen et al., 30). Duffy et al. defined these communication skills as, “specific tasks and observable behaviors that can include interviewing to obtain a medical history, explaining a diagnosis and prognosis, giving therapeutic procedures, and providing counseling to motivate

participation in therapy or to relieve symptoms” (Duffy et al., 497). They also defined interpersonal skills as skills that “focus on the effect of communication on another person” (Duffy et al., 497).

Shortly after anthropologists began to circulate illness narrative use, in 1977, Cohen et al. evaluated the Communication and Interpersonal Skills medical school courses offered at the pre-clinical and clinical level. Cohen et al. sent out self-reply postcards and two follow-up questionnaires to 79 medical schools which assessed the number, content, teaching staff, and teaching methods of IPS courses offered. Cohen et al. found that only 80% of programs at least one IPS course and these schools offered an average of 2.5 courses, 90% of which utilized video technology. Despite its multimodal advantages, video technology was likely only used to show standardized videos and prevented students from role-playing or actually interacting with patients. They also found that the inclusion of IPS courses was relatively new, as 40% of the programs were less than five years old, indicating that before 1975, “most medical students... had little or no explicit training in this area beyond that which may have been offered in psychiatry clerkships or part of physical diagnosis courses” (Cohen et al., 34). Interestingly, the majority of the courses were taught by psychiatrists, then physicians and then psychologists. Cohen et al. believed that a more diverse teaching staff would improve the quality of IPS courses (Cohen et al.).

Although these findings signify substantial improvement and growth of the use of narratives in medical education over past years, none of the courses included lessons on information-giving/counseling skills and patient education. Even if these schools did discuss these topics, none of the instructors or medical schools had a way to directly evaluate a student’s proficiency

in interpersonal or communication skills and most IPS courses only followed students through the preclinical years (Cohen et al.).

In 1991, Drossman et al. conducted a follow-up study to assess progress in IPS course offerings and education since 1977 and found that the quality of IPS courses had improved substantially. Many of the IPS courses were taught by staff with diverse backgrounds and included role-playing or simulated patients to practice doctor/patient communication with and support groups designed to increase doctor empathy were made available at the medical schools.

As of 2004, medical schools had improved their IPS programs and were offering better resources to medical students. The “Accreditation Council for Graduate Medical Education” (ACGME) now will only accredit medical schools that include interpersonal and communication skills courses that assess a student’s proficiency. In addition, the “American Board of Medical Specialties” (ABMS) which a student must pass to become a doctor includes a section on IPS and communication skills (Duffy et al.).

Today, some medical school teachers, like Rita Charon, have experimented with other techniques to teach their students how to effectively communicate with their patients. Mishler speaks highly of the course: “Rita Charon offers a course to medical students in which she asks them to keep a ‘parallel chart’ on their patients where they can write about ‘aspects of the patient or the illness that are critical to recognize for effective care but that do not belong in the hospital chart” (Mishler, Patient Stories 443).

Recently, Rita Charon and Sayantani DasGupta offered another medical school course in which medical students write their own illness narratives to heighten their empathy for patients. Charon and DasGupta designed the curriculum to fit their three-part definition of empathy, “a cognitive

component in which the clinician enters the perspective of the patient, an emotional component in which the clinician puts himself or herself in the place of the patient, and finally, an action component in which the clinician communicates understanding by checking back with the patient” (Charon and DasGupta, 351). Throughout the semester-long course, students were expected to write an illness narrative about a personal illness experience. Students shared their narrative with the class each week, and returned home to reflect and rewrite the narrative in different genres.

Charon and DasGupta observed that by focusing on the students’ own bodily experiences, students developed a deeper empathy and decreased the doctor dissociation between body and mind typical of the medical world. Anthropologists believe that students can improve doctor/patient communication by identifying how their own backgrounds affect their interactions with others.

Although all medical schools must now include IPS and communication skills courses, anthropologists still observe a decline in student empathy in the later years of medical school. Erdmann et al. claim that the, “Jefferson Scale of Physician Empathy” (JSPE) test, which can quantify a doctor’s sense of empathy by asking respondents twenty questions that they must answer on a seven-point scale. By distributing the test to 125 medical students during Year 1 and then during Year 3 of medical school, Erdmann et al. discovered in difference in student empathy over time (Erdmann et al.).

Robert Klitzman, an associate professor at Columbia University, discovered that seriously ill doctors who had “become” patients themselves might be able to suggest the best techniques for teaching empathy to medical students. Klitzman interviewed forty-eight doctors, a dentist and a

medical student who were all very sick, to ask them whether empathy could actually be taught in medical school, and if it could, how. Several participants claimed that students could only learn empathy by spending a night as a simulated patient in a hospital to witness a patient's, "helplessness, loss of power over one's very body and life, confusion, and confrontation with the unknown" (Klitzman, 448). Unfortunately, a few doctors concluded that empathy cannot be taught, but only achieved through actually being sick oneself. If we consider the actual definition of empathy, to know what another is feeling or going through, it makes sense that a person might only achieve this through experience. However, some hopeful doctors believed that although students cannot be taught empathy from textbook, they might be able to learn through extensive role-playing. Klitzman suggests that doctor empathy might be taught through, "charting at the bedside instead of after leaving a patient, asking patients if they had any questions at the end of interactions, acknowledging having kept patients waiting, and increasing awareness of nonverbal interactions" (Klitzman, 451). Educators should heed this advice as it comes from the most knowledgeable source on patient-care, doctors who have become patients (Klitzman).

Frank also argues that doctors can build a stronger bond and trust with their patients through the use of narrative because it allows the doctor and patient to build upon the personal aspects of the patient's life. Not only does the doctor assign a personality to a list of symptoms, but the patient also begins to see the doctor as a person, rather than a dominating and fearful figure. As trust builds between doctor and patient, Frank suggests that the tension so typical of the clinical atmosphere may subside (Frank, *Standpoint of Storyteller*).

Furthermore, Frank believes that narratives might indirectly improve a patient's health by reducing the percent of misdiagnoses (Frank, *Standpoint of Storyteller*). Drossman et al. forward Frank's point and agree that, "The accuracy of diagnoses and the establishment of therapeutic

physician-patient relationships depend on effective communication within the medical interview” (Drossman et al., 2101). As patients recite their narrative, patients mention routine tasks that doctors could potentially identify as an underlying cause of their illness and spark a doctor to rediagnose a patient. Frank cites one example where a clinician diagnosed a patient as mentally retarded, and then retracted that diagnosis as the family developed their narrative. The clinician later diagnosed the patient with complications due to a head injury (Frank, *Standpoint of Storyteller*).

More than this though, Frank claims that illness narratives will improve treatment plans by teaching doctors why patients seem uncooperative or don’t think treatment is important. Doctors can realize through narrative what patient life aspects prevent him from following his treatment plan. Rather than simply labeling this patient, “difficult,” the doctor can formulate treatment plan better suited to the patient (Frank, *How can they?*). Mishler recalls several occasions where doctors have labeled patients as difficult without considering a patient’s reasons for refusing healthcare, such as the inability to pay for it (Mishler, *Patient Stories*).

Sam Migliore studied the use of the folk illness term, “nirbusu,” within a community of Sicilian-Canadians by writing illness narratives for Sicilian-Canadian patients. Although “nirbusu” directly translates to English as, “nerves,” the term can be translated several different ways in Sicilian-Canadian communities. Migliore discovered that members of this community used “nirbusu” to describe anything from the physical “nerves” within the body to a feeling of emotional distress brought upon by upsetting events. When doctors examine a patient’s narrative, they pick up on hidden motives that differentiate between a patient’s representation of his symptoms and his actual condition (Migliore).

Clark and Mishler proved that illness narratives can improve doctor/patient communication by video-taping the interactions of two different residents with their respective patients—one a Black male epileptic, and the other a Black female diabetic—to reevaluate treatment that was not suitable for either patient. The first patient, the man with epilepsy, is treated by a resident who allows his patient to control their discourse. The second patient is treated by a resident who grants her very little power or control over doctor/patient communication. The Black male and his resident coauthor a coherent narrative that improves the patient's understanding of his condition and new treatment plan. In contrast, the second resident interrupts his patient several times if he doesn't feel his patient's extra details pertain to his question. As a result, the resident fragments his patient's recollection of her illness experience, preventing her from forming a narrative. The second resident fails to acknowledge his patient's struggle to control a chronic illness or offer his patient empathy (Clark and Mishler).

So, who should be the first to initiate this narrative-based interaction? According to Frank, it should be the doctors. The more dominating figure, the doctor, must initiate narrative formation because he is in the more powerful position. When doctors decide that outstanding patient care is worth ceding authority, doctor/patient communication will become more effective. (Frank 2002) Doctors must begin by prompting narrative discourse with his patient and allowing the patient to tell their story free of interruption (Frank, Standpoint of Storyteller).

Certainly, the largest obstacle, as Mishler states, is convincing doctors to “interrupt the ‘voice of medicine’ and give priority to the ‘voice of the lifeworld’” (Mishler, Patient Stories 437).

2. Helping the patient cope with the illness and crisis and redefine meaning in their life

In addition to improving doctor-patient communication, narrative can help patients to make sense of traumatic events in their life by building coherence between them. Anthropologists

claim that the use of illness narratives may also improve a patient's ability to cope with his disease. Migliore explains that a person constructs his version of reality by naturally assigning meaning to everyday events that would otherwise seem random and insignificant. Williams states that people link separate events through meaning to make sense of life and what has happened to them. Detrimental events can disrupt a person's vision of reality, making it difficult for that person to process the influx of events and continue emotionally (Williams). Events like battling cancer or losing a loved one are so emotionally-damaging that people cannot fathom why these events have come to pass or where these events fit in their life. Without meaning, a person's life-narrative is fragmented, and the people behind these fragmented narratives are distraught (Migliore).

Illness narratologists believe that illness narratives can reestablish meaning and find a place for events that have interrupted a patient's life-narrative. Williams states that when people construct a story through discourse or writing, they naturally tie their past, present and future together and gradually develop "autobiographical coherence" by incorporating detrimental experiences into their overall life narrative (Williams). Narrative helps patients cope with abrupt and drastic emotional or physical change because, as Patricia Hampl, memoirist, states, "our capacity to move forward as developing beings rests on a healthy relation with the past" (Hampl, 33) (Migliore).

Hampl points out that writers who create autobiographical narratives benefit not because they are factually true, but because they are emotionally true to the writer. Humans are unable to recall memories in detail or sequentially, but can only remember meaningful events as discrete images. People can uncover the emotional truth of an event by writing down their recollection without paying attention to whether their account is factual. After transcribing a first draft, Hampl claims

that writers must analyze how they presented the event to determine why they considered certain details as worth remembering. As writers examine their first draft, they identify an event's meaning by discovering the hidden intentions and emotions attached to it. After a person ascertains the emotional truth of an event, he then writes a second draft by fleshing out details he recognizes as non-factual and writing according to the story's true meaning. Hampl claims that this method of recording life narrative "isn't a lie, but an act of necessity, as the innate urge to locate truth always is" (Hampl, 31).

Christensen and Egerod believe that illness narratives written by health staff could be especially useful to help patients recover in an ICU unit. Patients are usually treated in the ICU after an acute, unexpected illness event and as a result, are unable to fully comprehend what has happened to them. According to Migliore, ICU patients cannot emotionally heal until they glue back together the fragments of their experience through narrative. Christensen and Egerod exemplify illness narrative use within an ICU where nurses recorded personal observations of the patient, patient treatments or conditions, guest visits, and the patient's physical and emotional health. Patients can use these written narratives to fill in memory gaps during periods of unconscious due to surgery, recovery, or acute illness. In fact, Christensen and Egerod report that some patients elected to see pictures of themselves taken during these times in order to form an even more concrete, coherent representation of their illness experience (Christensen and Egerod).

Bingley et al. claim that illness narratives are also important and widely used in many palliative and hospice care facilities. Clinicians in palliative and hospice care use narrative to help patients form a coherent story of recent events during the last days of their lives. Patients cope with the reality of death through "narrative reconstruction" of their past, present and what is to become of them by choosing when, if at all, they wish to write their narrative, and what they wish to write

about. Palliative clinicians accept illness narratives because the patient's emotional health is of primary concern since there is no diagnosis or change in treatment this late in illness. Certainly, where there is no room to improve the patient's health, doctors and therapists have the time and integrity to assist the patient with emotional troubles and are more willing to consider treatment, like illness narratives, that is not quantitative or concrete (Bingley et al.).

Frank claims that patients improve their emotional health through narrative because they gain an element of control in the clinical setting. By developing their own narrative, whether oral or written, and presenting it to doctors, patients begin to tell their own story of their illness, on a day-to-day recollection or as a reflective summary of illness-related events, years later. When patients control what topics are discussed and how much time is given to each, a patient's overall well-being also improves in addition to doctor/patient communication (Frank, Standpoint of Storyteller).

Helping the Patient Create Empathy in a “Listening Community” or in the Public at Large

Patients also use illness narrative not just to cope with their own illness but to gain the empathy of those around him. Patients share illness experiences with members of their “listening community,” or the group of people, usually from the same culture, with whom they wish to share their narrative. When an ill person shares his story with people from the same culture or upbringing, they are more likely to receive an empathetic response because they likely share the same values and morals. The support of a “listening community,” usually made up of friends and family, can be especially therapeutic to a patient when he is battling with disease (Frank, Standpoint of Storyteller).

When illness narratives are published, they are often used as a platform to gain understanding or support from the public for a particular disease. Frank states that when an author shares his narrative with an audience from his culture, the author is more likely to receive empathy and understanding because they share similar morals and values (Frank, *Rhetoric of Self-Change*).

Readers who suffer similarly or from the same illness as the author can benefit from a published illness narrative through empathy. In this sense, a published narrative functions as a type of therapy for both its author and readers. Although an author usually meets misfortune during his narrative, fellow-sufferers do not automatically assume that the same will happen to them. Frank claims that narratives are less discouraging than a doctor's diagnosis because they don't say "this will happen to you," but rather "this is what I have gone through myself, and this is what I have learned"; published illness narratives are used to inspire and comfort the similarly ill (Frank, *Rhetoric of Self-Change*).

The general public can also learn from illness narratives. Many authors write their personal stories in the hopes that all readers, not just fellow-sufferers, will read their narratives and witness the changes each author experienced. Even though the author's illness may have sparked an author's self-change, it doesn't mean that the change can only occur due to illness. For example, although illness may have prompted the author to seize the day and travel the world, so might a healthy person absorbed in his job and then fired be inspired to realize and do the same thing (Frank, *Rhetoric of Self-Change*).

Finally, and perhaps most obviously, authors publish illness narratives to gain support from the public, whether monetary or emotional. Many people who publish their illness narrative were previously published and therefore have the public voice, notoriety, and wealth to publish again.

Although there have been some well-known illness narratives published by unknown writers, it is usually easier for highly-regarded writers to write and publish their illness narrative (Bingley et al.).

Frank actually argues that it is the duty of those able to publish their illness narrative for those who suffer equally but are unable to do so themselves and upholds these people to three ethics: the Ethic of Recollection, the Ethic of Solidarity and Commitment, and the Ethic of Inspiration (Frank, Wounded Storyteller).

