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

Broderick Fox, *Occidental College*



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The Making Sense Of: Hub

'MSO: Dying and Death'



2011

Exploring Issues of Care, Dying and the End of Life

Edited by

Sue Steele and Glenys Caswell

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

Broderick Fox

Abstract

This chapter will examine assisted video autobiographies that seek to break taboos around visualizing 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 active, shared authorship in their production that parallel the possibilities for active, agented, and communally-experienced dying and death 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 dying and death in the digital age.

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

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'² which have been met with varying degrees of social acceptance and prudery in Western culture since the Middle Ages. Michel Foucault takes this idea further, characterizing 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 these 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 secularized 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.'⁴ 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.

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.

Here lies the true challenge to the limits of death's representation: rather than sanitizing or sensationalizing dying and death, how can we return progressive engagement with such matters to popular discourse? How may we reclaim the gaze upon 'natural' death from privileged eyes? 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 onto 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. It is also important to note that both videos were produced in the pre-digital, pre-You-Tube 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, 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 I/eyes—Joslin and Massi offering visible proof that equally powerful feelings of commitment, love, and loss exist outside the hegemonic heterosexual model.

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 road trip honeymoon, domestic hamming for the camera with friends. But all changes on their second Thanksgiving together when Mel is diagnosed with liver cancer. Rather than shut the camera off, the couple keeps it rolling, with the video increasingly transgressing traditional home movie contexts to include the doctor's visit and the chemotherapy session.

It is only after the death of her husband that Michelle consciously steps into the position of filmmaker, constructing a public text from the couple's private images and using the act of editing as her own grieving process, literally making some sense of Mel's death through 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 videos such as these, which neither romanticize 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 utilized 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 functioning as a catalyst for difficult conversations.

During a pre-chemo retreat to the Joshua Tree National Park it is Mel behind the camera, asking Michelle if she's thought about what she'll do if he dies. As Mel's condition worsens however, Michelle soon becomes the sole camera operator. She tells us, 'The camera has become my saving grace. It gives me some kind of job to do in this situation.'⁵ Michelle increasingly reverses the medical gaze, turning her camera onto conversations of doctors, nurses, and technicians, her off-screen voice demanding explanations of release forms and translations of scan images.

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'.

Behind the camera Mark's bright, cheery tone is suddenly broken, 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!⁶

Both videos explode 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, and inviting us to face not only the mortality of Mel, Tom, and Mark, but also our own.

4. Scenes of Natural Death

Death: A Love Story and *Silverlake Life* not only address issues of dying and death; the videos culminate in the actual deaths of their ailing protagonists. In both works, documenting the actual moments of death becomes a shared enterprise, a means of mourning, and a route to demystifying the death process.

To represent the actual moment of Mel's death, Michelle Le Brun opts for a Barthesian approach, abandoning the moving image in favour of a still photograph of Mel, sick but still alive. For Roland Barthes, death is at the core of every photograph. The still image removes the subject from time, forever resonating with the dichotomous *punctum* of 'he is dead and he is going to die.'⁷ In Mel's final

moments she chooses to turn off the video camera and instead record Mel's words with a less-intrusive audio tape recorder. Over a still photograph of Mel in the hospital superimposed with poetic images of flames and nature, Michelle tells us:

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.⁸

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 is permitted to be a natural one.

In *Silverlake Life*, the video camera passes from Tom Joslin to his partner 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 Joslin's former film student, Peter Friedman, who inherited the challenge of distilling the repository of collected video into a finished work. *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 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.⁹

By the time of Tom's death, the making of *Silverlake Life* has become a collective 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.

The processes of natural dying and death modelled in these videos—non-violent death experienced in community in accordance 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 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: each of these moments contains a core element of catharsis 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 a) the victimhood so frequently characteristic of mainstream representations of illness and mortality and b) the melancholy or hysteria so often associated with mediations of grief.

5. Digital Death

I underscored at this chapter's outset the distinctly analogue 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.

And yet, as I have argued in other critical contexts¹⁰ and in my own autobiographical video production work¹¹ 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 dying and death 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>)¹² 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 un contemplated and depoliticized uses of social media sites and digital media production practices towards groundbreaking 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, democratized media production in the United States isn't corporate hegemony, government censorship, or access to the means of production and distribution, but our own imaginations.

Notes

¹ T.S. Eliot, *Sweeney Agonistes: Fragments of an Aristophanic Melodrama*, Faber & Faber, London, 1932, pp. 24-25.

² G. Gorer, 'The Pornography of Death,' *Encounter*, October 1955. Reprinted in appendix of Gorer's, *Death, Grief and Mourning*, Arno Press, New York, 1977, p. 195.

³ M. Foucault, *The History of Sexuality*, Vol. 1, 1976, trans. R. Hurley, Vintage Books, New York, 1990, p. 3.

⁴ M. Kearl, *Endings: A Sociology of Death and Dying*, Oxford University Press, New York, 1989, p. 406 as quoted in D. Jacobs, 'The Art of Mourning: Death and Photography', *Afterimage*, 1996, p. 9.

⁵ M. Le Brun, *Death: A Love Story*, Hearken Productions, 1999, 64 min.

⁶ P. Friedman, T. Joslin & M. Massi, *Silverlake Life: The View From Here*, Docurama, 1993, 99 min.

⁷ R. Barthes, *Camera Lucida: Reflections on Photography*, trans. R. Howard, Hill and Wang, New York, 1982, p. 95.

⁸ M. Le Brun, *Death: A Love Story*.

⁹ P. Friedman, T. Joslin & M. Massi, *Silverlake Life: The View From Here*.

¹⁰ B. Fox, 'Shooting Pains: Addressing Illness-Related Pain through Video Autobiography', *Making Sense Of Pain: Critical and Interdisciplinary Perspectives*, J. Fernandez (ed), *Probing the Boundaries*, Inter-Disciplinary Press, Oxfordshire, 2010, pp. 249-257.

¹¹ B. Fox, *bfoxfilms*, YouTube channel, Last updated April 28, 2010, Viewed on December 10, 2010, <http://www.youtube.com/user/bfoxfilms>.

¹² L. Svart, S. Gage, R. Finch, D. Colburn & E. Madrid, *Living to the End*, Website of *The Oregonian*, Last updated July 13, 2010, Viewed on December 10, 2010, <http://next.oregonianextra.com/lovelle>.

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