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Invitation to Witness: The Role of Subjects in Documentary Representations of the End of Life

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This article considers recent media texts from four Western countries that invite audiences to watch someone die. When dying people resist the default of social invisibility by participating in documentary media, they challenge hegemonic attitudes about dying and physical fallibility, even as they introduce this aspect of life into the logics of media visibility and self-disclosure. I focus on their invitation to witness and the faith in the possibilities of media visibility they express by agreeing to die on camera, bearing in mind the power relations among dying people, media professionals, and audiences within which this invitation occurs. The participants in these texts articulate a desire to deprivatize the deathbed in order to help other dying people and their caregivers. Their motivation speaks to the idea that seeing death may puncture the neoliberal fiction of the autonomous, invulnerable self.

Keywords: image ethics, documentary, witnessing, death and dying, visibility

In a scene from the 2003 documentary *Dying at Grace* (King, 2003), two people stand by the hospital bed of their friend Rick, who is very close to death (see Figure 1). "He looks like a Renaissance painting," one of them remarks. Rick's friend references the art of a distant past to make sense of what she sees. Her comment points to the dearth of contemporary visual representations of nonviolent forms of death and dying. Its invisibility is so normal that many may not even notice this representational gap until faced with an illness that makes it suddenly loom. When I watched this film on public television in 2003, a few weeks after my mother died of cancer at home, I recognized Rick's friends' sense of awe as they grappled with a fact of life that had, into adulthood, eluded their direct experience or even their gaze.

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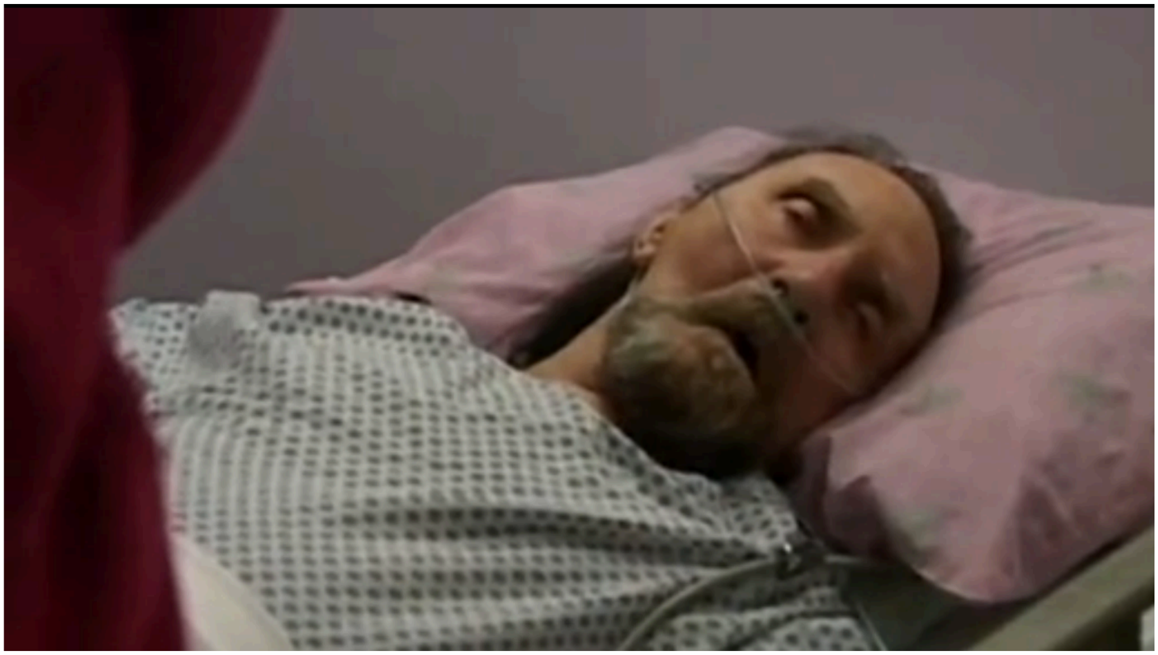

Figure 1. Screen capture from* Dying at Grace *(2003), documentary by Allan King. This scene is described as "The Agony of Rick" by his friend in the film. By permission of Allan King Films.

Death Denial and Taboo?

Whereas death for most of human history has been experienced and facilitated by the family and extended community, today many people in industrialized nations have little direct experience with the end of life (Gawande, 2014; Institute of Medicine, 2014). The extension of this avoidance to media representations, at least for the nonviolent forms of dying that people of relative privilege are most likely to encounter, has been frequently commented on (Aaron, 2014; Ruby, 1995; Townsend, 1998). As Phillipe Ariès (1985) wrote, "Relegated to the secret, private space of the home or the anonymity of the hospital, *death no longer makes any sign*" (p. 266). In 1984, Vivian Sobchack observed, "Our documentary films . . . avoid the representation of death. Indexical in code and function, they observe the social taboos surrounding 'real' death and generally avoid reference to it" (p. 286).

There is some debate as to whether death denial really is as strong today as it was in the mid-20th century, when scholars such as Becker (1973/1997) and Kübler-Ross (1970) brought it to scholarly and public attention. Lately, scholars note a greater media preoccupation with death (Foltyn, 2008; Green, 2008), a perception confirmed by the Institute of Medicine's 2014 *Dying in America* report that documented a marked increase in news and entertainment coverage of death. This representational shift may be related to a slow pendulum swing away from the medicalization of end-of-life care, with Americans starting to die at home in greater numbers rather than in institutions (Institute of Medicine, 2014). I agree with Norfleet (1993), however, who has argued that the taboo against *looking* at the end of life largely continues. She writes, "We want to see what death looks like, yet we don't want to" (p. 30). Even as we are increasingly exposed to spectacular forms of death in fictional media, questions about the propriety of gazing at real dying people continue, for example, in critical responses to photographers such as Sue Fox, Nan Goldin, and Richard Sawdon-Smith who take dying people as their subjects (Townsend, 1998). As Foltyn (2008) has suggested, in the late 20th and early 21st centuries, "death has been more hidden than denied" (p. 169).

