

Shooting Pains: Autobiographical Video as a Means of Addressing Illness-Related Pain

TABOO

Despite a proliferation of new media technologies and interfaces for communication and exchange, Western society still places strong social proscriptions on the candid discussion of pain, illness, and natural death. Mediations of illness have been superseded by discourses of wellness and anti-aging, which seem to equate acknowledging pain with weakness and illness or body failure as personal failures.

As Tony Kushner's character Roy Cohn states in part two of *Angels in America: Perestroika*,

The worst thing about being sick in America is you are booted out of the parade. Americans have no use for the sick. Look at Reagan: He's so healthy it's hardly human, he's a hundred if he's a day, he takes a slug in his chest and two days later he's out riding ponies in his PJ's. I mean who does that? That's America. It's no country for the infirm. (Act 2, Scene 1)

In a New Media context, YouTuber *1938Superman* posted a video log or *vlog* in 2006 recounting his bout with testicular cancer, and amongst the specific and productive responses from fellow cancer patients, medical professionals, and the occasional general well-wisher, also received this response in the chain from user *coltzeu*, a 25-year-old male:

I wish YouTube administration would ban stupid people from posting videos like this. It's totally unobjective... You shouldn't tell your problems to everyone on YouTube. Nobody cares. People don't want to hear about tragedies.

We live in a secularized age of psychoanalysis, where taboos surrounding birth and sex have been shattered. Procreation no longer even mandates physical copulation, but a (safe) sex life is part of a larger plan of healthy living prescribed by a medical community that, as Lisa Cartwright argues in *Screening the Body: Tracing Medicine's Visual Culture*, has subsumed organized religion as the major institutional molder of cultural death fears and immortality desires (406). To qualify Cartwright's characterization, I would argue it is not simply modern medicine, but rather, a combination of medicine, media, and corporate capitalism which now drive a surface American preoccupation with wellness and longevity, while the nation ironically continues to lag dramatically in healthcare outcomes and medical coverage of its citizens, compared to other Western nations.

With natural death removed from the home, productive public discourse around pain and illness has largely become a private/ized matter, ceded to the "professional" gazes of the medical, pharmaceutical, and funerary industries. In the American context, beyond fictional melodrama or action films the address of physical and emotional pain comes most pervasively in the form of television advertisements for the latest antidepressant or analgesic—shiny happy people in soft focus and slow motion beam as they stroll on a beach or play ball with children as a voice invokes us to "Ask your doctor if X is right for you." Such pharmaceutical ads are followed by other prescriptions/proscriptions Revlon spokesmodels admonishing us to, "Defy it!" with the question of whether "it" is aging...or death...left ambiguous.

In *Home Movies and Other Necessary Fictions*, filmmaker and scholar Michelle Citron offers a contemplative history of home movie images in American culture. While amateur motion picture technologies' evolution from Super 8 film, to analog video, to digital video camcorder, and now

to Web and Flip cams (along with unprecedented access to the means of post-production capacities via nonlinear editing software packages) has been dramatic, the strict code of "appropriate" home movie recording situations has experienced little change:

We film the Christmas dinner with family and not the meal eaten alone; birthday parties, not the emergency room visits; baby's first step, not fighting with the adolescent; vacation, not work; wedding parties, not divorce proceedings; births, not funerals (19).

And yet a growing corpus of first-person videos since the early 1990's have done precisely the contrary—using consumer video cameras and autobiographical acts of video diary, confession, and documentary as forms of pain management, coping, and self-exploration in times of extreme vulnerability brought on by illness. There are many fascinating autobiographical acts addressing a broad range of physical, psychological, and emotional pain, but for the sake of specificity, I focus here on illness-related pain video as the specific medium through which patients and their caregivers have sought to make sense of it.

This paper will look to works such as *Silverlake Life: The View From Here* (1991), *Fast Trip, Long Drop* (1999), *Sick: The Life of Bob Flanagan, Supermasochist* (1997), *Death: A Love Story* (1999), *My Left Breast* (2000), *The Odds of Recovery* (2002), *Crazy Sexy Cancer* (2007), along with vlogs (online video logs posted to social networking sites such as Facebook and YouTube) to explore the possibilities of first-person video as a means of both subverting and transcending social proscriptions/prescriptions for managing, discussing, and even “performing” pain in the public sphere.