Frank refers to the Ethic of Recollection as, the “responsibility to recollect the past when author’s new voice is found so that the mistakes made in the past can be realized and showed to others.” Although the Ethic of Recollection can be manifested in others ways, published illness narratives make it easy to share one’s knowledge with the public. Authors share what they have learned with others in society, not just the ill, so they don’t make the same mistakes as the author (Frank, Wounded Storyteller).

Frank defines the Ethic of Solidarity and Commitment as the responsibility of ill people who have access to publication or broadcasting services to “use their voice to speak with fellow-sufferers that may not have the opportunity or talent to speak for themselves.” According to this ethic, ill people with the resources to publish must do so to comfort those who suffer from the same illness but are unable to share their story with the public (Frank, Wounded Storyteller).

Frank’s final ethic, the “Ethic of Inspiration,” states that stories of illness must “show what is possible in impossible situations to inspire humans.” This ethic demands that authors must not only share their illness narrative with fellow-sufferers, but also with society in general to show one of hope, optimism and acceptance. Authors can prove to others that even in the darkest of

moments, the human spirit can persist. Certainly, this is inspirational and it is the duty of these ill people to share this journey with others (Frank, *Wounded Storyteller*).

A popular example of a published illness narrative is Audre Lorde's, *The Cancer Journals*, a quest illness narrative in which she describes and reflects on her struggle with being African American, a lesbian and having breast cancer to gain support and understanding from others. Another popular published illness narrative, *Needles-A Memoir of Growing Up with Diabetes*, written by Andie Dominick follows the journey of a diabetic from diagnosis up through marriage and provides a first-person account of the difficulties of living with Type I Diabetes.

3. Helping doctors to find appropriate diagnoses and treatment alternatives

Cheryl Mattingly argues that illness narratives are used between clinicians, doctors, therapists, and nurses through everyday conversation. Mattingly observed at a university hospital in Boston, that medical personnel ironically create their oral illness narratives about their patients and share them through casual conversation with coworkers throughout the work day (Mattingly).

As clinicians develop their patient stories, they include details from the patients' personal lives that otherwise wouldn't appear in medical records. Colleagues use these personal details to suggest alternative treatments for patients who aren't cooperating with treatment and relate other patient cases as a form of comfort or to identify a misdiagnosis (Mattingly).

Patients benefit from story-telling when clinicians discuss alternative treatments that otherwise may have not been considered. Colleagues naturally consider a patient's chart in conjunction with personal life to devise a treatment plan the patient is likely to follow. Sometimes, and perhaps more importantly, doctors realize a misdiagnosis through clinician discourse because together they coauthor an all-inclusive narrative that is easier to comprehend (Mattingly).

Unfortunately, there is a limited amount of research on this topic available. Most current research focuses on areas that demand the most attention—illness narratives to improve doctor/patient empathy and illness narratives to redefine meaning in a patient’s life. Perhaps in the future, more attention and funding will be allotted for doctor-to-doctor illness narratives and the use of narratives to improve health outcomes (Mattingly).

4. Helping doctors to reflect on traumatizing illnesses so they can cope and make sense of them

Even less research has focused on the use of illness narratives as a platform for doctors to reflect on traumatizing diseases they have witnessed. Although doctors witness disease every day, on occasion doctors witness cases that are so horrifying, so bizarre, and so difficult to comprehend that they are left emotionally scarred by what they have experienced. Many clinicians are bothered by the unfathomable difficulty and pain, both physically and emotionally, they imagine their patient suffers from.

Some doctors prefer to write about their experience in an illness narrative because it comforts them. By forming their own narrative, doctors form a coherent recollection of their experience and find a place in their life where this experience makes sense temporally and causally.

Oliver Sacks, a famous neurologist, has published several narratives that could be classified as under this purpose. In his book, *The Man Who Mistook His Wife for a Hat*, Sacks presents several short narrative pieces, each describing his experience with a different patient and the horrific and peculiar nature of each experience. What is most distinctive about many of the pieces in this book is the detail with which Sacks writes of his patients. He incorporates personal details and other aspects of the patient’s life, proving to the reader that he has abandoned the traditional doctor/patient communication by connecting with the patient on an emotional level (Sacks).

Sacks abandons traditional doctor/patient communication and believes that doctors should approach disease the same way as Hippocrates approached it—both as a story and a case. He finds it impossible to separate a patient’s personal life from his medical life and still form an accurate representation of an illness experience because a medical chart cannot convey the, “suffering, afflicted, fighting, human subject” that is affected by the disease (Sacks, viii). Many doctors are unable to process a horrific disease personally and morally if medical standards prevent them from getting to know the patient as a person, rather than a test subject, like a “rat” (Sacks, viii). Sacks cannot emotionally dissociate from a patient without betraying his own values and explains that, “I feel myself as a naturalist and physician both; and that I am equally interested in disease and people; perhaps, too, that I am equally, if inadequately, a theorist and a dramatist, am equally drawn to the scientific and the romantic, and continually see both in the human condition, not least in that quintessential human condition of sickness—animals get disease, but only man falls radically into sickness” (Sacks, vii). Sacks can only practice medicine effectively by emotionally interacting with patients because it satisfies his personal desire to connect with them as humans.

Sacks recalls clinical experiences in *The Man Who Mistook His Wife for a Hat*, by intertwining information from the patient’s medical chart with his life history. In his story, “The Lost Mariner,” Sacks describes the case of Jimmie G., a veteran of World War II who can no longer form new memories and cannot remember anything that has happened after 1945. After multiple clinical visits, Sacks discovers that Jimmie suffers from the rare Korsakov’s syndrome, which was caused by damage to the neural mammillary bodies provoked by years of excessive alcohol consumption. Sacks incorporates Jimmie’s personal life and personality traits in his illness narrative because it is the only way he can relay the true nature of Jimmie’s disease to other

people. He exemplifies this when he describes how the facility initially reacted to Jimmie's case, "All of us had high hopes of helping Jimmie—he was so personable, so likable, so quick and intelligent, it was difficult to believe that he might be beyond help" (Sacks, 35). Interestingly, Sacks eventually realizes that any possibility of treatment for Jimmie lies far beyond the medical mind-frame when he learns that Jimmie finds comfort in religion, music, and other arts, because his ability to process these activities is unimpaired.

Perhaps though, Sacks derives his patient empathy and need to emotionally interact with patients from his own experience with illness. Oliver Sacks was a patient himself after he was seriously injured in a bull accident that caused him to feel as if he had lost his leg even though it was still intact. Either way, doctors that treat horrifically ill patients find comfort by forming coherent narratives to make sense of their experience.

Illness Narrative Plots

According to narratologist, Arthur Frank, illness narratives can have three basic plot themes depending on the point in a person's illness, his diagnosis, and his treatment. These are the restitution narrative, the chaos narrative and the quest narrative. Patients whose illness ends well generally follow the restitution narrative and sometimes the quest narrative; a patient whose illness is difficult, ends poorly, or has not yet been resolved generally follows the chaos narrative (Frank, Wounded Storyteller).

Restitution Narrative

Anthropologists identify the main theme of the restitution narrative as, "I'm fine but my body is sick, and it will be fixed soon," a theme that is most commonly promoted by the medical industry. Patients believe that although they are they are sick they will soon get better and continue on with their lives. Doctors and patients tend to ignore any chance of complications or

death because they assume medical treatment will free their body of illness. If their disease is cured, the experience as a whole eventually meshes with and is seen merely as a small bump in the person's entire life narrative. Restitution narratives are common among people who have a minor infection, such as an ear infection, that receive medicine from the doctor and are cured with no long-term effects (Frank, Wounded Storyteller).

Frank claims that the medical world has had a large influence over the restitution narrative's popularity. Clinicians tend to assure their patient, even at diagnosis, that their treatment plan will be effective and everything will eventually go back to normal. Medical brochures, websites, and other publications show evidence of its presence by only including patients who appear happy and healthy after a successful treatment and neglecting to feature patients while they are still sick. Frank exemplifies this with a cancer clinic pamphlet that features only people who have been cured and only one piece of medical equipment surrounded by a happy medical staff. Likewise, TV commercials for medical facilities only feature stories of people they have cured (Frank, Wounded Storyteller).

Medical staff members even force the restitution narrative on a patient after a first attempt at treatment fails by assuring him that their second attempt or alternative treatment will succeed. Frank attributes this to the tendency of clinicians to view a patient as a type of "puzzle," rather than a "mystery," that must and can be solved. Unfortunately, when doctors force the restitution narrative on a patient even after treatments and alternative treatments continue to fail, a patient may come within inches of death before they realize they will not see a cure to their ailment. As a result, doctors prevent their patients from forming their own narrative and understanding of their condition before they pass on. Patients and their families are unable to even make sense of or find closure to their situation before it's too late (Frank, Wounded Storyteller).

Chaos Narrative

Interestingly, Frank questions whether the plot theme, “chaos narrative,” should even be considered as a narrative. According to narrative theory, a narrative must be temporally and causally coherent, and this type of coherence just isn’t present in the chaos narrative. When a patient’s experience adheres to the chaos narrative, he doesn’t have a full understanding of what has happened to him because his illness prevents him from distancing from the illness long enough to link certain events together to form a story (Frank, Wounded Storyteller).

Frank claims chaos narrative patients use the phrase “and then” to connect thoughts because the patient doesn’t know where to begin thoughts without a coherent narrative. Patients jump from topic to topic chaotically linking each with the phrase, “and then,” unable to provide a comprehensive answer for his listener. There is so much chaos in the patient’s life, that one topic leads him to think of another topic. Unlike the restitution narrative, the patient openly confronts his own mortality and accepts it as a possible and sometimes likely outcome (Frank, Wounded Storyteller).

Unfortunately, society makes little room for the “chaos narrative.” People don’t want to hear how illness can create chaos or a mess out of a previously normal life. Frank states that people don’t want to hear of ill experiences that don’t end in restitution, because it means that the same thing could happen to them. Rather, society thrives on stories that promise that even in the darkest of situations, the human spirit endures and triumphs (Frank, Wounded Storyteller).

Likewise, the medical community also shuns the chaos narrative and tries to force the restitution narrative on suffering patients. Even when people are in the midst of the chaos narrative and cannot process their current situation, doctors insist that medical treatment will make everything okay (Frank, Wounded Storyteller).

If society and doctors accept the chaos narrative, patients will be more likely to talk out their situation. When patients are able to seek help without fearing rejection, they will begin to form a coherent narrative out of their illness experience (Frank, Wounded Storyteller). According to Hampl, patients must draft out their scattered recollections of traumatic events to form connections between discrete images and memory fragments that don't make sense to the patient as they were stored. When patients create this coherence between incomplete memories, they likely will exit the chaos narrative to enter either the restitution or quest narrative.

Quest Narrative

Perhaps, the most inspirational of illness narrative plot-themes, is the quest narrative because it gives the most control to the patient. According to Frank, the patient's voice is heard most clearly in the quest narrative (Frank, Wounded Storyteller).

Patients approach illness as an opportunity to change from their "old self" to a "new self," after the illness. They embrace illness as a "journey" that offers self-change and growth (Frank, Wounded Storyteller).

Narratologists separate the plot of the quest narrative into three different stages: departure, initiation, and return. At departure, the patient refuses to admit the presence of symptoms because he fears the arduous path of treatment. When the patient accepts his sickness as a journey, he enters the initiation stage. When his journey is over, he "returns," and is responsible for sharing what he learned with others (Frank, Wounded Storyteller).

Automythology, or the path of "The Phoenix" reborn out of his ashes, is often compared to the quest narrative because it creates "phoenixes" out of patients. He observes the four major paths

of change as “Who I Have Always Been,” “Who I Might Become,” “Cumulative Epiphanies,” and “Reluctant Phoenixes” (Frank, Rhetoric of Self-Change).

Frank describes the first path, “Who I Have Always Been,” as people incorporate their illness experience into the vision and meaning of their former self. Those who follow the “Who I Might Become” path use what they have learned on their journey to create a new self completely distinct from their old self. Perhaps the most tragic of Frank’s phoenixes are those who have a “Cumulative Epiphany.” These patients discover that their entire life has been shaped and defined by their illness. “Reluctant Phoenixes” claim that their illness has not affected their life or self-perception at all. However, Frank believes that reluctant phoenixes have experienced at least some change because he felt the need to write something. Frank compares the change in reluctant phoenixes to the change in more outspoken phoenixes, “To see this similarity we must ask, why did he bother to write?...the self must be told. To remain available to himself, he must publicly witness his own suffering and continue to work out its implications, ‘quietly,’ but not at all silently” (Frank, Rhetoric of Self-Change).

Many of the narratives in the book, “What Happened to You?” exemplify the quest narrative well. One quest narrative within this book is, “Agoraphobia: Letting Go,” written by Pam Mason, where the author describes

Criticisms of Illness Narratives

Despite the support of anthropologists and narratologists, illness narratives still meet harsh criticism. Atkinson criticizes illness narratives because they provide non-methodological approach to medicine that is prone to bias (Frank, Standpoint of Storyteller). Even a slight exaggeration in a patient’s narrative might jeopardize his life if the doctor considers it seriously in diagnosis; without a way to ascertain a story’s validity, narrative in the medical industry is too

risky. Cheryl Mattingly agrees that physicians should primarily consult a patient's chart and test results, and perhaps allow a patient's illness narrative to supplement it (Mattingly).

Bingley et al. warn that the different levels of narrative interpretations provide further room for error. Patients interpret their experience to form a narrative and then share it with a "listening community" that must interpret the narrative to comprehend it. Since two people are unlikely to identically interpret the same series of events, a second level of interpretation occurs even if the writer or listener didn't intentionally misinterpret the narrative. However, I must counter that multiple interpretations allow for a better diagnosis and treatment plan, especially if doctors and patients use narrative to discuss their differences and negotiate meaning.

But we ask, is validity really the point of an illness narrative? Anthropologists claim that illness narratives are created to redevelop meaning in a person's life. Hampl agrees that narrative doesn't need to hinge on factual accuracy, but rather it "is a particularly open form, inviting broken and incomplete images, half-recollected fragments, all the mass (and mess) of detail. It offers to shape the confusion—and, in shaping, of course, it necessarily creates a work of art, not a legal document" (Hampl, 33). Even if doctors are unable to use patient narrative for its factual content, they can determine the hidden motives and emotions of their patients just by observing what and how a patient's material is presented. According to Hampl, all personal accounts, and I would include doctor-recorded patient charts, have some angle of subjectivity and "are only valiant attempts to consign the truth, the whole truth, and nothing but the truth to paper. Even they remain versions" (Hampl, 33). Anthropologists may even wish to consider the biases present in doctor-written patient charts that are supposedly factually true. Logically though, the illness narrative like belongs secondary to the medical chart where it can be evaluated in conjunction with a patient's medical history.

Critics and narratologists warn that illness narratives might cause patients to reveal too much information. As Mishler points out, the traditional Q&A patient-interviewing specifies the amount of information that a patient will share (Mishler, *Patient Stories*). If a doctor coauthors an illness narrative with a patient, the patient may get caught up in his narrative and accidentally reveal information he intended to keep private (Freshwater and Holloway).

Doctor-Incentive to Use Illness Narratives

Anthropologists can develop copious amounts of research that supports the clinical use of illness narratives, but unless doctors are willing to employ them, the research is useless. Although illness narratives certainly benefit the patient, doctors may refuse to put in the extra effort if there is no other incentive.

