

FILMMAKER-AUDIENCE RELATIONSHIP IN MEDICAL DOCUMENTRY

by

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ABSTRACT

As a filmmaker, as well as a person with epilepsy I would like more people to know about epilepsy on an intimate level even if they do not have, or know anyone with epilepsy. In this paper I will compare the techniques used to explain a medical disorder in three different films. What can the filmmaker do to both capture the attention of their audience in order to explain what life can be like for someone with a particular disorder? I argue that, by blending a personal approach with the use of experimental techniques, a filmmaker can appeal to a wider audience by expressing the emotional or experiential reality of living with a given disorder. My own thesis film, *Seizing the Unrecorded*, shows my own journey to understand how my filmmaking and my epilepsy are connected. Using similar techniques to those found in essay and performative films, I go beyond simply explaining what epilepsy is scientifically, and engage the viewer in larger questions such as the concept of what is memory, what it means to be vulnerable, and the emotional as well as physical costs of epilepsy.

INTRODUCTION

For the purpose of this essay, I analyze the level of connection between the audience and the characters portrayed in three illustrative examples from the medical documentary genre, as well as my own thesis film. How do these films develop a connection between the audience and the characters?

The first, *Epilepsy: A Guide for Patients and Families*, directed by Alan Weiss in 2013, is made in a traditionally objective/informational style intended to keep the audience at a comfortable, clinical, distance. The second, *Jabe Babe: A Heightened Life*, directed by Janet Merewether in 2005, is a performative documentary that explores not only Jabe's medical condition of Marfan syndrome, but also her history as a foster child, her adolescence, and her career as a dominatrix. The film achieves a level of intimacy that is absent in *Epilepsy: A Guide*. The third example, *Edge of Dreaming* (2009), is a personal film in which Amy Hardie, the director, employs a highly poetic, self-reflexive style that brings her audience directly into her life and even into her dreams.

My own film, *Seizing the Unrecorded*, represents my attempt to create a film that spans the performative, observational, and poetic modes in order to both educate my audience, and connect them, on a personal level, with both my characters and myself. I want the audience to empathize with the characters in the film.

Not everyone can relate to having epilepsy, but anyone can relate to wanting to know the answer to a question. In the case of my thesis film, the question I hoped to answer was, what is "wrong" with me, medically speaking, and whether or not the process of filmmaking itself was giving me seizures. I wanted to know if it was just a

coincidence that I started having seizures the same semester I took my first filmmaking class. With this question at its core, I chose to make *Seizing the Unrecorded* as an essay film since essay films are characterized by a “continual asking of questions—not necessarily finding ‘solutions’, but enacting the struggle for truth in full view” (Lopate 245).

With this film, I attempted to synthesize the informative style of *Epilepsy: A Guide*, with the symbolic, performative style of *Jabe Babe*, as well as the personal intimacy of Hardie’s *Edge of Dreaming*. In doing this, *Seizing the Unrecorded*, attempts to both inform the audience about epilepsy, as well as make the audience feel a little of what it’s like to live with this condition.

The purpose of my thesis film is to question the portrayal of epilepsy in documentaries, and also to document my journey to find other people with epilepsy in order to learn more about my illness and myself. I wanted my audience to both learn something about the nature of epilepsy and to recognize that these are people with very different backgrounds, people who struggle with universal issues beyond their epilepsy. It is their history as individuals that defines them, and not that they happen to experience epileptic seizures. In my own case, I am a documentary filmmaker first, and a person with epilepsy second, and so the true goal of my film is to communicate a fundamental human truth to a general audience who may or may not suffer from epilepsy. Simply put, you are not defined by adversity, but by victory.

CLINICAL DISTANCE

Epilepsy: A Guide for Patients and Families, keeps its audience at arms length through its use of narration, expert interviews, and onscreen text – all hallmarks of the classically “objective” medical documentary. The level of connectivity between the audience and the characters portrayed in the film is dictated not only by the methods the filmmaker uses to portray the characters themselves, but also their decision to use a voice-of-God style narration, intertitles, and other elements of the informational or expository mode.

The film features eight characters in total, three of whom have epilepsy: Tamara, Lourdes, and Fred; two neurologists, Dr. Daniel B. Hoch and Dr. Gregory Cascino; and the family members of people with epilepsy. In addition, the film features a narrator whose voice guides the audience through the film. Driven by a voice-over narration that places a great emphasis on creating “the impression of objectivity, and a well-supported argument,” *Epilepsy: A Guide* is clearly an expository/informational film. The ‘objective’ narrator is an extension of the filmmaker himself, a character that, “has the capacity to judge actions [...] without being caught up in them” (Nichols 107).