THE MEDICAL GAZE

Su Friedrich's *The Odds of Recovery* (2002) begins with a pre-title montage of awkward semi-private moments when one is left in the medical examining room to change into some form of institutional garment. In no fewer than ten different medical appointment contexts, Friedrich repeats the ritual of pulling her clothes on and off, donning a dizzying array of robes, jackets, wraps, and gowns, each with its own unexplained process of ties, adhesive strips, or buttons, rarely even an indication of what is the front and what is the back. Behind her the imposing screens and implements of medical examination change but the examining rooms remain eerily the same in their institutional lighting and the lone chair left for one to place personal belongings onto. Friedrich picks up a pink paper tarp and intones, “Like...what the fuck is this? Oh I thought it was a robe. It's just a cowl. OK.”

Soon Friedrich matures in her fluency in medical semiotics. A physician tells her, “Let's have you up here, and I'll need your knees,” which Friedrich immediately translates into a taxonomy of disrobing: “Ok, so just pants and shirt.” With a mixture of humor and despair, Friedrich disrobes yet another time lilting an improvised stream of verse: “Get dressed. Get undressed. Get dressed. Get undressed. Eat your lunch. Wait. Get undressed again. Get dressed. I'll talk to her. I'll talk to you. She'll talk to you. I'll talk to her. Talk to each other.”

In the montage's final medical visit, she confides, “I'm sure you're tired of seeing me change, so I'll just do it quickly.” She removes her top and picks up a thin paper sheath off the examining table. “Ah it's blue. Sometimes it's pink, sometimes it's blue.” She deftly snaps the thin piece of paper into three dimensions, swinging her arms through the materialized holes. “This is what we call a jacket. You see this, it has tape so you can make it stick together.” She seals the adhesive strip across her chest with a flourish, playfully modeling for the camera. “See? Jacket!” In all these changing moments, Friedrich is left alone in the room. So whom is she really speaking to? No to herself but to us, an assumed future audience, who though not physically present with her in the moment are so by proxy, providing a form of witness, support, and alliance.

Lest anyone think only Friedrich, a seasoned avant-garde filmmaker, is daring enough to transgress Citron's list of "appropriate" filming situations, it should be stressed that nearly all of the emerging corpus of first-person illness videos turn small, unassuming consumer cameras onto examining room confessionals and doctor interactions, countering the official, unblinking stare of a *medical gaze*. The genesis of this medical gaze lies in the fact that in order to know our own body and its condition well, we are often at the mercy of medical experts for the translation and relaying of specialized information and for their literal bodily insight via x-ray, scan, or scope.

In her compelling article "Medical Identity: My DNA/Myself," Kay Cook points out many striking and rarely considered sites of power discrepancy between doctor and patient—most crucially within the medical file. Cook argues that filling out medical forms with personal and family history is, in a sense very much a form of autobiographical transcription. But the resulting document and the subsequent additions to it by "professional" hands are filed away, access restricted to a privileged few. Cook writes:

I have my file, which is always placed outside the office door while I am inside, usually cold and shivering under a paper garment. The folder is both secret and public; so is my body. The information sheathed in the folder outside has an eerie correspondence to the coarse paper garment that hides my body momentarily from the medical gaze (71).

We offer up our bodies for the taking--blood, tissue, saliva--and allow our "selves" to be imaged and recorded on x-ray film and endoscopic video. The urine sample, the MRI, and the medical file: all are forms of medical surveillance-body surveillance-requiring some privileged, specialized knowledge to decipher their meaning, to allow us to "know" ourselves.

Bringing the video camera into the medical sphere permits patients to comment directly on the often frightening and dehumanizing experiences of the hospital, and even to return the medical gaze. In *Death: A Love Story* (1999), Michelle Le Brun collaboratively documents and later tries to make sense of her husband Mel's battle and ultimate death from liver cancer. Not a filmmaker before the incident, she picked up the family Hi-8 video camera at the time of Mel's diagnosis and never put it down. Michelle guides us through the images via a present-tense voice-over track, culled from her journal entries written over the eight-month span of Mel's illness. The resulting work thereby merges and subverts, not one but two traditional forms of private inscription—the home movie and the diary—entering each into public discourse. The camera enters hospital rooms and squares off against doctors and nurses, Michelle telling us, "The camera has become my saving grace. It gives me some kind of job to do in this situation."

