SECTION I
INSTITUTIONAL VOICES

2. MEDICAL DOCUMENTARIES

Demedicalisation of Death

The first scene of the television documentary *Being Mortal* (Jennings 2015) leads the viewer from the street outside a Boston hospital to its busy hallways, where doctors and nurses navigate the floors. The camera follows Atul Gawande scrubbing in for surgery, while the surgeon's voiceover sets the scene:

> I've been a surgeon for more than a decade now. In medicine, your first fear as a doctor is that you're supposed to be able to fix a problem, and our anxieties include wanting to seem competent, and to us, competent means I can fix this. […] Among the most uncomfortable difficulties was grappling with those cases where we couldn't solve the problem. The two big unfixables are aging and dying. You know, they're not – you can't fix those. (Jennings 2015)

The opening displays the conflict explored in the documentary – is death a medical failure, a broken promise for the patients, or something that should be embraced as a natural part of life?

Similar discussions emerge from cinema's relationship with death. Since the early twentieth century, cinema, along with medical technology, has served as a sign of modern society and cinema has eagerly supported a technological vision of society. Early documentary films, for example, represented scientific technology with authority and sociopolitical importance (Tabernero 2018). Since early cinema, Kirsten Ostherr (2013) and José van Dijck (2005) argue,

audiovisual media has imagined, conceptualised, and represented medical knowledge to the public in ways that have both informed and entertained the audiences, and promoted and popularised medical technology and expertise. In addition, medical professionals have utilised film technology to document medical procedures to standardise and verify the medical practices (Ostherr 2013, 4–7; van Dijck 2005, 9–14). In other words, cinema and, subsequently, television programming have participated in building up the medical authority in western societies. These representations often promise that medicine and physicians have almost omnipotent powers to cure and save patients (Ostherr 2013, 168–9; Painter, Kubala, and Parsloe 2020, 330–1; van Dijck 2005, 33–4; Henderson 2010, 201–3). Consequently, typical storylines cast death in the problematic role of being a failure in modern society.

Since the late twentieth century, however, audiovisual narratives of the medical field have diversified. Contemporary end-of-life documentaries exemplify the critical voices about the conception of the omnipotence of the medical field. Many end-of-life documentaries align themselves with the death awareness movement's goals to make death visible, approachable and a natural part of life, instead of a sign of failure of care. In this chapter, I analyse medical documentaries that focus on end-of-life care at hospitals, particularly in the intensive care units (ICU), which provide critical care, life support and constant surveillance for patients whose lives are at immediate risk. These films include *Edge of Life* (Theroux 2014a), where British-American documentarist Louis Theroux explores the American way of death at the Cedars-Sinai Medical Center in Los Angeles; *The First Wave* (Heineman 2021), which observes Long Island Jewish Medical Center amid the Covid-19 pandemic in New York City; *Extremis* (Krauss 2016), which was filmed at the intensive care unit at Highland Hospital in Oakland, California; *Facing Death* (Navasky and O'Connor 2010), which investigates end-of-life care at an emergency care unit at the Mount Sinai Hospital in New York City; *Being Mortal* (Jennings 2015), which follows the journey of a surgeon, Dr Atul Gawande from Brigham and Women's Hospital in Boston, Massachusetts; and a short documentary *Dying in Your Mother's Arms* (Beder 2020), which shadows Dr Nadia Tremonti's work at Children's Hospital of Michigan, Detroit. All these documentaries discuss medical, social and emotional aspects of end-of-life care choices, and at the same time rewrite cinematic traditions that celebrate medical technologies.

As public affairs documentaries, these films take an investigative reporting approach to the social issue of end-of-life care in television broadcasting (Aufderheide 2008, 77). Commissioned by the BBC, Theroux's *Edge of Life* is part of the LA Stories documentary series on the underbelly of Los Angeles. *The First Wave*, distributed by National Geographic, an American television network known for its non-fiction programming, won several Emmy awards. *Extremis* is a Netflix-distributed documentary, which earned its director Dan

Krauss, a graduate from Berkeley Graduate School of Journalism, an Academy Award nomination in 2017. *Facing Death* and *Being Mortal* are Frontline documentaries in the American Public Broadcasting Service (PBS) investigative journalism series that explores controversial topics to 'spur change and reform' (GBH 2018). And last, *Dying in Your Mother's Arms* is distributed by the New York Times op-docs series, where filmmakers platform opinionated non-fiction films. These 'investigative' production contexts frame end-of-life care as a controversial topic that needs a public change of attitudes to embrace mortality and accept death.

