

PATIENT-SUBJECT AGENCY IN SLEEP DISORDER DOCUMENTARIES:
AN ANALYSIS OF THREE FILMS

by

Emily Rebecca Narrow

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master of Fine Arts

in

Science and Natural History Filmmaking

MONTANA STATE UNIVERSITY
Bozeman, Montana

April 2014

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ACKNOWLEDGEMENTS

Thank you to Oberlin College, which provided me much-appreciated financial assistance via an Alumni Fellowship.

Thanks to the faculty and students of the Science and Natural History Filmmaking Program at Montana State University. Special thanks to Gianna Savoie and Kathy Kasic for chairing my thesis committee – your support and constructive criticism were crucial to this endeavor. Special thanks to my thesis committee chair, Dennis Aig, for your patience, support, and inspiration.

Thank you to my friends and family, especially my parents David Narrow and Carol Schechter, for your undying love and support.

A final thank you to my friend Karyn, the strongest person I know.

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ABSTRACT

A patient-subject in a sleep disorder documentary is particularly vulnerable to disenfranchisement and is often unable to govern her own portrayal. This is because the patient-subject of a sleep disorder documentary falls within a unique nexus of controlling power structures and gazes that are rooted in medical sociology, documentary filmmaking ethics, and the sociology of sleep. Relying on past scholarship on medical documentaries in general, I identify three themes that signal disenfranchisement of the patient-subject: when authority of knowledge rests with the doctor and/or the filmmaker, when the doctor is active while the patient-subject is passive, and when the patient-subject is exposed to voyeurism. I then analyze three sleep disorder documentaries for how well they maintain patient-subject agency.

CHAPTER ONE

INTRODUCTION

The notion of the gaze postulates that by observing a subject we can understand and gain knowledge about that subject, and in turn gain power over that subject. The very act of looking creates a divide that privileges the one who looks, over the one who is looked at. The gaze, therefore is a socially-charged act that is couched in issues of power, subjectivity, and representation. Contemporary studies on this topic frequently refer to the work of French philosopher Michel Foucault and feminist film theorist Laura Mulvey, both of whom identified the inextricable connection between the gaze and power. Mulvey states that, “the look, pleasurable in form, can be threatening in content” (837), an observation that proves true in multiple arenas of the human experience. Foucault and Mulvey’s work on the effects of the gaze laid the foundation for relevant scholarship in fields as varied as gender studies, media studies, and the sociology of medicine.

The issue of the gaze is particularly relevant within the realm of documentary film studies when analyzing medical documentaries, especially ones about sleep disorders. A sleep disorder patient featured in a documentary film (a role that I will hereafter refer to as the patient-subject) is particularly at risk for disenfranchisement because she falls within a unique nexus of converging and controlling gazes. She is 1) a medical patient observed by doctors; 2) a documentary film subject observed by filmmakers and film audiences; and 3) frequently a sleeping individual observed by awake individuals. A

patient-subject in a sleep disorder documentary is therefore particularly vulnerable to disenfranchisement, which robs her of the power to govern her own portrayal. These power structures stem from the influence of medical sociology, documentary filmmaking ethics, and the sociology of sleep. Relying on past scholarship on medical documentaries in general, I identify three themes that signal disenfranchisement of the patient-subject. These three themes are when authority of knowledge rests with the doctor and/or the filmmaker, when the doctor is active while the patient-subject is passive, and when the patient-subject is exposed to voyeurism. I then analyze three sleep disorder documentaries for how well they maintain patient-subject agency.

CHAPTER TWO

SLEEP DISORDER DOCUMENTARIES

I define a sleep disorder documentary as a narrative, non-fiction film about real individuals' personal experiences with a sleep disorder. The primary goal of these films is to provide entertainment within a documentary context. I have therefore avoided films that were strictly created as instructional tools for patients or practitioners. I have also limited my analysis to only those films produced since the year 2000, in order to understand how these sleep disorder documentaries reflect the cultural and sociological landscape of the emerging twenty-first century.

Sleep disorder documentaries are a unique site for analyzing issues of agency and power, because they are byproducts of the sociology of medicine, the ethics of documentary filmmaking, and the sociology of sleep. We can analyze how each of these three areas of study impacts patient-subject agency in sleep disorder documentaries, and how they combine to form new challenges regarding power and representation.

Sociology of Medicine

A sociological understanding of Western medicine helps us to better understand sleep disorder documentaries, especially the complexities of the doctor-patient relationship. Medicine is held in the highest regard in Western society, and wields a great deal of social power. Bernice Pescosolido, the Distinguished Professor of Sociology at Indiana University, begins her essay on the status of the medical profession by stating,

“The modern profession of medicine stands among the powerful, if not the most powerful, of occupational groups in contemporary society” (173). Deborah Lupton, Professor of Sociology and Cultural Studies at Charles Sturt University in Australia states, “in modern western societies the institution of medicine has an important part to play in social control, in shaping the regulation of human action, the department of human bodies and the construction of subjectivity” (21). When a doctor observes a patient in a clinical setting, their interaction is informed by sociological norms that reinforce hegemonic ideas about medical authority and control.

Critical to this dynamic between doctor and patient is the concept of the “clinical gaze,” attributed to French philosopher Michel Foucault from his book *The Birth of the Clinic*. The clinical gaze is the authority with which doctors (as well as medical technicians, hospitals, and the medical establishment as a whole) can observe and interpret the patient’s body, to a degree where a doctor can know the patient’s body more than the patient herself. Foucault writes, “Doctor and patient are caught up in an ever-greater proximity, bound together, the doctor by an ever-more attentive, more insistent, more penetrating gaze, the patient by all the silent, irreplaceable qualities that, in him, betray – that is, reveal and conceal – the clearly ordered forms of the disease” (15-16). The doctor uses a “penetrating gaze” to determine the truth of the case, while the patient is less an individual than a series of signs and qualities that betray the presence of a disease. This privileged access to knowledge confers great power and agency to the doctor within the doctor-patient relationship, because it allows the doctor to judge a patient’s body against a preconceived model of what is normal and healthy. Medicine

“assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives” (Foucault 34). In the clinical setting, the value and meaning of a patient’s body is not determined by the patient, but by the medical establishment. Kirsten Ostherr is a Professor of English at Rice University and a media scholar who specializes in health and medical visualizations. She writes of the clinical gaze, “This is a gaze that is authorized to look at our private, hidden parts, to examine our vulnerable qualities and quantities, and declare them ‘normal’ or ‘pathological.’ The look of the doctor at the patient carries enormous power” (3).