Similarly when YouTube vlogger *phaedress*, a 40-year-old Canadian breast cancer patient returns for a post-chemo, post-radiation mammogram in November of 2006, she brings her camera along, addressing viewers through the camera while she nervously tries to rationalize why the doctors have re-scanned her breast three times and left her waiting for an hour with no update. First she fills the time by filming and narrating a funny poem, "Ode to a Mammogram" her doctor and the technicians have posted to the wall about the physical pain and discomfort of mammograms, which culminates in the final stanza, "This machine was created by a man. Of this I have no doubt. I'd like to stick his balls in there, and see how THEY come out!" Then as her wait drags and nervousness and doubt set in, she turns her camera onto herself:

OK, so positive thoughts. You know what's really cool is I know I'm not alone. For one thing my sweetheart is waiting for me in the other room...For another, the nurses here are all very sweet and personable, and they make me feel comfortable [...] And then there's you. I can't help myself. I'm always thinking about that no matter what I do, in a way it could be just material for a video. And I suppose it's a form of disassociation—you know, I'm not terrified; I'm just interested and wanting to feed your curiosity in the process. Ok, I take

it back. I'm terrified but it's less terrifying when you get to share it with other people.

Since then, this vlog (one in a series of phaadress' cancer testimonials) has been accessed over 1,600 times on YouTube, with comments from a range of fellow cancer patients, cancer survivors, women apprehensive about mammography. Many thank her for the poem, and user *Knightengale* commends phaadress for the candor of her vlog:

A real life situation, not done the way the "real media" would portray this situation, with dramatic music to only pull on people's emotions, but an honest real life view of that room, and the real emotion involved. Thanks again for sharing this experience with us.

My isolation and critique of a privileged medical gaze is certainly not meant to demonize medical professionals; in most of the video works under examination here it is remarkable how willing doctors and nurses are to appear on camera and to answer patient questions. But as these examples indicate, there are many powerful functions and possibilities that result from patients and caregivers turning cameras back onto the medical establishment—ranging from having a confidant and witness in the lonely examining room, to gaining a sense of agency or utility, to simply demystifying medical procedures and processes for fellow patients.

THE PAIN DIARY

In fact, many physicians actively encourage patients to keep *pain diaries*, but the form and function of such diaries are far from personal. In a Health.com video series also posted on YouTube, pain medicine specialist Dr. Russell Portenoy of New York's Beth Israel Medical Center instructs patients to become aware of their pain and to describe it in the following terms:

The patient just needs to indicate what the date is, typically indicate whether the diary is being filled out two times a day or one time a day or four times a day, and then to indicate specific things that are happening at the time that the diary is completed: What's the pain on a zero to ten scale where zero is no pain and ten is the worst you can imagine? Are you out of bed at that time? When did you take the medication in relation to that time? Are there other symptoms at that time? And then that diary can be brought to the physician, and in just one minute the physician can see what happened during that whole period of time and get a sense if the patient is making progress or actually doing more poorly.

Like the patient medical file, such diaries are largely restricted to a medical semiotics, written for a specific audience of physicians. There is certainly medical value to such pain diaries, but the video diaries under investigation here are far more personal and confessional in nature. Scholars such as Michael Renov have written at length on the "confessional" nature of video, linking such acts to the three other historical realms of confession in Western society—the church, the courtroom, and the analyst's chair. Much was also made in the 1980's about the emerging talk show genre on daytime television as a new public sphere focused on the confession. Each of these contexts is rooted in a form of personal divulgence in the pursuit of relief or absolution, but like the medical gaze, each also is fraught with an inherent power imbalance, where the words spoken fall on privileged ears with the power to grant mercy or judgment.

