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# Shooting Pains: Addressing Illness-Related Pain through Video Autobiography

Broderick Fox, *Occidental College*



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# Shooting Pains: Addressing Illness-Related Pain through Video Autobiography

*Broderick Fox*

## Abstract

This paper will look to autobiographical videos and emergent uses of social software sites such as YouTube to explore the possibilities of first-person media as a pain management tool. Beyond the therapeutic possibilities, the paper will also explore the potential of such personal media acts as a means of breaking down taboos around pain and illness – offering up models for managing, discussing, and even ‘performing’ pain in the public sphere.

**Key Words:** Video diary, autobiography, performativity, social media, vlog, pain diary, pain management, illness, digital democracy, public sphere.

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## 1. 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 Mediations of illness have been superseded by discourses of wellness and anti-aging, which seem to equate acknowledging pain with weakness and illness or body failure as personal failures. In this paper, I will profile a range of video makers and *vloggers* (video bloggers) who have turned consumer-grade cameras onto themselves as a means of engaging and managing illness-related pain.

Pain videos are not a digital phenomenon. Many of the most indelible examples of pain media are decidedly analog, predating the Internet or the ubiquity of digital cameras. We can all recognize how the Web has revolutionized opportunities for exhibition, distribution, and community formation heretofore impossible. But is technology perhaps outpacing taboo and cultural ideology? Digital democracy may still not be ready for certain subject matters.

In *Home Movies and Other Necessary Fictions*, filmmaker and scholar Michelle Citron offers a contemplative history of home movie images in American culture:

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.<sup>1</sup>



While amateur motion picture technologies' evolution from Super 8 film, to analog video, to digital video camcorder, and now to Web and Flip cams has been dramatic (along with unprecedented access to the means of post-production capacities via nonlinear editing software packages), the strict code of 'appropriate' home movie recording situations has experienced little change.

Such *bio-power* (a term coined by Michel Foucault to describe the ways in which we all self-regulate and self-censor our thoughts, actions, and appearances in relation to perceived social norms<sup>2</sup>) can occasionally be seen posted in the user comment streams on YouTube, in response to autobiographical pain video logs or *vlogs* uploaded there. YouTube vlogger *1938Superman* posted a vlog in November, 2006 recounting his bout with testicular cancer. Amongst the specific and productive responses from fellow cancer patients, medical professionals, and the occasional general well-wisher, his video also received this response in the chain from a 25-year-old male user:

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.<sup>3</sup>

In the face of such potential self-exposure and excoriation, why would someone point the camera onto their pain and then choose share it with a public, often emboldened by the Web's anonymity to produce lazy language and hate speech? The remainder of this paper will explore some of these motivations, along with some of the personally and culturally transformative potentials of pain diaries.

## 2. Beyond the Medical Gaze

Physicians often instruct patients and caretakers to keep pain diaries, but like the medical file, these autobiographies are coded in medical terms and authored not for self or peers, but for medical professionals. Speaking on this peculiar tension in relation to the medical file in her article 'Medical Identity: My DNA/Myself,' scholar Kay 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.<sup>4</sup>

Medically prescribed pain diaries are similar in their tension between author and audience. Patients' experiences of pain are reduced to a number scale,

accompanied by time of day, time since last medication, other concomitant symptoms, and level of activity at the time.

There is certainly medical value to such pain diaries, but the video diaries under investigation here are far more personal and confessional in nature. Documentary 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.<sup>5</sup> 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 alternate mode of expression and confession, as the camera functions as a silent, non-judging proxy for an implied listener or audience, who depending on the desires of the patient may never actually be publicly screened.

In *Silverlake Life: the View From Here* (1991), the illness is AIDS, and the video camera begins autobiographically in the hands of 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 stigmatisation of those with the disease.