The film conforms to a classical expository construction, with expert interviews interspersed between screens of text. The first section is titled “What is Epilepsy?” followed by other equally prescriptive sections such as:

How is Epilepsy Diagnosed?, Medicines for Epilepsy, Surgery for Epilepsy, Other Treatment Options for Epilepsy, Helping Someone Who is Having a Seizure, Planning Ahead, Living Well With Epilepsy, and Real Choices, Real Hope.

The filmmaker, Alan Weiss, chose to organize these sections according to a strict chronological logic from diagnosis to treatment and beyond. While the film does offer the occasional hints at the emotional consequences of living with epilepsy, this thread is wholly overwhelmed by the medical consequences, cures, and characteristics of epilepsy as a disorder. Tamara, Lourdes, and Fred each tell a brief story about how their epilepsy started, and how medical treatment has cured them of their seizures. They are presented as success stories, characters meant to make other people with epilepsy feel hope, instead of feeling alone.

According to the narrator, “The more closely you stick with your treatment plan, the better your chances of reducing, or eliminating your seizures.” Immediately after this statement, Lourdes continues the thought, “If your medications are working...you’re a compliant patient, you keep your appointments. You can have a normal life like everybody else.”

Paradoxically, for someone like me, whose epilepsy has resisted medical treatment, these testimonies only serve to further alienate me from what the filmmaker presents as the idealized epilepsy patient. By building Tamara, Lourdes, and Frank into idealized versions of themselves as success stories, Weiss ignores those whose epilepsy continues to be an issue, and prevents them from forming a connection with his characters on a level beyond a shared illness. Empathy from the audience towards the characters is minimal. For a general audience that does not have epilepsy, this single-minded focus on the illness, over the people with the illness, leaves them with almost nothing in common through which to build a connection.

Weiss' idealized approach to his characters extends to his expert interviews, Dr. Hoch, and Dr. Cascino. Both accomplished neurologists, they discuss various treatment options for epilepsy, including medication, electronic aids such as the vagus nerve stimulator, dietary recommendations, and surgery. As with the idealized patients, Weiss also presents his doctor characters according to the popular caricature of a doctor: exclusively male, wrapped in a perfectly white robe, and surrounded by medical gadgetry. Never does Weiss show the personal interactions between doctor and patient, such as the discussions of side-effects, or the major life-changes triggered by epilepsy such as job-loss, familial pressure, and other "intimate" facets of their patient's lives.

Ostensibly, *Epilepsy: A Guide* is intended for an audience member who has been newly diagnosed with epilepsy, or their family members. It explains the proper method for treating a person while they are having a seizure, some of the triggers for epilepsy, and that epilepsy is one of the oldest, and most common neurological disorders.

While Weiss does attempt to build a connection between his audience and the characters in his film by presenting them in their own home, this attempt to personalize the characters is immediately undercut by the narrator's introduction. For example, when the narrator introduces Tamara she states, "Tamara is an active young woman with a bright future. At Emerson college in Boston, she's already working as a broadcast journalist" (Weiss 2013).

By introducing Tamara, instead of letting her introduce herself, the filmmaker defines her personality for her. In effect, he puts words in her mouth, contradicting what I consider to be the fundamental purpose of an interview, which is to allow a character the

opportunity to speak for themselves. If, for example, Tamara had said, “My name is Tamara, and I am going to Emerson College to study to be a broadcast journalist,” then the filmmaker has now allowed her to define herself as Tamara sees fit.

This effort on the part of the filmmakers to compartmentalize their interview subjects is most evident in the way Weiss singles out his expert interviews for particular attention. The vast majority of the statements made in the film about epilepsy are not from those who actually live with the condition, but by the two neurologists, Dr. Daniel B. Hoch, and Dr. Gregory Cascino. While they are both noted epilepsy experts, neither Dr. Hoch nor Dr. Cascino suffer from seizures. The medical credentials of Dr. Hoch and Dr. Cascino are twice presented on-screen, with their titles and specific accomplishments listed along with their names.

Strict privacy laws regarding patient confidentiality make it understandable that Weiss would chose to omit the family names of the patients he interviewed. However, it is telling that their names are completely absent from the credit screen, without even so much as a special thank you. By contrast, Weiss gives both doctors top-billing in the credit sequence, complete with their full medical credentials. Also included, is the celebrity host John O’Hurley, the narrator, Jocelyn M. Sigue, and the entire production staff, all of whom are thanked by name. By exempting the epilepsy patients from the credits, and so, making a distinction between them and the rest of the cast, Weiss reduces the epilepsy patients to the level of props.