Public affairs documentaries blur the boundaries between journalism and creative filmmaking. In the early twenty-first century, journalistic values such as neutrality, fairness, balance and a desire to inform and educate the viewer were still at the core of journalistic documentaries (Kemmitt 2007; Nichols 2017, 105–6). By the 2010s, however, television documentaries increasingly became tools for journalists to dive deep into the stories, give voice and faces to those involved, to engage audiences and communities, to advocate arguments and to promote social change (Nash and Corner 2016; Charles 2013, 384–8). Matthew Charles (2013, 384) argues that the change from idealisation of objectivity to telling engaging and persuasive stories also transforms the ethical practices of the public affairs documentaries. Traditionally, the evaluation of documentaries' ethical practices has favoured an assessment of film's rhetorical and discursive practices, or in other words, how credibly and truthfully the social issues are represented for the viewer (Eitzen 2007; Plantinga 2013; Austin 2012; Brylla and Kramer 2018). The increasing use of emotive and engaging storytelling guides the notion from cognitive evaluation towards the affective aspects of arguments (Brylla and Kramer 2018). This brings us back to Charles's argument that contemporary public affairs documentaries want to create social change through attachment, and as such, attachment becomes the documentaries' most important ethical practice (Charles 2013, 384–8). In this chapter, I argue that medical documentaries about end-of-life care combine rhetorical and affective arguments in ways that allow the viewer to cognitively evaluate both sides of medicalisation and demedicalisation arguments. At the same time, these films' affective aspects encourage attachment with the goals of demedicalisation.

Mediated and Cultural Traditions of Medicalisation

In the early days of death education and death awareness movements, one of the most common arguments was that western cultures suffer from a denial of death that leads to alienation and marginalisation of not only death but also of dying individuals (Ariès 1975; Bauman 1992; Elias 2001). Death denial is spurred on by institutionalisation and medicalisation of death, where

professionals, and particularly medical professionals, take care of the dying process, and death takes place in hospitals, nursing homes and hospices (Quinlan 2009). Medicalisation processes place death firmly under medical authority and also transform social, psychological and spiritual aspects of dying to a medical problem that can be managed with medical interventions (Hetzler and Dugdale 2018, 767; Conrad 2007, 4; Sadler et al. 2009). The death movements have rallied against these processes, which they see as inhumane and bureaucratic (Walter 2020, 101–2). The criticism targets 'overmedicalisation', which refers to aggressive medical interventions such as tube-feeding or ventilators to extend life. Overmedicalisation is seen to favour physicians' experience in shaping end-of-life experience, which isolates patients into hospitals where they are treated as medical objects instead of autonomous beings whose social and mental well-being matters (Field 1994; Hetzler and Dugdale 2018; Zimmermann and Rodin 2004; Lofland 1978, 61–72). Thus, overmedicalisation is seen to prevent a 'natural' dying process where death is accepted as a part of life.

Many end-of-life documentaries align themselves with death movements' goals to make death visible and approachable in the public sphere. This premise also drives their critical referencing of medicalisation. At the same time, the documentary films come from a long filmic and televisual tradition of endorsing the medical field's scientific, social and cultural authority. Since the 1950s, the popular medical dramas in western countries have represented devoted and heroic physicians with omnipotent powers and superior medical technology to cure their patients, which has served to normalise the medical gaze and has reassured audiences about functioning medical systems (Ostherr 2013, 168–9; Painter, Kubala, and Parsloe 2020, 330–1; van Dijck 2005, 33–4; Henderson 2010, 201–3). Non-fiction films and programming established medical topics in the 1970s. Early medical documentaries, such as Frederick Wiseman's *Hospital* (1970) and the documentary series *Operation: Lifeline* (NCC, 1978–79) gave viewers behind-the-scenes access to witness how real, and respectable, doctors treated real patients. Investigative journalism shows, such as *60 Minutes* (CBS, 1968–), linked medicine to the idea of progress, and American television introduced television doctors advocating medical education (Ostherr 2013, 171–9). In these early representations, the medical approach could solve whatever problems there were, including the patients' social problems.

Fictional programming, such as the British medical drama *Casualty* (BBC One, 1986–), Australian drama *G.P.* (Australian Broadcasting Corporation, 1989–96), and the American series *ER* (NBC, 1994–2009) started to add social realism and criticism of healthcare systems to medical programming in the late 1980s and early 1990s (Henderson 2010; Lupton 1995), while non-fictional programming began to focus on reality television. This turned the gaze from

doctors and hospital life towards patients, and promoted healthy lifestyles through inspirational, yet moral narratives (Painter, Kubala, and Parsloe 2020, 330–1; Ostherr 2013, 201). In hospital documentaries, such as *Hopkins 24/7* (ABC, 2000) or *Boston Med* (ABC, 2010), the occasional death of a patient provided realism to stories that were more frequently uplifting (Ostherr 2013, 193–200). Representations of the medical field have grown more complex over the years, but the grand narratives where patients can be fixed and discharged thanks to high-tech interventions and the staff's admirable efforts have endured (Hetzler and Dugdale 2018, 767; van Dijck 2005, 26; Ostherr 2013, 201). The mediated images thus continue to support medicalisation, which creates expectations of the omnipotent nature of modern medicine.

