The Final Cut: End-of-Life Empowerment through Autobiographical Video Documentary

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Dying is all about human beings in relationship with themselves and with one another. It identifies a relational process, a coming to terms with limitation; and 'a good death' identifies a dying process that has been marked by personal growth, deepening understanding, and the expression of care, not only from care-givers towards the dying, but from the dying toward themselves and in relation to those who care for them. Death is one thing, dying another. Dying is a process of tremendous variability. Rather than being an abstract universal, dying is profoundly personal and intimate. This book exemplifies the crossing of boundaries, perspective and disciplines to illuminate the intimacy of dying.


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ESSAYS ON CARE AND THE INTIMACY OF DYING

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The Final Cut: End-of-Life Empowerment through Autobiographical Video Documentary

Broderick Fox

Abstract
This chapter will examine assisted video autobiographies that seek to break taboos around visualising natural death and dying. Turning the camera onto death in one sense posits limit-cases to photographic representation and documentary ethics. The videos in question, however, each propose routes to shared authorship in their production that parallel the possibilities for active, agented, and communally-experienced death and dying that have become all-too-rare in Western society. The chapter closes with a meditation on the potentials for and limitations on such independent video discourse around death and dying in the digital age.

Key Words: Autobiography, performativity, social media, video, illness, death and dying, documentary ethics, grief, collaborative authorship

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1. The Denaturing of Death

Birth, and copulation, and death.
That's all the facts when you come to brass tacks:
Birth, and copulation, and death.¹

Geoffrey Gorer opens his oft-quoted article ‘The Pornography of Death’ with these lines of T.S. Eliot’s, defining birth, sex, and death as the ‘triad of basic human experiences’ which have been met with varying degrees of social acceptance and prudery in Western culture since the Middle Ages.² Michel Foucault takes this idea further, characterising seventeenth-century culture as one in which bodies ‘made a display of themselves’:

Sexual practices had little need of secrecy; words were said without undue reticence, and things were done without too much concealment; one had a tolerant familiarity with the illicit.³

A seventeenth-century society of the open bedroom, where birth, sex, and death scenes played without taboo, yielded to the Victorian Era of the nineteenth century, which saw a closing of the bedroom door in relation to sex and birth. Social mores of the time fused two components of the life triad, with copulation subjugated to the sole purpose of procreation. Yet the bedroom door remained open for the nursing of the sick, the death vigil, and the post-mortem viewing. Parents often
transported the corpses of children to the photographer's studio to have a memorial portrait captured by daguerreotype. With the long exposure times necessary for early photographic processes, the dead in fact made ideal subjects.

Today we live in a secularised age of psychoanalysis where taboos surrounding birth and sex have been shattered. Procreation no longer even mandates physical copulation, and a (safe) sex life is part of a larger plan of healthy living prescribed by a medical community that, in the words of sociologist Michael C. Kearl, "has replaced organized religion as the major institutional molder of cultural death fears and immortality desires." Of the triad of basic human experiences described by Eliot's verse, an inversion has occurred; death now stands as the final taboo of modern Western culture.

In *Inventing the American Way of Death: 1830-1920*, scholar James J. Farrell traces how notions and practices such as the professionalisation of the funeral director, the normalising of embalming, and the transformation of personal acts of body disposal into an impersonal American industry occurred over the span of less than a century. Consequently, though we may feel we are making personal choices as we select amongst the very finest coffin models dispensed from funeral home franchises who can 'package' our final respects like perks on a Hawaiian vacation, Farrell argues:

... funerals are custom-made only in the same sense automobiles are, and the price we pay for paying our last respects in the American way of death is the price of our personality, which we have purposely withheld from the funeral. By our passive role in directing our funerals, we have transformed an important rite of personal passage into an impersonal rite of impassivity.

The resultant 'American way of death' leaves us largely blind to the cultural construction of our conceptions of appropriate body disposal, and even of appropriate ways of expressing grief.

Perhaps most disturbing, the resultant power imbalances between medical/ legal/funeral forces and the individual go largely uncontemplated by Americans. With all the political sites of hegemonic resistance and claims for agency in social movements, why is it that empowerment in one's own end-of-life decision making is so rarely championed or discussed? Why is it simply taken for granted, for example, that death must occur in a hospital; a funeral must cost at least $8,000; a casket is legally required for burial; home viewings and services are impossibility; or that embalming is legally mandated? What social, ideological, or internal forces keep us from seeking out the full information?

