

HOW DOCUMENTARIES CAN HELP SHAPE
HOW SOCIETY COPE WITH DEATH

by

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ABSTRACT

We live in a society that fears, denies, and attempts to conquer death. This dominant cultural attitude towards death is detrimental to everyone involved in the dying process. There is a collective of people comprised of doctors, therapists, parents, spouses, nurses, and children who believe in the human capacity to die well. This group of individuals has a vision for transforming how we die in our country. At the center of that vision is an effort to effectively communicate to the general public that there is a crisis surrounding end-of-life experiences. Moreover, this group of individuals discovered that the most effective way to communicate this message to the public is to share stories of those who have died in a manner that both informs and educates the public. Documentary films focused on death and dying stories that both inform and engage the viewer have the ability to greatly sway social constructs surrounding death and dying. Thus, the documentary, if done well, can be a powerful tool for helping people cope with the process of dying. By examining three death and dying documentaries, and isolating the techniques used by filmmakers to inform and engage the audience, I provide recommendations for making an effective death and dying documentary.

CHAPTER 1

INTRODUCTION

Death belongs to life as birth does. The walk is in the raising of the foot as in the laying of it down.

Rabindranath Tagore, "Stray Birds"

We live in a society that fears and denies death; we do not talk openly about it and we are uncomfortable being in the presence of those who are dying. When we cannot deny it, we disguise death with folk tales, allegories, and jokes (Nuland xv). Elizabeth Kubler-Ross, author of the groundbreaking book, *On Death and Dying*, writes, "We use euphemisms, we make the dead look as if they were asleep, and we have long and controversial discussions about whether patients should be told the truth" (7). And even when death is right before us, we have developed a modern way of dying that removes death from the private sphere and places it in the hospital where, as Sherwin Nuland, author of *How We Die*, says, "it remains hidden and cleansed of its organic blight" (xv).

Additionally, we not only try to avoid death, but we see it as something to conquer. Dr. Ira Byock, a palliative care physician, writes in his webblog "Living With Dying," "We declared war on cancer, created the National Institutes of Health and invented the Telethon. We approach conquering illness like we approached putting a man on the moon. Death is not optional. People I know are searching for guidance" (Byock, Webblog).

People search for guidance because their loved ones are still dying, and when death approaches, these social realities impact the dying experience (Byock 242).

Furthermore, there is a collective of people comprised of doctors, parents, spouses, nurses, and children who believe that our culture's approach to death is detrimental to everyone involved in the dying experience. This collective has a common vision for shaping how we cope with death in our country.¹ At the center of that vision is an effort to effectively communicate the problem to the public. Effectively in this context means two things. First, it means to **inform** the public that the current paradigm surrounding death and dying negatively impacts people who are dying. Second, it means to inform in a manner that **engages** the public. Moreover, the collective has determined that sharing personal death and dying stories is an effective method for shifting the death and dying paradigm because stories have the potential to educate and engage the public. Although there are many mediums in which authors effectively share death and dying stories, this paper focuses specifically on documentary films.

In some way, all documentary films focused on death and dying issues are geared towards sharing the dying experience with the general public. Many documentary filmmakers who take on such projects find that the most effective way to impart the experience of dying is to share the personal stories of the people who are facing death. As a result, death and dying films are typically rich in character and human emotion, giving the audience something people can relate to and care about. Therefore, when a film of this nature is done well and contains the critical information to spread to the public, it has the ability to greatly impact the audience and potentially sway social constructs.

The goal of this paper is to pave a path for changing how we approach death in America by providing recommendations for making an effective film about death and dying--a film that both informs and engages the public. In order to pinpoint the ways in

which a death and dying documentary should inform the public, I first explore the current paradigm surrounding the end of life experience in America. In order to isolate the features that help documentary films engage the audience, I examine three death and dying films that rely heavily on personal stories. Following these analyses, I turn to my own work and discuss the content, style, and goal of my death and dying film. Finally, I summarize my recommendations for making an effective film about death and dying.

CHAPTER 2

THE END OF LIFE EXPERIENCE IN AMERICA

The current death and dying paradigm in America has led to a crisis surrounding how we die. In her book, *Refuge*, Terry Tempest Williams hits on a key component in the relationship between our attitude towards death and the end-of-life experience when she writes, “Dying doesn’t cause suffering. Resistance to dying does” (53). Sherwin Nuland echoes this sentiment and takes it a step further when he writes “The great majority of people do not leave life in a way they would choose...we live today in the era not of the art of dying, but the art of saving life, and the dilemmas in that are multitudinous” (265). These dilemmas arise due to our fear and denial of death, and when it comes to the emotional nature of dying, there are three main issues common to everyone involved in the dying process: a difficulty communicating about death, a loss of dignity for the terminally ill, and societal alienation of the dying.² By exploring these issues, I provide the reader with a depiction of what most people face when they die in America.³ In addition, one of the two main goals of the death and dying documentary is to inform the public. Therefore, an effective death and dying documentary film must identify and help remedy these specific issues.

Communicating About Dying

As a psychiatrist devoted to learning from patients who were close to death, Elizabeth Kubler-Ross, gained an insight into the emotional nature of dying.⁴ Over decades of research, she learned that when a culture fears death, it is not just the patient

who struggles to communicate about death; caregivers, family members, and everyone else involved have an equally difficult time talking about it. Moreover, opening the doors of communication is more complex than many realize because each entity involved--the patient, the doctor, and the family--has unique obstacles to overcome.

Oftentimes, the dying patient who believes she needs to conquer death, equates facing death with giving up or losing hope. Thus, the act of verbally saying the word *dying* makes her feel as though she has accepted defeat. One way to avoid this anguish is to avoid talking about death altogether, and instead, focus on fighting and finding solutions. A physician has the potential power to ease the patient's burden by sharing the language of death and approaching dying not as a failure, but as a part of living. However, everyone in our society, including doctors, is affected by the social constructs surrounding death. In *How We Die*, Sherwin Nuland reveals that otherwise honest and beneficent physicians don't communicate to their patients about dying because they don't want to take away hope (223). He states,

The hell whose access road is paved with those good intentions becomes too often the hell of suffering through which a misled person must pass before he succumbs to inevitable death. This is one of the ways in which his profession manifests the entire society's current refusal to admit the existence of death's power and perhaps even death itself. (223-224)

Nuland's powerful words convey the difficulty even those in the medical community have when it comes to communicating about death.