End-of-life documentaries, at least partially, challenge this tradition. Theroux's documentary *Edge of Life* (2014a) asks if something has gone wrong with the medical system when enormous amounts of money and resources are spent on aggressive care at the end of life. The filmmaker visits an LA hospital where he follows the stories of three young adults, Donta, Javier and Langston, who all have poor recovery prospects. During the filming, both Donta and Javier die after several cycles of aggressive cancer treatments. In Javier's case, the physician suspects that the treatments may have shortened rather than lengthened his life. The viewer is asked to evaluate whether the aggressive treatments are overmedicalisation and worth the risks.

Medical documentaries and programming have been criticised for promising the viewer that salvation comes in the guise of medical expertise and technologies. When the media focus has been on curing illnesses, saving the patients and framing the end of life as a medical issue, many physicians have claimed that the omnipotent view of medicine has created unreasonable expectations that most patients can be fixed (Hetzler and Dugdale 2018). *Edge of Life* discloses similar concerns among the physicians, who admit to Theroux that their patients do not want to listen and understand when they say that there are no more treatments available. In the case of Donta, a group of doctors enter his room to tell him that there is nothing more to be done and the next step is comfort care. Donta struggles to accept the news, and while he agrees to move back home, he sees this as an avenue to search for alternative treatments. A relative of Donta supports this decision, and when Theroux tries to challenge the need to fight, the relative asks what Donta is supposed to do. 'I mean, just sit there, and just die? I would not do it and I would not encourage him to do it. But to lay there and do nothing, I don't think that is an answer' (Theroux 2014a). The relative continues to believe in the power of medical interventions and reads the doctors' refusal to try anything new as a sign of 'human error'.

In Javier's case, similarly, both the patient and his girlfriend maintain their belief in medical processes until Javier's death. In a discussion by Javier's bedside, Dr Linhares is the bearer of bad news: the cancer treatments, once

again, have failed, and the cancer has strengthened its hold. The physician suggests that it is time to start thinking about a different approach but also lists potential medical options. Javier chooses to try another set of treatments: 'Really, they are offering me nothing or something, so I might just take something.' Theroux interjects by asking what would justify not going through new treatments and allowing Javier to go home, instead of staying at the hospital. The physician admits that there would be benefits to discontinuing treatments, yet Javier is not convinced. To him, discontinued treatments represent a death sentence.

In the same discussion, Javier reveals that he blames himself for letting people down. When Theroux challenges this view, Javier falls back on the metaphor of fighting the cancer and sees himself as a 'garbage outcome of the struggle'. The fighting metaphor is a common way to make sense of illness. The metaphor aligns itself with a medicalised view of seeing death as a failure, but in addition, it internalises a view that one would have agency over illness. This sense of agency, in some cases, can turn to a positive asset that gives a sense of maintaining control in a difficult situation, but in most cases, it engenders negative feelings when patients blame themselves for their 'weakness' in stopping the progression of illness (Semino et al. 2017; Semino, Demjén, and Demmen 2018). In Javier's mind, the fighting metaphor becomes baggage that spurs him to continue treatments despite growing frailty. In the end, he dies only two days after starting the new round of treatments.

Theroux tries to place some responsibility over the situation on the physician. After their discussion by Javier's bedside, Theroux questions Dr Linhares in the corridor. Why did she make Javier's situation appear more optimistic than it was? The physician replies that she does not have the heart to take away Javier's hope. The film's audiences appear stricken by this contradiction as well. In a Q & A event on Theroux's Facebook page, a viewer asks, 'Do you feel that the doctors and nurses weren't being frank enough to the patients about their condition?' Theroux replies:

> I think Dr Jones and Dr Gould (Langston's doctor and Donta's, respectively) were aware of the dangers of soft-soaping the prognosis and so they were a little more blunt in the way they gave the news. Dr Linhares took the opposite approach, trusting Javier to read between the lines. Maybe there's a way of imparting the information in a way that is both clear and also open to the possibility of hope. (Theroux 2014b)

Theroux's answer speaks to the conflicting emotional aspects of the documentary. While the cognitive argument shows that the physicians recognise the challenges related to the medicalisation of terminal illnesses, the film also shows the situations from the perspective of those who are ill. Medicalisation,

for them, is about hope. Donta and Javier do not choose to die a medicalised death, but they keep on hoping, a solution that is emotionally understandable. When Donta begs for any positive news, tears running down his face, the viewer can understand why the doctors might be tempted to try one more treatment.

In *Edge of Life,* Langston's story turns the scales in favour of hope. Langston has a traumatic head injury and the medical professionals predict that he will not wake up from coma. His family is unwilling to give up, arguing time after time that Langston is not a type to give up, that he is a fighter. After thirty-seven days in intensive care, Langston wakes up, and after rehabilitation he returns to his life. The unexpected and sudden turn of events, as Natalie Harrison (2014, 568) writes about the documentary, 'shows both sides to end-of-life care: when the time comes to give up fighting, and also when the fight can turn into a miracle Hollywood ending'. In a way, *Edge of Life* exemplifies the dilemma between hope and the realities of end-of-life care. In this film, it is the patients that keep on hoping and fighting, whereas the doctors maintain a realistic approach to what the medical field can do to prevent – or delay – death and dying.