Gone are the days of seventeenth-century death masks and nineteenth-century post-mortem daguerreotypes. We prefer to remember our loved ones as they were in the prime of life, and if an open casket viewing is called for, the mortician does

his or her best to 'make-up' that resemblance. With viewing of 'natural' death and dying removed from the home and viewing rights conferred to the privileged gazes of medical, funerary, and legal representatives, what remains for us to see are images of romantically veiled or violent death on television, film, video, and the Internet.

Two chapters in particular from this volume provide insight into how both mediated and biased views of death and dying extend into the medical sphere, with sobering implications. In her chapter in this volume, 'Nursing the Dying in the Emergency Department: The Importance of Therapeutic Intimacy,' Cara Bailey underscores how spectacular cases - those involving 'unexpected acute medical illness or a sudden and often tragic event' - preoccupy the energies, resources, and perhaps most importantly, whatever emotional and intersubjective investment staff can provide in the hospital emergency department (ED). This is understandable to a point, as the ED is meant to be the place of life saving, life-sustaining treatment. And yet, for terminally ill patients whose conditions require periodic address in the ED as new symptoms or crises emerge in relation to their terminal conditions, the attention and treatment conferred is often of diminished quality, though emergent and palliative care for the terminally diagnosed can and should be considered medically and socially vital.

Conversely, Kathryn Brown and Sarah Weeks in their chapter in this volume, 'Code Levels in Cardiology: Who, When and How?,' underscore that patient understanding of cardiac resuscitation codes - the invasive nature of such procedures, their physical consequences such as broken ribs and other bodily trauma, and the potentially substandard outcomes including brain damage and vegetative states - is incredibly poor. Such lack of information is no doubt influenced by popular representations of medical trauma on television, where resuscitation is often successful and depicted simply as the momentary jolt of defibrillator paddles, followed by complete, uncomplicated stabilisation of the patient. Perhaps more disturbing is their finding that one of the other major contributors to such misinformation is the lack of training or comfort on the part of physicians to initiate substantive conversations about advanced directives well before the moment of medical crisis. The fact that the other authors in this anthology address similar misrepresentations or lack of address of death and dying across a range of cultural contexts, makes clear that this is not simply an American problem.

Here lies the true challenge to the limits of death's representation: rather than sanitising or sensationalising death and dying, how can we return progressive engagement with such matters to popular discourse? How may we reclaim the gaze upon 'natural' death from privileged eyes and from professionals and patients alike who choose to look the other way rather than have an important conversation? My discussion focuses on two works in particular to make its case for independent video as a powerful medium for such exploration: Mark Massi, Tom Joslin, and
Peter Friedman's *Silverlake Life: The View from Here* (1993) and Michelle Le Brun's *Death: A Love Story* (1999). Both are autobiographical videos that involve the infirm and their significant others turning consumer-grade cameras onto end-of-life decision making processes, the physical processes of dying, and actual moments of natural death.

Such videos not only produce discourse around death and dying options in a productive public sphere, but their production also necessitates a rare form of collaboration and shared authorship between caregivers and the dying. Such use of video is therefore not only an important route to larger cultural understanding but also an incredibly empowering and therapeutic tool for participating patients and loved ones as they attempt to make sense of death.

The two videos examined here are unique in their specific content and formal strategies, and yet each features an embodied subject/collaborator whose specific circumstances and identity engage us, implicating us, and defy our attempts to ‘other’ them or to delegitimize their representations of death and dying purely to the symbolic. It is also important to note that both videos were produced in the pre-digital, pre-YouTube world, an important distinction that I will return to in my conclusion as I look to digital possibilities for mediating natural death.

2. Subverting the Home Movie

*Silverlake Life: The View from Here* begins as the video project of veteran filmmaker Tom Joslin as he documents his daily battle with AIDS. And yet, with the exception of clips from earlier Joslin films, the finished work is culled solely from thirty-five hours of Hi-8 home video. The video subverts ideologies of home movie recording, not only by confronting illness and death, but also by the domestic partnership transcribed: Joslin and his lover of twenty-two years, Mark Massi. 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.

Through the imaging of their domestic space and daily life, AIDS becomes personified through real eyes, Joslin and Massi offering visible proof that equally powerful feelings of commitment, love, and loss exist outside the hegemonic heterosexual model (although societal attempts to invalidate this fact extend all the way to Joslin’s death certificate shown late in the video, which designates him as “unmarried”; there is literally no space for Massi in the official record).