Our three epilepsy patients, Tamara, Lourdes, and Frank are each presented as stereotypes: the youngest patient, Tamara, is a college student, and roughly the same age

I was when I first started having seizures. A platinum blond with a cheerleader smile, Tamara is very photogenic, an easy fit for the idealized American college girl. Our second character, Fred, represents all the patients with late-onset epilepsy that develops when someone reaches their fifties or sixties. Rounding out the cast, is Lourdes, a Hispanic nurse at the local hospital who fulfills the dual role of both middle aged patient, and who also appears on behalf of all ethnic patients with epilepsy.

In addition, Lourdes' husband Luis is also interviewed. The only family member present in the film, Luis represents those who do not have epilepsy themselves but whose lives are nonetheless affected by it. Luis' interview is of particular note, as he is the only character to display any appreciable degree of emotion with a teary admission of just how scary it is to witness his wife have a seizure: "The scariest part of the whole thing is when your wife doesn't recognize you." This is the only time a character expresses a feeling that someone without epilepsy could relate to.

By contrast, my film is full of emotional moments as characters relate traumatic experiences from their childhood, such as when they were teased by classmates, growing up in a broken home, sensations of drowning, or a terrifying experience of pure blackness. All of these moments are universal, to a certain extent, and allow an audience to relate to the lives of my characters and so build an emotional connection with them. Empathy from the audience towards the characters is present. In this way, *Seizing the Unrecorded*, stands apart from *Epilepsy a Guide*. Weiss' insistence on reducing his characters to one-dimensional caricatures as epilepsy patients rather than people living with epilepsy, keeps his audience at arms length and limits the popular appeal of his film.

It is important to note that *Epilepsy: A Guide*, credits Sunovion Pharmaceuticals Ltd. as its primary sponsor as part of a whole series of informational films about various neurological disorders including Parkinson's disease, Alzheimer's, and multiple sclerosis. As a pharmaceutical company first, and film producers second, Sunovion is not interested in the wider potential of this film series, and address only those who would be interested in either prescribing or ingesting pharmaceutical drugs as a means to control or minimize their symptoms. My film, by contrast, seeks to develop an empathetic connection between a general audience and its characters. People with epilepsy do not live in isolation. As Luis says in *Epilepsy: a Guide*, it can be just as scary to witness someone having a seizure as to actually experience it. By reaching out to my audience, I encourage them to empathize not only with the experience of having a seizure, but also with the lives of my characters as individuals.

At twenty-eight-minutes long, *Epilepsy: A Guide* is almost exactly the same length as my own film. Typically, documentary films attract a general audience by telling the stories of real, but extraordinary, people. *Epilepsy: A Guide for Patients and Families*, however, presents its characters as being "extraordinary" purely by reason of their having epilepsy. Since all the characters in my film have, or have had, epilepsy, my challenge as a filmmaker was to present them in such a way that a general audience could relate to them as individuals, rather than just as epilepsy patients. To do this, I drew inspiration from filmmakers such as Amy Hardie and Janet Merewether whose films about people with rare illnesses managed to transcend the confines of the medical sub-genre to both educate and entertain a general audience.

PERSONAL CONNECTION WITH THE PERFORMATIVE MODE

Moving away from the purely objective, the feature documentary *Jabe Babe: A Heightened Life*, directed by Janet Merewether, introduces us to a woman living with Marfan syndrome, an exceedingly rare condition that interferes with the body's connective tissues resulting in unusual facial features and exaggerated body proportions.

What makes *Jabe Babe: A Heightened Life* of particular interest to me is how Merewether uses the performative mode to allow the audience to connect directly with Jabe. For example, when Merewether has Jabe visit the hospital where she was diagnosed, as well as the foster homes where Jabe once lived, she does not direct Jabe in what she says or what she does. Instead of directing her, Merewether simply allows Jabe to address the audience directly as if she were a performer on a stage.

This is characteristic of the performative mode, which seeks to build engagement between the audience and the filmmaker through the “subjective and expressive” power of film (Nichols 34). Jabe performs for the camera in specific scenes that are meant to emphasize what she is talking about, whether she is speaking about her career as a dominatrix, or a certain aspect of living with Marfan syndrome.

While *Epilepsy: A Guide* stays firmly focused on epilepsy and its medical effects to the exclusion of its characters, *Jabe Babe* reveals its heroine Jabe as someone leading an extremely interesting – even scandalous – life. Merewether brings her audience deep into Jabe's personal history, including her childhood in a series of foster homes, her romantic relationships, and even her career as a dominatrix. The title itself, *Jabe Babe: A Heightened Life*, alludes to Jabe's unique perspective as someone extraordinary in both

physical stature and personal perspective. Merewether is interested in Jabe not as a medical rarity, but as a whole person, as immediately established in the opening shot of a pink diary cover with the label, “This story belongs to Jabe Babe.”