In addition to the patient and the doctor, the family is also an important link in the communication triangle. Unfortunately, family members commonly have the most difficult time talking about a loved one's demise. To the family, accepting death is equivalent to giving up on their loved one. So instead of embracing the next phase of life,

the family demands that everyone keep fighting, and as a result, “Attention is directed towards preserving life at all costs--quite literally. Considerations of money, physical comfort, human dignity, and the quality of life experience are, at best secondary” (Byock 243).

The communication obstacles that stand before the majority of dying individuals and the people around them are often insurmountable. Most people who are dying never talk about death. As a result, many feel lost and alone in their struggles, and they suffer emotionally because of it. In the end, everyone involved is shocked and feels like there is so much they could have said.

A Loss of Dignity

Many dying people’s greatest fear is losing their self-respect. For those with debilitating terminal illnesses, getting dressed, bathing, eating, and carrying out other daily tasks, requires dependence on family members and strangers. This dependence can make a person who is terminally ill feel undignified. In addition, as reliance on others for care increases it is common for the dying patient to become more removed from the things that once defined them. Consequently, not only does the individual feel that she no longer contributes and is a burden to others, but she also feels that what gave her life meaning is at risk.⁵ However, this attack on one’s personhood is not just an internal force. Externally, society reinforces the belief that lack of independence and function deems a person undignified. Dr. Ira Byock explains, “The physical signs of disease or advanced age are considered personally degrading and the body’s deterioration, rather than being regarded as an unavoidable human process, becomes a source of embarrassment” (86).

People who are terminally ill sense society's alienation, and accordingly, this external influence intensifies the feelings of shame a dying person faces.

Social Alienation of the Dying

Society's external influence on the dignity of people who are dying is one aspect of how society as a whole treats the dying. When we turn away from death and refuse to accept it, we unintentionally isolate those who need our support (Byock XIIIV). While consciously we may participate in fundraisers for breast cancer, volunteer at elderly homes, and give a compassionate smile at a hospital, subconsciously we cannot escape our own fear of death. Thus, we do not want reminders of death in our daily lives. We would prefer the sick be removed from the public sphere, and cared for by others, so the suffering is hidden (Kubler-Ross 6-7). This dominant societal treatment of the dying perpetuates the very fears most of us have about death--a fear of abandonment, of no longer belonging, and of dying in pain both physically and emotionally.

In summary, between everyone struggling to communicate about death, the patient feeling undignified, and society inadequately nurturing the dying, the majority of people who die from terminal illnesses and old age suffer more than is necessary. Kubler-Ross states, "Dying nowadays is more gruesome in many ways, namely, more lonely, mechanical, and dehumanized" (8). Dying will always be hard, but in order for it not to be horrible, people must recognize that there is a crisis surrounding the end-of-life experience. Furthermore, by addressing the issues discussed above, many believe there is hope for changing how we die.

CHAPTER 3

A POSITIVE VISION FOR CHANGE: SHARING STORIES

Amongst the doctors, nurses, parents, and children who believe there is a crisis surrounding the current dying experience, there is a positive vision for changing how we die in America. This group of individuals- the collective- believes that we can communicate about death, that the terminally ill can feel dignified, and that society can be more supportive of the dying. The collective's goal is to help redefine how we approach death and in doing so, help make the transition from life profound and intimate, where one's living, not dying, experience gives rise to accomplishment (Byock 57). Dr. Ira Byock writes:

Ultimately, a durable resolution of the crisis will require a transformation at the deepest level of American culture. Cultural values and expectations related to dying must shift away from the denial of death...toward an understanding of dying as a part of full, even healthy life. (246)

However, for many, the concept of Dying Well⁶ is difficult to even comprehend (Byock 36). Therefore, from its early origins, the movement to change how we die in America focused intensely on how best to communicate the crisis to the public.

The collective quickly discovered that the most effective way to achieve common ground and captivate the public was to share personal stories about death and dying. As a result, Dr. Ira Byock structured his the entire book, *Dying Well*, around his patients' personal stories. Sherwin Nuland tells stories about his patients who have died throughout *How We Die*. Nuland, like Byock, uses stories to emphasize his reflections on life's final chapter. Most of us have had to deal with death to some degree. Thus, when

we hear personal stories, we relate and feel an emotional connection to the people in the story. By telling the stories of people who have died, we contribute to society in a vital way. The exchange of these stories can serve as sparks from which Americans are ignited into action to change how we die (Byock 247).⁷

Sharing stories via the written word is powerful, but it has its limitations, as Elizabeth Kubler-Ross explains in *On Death and Dying*:

The part that cannot be shared with the reader is the experience that one had during such a dialogue: the many non verbal communications that go on constantly... the sighs, wet eyes, the smiles, gestures with the hands, the empty look, the astonished gaze, or the outstretched hands--all communications of significance which often go beyond words. (182)

While written text is limited in its ability to fully convey “communications of significance,” documentary film has the ability to reveal the moments that Kubler-Ross says go beyond words. Ultimately, a documentary film that not only pays attention to the death and dying issues discussed in this paper, but also aligns itself with the collective’s focus on sharing stories, has the potential to contribute significantly to the collective’s effort to improve how we cope with death in America.

CHAPTER 4

SHARING STORIES WITH DOCUMENTARY FILM

In the preface of, *On Death and Dying*, Elizabeth Kubler-Ross ruminates on the task of writing a book that informs people about the experience of dying, posing questions such as:

Where do I begin? What do I include? How much can I say to strangers who are going to read this book...how many things are communicated nonverbally and have to be felt, experienced, seen and can hardly be translated into words? (preface)

The documentary filmmaker, who, like Kubler-Ross, embraces the task of sharing the experience of dying to the public, has to ask herself these same questions.

Although the filmmaker can utilize tools that go beyond words (she has video, raw sound, music, and graphics), she still has to translate a very personal and complex experience to viewers. The stories she chooses to share, the ethics she embraces, the rhythm and pacing she sets forth, the music, the symbolic visuals, and the splicing of interviews and observational footage, all determine the intellectual and emotional impact the film has on its audience. In the end, all of these elements determine whether or not the film is effective in achieving its goal, and that goal varies in each death and dying film. Some may need to share a story for a personal reason; maybe another has a very clinical goal in mind. Methods and goals vary, however, through my research on documentaries on death and dying, I have discovered that within each of these surface level goals lies a more universal goal: to change how Americans go through the end of life process. In other words, these films aim to contribute to the collective's effort to change the current

paradigm surrounding death and dying. Therefore, the overwhelming question is, “How can filmmakers achieve this goal?” In the following section I answer this question as it relates to three documentary films focused on death and dying issues.