The clinical gaze is not restricted to the simple act of a doctor literally looking at a patient. Rather, it includes all of the associated diagnostic tests and practices that doctors utilize to diagnose an illness. The doctor has the power to visually see the inner workings of the patient’s body through the use of increasingly sophisticated visual medical technologies (MRI, CT, endoscopy, ultrasound, etc.) that are accessible only to the medical establishment. Such imagery reinforces the doctor’s medical authority in several ways.

The medical establishment positions the doctor as gatekeeper to new modes of visualizing the self because access to the machines that create these visualizations is strictly controlled by the medical establishment. The average person cannot purchase an MRI machine in order to view images of his interior body. Access to an MRI machine is only possible when a doctor determines it to be medically necessary, at which point the

doctor grants the patient access (access that is severely limited and controlled by the medical establishment).

Medical visual imagery also reinforces the doctor's authority of knowledge because it is treated as an indexical representation of reality. Kelly A. Joyce is a medical sociologist and is currently the Director of Drexel University's Center for Science, Technology, & Society. Her research into the emergence of computer-based medical imaging technologies revealed that in both popular culture and medical culture, "medical images appear to offer the possibility of accessing the inner body without mediation to discover truth" (10). Her research uncovered a re-occurring narrative, where "MRI examinations can reveal the truth about one's physical condition, produce a definitive medical diagnosis, and reveal one's identity" (2). If an MRI scan is an indexical image that 'reveal(s) one's identity', and doctors are the only ones who are able to interpret this image, then doctors have a great deal of power to construct a patient's identity. Such medical imagery thereby plays a crucial role in bolstering the authority claimed by the clinical gaze.

Ethics of Documentary Filmmaking

Just as a doctor can determine the meaning of a patient's body within the realm of medicine, a filmmaker can control the portrayal of a human subject in a documentary film. A postmodern approach to documentary film, while it recognizes an indexical relationship between film and reality, understands that the way individuals represent and interpret that reality is subjective and variable. Postmodernism accepts that a

documentary film doesn't present *the truth* so much as it presents *a truth*. But whose truth is it? Ultimately it is the filmmaker who takes an indexical record of the historical world and manipulates it to fit his message. A documentary film is as much a reflection of the filmmaker as it is of the subject. Film scholar Bill Nichols states:

As a machine the camera produces an indexical record of what falls within its visual field. As an anthropomorphic extension of the human sensorium the camera reveals not only the world but its operator's preoccupations, subjectivity, and values. The photographic (and aural) record provides an imprint of its user's ethical, political, and ideological stance as well as an imprint of the visible surface of things. (79)

It is the filmmaker's ethics, politics, and ideologies that drive his creative construction of a documentary film. So a filmmaker who makes a documentary about a human subject has a great deal of power over how that subject is portrayed.

Documentary film scholars have written a lot about this uneven power dynamic between the filmmaker and the subject. Their work has its foundations in Laura Mulvey's essay, "Visual Pleasure and Narrative Cinema" which explores the problem of gender in cinema with regards to the male gaze that finds pleasure in looking at the female object. While Mulvey's essay focuses on Hollywood film, and the effects of the gaze from the standpoint of gender studies, it sets the stage for the complex power relations involved with the cinematic gaze in documentary film as well. Mulvey states:

Playing on the tension between film as controlling the dimension of time (editing, narrative) and film as controlling the dimension of space (changes in distance, editing), cinematic codes create a gaze, a world, and an object, thereby producing an illusion cut to the measure of desire. It is these cinematic codes and their relationship to formative external structures that must be broken down before mainstream film and the pleasure it provides can be challenged. (843)

Before we can break down patient-subject disenfranchisement in sleep disorder documentaries, we must better understand the power relations produced by the gaze of documentary's cinematic codes.

There is little sociological work about the documentary filmmaker-subject relationship (as opposed to the doctor-patient relationship) because being filmed for a documentary is a relatively rare occurrence. Furthermore, the process of making a documentary film can vary widely based on factors such as budget, crew size, intended distribution, etc. to the point that sociological research into the process wouldn't prove fruitful. However, filmmaking ethics are always applicable in documentary film production, no matter the particulars of the situation. This is because documentary filmmaking, at its core, is a process of representing a human being, and such a process of representation is always informed by particular values. Film scholar Kate Nash examined the issue in light of the work of philosopher Emmanuel Levinas:

The risk inherent in representation is that of subsuming the other in a totalizing visual system, overlooking difference, and in doing so annihilating the other. To represent is to run the risk of presenting the other as a "something" to be "experienced," placing the Other within a symbolic order and founding knowledge of the other on the basis of similarity to the self. (231)

The risk of 'subsuming the other in a totalizing visual system' is increased in documentary filmmaking because the industry does not have an official code of ethical practices to which its practitioners are held. Most filmmakers have their subjects sign consent forms before participating in filming, but these forms do more to provide legal cover for the filmmaker than to protect the subject. In reality, ethical concerns about a subject's portrayal are most often left to the filmmaker's judgment. The hope is that all

documentary filmmakers will portray their subjects in a fair light, and that they will consider doing so a top priority. The reality, however, is that current systems of documentary filmmaking leave the subject minimal control over how they are portrayed.¹

Sociology of Sleep

The sociology of sleep is a growing area of study. It may seem odd that an unconscious, biological process such as sleep needs to be examined from a sociological standpoint. It is becoming increasingly apparent, however, that the way we view sleep has shifted over the last several hundred years, and this shift is closely tied to changes in cultural attitudes and societal practices. Sociologist Simon J. Williams explains, “*when, where and how we sleep are all, to a considerable degree, socio-cultural matters, including processes of social scheduling and management in our waking lives*” (178). Sleep and sleep disorders are increasingly being viewed in a medical context, and as such they are subject to the characteristics of the sociology of medicine and the clinical gaze, as previously described. Recent scholarship on the sociology of sleep, however, reveals tropes that are unique to this specific field – and which are particularly relevant to any study of patient-subject disenfranchisement in sleep disorder documentaries.