Jabe Babe: A Heightened Life is a film about Jabe as a person who *happens* to have Marfan syndrome, and not a film about Marfan syndrome itself. This distinction is evident in nearly every aspect of the production. When Jabe talks to the camera she does not filter out vulgar words in her speech. She mentions having experienced sexual abuse, and her feelings of worthlessness. She is not afraid to say both the good and the bad things about her life, her family, and her illness.

This stands in stark contrast to the characters presented in *Epilepsy: A Guide for Patients and Families*, who do not even reveal their family names. Merewether is not afraid to show the disturbing consequences of treating Marfan syndrome, such as graphic footage of Jabe’s open-heart surgery, and the jagged scars that now run between her breasts as a result. *Epilepsy: A Guide*, never shows anyone having a seizure, either in archival footage or recreation. By contrast, Jabe is not afraid of revealing her imperfections, whether physical or emotional.

For example, while Jabe shares many reservations about her job as a dominatrix, she also reveals a personal satisfaction at being uniquely suited for the profession as an unusually tall woman, a direct consequence of her Marfan syndrome. Jabe even appears in full dominatrix regalia complete with a leather whip and reveals a sense of humor about her job as she sits and steps on little plastic men who scream in appreciation. Performative sequences like this are both entertaining for their outlandishness, and also

allow the audience to see into Jabe's thought process as she reveals her struggle with both the positive and negative consequences of Marfan syndrome on her life and personality.

Merewether extends this connection between Jabe and the audience through the use of visual metaphors that illustrate Jabe's unique perspective on life. Since not everyone knows what it feels like to be very tall, Merewether presents Jabe Babe as a giant within a miniature town. Beyond just a visual gag, Merewether uses the set to full effect as a storytelling tool. For example, as Jabe relates her experiences moving from one foster home to another, she lifts the lid from a miniature house to reveal the story unfolding within.

While some documentary theorists have warned that the "performative element could be seen to undermine the conventional documentary pursuit of representing the real" (Bruzzi 155), Jabe's performance reveals the essence of what she feels about her own life, and allows the audience to connect with her on a personal and emotional level. This emotional connection between Jabe and the audience comes to a head when Jabe reveals her desire for children, but also her fear that they might also have Marfan syndrome. It is here that Jabe explicitly states the throughline of the film: "I don't agree with people being wiped out just because they've got something wrong with them."

By allowing a general audience the chance to connect with Jabe on a personal level, Merewether underscores the point of her film: that being diagnosed with a rare illness does not need to define someone's life, nor does it render them disposable.

Similarly, my own film, *Seizing the Unrecorded*, seeks to present my characters on a personal level with complicated stories, not simply epilepsy patients. Drawing

inspiration from performative sequences from *Jabe Babe: a Heightened Life*, I intentionally made scenes that exaggerate the stories told by my characters. Merewether did everything visually possible to make sure the audience knew that Jabe felt overly tall and out of place. Performative scenes in my own film, such as falling in water, and Jell-O brains being chopped up visualize what my characters are talking about and more vividly engage the audience.

THE PURE INTIMACY OF THE FIRST PERSON FILM

In *Edge of Dreaming*, documentary filmmaker Amy Hardie experiences a dream where her horse George tells her that he is about to die. Disturbed by her vision, she gets up in the middle of the night to find him dead and lying on his left side, exactly as he'd described. Not long after, she has another dream where her ex-husband Arthur tells her that she is going to die within the next year. Because of the eerie accuracy of her first dream, Amy worries that she might actually die before she turns forty-nine. *Edge of Dreaming* chronicles her life during that year, as she spends time with her kids, reminisces about the past, falls ill, researches the sometimes spooky power of dreams, but ultimately recovers to celebrate her forty-ninth birthday.

As both the filmmaker and subject, Hardie brings the audience into her life, her thoughts, and even into her dreams. This personal approach is enhanced by her raw and observational style. There are no onscreen titles, complicated lighting setups, or inter-titles in *Edge of Dreaming*, and her "expert interview" with her neurologist shows him lounging sideways on a couch, in stark contrast, for example, to the stiff framing of the interviews in *Epilepsy: A Guide*.

Further distancing her film as a purely informational documentary, Hardie employs extensive use of symbolism to emphasize "visual associations, tonal or rhythmic qualities, descriptive passages," which are all characteristic styles of the poetic mode (Nichols 33). For example, the concept of time passing through the year is visually represented by the presentation of all the seasons of the year. When Hardie contemplates how her own mind may have convinced her that she was sick, she shows images of

cracks in the earth and ice that evoke the interconnected spider-web of neurons that make up the brain. Hardie even ties her contemplations about death to the fragility of the world itself by showing images of the land eroding away.