CHAPTER 5

SELECTING FILMS FOR ANALYSIS

The definitive goal of this paper is to provide recommendations for making an effective death and dying documentary.⁵ In order to make these recommendations, I have to understand the fundamental issues of the death and dying crisis. It is also essential that I familiarize myself with the existing archive of death and dying films and the degree to which different filmmaker styles succeed at engaging and informing the audience. The archive of death and dying films is vast, varying greatly in form, style, and content. On one end of the spectrum, the archive includes films utilizing the traditional expository mode of representation. In order to introduce ideas, these films use voice-over narration, formal interviews, and b-roll to conceal talking heads. The filmmaker typically presents a linear generalized discourse that straightforwardly discusses death and dying issues. Films such as *Pioneers in Hospice* (2004) (*PIH*) or *More Than A Failing Heart* (2002) are on this end of the continuum. *PIH* teaches the viewer about the development of hospice care, focusing on the legacy of the founders of the modern hospice movement. Although *PIH* informs the viewer at length about death and dying, its didactic approach fails to engage the audience.

On the opposite end of the spectrum, the archive consists of death and dying films that reject the expository mode of representation, and instead embrace an observational style rooted in the Direct Cinema movement. By closely following subjects and capturing intimate expressions and conversations, these films tend to share the emotional nature of dying. In addition, the audience learns about death and dying issues by glimpsing into the

life of someone who is dying. Films on this end of the continuum include, *Letting Go: A Hospice Journey* (1996) (*LGHJ*) by Albert Maysles and *Near Death* (1989) by Fredrick Wiseman. Each of these films depends heavily on the interactions played out before the camera. In these exchanges, the filmmaker gathers the footage they need to captivate their audience and reveal content that gets to the core of the dying experience. Films of this nature, if done well, both inform and engage the audience. In an attempt to align this analysis with my research goals, I selected three films that fall towards this end of the continuum. In addition, since I am concerned specifically with dominant cultural attitudes towards death and dying within the United States, my preliminary criteria for selection included that the films be: 1) centered on death and dying issues within the United States, 2) produced by U.S. filmmakers, and 3) created within the last few decades.

The three films I selected are *Death: A Love Story* (1999) by Michelle LeBrun, *Complaints of a Dutiful Daughter* (1994) by Deborah Hoffman, and *Letting Go: A Hospice Journey* (1996) by Albert Maysles, Deborah Dickson, and Susan Frömke. I will examine the structure of each film and discuss how directorial choices either support or impede the film's ability to inform and engage the audience. By isolating the aspects of each film that support the collective's mission to alter the way we approach death, I'll establish recommendations for how to make an effective death and dying documentary.

CHAPTER 6

“DEATH: A LOVE STORY”

Michelle Le Brun's *Death: A Love Story (DLS)* (1999) is both Le Brun's tribute to her late husband, Mel Howard, and her personal account of her and Howard's journey while facing death. Through a mixture of participatory footage shot by Le Brun and Howard, reflexive narration, dramatic music, and symbolic visuals, this film recounts the couple's struggles as they confront Mel's liver cancer, navigate the medical system, and search for solutions with alternative treatments. As Mel loses control over his body, he shifts his focus from surviving to enlightening himself spiritually. With this shift Howard opens up verbally about dying. As a result, he talks with the camera and his wife, friends, and doctors, about his frustrations and fears about dying. Howard also talks about his desire to find inner peace as he dies. Towards the end of the film Howard says that he has learned the importance of healing over curing and that, "authentic healing is an opening of the closed spaces in my heart." Through these exchanges, *DLS* familiarizes the audience with the experience of death and helps create an emotional connection between the audience and Le Brun and Howard's story.

Although the film is filled with Howard's engaging conversations on dying, Le Brun guides the personal narration. Unfortunately, Le Brun's narration is one of the most poorly executed aspects of this film. It is not only distractingly melodramatic, but it also fails to reveal Le Brun's true emotions and thoughts concerning the loss of her husband and his struggle with cancer. During an interview, Le Brun said that she decided to make this film after Howard died, and her inspiration for her narration was her journal entries.

In addition, Le Brun said that making the film became a healing experience that taught her so much about living and spirituality, and she wanted her narration to share what she had learned. Despite her intentions, Le Brun does not share the same level of intimacy in her narration as she recorded in her journal, nor do her words and voice reveal the journey she went through. Only in one scene in the film do we feel what Le Brun feels when Howard dies. Le Brun is crying and expressing her love for Howard and what he has taught her. Unfortunately, this moment lasts only a few seconds and the overall emotional distance of Le Brun's narration counteracts the engagement formed through Howard's monologues. In fact, when the film transitions from Howard's honest and unflinching thoughts on death to Le Brun's scripted surface-level narration, the contrast is so severe that the viewer feels abrasively removed from the story. Le Brun failed to recognize that in chronicling her and Howard's journey as a couple, she needed to share what she felt to the same degree that she shared Howard feelings.

What further impedes Le Brun's narration is the music and visuals that accompany it. Each time Le Brun goes into her narration, the tone of the film shifts. The music becomes dramatic and the visuals fade from interactive footage of the couple to cliché symbolic images--we see fire burning overlaid on an image of the couple, or we are sent flying down a CGI tunnel that looks like the inside of a vein. These creative choices further shock the viewer and distance him from the story. The failure of Le Brun's narration to engage the audience detracts from the effectiveness of the film. However, in the following paragraphs, I discuss techniques used in *DLS* that do provide viewers with insight into the critical issues involved in the dying experience. I also note techniques that further hinder the effectiveness of the film.

Filmic Elements that Help Inform

Illustrating Dignity

In the final scene of *DLS*, we do not see Howard die, but we hear his final thoughts, and we listen as he meets death with dignity, acceptance, and curiosity (Hunter 1). By giving Mel Howard the opportunity to share his voice throughout the film and by showing that he is more than a set of medical problems to be solved--that he is a dynamic human being--*DLS* helps restore the dignity stripped away from all terminally ill and elderly individuals.