The charges of sensationalism sometimes levied against end-of-life texts suggest that these images will be titillating or a spectacle, that we will view dying people in a way that objectifies and distances us from them. Sontag (1979) has expressed the concern that the ill are too easily seen as Other by the well, as a foil that confirms their own wellness. The risk looms large that in being exposed to the Other via visual mediation, viewers will use their spectatorial habits of objectification and distancing, thereby reducing the Other to an object incorporated into or mastered by the self. Such a possibility, even in a face-to-face context, is captured by Tanner (2006), writing about the scene of her father attending a family wedding in the last weeks of his life:

> The unease in that crowded room circled around a body rendered so abject by the process of dying that it transformed the familiar subject into an unfamiliar object. My father's body registered his impending death; in turning away from it, they would turn away not from him but from the anticipation of his loss and their own implied mortality. (p. 1)

In public, death's taboo inspires avoidance and denial; in private, the fear is that people will respond to images of death in morbid or voyeuristic ways.

Allan King, director of the aforementioned Canadian documentary film *Dying at Grace*, which follows people's end-of-life experiences in a hospice ward, was accused of sensationalism. One interviewer reported that he had watched the film with a friend who had pronounced it to be, in essence, "pornography." Didn't King feel like a voyeur in making this film, he asked? (Brown*,* 2003). When British reality star Jade Goody participated in a reality program that documented her experience with terminal cancer, the producers were widely accused of being exploitative, audiences of being ghoulish and voyeuristic, and Goody herself of inappropriately exploiting her illness for material gain (Kavka & West, 2010). Responses to these instances and others suggest that norms of publicity and privacy in death and dying are very much in flux, shaped by generational change, greater policy attention to end-of-life issues, and an increasing representation of the end of life in media.

The Politics of Making the Private Public

In this article, I examine professionally produced media texts that make an ethical claim for showing death, by self-consciously moving it from the private sphere to media visibility. In contrast to past examinations of documentary visual representations of "natural" death, most of these texts were, or at least aimed to be, "popular" rather than limited to specialized audiences of exclusive art galleries and film festivals. As such, they all involve dying people relinquishing representational control to professional media producers, thereby making them particularly vulnerable kinds of subjects. In contrast to similar texts from the past, such as 1976’s *Dying* (Roemer, 1976), the four primary texts I examine actually show death on screen as it occurs or shortly afterwards. They came on the scene at a historical moment in which cultural discourses are allegedly becoming freer about end-of-life issues, but the visibility of dying people (at least, of natural causes) in the public sphere remains limited. My focus is to theorize the decision of the dying people who participated in these media texts to sacrifice privacy in such a profound way. In so doing, I connect debates about the navigation of publicity and privacy by so-called ordinary people in the digital age with longstanding debates about the ethics of gazing at the end of life through mediated representations.

Media producers and ordinary people who make or participate in these texts “out” death and dying from the private realm. The language of sexuality that I and others use to comment on these kinds of texts reflects the taboos that have surrounded death in Western cultures. Ariès (1974) famously wrote, “in the twentieth century [death] has replaced sex as the principal forbidden subject” (p. 92), reinforcing Gorer’s (1955) earlier observation that whereas sex had become “mentionable” since Victorian times, death “*as a natural process*” was now “unmentionable” (p. 50). As Tait (2008) and Dean (2003) have observed, pornography has become a ubiquitous metaphor for images of death that inspire moral outrage. Dean explains that after World War II and the Holocaust, the photography of death that circulated inspired the use of the term *pornographic* to argue that these images “reduced men’s sacred bodies to objects of excitement, pleasure, or domination” (p. 91). However, as Tait argues, the metaphor relies on narrow assumptions about the moral status of pornography, and ignores important ways that looking at sex differs from looking at death. She writes, “the term [pornography] does not automatically invoke notions of degradation but may signify pleasure, performance, or transgression” (p. 96).

Unlike the “death porn” that Tait (2008) analyzes, and despite complicated questions of consent in professionally produced pornography, those portrayed in porn and end-of-life texts voluntarily share their physical experiences and transformations with the public through media. In a less pessimistic reading of the value of pornography, the potential of both kinds of texts to publicize corporeal experiences in ways that are instructive or illuminating allows us to turn this metaphor on its head. Queer and feminist pornography, for example, have been hailed as political in making multiple forms of desire visible in the public sphere and providing models for sexual expression (Taormino, Parreñas Shimizu, Penley, & Miller-Young, 2013). Norms of privacy are inextricably linked to social hierarchies and regulatory regimes shaped by heteronormativity and patriarchy. As Berlant and Warner (1998) argue, “there is nothing more public than privacy” (p. 587). Similar to arguments about the political possibilities of pornography, we can understand visualizing the end of life as a political move: Producers and participants hope to inspire changes in public discourse, social learning, and connections between participants and audiences. Some AIDS activists, in particular, used images of young, dying men to call for public attention and government dollars for disease treatment and research, particularly in the 1980s when there was little public empathy or responsiveness to the crisis, although this strategy was not without controversy (Crimp, 2002; Tanner, 2006). If the end of life is a sphere of intimacy that social norms dictate be kept private or restricted to “immediate family,” then inviting the public gaze to the deathbed “queers” the end of life.