Edge of Life understands the patients' individual choices, but it questions the sustainability of the medical system to meet these demands. In an interview for the *Daily Mail*, Theroux argues that the optimism of his documentary is linked to the US context and the American way of funding healthcare, where if one has insurance, there is a temptation to try every option available, even if this makes American end-of-life care one of the most expensive amongst western countries (Styles 2014). The article's writer, Ruth Styles (2014), boils the cultural difference down to claiming that in *Edge of Life*, 'doctors, families and patients continue to treat patients long after they would have been dispatched to a hospice in the UK'. All the documentaries in this chapter focus on American end-of-life care, which is not coincidental nor a random choice. While the theme is referenced and discussed in other western documentaries, American medical documentaries give this issue a front-row seat. These documentaries highlight the dilemma of an expensive and potentially overmedicalised healthcare system and the patients' expectations that are fuelled by media representations of medical technology and heroic doctors fighting off death.

In comparison, Matthew Heineman's Covid-19 pandemic film, *The First Wave*, never suggests that acute patients should not be given every option for recovery. Yet, even this documentary comments on the organisation of American healthcare. The high proportion of racial minorities among hospitalised patients connects the pandemic to questions of structural racism in society. In the film, the minority patients struggle for breath simultaneously when the camera visits the streets to film Black Lives Matter protests over

George Floyd's death in police custody. The protest slogan 'I Can't Breathe' becomes symbolic on several levels.

The First Wave focuses on the difficult situation that New York City faced during the spring of 2020, when the city became the hardest-hit region in the country in the early phases of the pandemic. The filmmaker Matthew Heineman, who had previously filmed *Escape Fire: The Fight to Rescue American Healthcare* (Froemke and Heineman 2012), used his contacts to gain access to show what was happening at the hospitals and to put a human face to the pandemic. He started filming in the early stages of the pandemic, and due to having no planning time, the team ended up filming events as they unfolded. The story was edited together later on, including the discussion on structural racism (Luers 2021).

Compared to *Edge of Life* and other films discussed in this chapter, intensive care is portrayed in positive light in *The First Wave*. The patients need critical care for acute conditions instead of chronic diseases. Thus, the film avoids discussions on overmedicalisation or whether these patients should be supported with expensive care. The focus is on healthcare professionals, such as Dr Nathalie Dougé, yet the events evolve around patients, some of whom survive while others die. The threat of death and loss is tangible in many scenes, where a staff member calls family members to inform them that their loved one has died, where staff rush to a patient's side only to return quietly and solemnly, or when resuscitation turns into disbelief and inaction. The medical experts' emotional and embodied reactions become the core of the story, for example, when Dr Dougé breaks down in the corridor and cries over the situation and her patients. These emotional reactions were important to the director, who comments in an interview with *Filmmaker Magazine*:

> There was so much fear and sadness and deeply troubling moments throughout the shoot, but the overall feeling we kept was to appreciate the incredible fortitude and courage and love we witnessed every single day between the staff and the patients we were documenting. That feeling of inspiration pushed us day in and day out. (Luers 2021)

The comment shows how in this film, the medical experts do more than discuss options and provide medical care. In many ways, the medical staff replaces the role that the family members play in medical documentaries. They connect with their patients and care for them, turning the medicalised environment into humane space. In comparison, family members depend on remote connections and video calls.

While *The First Wave* acknowledges the physical and affective care by the medical staff, it does not paint a rosy image of the deaths in the medicalised environment. On one occasion, Dr Dougé complains about how she hates the

isolation the patients are forced into. The ability to communicate, say goodbyes, and be accompanied by loved ones would be the preferred way to die, but in the face of a pandemic all care options are explored (most often this requires sedation of the patient) just in case one of them would work. Pandemic deaths are pictured as lonely, isolated and medicalised. While they are not pictured as good deaths, the blame is directed towards the novel virus instead of overmedicalisation. This becomes clear in a few cases where the patients survive. From the beginning of the documentary, the filmmakers follow the stories of Ahmed, a NYPD school safety officer, and Brussels, a nurse who contracted the virus. They both are hospitalised for a long time, and at times, their recoveries seem unlikely. When both finally pull through and can return home to their rejoicing families, the documentary ends with a sense of hope and appreciation of what good the medicalisation can do when it is properly deployed in acute situations to prevent premature death, as opposed to being used as an alternative to end-of-life care.