Of particular note is the symbol of the snake, which first appears in the dream where she learns that she is going to die. By the end of the movie, however, the snake returns as a festive firework during her forty-ninth birthday party. This transformation of the snake from a negative symbol to a positive one echoes Hardie's own journey from her fear of death to her acceptance of it:

I wanted to structure the film as a journey for the audience, to which they would bring their own experiences and background. This commonality indicated that I was working at the level of the collective unconscious, where the content of certain shots, and the sound, might be recognized on a *symbolic* level. Once the film was completed I wanted to explore the connection with audience more (Hardie 385).

Hardie also makes a point to establish herself as a professional documentary filmmaker. She includes many shots of herself looking through a camera. By establishing herself as a filmmaker, she frames the film as being from her own point of view. She further develops this perspective by using extreme close-ups of typically private moments such as writing in a diary. These sequences follow the tip of the pen as she writes down her thoughts in real-time. In one sequence she writes, "So real, but just a dream." She then makes a point of underlining the word "dream" not once, but twice: the first underline quick and confident, the second hesitant – suddenly doubtful. This extra layer of performance serves to bring the audience even deeper into her subjective space by allowing them to witness her reactions to the dream as she wrestles with its meaning.

In this way, *Edge of Dreaming* is able to engage the audience on a level beyond that of the typical informational documentary. In an article written by Amy Hardie herself entitled “Symbolic Cinema & Audience Engagement,” (2011) she observes that her test audiences, “associated documentary with facts and being given information.” Hardie then states that she, “set out to involve the audience’s ‘observing consciousness,’ their response to the documentary film of this year of my life, at every stage of editing.” (Hardie 378).

By opening up the *Edge of Dreaming* in the rough-cut phase to the audiences, Hardie offered them “a role in creating meaning” in the film (Hardie 381). In early versions of her film, Hardie states that she went, “to considerable lengths to ensure that ideas about death were deeply embodied in experience, and were not presented as information” (Hardie 381). However, she found the outcome of these screenings to be “surprising” when audiences thought that she had fabricated the whole thing. Hardie was “shocked” that an audience would “interpret the documentary as something staged,” even when she explained that the film was authentic, with none of the sequences “faked or rehearsed” (Hardie 381). Even though some audience members thought scenes were staged, some people thought that the depth of the personal perspective, and symbolism in the film allowed them to connect with the film more.

The extent to which audiences were able to engage with the film is evident in this quote from an audience member speaking about her own reaction to the film:

Because of the spaciousness in the film, the poetry in the images, I found myself more and more drawn into the film. There was space for me. [...] I was drawn into a participatory role, actively witnessing and engaging with themes and issues that are both universal and deeply mine (Hardie 388).

Besides helping her audience to better engage with the film, Hardie discovered that connecting with her audience through test screenings was also helpful to her process of making the film: “My involvement with audiences pushed me to go deeper into my unconscious” (Hardie 348). From this connection with the audience, Hardie said her film was “actively shaped by the audience’s demands” (Hardie 348).

In the follow-up interview that plays at the end of the film, Hardie makes clear the lesson embedded in her film: “if it ever seemed likely to you that perhaps you’re not going to live very long, one thing you do is look at what you love.” For Hardie, what she discovered is that she, “really enjoyed looking through the camera,” and that by making films she, “wants her audience to go with [her] on a journey” (Hardie 348).

Similarly, I contemplated the possibility of my own death due to epilepsy in *Seizing the Unrecorded*. In my own film, I faced a question that I did not want to confront: Does my love of filmmaking cause me to have more seizures, and in turn, increase my risk of death? As a filmmaker myself, I followed Hardie’s example and looked at what I loved, which is using the camera to interview strangers and connect with them.

STRIKING A BALANCE: INCORPORATING THE ESSAY FILM

In my thesis film, *Seizing the Unrecorded*, I employ a broad range of expressive aesthetic techniques such as performance, sculpture, painting, and stop-motion animation. For example, instead of describing a seizure in medical terms as a “symptom of the brain, what some people call short circuiting,” (Weiss 2013), I use the visual example of a 5 year old scribbling on a page, which is the subjective analogy given by one of the characters in my film when he describes his own experience of having a seizure. Epilepsy itself is not a uniform experience, and no two people experience their seizures in the same way. One of my characters, Jennifer, suffers from tonic-clonic seizures, which are characterized by severe muscle stiffness including the lungs. For her, a seizure feels like she’s drowning.