As Foucault (1990) argued, things that are supposedly taboo often inspire a great deal of discourse that is aimed at managing and making claims for institutional authority over the taboo subject. Just as Foucault's repressive hypothesis drew attention to the way that sexual repression was paired with specialized discourses and forms of authority over sex, so might the cultural story about death denial in Western cultures, told by Gorer, Becker, and others, underpin what are actually widespread discourses about death and dying. Daring to counter the taboo by showing death could be understood as merely a political posture of rebellion against societal norms. Or these kinds of "incitements to discourse" about the end of life may be bringing it into heretofore unrecognized forms of regulation by the self or via institutions (Foucault, 1990, p. 34). Would the medical profession like to prepare the public more for the end of life, in order to make them more docile subjects for end-of-life care? Are policy makers encouraging people to be more prepared, self-regulating subjects in the hopes that they will use fewer precious health care resources at the end of their lives?

Although I do not rule out institutional interests in promoting particular discourses about death, more germane in Foucault's (1990) analysis, I would argue, is his observation that the nature of political power in the last few hundred years has shifted from a focus on controlling death to controlling life. As he wrote, "it is over life, throughout its unfolding, that power establishes its dominion; death is power's limit, the moment that escapes it; death becomes the most secret aspect of existence, the most 'private'" (p. 138). The latter analysis of the politics of death, where confronting its existence is a challenge of sorts to prevailing ideologies and workings of power, bears more on how and why people participate in these productions.

In contrast to ideas about the political value of publicizing intimate experience, recent media theory—informed by developments such as reality television, the culture of self-disclosure through social media, and the rise of celebrity culture—has emphasized the erosion of privacy in contemporary media culture, warning of the exploitative nature of media publicity. These critiques argue that the private self is mined for value that serves capital (Andrejevic, 2004; Calvert, 2000). People bare all, literally or metaphorically, lured by the promise of celebrity or, even more insidiously, by the sense that sharing the self with millions of strangers is a route to being their most authentic selves. Our media culture of relentless publicity raises the concern that ordinary people will be exploited, even if they agree to participate voluntarily (Andrejevic, 2004; Brenton & Cohen, 2003), an argument that has also been made about women who "agree" to appear in porn (MacKinnon, 1985). The promise of fame, combined with a misleading but culturally resonant narrative that appearing in media is a form of empowerment and free choice, stack the deck in favor of producers and against the interests of subjects (Pitcher, 2006). The result is a media culture that has allegedly left no stone of social life unturned.

This suggests a contradiction, however: What does it signify that looking at death is still understood by many as taboo in a media context in which supposedly "anything goes"? Perhaps that the end of life is sacred and, like any sacred thing, should not be easily touched or seen (Douglas, 1984). But, like sex, it can also signify that dying is shameful. To die is to "give up," to "lose the battle" with illness or old age. Dying is undeniably a time of physical weakness and dependence, qualities not easily embraced in cultures shaped by neoliberal policies that assume, and therefore require, independent self-sufficiency. As Sobchack (1984) has observed, the natural death, "insupportably subversive of our culture's myth of process as progress, has led to the spatial displacement of lived-bodies undergoing the process of decay" (p. 289). Similarly, Hallam, Hockey, and Howarth (1999) write, "When emphasis is placed upon control and the regulation of the body as a prerequisite for the maintenance of self-identity, the dying body and the dead body acquire terrifying qualities" (p. 21). Our health is increasingly perceived as a matter of personal responsibility (Crawford, 1980), an aspect of the shift in the logic of state power from governing death to governing life identified by Foucault (1990). Maintaining good health becomes a moral issue because it presumably leads to the independent, self-sufficient body that does not burden others or the state.

These disciplinary regimes of visibility and "healthism" (Crawford, 1980) potentially come into contradiction with each other, complicating how we theorize the decision of subjects to appear in end-of-life texts. Healthism—the normalization of good health as an expression of the good subject—implies the undesirability of gazing at the sick, the dying, and the disabled. When dying people resist the default of invisibility by appearing in documentary media, they challenge hegemonic attitudes about death, dying, and physical fallibility, even as they introduce yet another aspect of life into the logic of media visibility and self-disclosure.

Therefore, we should consider the significance of the invitation to witness, bearing in mind the power relations among dying people, media professionals, and audiences within which such an invitation occurs (considering the conditions of the invitation does not necessarily require a firm pronouncement about the outcome). Rather than focus on the pitfalls of sharing private experience through media, I consider the faith in the possibilities of media visibility expressed so powerfully by people who agree to die on camera. The decision to "go public" at a time of great vulnerability suggests a deep faith in the media's capacity to do justice to the experience—an unfashionable stance. Some scholars have considered similar questions. Lange (2007), for one, has argued that the "shared intimacies" of video bloggers are political to the extent that they introduce topics and experiences that remain largely unaddressed into the public sphere (p. 5). Grindstaff (2009) rejects the notion that ordinary people participating in reality genres are motivated only by the desire for celebrity and stardom. Rather, she acknowledges an array of motivations, including having "a life-changing experience to share, wanting to impart information or have one's feelings/experiences publicly validated" (p. 82).

Sharing one's experience of dying through media could, of course, be a misguided bid for immortality by using "visibility as a final challenge to the obscurity of death" (Kavka & West, 2010, p. 223), a perspective that aligns with Becker's (1973/1997) argument that we use the "vital lie" of human character to repress our fear of death (p. 47). People's motivations are no doubt complicated, and denial can conceivably persist even while engaged in a project whose purpose is precisely to face death. However, the preponderance of evidence suggests that people participate in these projects out of a desire to shape the available stories and images that circulate publicly about the end of life. This certainly may help dying people resist the terror of death by using their final days for something that feels meaningful, even heroic. At the same time, this final gesture can be considered an act of generosity, reflecting an understanding of the role that certain kinds of visibility play in shaping political and social life.