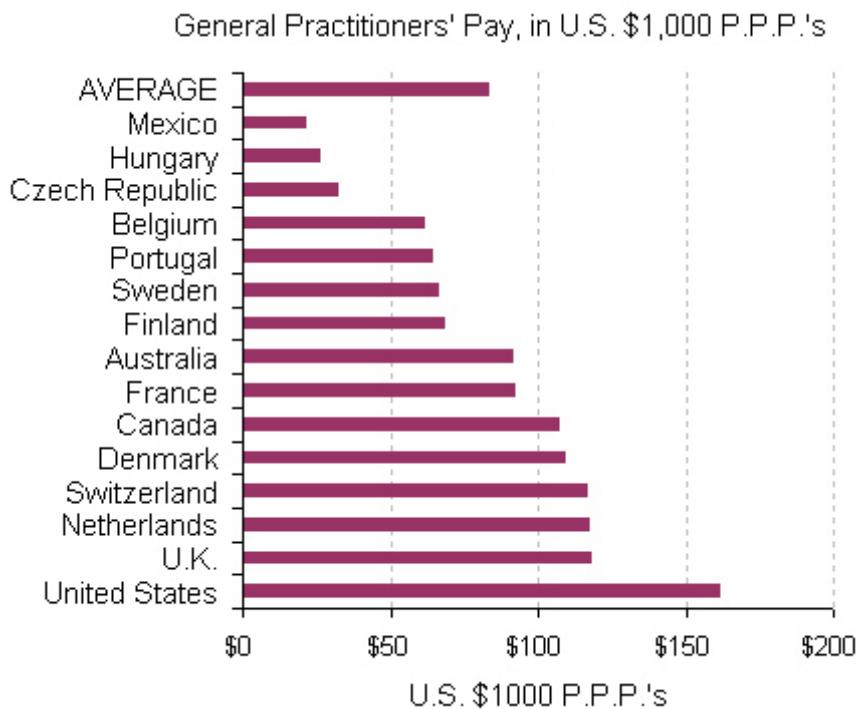
Patient-care as a Commodity

Perhaps if doctors view patient-care as a commodity that can be bought and sold, purchased and then returned, then they will value patient satisfaction (Ross et al.). If we compare patient-care to customer-care in a restaurant, then we can see the doctor serving his patient as the waitress waiting on her customer. If a doctor cannot meet these expectations, then a patient has the same right to change providers just like a customer has the right to choose a different restaurant.

According to Ross et al., a market thrives on satisfying minimally what a person needs and ideally, what a person wants. Although every doctor can provide the minimal healthcare a person requires, a patient chooses between doctors based on a doctor's interpersonal skills or educational background.

What Universal Health-Care May Mean for Patient-Care Quality and the Future of Illness Narratives

In recent debates, American politicians considered adopting universal healthcare for the United States. According to Scott Gottlieb of *The Wall Street Journal*, most physicians will actually see significant declines in their salary if universal healthcare is passed because it is modeled after the Medicare program. Physicians tend to profit more through patients that are privately-insured because government-run programs only have to pay doctors an average of 70%-80% of what private insurance companies pay. If we compare the average salary of an American physician, to the salaries of physicians in countries that operate through universal healthcare, such as the United Kingdom, France, Australia, or Canada, income differences are both outstanding and foreboding. (Figure 3) According to Catherine Rampell, a writer for *The New York Times*, the average salaries for general practitioners in the United Kingdom, France, Australia and Canada are \$118,000, \$92,000, \$91,000, and \$107,000 respectively, compared to an average salary of



\$161,000 in the United States

(Rampell). If politicians

decide to pass the healthcare

reform, American physicians

are likely to see a similar drop

in wages (Rampell).

Under the universal

healthcare, doctors are not

paid based on patient

satisfaction or outcome, but

Figure 3: Bar Graph of General Practitioner's Pay in Various Countries as Conducted by the Congressional Research Service Analysis (Rampell)

according to the number of patients a doctor sees in a day. Doctors are likely to squeeze in as many patients as possible to make up for salary reductions.

What does this mean for the fate of illness narrative use within the clinical field? If a doctor is paid per patient rather than by the quality of care he provides, then there is little incentive for doctors to introduce illness narratives within their practice. Or, perhaps even more importantly, not enough time. Customers are willing to pay more for a higher-quality product and workers are willing to work harder if it means that they might be rewarded financially. Likewise, patients are willing to pay higher insurance premiums for higher-quality healthcare and doctors are willing to work harder to meet patient needs to increase their revenue. Universal healthcare will not drive doctors to uphold patient satisfaction because it is not based on these capitalistic ideals (Gottlieb).

Anthropologists have urged physicians for years to improve the quality of doctor/patient communication through narrative. Even though medical students are now trained using narrative cases and video clips, yet doctors still predominantly use the Question-and-Answer interviewing format and with universal healthcare the likelihood of narrative interviews may be less likely.

Although there are many purposes for creating illness narratives in the medical center and in the patient's life, in my exploratory project, I chose to focus on how a video illness narrative constructed by a patient in her personal life might help a patient to interpret her illness experience and how she might benefit from creating one. I am particularly interested in video narrative because there is little research available on video as a medium for illness narrative and I believe it might be especially powerful because it is a multimodal platform.

Methodology

Illness Narrative and Interpretation

Much of the literature has suggested that writing a story or listening to another person's story can influence the way that a person understands an illness-related event and responds to it. In my project, I co-constructed an illness narrative with a diabetic woman and then adapted that story to create a video that she could share with others. Throughout the process, I posed several research questions. My first set of questions investigated how a video illness narrative might influence how people interpret an illness experience:

How might video illness narrative influence a patient's interpretation of what has happened to her? How might video illness narrative influence how family and friends interpret the patient's illness experience?

Although narratologists have conducted substantial applied and theoretical research on oral and especially written illness narrative, there are limited studies that focus on video as a platform for illness narrative, especially those that investigate how narrative can benefit the patient and their social networks. According to W. J. T. Mitchell, visual information, like images and film, are much more powerful than written or oral communication because they can more strongly change the way we remember and assign meaning to events, making them more memorable. I believe that patients and researchers could capitalize on the capabilities of visual media to create visual illness narratives that may be very effective in forwarding any one of the four major purposes of illness narrative. However, I am personally interested in examining how the co-production of a video illness narrative with the patient might help the patient to interpret and make sense of discrete illness-related events in her life.

In order to address this question, I decided to co-construct a video illness narrative with my sister, “Dawn,” a 19-year-old Type I diabetic woman, over a four week period. Dawn volunteered for this project. At the start of the project, I needed to ascertain her current interpretation of her illness experience, including illness-related problems and life goals. I wanted to compare her initial representation with the final story she presented in the video in order to see possible differences in how she viewed her illness after constructing and revising fleshed-out narrative on film.

Gathering the patient’s and her community’s initial explanatory models

At my first meeting with Dawn, I began by explaining exactly what an illness narrative is, how one is constructed, how she and I would work together to write and film an illness narrative, and how experts claim that illness narratives have generally helped some patients. A script of this conversation can be found below.

Illness-Narrative Explanation

Humans use narrative in their daily lives to function, to tie separate events together and to find where each series of events fits into their overall life. When people encounter traumatic events, such as illness, their image or perception of the world is disrupted and they remember these events as discrete episodes. Anthropologists believe that people can find a meaning for these events in their lives by placing them into a coherent narrative about their experience. They believe this can help the patient move on emotionally.

People who have experienced stressful illness-related events might benefit from creating an “illness narrative,” which is a story that explains how you initially got sick, what you

thought and did about it, and how you and the illness have transformed over time. Even if you feel you have overcome your illness-related problem, when you write about your diabetes-related experiences you may uncover problems or stresses that you pushed aside, but never fully accepted or understood.

Illness narratives can also be helpful for the friends and family of an ill person because your detailed story might help them develop understanding and empathy. In addition to helping you identify and resolve or reflect on illness-related problems, I will be sharing your story with others to see how it affects their understanding and empathy towards your illness experiences. I will survey people you identify as important in your life before and after showing them your video illness narrative.

In order to understand and to create an accurate profile of the patient and her life context, I organized a list of questions typically used to solicit demographic information and presented them to Dawn at our first meeting.

According to Kleinman and many other anthropologists, certain elements of a patient's demographic profile can affect his perception of an illness-related experience. Fridlund et al. discovered in a study that investigated healthcare satisfaction factors, that a patient's age, gender and education level alter a patient's expectations of medical care and therefore relate to patient satisfaction with treatment. Older people, men and less educated individuals were generally more satisfied than their counterparts because they had lower expectations of patient-care. Patient expectations can also be affected by their cultural background because different cultures value different aspects of medical interaction and communication and understand disease and physical functions differently (Fridlund et al.).

I therefore constructed a demographic questionnaire that included patient age, gender, education level, and culture background that could be used to help me understand her condition and past interpretations of doctor-patient encounters. Since I know Dawn personally, I understood this information, but will present this information here for readers.

Below, I include a copy of the demographic questionnaire.

Table 1: Demographical Background Patient Questionnaire

Name:
Age:
Gender:
Education Level:
Race:
Religion:
Hometown:
Family Income Level:

Kleinman strongly asserts that doctors must consider both the patient's and family's explanatory models, or their interpretation and explanation of what has happened to them or their loved one, in order to deliver effective patient-care. Oftentimes, a patient's explanatory model is affected by his life history, including events obviously related to, but also events that may at first seem unrelated to illness. Kleinman suggests that doctors or researchers can benefit from constructing a brief history of the patient's life. Doctors must ask patients to describe prior life obstacles and illness-related problems and the methods they used to overcome them. Kleinman claims that if

doctors can identify themes in the life history, then they can apply them to the patient's current situation and better understand the patient's personality and coping mechanisms. Although a doctor's interview protocol includes a section about the patient's life and social history, many doctors don't value or ignore this section because they believe that the information is irrelevant.

Kleinman claims that after doctors obtain a patient's life history, they must ask the patient specific questions about illness-related experiences that will help his patient construct his "explanatory model," or his interpretation and explanation of what has happened. Kleinman also forwards that the family's explanatory models of the patient's can reveal how those closest to the patient interpret his illness experience and why they react to situations in a particular manner.

Adler et al. furthered Kleinman's concept of the explanatory model by establishing the five doctor questions that should be used to co-construct a patient's explanatory model. They identified these five questions as:

- *Who is this patient?:* Doctors can only communicate effectively with patients when they know a patient's emotional self and his personal life. They must understand the patient's life story, including obstacles and responses, to predict how the patient will respond to his illness and what he expects of doctor-patient care.
- *What does this patient want from the physician?:* Doctors must determine what a patient expects from his physician and medical team and then compare his patient's expectations with his own expectations of the medical encounter. They must examine the patient's goals for health, life and medical care and discuss with the patient how they will approach these goals together.

- *How does this patient experience this illness?:* Doctors must understand how the patient's illness affects his daily and personal life, including his relationships and self-image. They must understand how the patient interprets these challenges and responds to them.
- *What are the patient's ideas about the illness?:* Doctors must learn what the patient thinks and knows about his illness.
- *What are the patient's main feelings about the illness?:* Doctors must evaluate how the patient has emotionally responded to the illness.

By soliciting the patient's explanatory model, I could uncover Dawn's unspoken motivations and intentions and use these to understand her "intentional state," which Bruner identifies as a central feature of narrative. After establishing Dawn's "intentional state," I could apply this feature to ascertain the causal coherence, another feature of narrative, between her actions in the written illness narrative and while I worked with her. In order to help the patient create her explanatory model, at our first meeting I asked Dawn a list of preliminary questions I designed that incorporated the ideas of Adler et al. and video-taped her responses. My adapted questions appear in Table 2.

I also tried to understand the explanatory models of Dawn's family members and close friends as well as those of health care professionals in a university setting since these are or could be members of what Frank calls Dawn's "listening community," or the individuals with whom a patient shares his illness story. I set up a meeting with Dawn's mother, "Judy," and Dawn's friend, Katharine and asked these individuals a similar set of questions (changes to the questions appear in brackets).

Table 2: List of the Preliminary Questions

1. Give a brief a summary of the history of your [Dawn's] illness, including your [her] diagnosis and history up until recently.
2. What problems does your [Dawn's] illness currently cause [her] for you? Which of these has created the biggest struggle for [her] you?
3. How do [Do you think] these problems interfere with the goals you have [Dawn has] set for the future, even simple goals for the near future? [If so, how do you think they affect her future goals and why?]
4. How do you think your [Dawn's] life would be different now if you [she] had never been diagnosed with Type I Diabetes?
5. Have your [Do you think Dawn's] future plans changed at all since or because of your [her] illness? [What do you think she has changed?]
6. If you [Dawn] could change one thing about your [her] disease and how it affects your [her] life, what [do you think it] would it be? How can you [she] change it? How can others help you change it? [How could you help her to change it?]
7. What do you hope to get out of making a video illness narrative? [Not asked to Listening Community]
8. [In what ways do you treat Dawn differently than other people, positively, negatively, or neutrally, because she has Type I Diabetes? How do you think these adjustments in behavior help Dawn?
9. [What role do you currently feel that you play or are responsible to play in Dawn's illness experience?]
10. [How do you think the way you act around Dawn can influence how she reacts to and manages her Type I Diabetes?]
11. [Do you have any other comments to add?]

Although these questions provided important background information on the patient's explanatory model and the models of some of her listening community, my literature review suggests that patients tend to remember illness-related events as disconnected fragments, but can

often fill in these gaps by writing or telling these events in a story. Therefore, at our first meeting I also asked Dawn to write a short story that exemplifies an important illness-related problem.

Lorraine Higgins and Lisa Brush developed a method to elicit narratives from a group of women welfare recipients in order to better understand the obstacles and resources in their lives and to examine their motivations and constraints. They hoped that creating these stories would help these women understand their own lives better and help others understand them in ways that go beyond the stereotypical portrayals of welfare recipients. Participants began by identifying their past and future goals and the conflicts that might interfere with them, or their “reals versus ideals,” that prevented the women from achieving them. A mentor and each woman then co-constructed narrations of a particular conflict by asking the women to tell a story that illustrated it.

In Higgins and Brush’s project, they found that the women’s first drafts lacked significant causal coherence between events and that they often glossed over important details and underlying problems. As a result, the mentor then asked them to elaborate and explain the story in more depth by probing more deeply with cause-and-effect questions such as, “Why did you do that?/What caused that to happen?/What were you thinking at the time?/What happened after that?” By asking these questions, the women remembered details and relationships between events that they did not previously include and used this information to improve the causal coherence between narrative events in their fragmented first drafts (Higgins and Brush).

Although Higgins and Brush created narratives for welfare-recipients, who also dealt with trauma and stress, I incorporated the “reals versus ideals” technique to help the patient determine which illness-related events prevented her from attaining past and future goals. In Preliminary

Question 2, I asked “What problems does your illness currently cause for you? Which of these has created the biggest struggle for you?,” and we focused Dawn’s narrative on one of these problems.

I instructed her to transcribe and email me a short story that illustrates this problem in her life within two days to allow Dawn time to reflect on and write thoughtfully about this problem.

Below, I include the narrative instructions that I gave her.

Write a story that exemplifies one of the most important problems you cited. Include what you have tried to do to address it and what may have resulted.

In addition, I planned a second meeting with Dawn so that we could reread the story and identify possible gaps, ambiguities or missing details that she may have inadvertently omitted, but that would help a reader make sense of the problem, its causes and her responses just as Higgins and Brush did.