Water has a presence throughout my film. As a visual tool, I used water to visually represent the subjective experience of having a seizure. Jennifer describes her seizures as feeling like she’s on the edge of drowning, an experience I illustrate by overlaying a shot of a lake partially covering her face. While most people cannot relate to the experience of having a seizure, most everyone understands the danger of drowning, or at least a sense of breathlessness.

Beyond simple visual metaphors that express un-filmable emotional realities, water also afforded me a chance to literally make invisible things visible, specifically the air we breathe, and rely on to live. In the performative opening sequence of my film, I show myself falling backwards into a pool of water. When Dr. Schachter states that, “the muscles stiffen,” I freeze-frame with the water hanging mid air. As his description of a

seizure continues, I sink deeper into the pool as bubbles of air stream from out of my nose. At the crucial moment when my “seizure” finishes and I “come back to life,” I reverse the flow of images so that the air returns into my body and I swim back out of the water.

While a lot of this film is about my own journey to learn about the connection between filmmaking and my seizures, it is also very much about my desire to meet and get to know other people with epilepsy. I did not, however, want to characterize my main characters, Chase, Cory, and Jennifer, as epileptics, but as people who happen to have epilepsy. In so doing, I hoped that my audience might form a personal connection with them. I give my audience glimpses into the private lives of my characters, and also myself, both inside and outside of the hospital, as we struggle both with the consequences of our epilepsy, and also with the trials and tribulations of life itself, including child-abuse, public school, making a living, finding your passion, family responsibilities, and so on. Unlike *Epilepsy: A Guide*, I choose to introduce each of my characters with their full name, as well as the city in which I interviewed them, since I wanted the audience to realize that the characters in my film are not ashamed of having seizures, and that people with epilepsy can be found all over the United States.

As I stated earlier, *Seizing the Unrecorded* is an essay film because it asks many questions and is extremely personal. How does epilepsy relate to my filmmaking? How does epilepsy affect other people? According to Dr. Laura Rascaroli, film theorist at the University College Cork in Ireland, there are three poles to the essay film: “the pole of the personal and the autobiographical; there is the pole of the objective, the factual, the

concrete particular; and there is the pole of the abstract universal” (Rascaroli 26).

In *Seizing the Unrecorded*, I address all three of these poles: as the director of the film (personal and autobiographical), factual information about epilepsy (concrete particular), and through my use of symbolic images of the human brain (abstract universal).

As both the director of the film, and a character within it, all of the people I visit during the film become a part of my personal story. Intimate stories from the lives of Chase, Cory, and Jennifer develop the personal side of living with epilepsy, while Dr. Steven Schachter fulfills the role of the “factual pole,” as an expert that provides a medical definition of epilepsy. Dr. Schachter’s explanations, in combination with the EEG and MRI images recorded during my stay at the epilepsy clinic, form the factual core of my film. Even though I critiqued *Epilepsy: A Guide for Patients and Families*, as an objective and informational film, I appreciate the knowledge it gave its audience about epilepsy. I did not want to completely lose certain “informational” facts about epilepsy in my own film because I feel as though epilepsy is still misunderstood by the general population.

The “abstract and universal pole” comes in doses throughout the film through my use of symbolic and illustrative visuals, including chopped up Jell-O brains, water, scribbles, and so on. As inspiration, I drew from Hardie’s use of her own handwriting in *Edge of Dreaming*, a technique that I felt was very effective in inviting the audience into her internal emotional state of mind. Similarly, I show myself erasing a drawing of my brain to show the effect my seizures have had on my memory.

Through my use of these expressive techniques, *Seizing The Unrecorded* attempts to reveal what people with epilepsy really feel about having seizures. By blending elements of the poetic, performative and informational modes, *Seizing The Unrecorded* is at “the crossroads of fiction, non fiction, and experimental film.” (Rascaroli 36). I chose to hybridize my approach to this film in order to explain not only what epilepsy is in a medical sense, but also what it’s like to live with epilepsy on a day-to-day basis: Jennifer feels as though she is drowning when she is having a seizure, Cory feels like he is choking, and Chase feels like his seizures are complete blackness. By contrast, I do not give a symbolic representation of my own seizures because for me, I don’t so much experience them, as witness their effects after the fact through film.

As a character, Chase represents those for whom medication or surgery proved successful in treating their epilepsy. I introduce Chase with a recreation of his first seizure when he was nine years old in a fourth grade classroom. Since this is a reenactment, I distinguished it from the rest of the film by desaturating it to black and white and by using a hand held camera. I used brief flashes of light between shots to evoke the overwhelming feeling of a seizure. Point-of-view shots place the audience inside Chase’s head and make them a participant in his seizure as his view of his class report blurs and drops to the ground.