¹ My focus on the power of the documentary filmmaker to control the portrayal of a subject in a documentary film is not meant to ignore reception theories that focus on the possible active role of the spectator. I do not deny the active spectator’s ability to resist the dominant/preferred ideology of a text by engaging in negotiated and oppositional readings. The end result for the human subject of the film, however, remains unchanged in that they still wield little control in the process. Although the spectator may reject the filmmaker’s ideology when watching a documentary, that interpretation is based on the identity of the spectator. Once again, the film’s human subject has no direct control over the situation.

One important revelation is how sleep has become increasingly privatized. In previous centuries, sleep was a more public activity, in the sense that multiple family members would share a bed, and sleeping naked was a common practice. Williams states, “The bedroom has become one of the most ‘private’ and ‘intimate’ areas of human life, and sleeping, like most other bodily functions, has increasingly shifted ‘behind the scenes’ of social life . . .” (181). This shift towards sleep as a private activity has an important consequence when a sleeping person’s privacy is violated. When a conscious (i.e. awake) individual observes an unconscious (i.e. sleeping) individual, a power structure emerges that easily confers power to the former over the latter. I refer to this concept as the *conscious gaze*.

The conscious gaze is a unique power structure because it requires almost no credentials; simply by being conscious, and by watching someone who is not, one person can gain power over the other. Doctors earn the authority of the clinical gaze by completing over eleven years of medical training and by passing a licensing exam, while documentary filmmakers must acquire filmmaking equipment and make contacts in the documentary film industry. The only credential of the conscious individual though, is that they are awake while someone else is not. The conscious gaze is also unique because it does not require the permission of the unconscious individual. At minimum, a patient agrees to be observed by a doctor, and a subject agrees to be filmed by a documentary filmmaker. A conscious individual can easily observe an unconscious individual without gaining the latter’s permission however, because the unconscious individual is inherently unaware of the act as it is happening.

Sociologist Brian Taylor talks about how the act of being watched while sleeping, (i.e. the conscious gaze), is infantilizing and ultimately disempowering:

Part of the experience of being in hospital, or indeed in prison is of having one's sleep inadvertently, and often deliberately, observed by others, a situation not usually encountered since one's own childhood. Again, documentary texts on the aging process often refer to institutionalized old peoples' complaint of a 'lack of privacy'. One component of such denials of privacy is the ability, power and authority of others, of strangers, to 'look in' when residents are asleep. (466)

This is extremely relevant for patient-subjects featured in sleep disorder documentaries because they are often shown sleeping within the films. This means they are ostensibly subjected to the conscious gaze of doctors, documentary filmmakers, and film spectators.

CHAPTER THREE

THEMES OF DISENFRANCHISEMENT

At the intersection of medical sociology, the ethics of documentary filmmaking, and the sociology of sleep, falls the sleep disorder documentary - a cultural text that has received little academic study. It represents, however, a unique amalgamation of power relations associated with controlling gazes, and is therefore an important site to study patient-subject disenfranchisement and agency.

But before I can begin analyzing these films for patient-subject disenfranchisement, it helps to have a framework upon which to structure my analysis. Although there is almost no scholarship about patient-subject disenfranchisement in sleep disorder documentaries, there is an emerging body of work on this issue for medical documentaries as a whole. Medical documentaries, for our purposes, are distinct from sleep disorder documentaries only in that they can be about *any* disease, illness or disorder. As such, there is a growing body of critical work that has begun to analyze how patient-subjects are disempowered in medical documentaries.

By reviewing the scholarship on contemporary medical documentaries, I have identified three themes that typically signal disenfranchisement of the patient-subject. The first is when authority of knowledge rests with the doctor and/or the filmmaker. The second is when the doctor is active while the patient-subject is passive. The third is when the patient-subject is exposed to voyeurism.

In medical documentaries, the medical establishment (doctors, medical technicians, and hospitals) is associated with objective, scientific knowledge while the patient-subject is not.² Doctors work from a position of presumed superior knowledge and have the right and power to dictate how patient-subjects should behave. This authority of knowledge directly mirrors that seen in medical sociology (as I have previously explored). Craig Hight and Catharine Coleborne are Senior Lecturers in Screen and Media Studies, and in History (respectively) at the University of Waikato. Their review of the 2001 BBC documentary series *Superhuman* found the series to be “a case study of a hegemonic discourse assimilating and naturalizing alternative discourses. Medical practitioners are presented as ‘enlightened’ in more than one sense – possessing superior knowledge, but also caring and able to incorporate a growing variety of medical repertoires” (243). Documentary filmmakers rarely challenge this authority of knowledge; rather, they frequently align themselves with the medical establishment’s all-knowing position. Explanations of complex medical processes are carried out by the doctors in the film, or by the filmmakers via narration, onscreen text, or computer-generated visualizations.

Patient-subjects rarely provide factual medical information in medical documentaries. Instead, they act as a source for emotional reactions. This depiction of patient-subjects as “needy, deserving and grateful patients” only serves to normalize the

² For multiple sources that explore how the medical establishment is associated with objective, scientific knowledge in medical documentaries, see Ostherr 190-214; Lupton 57-58; Christenson and Ivancin 10-11; and Hodgetts and Chamberlain 317-333.

position of power that the doctor holds as the bearer of objective knowledge (Hodgetts and Chamberlain 330).