I provided Dawn with a FlipShare UltraHD video camera and instructed her to record images to supplement her story and the problem the week after our initial meeting. See Appendix A for specifications and information about this camera.

In a video illness narrative study, Buchbinder et al. used video illness narrative to follow the at-home lives of four adolescent Type I diabetics and to determine whether patient blood sugar levels were related to each patient’s lifestyle and level of parental involvement. They provided each patient with a tripod and a camcorder and instructed each person to record two hours of video each week that included diabetes-related elements for four weeks. Patients also

interviewed family and close friends on their personal experience with the patient's disease (Buchbinder et al.).

At our first meeting, I used this self-filming methodology by video-taping Dawn's responses to the preliminary questions and then leaving a camcorder with and instructing her to tape any incidents that pertained to the problem she wrote about in her illness narrative over the next week.

Constructing and showing the elaborate narrative

At our second meeting, I reread Dawn's written illness narrative with her and stopped at sentences that lacked detail, seemed confusing, or could benefit from further explanation to ask Dawn several cause-and-effect questions similar to those used by Higgins and Brush such as, "What caused that to happen? Why did you do that? What happened after? How did you react to that?" to probe for more detail or explanation. I transcribed Dawn's responses next to the appropriate section of her narrative as she spoke, so that she could return to them after I left and incorporate the elaborations in a second draft of her written illness narrative.

We also reviewed the clips that she taped over the past week, discussed how they related to her written narrative and how, if necessary, she could change her filming technique over the next week. I left the video camera with Dawn again and instructed her to record clips for another week.

At our third meeting, we reviewed and discussed her revised narrative and new video clips and how all of the clips might collectively be used to visually represent her written illness narrative as another layer of elaboration.

After this, we picked the clips that best represented her written illness narrative and used Adobe Premiere Pro on a WPI Academic Technology Center (ATC) laptop to cut and rearrange the video segments into an order that correlated with her final written illness narrative. I used the video camera to video-tape Dawn while she read her final written illness narrative so that we could sync the audio track to pictures that Dawn picked to represent her past diabetic experiences, diagnosis and life today. We used portions of Dawn's preliminary questions at the beginning of the video to exemplify Dawn's past experiences with diabetes and to give a brief summary of her illness-related problems up until now. In addition, I also helped Dawn to choose and edit three different songs into her video illness narrative to convey the emotions she experienced in certain portions of the video.

Changing Interpretations

To answer my research question about Dawn's changing interpretations, I took notes on the differences I saw between her initial response to my questions and her initial narrative and the fully developed narrative in the final cut of the video. I also asked Dawn to keep a journal and I also kept a journal to reflect on the process. Some of these entries helped me to answer this question as well.

To determine how Dawn's video narrative might influence her listening community's interpretation, I compared their response to the preliminary questions (above) with their responses after they viewed the finished video. I began each session by asking each participant a set of questions similar to the preliminary questions I asked Dawn. The differences between the sets of questions are denoted by brackets in Table 2. If the participant brought up additional important topics in his or her answers, I provided a prompt to further discuss that topic before I proceeded to the next question. After the participant's preliminary question session, I played a

copy of Dawn's video illness narrative. I determined whether a video illness narrative has the potential to change a "listening community" member's explanatory model by asking each participant the same questions he or she had answered before the viewing session and recording his or her responses.

Challenges in Constructing a Video Illness Narrative

Anthropologists invested decades of energy and resources into the development and promotion of the written illness narrative that they have had little time to investigate the advantages that other illness narrative platforms offer, like video. Although video has a greater capacity to immerse an audience because it is multimodal, I felt it was important to record the obstacles and the solutions to these problems that Dawn and I encountered during the video illness narrative production process so that other researchers could use this information in future studies. My next research question was therefore:

What are the challenges of co-constructing a video illness narrative with a patient?

In order to accurately log the video production process, Dawn and I kept separate journals to date and record the obstacles and solutions as we encountered and confronted them. At our first meeting I left a journal with Dawn that had pages I separated into an optional format with three columns labeled, "Date," "Obstacles," and "Solutions." I instructed her to write down anything she found difficult throughout the video production process under the "Obstacles" column and to write down how she solved these obstacles under the "Solutions" column. I divided my journal into the same three columns, but left additional space for any other field notes I found important enough to record. Below is the format I used on each journal page.

Table 3: Dawn’s Journal Format

Date	Obstacles	Solutions

Table 4: My Journal Format

Date	Obstacles	Solutions
Field Notes		

Benefits of Video Illness Narratives

In addition to possible changes in the patient’s and the listening community’s interpretations, I suspected that there could be other benefits. Much of the literature recognized other benefits such as influencing how a patient responds to her illness and developing empathy in the listening community. To explore this, I asked:

What are the benefits of creating a video illness narrative for the patient? What benefits may result from showing the video to the listening community?

In order to assess how a video illness narrative might benefit a patient, I also instructed Dawn to record if and how she felt the video illness narrative benefited her over the three-week period in the same journal previously mentioned. In addition, I also described any benefits that I observed during my interactions with Dawn in my own journal. I particularly listened for and recorded any comments that Dawn mentioned about how the video production has affected how she deals with her diabetes, how the video had affected her perception of the disease, new ways she had implemented to deal with any of her illness-related problems, and insights on her future with diabetes. I also asked members of her listening community how they benefited from watching Dawn's video.

In conclusion, I asked the following research questions:

- **How might video illness narrative influence a patient's interpretation of what has happened to her? How might video illness narrative influence how family and friends interpret the patient's illness experience?**
- **What are the challenges of co-constructing a video illness narrative with a patient?**
- **What are the benefits of creating a video illness narrative for the patient? What benefits may result from showing the video to the listening community?**

Over a three-week period I collected several types of data, including interview responses, written drafts and videos, and journal notes kept by myself and the patient. Table 4 reconstructs the steps I took to complete the video construction and my analysis of the data.

Table 5: Summary of Tasks Completed during Meeting Times with Dawn and Tasks Assigned to Dawn to be completed after Meetings

Activities	Location	Time
<p>Meeting 1</p> <p>Tasks:</p> <ul style="list-style-type: none"> • Asked and filmed preliminary questions • Dawn filled out Demographic Questionnaire 	<p>Saint Anselm's College</p> <p>Assignments:</p> <ul style="list-style-type: none"> • Write narrative within 2 days to exemplify the most important illness-related problem • Use video camera to record events or confessionals that demonstrate the illness-related problem presence in her daily life • Record obstacles and benefits associated with producing the written illness narrative or video recordings in a journal 	<p>3/13/10 ~5 PM</p>
<p>Meeting 2</p> <p>Tasks:</p> <ul style="list-style-type: none"> • Reviewed video clips that Dawn had captured over the past week • Reread Dawn's written illness narrative together and asked cause-and-effect questions to probe for more narrative detail 	<p>Saint Anselm's College</p> <p>Assignments:</p> <ul style="list-style-type: none"> • Incorporate new narrative details and expansions into original written illness narrative • Use video camera to record events or confessionals that demonstrate the illness-related problem presence in her daily life • Record obstacles and benefits associated with expanding the written illness narrative or video recordings in a journal 	<p>3/20/10</p>
<p>Meeting 3</p> <p>Tasks:</p> <ul style="list-style-type: none"> • Reviewed video clips that Dawn had captured over the past two weeks • Selected the most important video clips to include in the video illness narrative • Used Adobe Premiere Pro to edit these clips together 	<p>Worcester Polytechnic Institute</p> <p>Assignments:</p> <ul style="list-style-type: none"> • Finish the obstacles and benefits journal and return to me within the next week 	<p>3/26/10-04/03/10 (additional time to finish edits)</p>

and synced audio recording of written illness narrative to pictures from Dawn's past

Meeting 4

Plymouth, MA

04/03/10

Tasks:

- Ask Dawn's mother list of "Listening Community" Questions and record her responses
- Show Dawn's mother the final video illness narrative
- Ask Dawn's mother post-video questions and record her responses

Assignments:

- None

Meeting 5

Skype Video Session

4/12/10

Tasks:

- Ask Dawn's friend list of "Listening Community" Questions and record her responses
- Show Dawn's friend the final video illness narrative
- Ask Dawn's friend post-video questions and record her

Assignments:

- None

Results and Discussion

Over a period of two weeks, I interviewed Dawn once, had her draft a narrative and then had her revise it. Then in the final week, Dawn read her narrative on film and we used Adobe Premiere Pro to edit video clips, pictures, the audio track of her final written narrative, and three musical tracks together into a coherent elaborate visual narrative.

The Illness Narrative Video

Dawn's final video illness narrative, "Blood Sugars and Brownie Temptations," was approximately 15 minutes long. The video is in three different segments as described below. The video credits are included in Appendix C. Please refer to the DVD attached to the hard copy of this project.

We included segments from the preliminary questions interview at the start of the video to share Dawn's explanatory model with viewers. She began her explanatory model with a brief history of her diagnosis and then explained the daily struggles of a Type I diabetic. She explained that these difficulties not only included having to balance carbohydrate intake with insulin injections, but also the social aspects that come along with having a chronic illness. Dawn concluded this portion with her fears of future disease-related complications, like losing a limb or becoming blind. In the next portion of the video, Dawn read her final written illness narrative while pictures and video segments chosen to represent specific moments in her narrative, such as pictures of New Orleans, film segments recorded at school and pictures of her diagnosis, played over it. In the final segment, Dawn reflected on any new future plans and goals in diabetes management that she had set since the project.

In addition to producing the actual video, my goal was to learn about the process and some of its effects. Below, I explain how Dawn's interpretation of disease and that of her listening community evolved as we produced her video illness narrative.

Changing Interpretations

One of my initial research questions asked: How might video illness narrative influence a patient's interpretation of what has happened to her? How might video illness narrative influence how family and friends interpret the patient's illness experience? In Dawn's initial draft of her written illness narrative, she tended to gloss over certain details which left gaps in narrative events. After I read over the first draft of Dawn's narrative, I took note of the regions she had glossed over and asked her questions so she could expand upon these aspects of the story at our meeting. Dawn tended to omit three different types of information throughout the narrative:

1. Reasoning behind choices
2. Explanations of disease-related terminology and treatment processes/tools
3. How she relates to her friends in the context of her illness

Below, I include a copy of Dawn's initial written illness narrative where I have bold-faced these "gap" areas of limited that might disrupt causal coherence.

Table 6: Dawn’s initial written narrative.

Areas that she glossed over are numbered and bolded in the text and then explained in the side column.

It is the first week after Spring Break, and I have just returned to Saint Anselm College from Spring Break Alternative in New Orleans. After a whole week of being active, running around with kids, and walking all over the French Quarter, my blood sugars have been very manageable, and better than before. **(1) However, now that I have back in New Hampshire for a few days, my blood sugars are beginning to get higher, and I am in need of an insulin adjustment.** **(2) This balancing act of creating the right insulin to carb ratio, basal rates, and correction factors takes more than just a day or two to figure out.** Unfortunately for me, I have my Humanities midterm, which is equivalent to 20% of my grade, on Wednesday, and today is Tuesday.

I’m at the library today after class, and study for a few hours. I understand the basic concepts and outline what we need to know for the exam. Now, it’s about six p.m. and I need to get dinner before going to the housing open house at seven. I head over to Davison, the dining hall, with my friend Allison. **(3) I check my blood sugar, and it’s on the higher end of the normal range, but still acceptable.** **(4) For dinner, I choose a salad with Italian bread and milk. After this, Allison and I are still a bit hungry so we head up to get dessert: a delicious brownie. However, I do not take into consideration the consequences I will have later that night.**

By the time I head over to the library, it is about eight o’clock, and I am feeling more lethargic and tired than usual, with a slight headache. I find my friend Rachel in the library, who I’ll be studying with, and sit down. We begin to outline answers for possible essay question. However, at this point I am finding it difficult to concentrate and am not absorbing much of the information. **(5) After about forty five minutes, Rachel gets up to use the restroom, and I take this opportunity to check my blood sugar.** I wait for the glucometer to count down from five to reveal my sugar level...and it’s in the three hundreds. I give myself the appropriate amount of insulin, but unfortunately my sugar won’t be down to normal for at least a couple of hours. All I really want to do right now is curl up under my warm blankets and go to sleep; the last thing on my mind is studying. I continue to look blankly at the information for a couple of hours longer, and get to bed by midnight, feeling unprepared for my exam tomorrow morning at ten thirty. I have set my alarm clock for seven a.m. so I can study in the morning, when I know my blood sugar will be better.

When I wake up the next morning, I am still tired, and know that I could have gotten a better sleep. But my blood sugar is back to normal, and now it’s time to study and cram as much information into my head as possible. By the time I get to my Humanities class, I am tired, hungry, and stressed out, yet feel more prepared for this exam than I had last night. After my midterm, I walk out feeling pretty good about the exam, I just wish I could have gotten here without all the stress and cramming. I walk to Davison to grab some breakfast, and now can only hope that my midterm grade is a decent one.

(1) Dawn neglects to explain why being in New Hampshire caused her blood sugars to increase. Were there things that she could have been doing to keep them stable? Should she have anticipated this problem before she got home? What factors changed?

(2) Dawn glosses over several diabetes-related terms, like insulin-to-carb ratio, basal rates, and correction factors that the average person would be unfamiliar with. How does she measure these things? What’s involved?

(3) Dawn doesn’t explain what the normal range for a diabetic’s blood sugar is or how much higher than normal her reading was.

(4) Dawn glosses over the reasoning and thought-process behind her decision to select a “delicious,” but knowingly unhealthy brownie. Did she feel pressured by her friend to get the same dessert? Were there any other desserts she could have selected from?

(5) Dawn explains that she waits until her friend leaves to check her blood sugar, but doesn’t explain why or how this might affect her blood sugar levels. Was it a coincidence that Rachel left at the same time Dawn planned to check her blood sugar? Was she embarrassed to check it in front of her friend?

1. Reasoning behind Choices

Dawn tended to gloss over her reasoning and thought-process behind certain decisions, just as the welfare recipients did in the Higgins and Brush study. In several instances, readers might

believe that an event has “just happened” for no reason because the motivations and thoughts that led up to Dawn’s choice or actions are not explained. According to Bruner, this causal coherence and the intentional states of characters are two key parts of any narrative. She omits this type of information early on in the first draft of her narrative. In one instance, Dawn describes how she spent her past week in New Orleans, and then explains that, “now that I have been back in New Hampshire for a few days, my blood sugars are beginning to get higher, and I am in need of an insulin adjustment.” (See Above Figure) Although Dawn shares that her blood sugars have gotten higher since she returned from her trip, she doesn’t explain why being in New Hampshire would cause this or if she could have prevented it. Were there things that she could have been doing to keep them stable? Should she have anticipated this problem before she got home? Were there situational factors that changed her levels? Dawn omits important causal detail that could explain why her blood sugar levels were so high.

Perhaps most interestingly, Dawn even excludes detail at the narrative’s most consequential event—the climax. She explains in her first draft that, “Allison and I are still a bit hungry so we head up to get dessert: a delicious brownie. However, I do not take into consideration the consequences I will have later that night.” Dawn glosses over another important element of narrative, the rising action, because she doesn’t list any of the factors that led up to or factored into her final decision to eat a brownie filled with unhealthy carbohydrates. Did she feel pressured by her friend to eat the same dessert? Were there any other desserts that she could have chosen from? Was she unaware of the harm it could do or were there factors she thought would reduce the risk, factors a reader might not see? Dawn doesn’t explain the thought-process that led to her climactic decision, which minimizes the story’s rising action by glossing over the story’s strongest turning point. Additionally, a reader might view this as irrational behavior; if

she is a diabetic why would she eat something so unhealthy? Such an unlikely choice deserves an explanation.