Unlike Chase, whose seizures were cured by surgery, the character of Cory still has seizures but is able to keep them under control. The teasing he experienced as a child is a common experience for both people with and without epilepsy, a story that most people can relate to. A general audience may not know what it feels like to have a tonic-

clonic seizure, but they are likely to empathize with the feeling of being teased.

Jennifer's epilepsy is the result of a disturbing incident of domestic abuse against her mother while she was pregnant with Jennifer. For Jennifer, her seizures are so severe that they put a stop to her PhD, her career as a teacher, and left her paranoid about her unexpected death, and what that would mean for her two children Jacob and Mirium.

In Jennifer's case, because of the graphic nature of the violence she experienced as a child, I knew that reenactments would be inappropriate for this sequence in my film, and chose instead to use visual and conceptual abstractions to illustrate communicate her story. To this end, I fabricated several model brains from Jell-O which I then froze, chopped up, smashed, melted, or otherwise destroyed on camera to symbolically evoke the damage done to her brain. These illustrations are especially helpful to a general audience who are likely unable to read an MRI, or understand complicated medical jargon. For example, Chase's epilepsy was caused by a serious case of 'hyperpyrexia' – or a very high fever – an experience that I illustrate visually by melting a brain in a pan. In another sequence, I stab a Jell-O brain with surgery tools while he describes the experience of undergoing radical brain surgery while still only a preteen. In this way, the Jell-O brain becomes a recurring motif for the causes and consequences of epilepsy, allowing a general audience to both connect with the emotional experience of living with epilepsy as well as its medical causes and consequences.

Ultimately, the conversations that I had while visiting with Chase, Cory, and Jennifer encouraged me to finally undergo testing at the University of Alabama at Birmingham Epilepsy Center. Here, I learned why I have seizures, and what triggers

them. I discovered that the source of my seizures is a softening of tissue (encephalomalacia) in the left occipital lobe, the lobe that controls my visual cortex. Even though I do not automatically have a seizure because of flashing lights, this diagnosis confirmed my worst fear: filmmaking is one of the primary triggers of my seizures.

At the end of *Seizing The Unrecorded*, I reflect on what I've learned about myself and wrestle with the consequences of my diagnosis: if filmmaking is causing my seizures, then should I quit making films?

Because my seizures affect my memory, my own experience of my seizures disappears with the seizure itself. In the epilepsy clinic sequence, I include security camera footage of myself having a three-minute seizure. This is an important moment in the film, as it is the first time anyone has ever recorded me having a seizure. It is also the first time I "see" my self have a seizure, and form a visual memory of having a seizure.

Film provides a "memory theatre," a way to remove the "burden [of committing] sequence and detail to memory" (Nichols 50). As such, films have become a source of "popular memory," a memory that gives us a "vivid sense of how something happened in a particular time and place" (Nichols 50). Once a film is polished and complete, the viewer can watch it over and over again without worry that it will disappear.

Throughout the film, my narration remains oriented in the first-person, with the exception of the closing sequence where I switch it to the second person and address the audience directly, both with my narration and by looking directly into the camera:

When I film someone, something magical happens. All of a sudden, your differences do not matter. You can ask them anything you want, and they will answer you as if they've known you their whole lives. [...] All of a sudden they're your friend. (Pfau 2014)

My decision to engage the audience directly puts the audience into my own perspective as a filmmaker. From behind the camera, the filmmaker is always external to the lives of their subjects. In the penultimate sequence of the film, I appear twice on the screen: once as a person sleeping, and again as a filmmaker filming myself. In this moment, from behind the camera, the audience and I share the same perspective. As the person sleeping slowly fades away, we are left only with the filmmaker and the images recorded to the camera.

As a filmmaker, it was not important to me that the viewer remembers everything about the science of seizures. Instead, I wanted my audience to build a personal connection with a group of people who happen to have epilepsy. Chase, Cory, and Jennifer have all refused to let their epilepsy rob them of their passions. Likewise, I discover that I am grateful for the cinema camera as it allows me to see what happens to my body when, as Dr. Schachter would say, my “record button is not pushed.” Not only do I decide to continue making films, but I realize why filmmaking is so precious to me. As my seizures continue and my memory gets worse, filmmaking may become my only way of remembering things.

CONCLUSION

The film scholar Bill Nichols, author of the textbook, *Introduction to Documentary*, differentiates between two methods that filmmakers use to portray images: “photographic realism,” and “psychological realism” (Nichols 92, 93). If a movie is filmed with “photographic realism,” the camera portrays the images just as a person would see them if they were present, using eyelevel shots and minimal lighting and sets. This style is typical of the informational mode where, “qualities such as distance, neutrality, disinterestedness, or omniscience” make the film seem more credible to the viewer (Nichols 107).