It is also quite common in medical documentaries for doctors to be characterized as active while patient-subjects are characterized as passive.³ Doctors gain agency through examining patients, conducting medical tests, doling out treatments, performing autopsies, etc. Meanwhile, patients are the passive recipients upon whom the doctors act. This passivity means that patients often have little agency in regards to their own treatment. In medical documentaries, patient-subjects frequently accept the medical recommendations of the doctors, with little discussion about the risks involved with treatment. For example, in one episode of *Superhuman*, a patient named Matthew undergoes a ground-breaking hand-transplant. Matthew, “becomes a patient seeking a ‘better’ hand despite the relatively successful use of a prosthetic hand” (Hight and Coleborne 241). Several months after the successful surgery his wife comments that, “it has brought them ‘harmony’ and a ‘happiness’ she never knew was missing” (241). Despite a lower costing, successful alternative (the prosthetic hand), Matthew and his wife acquiesce to the recommendations of the doctors.

There are rare cases in medical documentaries where a patient-subject shows agency by challenging or disobeying the authority of the medical establishment. For example, a patient-subject might not immediately accept a doctor’s recommendation for treatment, or they might refuse it altogether. Such challenges to the medical

³ For multiple sources that explore how doctors are active while patient-subjects are passive in medical documentaries, see Ostherr 190-214; Lupton 57-58; Christenson and Ivancin 9; and Hodgetts and Chamberlain 317-333.

establishment, however, are almost always neutralized or result in a negative outcome for the patient. Kirsten Ostherr examines a typical scene in the 2000 ABC documentary series *Hopkins 24/7* in which a surgeon exhibits an impervious demeanor to his gunshot-victim patient, who verbally threatens the surgeon. “From the vantage point conveyed in this encounter” says Ostherr, “doctors, not patients, call the shots. Any effort at patient empowerment here is defensive to the point of farce . . .” (193-194). Later on, Ostherr concludes that, “good outcomes are presented as the result of following the course of treatment indicated by an imaging study. In contrast, bad outcomes are often presented on the series as a consequence of a patient’s bad decisions” (196).

The very act of observing the human body (necessary for both medicine and filming social actors) can easily slip into voyeurism. The term voyeurism has sexual overtones, based on a clinical definition whereby a voyeur observes unsuspecting individuals who are naked or engaged in sexual activity for the purpose of achieving sexual excitement. Voyeurism as applied to medical documentaries need not be sexual, however. Clay Calvert refers to mediated voyeurism, which he defines as, “the consumption of revealing images of and information about others’ apparently real and unguarded lives, often yet not always for purposes of entertainment but frequently at the expense of privacy and discourse, through the means of the mass media and Internet” (2-3). Such a broad term might seemingly include all documentary film, but what is critical here is the line, “at the expense of privacy and discourse.” First, this distinction suggests a boundary between what is private and what is public. There may be information or images that are revealed in a medical documentary which the patient-subject would not

otherwise share with strangers. Secondly, the patient-subject is not given an avenue of discourse, in order to contribute to the meaning of the images of themselves which appear onscreen.

As such, documentary scholars have found fault with the way that medical documentaries typically disenfranchise the patient-subject through voyeurism and spectacle.⁴ They were especially critical of cases where the patient-subjects were not conscious of the filming process (infants, dementia patients, etc). A BBC televised series from 1998, titled *Nurse*, had one episode where a nurse and a student aided a female patient with dementia onto a toilet. During the process, the camera revealed the woman's intimate body parts. Kevin Kendrick and John Costello are Lecturers in Nursing at the University of Leeds and the University of Manchester respectively. They discuss how this scene turned viewers into voyeurs: "They became voyeurs in the fullest sense because they were allowed to gaze covertly and anonymously at a 'private spectacle': there are few more private spectacles open to a voyeuristic gaze than being filmed during the intimate body processes of elimination" (20). This is a clear case of mediated voyeurism as defined by Calvert because it is at the expense of privacy and discourse.

The scene in *Nurse* is an example of voyeurism, but it is also an example of the conscious gaze. The woman with dementia was not conscious that she was being filmed, just like a sleeping patient-subject in a sleep disorder documentary is not conscious that they are being filmed. In the case of most sleep disorder documentaries, the patient-

⁴ For multiple sources that explore voyeurism in medical documentaries, see Hight and Coleborne 241; Kendrick and Costello 15-22; van Dijck 537-556; and Myser and Clark 45-67.

subject eventually regains consciousness, and therefore regains some power; this is not true of a dementia patient. Some sleep disorders, however, do result in permanent dementia. Fatal familial insomnia (featured in the first film that I analyze) is such a disease, making the work previously done by Kendrick and Costello especially pertinent. The conscious gaze only increases the threat of voyeurism in sleep disorder documentaries because the patient-subject, (unaware of the situation), is unable to contest it.

CHAPTER FOUR

ANALYSIS OF THREE SLEEP DISORDER DOCUMENTARIES

For my analysis of patient-subject agency in sleep disorder documentaries I will highlight three films: “Dying to Sleep” (2006) an episode from the television show *My Shocking Story* by Fox Television Studios and The Incubator for the Discovery Channel, *Wide Awake* (2006) by Alan Berliner (which aired on HBO), and my own film, *The Survivor* (2014). I analyze each film for recurring themes of authority of knowledge, passivity, and voyeurism. I argue that “Dying to Sleep” stands as a typical example of a commercial or mainstream documentary that disenfranchises its patient-subjects. *Wide Awake* and *The Survivor* however, are both strong examples of documentaries where the patient-subject maintains agency. In the case of *Wide Awake*, I explore how Alan Berliner retains enormous control over his portrayal because he is both the filmmaker and the patient-subject. For *The Survivor*, by analyzing my own film, I can look at how the film succeeds in preserving patient-subject agency with the understanding that it was a primary goal of mine while I was creating the film.