Personalized video pain diaries are therefore an incredibly powerful mode of expression, as the camera functions as a silent, non-judging proxy for an implied listener or audience. In *Silverlake Life: the View From Here* (1991), the illness is AIDS, and the video camera begins autobiographically in the hands of veteran filmmaker Tom Joslin as he documents his daily battle with the disease. With the exception of several clips from earlier Joslin works, the finished piece is culled solely from thirty-five hours of home video. As such, the groundbreaking video represents both a reinvigoration and expansion of the medical form of the pain diary and a subversion of home movie ideology, not only in filming illness but also in the constituency of the

American "family" transcribed therein: Joslin and his lover, of twenty-two years Mark Massi, documenting their battle with AIDS at the height of American cultural panic and stigmatization of those with the disease.

Massi is in the early stages of AIDS-related illness himself, Kaposi's sarcoma lesions dotting his body, but he functions as Joslin's primary caregiver. Joslin, feeling helpless, takes a camera everywhere with him and even has a tripod set up next to his bed, which permits him to record diary entries on sleepless nights when pain and worry set in. Tom videos one particularly emotional entry from the passenger seat of the car as he waits for Mark to finish running just one more errand than promised. Emaciated and exhausted, Tom rails about the afternoon and his helplessness:

Went to Dr. Matt's and went through our usual thing this morning—the pain—which was fine, and I got too tired to film towards the end and went and slept in the car while Mark had lunch. I didn't have lunch because we were going to go right home [his voice gets panicked and tearful for a moment]. I remember he said we were going to go right home [...] And then we're on the way home and he says, "Look we're almost done. I'm going to go to the health food store," which is NOT on the way home. And it is now 3:30. So we go to the health food store, and I sit in the car and try to sleep and can't. So then he comes back and says look, there's only one more stop. I'm gonna go to the Mayfair. Get tonight's dinner so I don't have to go out again. We've got to protect my health. Meanwhile I haven't had fucking dinner. I haven't had any, Jesus! You try to be helpful, getting screwed time and time again! [Roaring] I hate being a nice guy!

Such confessional moments on video are visceral and distinctly in the present tense, capturing an immediacy and a time-based audiovisual *presence* unattainable by even the most effusive of written diary entries. Here, the pause or hesitation, the tone of voice, the emphasis of a certain word, the physical appearance of the patient, and the realities of their surroundings are all indexed, providing a compelling and three-dimensional portrait of their experience. This entry does not provide all the information requested by physicians in a pain diary designed for the medical gaze, but one can imagine a range of benefits to caregivers, patients, and physicians alike, who are able to see the effects of illness-related pain and fatigue in real time. So many fictional and documentary mediations of illness perpetuate the same tropes—patients are either passive objects or active agents of positivity in the face of adversity. Seeing Tom despair and rage is both arresting and potentially refreshing for patients who feel alone in or ashamed of their own private rage, rarely validated or modeled in mainstream media or the wellness industry.

PERFORMING PAIN

As such, video diaries could be said to constitute a form of bodily *performance*, bringing people out of their minds, doses, diagnoses, and passive states as patients, and into a physical, active form of self exploration and self-expression, subverting the traditionally incapacitating and paralyzing effects of pain.

In *Sick: The Life of Bob Flanagan, Supermasochist* (1997), filmmaker Kirby Dick compiles material from a wide range of sources to document the death of his friend Bob Flanagan—performance artist, writer, filmmaker and self-proclaimed "Supermasochist." Flanagan, who dies during the course of filming *Sick*, was an artist whose work in a variety of mediums was expressly autobiographical—addressing his lifelong fight with cystic fibrosis and his use of masochism as a means of subsuming uncontrollable disease-related pain to pleasurable, consensual pain of a sexual and intimate nature, exacted by his partner and artistic collaborator of fifteen years, dominatrix Sheree Rose.

Flanagan thus made a life and a career of *performing* pain, through films, music videos,

performance art pieces, writings, and installation works, which all centrally featured his ailing body, and inevitable mortality. For a piece called *Visiting Hours*, Flanagan would set up a hospital bed inside a gallery space and remain in bed, holding visiting hours with gallery visitors. Going home or back to the hotel at night, he would otherwise remain in bed for the duration of the gallery show's run, sometimes weeks at a time. Periodically in an event they referred to as "the ascension", Sheree would pull on a rope attached to Bob's ankles and hoist his body up from the bed, his hospital robe slipping off in the process, until he hung suspended upside down from the ceiling of the exhibition space—a nude, pierced, eroticized, inverted Christ figure.