Exposing Our Denial of Death

Throughout *DLS*, there are scenes involving Howard's doctors. In these scenes, the viewer witnesses first hand how the medical community approaches death with the same denial that society does. Instead of helping Howard accept death, his doctors avoid the topic and dwell on unlikely solutions. The viewer also witnesses the event in which Howard rejects further treatment and his doctors refuse to be involved in his continuing care. With these scenes, this film illustrates a fundamental problem with how our culture approaches death and how it is detrimental to the dying process.

Filmic Elements that Hinder Engagement

Inconsistent Motivation

During *DLS*, Le Brun repeatedly justifies filming her and Howard's lives. In one instance, she states, "The camera is good for me, it gives me purpose amidst all this."

This powerful statement added to my understanding of Le Brun's experience and consequently drew me into Le Brun's story. However, in another instance Le Brun says, "Our friends said we should keep the camera rolling." Most of her justifications are similar to this one, and it is as though Le Brun is trying to persuade the viewer that she and Howard were objective bystanders in the filmmaking process. However, this conflicts with the message that Le Brun promotes from the beginning of the film--that this is their story, told by them. The viewer perceives this contradiction as a lack of confidence from Le Brun in her decision to make a film about Howard's death. This inconsistency in filmmaking motivation is confusing and distracting to the viewer.

Inconsistent Approach

Many scenes that include both Le Brun and Howard appear as if the filmmakers were trying to make the scenes feel Cinema Vérité, or purely observational. As a result, Howard and Le Brun try to act as though the camera is not there. Yet, Le Brun and Howard control the camera and the story, thus there is no way this film can provide an objective representation of the couple's experience. However, in other scenes, Le Brun and Howard fully acknowledge the camera and talk about its role in their lives. Although the latter is a much more honest approach, this inconsistency in filmmaking style is both confusing and distracting.

Structural Repetitiveness

In the structure of *DLS*, Le Brun and her editor repeatedly tell then show then tell again. For example, at the beginning of the film, Le Brun establishes her and Howard's love for each other with introductory narration. Then, we see a few minutes of footage of

them kissing and getting married. Then Le Brun continues to show similar scenes, but supplements the footage with more narration that tells the audience again just how in love she and Howard were. At the end of this segment, I felt that instead of letting me witness the love between Le Brun and Howard, it was forced upon me.

DLS Conclusion

Although *DLS* has elements that strengthen the story and provide the audience with insight into the death and dying process, it is not effective in engaging the audience. Overall, analyzing *DLS* taught me more about what not to do than what to do to make an effective film about death and dying.

CHAPTER 7

“COMPLAINTS OF A DUTIFUL DAUGHTER”

Complaints of a Dutiful Daughter (CDD) (1994), an Oscar-nominated documentary, explores filmmaker Deborah Hoffman’s relationship with her mother during the onset of Alzheimer’s Disease. While chronicling her mother Doris’s mental deterioration, Hoffman shares a profoundly insightful, personal, and at times comical, account of coming to terms with her mother’s illness. Since its release, *CDD* has helped redefine Alzheimer’s and minimize the fear long associated with this illness. However, *CDD* is more than a film about Alzheimer’s. Ultimately, *CDD* examines a critical subject relating to death and dying--as Americans enter into the final phase of life, more and more people are faced with life-changing challenges. By weaving together old photographs, home movies, modern video, old phone conversations, literal and symbolic b-roll, quirky graphics, and witty narration, Hoffman presents a moving personal narrative that gives the audience insight into how to navigate these challenges. For this reason, I included *CDD* in my analysis.

Unlike *DLS*, which moves at an unsettling fast pace, *CDD* is slow to medium-paced, allowing critical moments with Hoffman’s mother, Doris, to breathe. Hoffman also effectively uses music to intensify emotional and comic scenes. In *CDD*, Hoffman establishes her discourse and engages the audience through the use of a reflexive personal narrative. Through this confessional style narration, Deborah shares her desire to cure the incurable--her mother’s deterioration. As the film progresses, Hoffman’s narrative reveals that her desire to control Alzheimer’s gives way to an acceptance that allows her

to truly live in the moment with her mother during Doris's final phase of life--a liberating act for both women. Teresa Bergman notes, "The goal of engaging the audience via personal narrative can be extremely effective...the convention of a personal narrative can normalize, naturalize, and moralize" (Bergman 24). As we saw with Le Brun's *DLS*, not all attempts at personal narratives are successful. Le Brun's failure to open up and sound natural in her narration prevented the audience from forming a connection to Le Brun's story.

In *Toward an Aesthetics of Natural Performance*, Nathan Stucky writes, "Natural performance is fundamentally neither an appearance of reality nor a mere imitation" (171). What separates Hoffman's narration from Le Brun's is that Hoffman's personal narrative format "is marked by naturalism's influence" (Bergman 24). As Bergman points out, "Hoffman went to extraordinary lengths to achieve the performance of 'naturalism'" (Bergman 24). Hoffman is an award-winning documentary film editor who knew that in order to engage the audience she needed to give a performance that appeared genuine. Hoffman utilized three techniques to achieve this natural performance. First, in a personal interview, Hoffman said that she recorded her narration in a manner that would catch her "off guard" and therefore come off as unscripted (Bergman 24). Second, she chose to deliver her narration through personal on-screen interviews. In her essay for *The Search for Reality: The Art of Documentary Filmmaking*, Bettina Gray writes, "the live interview offers a drama of realism" (Tobias, 88). Moreover, Bergman observes that the documentary interview "reflects the contemporary understanding of what truth should look like and sound like in a documentary interview" (24). Hoffman uses this culturally accepted form of documentary discourse to ensure that the audience interprets her

interviews as revealing feelings and observations that are honest and trustworthy.⁸

Finally, the third technique Hoffman employed in order to enhance her performance of naturalism was openness. Hoffman openly shares how she felt during this experience and how she processed her emotions. In one scene towards the end of the film, Hoffman and her mother smile as they watch a patient dance to music at Doris's care facility. As the camera pans, Hoffman's states:

Everybody who's there has a disease they'd rather not have. Everybody in there is going to get worse. Everybody's essentially going to die from what they have there and there's nothing uplifting about that. But once you accept the parameters--my mother has Alzheimer's--but if you can accept that, it can still be a very joyful life.