*Death: A Love Story* is also a work composed almost entirely of Hi-8 camcorder footage shot by a non-professional, without any designs of a larger, publicly-released work in mind at the time of shooting. The video opens with traditional home movie images of Mel and Michelle, a couple in love: travel images of a European vacation together, video tape of their wedding, and excerpts from their road trip honeymoon. Over these traditional home movie images, Michelle Le Brun explains the genesis of her video:

We bought a new video camera, which we play with all the time these days. Our second Thanksgiving in Los Angeles, Mel is diagnosed with primary liver cancer. Our friends suggest we keep the camera rolling.

This is precisely what the couple does, their Hi-8 video camera increasingly transgressing traditional home movie contexts to include doctor’s visits and the chemotherapy sessions. It is only after the death of her husband that Michelle truly steps into the position of filmmaker, constructing a public text from the couple’s private images.

The act of editing the footage becomes a grieving process for Michelle who makes some sense of Mel’s death by revisiting and assembling the footage into a narrative of wider cultural relevance. In the completed video 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.

Viewing these videos, which neither romanticise nor ‘other’ death, it becomes far more difficult to dismiss the onscreen living and dying of Mel, Tom, and Mark as simply someone else’s problem. Many of us now own or have access to video cameras (of far superior quality to the ones utilised for these pre-digital projects) on our cell phone, iPod, or computer. The ‘home movie’ format of each provides a point of engagement: making private images a matter of public discourse and extending the potential means of production to individuals, voices, and subject matters heretofore excluded from mainstream programming.

3. Collaborative Authorship

Far from eliciting the customary realist documentary ‘gap’ between photographer and subject, the presence of the camera in these works seems to function as a means of bringing the couples closer, allowing them to be part of a shared enterprise and often functioning as a catalyst for difficult conversations. Such dynamics can find some analogy with ethnographic filmmaker Jean Rouch’s notions of cinéma vérité, or ethnographer and scholar David MacDougall’s related call for a participatory alternative to ethnography’s traditional one-way observational encounter. Both Rouch and MacDougall’s call for documentary encounters between two parties meeting as equals in a third space that is the domain of neither alone.

During a pre-chemo retreat to the Joshua Tree National Park in *Death: A Love Story*, it is Mel behind the camera, making his wife the focus, asking Michelle if she has thought about what she will do if he dies. Never in the videos at hand is there an attempt on the part of the non-dying to distance or extricate themselves from the texts. In fact, in certain moments, the enterprise of making a video seems
to afford our caretakers with a much-needed outlet, or confessional. This certainly seems to be the case for Mark Massi, in the last week of Tom's Silverlake life, where with one diary entry he tells us:

Today's June 25th and it's really hot - over 100 degrees or something in the house. Tom's lying in bed here, all nice and cool.

From behind the camera Mark's bright, cheery tone breaks as he starts to cry.

And I haven't done any video recording for the last couple of days because I felt really bad. I gave Tom some food that didn't settle well and it made him throw up all night and I was just ashamed I had done that, and I was afraid to turn on the camera because everybody would think he was weaker again, and I love him so much!^11

Both videos explore traditional notions of singular authorship and of clear demarcation between producer and subject. It seems the recording of death and dying mandates a unique complicity between practitioner and subject, an intersubjective space that extends out to the viewer as well: implicating us within the fold, inviting us to face not only the mortality of Mel, Tom, and Mark, but also our own.

4. Empowerment and Mirroring through the Camera

Despite or perhaps because of the relative cultural invisibility of death and dying, (failing bodies are often met with reactions of surprise or fear by those unfamiliar or uncomfortable with the prospect of death. Equally disconcerting, patienthood is often a passive state, requiring individuals to subject themselves to the frequent scrutinising gazes of medical personnel and technologies in order to be able to fully see or know their condition.

The effects of such cultural, medical, and technological mirroring can have profound impacts on the self-perception and self-image of the patient. In Silverlake Life, Mark and Tom video tape themselves finding momentary relief from the daily realities of their disease in a motel pool complex out in Desert Hot Springs, California. Suddenly, a cut reveals a very different Mark - out of the pool and wearing a shirt - huddled into a fetal crouch as he addresses the camera:

The woman who owns this place is very nice. She's very nice to us and she would like me to keep my shirt on so I don't freak out any of the people. And I do that but then it also feeds into that bad part of me that I don't...You know, being self-conscious and disliking my body and whatnot. And mostly I worry about those things because I don't want to upset other people by having to look at ugly me. So it ends up feeding into a bad part of me where I should just normally be proud of it.12

It is at this moment that the camera captures a distinct shift in Mark's words and demeanor, from shame (fuelled by outward perceptions) to pride (stemming from internal self-conception). The sequence closes with him proclaiming, 'Because normally I'm proud that I've been alive this long and it's just like, screw you! I'm the strongest, I'm not dead.' Mark and Tom's instinct to produce a video journal in the moment to process the experience certainly does not eliminate the external judgments or momentary feelings of shame, but it does provide an active outlet for working through such experiences not only for them in the moment, but subsequently for us as audience members as well. Through the camera, those on the margins have the opportunity to control the gaze upon themselves, becoming the authorities and sharing important perspectives and insights in a reflexive process that is both cathartic for themselves and instructive for any future audience.