Desire for Death Acceptance

Extremis (Krauss 2016) debates medical, emotional, social and moral difficulties related to end-of-life care choices. The film foregrounds physicians, Dr Jessica Zitter and Dr Monica Bhargava, who care for their patients at a hectic intensive care unit. In an interview for *The Moveable Fest*, director Dan Krauss explains:

> What really fascinated me is that, as an ICU physician, she [Dr Zitter] is, on a daily basis, confronted with questions that really transcend medicine and science. I hadn't thought about doctors having to take on the role of a counselor that has to help shepherd families and patients through the most fundamental questions of their core humanity. (Saito 2017)

In the documentary, the two physicians represent different sides of the medicalisation argument. Dr Zitter speaks against overmedicalisation. Halfway through the documentary, she recalls a time they tried every trick to save a patient before a nurse accused them of torturing the patient. This made the physician realise the limitations of the life-saving mode. The critical view on medicalisation is contrasted by Dr Bhargava, who argues that specialists and further treatment options bring hope for the families. This conflict – whether to maintain hope or letting an individual die 'naturally' – creates the core of this documentary as well. The conflict is played out in the trajectories of two patients, Donna and Selena, whose families make opposite choices. Donna's family decides to remove the ventilator and say their goodbyes before Donna passes away a day later. Selena's family decides to continue life-sustaining

treatment where Selena is surgically attached to the ventilator before dying about six months later. While the documentary appears to represent fair and balanced arguments for both sides, affective images and attachment with the dying patients align the viewer with the narratives of demedicalisation and acceptance of death.

The documentary introduces Donna strapped to a hospital bed, with a ventilator helping her breathe. The scene starts with the peeping sound of the ECG machine and the whooshing of the ventilator, which guide the viewer to pay attention to the presence of medical technology. The sounds diminish when Donna's husband starts talking to her in a soothing way. The husband is worried that the only functioning thing is the ventilator, and he admits to the doctors that he had promised Donna he would do everything he could, but that reality is here now. When Donna is able to signal that she wants the breathing tube removed instead of being connected to the machines, the husband tearfully whispers, 'You did the right thing.' Donna's part of the film finishes with her smiling after the removal of the tube and telling everybody to calm down. Both Donna and the family appear to accept the approaching death, even when they are saddened by the loss. Also, Donna has autonomy to decide on her treatment, which allows everybody to say their goodbyes without intervening medical technology. Donna's demedicalised death is pictured as comforting for everybody involved.

Selena's case contrasts the death acceptance narrative. Her response to any stimulus is very limited, which means that all care decisions are made by surrogate caregivers, mainly her daughter and brothers. To highlight the patient's lack of autonomy, the camera rarely visits her bedside. Consequently, Selena becomes part of the film's background. The visual and narrative focus is on the family members who struggle to accept the physicians' estimation that Selena will not wake up. The family is against stopping the treatments because of their spiritual views and trust in the medical profession. While Dr Zitter admits that seeing such critical situations daily has dwindled her optimism, Selena's daughter continues to look for a miracle. For her, Selena's survival of CPR (cardiopulmonary resuscitation) is a sign that her mother has chosen to stay. Selena's family equals medical technology with life, and due to their religious beliefs, with God's will. One of the brothers argues that living is a sign of God's powers, and if it were God's will, Selena would die regardless of medical interventions. The family likens the removal of medical technology to committing a murder. In Selena's story, technological optimism and religious beliefs lead to a medicalised death.

Rhetorical, narrative and aesthetic choices create judgements of these two choices. Rhetorically, Dr Zitter, who is frustrated by medicalised deaths and whose voice and experiences are given most time and space in the narration, becomes the primary representative of the ICU. Narratively, the endings where

Donna's family is rewarded with reassuring goodbyes and Selena dies being hooked to a machine without any agency, add emotional argumentation for the undesirability of medicalised death. Donna's case speaks for quality of life and agency of the patient, while Selena represents quantity of life and lack of agency. And aesthetically, Dan Krauss, the director of the film, draws from *cinéma vérité* and observational traditions to build authenticity that supports the trustworthiness of the demedicalisation argument.

In another media interview, Krauss idolises observational modes of filmmaking and argues that in *Extremis* he wanted to 'do something that was pure' (White 2017). 'Pure' connects to the *cinéma vérité* tradition, where filmmakers understand observational modes as representing honesty and authenticity in ways that could provide a 'pure', or an objective, view of the documentary's subject (Hall 1991). *Cinéma vérité*, which emerged in Europe and North America in the 1960s has highly influenced the making of social issue documentaries (Borum Chattoo 2020, 29), including the style of early medical documentaries, such as Frederick Wiseman's *Hospital* (1970). Here, the ambient sound as well as the images of medical technologies give an impression of unmediated reality, while institutional scenes of rushing doctors convey a sense of authenticity (Ostherr 2013, 154–9). The arrival of lighter, portable cameras and sound equipment allowed filmmakers to access lived experience easily, which led them to favour a 'fly on the wall' approach. They recorded and observed, typically with a hand-held camera, and brought these moments to the viewers without voiceover commentary, added music or sound effects, as if to emphasise the 'real' feeling of the films (MacDougall 2018, 1–2; Hall 1991). Despite the values of 'pureness', 'authenticity' and 'real', all documentaries are recorded from a perspective. As David MacDougall (2018, 5–6) argues, documentary filmmaking is never neutral observation, but participant observation. In this case, observational aesthetics add a feeling of trustworthiness and verifiability of the arguments.