Flanagan effectively reversed all customary notions of doctor/patient power in which the patient surrenders to the penetrating eyes and hands of an all-knowing medical gaze. Rather than deifying a medical figure, Flanagan found affinity between Christ and himself, Christ being, in his words, "the first and most famous masochist." He turned the restricted, privatized space of the hospital room into a public space and event, inviting an audience to gaze upon his scarred body, and got off on it in the process.

On paper, it may be difficult for many to imagine intersubjective resonance with Flanagan—a man who frequently nailed his penis to a board during live performances. And yet there is an important correlation that can be drawn between the medical patient and the masochist, and by extension between the video diarist and performance artist. In the videotaped exhibition of *Visiting Hours* included in *Sick*, Bob tells a reporter:

The stereotype of the masochist is sniveling and weak, and it's actually not true. The masochist has to know his or her own body perfectly well and be in full control of their body in order to give control to somebody else. So the masochist is actually a very strong person. And I think some of that strength is what I use to combat the illness.

Change all the occurrences of "masochist" in the passage above to "patient," and you will quickly see how the power of Flanagan's autobiographical, performative example holds much in common with the performative and cathartic possibilities of confronting pain through video. Excerpts such as Tom Joslin's car rant detailed earlier provide an active means of externalizing pain—translating and transmuting it into words, expression, emotion, and movement.

Perhaps most importantly, through such performative acts, the watchful glass of the camera lens offers up a mirror to self. Rare is it that a video entry remains static in its expression of pain. The act of performance most often leads to the innate desire to apply a sense of structure, trajectory, or significance onto the episode. As such, a wave of nausea, or a sleepless night gripped in fear or worry progressively takes shape and finds links or associations to a larger perspective, point, or synthetic result beyond the moment.

Such a trajectory can be seen in Gerry Rogers' *My Left Breast* (2000) in which the Canadian Rogers chronicles her post-mastectomy bouts with chemotherapy and radiation therapy. In an early morning video diary shot in front of a mirror, Rogers, bald and in her flannel pajamas, turns not to her partner Peggy but to the camera to perform her pain and discomfort:

It's um, Saturday December 4th? 5th? Something like that. And I feel probably the sickest I've felt, so this is not bad. I'm pretty nauseous. I was up a few times last night throwing up a bit. It's like my whole body goes flutter, flutter, flutter, flutter, flutter [she begins panting] and the thought of even water, I can't...I haven't been able to drink anything yet today. And I've got to take those three little pills I have to bless. Not quite sure yet how I'm going to get them down. Just even the thought of it makes me nauseous. But I'm pretty good. [Long pause.] I'm really tired of this...

Her voice becomes fragile, suddenly fighting back tears. Then with a visual dissolve effect, she advances to a later moment in the entry, perhaps cutting out a moment of tears or simply a digression. She continues:

People ask me if I have any feelings about...or any new thoughts on suffering or life and death, and I don't. [She blinks back tears again.] Only that love and tenderness are so important to me right now. If anybody shows me any love and tenderness it melts me, but it gives me...pleasure or peace or...something. And I love to be touched. I love to be touched gently. I love to be touched with love, because I feel like I'm a little bit untouchable these days. And not, uh, definitely not the most...desirable. [Long pause]. But I guess thinking about it, it's realizing how radicalizing love, and compassion, and tenderness is. [She holds back tears once again.] And that that seems to brush away everything else.

A diary entry spurred by pain, sleeplessness, and nausea in fact serves to translate such negative physical sensations into an articulation about the restorative, palliative power of touch and expressions of love. As Eve Sedgwick, Thomas Waugh, Judith Butler and others have explored, notions of performativity so prevalent in queer, gender, and now documentary studies derive from speech act linguistics, “defining a category of utterance that executes, enacts, or performs the action that is uttered (Waugh, 110).” Hence just as gender realities are created through “sustained social performances (Butler, 141)” so too are notions of illness and wellness. Performances of pain on video are not so much constative descriptions of pain as they are performative translations and transformations of seemingly senseless physical and emotional suffering into acts of personal pain management and larger humanistic understanding.