Showing the End of Life

The four texts discussed here share goals and representational strategies for showing the end of life on screen. They come from different documentary forms (television, photography, and film) as well as different national contexts in the West (United Kingdom, Canada, Germany, and United States). Although these countries have somewhat distinct policies and social norms about the end of life, they operate within the same general medicalized, institutionalized paradigm. These texts are from the 21st century, therefore produced in a media context of greatly expanded access to information via digital communication technologies. They focus on visually documenting the end of life, including actually showing death (the moment itself or the body after death), but do not engage with the issue of physician-assisted suicide (numerous documentary texts focus on this policy issue, and some show the moment of death, but these representations have a more specific set of political goals). I draw on the texts themselves, press coverage, and DVD and online extras when available. My analytic approach is critical given that the questions I ask are shaped by a focus on social power and inequalities, and interpretive given my efforts to understand what the participants and producers of these media texts believe they are doing, as much as it is possible to reconstruct. The analytic process was iterative in nature: tacking back and forth between relevant bodies of scholarship and media texts to construct the sample of texts that capture an apparent contemporary impulse to represent the end of life visually, as well as to be sensitized by theories and concepts in order to read these texts and their paratexts (interviews, reviews, etc.) in dialogue with scholarship on image ethics, the history of visual representations of death, and shifting regimes of publicity and privacy in the digital age.

Two of the texts are television programs. In 2011, the BBC broadcast an episode of a documentary series called *Inside the Human Body* (Mosely & Gillings, 2011), which showed the decline and death of an 84-year-old man from cancer, a first on British television. The program led to some outcry, with the *Daily Mail* reporting, "Critics said last night . . . the BBC had gone too far in choosing to broadcast Gerald's death and that it was a cynical attempt to boost ratings" ("Coming to a TV Screen," 2011, para. 6). The article quoted the campaign director of Care Not Killing, a British organization that promotes palliative care and opposes assisted suicide, who said, "Some aspects of life are so personal and private that even if individuals give their consent to be broadcast, we are wiser to keep them private" ("Coming to a TV Screen," 2011, para. 7). The newspaper's moralizing protests were ironic considering its usage, without permission according to series producer Alice Harper, of a screenshot of Gerald on his deathbed surrounded by his family, which, unlike the program itself, did not warn readers or provide context (personal communication, June 28, 2017).

While a death from natural causes appeared on broadcast television in the United Kingdom in 2011, in 2013 U.S. television followed suit with *Time of Death* on premium cable channel Showtime (Cutforth & Lipsitz, 2013). Created by Magical Elves, the producers of such popular reality programs as *Top Chef* and *The Real L Word*, this six-episode series features eight people dying of a variety of illnesses. Among the eight profiles, two people die on camera, and we see the bodies of three others after death. Responses to *Time of Death* in the United States were more positive than initial critiques of *Inside the Human Body*, with just some critics' and viewers' comments online raising the charge of voyeurism. For example, the *Hollywood Reporter* (Keene, 2013) praised *Time of Death* but also suggested that its intimacy was "arguably to the point of invasiveness" (para. 2): "the camera lingering on a lifeless body never feels quite right" (para. 7). However, *Time of Death* aroused very little interest on shock sites such as Findadeath.com ("Thread: 'Time of Death,'" 2013), on which self-proclaimed "death hags," who are fascinated with the details and images of celebrity deaths, pronounced the series too depressing to watch.

The third text is the 2003 film *Dying at Grace* directed by Allan King (2003)—a prolific Canadian documentary filmmaker. *Dying at Grace* is an observational documentary of the palliative care unit at the Salvation Army's Toronto Grace Health Center. Filmed in the tradition of his many other "actuality dramas" (as King calls his films), the camera follows five subjects through their final journeys, ranging from months to just a few days. The film announces its frank approach to death in its opening scene, in which nurses wrap up a recently deceased person and take him to the morgue. The level of access King negotiated is remarkable. We observe the patients' very visible declines. We listen in on their conversations with the chaplain. The camera does not look away when its subjects cry or exhibit paranoia, when their eyes roll back in their heads, or when their breathing becomes labored in their final days and hours. It lingers in close-up on the patients' faces, both before and after death. The film captures the last breath on camera for two of the five people profiled.

The fourth text is the 2008 photography exhibit titled *Life Before Death,* which traveled internationally from Germany, with substantial sections of the exhibit also appearing online in press coverage and a video ("Life Before Death," 2008a, 2008b). The collection is now available to purchase online as an e-book (Lakotta & Schels, 2015). Photographer Walter Schels took portraits of 26 hospice patients in Germany, ranging in age from infancy to an 83-year-old, both before and then very shortly after their deaths, while his partner Beate Lakotta interviewed the project's participants about their experiences at the end of life to inform the text that accompanied each portrait ("Death Watch," 2008).