2. Explanations of disease-related terminology

I also observed gaps in Dawn's initial draft where she neglected to define several disease-specific terms that would be unfamiliar to outside readers. In the beginning of her narrative, she uses terms like, "insulin-to-carb ratio," and, "basal rates," that only people familiar with diabetes would understand. In another instance later on in the narrative, Dawn states that "her blood sugar is on the higher end of the normal range, but still acceptable," but doesn't explain what the normal blood sugar range for a diabetic is. Although Dawn and her family may be familiar with these terms, readers might find it difficult to form causal coherence between narrative events if important terminology and values are not defined.

3. How she relates to her friends

Certain areas in the first draft of Dawn's narrative lacked coherence because she didn't explain how her relationships with friends influence her behavior or how her disease has shaped her relationships. Towards the end of her narrative, while Dawn and her friend are at the library she explains that, "After about forty-five minutes, Rachel [her friend] gets up to use the restroom, and I take this opportunity to check my blood sugar." Since Dawn knows that having a brownie for dessert might raise her blood sugar, it is possible that she had waited to check her blood sugar until her friend left for a reason, but Dawn fails to develop this cause-and-effect relationship. Did she wait until Rachel got up to check her blood sugar because she was embarrassed to do it in front of her? Was it a coincidence that Rachel left at the same time that Dawn had planned to check her blood sugar? Since Dawn

Table 7: Dawn’s second draft of her written narrative. Areas that she had previously glossed over or that had gaps in narrative events were clarified and are numbered and bolded in the text and then explained in the side column.

It was the first week after Spring Break during sophomore year, and I had just returned to Saint Anselm College from Spring Break Alternative in New Orleans. After a whole week of being active, running around with kids, and walking all over the French Quarter, my blood sugars had been very manageable, and better than before. In New Orleans, everything was set up so there was much more walking being accomplished than realized. The first couple of days we arrived, we walked all over the French Quarter, Bourbon Street, and the Riverside. Even small things, like parking the car away further away from the dormitory, added more walking to my schedule. We walked to meals, and explored the different restaurants we could eat at. All of this walking helped to keep a baseline for my blood sugars, which worked out well to balance the new foods we’d been trying. While in New Orleans, I tried crawfish, gumbo, jumbalaya, homefries, grits, and beignets; many of these cultural foods were high in carbs and sugars, so I definitely needed the exercise to use up more of these extra carbohydrates. **(1) However, now that I had been back in New Hampshire for a few days, my blood sugars were beginning to get higher, running on average between 150 and 200 mg/dL, when the norm is 80-150 mg/dL for a diabetic. When trying to keep blood sugars at a healthy level, you need to change your insulin levels according to change in exercise routines and now I was in need of an insulin adjustment.** This balancing act of creating the right insulin to carb ratio, basal rates, and correction factors takes more than just a day or two to figure out. **(2) My insulin to carb ratio, or the amount of insulin needed for X amount of carbs, is different for everyone, and changes with exercise.** Unfortunately for me, my Humanities midterm, equivalent to 20% of my grade, was scheduled for 3 days after I returned from my trip. I hadn’t had any time to prepare for the midterm over break, except for reviewing two textbooks on the airplane, so I was not very prepared for the upcoming exam. Also, I had not taken into consideration the fact that my blood sugars probably would be out of control when I returned.

After Anatomy and Physiology on Tuesday, I walked to the library around one to study by myself and did not leave until after 5. After this study session, I was able to understand the basic concepts and outline of the chapters for the exam. At this time, I headed to get dinner before going to the open house to tour upper class housing at seven. I started for the dining hall and texted my friend Allison to let her know I was on my way. I checked my blood sugar in the library, before I left because it is more private and less people than there are at the dining hall. **(3) At this point, it was a little higher, about 160 or 170, but still acceptable.** For dinner, I chose a salad with Italian bread and milk, a pretty healthy choice for diabetics; this entire meal was low carb, excluding the bread. **(4) After this, Allison and I were still a bit hungry so we headed up to get dessert. The problem with desserts at Davison is that the vast majority that the dining hall offers are way oversized and unhealthy. Allison headed to the brownies, and her dessert tempted me into buying the same dessert.** However, I didn’t take into consideration that this simple dessert would raise my blood sugar, or how it would affect my studying later that night.

By the time I headed back to the library, it was about eight o’clock, and I was starting to feel more lethargic and tired than usual, with a slight headache because my blood sugar had gotten really high. I had taken extra insulin for the brownie, but I was unsure of how many carbs it contained because the size was much larger than usual, and because the dining hall does not provide Nutrition Facts for their food. I probably hadn’t taken enough, but I wouldn’t know for sure until I gave the insulin a couple hours to work. I found my friend Rachel in the library, who I was meeting to study with, and sat down. While we began to outline answers for possible essay questions, I was beginning to find it difficult to concentrate and was not absorbing much of the information; I definitely could have been more efficient in studying if my blood sugar was at a better level. Due to my high blood sugar, I was feeling lethargic, sick to my stomach, and had a painful headache. **(5) After about forty five minutes, Rachel got up to use the restroom, and I took this opportunity to check my blood sugar, since she doesn’t know I have diabetes, and I didn’t feel like bringing it up now.** I waited for the glucometer to count down from five to reveal my sugar level...and it was in the three hundreds. I gave myself the appropriate amount of insulin, but unfortunately my sugar wouldn’t be down to normal for at least a couple of hours. All I really felt like doing is curling up under my warm blankets and go to sleep; the last thing on my mind was studying. I continued to look blankly at the information for a couple of hours longer, got my essays finish, and got to bed by midnight, feeling unprepared for my exam tomorrow morning at ten thirty. I set my alarm clock for seven a.m. so I could continue studying in the morning, knowing that my blood sugar would be better, since the insulin would have time to work.

Waking up the next morning, I was still tired, and knew that I could have gotten a better sleep. But my blood sugar was back to normal, and it was time to study and cram as much information into my head as possible. By the time I got to my Humanities class, I was tired, hungry, and stressed out, yet felt more prepared for the exam than I had the previous night. After my midterm, I walked out feeling pretty good about the exam, I just wished I could have gotten to this point without all the stress and cramming. I walked over to the Davison Dining Hall to grab some breakfast, and could only hope that my midterm grade would be a decent one.

(1) Dawn explains that she exercised superfluously each day in New Orleans, so she didn’t need to take as much insulin as she did back home. When she got back to New Hampshire, she wasn’t exercising as much, so she had to adjust her insulin.

(2) Dawn explains confusing terminology like “insulin-to-carb” ratio. However, she still didn’t define “basal rates” until I asked her a second time so we could include it in the final narrative draft in the video.

(3) Dawn now defines a higher than normal blood sugar and we can compare this with the average blood sugar for a diabetic that she explains earlier in the narrative.

(4) Dawn explains that she felt pressured by her friend to choose the same dessert. Although she shared with me that she also is easily influenced by others when it comes to food selection, she neglected to include this until I asked her a second time.

(5) Dawn explains that Rachel doesn’t know she has diabetes, so she didn’t want to check her blood sugar in front of her.

glosses over this detail and doesn't provide a reason for waiting, readers cannot be sure of her motivations and therefore, as Bruner explains, cannot fully comprehend her "intentional state."

At our second meeting, Dawn and I read over the first draft of her illness narrative together. When we arrived at an area that she glossed over I asked her questions that probed for cause-and-effect relationships or in some cases, more detail. Using this technique, we uncovered important information that Dawn had omitted in her initial draft, which she then incorporated in her final draft.

Below, I include a copy of the second draft of Dawn's written illness narrative where I have bold-faced areas of improved causal coherence and provided additional notes about each instance in the side margin.

When I asked Dawn detail-probing questions, she clarified each type of gap that she had initially glossed over by developing the cause-and-effect relationships between events.

1. Reasoning behind choices

In Dawn's second draft, she expanded upon the decisions she made in the first draft of her narrative by explaining the reasoning that led to each choice. At our second meeting, she explained that her blood sugars were out of control when she returned to New Hampshire because she wasn't exercising as much as she was in New Orleans. She claimed that the change might have been less drastic if she had gone to the gym at school for an hour a day. By incorporating these details in the final draft of her narrative, she improved the causal coherence of her story, "In New Orleans everything was set up so there was much more walking being accomplished than realized...now that I had been back in New Hampshire...my blood sugars were beginning to get higher...to keep your

blood sugars at a healthy level, you need to change your insulin levels according to change in exercise routines and now I was in need of an insulin adjustment.”

Dawn also used narrative detail uncovered during our second meeting to build upon the story’s climax, her choice to eat a brownie. In her second draft, she shares that she can be “easily persuaded by others” to make unhealthy decisions if she feels pressured by her friends. When her friend, Allison, decided to get dessert, it became more difficult for Dawn to resist the temptation. Although Dawn shared this information with me at our second meeting and agreed to include this detail in her subsequent draft, she didn’t include it until I approached her about it a second time. When I asked her why she didn’t add it, she explained that she didn’t want to write that she was easily influenced by others because she is only easily persuaded by others when it comes to food selection, and not other more dangerous substances, like drugs. Thus, she clarified this phrase and incorporated it in her final video narrative, “Allison headed to the brownies, and her dessert tempted me into buying the same dessert. However, I didn’t take into consideration that this simple dessert would raise my blood sugar, or how it would affect studying later that night because I’m easily influenced by others when it comes to food selection.” Certainly, this highlights the role she plays in her own self-care because it explains that she can sometimes tune out the risks in order to join her peers in certain activities. Later we see how she responds to this need to be more conscious of each illness-related decision she makes.

2. Explanations of disease-related terminology

Dawn also clarified terms like “insulin-to-carb ratio,” and, “basal rates,” that only people familiar with diabetes would understand. She defines these terms in her final narrative, “This balancing act involves taking the right amount of insulin in relation to the number of carbs that I consume and adjusting the basal rates, or the baseline amount of insulin that the pump distributes per hour.”

In her final narrative, she also explains that a “high, but still acceptable” blood sugar is “about 160 or 170.” She also puts this in perspective for readers because she defines the normal blood sugar range for a diabetic as 80-120 mg/dL earlier in the narrative. By explaining this disease-related terminology and information, Dawn creates a causally coherent account not only for herself, but especially for her readers because these explanations help them understand the delicate balance of maintaining healthy blood sugars and the consequences when she doesn’t.

3. How she relates to her friends

Additionally, Dawn improved the causal coherence of her narrative by further explaining how the nature of certain friendships might influence her behavior. At our second meeting, she shared that she waited until Rachel got up to check her blood sugar because she felt uncomfortable checking it in front of her; in fact, her friend *didn’t even know* that she had diabetes. She incorporates these details as seen here, “After about forty-five minutes, Rachel got up to use the restroom, and I took this opportunity to check my blood sugar, since she doesn’t know I have diabetes, and I didn’t feel like bringing it up now.” This not only shows readers that Dawn is uncomfortable with her disease, but also how this discomfort creates another obstacle to effective disease management.

Supplementing Listening Community Interpretations

Before the listening community watched Dawn's video illness narrative, they exhibited a limited understanding of Dawn's illness experience. Transcripts of the Pre-Video and Post-Video interviews with listening community members are included in Appendix D and Appendix E. Although Dawn's mother, Judy Johnson, could identify each of her illness-related struggles and her friend, Katharine, could identify at least some, their knowledge on these topics lacked any detail or further explanation. However, when I asked Judy and Katharine the same preliminary questions after they watched Dawn's narrative, I observed a significant increase in depth and detail to several of their answers. A list of the preliminary questions that I asked the listening community can be found in the methodology section.



Figure 4: “Dawn” (left) and her friend Katharine, a member of her “Listening Community”

Originally, Katharine believed that Dawn's problems centered mainly on “watching what she eats” and that she has to “take into account that she can't drink at parties because of the diabetes,” but in her post-questions she claims to have not realized the many social effects that come along with having Type I Diabetes.

Katharine summarizes her

misconception, “I guess social problems are a pretty big issue, especially since we're on a small college campus and people always know other people's business through word of mouth. Dawn might be more hesitant to tell people about it. I guess she's probably selective of who she tells

and at the same time she has to remember who knows. I see it differently because she is comfortable talking about insulin and discussing her diabetes with me, and I've never been around anyone she's not comfortable sharing it with."

Dawn's mother was also surprised to learn that her daughter was still uncomfortable sharing her disease with others at school. Judy explained she assumed that Dawn didn't like to talk about her disease because she didn't like to focus on it and didn't realize that Dawn was still dealing with other unsettled issues. She explains this struggle to communicate with her daughter in the post-questions, "She's not as comfortable as I thought she was with testing her blood sugars in front of people at school. Her friend went to the bathroom and she tested her blood sugar and I actually thought she was more comfortable than that. She comes across as very laidback and relaxed, but now it's obvious that there is a lot on her mind."

Additionally, Katharine also underestimated how much balancing your sugars with insulin and exercise can interfere with a diabetic's life. Originally, she thought if Dawn didn't have diabetes, her life would only change because she "wouldn't exercise as much and would be more apt to indulge into sweets and maybe she wouldn't be thinking about her diet as much as she needs to." However, after she watched Dawn's video she expands this thought by saying, "If she didn't have diabetes she wouldn't have to worry about maintaining what she eats or putting time aside for exercising and organizing a meal plan on top of time for her classes." There even seems to be more coherence between all of Dawn's life events and how her disease constantly affects how much time and effort she must put into these tasks.

Although Dawn's mother admits that she already knew of her daughter's illness-related struggles, she felt that watching her illness narrative and actually hearing Dawn explain these

issues added a different dimension to her perception of Dawn's experience. Judy, like Katharine, learned that just how much these illness-related issues can interfere with Dawn's day-to-day life, "I already knew many of the issues that she deals with, but to see how much she thinks about it and how much time it takes, shows on a day-to-day basis how much it affects her."

In another instance, Katharine's perception of Dawn's career choice drastically changed after she watched the video narrative. Katharine initially believed that Dawn could use her experiences as a diabetic to be "more empathetic" towards her patients and she "could relate to anyone who has it and comfort them because she has a real idea of the disease and knows how to deal with it."

Although she still recognizes this, she now also sees that Dawn will meet challenges as a nurse because of her condition. She will also be obligated to share her condition with her colleagues "in case there's a complication with it," even if "she may not want to tell them." Every person should have a right to privacy, but chronically-ill people are stripped of that privilege in situations where their condition poses a threat to their own safety or the safety of others.

Confronting Obstacles

Unfortunately, there is little research available on video-based illness narratives since anthropologists have focused on compiling research on written patient stories. Therefore, I recorded the obstacles that Dawn and I confronted while we constructed her narrative so that future studies or projects can reference this information. One of my original research questions asked: What are the challenges of co-constructing a video illness narrative with a patient?

Throughout the process, we met four different types of obstacles: emotional discomfort filming and publicizing her disease, shyness in front of the camera, difficulty giving accurate and descriptive answers, and technical difficulties.