Of course, power and agency of portrayal in documentary film is quite fluid. Rarely can we say that a documentary disempowers the patient-subject during every moment of the film; likewise, it is rare to find a documentary where the patient-subject is empowered during every moment of the film. Such fluidity of power dynamics can be found in all three of the films mentioned. If we thoroughly analyze the creative and narrative techniques of a sleep disorder documentary, however, we can often see a pattern

emerge whereby the filmmaker's creative decisions either privilege patient-subject agency or reject it.

“Dying to Sleep” (2006) Episode of the
Television Show *My Shocking Story*

Synopsis

“Dying to Sleep” is an episode of the television show *My Shocking Story*, produced by Fox Television Studios and The Incubator for the Discovery Channel. *My Shocking Story* presents extraordinary stories from around the world, focusing on people with bizarre medical conditions. This particular episode is about a disease called fatal familial insomnia, or FFI. Fatal familial insomnia is a rare genetic disorder that prevents an individual from being able to sleep, and which ultimately results in death. “Dying to Sleep” chronicles several families that have a history of FFI, including a family in Italy, and a family in Maine. Doctors only discovered FFI about 30 years ago, when it presented itself in two Italian sisters, both of whom quickly died from the disease. When their brother, Sylvano, started showing signs of the disease in 1983, he allowed neurologists to observe him until his death a few months later. It is because of this work (and the results of Sylvano's autopsy) that the doctors were able to announce the discovery of a new disease: fatal familial insomnia. The members of the Italian family chose to keep their last name a secret. The family living in Maine, in the U.S., however, did not keep their full identities secret. The White family consists of the mother, Joann, and her two children, Meghan and Andy. At least 15 of their relatives have died from FFI, including Joann's husband (Meghan and Andy's father), Rick White. Meghan and

Andy each have a 50% chance of having the gene that causes FFI, and they travel to California for a blood test to determine whether they have the disease.

Analysis

Scientific information about FFI is frequently provided by the filmmakers in “Dying to Sleep” via voiceover narration. “Dying to Sleep” relies heavily on voice-of-God narration, which is performed by Richard Lintern. The documentary makes no attempt to introduce him to the viewer or to explain his connection to the topic of FFI. Within the expository tradition of documentary, the voice-of-God narrator exists outside of the world of the story, and has a privileged position of omniscience. His credentials are irrelevant, and his authority on both the content and significance of the unfolding events goes unchallenged.

“Dying to Sleep” has frequent talking-head interviews with doctors who provide expert medical knowledge about FFI. They act as medical experts about the specific cases they have treated and about the scientific nature of sleep and sleep disorders. This aligns with the standard trope of medical documentaries: doctors are the authoritative source for medical knowledge. While the doctors in “Dying to Sleep” do exhibit emotions towards their patients in one or two rare instances, most often the episode portrays them as objective and scientific: they are more devoted to the study of medicine than to the patients themselves.

This mentality can be seen in Dr. Lugaresi, the Italian neurologist who treated Sylvano at the end of his life. After Sylvano’s death, Dr. Lugaresi sent Sylvano’s brain for analysis to a former student, Dr. Pierluigi Gambetti, who worked in the United States.

Dr. Lugaresi recalls his conversation with Gambetti: "I said 'Gambetti, immerse yourself in this case! Drop everything else! Focus on this because we will make a great discovery.'" It is clear that any identity Sylvano had as a human being is no longer important to Dr. Lugaresi. All that remains of Sylvano is a disembodied brain, the value of which lies solely in its ability to provide medical knowledge to the doctors. Dr. Lugaresi is squarely focused on the prospect of medical discovery, and the role that he might play in such a discovery.

"Dying to Sleep" repeatedly frames its patient-subjects as passive characters that have little control over their lives. For example, the narrator in "Dying to Sleep" relies on sensational language that often marginalizes the patient-subjects. The narration states, "Fatal familial insomnia is a deadly brain disease that lies dormant in its victims for up to fifty years. Once it becomes active it's unstoppable. It condemns its victims to perpetual sleeplessness, until it kills them." The active agent in this description is clearly the disease. The narration characterizes FFI as a conscious predator capable of action verbs, such as "condemns" and "kills." Meanwhile, those who suffer from FFI are passive "victims" who have no control over their fate.

Later, when commenting on the Italian family's decision to remain anonymous, the narration again relies on sensational language. "The disease, and the stigma of madness that it inflicts on its victims," intones the narrator, "have caused the Italian family such anguish that they have chosen to remain anonymous." It is possible that the family chose to remain anonymous because of the "stigma of madness" associated with FFI, but it is far more likely that their decision is a result of the complex and multifaceted

issues that arise when a family is struck by a genetic neurological disorder. The Italian family is likely dealing with complex ethical issues involving medical privacy, research participation, and family planning (Bechtel and Geschwind 34-41), all of which likely contributed to their decision to remain anonymous.

The narration makes no mention of these other factors, however, instead focusing on the dramatic flair of “the stigma of madness.” In fact, it is the narration that even brings this up as a potential issue to begin with. None of the patient-subjects, their relatives, or any of the doctors express concerns about a social stigma of madness associated with FFI in a modern context. The documentary does discuss how in earlier generations, members of the Italian family were committed to a “lunatic asylum,” but this is only to point out how surprising it is that the illness wound its way through generations without ever being noticed, and to confirm the disease’s genetic component. It is the narration, and the narration alone, which suggests that there is a “stigma of madness” associated with FFI, and so it is really the filmmakers who suggest that patient-subjects ought to be ashamed of the condition, and therefore ought to resort to the passivity of anonymity.

This rhetoric is dangerous not only because it marginalizes the patient-subject, but also because it explicitly supports the idea that the patient-subject *should* be ashamed, i.e. the patient-subject *should* be marginalized. The film makes a moral judgment about the nature of the disease and concludes that disenfranchisement is the best course of action for the patient-subjects in this case. Maintaining their anonymity may have originally been an act of empowerment for the Italian family; anonymity could easily be an act of

defiance towards the judgmental gazes of the outside world. “Dying to Sleep” denies this potential interpretation of the act in favor of a much more satisfactory one where anonymity is required in order for patient-subjects to hide their shame.