In Death: A Love Story, Michelle progressively disappears from the screen. And yet she is still ever-present behind the lens, pushing her camera into the faces of doctors, nurses, and technicians; her off-screen voice demanding explanations of release forms and translations of scan images. She tells us, 'The camera has become my saving grace. It gives me some kind of job to do in this situation.'14 Far from hiding behind the camera, Michelle finds voice through it. The camera becomes an equalising force: Michelle squares off against the medical gaze through the viewfinder, creating an information file of her own on tape.

Mel's onscreen experiences underscore the passivity of patienthood and many components of the dying process in a different, but related way, underscoring the non-act of waiting. Doctors prescribe and perform procedures. Patients, on the other hand, are repeatedly told to 'wait and see.' Mel returns home from the hospital, after chemotherapy, to wait - 'waiting to hear if the tumour died, waiting for word of a liver donor.'15 But as Michelle tells us in voice-over, and as we see visually onscreen, Mel does everything but wait. Instead, he researches and seeks out no fewer than ten courses of homeopathic and alternative healing - American Indian, Chinese, Ayurvedic, electromagnetic, enzymatic. Michelle tells us: I ask Mel, "How do you know what's working if you're doing so many things?" He says, "Ultimately, honey, you don't. You've just got to try everything."16

Ten different holistic and alternative treatments may seem excessive, possibly the mark of desperation. Yet one can also read Mel's research and participation in such efforts as a choice for action. He has not abandoned modern medicine, but being sent home to passively wait for a liver, Mel in a sense prescribes and claims active decision-making at a time when science has rendered him impotent.
It is important to underscore that Mel also goes to see a friend who knows about acquiring 'final exit' drugs. This acquaintance has loved ones who committed suicide in the late stages of AIDS, and as Michelle puts it, this man 'understands what it is to have choice in one's own death.' It is startling to see Mel discussing the specifics of Phenobarbital and Valium with the same attention and seriousness of purpose with which he, only moments before (in video time), espoused the distinction of the Qi-Light as the only homeopathic remedy of its sort to have FDA approval.

Initially, Michelle appears startled as well, reading a journal entry from the time on the voice-over track in which she balks at the question of whether she could ever become an accomplice to drug-assisted suicide. And yet, through Mel's example, we begin to realize that simultaneous researching of both curative and suicidal techniques is not so contradictory. In planning and exploring various contingencies, Mel reveals to us that acceptance of one's own mortality is not synonymous with passive resignation or quiting. Rather, the process of claiming agency and 'choice in one's own death' can be an intensely active and empowering one.

In Silverlake Life, Tom and Mark also seek out (and record) non-traditional remedies involving 'aura modification' and 'herbal reflexology,' but, thankfully, it seems they also have a good relationship with their physician, Dr. Jenkins. Nonetheless, Silverlake Life also reveals a subtle, but interesting, subversion of the medical gaze, which is specific to the nature of AIDS as a disease and social phenomenon. Although physicians in the late eighties and early nineties (the time when Tom and Mark taped their doctor visits) had specialized knowledge in the reading of results and prescribing new medication cocktails, I would argue that no other disease of the modern world has so narrowed, or at least so transformed, the gap between patient and doctor than AIDS. Particularly in the early years of AIDS, physicians relied heavily upon patient experience to understand the transmission, progression, and treatment of the virus.

Tom's doctor is able to impart his medical, scientific expertise, but Tom and Mark have an equally striking realm of practical, lived expertise, culled from watching and actively experiencing the demise and death of their own friends to the disease. In one of the final scenes before his condition dramatically deteriorates, Tom sits in bed, looking into the camera, the KS lesion on his right eyelid already prominent, and recounts his most recent doctor visit to Mark:

Dr. Jenkins in the office the other day during our monthly visit says, "Well it's kind of time, Tom." And then he looks at me and says, "Well you should maybe start looking for a hospice." The corollary of all that information of course means that the average life span in a hospice is two months...
from the site of his own bed. But with a single edit, Tom transforms from dying to dead. Mark shakily recording the corpse and narrating to us live from behind the camera:

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.