Extremis uses observational techniques to continue the tradition of authenticated medical life of hospitals. The hand-held camera creates an awareness of 'being there'. And while the opening titles, closing titles and the two montage sections of daily lives at the ICU have added non-diegetic sounds, the sections that focus on Selena's and Donna's stories create a soundscape of recorded dialogues, medical equipment noise and the background buzz of a busy ICU ward. The unfiltered sounds of medical technology emphasise the authentic mediation of hospital space, but they also guide the viewer to pay attention to the medical technology to which the patients are attached and whereby their lives are artificially prolonged. The sounds and images of the medical devices suggest artificiality of life-continuing treatments, illustrating the criticism in Dr Zitter's reflection of the medical profession's problematic relationship with death and dying.

Together, the rhetorical, narrative and aesthetic solutions challenge the authoritative role of medicalisation. In addition, comparison of Donna's and Selena's stories actualises questions of the benefits of death acceptance and the negative consequences of death denial. The comparison is familiar from (fictional) medical programming. Based on American, Australian and British medical dramas, Jennifer Freytag and Srividya Ramasubramanian recognise 'bad' and 'good' deaths. Bad deaths are those where the patient (or their caregiver) refuses treatment and takes the blame for death, or where medical professionals make a mistake, which becomes a teaching opportunity for the professionals while ignoring the patient's perspective. Good deaths are heroic narratives of sacrifice (organ donations) or end-of-life moments where the dying person accepts their death and offers wisdom and advice for the living. Thus, if a patient must die in a medical drama, death acceptance is a dignified and comforting choice that makes death meaningful (Freytag and Ramasubramanian 2019).

In *Extremis*, Donna and the family embrace demedicalised death. Their moment of goodbyes is meaningful and dignified, and a sign of 'good death'. In contrast, in Selena's case, the family opposes the medical professionals' evaluation of the situation. As such, the family also 'takes the blame' over the medicalised death that Selena goes through in the following six months. However, as Freytag and Ramasubramanian (2019) argue, the grand narratives of medical programming favour the existence of institutionalised medical systems, which marginalise the social, cultural and spiritual aspects of dying. Selena's family's religious beliefs are contrasted with the medical knowledge and authority in ways that encourage the viewer to question their choices. Thus, in challenging the practices of medicalised death, the documentary frames medicalisation as arising from the patients' and families' unrealistic expectations, whereas the medical professionals appear as responsible and humane users of medical knowledge and technology. The documentary thus continues to maintain the medical field's authority to evaluate the best possible dying process for the patients.

Questions of Agency

In ICU care, where hard decisions are an integral part of the work, *Extremis* is not the only film that stands for the death acceptance storyline and shows consequences of death denial in a critical light. *Facing Death* (Navasky and O'Connor 2010), an hour-long television documentary, also focuses on end-of-life care choices when patients and their families have to choose when to stop or continue aggressive medical procedures. Compared to the observatory mode of *Extremis*, *Facing Death* takes an expository approach, where a voiceover narrator frames the debates on ethical and moral issues of end-of-life

care (Nichols 2017, 107–8). At the beginning of the film, the narrator states that many Americans die in hospital after prolonged illnesses, which, due to medical advances, are treated with expensive and aggressive interventions. From this starting point, various medical professionals voice their views, and once again, the documentary seemingly represents a balanced view on the topic.

The views that support medicalisation explain treatments as the right of an individual and as a medical institution's responsibility to sustain life. A professor at Harvard University, Dr Groopman, favours modern medical science and says that treatment should never be reduced to expenses or statistical probabilities, because if there is a chance to defy expectations, an individual's life is worthy of a potential medical failure. Physicians working with bone marrow transplants express slightly more hesitant views but they understand the patients' hope for treatment. They follow the patients' wishes to try out further treatment options even when they recognise potential suffering from treatments which have low odds of working. Dr Keren, for example, confesses that after the death of a patient, the physician questioned whether they had provided any quality of life. Perhaps accepting the situation would have given some comfort, if not for the patient then for those around them. These voices represent the high-tech medical options that, despite their risks, can turn to success stories, which encourages the physicians to support patients' hopes for cure.

The ICU doctors of *Facing Death* express the most critical views on medicalised death. Many of them feel that intensive care is misused; their efforts postpone impending death in cases where underlying diseases cannot be removed or fixed. For example, Dr Muller argues that medical technology has complicated end-of-life decisions with the question of 'what if'. This uncertainty has led patients and their families to expect technology to save lives, even when the trade-off can be devastating, and patients might not have the lives they want after invasive and aggressive treatments. Dr Nelson calls these patients 'broken survivors of intensive care', who suffer when families must choose between allowing and not allowing life through technology. Decision-making is often especially difficult at the ICU, where most patients are sedated and unable to express their views. Dr Nelson, for example, sees the patients as 'vulnerable' and 'voiceless', dependent on their families who are struggling to let go. Thus, while the potential of technology plays a key role in these argumentations, the documentary also highlights the question of patients' agency, which offers affective arguments to accompany the rational arguments of the medical staff.