The inclusion of footage of advanced FFI sufferers in “Dying to Sleep” is a strong example of voyeurism. A key source of B-roll footage in “Dying to Sleep” is an archive of video recordings of FFI patients, taken at the Bologna University Hospital in the 1980’s. The footage shows patients at the advanced stages of the disease; they suffer from dementia, loss of muscle control and coordination, and they are visibly exhausted. We see a frail Sylvano in pajamas struggle to walk around his hospital bed, aided by a hospital staff member. An unidentified, frail, man reaches out with his hands towards nothingness. A woman, who can barely walk, is led to bed by caregivers. One memorable shot, which is repeated half a dozen times throughout the episode, is a medium close-up of an exhausted Sylvano, his eyes keep closing as his body attempts to drift off to sleep, but they repeatedly re-open with a jolt.

The producers and distributors of “Dying to Sleep” (Fox Television Studios, The Incubator, and the Discovery Channel), might argue that this footage is not voyeuristic because the episode’s primary goal is to educate viewers about a deadly disease. If we return to Calvert’s definition of mediated voyeurism, he does qualify that such an act is “often yet not always for purposes of entertainment” (2) which separates the low-brow goal of entertainment from a higher-brow motivation such as education. The episode’s producers might argue that the film’s value as an educational tool warrants the use of the footage of the Italian patients, and that the inclusion of this footage was not merely for

entertainment purposes – thus protecting themselves from allegations of voyeurism. This argument seems particularly flimsy, however, given the rarity of the disease in question, fatal familial insomnia. The narration boldly states that the disease is so rare that it afflicts “just thirty families in the world,” making it extremely unlikely that any information provided in the show will prove useful to viewers in the context of health education. Communications Professor Peter Christenson (of Lewis and Clark College), and Communications Assistant Professor Maria Ivancin (of American University) write that:

. . . these shows are not intended as education, but as entertainment. When the following observations imply criticism, it is only in the context of health education, not in the context of entertainment value. For instance, if the tendency of the shows to feature rare or bizarre conditions places a limit on the usefulness of the information, this tendency is quite understandable and natural in the context of entertainment. (7-8)

Furthermore, the footage of the Italian FFI patients seems to squarely be at the “expense of privacy and discourse” (Calvert 2), qualifying it as a case of mediated voyeurism.

The footage of the Italian FFI patients shows people who have suffered months of mental and physical decay, and who are so close to death they probably bear little resemblance to their former selves. This kind of mental and physical decline is usually a personal and private experience that people do not broadcast to strangers. Meanwhile, the dementia (and subsequent deaths) of these patients means that none of them can contribute to any discourse on these images. They are permanently subjected to the voyeuristic, conscious gaze of untold television viewers. They may have consented to being filmed before reaching this mental state, but now that they have descended into dementia, they have no

recourse to control, limit, or stop themselves from being filmed. The conscious gaze only enhances the disenfranchising nature of voyeurism in this sleep disorder documentary.

Wide Awake (2006)

Synopsis

Wide Awake (2006) is a documentary film by Alan Berliner about his difficulties with insomnia. Berliner combines a variety of filmic techniques (archival footage, rhythmic montage, talking-head interviews, family home movies, and essayistic narration) to explore the torment he feels as an insomniac, which he likens to someone being “jetlagged in their own time zone” (*Wide Awake*). Berliner traces the history of his sleeping difficulties, and the problems that it causes with his wife and newborn son.

It is important to note that while both “Dying to Sleep” and *Wide Awake* are sleep disorder documentaries, they were made for very different purposes. “Dying to Sleep” is an example of Reality TV, made by corporate producers primarily for entertainment, (for their client, the Discovery Channel). *Wide Awake* is a personal, independent documentary made by a single filmmaker, who probably had more creative control over his film. The fact that “Dying to Sleep” is an example of Reality TV, however, should not excuse it from issues of patient-subject agency. “[R]eality programming is negotiating, subtextually at least, with such issues as sexuality, class, and power in the twenty-first century” (Simon 198). “Dying to Sleep” could have maintained patient-subject agency, while still being a commercially successful example of Reality TV.

Analysis

Berliner gains agency in *Wide Awake* by subtly challenging the authority and ability of sleep doctors, (i.e. the medical establishment). Like “Dying to Sleep” Berliner’s film features numerous talking-head interviews with medical experts. But unlike the previous film, none of the doctors are identified within the film. Their names, their titles, and their medical credentials are not provided.

Berliner also rejects the notion that the use of advanced medical imaging technology truly gives doctors the ability to see inside of him. A sequence of shots shows Berliner having electrodes attached to him in order to participate in an overnight sleep study. He comments on the situation with the following narration:

Those electrodes are monitoring my brain waves, my eye movement, my heartbeat, my breathing, the oxygen in my blood, the muscle tone in my chin, my leg movement. Not only that, but there is a camera on the wall, and a microphone hanging from the ceiling. The only thing they can’t record is what’s going on inside my head. (*Wide Awake*)

This comment exposes the artificiality of the concept that the doctors can truly know Berliner, and know what is wrong with him, through ‘objective’ medical observation. The only way to truly understand the patient’s insomnia is to understand what goes on in his mind. In a rare turn, it is the patient who holds exclusive access to this knowledge, and with it he gains power over the doctors and the medical establishment. Berliner defeats the clinical gaze; he rejects the notion that doctors have the ability to define his identity by using medical imaging technology.

Alan Berliner is not a passive patient-subject in *Wide Awake* because he frequently challenges the societal norms associated with medicine and sleep. Berliner

recites a litany of clichés about good sleep habits early in the film. The last cliché, (“Early to bed, early to rise, makes each of us healthy, wealthy, and wise”) elicits the following response from Berliner: “That’s a bunch of crap.” The mantra of ‘Early to bed, early to rise’ is a normative cliché that blames a person’s unhealthiness, poverty, and stupidity on his own poor sleep habits. Berliner immediately rejects this claim. Berliner later asks one of the sleep doctors what should be going through his mind when he goes to sleep. The doctor replies, “that you love the way that pillow feels, that you love the way that bed feels, that you’ve never felt more comfortable in your life, and the next thing is – nothing. You just lie there enjoying how wonderful it feels just to be in this bed.” Berliner, unsatisfied with this answer, shoots back, “That sounds like science fiction.”