MAKING SENSE OF PAIN

Video diaries are certainly transformative in the moment, but along with their immediacy comes the subsequent and more enduring power to screen, reflect upon, and make sense of such entries—deciding how and with whom a patient might want to share these performances. The reason Gerry chose to cut out a portion of her diary entry above is less important than the fact that she had the power to do so through the editing process.

Editing, contextualizing, and distributing video diaries, even if done only in the simplest and most rudimentary ways—reviewing, cutting out or together bits with a program like iMovie, uploading to YouTube or another such social networking site, and providing a title and description for a search engine—are reflexive acts, demanding retrospection and processing. By juxtaposing or assimilating different moments of footage and by providing context, patients are in fact making sense of pain through *narrative*. The singular bout with pain becomes but one moment in a larger reality rather than the defining characteristic of an individual, as in the traditional medical pain diary template.

Even the momentary rage and frustration felt by Tom Joslin in the *Silverlake Life* scene described earlier soon gets placed into a larger context and perspective. Over shots of Mark painstakingly filling gel caps with the powder picked up from the herbalist on the errant errand run, Tom quietly reflects, “Of course it wasn't really Mark's fault. It's just anger at my incapacity to do normal things that I used to be able to do, and it gets me so angry.” In the following scene, filming from bed, Tom turns the camera onto Mark and permits him to voice his own perspectives on the pains of being a caregiver:

Tom: You were telling me something a minute ago that I wanted to hear and put on tape.

Mark: What. About loving you?

Tom: Yes. That's all.

Mark: [Laughing.] Oh I just know I do. What did you ask? How much?

Tom: No just, do you love me.

Mark: I said it hurts, because I can't stand seeing you sick. Drives me crazy. I can't do anything about it. Can't control it. I don't know what it is. And it makes you unhappy, and it makes me unhappy. Drives me nuts. Sometimes it makes me very angry; those are probably the times I can't do anything about it. And other times it hurts. Because I can't do anything for you. And then sometimes it scares me.

With an edit, we now see Tom in bed from his bedside camera stand, as Mark kisses him on his forehead, both cheeks, his chin, and nose, before lightly stroking his hair. Tom turns to camera and tells us, "Now there's a goodnight kiss, huh? I bet you people don't get those."

Making sense of pain through video is in many respects a process of *mirroring* in the psychodynamic sense of the term. For those excised from mainstream media and popular discourse—minorities and the marginalized existing outside of heteronormative models of health and propriety—there really have been no opportunities for healthy narcissism and cultural mirroring not only directly for the individual patient but for us all, who by proxy are forced to confront our own mortality.

By sequencing together four successive video interactions, Tom and Mark are able to model a trajectory of conflict, reflection, reversal, and resolution around their physical and emotional pains, not only for themselves, catalyzed by the camera and the act of filming, but for us as audiences as well, the scenes imbued with enduring vitality and immediacy though we are now removed from the actual events by decades, both men long-since deceased.

EXPERIENCING DEATH

Beyond their lone video-diary moments, the corpus of videos under examination here are rarely created alone, but rather in distinct collaboration with caretakers and life partners. Video production, like illness and recovery, is intrinsically a collaborative process. This is a profound point to make, because along with providing a private outlet, confessional, and punching bag, the camera and the associated practice of personal video making can also afford a sense of shared enterprise as well as a recognition and potential deepening of the relationships and support systems the patient has around them.

In "Filling up the Hole in the Real," Michael Renov advances his arguments about the functions of film and video as means of mourning and memorialization by quoting Jacques Lacan: "The one unbearable dimension of possible human experience is not the experience of one's own death, which no one has, but the experience of the death of another (163)." *Death: A Love Story, Sick, and Silverlake Life* not only address issues of illness-related pain, these videos culminate in the actual deaths of their ailing protagonists. As such, the films challenge both Lacan's assertion that experiencing one's own death is an impossibility, and the idea that the death of another need be unbearable.