Not only do statements like this help Hoffman achieve a performance of naturalism, and thus a trust between storyteller and viewer, they also helps pave a path for communicating about the difficult topics surrounding terminal illnesses--an essential feature for any death and dying film. Consequently, Hoffman's personal narrative is the most compelling aspect of her film. However, there are many additional methods Hoffman uses to strengthen *CCD*, including:

Methods That Strengthen

Use of Humor

Hoffman integrates humor into *CDD* structure through her witty narration, her selection of humorous footage of her mother, and in the way she breaks the film up into chapters based on her mother's obsessive stages. She continues to give the film a whimsical feel by using amusing graphics and visuals to illustrate each stage--the banana period, the Lorna Doone cookie period, and many more. Each of these filmic devices

gives the film levity and makes a difficult topic accessible and inviting to the audience (Bergman 27).

Immediate Immersion

In the opening scene of *CDD*, Hoffman asks, “Do you know who my mother was?”

Doris shakes her head no.

“You!” says Deborah. “I was your mother? How can I really be your mother?”

Doris laughs, “Something went wrong!”

With this scene, *CDD* instantly introduces the viewer to the emotional atmosphere that shapes the film. This technique not only hooks the viewer to the story, but also informs him of the film’s discourse early on, helping him absorb key information about death and dying presented throughout the film.

Showing Not Telling

Throughout her film, Hoffman includes scenes like the one described above but, unlike Le Brun in *DLS*, she does not overwhelm the viewer with didactic narration that reiterates what he is watching. Thus, with these scenes, Hoffman establishes the practice of “showing not telling.” By showing us Doris’s life, the audience makes his or her own conclusions about Hoffman’s experience, and this has a positive effect on the film as a whole.

Restoring Dignity

In *CDD*, Hoffman introduces the audience to her mother, who, despite her deterioration to Alzheimer's, retains the essence of who she is--a stylish, charming, funny, and articulate woman (Freedman 2). As a result, many regard Hoffman's film as a tribute to her mother's intelligence and dignity. When Hoffman gives her mother a voice and honors her for all that she has been during her life, not just how she is defined now by Alzheimer's, *CDD*, like *DLS*, helps restore the dignity to all people plagued with debilitating terminal illnesses.

CDD Conclusion

CCD teaches how we can grow with our families as they enter the final stages of life through illness and age. Moreover, although *CCD* is focused on Alzheimer's, the directorial choices and stylistic achievements present an engaging story and informative discourse about issues relating to death and dying, and thus watching this film taught me many things about making an effective death and dying documentary.

CHAPTER 8

“LETTING GO: A HOSPICE JOURNEY”

Letting Go: A Hospice Journey (LGHJ) (1994) is a moving documentary by filmmaker Albert Maysles and his associates Deborah Dickson and Susan Fromke. I chose to analyze *LGHJ* because Maysles uses a filmmaking style much different from Deborah Hoffman's.

Filmmaker Albert Maysles helped to pioneer the Direct Cinema movement in the late 1960s with such films as *Salesman* (1968) and *Gimme Shelter* (1970). On his web page Albert Maysles writes, “As a documentarian, I happily place my fate and faith in reality. It is my caretaker, the provider of subjects, themes, experiences--all endowed with the power of truth and the romance of discovery. And the closer I adhere to reality the more honest and authentic my tales” (www.Maysles.com). In *LGHJ*, Maysles applies a Direct Cinema approach to capture the end of life experiences of Ralph Armstrong, who is dying from terminal brain cancer; Anna Turner, who is dying of lung cancer; and 8-year-old Michael Merseal, who is in the final stages of an incurable brain disease. On their website, Maysles, Dickson, and Fromke write:

In our society, death fills the airwaves, it targets strangers, creates statistics. Yet when it finally gets personal, we are ill-equipped. Coping with the inevitability of death is the subject of *Letting Go: A Hospice Journey*. Exploring this almost taboo subject through the stories of three hospice patients, the film creates an understanding of the hospice movement. (Maysles.com)

Adding to this synopsis, this ninety-minute documentary relies on hand-held camera work and, unlike *DLS* and *CDD*, does not use any narration, and only uses music and b-

roll when it transitions from one story to the next. The pace of *LGHJ* seems to parallel the pace of life and the affect is a peaceful one. As the film transitions from one story to the next, it presents an authentic uninterrupted look at the lives of those who are dying. As we watch these individuals suffer, grow, live, and then die, the observational nature of the film allows us to grieve with the subjects instead of drawing back, and because of the intensity of the stories, we watch intently and grow from it.

What distinguishes *LGHJ* from the other two films in this analysis is that it takes a comprehensive look at the end of life experience. Each of the three stories Maysles shares focuses on different aspects of the dying process. Merseal's story focuses on the family--their struggles and how they prepare for Michael's death. Turner's story delves deeply into the subject of denial and the role religion plays in facing death. Armstrong's story teaches us about trying to find dignity during life's completion and the importance of healing wounded relationships before we die. Maysles's ability to engage the audience through his intimate storytelling and thoroughly examine issues surrounding death and dying makes this an effective film through the use several effective techniques:

Methods That Strengthen

Immediate Immersion

Previously I discussed how *CDD* immediately immerses the viewer in the atmosphere that shapes the film. *LGHJ* begins with scene that is as equally gripping and captivating as Hoffman's opening scene in *CDD*. We see a montage of intense moments from each story: Michael starts to seizure; Ralph asks about the actual moment of dying; and Anna lies in her bed on the verge of death, expressing that she hopes god will save

her. As stated earlier, this technique of immediately immersing the audience in the intensity of the dying experience not only hooks the viewer to the story, but also informs the viewer of the film's narrative.

Showing Not Telling

In an early scene in *LGHJ*, Michael Merseal's father, Michael Sr., talks to Maysles, who is behind the camera. While he expresses that he is not in denial about Michael's future, and that he has to be strong for his family, Michael Jr. desperately gasps for air. With a look of fear, Michael Sr. frantically jumps up and runs to his son. He caresses him until his breathing returns to normal. This riveting scene exemplifies the essence of the Direct Cinema movement--to let the camera reveal without the distraction of expository dialogue or narration. As *LGHJ* moves fluidly from story to story, each moment spent with the characters is filled with cherished words, intimate gestures, and subtle glances, and thus paints a multi-dimensional portrait of the dying experience.