Each of these occurrences may seem trivial in the larger scheme of patient-subject agency in sleep disorder documentaries. They mark a subtle shift, however, in the way that patient-subjects can subvert traditional social and medical power. Berliner’s rejection of these edicts is not violent, so much as it is humorous. He uses humor to highlight the ridiculousness inherent to traditional social and medical edicts about sleep. Past medical documentaries have shown that outright challenges to the medical establishment result in negative outcomes for the patient. Berliner’s subversive use of humor allows him to challenge authority, without suffering those same consequences.

A cursory review of *Wide Awake* might find that the film is just as guilty of voyeurism as any other typical medical documentary. However, a deeper analysis reveals how Berliner manipulates voyeuristic scenes to his advantage. Early in the film there is a

series of jump cut shots of Berliner tossing and turning in bed. The camera is directly above the bed, so as to frame the subject (Berliner), in a perfect medium close-up shot. This positioning means that the viewer is literally looking down upon Berliner, like a scientist looking at an amoeba through a microscope. This footage is highly voyeuristic: the viewer gets a direct view of a shirtless Berliner as he tosses and turns in bed, an experience that is usually intimate and personal. At first it would seem that this is a classic example of the patient-subject losing agency.

Crucial to this scene perhaps is the accompanying voiceover narration (read by Berliner) whereby he narrates the anxious thoughts that run through his head as he struggles to fall asleep:

I can't take it anymore. Go to sleep. Forget it. Think pleasant thoughts. Think pleasant thoughts. Inhale. Exhale. The baby's coming in two months. I've never changed a diaper in my life. Do I watch the birth? Or film the birth? Shooting it would be better for the film. But how can I watch the birth of my child through a lens? Just relax. I'm too tired to relax! I'm going to be a zombie tomorrow. I feel like a zombie right now . . . (*Wide Awake*).

Berliner's voiceover narration is actually the inner monologue of his thoughts when he is struggling to sleep. This breaks down the barrier between the viewer and the viewed (which is necessary to voyeurism) and instead causes the spectator to physically and mentally identify with the patient-subject onscreen. Berliner intentionally draws us into his physical and mental anguish to the point where we begin to experience it ourselves. In her writings about body genres, Linda Williams explores the ability of films to incite a physical reaction in viewers, where "the body of the spectator is caught up in an almost involuntary mimicry of the emotion or sensation of the body on the screen . . ." (4).

While Williams limits her analysis to horror films, melodramas, and pornography, it is not hard to see that Alan Berliner makes use of this technique in his documentary about insomnia. Berliner tosses and turns in his bed, and the spectator squirms in their chair. Berliner's anxious stream-of-consciousness invades the thoughts of the viewer, so they too experience Berliner's restless mental state. As the patient-subject of the film, Berliner gains agency in this scene by psychosomatically affecting the spectator.

Berliner's status as both filmmaker and patient-subject obviously place him at an advantage for maintaining agency. This is not, however, the only arrangement where a patient-subject can maintain agency in a sleep disorder documentary. Many of the techniques that Berliner uses (rejecting the truth claims of medical imagery, subversive humor, etc) could easily be used in a non-autobiographical documentary.

Additionally, while Berliner succeeds in maintaining his own agency, he fails to maintain his wife's agency in *Wide Awake*. He voyeuristically films her while she is sleeping, and when he accidentally wakes her up, she is extremely angry to find a camera in her face. He also films her when she tries to shower, and when she's on the toilet; both times she asks him to stop. This footage is just as voyeuristic as any shown in "Dying to Sleep". This shows how important it is for *any* filmmaker making a sleep disorder documentary to evaluate the ethics of their practices.

The Survivor (2014)

Synopsis

The Survivor is a fifteen-minute documentary film about one woman's experiences with sleep apnea. The film follows Karyn, (a woman from Helena, Montana) as she deals with the medical, financial and personal difficulties that sleep apnea has caused her. The film relies almost entirely on Karyn's own voice to propel the narrative. In a series of sit-down interviews, Karyn defines sleep apnea in her own terms, talks about how it has affected her life, and shares her personal experiences in seeking treatment. Karyn's reflections are often paired with B-roll footage of her medical appointments and of her home life.

I produced *The Survivor* as part of a Master of Fine Arts degree in Science and Natural History Filmmaking from Montana State University. My desire was to create a sleep disorder documentary based on Karyn's personal experiences with sleep apnea. My goal was not to educate the viewer about the mechanics of sleep apnea, nor was it to champion (or chastise) treatment options recommended by the medical establishment. My goal, rather, was to convey to the viewer the practical realities that come with having this disease and the emotional effects of those realities. If I wanted viewers to align themselves with Karyn, I needed to create a film that privileged her agency.

Analysis

The patient-subject of *The Survivor*, Karyn, provides almost all of the exposition in the film. She provides all of the voiceover narration, and, except for three shots with

onscreen text, she is the sole source for narrative information. Although doctors and medical technicians are occasionally seen in the film, (during B-roll footage of Karyn's appointments), their voices are not heard.

Early on in *The Survivor*, Karyn explains what sleep apnea is, using her own words. Her description, while not inaccurate, is much less detailed than one that a sleep doctor might give in a typical medical documentary. What is most important here is not that the viewer learns the medical definition of sleep apnea, but rather that he or she understand how Karyn conceives of sleep apnea in her own head. The audio track of Karyn's explanation of sleep apnea accompanies footage of her participating in an overnight sleep test. The definition of sleep apnea is tied to the process that a patient must undergo in order to be diagnosed with it. In this way, the understanding of the disorder is linked to the patient-subject's first-hand experience, rather than the medical establishment's objective knowledge.