Why did these media producers undertake these projects? Allan King reported that his motivation to make his film was his own fear of the process of dying (he died in 2009 at the age of 79). He explained,

> People used to be accustomed to death, so death was a familiar figure and a familiar experience, so I think it was less terrifying because it was less strange. To be able to look death straight in the face is a big advantage. I think it's the reward of the film. (quoted in Cowan, 2003, p. B4)

This motivation is similar to that of Walter Schels, who reported,

> I experienced the World War, and at the end of the war I was nine years old, and the house we lived in was bombed, and I saw a lot of dead people. So I had the rest of my life, very much in fear, about death. So I also wanted to get rid of it [the fear of death]. ("Life Before Death," 2008b)

Just as King aimed to intervene in a culture that denies death, Lakotta and Schels argued for the value of facing, literally, what we fear. The introductory text to their exhibition reads, "Death and dying are arguably our last taboos . . . opportunities to learn more about them are rare indeed" (quoted in Sinclair, 2008, paras. 1–2). Both King and Schels, despite reaching their 70s, had remained quite insulated from what natural forms of death looked like and were fearful of it. Making these projects was educational for them personally, which they hoped would also be the case for viewers.

Facing Death

All four texts privilege the faces of dying people as an entry point into this experience. *Dying at Grace*, although it includes a wide variety of activities in the palliative care unit, spends considerable time in close-up on the patients at different points throughout their process, including while they sleep or are unconscious. The closer they are to death, the tighter the close-ups. Indeed, the film ends on an extended close-up of one patient, Eda, as she dies on camera. Schels' photographs are large, close-up portraits, devoid of much in the way of background. The two television texts, *Time of Death* and *Inside the Human Body*, invite viewers to connect with the faces of their subjects mostly through frequent close-up interviews.

In considering how these texts emphasize looking at faces as a technique for connection and understanding, Levinas's (1998) perspective is illuminating. Levinas writes that gazing on the Other's face is a powerful form of address in its confrontation of self and Other. But it's a "powerless" form of power: "The frailty of the face is paradoxically the source of its command: its address is what exposes my primordial responsibility toward the Other" (Pinchevski, 2005, p. 76). For communication to be ethical, we do not merely gaze at the Other's face, we respond to it—all before informational "content" is exchanged. The choice in these texts to focus on dying faces reflects the implicit argument that we should gaze at death, in contravention to prevailing social norms. Although privileging the face as a site of visual knowledge can certainly deepen habits of objectification or a false sense of knowing another's experience, Levinas's analysis of the encounter with the Other's face feels descriptive of the experience of encountering these "fragile" faces up close.

The Showtime series *Time of Death* varies in the proximity it offers the viewer to its dying subjects, arrangements apparently shaped by the subjects themselves. In fact, discussion on camera about why these individuals chose to participate in the project and their decisions regarding what would be filmed is a distinct feature of this text compared with *Dying at Grace* and *Inside the Human Body*, and may help explain the relative lack of outcry in response to *Time of Death*. At times, we see subjects asking the crew to turn off the cameras, or family caregivers explaining why some moments were not filmed and why. Some participants consented to more fully share their death experience on camera than others, including Cheyenne, a relatively young man whose death from ALS happens on screen and, perhaps most devastatingly, 19-year-old Nicolle (the youngest subject of the series), whose death from skin cancer we see occur at home surrounded by her family. With the question of consent handled explicitly, viewers and critics may have wondered less about exploitative relations behind the camera than with, for example, *Dying at Grace*. As Pitcher (2006) suggested about *Girls Gone Wild* (a very different text, but one that similarly involves people who agree to share something physically intimate on camera), this strategy can be understood as an effort to frame subjects' participation as simply a matter of individual choice, a "staging of agency." Pitcher argues that emphasizing the consent of the subject on camera has the function of taking our attention away from the unequal power relations between producers and subjects, in part because of how cultural ideologies of visibility are routinely presented as empowering. This critique takes us to the heart of the ethical challenge posed by these texts, which claim that their visual representation of dying is an ethical response to a culture that denies death: What is, and what should be, our relationship to the subject who dies on screen?

The Dying Subject on Screen

Why people participated in these documentaries and whether the images are inherently exploitative, despite formal consent procedures, are crucial questions, not least because none of the dying participants can respond to the final texts. King defended the ethics of *Dying at Grace* by arguing that he could not have made the film without the agreement and investment of participants. According to King, his participants, who underwent a lengthy consent process, had viewed their participation as a final gift that might help others. He argued, "The task must be as rewarding to the subjects as to the filmmaker. In this case it permitted dying people to pass on an invaluable legacy to the living and helped make their own experience more meaningful" (quoted in Brown, n.d.). This refrain is heard across the texts. Gerald, featured in the BBC documentary *Inside the Human Body*, also explained his decision to take part in terms of his hope that the program would help others (Deacon, 2011). Schels and Lakotta mentioned the surprisingly high rate of interest in participating among the hospice patients they approached (Moorhead, 2008). Lakotta said that several patients appreciated the chance to discuss their experience of dying in a frank way; many friends and relatives would unwittingly prevent such talk.

The caption accompanying the photos of Heiner Schmitz, one of the subjects in the *Life Before Death* exhibit (see Figure 2), reads in part,

> Heiner's friends clearly didn't want him to be sad and were trying to take his mind off things. They watched football with him just like they used to do: they brought in beers, cigarettes, had a bit of a party in the room. "Some of them even say 'get well soon' as they're leaving; 'hope you're soon back on track, mate!'" says Heiner, wryly. "But no one asks me how I feel. Don't they get it? I'm going to die!" ("Life Before Death," 2008a, para. 14)

Lakotta reported, "Some of the dying said, 'It's so good you're doing this—it's really important to show what it's like. No one else is listening to me, no one wants to hear or know what it's really like'" (Moorhead, 2008, p. 6).