In all three works, documenting pain and illness becomes a shared enterprise and a route to making sense of death. As mentioned earlier the camera becomes Michelle Le Brun's "saving grace" in addressing and coping with husband Mel's cancer. It is only after Mel's death that Le Brun decides to attempt to make a work for public viewing out of her Hi-8 videos and written diary. As such, the editorial process very much becomes a form of grieving and a making sense of her own emotional pain and of the death of her husband. In his final moments she chooses to turn off the camera and instead record Mel's words with a tape recorder. Over a still photograph of Mel in the hospital superimposed with poetic images of flames and nature, Michelle tells us in voiceover:

I draw the curtains and crawl into bed with Mel. It's the first time since the transplant I've been able to really snuggle my head against his chest and mingle my legs with his. Several friends show up throughout the day... we all sit; the energy in the room is palpable though invisible.

We then hear Mel's voice from the tape recording, describing to Michelle the angels he sees around the foot of his bed: "Tough guys in Mexican suits, Puerto Ricans and Jews, fat people and short people, and silly people in plaid shorts. And they seem to be enjoying themselves in a big, big way." In these last hours, the hospital room is no longer a medical space. It has been reclaimed as a site reminiscent of the seventeenth century deathbed scene. Medical care is terminated and Mel's death permitted to be a natural one.

In *Sick*, Flanagan's friend and filmmaker Kirby Dick similarly acknowledges the intense personal and artistic partnership between Flanagan and Sheree Rose, who has made Bob's body her own artistic canvas and performative object for fifteen years. Dick is not present in the hospital during Flanagan's last days. Instead, he and Sheree set up a Hi-8 camera on a tripod in the hospital room, and the choice of what to record and not to record falls to her. In a final bedside moment with Bob, Sheree permits us to see her cradling an unresponsive Bob in his last living minutes: "I'm gonna stop crying. I'm gonna stop crying. I'm gonna stop crying. I'm gonna be OK. OK? You hold on; hold on just a couple more minutes? Hold on to me. Hold on just a few more minutes?"

Suddenly the film cuts to a series of still photographs, not of Bob, but of his corpse. It is clear from the use of natural window light and the artful compositional attention to Bob's tattoos, scars, and piercings, that these are not "official" images. Taken by Sheree, the photographs are reminiscent of the nineteenth century commonplace practice of memorializing one's deceased through daguerreotype. Sheree subverts the medical gaze, reclaims the taboo documentation of the corpse from the exclusive realms of autopsy and forensics, and channels her own grieving process through her own proclivity for photography. Rose's photographs constitute a powerful sequence of memorial and contemplation in *Sick*, reinvigorating both a photographic process and its associated rite of emotional *processing* that was lost in the twentieth century as images and sights of illness, natural death, and dying were eliminated from the domestic sphere and public consciousness, ceded to the privileged gazes of medical, legal, and funerary professionals.

In *Silverlake Life*, the video camera passes from Tom Joslin to lover, Mark Massi, when Tom becomes too ill to continue shooting. When Massi himself succumbs to AIDS, the roles of co-director and editor ultimately fall to a former film student of Joslin's, Peter Friedman, who inherited the challenge of distilling thirty-five hours of collected footage into a finished work. In their article "Love, Death, and Videotape: Silverlake Life," Beverly Seckinger and Janet Jakobsen herald the film for its queering of the traditional singularity of documentary authorship and of the inherent power imbalance between filmmakers and subjects cast as distinct "others." *Silverlake Life* subverts the medical gaze by returning the site of death to the home; we see Tom's slow decline from the site of his own bed. But with a single edit, Tom is suddenly dead, Mark shakily filming the corpse:

This is the first of July and Tommy's just died. And I sang to him, I sang to him [breaks into You Are My Sunshine]. Isn't he beautiful? He's so beautiful. This is for you, Tommy. All of us, all of your friends will finish the tape for you. OK? We promise. Bye. Bye Tom.

The video has become a shared enterprise; a reason to go on living and a means by which a group of family and friends can reminisce, feel useful, bear witness, grieve, heal, memorialize, and defy silencing discrimination and social stigma around homosexuality and AIDS.