Agency can be defined as an individual's ability to act freely, to make choices and impact the world around them (Giddens and Sutton 2017, 23), and is often connected to such terms as self-determination, autonomy and empowerment. *Facing Death* introduces seven patients: Albert, John, Norman, Condolena,

Robert, Diane and Martha. The patients stand as illustrative examples to the argumentations of the physicians, and their main function is to give depth to the debates over potentials and limitations of medicalised death. This also shows in the on-screen time allocated to the patients, who appear on-screen for 12:31 minutes out of the total length of 53:40 minutes. Divided between the seven patients, this gives most of them less than two minutes of on-screen visibility. Consequently, the viewer does not learn their personal stories beyond medical questions.

Most on-screen time is dedicated to transplant patients who can express their agency. Albert is having complications from transplants, but he is unable to accept that he cannot be treated, and at the end, interventions cause him to have a seizure, and he dies a week later without being able to communicate with his wife. Here, the inability to accept death becomes unwanted, or even 'bad' death. Similarly, Norman is afraid of dying, but he is growing tired with the treatments and hospitalisation. After struggling to decide, the family chooses comfort care, and Norman dies from complications two days later. The physician evaluates that the treatments did not prolong his life, but did make his death more difficult. In comparison, John, who is in a rather similar situation, represents the potential of a good death. John is undergoing further aggressive cancer treatments, but his wife is tormented by the negative consequences of treatments. When John's condition deteriorates, a doctor asks them to consider the quality of life. After an emotional struggle John accepts hospice care (or, in other words, accepts his impending death), and he dies a day later.

The filmed ICU patients have limited agency in the documentary. Unreactive Robert shows what heavy sedation does to a person when the treatment prolongs life but is painful. Condolena, Diane and Martha become examples of what it means to be mostly sedated and attached to a ventilator. There is very little room for patients' agency, which has been discussed in the ICU context in general (Laerkner et al. 2017). In all these cases, aggressive treatments and medical interventions have unwanted consequences, even if they comply with the requests of the patients or their families.

The aesthetic choices in the filming and editing of *Facing Death* highlight questions of agency. In several shots, Condolena, Robert, Diane and Martha are in the background, almost unrecognisable beneath tubes attached to medical devices. The physicians and family members are at the front as active participants debating and making decisions on behalf of the patient. The spatial use of imagery strips the patient of agency and gives it to others, people and machines. When mechanical ventilation assists or replaces the breathing of the patients, the respiratory machines are made the main visual elements of the documentary; images focus on medical technology instead of the patients (see also Hakola 2022). As such, *Facing Death* represents, and gives voice to, medical technology. It takes space on-screen, its mechanical sounds can be

heard, and it receives agency in the scenes with unresponsive ICU patients. Medical technology becomes an active agent in the narrative.

Objects can, in fact, have agency as they carry meanings, originate action, shape various practices and participate in constructing the social world (Latour 1996; Cooren 2010). In an ethnographic ICU study, Letizia Caronia and Luigina Mortari (2015) found that everyday objects, structures of space and medical technology had a more important role than merely providing a background for medical care. For example, when entering the patient's space, members of medical staff did not look at the patient first, but at the monitor which gave 'a specific representation of the patient's body, its boundaries and meaningful clues' (Caronia and Mortari 2015, 403). Both the diagnosis and the caregiving were shaped by technology. The ways in which monitors and other medical technology communicated messages to the caregivers could be seen as speech acts, declare Caronia and Mortari (2015). In other words, the medical technology has a voice which impacts the treatment of the patient.

In one of the scenes of *Facing Death*, the camera focuses on a close-up of the illuminated monitor of the medical device that measures oxygen levels and the breathing rhythm. Slowly, the camera pans to the breathing tube and follows its regulated movements. The impact is almost hypnotic. Then, the image slightly refocuses, giving a glimpse of the patient at the end of the tube (Figure 2.1). Even here, the face remains out of focus, unrecognisable. This image contrasts the blurred image of the person with medical technology, the breathing mask and its timely movements, which are in focus. This moment