By the time of Tom’s death, the making of Silverlake Life 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, memorialise, and defy silencing discrimination and social stigma around homosexuality and AIDS.

The processes of natural death and dying modelled in these videos - non-violent death experienced in community in accordence with advanced directives - suggest that the process of dying can be a profoundly active and empowering experience rather than one of passive resignation, fear, and taboo. Similarly, though Michelle and Mark certainly experience 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; each of these moments contains a core element of enthusiasm and memorial, made possible by the fact that these primary caregivers and partners were allowed to become active collaborators on a journey rather than passive, helpless bystanders. Active engagement in the creative process can be seen as a healing process demanding intersubjectivity and challenging both the victimhood so frequently characteristic of mainstream representations of illness and mortality and also the melancholy or hysteria so often associated with mediations of grief.

6. Digital Death

I underscored at this chapter’s outset the distinctly analog nature of each of the videos examined here. Each was produced in a pre-digital era when offering up incarnations of ‘self’ through video autobiography still constituted a revolutionary act. The world has since undergone a dizzying Web 2.0 transformation in a remarkably short span of time, with acts of self-transcription now a digital commonplace. One might imagine, therefore, that the digital discourse around natural death and dying, end-of-life decision making, home funerals, and palliative care would have similarly expanded.

Certainly the Internet has facilitated access to information and the formation of community around issues of natural death and dying, a field that is increasingly becoming synonymous with ‘green’ burials, promoting independent, chemical and cemetery-free body disposal options as not only personally agentic but ecologically sustainable. The National Home Funeral Alliance (NHFA) utilises the Internet and video posts as a means of promoting conferences and outreach (http://homefuneralalliance.org).

Elizabeth Westrate’s documentary, A Family Undertaking (2004), also powerfully demystifies the cultural and economic underpinnings of the funeral industry, chronicling a diverse array of families choosing to have home deaths and home funerals, along with support and training organisations available to facilitate such options such as death midwife Jerrigrace Lyons’ organisation Final Passages in Sebastopol, California. The documentary premiered on PBS’s P.O.V. documentary series in 2004 (P.O.V. also premiered Silverlake Life) and now streams on Netflix, making it a popularly accessible piece.

Though groundbreaking, A Family Undertaking’s funding by the Independent Television and Video Service (I.T.V.S.) and its release on public television are far from being representative of the sort of home-grown digital discourse now possible for most Americans. Even those without computers or recording devices of their own are rarely more than one individual, school, or public library away from accessing some means of digital self-representation.

And yet, as I have argued in other critical contexts (exploring the therapeutic possibilities of video as a means of illness-related pain) and in my own autobiographical video production work (which seeks to dismantle bodily tropes and taboos around gender, sexuality, and body dysmorphia), technological progress has in many respects outpaced ideological change. While amateur videos of violent and spectacular death circulate with unprecedented frequency online, autobiographical acts of digital media production that address natural death and dying are all but nonexistent.

A striking distinction can be found in the example of Lovelle Svart, a former researcher for The Oregonian who in 2007 collaborated with the online edition of the paper to chronicle her end-of-life experiences and choice to exercise Oregon’s Death With Dignity Act to end her five-year bout with lung cancer. Living to the End (http://next.oregonianextra.com/lovelle) is a Website endeavour that combines video diaries by Svart up to the day of her death, photographs and personal history segments, scans of court documents requesting life-ending medication, articles about Svart and her dying process by Oregonian reporters, information and links to end-of-life resources, and a robust comment feed where readers and viewers shared and continue to share their own related thoughts and stories. Along with a still photograph of Svart in bed on September 28, 2007, attended by her administering physician and family, the site also includes an audio recording documenting the actual process of Svart ingesting her prescribed lethal cocktail and passing into the comatose state she persisted in for five hours before dying.
Wherever one stands on the associated political battles around Oregon’s law, *Living to the End* models the powerful potentials for repurposing the largely uncontemplated and depoliticised uses of social media sites and digital media production practices towards ground-breaking autobiographical modes of cultural discourse. Spanning fifteen years and purposing the mediums of their moment, the examples of *Silverlake Life*, *Death: A Love Story*, and *Living to the End* suggest that the limiting agent restricting taboo-breaking, democratised media production in the United States is not corporate hegemony, government censorship, or access to the means of production and distribution, but our own imaginations.

Notes

12. Ibid.
13. Ibid.
14. Ibid.
16. Ibid.

Bibliography


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