The technique of "showing not telling" is very effective in documentary. Film theorist Brian Winston asserts, "Grounding the documentary idea in reception rather than in representation is exactly the way to preserve its validity. It allows for the audience to make the truth claim for the documentary rather than the documentary making the claim for itself" (Winston 253). Maysles recognizes this concept and lets these scenes give the film meaning. Moreover, people easily turn away from death as the subject matter in films such as covered in *LGHJ*, *DLS*, and *CDD*. By allowing the viewer to make the truth claim for the documentary, *LGHJ* allows each person to interpret the film in his/her own way, thus helping confront a difficult topic.

Welcoming Complexity

Despite Maysles's loyalty to observational footage, in an effort to ensure that the viewer fully grasps the complexity of the death and dying process, Maysles diverges from his traditional Direct Cinema roots. Throughout *LGHJ*, Maysles informally interviews people such as Michael's doctor, Ralph's therapist, and Anna's daughter and priest. These interviews are participatory even though we rarely hear Maysles's voice and never see him. When these conversations are creatively entwined with the observational footage, they have an amazing ability to educate the viewer about the complexity of end-of-life issues. This film embraces the complexity of the end-of-life process and uses this complexity to create an intricate timeline that flows and beautifully. Maysles's decision to include these interviews makes *LGHJ* informative and poignant.⁹

LGHJ Conclusion

Each personal story in this film is ultimately about trying to find peace during the final phase of life and showing that in finding peace not only can we grow as individuals but those around us can grow too. Through Ralph, Michael, and Anna's final moments of life, the viewer witnesses that dying is a highly individualized process, and he also learns that there is a continuum and a complexity when it comes to finding peace and dying well.

CHAPTER 9

“A DAUGHTER’S STORY”

My thesis film, *A Daughter’s Story* (*ADS*), is a 58-minute self-reflexive documentary recounting my personal experience with my mother’s terminal illness and death. This film is an intimate story about my journey to understand how my mother navigated through the obstacles she faced in dying due to the way our society approaches death. My hope is that by letting people join me on my journey, *ADS* will inform people about the emotional nature of dying and leave people with a sense of hope about dying well. This piece is also intended to honor my mother’s courageous will to live until she died.

ADS is comprised of my conversation-like narration with the audience, observational and interactive footage of my mother, and participatory interviews with family members and my mother’s doctor. Furthermore, as much as this project is a tribute to my mother and a personal exploration of my emotions during this period of my life, this film was also my first directorial endeavor with character-driven social-message filmmaking. Therefore, as I made this film I was searching for my voice as a filmmaker. During the filmmaking process this ambition translated to a willingness to take risks and apply filmic elements I have always been drawn to. Surprisingly, what I have discovered since the completion of *ADS* is that many of the directorial choices I made because of my enthusiasm to experiment stylistically have helped *ADS* stand out as a multidimensional, film about death and dying.

One such directorial choice was based on the fact I have always been drawn to reflexive filmmaking--films that engage in a metacommentary about the actual process of representing the historical world (Nichols 56). I chose to make *ADS* a self-reflexive film. Bill Nichols writes, “Reflexive texts are self-conscious not only about form and style...but also about strategy, structure, conventions, expectations, and effects” (57). Based on Nichol’s description, *ADS* has many reflexive moments. When in my narration I discuss how the filmmaking process transformed my view of my mother’s death, *ADS* is internalizing and commenting on issues relating to the actual act of social representation. This self-reflexivity is most apparent in the segment where I address the reasons I filmed my mother and reveal the ethical dilemmas I faced in filming something as intimate as dying. This segment begins with my following narration¹⁰:

This is one of those moments that I look back on and I’m so happy I filmed my mom...Most of the time, most of the footage in this film, was spontaneous unplanned, I just turn the camera on, sometimes held onto it, sometimes set it down. It was about somehow trying to capture the little things I was afraid I was going to forget.

Following this narration, we see a montage of shots where my mom asks both seriously and jokingly for me not to film her. Then the montage fades away and my dad and I are in my office. I ask him if mom knew why I was filming her and if that made her sad. He answers honestly--he says it was hard for her to be filmed knowing how sick she looked, but she knew why I was doing it and was supportive.

This scene is important not just because it shares how my mother was feeling but also because of how it impacts the audience. Documentary film lecturers Jane Roscoe and Craig Hight remark that reflexive documentaries give “a far greater role to the audience, expecting them to be able to arrive at their own conclusions about any given issue, and to

be able to determine for themselves what is ‘true’” (Roscoe and Hight 36). Based on what I have learned from *CDD*, along with other socially motivated films that employ reflexive techniques, I believe my reflexive choices add depth to my film. I believe my choices give my film a personal, honest feel that allows the viewer to experience my journey with me, and as Rosco and Hight note, allows him to make his own conclusions about my mother’s condition and my own experience.

The second most prominent directorial decision I made in *ADS* was my self-reflexive narration. Earlier in this paper I argued that Michelle Le Brun’s narration lacked the intimate natural feeling that Deborah Hoffman’s narration embodied, and therefore Le Brun failed to create an empathetic bond between the film and the audience. Like Hoffman, I recognize the importance of achieving a performance of naturalism in personal narratives in order to engage the viewer and build trust. Thus, I wanted my narration to feel as if I was writing a journal entry or having an intimate conversation with a friend. On some occasions, however, I found myself trying to write and record the perfect script. When I would play back what I recorded, I immediately knew it would not work. I would stop and think, “Don’t try to make something up, Katy. You went through this, these are your emotions--what did you feel?” Then, I would sit back, relax, and while I recorded my thoughts I would think about what I was saying and let my emotions flow accordingly.

Moreover, although my narration guides *ADS*, I have always been most moved by films that allow the viewer to spend a significant amount of time with the main character and subsequently feel a personal connection to them. Thus, I made the directorial choice to let footage of my mother carry the film, and I employed specific filmic techniques to

help the audience emotionally connect with her. One such technique was to evoke who my mother was in the tone of the film. This meant shying away from dramatic and depressing music and narration and instead gravitating towards music, footage, and narration that gave the film an energetic, quirky, colorful, and perseverant quality. By creating a tone that matched my mother's personality, I accentuated those moments in the footage where the viewer gets to know Susan and by doing so, I further developed the audience's relationship with my mother. In this same respect, I used humor in *ADS*. By sharing humor throughout the film, I not only hoped to strengthen the emotional connection between my mom and the viewer, but I also hoped to help lighten the mood of the film. By reminding people that it is okay to laugh amidst dying, levity in films like *ADS* and *CDD* make the audience more comfortable and thus help a viewer transition from moments of tears to moments where he or she is inspired and feels hopeful about the possibility of dying well.