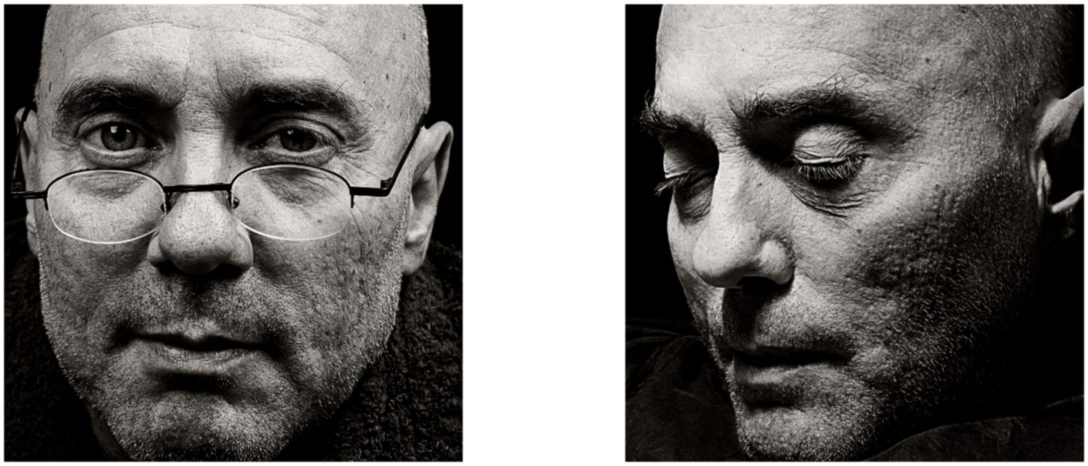

Figure 2. Portraits from **Life Before Death** ***(Lakotta & Schels, 2015, pp. 8–9). Heiner Schmitz, 52. First portrait (left): November 19, 2003. Second portrait: December 14, 2003. By permission of Walter Schels and Beate Lakotta.***

The participants in *Time of Death* also cited a culture of death denial and the harm that it inflicts on dying people and their caregivers as key to their motivation to take part. Maria Lencioni (see Figure 3), 48, the main character of the series whose struggle with Stage IV breast cancer is featured in all six episodes, explains her participation on camera, saying, "I hope in some way it might help somebody else facing the same horrible, awful, life-altering—life-ending—dilemma" (Cutforth & Lipsitz, 2013).

Her daughter Nicole (known as "Little"), whose amateur video footage is featured throughout the series, shares a similar view:

> *Time of Death* is a demonstration of living through the departure of loved ones, an example that I wish I had seen before walking through it myself. In part because there was no example, I felt driven to help create one. The show captures it all—the good, the bad and the ugly. It is my hope that my efforts may comfort those who feel alone. (Lencioni, 2013b, para. 9)

Similarly, Lenore Leffer, a 74-year-old woman dying from pancreatic cancer, draws on her own experience as a psychotherapist working with cancer patients: "We live in a death-denying culture and I don't want it to be that way. I want my life to have made some difference" (Cutforth & Lipsitz, 2013, Episode 2). Although the extent and nature of death denial in Western cultures may well be undergoing qualitative and quantitative shifts, it is clear that both producers and participants of these media texts experienced societal practices and attitudes toward death as isolating and fear-inducing.

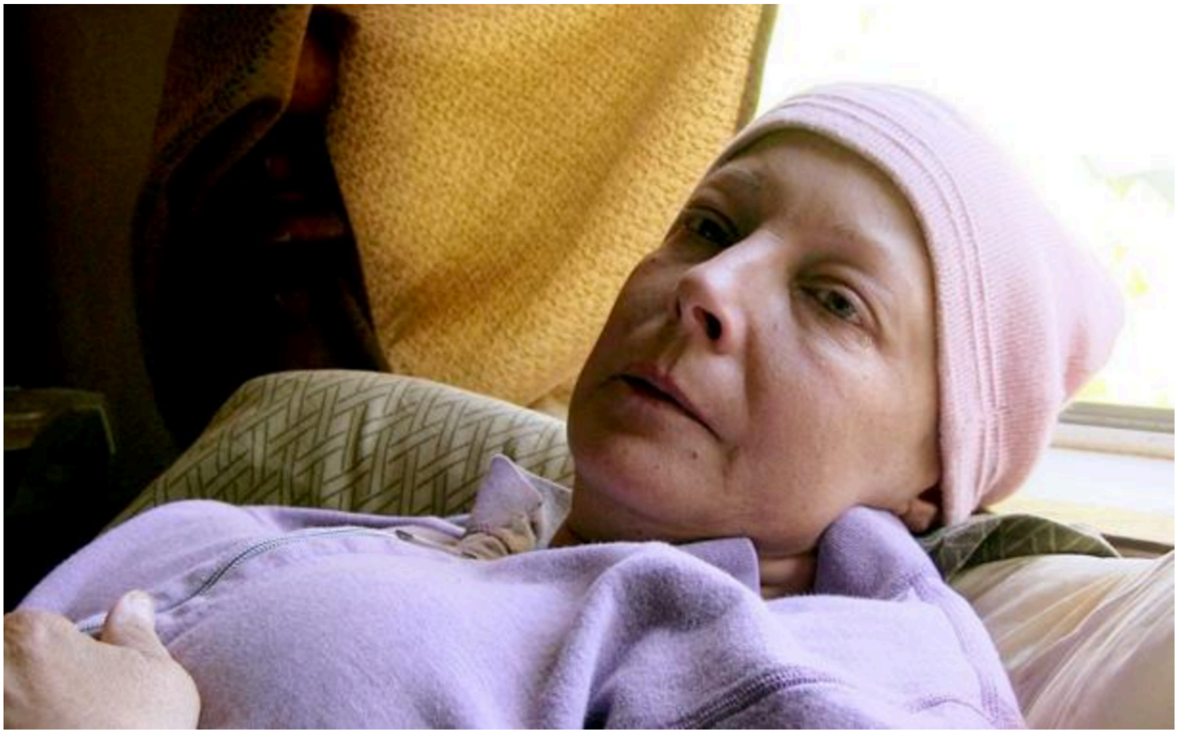

Figure 3. Maria Lencioni, featured in* Time of Death*. Source: D&J Productions/Showtime (Jensen, 2013).