1. Emotional discomfort filming and publicizing her disease

Although video has obvious advantages because it is a multimodal platform, patients who don't have much experience with film may find it intimidating. At our second meeting,



Figure 5: Dawn and her friends in Davison Dining Hall, a public location, at Saint Anselm

Dawn and I reviewed the clips she had taped the previous week and I noticed that she tended only to film segments that expressed her thoughts on daily life with diabetes and she only taped these within her college dorm room.

Though I believe that

these can be useful for a video illness narrative, I imagined that video of specific locations and scenarios that Dawn had described in her written illness narrative could also be useful because I thought the visual information might further stimulate Dawn's memory. Dawn explained that she didn't film in other locations because she felt embarrassed to carry and use the camera in front of her friends or in public locations where people would wonder what she was doing. I suggested that by explaining to her friends why she was creating a video narrative and bringing a close friend with her to film, she might feel more comfortable capturing this type of video. After the second week of taping, she captured a few more confessional-styled segments in her dorm room, but she also made

an obvious effort to film several public setting clips. In order to do this, Dawn was forced to talk about and share her disease with her friends; she was “outed” in the process. Although patients can also find written narrative difficult, it can be done completely in private because there is no need to consult or film friends or other people; video requires patients to be more public and open about their disease. I believe that this “outing” might encourage a patient’s recovery because it forces each patient to accept and think about what has happened to them. However, I don’t believe that future projects should necessarily force patients to share their experiences with others, unless they are emotionally stable.

2. Shyness in front of the camera

Another obstacle that we encountered throughout the process was that Dawn initially felt uncomfortable or intimidated when she was in front of the camera. When we met to film the preliminary questions, Dawn was very hesitant to answer questions or was at a loss for words towards the beginning of the session. However, after a few questions she began to feel more comfortable and our question-and-answer session turned into a much more relaxed, free-flowing conversation. In future studies, I would recommend starting the first session with questions that are not particularly important in order to get the patient used to talking in front of a camera.

In addition, Dawn had a difficult time deciding what to say in some of her “confessional” segments most likely because the camera was watching her and she wanted to express her feelings eloquently in case they appeared in the final video.

When we had set up to record an audio track of Dawn’s written narrative, she expressed to me that she felt uncomfortable reading her narrative aloud in front of the camera, but I

assured her that if she stumbled on a few of her words, I could edit out the mistakes.

Additionally, a patient might find that reading her narrative out loud encourages her own acceptance of an illness experience.

3. Difficulty giving accurate and descriptive answers

Even after Dawn seemed comfortable in front of the camera, she often found it difficult to provide detailed answers that could exemplify disease-related problems. When I had met with Dawn and members of her listening community, I learned that Dawn very rarely discussed her disease with others so she wasn't used to talking about her condition with others and it took her a while to think of specific information. However, when I asked Dawn specific cause-and-effect questions at our second meeting, it was easier for her to recall details about disease-related experiences. Still, it's possible that using video added another layer of self-consciousness that made it more difficult for Dawn to come up with descriptive answers.

4. Technical difficulties

I encountered several technical difficulties commonly associated with video. Dawn and her friends also had a difficult time keeping the camera steady, so I would recommend supplying a tripod if one is financially able to do so. Future studies might also consider arranging practice runs to improve the overall quality of the video, since an accurate visual representation of the patient's experience is important to its ability to stimulate the patient's memory.

Additional Benefits

As my literature review had suggested, illness narrative can have a range of benefits and Dawn experienced some of these while she created her video illness narrative and after when I shared

the final product with her listening community. I have categorized these benefits into two separate groups: New active response to illness and Empathy in the listening community

1. New response to illness

When Dawn began to articulate the cause-and-effect relationships between illness-related events, she began to see what she might have done differently to reach a better outcome. At my third meeting with Dawn, she told me that she began to set goals and develop tools for managing her Type I Diabetes in the future. She realized that only effective control of her disease now would prevent serious complications in the future, and without my prompting, she began to sketch out some plans for the future. The video narrative showed the risks of her behaviors and difficulties keeping on top of the disease, plus how she can easily be thrown off track by temptations, changes in schedule and the influence of friends. In order to more carefully and consciously track trends in her blood sugar levels, Dawn created a spreadsheet to record her daily blood sugars and any events that might have affected them, such as eating candy or exercising. When I last spoke with Dawn, two weeks after the end of the project, she had continued to enter all of her sugars up to date. Thus, creating a video illness narrative may potentially change how a patient responds to her disease. See Appendix I for a copy of Dawn's entire blood sugar spreadsheet.

DATE	Breakfast	Lunch	Dinner	Bed	Notes/Lows & Highs
3/22/10	73	226	228	105	Gym this morning after breakfast; pump off too long = highs?
3/23/10	74	234	76	133	Low during night at 2 a.m. – juice box and yogurt
3/24/10	76	113	89	122	Gym before dinner
3/25/10	59	144	56	87	
3/26/10	76	188	87	221	
3/27/10	123	127	223	156	
3/28/10	114	232	224	164	Candy after lunch and library all day (no movement)= high
3/29/10	71	260	96	136	
3/30/10	104	148	142	132	Gym @ night
3/31/10	156	144	336	201	
4/1/10	69	133	93	131	Run before dinner
4/2/10	103	212	133	127	BG low (72) after run @ 3:30
4/3/10	144	132	104	98	Run in afternoon
4/4/10	69	101	212	202	Easter (dessert in afternoon)

Figure 6: A portion of Dawn’s spreadsheet that she designed to keep track of her daily blood sugars

2. Empathy in the listening community

I also observed that the listening community can develop empathy by watching a patient’s illness narrative if their interpretation of the illness experience has changed. Although Katharine initially identified some of the struggles that Dawn faces, she learned of several other illness-related difficulties and the extent to which they interfere with Dawn’s daily life. Katharine shared with me that learning about Dawn’s disease has influenced her understanding of Dawn’s condition, “Definitely after watching the movies and hearing her diagnosis experiences, I didn’t realize some of the things she was going through. I see her as a stronger person—on top of all her nursing studies she has to deal with this disease, maintaining a gym schedule, watching what she can eat and on top of all that maintaining a social life, so I definitely see her as a stronger person because of that.”

Dawn’s mother, Judy, shared a similar heightened sense of empathy for Dawn’s condition after viewing her narrative. Since then, she shared with me that she wants to reach out to her daughter and talk to her about what she is going through, if Dawn is willing to. Judy explains this, “I wish I could be more a part of her life as far as helping her with her sugars or talking to her, so she can let me know how she feels, but she always acts like, ‘I’m fine, I’m fine, I’m fine,’ but I don’t

know how fine she really is. I wish she would let me in. I think it's important to have someone you can share your thoughts with about such a serious illness so they can help you with it. I don't know who she talks to about it. I don't think she talks to anyone about it, and that's not a good thing."

Conclusions

As Dawn constructed her video illness narrative, I was privileged enough to witness her interpretation and response to illness-related events slowly change over time as she not only accepted responsibility, but became more optimistic about a future with Type I Diabetes.

Although anthropologists have scarcely compiled research on visual illness narrative, this project suggests that video might help many patients react differently to illness and develop empathy in a listening community, as it did with Dawn.

According to Frank's classification of illness narrative plot, Dawn's written first draft only contained evidence of the restitution narrative, not that she will recover physically from illness, but that she will return to her former way of living by following treatment. This is typical of what the medical community encourages and sometimes enforces upon patients. After patients are diagnosed, they are generally taught that recovery can only be reached on the path back to restitution; as a result, many people overlook the "quest narrative," and neglect to consider illness as an opportunity for change, to become a "phoenix" reborn out of his past. When I first met with Dawn, it was very difficult for her to speak openly about her illness because she had never really talked to anyone about it before. While we worked through her written narrative she began to make sense of what her body was going through and how changing her response to diabetes might help her reach future goals. In her final video illness narrative, Dawn's story as a whole still adheres to the restitution narrative because she doesn't entirely redefine herself, but we see several instances of the quest narrative where she emotionally reflects on diabetes beyond the scope of its management and physical effects. She begins to consider how she might behave differently in the future, how she might reach out to others, how she might make better decisions in the face of peer pressure—rather than just assuming that everything will soon return to

“restitution” again without dealing with these underlying issues or accepting responsibility. Perhaps publicizing, sharing, and explaining one’s illness narrative with others can move a patient’s perception out of a reductive restitution narrative and into a more complex quest narrative that focuses on self-interpretation, motivations, and identity issues. During the final segment of her video, Dawn discusses the specific long-term management plans and goals for her illness and embraces her disease—seven-and-a-half years after diagnosis—as an opportunity for change.

Additionally, I believe that sharing Dawn’s illness narrative with members of her listening community might encourage an atmosphere at home and at school that fosters open discussion about her condition. Initially, I had also planned to interview and share Dawn’s final video with a health services worker from Worcester Polytechnic Institute, as I imagined that college healthcare figures might comprise Dawn’s listening community while away at school. Unfortunately, the time restrictions of this project and other schedule conflicts didn’t provide for the investigation of this possibility; see Appendix F for a record of the email correspondence with WPI Health Services. However, I would encourage future studies to consider this option.

Although patients might meet several obstacles while creating a video narrative, they might respond to these problems in ways that encourage patient recovery and empathy in the listening community. Initially, Dawn was uncomfortable publicizing her disease or asking friends to help her film, but in order to complete her narrative she was forced to overcome these fears and be open with others about her illness. On the contrary, patients can construct written narratives in private without interacting with others because there is no need to capture outside media.

On a personal note, this experience was very rewarding for me because I had the opportunity to not only talk openly with my sister about her disease, but also the opportunity to help her work through issues she had hidden away so she can build a healthier future with diabetes. Arthur Kleinman once said, “The chronically ill live at the margins” (Kleinman, *Illness Narratives* 47); as Dawn’s sister, as a member of her listening community, I also feel a heightened sense of empathy as I try to comprehend exactly what it must be like to live in that unrelenting balancing act, that constant struggle where health and happiness hinge on your every decision.

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Classical Plot Structure Image.

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A. FlipShare UltraHD Video Camera Specifications

UltraHD™ 2 Hours

The Flip UltraHD camcorder combines Flip Video's signature shoot-and-share simplicity with the power of vivid, vibrant HD video. With 2 hours of record time, you'll never miss another minute again. And because of UltraHD's pocket-sized portability, you'll truly be able to capture HD video anytime, anywhere.

Select a color:

Free Shipping

\$199.99

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Features

Accessories

What you get

Specifications

Simple to Shoot

- Easy-to-use, pocket-sized HD camcorder
- Start recording within 3 seconds of power-up; simple user interface features one-touch recording, making HD video easier and more fun than ever
- Captures 2 hours of incredible HD video on 8GB of built-in memory; no additional memory needed
- Comes with Flip Video rechargeable AA battery pack (recharges when connected to USB); Power Adapter sold separately ([buy now](#)); Camcorder also functions with two standard AA batteries
- Large 2.0 inch anti-glare display to play back and delete videos
- Fast lens - great low or bright light results; 2x digital zoom
- Convenient flip-out USB arm plugs directly into your PC or Mac to launch pre-loaded FlipShare™ software
- FlipShare software makes it easy to email videos, edit individual clips, make custom movies, capture still-image snapshots, and upload video to Facebook™, MySpace™, YouTube™ and other sharing sites
- HDMI™ output (mini-HDMI connector) makes it easy to watch video on your HDTV; Standard HDMI™ cables sold separately ([buy now](#))
- Records high-quality H.264 videos that are compatible with most video-playing applications, including Windows Media Player, QuickTime Player, and iTunes
- Video: 16:9 widescreen, HD 720p (1280 x 720) at 30 frames per second (fps) progressive scan; recorded as MP4 files
- "Child Safe" mode to prevent accidental deletions of clips
- Silent mode for recording in sensitive situations
- Tripod mount fits any standard tripod

Simple to Share

Pre-loaded FlipShare™ software for instant viewing, editing, one-click emailing, and online sharing:

- Browse, play back, organize and archive your videos
- Create movies with video clips, music and titles
- Edit clips and create still-image snapshots from video
- Instantly upload to Facebook™, MySpace™, YouTube™ and other video sharing sites
- Share your videos privately using attachment-free emails or greetings cards (free and unlimited video sharing)
- Create private Flip Channels to share your videos with groups of family and friends

B. Adobe Premiere Pro Software Specifications

General

Category	Creativity application
Subcategory	Creativity - video editing & production
Language(s)	Universal English

Software

License Type	Upgrade package
License Qty	1 user
License Pricing	Standard
Platform	Windows
Distribution Media	DVD-ROM
Package Type	Retail

System Requirements

OS Required	Microsoft Windows XP SP2 or later, Microsoft Windows Vista Business SP1, Microsoft Windows Vista Home Premium SP1, Microsoft Windows Vista Ultimate SP1, Microsoft Windows Vista Enterprise SP1
Software Requirements	QuickTime 7.4.5
Peripheral / Interface Devices	Sound card, DVD-ROM, Internet connection, OpenGL compatible graphics card, 1280 x 900 monitor resolution, 7200 RPM or faster hard drive
System Requirements Details	Microsoft Windows Vista / XP - 2 GHz - RAM 2 GB - HD 10 GB

Universal Product Identifiers

Part Numbers	65021063, 65021008
UPC	0883919163390, 0883919163291

C. Video Credits

Director:

Andrea Bisson

Producers:

Alyssa Bisson

Andrea Bisson

Editor:

Andrea Bisson

Advisor:

Lorraine Higgins

Drivers:

Andrea Fine

Andrea Bisson

Camera Women:

Alyssa Bisson

Talene O'Brien

Becky Damon

Andrea Bisson

Hannah Dubois

D. Transcripts from Listening Community Interview with Dawn's mother, Judy Johnson

Pre-Video Transcript

- 1. Give a brief a summary of the history of your [Dawn's] illness, including your [her] diagnosis and history up until recently.**

She was 12 years old when she was diagnosed, I try to be supportive as much as I can. It was easier for me to be more involved when she was younger, but now that she's gone off to college, it's more difficult. It's been hard. It hurts to see her have it, I wish she didn't have it and sometimes I wish I had it instead of her. If I could make that happen, I would. It's been hard because it's always hard to see your child hurt, because you know it's a relentless, neverending disease and you worry about the future and how she'll deal with any complications if they come along.

- 2. What problems does your [Dawn's] illness currently cause [her] for you? Which of these has created the biggest struggle for [her] you?**

I think it interferes with her daily living of what a typical 19 yr old should be living, physically, and it's emotionally draining. It's a neverending disease that causes her difficulties in everyday ways. She has to think of taking care of herself and her disease. She shouldn't have to think of a chronic illness right now. It interferes with probably her social life and just everyday life. She has to think of what she eats, when to take medicine, and how to juggle her exercise with eating; things that normal people don't even have to think of. It should be something she doesn't have to think of. It probably also affects her ability to study and test-taking times because she could be running low blood sugars and doesn't know it. Every part of her life is complicated because of

diabetes.

Right now her schooling is probably the most difficult. She's trying to go through school and get a career, but it's more difficult than it is for another person her age. It's harder to study because it makes her body more tired and she has to deal with that. She has to stop and take care of insulin and supplies, test her blood sugar constantly. I think it's probably tough at college right now and she wants to be like everybody else and not have to deal with all of this.