Additionally, there are many other features of my film that stemmed from my desire to find my voice as a filmmaker--features that help engage the audience. However, my film was also highly shaped by my desire to contribute to the archive of death and dying films. Therefore, it was just as important to me to inform the audience about specific death and dying issues as it was to engage them. Fortunately, as I was developing my film, I was researching this paper. As a result, my knowledge of death and dying issues helped guide my choices in story, structure, and message.

In a previous section titled, "The End of Life Experience in America" I relate that the three main death and dying issues are, the struggle to communicate about death, the question of dignity, and how society alienates the dying. I structured my film around

addressing these issues. First, by talking about death and dying issues directly in my narration and showing footage of my mother bravely talking about death with both her doctor and me, I believe *ADS* will help others communicate about death. Second, by sharing who my mother was beyond being a patient--her artwork, her humor, her family-- and by allowing her voice to be heard, I help illustrate that dying is dignified and that terminally ill people should feel dignified. And, finally, by showing the audience the ways in which my mother felt alienated by society and her own social biases, I heighten people's awareness of how our cultural treatment of death hurts those who are dying.

CHAPTER 10

THE ROLE OF SCIENCE IN DEATH AND DYING FILMS

The press release for *Complaint's of a Dutiful Daughter (CCD)*, stated, “Hoffman’s film is far from depressing or medical” (American Doc. INC website). This critique is to assure potential viewers that *CCD* is not too morbid or too scientific-- characteristics the critic believes will negatively affect a viewer’s attraction to the film. I encountered this kind of critique, varying in text but identical in intention, in many of the reviews I read while researching death and dying films. *A Daughter's Story (ADS)* is not a traditional science documentary, yet, *ADS* incorporates science. Therefore, each time I read a critique that suggested a film was not medical or scientific I asked myself, “What is considered scientific content in death and dying films?” In contemplating this question, I realized that most people have an inaccurate perception of how science can be represented in documentary films. *CCD*’s distributor believes Hoffman’s film is not medical, but I disagree, and I believe that the scientific content is actually an essential piece of any death and dying film.

Both *CDD* and *ADS* do not have doctors in white coats or elaborate graphics explaining technicalities of cancer or Alzheimer’s. However, both films are rich in medical content, yet the medical content is presented in a manner most people would not perceive as scientific. At the fundamental level, the medical content is information that helps the viewer understand what is happening physically to a person. This seems obvious, but the reason most people overlook this fact is because effective death and dying films intricately weave the medical content into the personal story of the film. In

CCD, the medical, or scientific, content is both Hoffman's breakdown of her mother's behavior and the footage of her mother displaying symptoms of Alzheimer's. In *ADS*, the medical content resides in the conversations between Katy and Rachel, and Katy and Dr. Weir. It also resides in the dialysis footage, the scene in which Susan processes that she is dying, and the footage displaying Susan's physical state-- the viewer absorbs "scientific" information.

Science regarded in this manner is everywhere in each of the films I analyzed. Dr. Ira Byock writes, "Dying cannot be reduced to a collection of diagnoses. For the individual and the family, the enormity and depth of this final transition dwarfs the myriad of medical problems. For the person, the process of dying cannot be understood as simply a medical event" (Byock 35). Just as Byock asks us not to exclude the emotional side of dying in comprehending the dying experience, we cannot exclude the physical aspect of dying either. Nor can we separate the emotional nature of dying from the physical nature of dying--they are inextricably linked. Sherwin Nuland notes, "It is by knowing the truth and being prepared for it that we rid ourselves of that fear of the terra incognita of death that leads to self-depreciation and disillusion" (Nuland xvii). Moreover, truth comes from knowing all aspects of dying, both the physical and the emotional. Thus, in a death and dying film attempting to genuinely represent reality and improve the dying experience, it is essential to tell a story that is rich both in human emotion and medical content.

This argument is not the only reason a filmmaker should integrate science into her death and dying film. Nuland explains:

Everyone wants to know the details of dying, though few are willing to say so. Whether to anticipate the events of our own final illness or to better comprehend what is happening to a mortally stricken loved one--or more likely out of that id-borne fascination with death we all share--we are lured by the thoughts of life's ending. To most people, death remains a hidden secret, as eroticized as it is feared. We are irresistibly attracted by the very anxieties we find most terrifying. (Nuland xv)

While socially we deny death, ironically, at the same time, we want to know the scientific details about why someone is sick or dying. A filmmaker can use this paradox to her advantage; by talking about the medical details of an illness or a death, she can appeal to the viewer's curiosity and subsequently ease him/her into a film that talks about the aspects of dying that most people wish to ignore.

CHAPTER 11

CONCLUSION

An effective social film inspires dialogue and from that dialogue the wheels of change begin to turn. I believe that if a documentary film is going to contribute to the collective's effort to shift the death and dying paradigm, the film has to inspire people to talk about their own fears and struggles with death and dying issues. The following recommendations might help filmmakers create documentaries that both inform and engage the audience, and therefore inspire people to talk.

RecommendationsScience Content

Based on the arguments stated in the previous section, a film about death and dying should not turn away from the medical content but instead embrace science and integrate it into the emotional content of the story. Death and Dying filmmakers should use science to captivate the audience and provide the viewer with a thorough perspective on the death and dying experience.

Sharing Personal Stories

In agreement with the collective's vision for change, death and dying documentaries should share personal death and dying stories. Although dealing with a more personal and intimate look at death and dying can be harder for audiences to digest

initially, this approach will successfully engage the audience and thus have a greater impact.

Showing Not Telling

Audiences are pre-disposed to turn away from the subject matter in death and dying films, and “showing not telling” is an effective method for holding an audience captivated and emotionally connecting them to the story. In addition, “showing not telling” permits each viewer to create his or her own meaning.

Natural Open Narration

If the film utilizes personal narratives, it is essential that the narrator be open about her experiences, as Deborah Hoffman does in *CDD*. In addition, the narrator should give a “Performance of Naturalism” in order to build an emotional connection and trust between storyteller and audience.