The emphasis within the films and in extratextual information about not just the consent but the active interest of the films' subjects to participate recalls Sobchack's (1984) observations about the 1976 film *Dying* that aired on PBS:

> The possibility of planned exploitation of human beings, of ghoulishness, of a cold voyeurism, is belied by the dying subject's openness to the probity of the gaze, by a collaboration with its interest, by a frequent address to the stare which inscribes the off-screen presence and intimate acceptance of the filmmaker . . . the bedchamber again becomes a space for public ceremony, a space organized, in part, by the dying subject. Under the dying person's self-direction, the filmmaker's stare becomes ethically simplified. (p. 296)

Participants in these projects are not behind the camera (which has occasionally occurred in documentaries in which the director has a terminal illness, as in *Black Is, Black Ain't* [Riggs, 1994] and *Silverlake Life: The View From Here* [Friedman & Joslin, 1993]), nor are they privy to the techniques of media production and ultimate editorial decision making. In that sense, it would be an overstatement to say that they are "self-directing." However, Sobchack acknowledges the agency of dying people in inviting others to witness their experience, as well as the idea that to witness such a thing can be an ethical relation, an act that brings "public ceremony" to an event that is not necessarily made more sacred through greater privacy.

Laura E. Tanner's (2006) analysis of Sharon Olds' book of poems *The Father*, about Olds' experience accompanying her father through terminal illness, illuminates how complicated the viewing relation between well and dying people can be. In the poem *The Lifting*, Olds' father, on a medical bed at home, lifts up his nightgown and invites her to look at his naked, wasting-away body. Tanner considers how both Freudian and Foucauldian theories of the gaze fail to capture the dynamics of this moment. Olds rejects the experience as defined by the eroticism of a daughter gazing at her father's nakedness, and Tanner rejects the idea that Olds sees her father through the medical gaze, in which the subjectivity of the patient is abstracted because of the focus on the diseased body (Foucault, 1973). Instead, Tanner writes, "In directing his daughter's look, Olds' father appropriates her vision to reclaim his status as subject of the gaze as well as its object" (p. 32). He asks his daughter to see his dying body as an object, which he is also doing as he tracks its rapid transformation, in order to relate to his experience of embodiment, "to locate him in his unfamiliar body without reducing him to it" (p. 32). Tanner calls the poem's sense of "subjective intermingling" (p. 35)—promoting connection and identification while never denying the difference between self and Other—radical.

A powerful but unverbalized moment when a dying person invites us to witness her experience along with her also occurs in the 2011 documentary *How to Die in Oregon*. Although not one of the primary texts I consider given its focus on physician-assisted suicide, the film offers a moment key to this analysis when Cody Curtis, a woman in her 50s who is dying of liver cancer, communicates silently but in a very intimate way with the filmmaker, and by extension viewers. In the final weeks of her life, Cody goes to the hair salon, and during a few minutes when the stylist leaves her alone, director Peter Richardson captures an extended shot of Cody looking at herself in the mirror. It is difficult to convey the intensity of this moment. In the rest of the film, we see Cody generally smiling (and sometimes crying), talking, and being very attentive to other people. This is one of the few moments when we see her being still, with herself; the grave expression on her face suggests that she may be confronting her mortality, as she regards her drawn, yellowing face. Richardson has described this moment as Cody's "gift" (quoted in Schnack, 2011, para. 18). The way she allows the camera and the audience to accompany her in this painful solitude is consistent with her invitation to the public to share the intimacy of her end-of-life experience via her participation in the film. Like Sharon Olds' father, and indeed all who participate in these kinds of media texts, a dying person inviting others to join her self-gaze is the viewing relation that allows us to identify with her embodied experience, and perhaps to ease her pain of solitude.

Jeff Jensen (2013), a television critic for *Entertainment Weekly*, reviewed *Time of Death* informed by his own experience as a caregiver for his wife, diagnosed with brain cancer. He emphasized the series' ability to inform and invite empathy rather than objectify the dying:

> *Time of Death* succeeds because its subjects and their families are willing to open their doors, let down their defenses, and surrender all vanity as they waste away. By sharing themselves this way, our capacity and empathy is stretched, and we gain insight and ideas for when death comes for us. (para. 8)

Jensen’s response to the series recalls Levinas’s (1998) argument about the preconditions of ethical communication:

> The plot of proximity and communication is not a modality of cognition. . . . It is not due to the contents that are inscribed in the said and transmitted to the interpretation and decoding done by the other. It is in the risky uncovering of oneself, in sincerity, the breaking up of inwardness and the abandon of all shelter, exposure to traumas, vulnerability. (p. 48)

The producers but especially the participants in these projects undertook this “risky uncovering,” and in so doing took a considerable leap of faith—that viewers would watch with empathy and a sincere desire to learn and prepare for the future, rather than watch in judgment or with morbid fascination. Although this reading is not guaranteed, the generosity of the gesture and the faith that it communicates about the public’s capacity to be open to others’ experiences through media are metamessages that beg for our attention.