3. How do [Do you think] these problems interfere with the goals you have [Dawn has] set for the future, even simple goals for the near future? [If so, how do you think they affect her future goals and why?]

I don't think it interferes with her goals. She has her goals, she's very strong-minded and determined to keep those goals no matter what she has to go through. She's just gonna keep her goals because she doesn't give in. Sometimes I don't think I know how much she is really hurting because I don't think she shares it with me. But she always goes to achieve, no matter how difficult it is for her she always achieves her ultimate goal. And it has been difficult at times, but she just keeps persevering.

4. How do you think your [Dawn's] life would be different now if you [she] had never been diagnosed with Type I Diabetes?

It would be a lot less stressful and it would take a huge stressor out of life that would never have been there if she had never been diagnosed. But I don't think it's held her back to be where she is, I think she would be in the same place because she was determined to do well in school despite her disease. It got complicated when she was diagnosed with epilepsy, which made everything even more difficult, but she still took it

in stride and she still focused on her ultimate goal. I still think she'd go into nursing and she would still want to go to great school and try to achieve like she is now. I think that studying wouldn't be as difficult for her because the medicine she takes for epilepsy and the high and lows make studying very difficult for her. But it doesn't stop her from wanting to go in the same direction, this is what she wanted in life. I don't think it ever will, but unfortunately complications could happen in the future and she'll have to deal with them if they do and she will, but I just pray to God that they never do.

5. Have your [Do you think Dawn's] future plans changed at all since or because of your [her] illness? [What do you think she has changed?]

I don't think her future plans have ever changed, but I think sometimes she questions certain aspects, but I think that some of these fears were relieved by one of the doctors. I know she wants to get married and have kids one day and I know she's thought of the complications during pregnancy as a diabetic and an epileptic, but she still wants kids someday and I want her to—she wants to. I don't think her future plans have really changed, but I do think that she's had to question things because these worries are there that wouldn't have been if she was never diagnosed. She knows what she wants in life.

6. If you [Dawn] could change one thing about your [her] disease and how it affects your [her] life, what [do you think it] would it be? How can you [she] change it? How can others help you change it? [How could you help her to change it?]

I think that she would change the risk of complications, like sight and kidney problems. The only way she can change that is if she gets a good grip on her sugars and controlling them every day. That's the hardest part of keeping her diabetes and sugars controlled; it can be very frustrating because it's still all over the place sometimes. I don't really know

what her sugars are because she doesn't really share them with me. I understand that she wants to be independent, but I helped take care of her for a while. I hope she has good control, because she could run into problems. I don't even know how her last Hemoglobin A1C was, which is a tests that tells what your average sugars were for the last three months

7. [In what ways do you treat Dawn differently than other people, positively, negatively, or neutrally, because she has Type I Diabetes? How do you think these adjustments in behavior help Dawn?]

I treat her the same as any of my other children. Of course I worry about her conditions, but I don't treat her any differently, I love them all the same. I worry about them all the same, but because of her conditions I have to say there is a part of me that when the phone rings late at night or unexpectedly, she's the first thing I think of because of her medical conditions and my heart sinks. She has complicated conditions and there is always a risk that something could happen. I probably do ask her more often than she wants me to, if she's okay and I try to be conscious of it because I know it bothers her because she doesn't want to be treated differently, like people sympathizing with her or making her feel different, but it's a natural tendency and I just want to make sure she's okay. But I'm careful not to put too much emphasis on it and sometimes I don't have to ask her because I can just tell by looking at her that's she not.

8. [What role do you currently feel that you play or are responsible to play in Dawn's illness experience?]

I'm responsible to play a role that is supportive of he and be there for her when she needs me. She doesn't want to me to single her out of the three kids, she wants me to let her go

and we'll be okay. I try. It's hard, I don't know, I have no choice now. I don't see her much, I don't really know how she is up there. I know she must be okay because she's succeeding at college, but it doesn't mean that anything couldn't happen, but she has to grow up. You raise kids to become independent and be successful and that's what she wants to do and she's doing a good job at it.

9. [How do you think the way you act around Dawn can influence how she reacts to and manages her Type I Diabetes?]

Well you can, if you hover too much over her, what she thinks is too much I don't, we do differ in that way. I don't know if it's just because I'm her mother, now that she turns older 17, 18, 19, she doesn't let me in much at all to help her. Sometimes I feel like I want to help her, but it counteracts the whole thing if I try, so I have to trust her. She became independent very quickly; if I overreact and she sees it it's not good. I have to try and know that she can take care of it and know that she'll be okay, but also be there when she does need me and I have to know the difference between the two.

10. [Do you have any other comments to add?]

Living with a child with diabetes, or any other chronic illness is like a roller-coaster world with many ups and downs. You have to just learn to go with it, to ride the waves and go with it, because if you fight it you will only get frustrated and upset, and it just stops you from making any progress. It becomes part of your life; when your child is first diagnosed you don't understand how you're going to live your life like before. I remember the doctors told us, 'it's like taking a newborn home from the hospital again.' You wonder how can I do this? How can you raise your child like this? How can you take care of your child? How can you make them okay? ...But they'll be alright. You learn to ride the

waves and go with the ups and down—and someday you have to let them go. If you can achieve all of that, then you can raise a child with a chronic illness; that they can feel independent enough when it's time to let them go. She did a lot of it though and it really depends on the child. She was determined since the day she was diagnosed to take care of it, and she did.

Post-Video Transcript

- 1. Give a brief a summary of the history of your [Dawn's] illness, including your [her] diagnosis and history up until recently.**

It would be the same as before, the diagnosis and everything and I still record the disease the same now, but I know how she feels now though. So I don't know if I would answer this question any different.

- 2. What problems does your [Dawn's] illness currently cause [her] for you? Which of these has created the biggest struggle for [her] you?**

Well, by watching the video it gave me more insight and I now see how much she is struggling to manage the disease and how diligent she is trying to become to be with it and how much time it really takes out of her day to juggle her sugars with exercise, and classes. It interferes with her studying when her sugars make her physically feel sick. I knew she had trouble with this, but I guess by watching the movie it gave me a more in depth picture of it. She never really complains about it, talks about. By seeing it I want to help her, but I don't know how much she really will let you help her. It's tough.

I think for her right now socially is a big thing. I think it's a big struggle to try to maintain her course load and feel well enough to perform like she needs to in school. At

the same time dealing with sugars can mean the difference between whether or not she passes her test. To her I think she wants to feel good and do that, but on the other hand social aspects are huge too. It's obvious, she gets really emotional in part of the movie when she says she doesn't want people to treat her like a child and draw attention to her illness, and then she feels like people don't really want her around if they're drinking or hanging out. They're both important to her right now, succeeding in school, but emotionally social aspects are huge to her. Then she wonders if someone is going to want to go out with her because of her diabetes; it's a big impact. Both strongly impact her, and they bother her.

- 3. How do [Do you think] these problems interfere with the goals you have [Dawn has] set for the future, even simple goals for the near future? [If so, how do you think they affect her future goals and why?]**

I think for the near future her goal is to get through school and become a nurse, and I think her diabetes impacts how well she's going to do. If she can't balance her sugars, it can mean the difference between passing or failing an exam, so it impacts that goal because she really want to become a nurse and succeed and graduate. She's doing okay now, but it can really impact her depending on how stable her sugars are. She wants to become social with everyone and have a relationship some day.

Short-term I think she'd like to be in a relationship, and long-term I think some day she wants to get married and have children; she knows that diabetes can impact that too.

- 4. How do you think your [Dawn's] life would be different now if you [she] had never been diagnosed with Type I Diabetes?**

It would be a lot different, but I think she always sort of been adventurous and independent. She likes to be independent and this holds her back as well as her epilepsy. I think she would still have the same goals like I said before but her whole being would be different; her state of mind would be different as far as the worries, the burdens, worrying about everything she eats and exercises. She has to put so much thought into that and she could focus more on what is important to someone at that stage in life, like career goals, and not worry “Am I going to feel well enough to study?” “Will my sugars be too high or too low?” It really showed me how much she has to figure out, she has to exercise before exams and it’s something that a young person her age shouldn’t have to worry about. It’s hard enough to be a young person trying to figure out things and become independent, and she should not have to worry about sugars and long-term complications; losing a limb obviously worries her. She wouldn’t have any of these concerns on mind or in her life if she didn’t have this horrible, relentless disease.

She’s not as comfortable as I thought she was with testing her blood sugars in front of people at school. Her friend went to the bathroom and she tested her blood sugar and I actually thought she was more comfortable than that. She comes across as very laidback and relaxed, but now it’s obvious that there is a lot on her mind.

5. Have your [Do you think Dawn’s] future plans changed at all since or because of your [her] illness? [What do you think she has changed?]

No, I think that she still holds the future plans, but I think she knows in her heart that it may not be as easy to attain like her goals of achieving a degree in nursing. I think she’ll do it though. She’s doing okay, but even functioning in the role of a nurse, she will function according to how her sugars are. I don’t think her goals have changed and I

think it's important for her to still have these goals. They drive her to achieve and have hope to achieve these goals and work towards them. It's more difficult for her though because of her illness, as far as school and getting into a relationship. I totally understand what she's saying and I think it does affect getting into a relationship. Whoever she dates has to consider how involved and how serious they want to get with someone who has a serious illness. I hope she does find someone someday who can handle her illness and realize what a beautiful person she is.

6. If you [Dawn] could change one thing about your [her] disease and how it affects your [her] life, what [do you think it] would it be? How can you [she] change it? How can others help you change it? [How could you help her to change it?]

I think that if she could just try to maintain her blood sugars without having to work so hard at it, if she could manage them just by eating and exercising into a regular routine her disease wouldn't take so much effort to think about. I think it's something that she would want to change so she wouldn't run into complications. As far as me, I wish I could impact her more as far as I should probably be more diligent about maybe making exercise more of my life and diet too and not have so many sweets. I've always wished that we could do that. I think the whole family could work at that. In the film she says she almost thinks she doesn't have control over it, which makes me wish she would let me in and let me help her more. It's a balancing act. She doesn't let me in much and I feel sort of guilty about that because I don't really know how her sugars are, but she doesn't let me know. I wish I could be more a part of her life as far as helping her with her sugars or talking to her, so she can let me know how she feels, but she always acts like, 'I'm fine, I'm fine, I'm fine,' but I don't know how fine she really is. I wish she would let me in. I

think it's important to have someone you can share your thoughts with about such a serious illness so they can help you with it. I don't know who she talks to about it. I don't think she talks to anyone about it, and that's not a good thing.

7. [In what ways do you treat Dawn differently than other people, positively, negatively, or neutrally, because she has Type I Diabetes? How do you think these adjustments in behavior help Dawn?]

I don't really think I treat her any differently. I still don't think I treat her any differently. I'm more concerned where her illness is, but I try not to show that as much because she gets defensive and she doesn't like to be hovered over, but inside I feel different because I know that she's so susceptible to all the complications. I worry about her. I can't help it. It's a very severe illness, but I try not to show it on the outside to her.

8. [What role do you currently feel that you play or are responsible to play in Dawn's illness experience?]

I try to be very supportive of her as much as I can be. I don't really think she lets me, but I'm always wanting to make sure that she has all her supplies, I ask about her sugars, like I said before all she really says is "I'm fine, I'm fine." I want to be more involved with her especially seeing the movie. I wish she'd let me help her and talk to me about it. I think it's important to open up about it and that does bother me that she doesn't. I'll always be there to talk about it, but it takes her to respond in a way that shows she wants to. It's really up to her how much she wants to talk about it.

9. [How do you think the way you act around Dawn can influence how she reacts to and manages her Type I Diabetes?]

If I act too anxious or worry she doesn't like it. It impacts her negatively so I try not to

show any alarm. When she was younger it was different because I knew her sugars, but now I don't know what they are because she doesn't live at home, she's always at school. When I'm with her and she runs low I get concerned because she has epilepsy too, and you have to be able to recognize which one it is and be aware of what's going on with her. Basically I just think you have to act confident in yourself about the disease, and you can learn to live with it as long as you manage your sugars. I wish we all had as a family become involved with exercise and diet because I think it would have made it an easier adjustment for her and it would have been good for us too.

10. [Do you have any other comments to add?]

I think it was a really good for me to see the video because that's a part of Alyssa that has never ever opened up to me and I probably never would have seen that part of her. I also think it's very good for her to verbalize her thoughts and feelings and put it out there and be able to see herself. I think it will help her positively in the long run and it will also impact me positively because I get to see how my daughter is really feeling and how this disease has impacted her over the seven-and-a-half years since she was diagnosed. I think it's good for all of us as a family. I already knew many of the issues that she deals with, but to see how much she thinks about it and how much time it takes, shows on a day-to-day basis how much it affects her. I want to let her know that I'm always here for her and I always try to be supportive and positive for her. It's good for all of us as a family to see it. It really lets you know how she's feeling and what she has to deal with.

E. Transcripts from Listening Community Interview with Dawn's friend, Katharine

Pre-video Transcript

- 1. Give a brief a summary of the history of your [Dawn's] illness, including your [her] diagnosis and history up until recently.**

Really all I know about diabetes is that the pancreas isn't producing insulin, so she needs to pump insulin into herself and needs to watch she eats and count calories. It really hasn't affected anything for me. She is usually pretty discreet about checking and testing blood sugar and giving insulin; sometimes I don't even notice if she's doing it. At this point I don't even think much of it either.

- 2. What problems does your [Dawn's] illness currently cause [her] for you? Which of these has created the biggest struggle for [her] you?**

I think a big problem for her to watch what she eats for sure, so if someone's eating a dessert she might not be able to eat it even if she wants it but know she can't have it. I know if she goes to a party and there's drinking she'll might to be inclined to drink too because that's what everyone else is doing, but has to take into account that she can't because of the diabetes, so I think those are the two main difficulties. I think the most troubling would be the desserts because it's more of a exposure for her. At Davison there are so many sweets everywhere and none of her other friends have diabetes, so it's nothing that they have to worry about, but Alyssa has to tone it back or not eat any at all.

- 3. How do [Do you think] these problems interfere with the goals you have [Dawn has] set for the future, even simple goals for the near future? [If so, how do you think they affect her future goals and why?]**

I'm sure they will affect her future goals with this disease in general. It affects anyone,

but I think because she wants to be a nurse it will make her more empathetic. She definitely has first-hand experience so anyone who has it she can relate to and comfort them and have a real idea of how to deal with it. So I think it might even help her more if she goes into that aspect of nursing.

4. How do you think your [Dawn's] life would be different now if you [she] had never been diagnosed with Type I Diabetes?

Well I know that she has to exercise a lot to keep everything in check .If she didn't have diabetes maybe she wouldn't exercise as much and be more apt to indulge into sweets and maybe not think about her diet as much as she needs to.

5. Have your [Do you think Dawn's] future plans changed at all since or because of your [her] illness? [What do you think she has changed?]

I don't think so, but we don't talk about diabetes that much. When I lived with her last year we talked about it every now and then. I hadn't really known someone that well who had diabetes so I never seen the process of taking blood sugars or insulin. It only came up out of my own curiosity, but other than that we don't talk about how it affects her lifestyle, so I don't know if it has changed any of her future goals.

6. If you [Dawn] could change one thing about your [her] disease and how it affects your [her] life, what [do you think it] would it be? How can you [she] change it? How can others help you change it? [How could you help her to change it?]