Karyn breaks the mold of the passive patient-subject by struggling with, and ultimately rejecting, the treatment recommended by her doctor. The standard treatment for sleep apnea is a CPAP machine, which keeps the patient's airway open at night by blowing pressurized air into the patient's throat. Every night, the patient must wear a face mask that is connected to the body of the CPAP machine by a plastic tube. In *The Survivor*, Karyn expresses gratitude to her sleep doctor, but immediately voices some concerns that she has with the CPAP machine. She reflects on the difficulty that she had trying to sleep with it. "It wasn't a very good experience for me, because, first of all, I am not one to have things attached to me when I go to bed. I like my freedom. I like to be

able to get up and move whenever I want, and I felt that I was tied down with this thing” (*The Survivor*). It is unusual in any medical documentary for the patient-subject to voice concerns about the doctor’s prescribed treatment. Usually patient-subjects immediately acquiesce to the doctor’s instructions.

Near the end of the film, Karyn eventually returns the CPAP machine, rejecting the prescribed medical treatment for her sleep apnea. She cites two main reasons for her decision: she struggled at night to wear the CPAP because it was so uncomfortable, and the CPAP was a financial strain that she couldn’t afford after her husband left her. Karyn describes at length how these two factors informed her decision, and the emotional difficulties surrounding such a decision. Unfortunately, Karyn does suffer additional medical problems after she stops using the CPAP. At the end of the film, the viewer learns that Karyn’s sleep apnea eventually causes a second optic stroke in her remaining good eye, which leaves her legally blind. On the surface, it would appear that this chain of events is in line with the traditional medical documentary, where bad outcomes are presented as a “consequence of a patient’s bad decisions” (Ostherr 196). *The Survivor* however, doesn’t blame Karyn for this outcome, nor does it demonize her for rejecting the CPAP. The film allows Karyn to discuss at length all of the factors that led to her decision. She explains how financially, the CPAP interfered with her ability to put gas in the car and to buy groceries. She also explains how the CPAP machine was more disruptive to her sleep than the original disorder it was supposed to treat. Karyn explains how difficult the decision was for her:

I really thought a lot about it, it’s not like I just kind of gave up on it real fast. Because I knew the importance of a CPAP machine. But you know,

do you feed yourself and put gas in the car to go to work, or do you pay for a CPAP? Well, gas in the car and eating is a little bit more important than the CPAP, so. And it came to that, it just, you know, it was an either-or decision I had to make. So, survival is number one. (*The Survivor*)

Karyn is not a typical patient-subject who is punished for exhibiting agency. She is a real human being who struggles with a tough personal decision.

I consciously tried to avoid creating a film that allowed the viewer to gaze voyeuristically at Karyn. Instead of having the viewer gaze at Karyn, I wanted the viewer to look through Karyn's eyes, to see and experience the world as she does. The primary technique I used to achieve this was by using point-of-view (POV) footage.

Early in the film, Karyn talks about how sleep apnea caused an optic stroke in her eye, which caused her to lose the frontal vision of her eye. Karyn says, "I looked up at the clock and I noticed that there was like a grayish-brown film on my eye". This line is followed by handheld, POV footage of a clock on the wall. At this point a large, grayish-brown splotch (created with computer animation) appears, and it blocks a large portion of the image. The footage represents what Karyn sees after having the optic stroke. The viewer gains access to Karyn's vision of the world, which prevents them from gazing at her voyeuristically.

Another section of the film that uses POV footage is when Karyn is no longer able to ride her motorcycle. Early in the film, Karyn explains how she and her husband ride Harleys, and that, "when you have your own bike it's like you have your own space, your own freedom, you just can do whatever you want on it" (*The Survivor*). When the optic stroke compromises her vision, however, she decides to give up riding her motorcycle for good. This section of the film shows POV footage of Karyn riding her

motorcycle. The footage comes from a camera attached to Karyn's helmet; the viewer sees what Karyn sees when she rides her bike along beautiful vistas. The viewer gets to experience the "freedom" of riding Karyn's motorcycle through her eyes. This POV footage makes it that much more emotionally devastating that Karyn has to give up her bike.

The Survivor is a sleep disorder documentary that maintains the patient-subject's agency. It privileges Karyn's knowledge and portrays her as an active, multidimensional character. She is not an object to be viewed, but a human being that the audience can identify with. When I was making *The Survivor*, I intentionally tried to preserve Karyn's agency, and this goal informed many of my creative decisions for the film. These decisions ultimately strengthened the emotional weight of the story. *The Survivor* can therefore stand as an example of how filmmakers can actually improve their films by not disempowering their subjects.

CHAPTER FIVE

CONCLUSION

Sleep disorder documentaries are a unique cultural text because they simultaneously shape and are shaped by today's society. They reflect current sociological norms in medicine and sleep, as well as contemporary ethical practices in documentary filmmaking. They then, in turn affect society by influencing cultural understandings of the topics they cover.

What is important to remember is that none of the power structures which can disenfranchise a patient-subject are completely immune to challenge and subversion. Filmmakers have the tools to reject patient-subject disenfranchisement in their films and embrace filmic practices that protect a patient-subject's right to control their own portrayal. Hopefully, my analysis will act as a valuable text for filmmakers looking to create sleep disorder documentaries in the future. Perhaps documentary film scholar Michael Renov says it best:

Much has been said about empowerment in recent years. The bottom line is that the artwork should encourage inquiry, offer space for judgment, and provide the tools for evaluation and further action - in short, encourage an active response. The film or videotape that considers its own processes rather than seals over every gap of a never-seamless discourse is more likely to engender the healthy skepticism that begets knowledge, offering itself as a model. (31)

A sleep disorder documentary that privileges patient-subject agency gives a voice to those social actors who have typically been stifled by more-powerful forces. This in turn

can positively affect current documentary film practices, as well as the way we look at medicine and sleep as a society.

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