Joslin 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 physical and emotional pain:

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*. [...] 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 [...] Meanwhile I haven't had fucking dinner. I haven't had any...Jesus! You try to be helpful, getting screwed *time and time* again! I *hate* being a nice guy!<sup>6</sup>

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. Transcribed here, one misses the cracks in Tom's voice as he comes close to tears, the pauses and hesitations between sentences to catch his breath, the varying volume and pace of his voice, his emphasis on certain words, his ravaged physical appearance, and the realities of his surroundings. The video preserves these details in a perpetual liveness, providing a compelling and three-dimensional portrait of Tom's experience. Joslin's 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 upbeat, active models of positivity in the face of adversity. In contrast, seeing the normally mild-mannered and genteel Tom despair and rage in the parking lot, railing against his 'nice guy' status is both arresting and potentially refreshing for patients who feel alone in or ashamed of their own private rage rarely validated or modelled by mainstream media or the wellness industry.

### 3. 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 paralysing effects 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.

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

It's um, Saturday December 4<sup>th</sup>? 5<sup>th</sup>? 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, 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 that 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 [...]  
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.] 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. 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.<sup>7</sup>

Gerry's video 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 gender, queer, and now documentary studies derive from speech act linguistics, which to quote Waugh, 'define a category of utterance that executes, enacts, or performs the action that is uttered.'<sup>8</sup> Hence just as gender realities are created through 'sustained social performances,'<sup>9</sup> so too are notions of illness and wellness. Performances of pain on video have the potential to go beyond constative descriptions of pain to become performative translations and transformations of seemingly senseless physical and emotional suffering into acts of personal pain management and larger humanistic understanding.

#### 4. Pain in the Public Sphere

When video diarists such as Tom and Gerry press record and speak, they are not simply talking to the camera or to themselves, but to *us*: an assumed future audience. Though not physically present in the moment, we are so by proxy, providing a form of witness, support, and alliance. When YouTube vlogger *phaedress*, a 40-year-old Canadian breast cancer patient, returns for a post-chemo, post-radiation mammogram, she brings her camera along. While she nervously waits, trying to rationalize why the doctors have re-scanned her breast three times and then left her waiting for an hour with no update, 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

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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.<sup>10</sup>

Making sense of pain through video is in many respects a process of *mirroring* in the psychodynamic sense of the term as detailed by the likes of Heinz Kohut.<sup>11</sup> 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 around issues of pain, illness, and mortality.

Ironically, this lack of representation perpetuates fear, taboo, and difference around what are perhaps the most universal and shared of inevitable human experiences. Autobiographical pain videos therefore have potential therapeutic and informational value not simply for the recording patient, but for us all, whether we are ill, a caregiver, a physician, or simply someone now healthy inevitably poised to perform at least one of these roles ourselves in the future.

Yet even 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. Negative responses and YouTube user flagging of her cancer diaries has led phaedress to preface each of her vlogs with the same fourteen-second disclaimer sequence: 'I am phaedress. Warning! Attention! Achtung! This video contains details about cancer. Still here? Last chance to click off!'<sup>12</sup>

Such vestiges of bio-power are no doubt in part what has led to the proliferation of closed online niche communities like *i2y.com* (an acronym for, 'I'm too young for this!'), a site that caters exclusively to young adult cancer patients and survivors under forty. Member-only Websites and closed support groups are important safe spaces where like can converse with and relate to like in ways that others of us might never be able to fully comprehend without such experiential knowledge.

But making pain diaries solely for other cancer patients and survivors is in some respects analogous to making pain diaries solely for the medical gaze. 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.

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, description, and keywords 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*. A 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.

In short, patients may not be able to stop their pain, but through video, they can become its director. Patients can choose what forms of performing pain are important and valid for them, rather than following a prescribed template. The presence of an implied *you*, manifested by the camera's gaze (be that a future larger audience or simply the 'other self') permits a sense of someone bearing witness/seeing and hearing one's pain. Patients have the power to keep such videos to themselves or to delete them altogether, freeing the process from predetermined outcome or significance.

Hopefully through the sharing of pain video diaries in the public sphere, patients can feel a sense of purpose, becoming part of community and turning video monologue into dialogue. By watching such videos, each of us has an opportunity to learn and grow – as physicians, caretakers or simply as fellow humans – cultivating tools with which we can make sense of our own inevitable pains and mortality.

## Notes

<sup>1</sup> M Citron, *Home Movies and Other Necessary Fictions*, University of Minnesota, Minneapolis, 1999, p. 19.