Put the Story First

Since the personal story is such an important aspect of an effective death and dying film, the filmmaker should prioritize capturing that story before anything else. For example, in the films I analyzed, the filmmakers sacrificed the perfect shots in order to capture the critical moments and statements. To elaborate, in both *ADS* and *CDD*, the filmmakers chose not to hire professional cinematographers to capture important events because they did not want to risk altering the atmosphere from one of comfort to unfamiliarity. Deborah Hoffman asked her longtime life-partner, Frances Reid to be her cinematographer for this reason. While discussing this choice, Hoffman said, “It had to

be the person who knew my mother as intimately as I did. It couldn't have been anyone else. The film wouldn't have happened without her.”

Address the Main Issues of Death & Dying

As a society, if we are to shift the paradigm surrounding death and dying we must address the major issues that affect the end-of-life experience. These issues include a lack of communication about death, terminally ill individuals feeling undignified, and society failing to adequately nurture the dying. A documentary film that addresses these three issues can be a powerful tool for helping people cope with death and dying.

Throughout my analyses I discussed how *DLS*, *CDD*, *LGHJ*, and *ADS* confront these issues. Based on these analyses, I recommend that a death and dying film show characters in the film using the language of death and being open about death and dying issues in order to help others communicate about death. In order to help restore dignity to the dying, I recommend that death and dying films show respect for the dying individual and give them an opportunity to not only show who they are but also to share their thoughts and opinions. And, in order to help society nurture the dying, I recommend that death and dying films be honest about how society currently treats those who are dying and how this affects their end-of-life experience.

In conclusion, in order to influence positive social change we must adopt a pro “dying-well” strategy of documentary deterritorialization- using effective death and dying documentaries to challenge and redefine cultural definitions of death and dying (Christholm 99). We need to transform our private anguish over the suffering of loved ones into something public that serves as a tool to dismantle the current paradigm

(Chrisholm 99). In noting the importance of making public issues that have been previously consigned to the private sphere, David Van Leer states, “Public announcement challenges society’s standards of normative behavior (and in some cultures its legal codes)” (125). Through our actions as filmmakers, we can help more people die well until the concept of dying poorly and suffering during death is foreign to us and to our children.

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APPENDIX A

NOTES

NOTES

¹ I refer to the group of individuals (doctors, nurses, hospice care workers, parents, children, authors, and artists) who have come together with a common vision of how to improve how we die in America as ‘the collective’. These individuals do not all belong to one organization, or call themselves, the collective. However, I use this term to represent how there is a group of individuals throughout this country who are aligned in their vision and effort to change the end of life experience.

² There are many negative aspects of the physical nature of dying that people also pinpoint as evidence that something is wrong with end of life experiences in our country. For example, there is much discussion about the management of pain for the dying. Ira Byock states in his book *Dying Well*, “Physical pain among the terminally ill exists because doctors lack the will, not the way” (60). In this section I specifically focus on the emotional obstacles people who are dying face because the emotional nature of dying is currently the most neglected aspect of the dying experience. Moreover, many believe that a transformation in how we die will mostly come from first making the emotional aspect perceived as equally important as the physical nature of dying.

³ I would like to note here that when I make reference to a dying individual, I refer only to those who go through some sort of dying process that is affected by how we approach death. Therefore, I’m including those individuals who die from terminal illnesses or from old age. I’m not referring to people who die instantly from accidents, for example.

⁴ In her book, *On Death and Dying*, Elizabeth Kubler-Ross writes, “In our unconscious mind we can only be killed; it is inconceivable to die of a natural cause or of old age. Therefore, death in itself is associated with a bad act...something that in itself calls for retribution and punishment” (2).

⁵ Dr. Ira Byock writes, “For someone who is dying, this problem is often the crux of personal suffering” (85).

⁶ *Dying Well* is the phrase the collective uses to represent their positive vision for dying. Dr. Ira Byock characterizes ‘Dying Well’, he says, “In contrast [to the term a good death], the phrase dying well seems better suited to describing the end-of-life experiences that people desire. It expressed the sense of living, the sense of process. To my ears it also carries a connotation of courage. Furthermore, dying well expresses what I have witnessed most consistently: that in the very shadow of death one’s living experience can yet give rise to accomplishment, within one’s own and one’s family’s system of values” (Byock 32).

⁷ In his final chapter of *Dying Well*, Dr. Ira Byock writes, “We need to reflect on the meaning of these stories. Beyond their power as individual stories, they can teach us some public policy lessons and show us the need for changing our culture” (241).

⁸ In *CCD* Hoffman further engages the viewer with her interview style narration by placing the audience as her primary referential relationship—she speaks directly to the audience and addresses any emotional responses she believes we may have because of her self-disclosures.

⁹ In one scene, Michael’s doctor, Dr. Ira Byock, is at a coffee shop. He is talking quietly and has a look of concern. He says: “We’re trying to counter two generations of people who have associated dying with suffering. By saying suffering can be controlled, this part of living that we call dying or the end of life isn’t so horrible, its poignant, it’s always sad but it’s not horrible, that’s an artifact of our modern mistreatment of the dying.” In another scene in *LGHJ*, Ralph Armstrong’s primary physician and Ralph talk about how hard it is for Ralph to discuss his emotions. They talk about how before he had cancer, Ralph never shared his feelings but that the emotional nature of death was forcing him to open up and as a result he was feeling more than he’d ever felt before. Following this scene, Ralph’s doctor is alone in his office with Maysles. The doctor says that what Ralph is experiencing is common and when the idea of death sinks in and the emotions follow, “you have to pay attention because this point is a tremendous point of possibility—a doorway to a new place”. The doctor says there is a death of identity and ego before a medical death. Not only is this another example of the poignant conversations this film capture and the depth to which it teaches the viewer about the dying experience, but this scene also illustrates how this film speaks both to people who are dying and also to people who are on the other side--the care givers.

¹⁰ The complete narration reads: “This is one of those moments that I look back on and I’m so happy I filmed my mom. The way she looks at me and smiles and talks- it’s so her. I just wanted footage of her...to remember her by and share with my family. Most of the time, most of the footage in this film, was spontaneous unplanned, I just turn the camera on, sometimes hold onto it, sometimes set it down. It was about somehow trying to capture the little things I was afraid I was going to forget.”