In contrast to the “objective realism” of the informational film is the quality of “psychological realism,” where the film seeks to convey an internal, emotional reality, such as feelings of “anxiety, happiness, anger, ecstasy” (Nichols 93). In this way, the filmmaker hopes that their audience will have an easier time connecting to the characters or the experiences depicted in the film. With its hyper-colorization, unrealistic proportions, and so on, *Jabe Babe: A Heightened Life*, is a perfect example of the use of experimental visuals to evoke vivid emotions, as one might experience in a dream.

If a scene in a film creates a feeling in the viewer such as sadness, relief, or humor, then the scene is more likely to be stored in more than one area of the brain: one memory for the visuals, and another memory for the emotions that the visuals evoked in the audience.

Epilepsy: A Guide for Patients and Families attempts to connect with viewers but fails to fully engage with its audience by focusing only on their intellect, as evidenced by

their the constant use of narration, the aloof expert-interviews, and dryly worded intertitles which ultimately overwhelm the humanity of the characters. The audience is able to perceive the facts presented in the film, but are unable to fully empathize with what the characters in *Epilepsy: A Guide* feel about having epilepsy. In a word, the characters in *Epilepsy: A Guide* are never vulnerable. For example, they do not explain what they feel like when they have seizures. This distance between the audience and the people on the screen prevents the development of empathy. For someone with epilepsy, seizures are not so much an idea to be talked about, but a physical reality that they live with.

In contrast to the characters in *Epilepsy: A Guide*, Jabe Babe's performance is very vulnerable and gives us a better understanding of what she really experiences on a daily basis. Likewise, Amy Hardie's dreamscapes in *Edge of Dreaming* are raw, emotional, immediate, and vulnerable all at once. It is this vulnerability that allows an audience to connect on an emotional level with Jabe Babe and Amy Hardie. It is not surprising then, that both of these films feature personal journals as significant visual elements, a symbolic opening of the character's most private thoughts.

In *Seizing the Unrecorded*, I make myself vulnerable. The fact that I admit that filmmaking is a trigger for my seizures puts my career at risk. My greatest fear is that I might be forced to give up filmmaking if it continues to harm my health. Ultimately however, the connections I made with Cory, Chase, Jennifer, and Dr. Schachter, and the stories that they shared with me gave me the courage to share my own story with the public, and convinced me of the power of the personal story. Simply put, the goal of my

film was not only to educate my audience, but to allow them to *feel* what a person with epilepsy feels.

I knew nothing about epilepsy before I was diagnosed with it. I used to think that you had to convulse in order to have a seizure. I have learned more about epilepsy by watching and making films about it than I ever have in a doctor's office. The intimate conversations I had with my neurologists have varied in length from five minutes to twenty minutes maximum. I conducted a total of nine interviews for this film and each of them were over twenty minutes. When I interviewed Dr. Steven Schachter, a world-renowned neurologist, I had his undivided attention for over two hours. That kind of attention would be impossible with any of the personal neurologists I've had over the past seven years.

While some films are produced by hospitals as purely informational pieces, others are more personal. Hundreds of people have posted videos of themselves or of their friends having seizures to YouTube. People want to connect and communicate with each other. They don't want to feel alone. Through film, these people come to terms with their epilepsy and how it affects them. Films are a powerful way for people with epilepsy to share their experience with each other and the public, and so learn something about each other and themselves.

My uncontrolled epilepsy remains my greatest challenge moving forward with my career. Will I drop a camera while seizing? How will I travel without being able to drive? Will I be able to sit at the computer to write a script or edit my films? Medications are so far ineffective, and if I chose to undergo surgery to cure my epilepsy, I risk going blind.

Seizing the Unrecorded was my most difficult film to make to date, and I suspect it will remain the most difficult film of my career, as it represents a crucial moment in my life. At one time, during the editing of this film, I was having as many as a dozen seizures a day. I had more seizure during the making of this film than I have had in the past seven years combined. I suspect that the reason for this sharp increase in the number and severity of my seizures is due to the stress of facing the possibility that I might be forced to quit filmmaking entirely. I knew that if I did not finish this film, I would never make another film again.

Now, having completed it, however, I find myself flooded with ideas for future films and projects. Whether it's shooting and editing on film, relying more on hand-drawn animations, or by producing physical installation pieces, I know now that I can find ways to minimize the amount of time I spend in front of a computer screen without sacrificing my passion for engaging an audience in a personal story.

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