Contrary to Lacan's assertions, through video enterprises, the specific ways in which Mel, Bob, and Tom each confront their own mortality and claim control of end-of-life choices suggest that one can, in fact, experience one's own death; that the process of dying can be a profoundly active and empowering experience rather than one of passive resignation, fear, and taboo. Similarly, though their collaborators—Michelle, Sheree, and Mark—certainly experience physical and emotional pain and distress over the course of their loved ones' body failures, we see that experiencing another's death need not prove "unbearable." Michelle's final moments curled up alongside Mel, tape recording his visions of angels; Mark's on-camera farewell song; Sheree's impulse to pick up her still camera: far from "unbearable," each of these moments contains a core element of catharsis and memorialization, made possible by the fact that all three partners were allowed to become active partners on a journey rather than passive, helpless bystanders. Active engagement in the creative process is a healing process demanding intersubjectivity and eradicating the *victimhood* so frequently characteristic of mainstream representations of illness and mortality.

PAIN IN THE PUBLIC SPHERE

These three death-defying works are all the more amazing in that they are decidedly analog, shot on consumer-grade video, with editing mandating access to specialized equipment and software, all before media production became a digital commonplace. Now, individuals in many cultures around the globe are no more than a degree of separation away from a video recording device and a computer capable of editing and uploading media. Users do not even need to purchase editing software, but rather can edit and manipulate their video material online via free *cloud computing* programs (meaning software and storage space are hosted by an online provider) such as One True Media (www.onetruemedia.com). This means that video shot with a cell phone or still camera's video function can be uploaded and edited from a computer at the local public library or community center.

And yet, with all these technological advances, fear and taboo still stand to curtail possibilities for a productive digital public sphere in which consumer technologies can be purposed towards making sense of illness, pain, and mortality. In addition to comments such as those left by YouTuber coltzeu, negative responses and YouTube user flagging of her cancer diaries has led phaadress to preface each of her vlogs with the same fourteen-second disclaimer sequence: "I am phaadress. Warning! Attention! Achtung! This video contains details about cancer. Still here? Last chance to click off..." the last image of this sequence is playful, superimposing the text over a photograph of a baby chick pecking at a keyboard, implying that many Web users are in fact naïve chickens hunting and pecking for meaning, only if it is safe and standard fare.

This is perhaps partly what has led to the proliferation of closed online sites related to illness—sites that are able to cultivate niche communities the likes of i2y.com (I'm too young for this!) which exclusively caters to young adult cancer patients and survivors under 40. Such niche spaces are understandable and important as safe spaces where like can converse and relate to like. In the predigital era, patients the likes of Gerry Rogers living in rural areas even resorted to techniques such as HAM radio in order to participate in closed breast cancer support groups:

I find that what I though I have such a wonderful community and so many friends and family who love me and support me, but what I really want to do at times, what I really need to do is talk to other women who have breast cancer, who have gone through it, and have gone through chemo. Because ultimately, you know, we feel alone, and sometimes in those moments...we feel so alone and so isolated, sometimes this really helps. So here I am in this tiny, dingy little library room in Carbonear, far away from everybody that I know and love, except for Peggy who is doing the camera, and the wonderful thing, the magic of technology is that I just flip this switch, and it's

instant community.

Through the examples in this paper, I hope to evidence the multiple values of pain videos:

- Immediate therapeutic impact for the recording patient
- A sense of collaboration and intersubjectivity with loved ones and caregivers
- Therapeutic and informational utility for other patients
- Training and treatment information for physicians and other medical personnel

But making pain diaries solely for other cancer patients and survivors is in some respects analogous to making pain diaries solely for doctors. The act of sharing such works with others outside of one's particular experience in a public sphere, whether that be via DVD or an online social networking site may lead to isolated incidents of viewer discomfort and unproductive comments, but it can also function as a bridge across the longstanding currents of taboo and silence surrounding illness, pain, and mortality in Western culture. Amidst the thanks and praise from viewers to phaedress' March 25, 2008 vlog *Life After Cancer*, YouTuber *Clarachk* quotes C. S. Lewis: "Experience, that most brutal of teachers. But you learn, my God do you learn." Hopefully through the sharing of pain video diaries, patients can feel a sense of purpose and community, and by watching, we have an opportunity to learn and grow before the brutality of personal experience is upon us, softening the blow and providing tools to face our own pains.

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