<sup>2</sup> M Foucault, *The History of Sexuality: An Introduction, Vol.1*, 1976,

R Hurley (trans), Vintage Books, New York, 1990, p. 140.

<sup>3</sup> 1938 Superman, *My Inevitable Cancer Video*, Nov. 24, 2006: [http://www.youtube.com/watch?v=8yB\\_6PT4Cho](http://www.youtube.com/watch?v=8yB_6PT4Cho).

<sup>4</sup> K Cook, 'Medical Identity: My DNA/Myself,' *Getting a Life: Everyday Uses of Autobiography*, S Smith & J Watson (ed), University of Minnesota, Minneapolis, 1996, p. 71.

<sup>5</sup> M Renov, 'Video Confessions,' *Resolutions: Contemporary Video Practices*, M Renov & E Suderberg (ed), University of Minnesota, Minneapolis, 1996, pp. 78-101.

<sup>6</sup> P Friedman, T Joslin & M Massi, *Silverlake Life: The View From Here*, Docurama, 1991, 99 min.

<sup>7</sup> G Rogers, *My Left Breast*, Women Make Movies, 2000, 57min.

<sup>8</sup> T Waugh, 'Walking on Tippy Toes: Lesbian and Gay Liberation. Documentary of the Post-Stonewall Period 1969-86,' *Between the Sheets, In the Streets: Queer, Lesbian, Gay Documentary*, C Holmlund & C Fuchs (ed), University of Minnesota, Minneapolis, 1997, p. 110.

<sup>9</sup> J Butler, *Gender Trouble: Feminism and the Subversion of Identity*, Routledge, New York, 1990, p. 141.

<sup>10</sup> Phaedress, *Cancer Reflections, Part Two*, Nov. 24, 2006: <http://www.youtube.com/watch?v=ydirSD8J6Eo>.

<sup>11</sup> H Kohut, *The Analysis of the Self: A Systematic Approach to the Psychoanalytic Treatment of Narcissistic Personality Disorders*, University of Chicago, Chicago, 1979.

<sup>12</sup> Phaedress, *Cancer Reflections, Part Two*.

## Bibliography

1938Superman, *My Inevitable Cancer Video*. YouTube. United States, Nov. 24, 2006, [http://www.youtube.com/watch?v=8yB\\_6PT4Cho](http://www.youtube.com/watch?v=8yB_6PT4Cho).

Butler, J., *Gender Trouble: Feminism and the Subversion of Identity*. Routledge, New York, 1990.

Citron, M., *Home Movies and Other Necessary Fictions*. University of Minnesota, Minneapolis, 1999.

Cook, K., 'Medical Identity: My DNA/Myself.' *Getting a Life: Everyday Uses of Autobiography*. University of Minnesota, Minneapolis, 1996.

Friedman, P., Joslin T. & Massi, M., *Silverlake Life: The View From Here*. Docurama. United States, 1991, 99 min.

Foucault, M., *The History of Sexuality: An Introduction. Vol.1.* (1976). R Hurley (trans), Vintage Books, New York, 1990.

Kohut, H., *The Analysis of the Self: A Systematic Approach to the Psychoanalytic Treatment of Narcissistic Personality Disorders*. University of Chicago, Chicago, 1979.

Phaedress, *Cancer Reflections, Part Two*. YouTube. Canada, Nov. 24, 2006, <http://www.youtube.com/watch?v=ydirSD8J6Eo>.

Renov, M., 'Video Confessions.' *Resolutions: Contemporary Video Practices*. University of Minnesota, Minneapolis, 1996, pp. 78-101.

Rogers, G., *My Left Breast*. Women Make Movies, Canada, 2000, 57 min.

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Sedgwick, E., *Epistemology of the Closet*. University of California, Berkeley, 1990.

Waugh, T., 'Walking on Tippy Toes: Lesbian and Gay Liberation. Documentary of the Post-Stonewall Period 1969-86.' *Between the Sheets, In the Streets: Queer, Lesbian, Gay Documentary*. University of Minnesota, Minneapolis, 1997, pp. 107-126.

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