I know she definitely wants a cure of course, but I think if that isn't a possibility maybe just like being able to maintain her disease easier, maybe not have to check her blood sugars as often or maybe not have to give insulin as much, maybe that would be more beneficial for her. If she has to do it in public, she might be more self-conscious around

people she doesn't know. One time she was waiting for someone she doesn't know well to leave so she could check her blood sugar and I think if she didn't have to check it as much I think it would be a relief for her and make her less self-conscious.

7. In what ways do you treat Dawn differently than other people, positively, negatively, or neutrally, because she has Type I Diabetes? How do you think these adjustments in behavior help Dawn?

Well, when she sent me a message on Facebook saying that I was her roommate and she has diabetes and epilepsy, at first I was like "Whoa." My neighbor has diabetes and I thought it would be interesting to see how she goes through the process. I like that she was very open about it and told me that she had the disease. It hasn't changed my views at all and when I got to know her I didn't really think about it. I was just like "Oh, she has diabetes; it's just another aspect of her."

8. [What role do you currently feel that you play or are responsible to play in Dawn's illness experience?]

Well, sometimes she asks for my opinion if she thinks that she should eat something and I kind of well ask her if it has too many carbs for you , "Do you think you should have that?" but I guess for people that know she has it and people that she trusts with that information she'll sometimes rely on them for advice, but I guess that's as much help I can give her really. Or like just having me there to reassure her to not have something if she had already had something earlier in the day.

9. [How do you think the way you act around Dawn can influence how she reacts to and manages her Type I Diabetes?]

I think that if I when I originally found out if I was judgmental or gave any negative vibes

she would have been self-conscious and would not have wanted to be open about it, especially because we were roommates. In the room she'll give herself insulin and do testing or wake up in the middle of the night, so if I had a negative reaction, that would have hurt her because she wouldn't have felt comfortable dealing with the disease in her own room.

10. [Do you have any other comments to add?]

No.

Post-Video Questions

1. Give a brief a summary of the history of your [Dawn's] illness, including your [her] diagnosis and history up until recently.

I didn't realize that there was so much involved after being diagnosed like the whole process, going to Children's hospital and going through learning how to prick your finger. I guess it's kind of obvious, but I didn't think of it like that before.

2. What problems does your [Dawn's] illness currently cause [her] for you? Which of these has created the biggest struggle for [her] you?

There's definitely the problem I guess of social aspects, of what people are going to think of you when you tell them or being hesitant to tell people if they don't know, or not wanting to share it with people. I guess social problems are a pretty big issue, especially since we're on a small college campus and people always know other people's business through word of mouth. Dawn might be more hesitant to tell people about it. I guess she's probably selective of who she tells and at the same time she has to remember who knows. I see it differently because she is comfortable talking about insulin and discussing her diabetes with me, and I've never been around anyone she's not comfortable sharing it

with.

- 3. How do [Do you think] these problems interfere with the goals you have [Dawn has] set for the future, even simple goals for the near future? [If so, how do you think they affect her future goals and why?]**

I think that since she wants to be a nurse she might feel more inclined to tell her colleagues whether she wants to or not in case there's a complication with it or if she feels it would be better that they know. She may not want to tell them but at the same time she might feel like she has to, especially in the nursing field.

- 4. How do you think your [Dawn's] life would be different now if you [she] had never been diagnosed with Type I Diabetes?**

Well she said in the film that she has to do a lot of preplanning of what she eats, when she's exercising has to take into account any school tests. She says she has to be smarter about what she eats before studying or before she takes a major test. If she didn't have diabetes she wouldn't have to worry about maintaining what she eats or putting time aside for exercising, on top of time for her classes to set up time for exercising or for a meal plan.

- 5. Have your [Do you think Dawn's] future plans changed at all since or because of your [her] illness? [What do you think she has changed?]**

I don't think she's changed any future plans. She might have changed what kind of field she wants to go into, but I didn't really talk to her about it. But I guess everyday is different so there's going to be changes with every day.

- 6. If you [Dawn] could change one thing about your [her] disease and how it affects your [her] life, what [do you think it] would it be? How can you [she] change it? How can**

others help you change it? [How could you help her to change it?]

If she could change the stress that it gives her; she said that when she came back from New Orleans, she was really stressed about maintaining decent blood sugar levels on top of finding time to study. If she could eliminate the stress that diabetes gives her, I think that would be real helpful.

I could help her change it. If she thought that she needed more exercise, I could be a gym buddy or go for a walk with her and hang out and talk, or go to library and help her study or help keep her focused when her blood sugars aren't good. If she's feeling unfocused maybe we could take a study break and get something in her to bring down her blood sugars.

7. [In what ways do you treat Dawn differently than other people, positively, negatively, or neutrally, because she has Type I Diabetes? How do you think these adjustments in behavior help Dawn?]

Definitely after watching the movies and hearing her diagnosis experiences, I didn't realize some of the things she was going through. I see her as a stronger person—on top of all her nursing studies she has to deal with this disease, maintaining a gym schedule, watching what she can eat and on top of all that maintaining a social life, so I definitely see her as a stronger person because of that.

8. [What role do you currently feel that you play or are responsible to play in Dawn's illness experience?]

Maybe just like a supporter or something. I know one time we went to a party and the next day she wasn't feeling too great, so I spent the whole day with her even when she

slept. I think she appreciated that. We watched a movie together and ate some food to take her mind off of it because she was feeling lousy. I encourage her and if she's looking for reassurance for what she should eat, she'll ask me sometimes.

9. [How do you think the way you act around Dawn can influence how she reacts to and manages her Type I Diabetes?]

I guess I don't really treat Alyssa any differently at all and I think she appreciates that. I think she appreciates when anyone treats her like a normal person. I think just constantly encouraging her, maybe if she doesn't feel like going to the gym, but if she has to go, then tell her, "If you think you have to go, then you probably should go." She keeps me informed on any changes she makes with her disease. For example, last year when she told me when she went from the insulin pump to the pen, and I think if she keeps me informed that it will make it easier for me to support her and help her out with it.

10. [Do you have any other comments to add?]

I think the video is an awesome idea. It definitely gives people who might not have knowledge of the disease new insights. I definitely learned some new things about her diagnosis and some of the struggles she faces that I might not see, like social aspects. I see it differently because she is comfortable talking about insulin and discussing it with me, and I've never been around anyone she's not comfortable sharing it with. I think it's cool she went to diabetes camp and if I had diabetes, I would definitely want to go do something like that because I would feel isolated.

F. Email Correspondence with Worcester Polytechnic Institute Health Services

☆ ● **Andrea Bisson** to healthcenter, Lorraine [show details](#) Mar 25 [Reply](#)

Good Afternoon,

I'm currently a senior at WPI and am completely an MQP in Technical Writing that focuses on using video as a platform for creating a patient's illness narrative. I've been working with a 19-year-old Type I Diabetic woman to coconstruct a video illness narrative that documents her struggle to maintain healthy blood sugars while away at college. Another portion of the project examines how a video illness narrative might affect how the patient's friends, family, and university healthcare professional figures interpret the patient's experience with the illness. I'm writing to ask if there is a healthcare worker at WPI Health Services that would be willing to meet for 45 minutes to an hour to answer, on film, a few questions about how they think a diabetic student experiences their illness, view the video illness narrative that we have created, and then answer a few follow-up questions on film. Any help would be greatly appreciated. Thank you very much.

Sincerely,

Andrea Bisson

[Reply](#) [Reply to all](#) [Forward](#)

☆ **Roberto, Regina A.** to me, Lorraine [show details](#) Mar 30 [Reply](#)

Andrea,

We would be willing to discuss your inquiry.
What is your availability and time frame?

Regina Roberto MSN APRN-BC
Director WPI Health Services
508-831-5520

☆ ● **Andrea Bisson** to Regina [show details](#) Apr 8 [Reply](#)

Hi Regina,

I apologize for taking so long to get back to you. I was having technical problems with my video editing software at the time and wasn't sure when I was going to be able to finish it, but this past weekend I was able to solve these problems and complete the video. I have a busy, but very flexible schedule and can meet most any day except from 9AM-11AM and noon on Wednesday because I have class. Please let me know what time is most convenient for you. Thanks!

-Andrea

- Show quoted text -

G. Record of my Journal Entries

Saturday, 3/13/10

Obstacles

- Participant took a while to feel comfortable answering questions in front of camera
 - Future studies, try starting with unimportant questions until participant feels comfortable and then ask preliminary questions
- Difficult to get access to video equipment that I could leave with participant for a week
 - Bought FlipShare video camera at Walmart
- Consider using a tripod, otherwise video comes out shaky unless you can find something to position it on
 - Set up camera near interviewer so that patient gives answers to both you and the camera

Benefits

- No need to write down patient's answers to questions, so I could fully engage in her answers and provide adequate prompts when necessary (could look at video later)
- Patient is given time to reflect on questions before writing her illness narrative
- Set up camera on object, so camera was more stable

Monday, 3/15/10

Obstacles

- Received patient's written narrative, but it is written in present tense. This makes the narrative more difficult to work with and I anticipate that it will also make it harder for us to rewrite it during our second meeting. I should have clarified this more when I gave her the written illness narrative instructions.

Tuesday, 3/16/10

After meeting with my advisor, we have decided it is best to ask Dawn to rewrite her narrative to replace present-tense verbs with past-tense verbs.

Saturday, 3/20/10

Meeting Two: Saint Anselm College

Obstacles

- Dawn tended to film only reflections on problem-related experiences and usually only in the privacy of her own dorm room. Although these can be useful for the video illness narrative, I imagine video of specific locations and scenarios mentioned in the written illness narrative will also be useful.
 - Instructed Dawn to include both types of video in the next week
- Many of the clips are very shaky because it was difficult for Dawn/her friends to find a smooth surface to position the camera on.
- Some of the clips filmed by Dawn's friends cut out the top portion of the scene and sometimes cut out the top of Dawn's head.
 - Discussed this with Dawn and Dawn's friend

- Tripod would have definitely been helpful, but I was unable to afford to buy one for this project.
 - Allows for self-filming as well
 - Recommend for future studies with sufficient funding
- Tended to film by herself/privacy of room because she was embarrassed to film in front of her friends or in public.
- Getting to participant's location is difficult if located far away. Saint Anselm is 1.5 hours away from where I live. If you find a patient who lives closer, you can meet with them more often and possibly further develop the video illness narrative. However, I wanted to work with my sister on this project so I could help her manage her disease, so the travel time was irrelevant for me.

Benefits

- Asking Dawn cause-and-effect questions and then following up with additional questions was very useful for eliciting more narrative detail and causal coherence events.
- Dawn also used journal to record additional plans and goals that she has set to manage her diabetes. Although she was asked to record obstacles and benefits, she also found that the platform was conducive to recording her personal goals. Evidently, writing the illness narrative seems to have increased her understanding of her illness already. Journal also seems to have several uses. Would recommend giving the patient a journal for all of these purposes in future studies. Perhaps participant could even take a video diary instead.
- Good to review clips from first week to ensure that participant is recording clips as you intended/in a way that can be included in video narrative.
- Would a video diary be helpful for researcher as well?

- Dawn already started spreadsheet to record her blood sugars and her daily actions that might influence them i.e. eating candy, exercising.

Monday, 3/22/10

- Received written narrative from Dawn. Dawn had tried to incorporate the details we had discussed on Saturday, but interestingly left out certain aspects e had discussed.
 - Some of these details seemed to assign blame to others or herself.

Tuesday, 3/23/10

- Advisor and I discussed the omission of narrative details. Possible that Dawn purposely left out details that were embarrassing or mad eher feel guilty about disease-related choices. We noted where important details were missing and I asked Dawn to incorporate this information where applicable in the narrative.

Saturday, 3/26/10

Meeting Three: WPI

Met with Dawn to review all clips and begin to edit video. We outlined the video by designating where to use each clip.

Obstacles

- Video editing software can be very difficult to work with
- Dawn felt uncomfortable reading her narrative aloud in front of the camera, but perhaps reading it aloud also encourages acceptance of illness condition

Benefits

- Dawn often had to ask friends to help filming or to film them. She this awkward, but this also forced her to be more open with the people she is close to. Written narrative can be done completely in private.

3/26/10-4/3/10

Obstacles

Video Editing:

Editing has been VERY difficult!! Although I checked that the video camera I bought produced film that could be edited with the editing software available, Adobe Premiere software, especially WPI's copy, still had several problems. I would advise others to experiment with the software they are planning to use to avoid technical issues.

H. Record of Dawn's Journal Entries

Obstacles filming:

- Filming in public places (i.e. dining hall, gym)
- Can't film in class (if blood sugar was high or low in middle of class, couldn't start filming in middle of lecture)
- Hard to film low blood sugars in middle of the night; I have a roommate, did not want to wake her up by turning on the light
- Harder to film self without someone else there to set up or hold the camera

Obstacles of diabetes realized through filming:

- Hard to have a constant schedule with exercising and diet to keep good control of blood sugars because:
 - Time management – making time to study and exercise and other activities
 - Times of classes on busy days interfere with times I could be at the gym especially on Mondays, Wednesdays, and Thursdays.
 - Other extracurricular activities
- Low sugars @night, especially after exercising
 - Cause less sleep and interfere with sleep cycles
 - Hard to manage correct insulin ratios with changing schedules
- High sugars
 - Due to not exercising or poor diet
 - Interferes with studying
 - Hard to pay attention in class

Interventions to change these problems:

- Try to plan out schedule in advance to incorporate studying and exercise
- Try not to eat a big meal within one hour before exams or studying
- If craving something sweet, grab:
 - Sugarless gum
 - Water
 - Exercise instead
- Create detailed spreadsheet with BG levels and explain reasons for highs and lows
- Exercise day before exams

I. Dawn's Blood Sugar Spreadsheet

DATE	Breakfast	Lunch	Dinner	Bed	Notes/Lows & Highs
3/22/10	73	226	228	105	Gym this morning after breakfast; pump off too long = highs?
3/23/10	74	234	76	133	Low during night at 2 a.m. – juice box and yogurt
3/24/10	76	113	89	122	Gym before dinner
3/25/10	59	144	56	87	
3/26/10	76	188	87	221	
3/27/10	123	127	223	156	
3/28/10	114	232	224	164	Candy after lunch and library all day (no movement)= high
3/29/10	71	260	96	136	
3/30/10	104	148	142	132	Gym @ night
3/31/10	156	144	336	201	
4/1/10	69	133	93	131	Run before dinner
4/2/10	103	212	133	127	BG low (72) after run @ 3:30
4/3/10	144	132	104	98	Run in afternoon
4/4/10	69	101	212	202	Easter (dessert in afternoon
4/5/10	365	174	177	194	Low last night – too much sugar to fix = breakfast high
4/6/10	119	142	216	252	
4/7/10	99	212	127	186	Run before dinner
4/8/10	96	147	281	74	
4/9/10	108		164	182	
4/10/10	108	76	108	214	
4/11/10	79		116	110	Gym before dinner
4/12/10	108	102	142	317	Gym before dinner
4/13/10	67	96	139	144	Low x2 last night; Gym before lunch; soccer at 8 pm – decreased basal due to exercise
4/14/10	97	101	126	198	
4/15	76		223	99	
4/16	214	202	76	99	(increased basal @ lunch)
4/17	96	222	176	127	Low last night
4/18	86	132	72	122	MS walk (5 miles) @ noon
4/19	83	247	80	62	
4/20	118	163			