Drawing attention to informed consent, whether in the text itself as in *Time of Death*, or in extratextual materials, can be viewed as a “staging of agency” that absolves media producers of responsibility and contributes to a simplistic narrative about the rights of subjects, boiled down to it being “their choice” (Pitcher, 2006). The variety of approaches that these participants took to invite the public to witness their end-of-life experiences, and the decision-making processes that were sometimes required as events unfolded, arguably illustrate a new realm of choice at the end of life that applies even beyond the context of media representation. In contexts in which the practices of privacy and visibility are more scripted and homogeneous, such as the Art of Dying practices widely subscribed to in Victorian Britain (Ariès, 1974), dying people and their families may be subject to strong social norms, but they are also released from certain kinds of difficult decisions: whether to tell others about their illness and prognosis, whether to retreat behind closed doors as the dying process advances or to invite family and friends to attend the bedside. As much as the decisions of these dying people are remarkable, their negotiations with the filmmakers are analogous to the way so many dying people today negotiate the relative publicness or privacy with which they live their final days. Although there are different ways of being visible at the end of life, in person or through mediated forms, these texts dramatize the evolving question of how to manage our visibility to others as we die.

Conclusion—The Politics of Deprivatizing the Deathbed

How are terminally ill people and their caregivers affected by the lack of realistic, public representations of “natural” death? Policy makers have continually expressed the need for more public discussion about end-of-life issues in the hope that an educated public will be better able to advocate for their wishes as they die and suffer less from fear of the unknown (Gawande, 2014; Institute of Medicine, 2014). Unfamiliarity with the end of life creates a void too easily filled with the institutional imperatives of hospitals and nursing homes, which often privilege “doing something” in the form of medical interventions over quality of life or, indeed, quality of death (Gawande, 2014; Institute of Medicine, 2014). Deference to these routines, combined with a lack of frank communication before illness arises, can fuel unnecessary suffering and even shorten people's lives. Indeed, medical staff explained that their decisions to take part in both *Dying at Grace* and *Time of Death* were informed by their belief that caregivers and loved ones would be better prepared if they had seen films such as these (Brown, 2003; Perkes, 2013), a motivation perhaps informed equally by empathy and a desire for greater efficiency. The producers and participants of these programs proceed under the assumption that seeing death may puncture the fiction of the autonomous, invulnerable self, a fiction that fuels unrealistic attitudes toward death and inattention to planning and policy questions surrounding the end of life.

There remains the risk that images of dying will not be received in the spirit in which they were offered, suggested by those commentators who saw these texts inviting a profane or disrespectful gaze. However, rather than simply eroding the value of privacy or the sacredness of the deathbed, the willingness of these subjects to die on screen points to the depth of their commitment to changing the culture. The risk they are taking is real and easily perceived. Their gesture thus appears all the more profound and their call to the well all the more urgent. A willingness to share personal intimacies through media is a particularly potent expression of faith in the power of media to connect and inform, one that has often been unfounded, as observers of talk shows, reality TV, and social media have noted. Although we should remain vigilant about the ways that media erode privacy, can we also retain language and concepts-at-the-ready for recognizing the power of media visibility and publicity to effect change, to be a valuable resource for living and dying?

The parallels between using the media to shed light on the end of life and the way people have used media and other public forms to confront social norms about sex and sexuality are striking. It seems more than coincidental that Little, Maria Lencioni's daughter in *Time of Death*, was inspired to participate in the series in part by her media activism in the LGBTQ community. She wrote about the program,

> I'm pretty sure that we treated other taboo subjects like this in the past too, like the clap, queers and professional women's basketball . . . all of which are here to stay despite how little people want to acknowledge them. Death has been systematically oppressed and as a result there are so little resources available to help the dying and to help the ones who live through a death close to them. (Lencioni, 2013a, para. 9)

Little's comments remind us that there is a fine line between privacy and loneliness, dignity and isolation. Our critical scholarship must defend the values of privacy and dignity while remaining open to the value of voluntary disclosure. Whether claiming recognition in public space for queer lives and practices, or asserting that dying is part of life and should be treated as such, people approach media representation as a potentially transformative cultural practice. Dying people enter these arrangements deeply disadvantaged in terms of representational power: They are vulnerable, they have no say over the final edit (although they can entrust their wishes to other people), and they are working with professional media producers who have careers to promote, audiences to please, and ratings to get. But this is not the only relevant power relationship at play. Also salient are the power relationships between dying people and the medical professionals, who have so many resources to "broker" the death experience and shape it according to institutional imperatives (Timmermans, 2005). And in society at large, dying people frequently find they no longer have a place or ways to be recognized and "seen," even while they still live.

Although media logics of visibility and social logics of privacy for dying people emerge from the same economic and social structures, they are not the same processes and do not affect people in the same ways. To make the end of life visible contradicts those social practices that institutionalize and privatize death and dying. As Tanner (2006) suggests, "Even as the patient is objectified by the medical gaze, he or she is simultaneously held accountable for a vulnerability to death which the culture would disavow" (p. 3). Although we recognize the myriad ways in which the deck is stacked against the rights of subjects, as well as the ethical complexities of our gaze, we must simultaneously hold in view the promise for recognition and connection that media representation offers in light of other social and institutional constraints. Dying people's experiences are constructed within regimes of media visibility, medical expertise, healthism, and individualism. These regimes overdetermine each other, but they do not produce a singular outcome. People find openings, or identify the hope for openings, in the contradictory logics among disciplinary conditions. When life itself is closing in and few openings remain, an invitation to others to witness the end of life is a gesture toward connection and community, inescapably shaped by both the affordances and limitations of the media forms within which it takes place. In contexts in which individualism and independence are hegemonic values, such a move can rightly be hailed as radical.

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