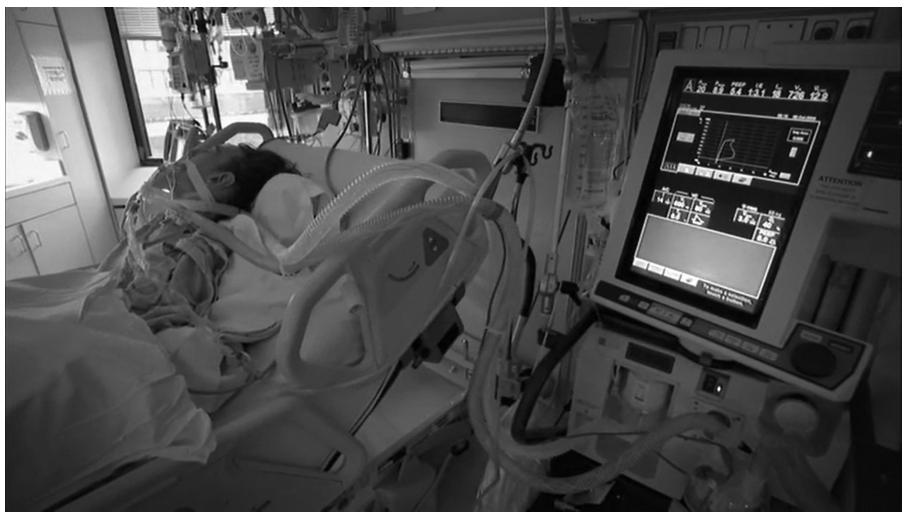

Figure 2.1 The shot focuses on the breathing machine in the documentary *Facing Death* (Navasky and O'Connor 2010).

frames medical technology as overtaking the subjectivity or agency of the patient: instead of an individual, one is dealing with a machine. This visual allegory prompts the question as to whether the medical options provide meaningful life and whether the families should let go and deal with the loss instead of seeing death as a (medical) failure.

In most cases, breathing tubes are eventually removed and the ICU patients die soon after. Only Martha is successfully taken off the ventilator, which encourages the family to continue treatments. However, a day later, Martha is back on the ventilator, where she remains a year later, unable to speak. The question whether the patients can breathe on their own builds narrative tension to the film, and the removal of breathing technology closes each of these stories (Hakola 2022). The visual emphasis of medical technology could support the medicalisation view, its ability to keep a person alive, yet in this documentary, technology connects to overmedicalisation that takes over the agency of the person. This aesthetic and affective choice supports a critical view on medicalisation of death, even when the interviewed physicians represent both sides of the debate.

Towards Demedicalised Death

Edge of Life, *Extremis* and *Facing Death* explain overmedicalisation with the availability and overuse of medical technology, but also with cultural expectations of what are regarded as omnipotent medical interventions. And while these documentaries are critical of medicalised death, they follow in the footsteps of medical programming where life-threatening illnesses are discussed in relation to treatment options, life-sustaining interventions and the possibility of dying. In such programming, discussions on hospice and palliative care are rarely or only briefly mentioned (Houben et al. 2016; Drukarczyk et al. 2014). *Being Mortal* (Jennings 2015), which is based on Dr Atul Gawande's eponymous book, shifts the discussion on overmedicalisation beyond the context of hospitalisation. The documentary describes his journey of learning to deal with dying patients, and as part of his learning process he talks to different doctors working with palliative care. These discussions, he hopes, will open himself, and through his example, others, to have discussions about death, dying and palliative care.

At the beginning of the film, Gawande reunites with the husband of his late patient. Together, they reflect on the desperate search for the cure and how, after the death of the wife, both regretted some actions and experimental therapies that took away precious time that could have been spent together with the family. Gawande was aware of the dire situation and admits that he avoided talking about death because in his understanding, medical competence equalled the capability to fix problems, but also because he sought to avoid

emotional discussions on death that, by design, uncomfortably move beyond scientific rationality. It seemed easier to continue treatments, even though they shortened, and decreased, the quality of the patient's life. This case inspired Gawande to learn how to speak about the end of life with patients (Frontline, PBS, 2015; Jennings 2015). Reflective meetings of this kind are rare in medical programming, where the stories rather stress the time of hospitalisation. The importance of preventive measures, care of chronic conditions, follow-up on long-term impacts of aggressive interventions and the need for palliative care are commonly excluded (Hetzler and Dugdale 2018, 767; van Dijck 2005, 14; Ostherr 2013, 201–2; Houben et al. 2016).

During the film, Gawande meets with Doctor Lakshmi Nayak and her patient Bill who is not ready to give up hope. While respecting Bill's stance, Nayak prepares him and his wife for the worst-case scenario. On-screen, the learning experience is visually emphasised: in the office, Gawande and Nayak are watching recorded material from a patient meeting. While the scenes are rolling, Nayak explains her course of actions by wanting to maintain some options for the scared family. When Bill's condition deteriorates, doctors convince him to consider hospice, which is a difficult topic for him and his wife to discuss. From these scenes, Gawande learns about a tactful approach to bringing the subject of death into the discussion.

With another doctor, Kathy Selvaggi, Gawande learns that meeting with patients is about listening. He learns to ask how the patients understand their situation and what their priorities are. Gawande follows Selvaggi's meeting with Norma, whose cancer treatment is not working. Selvaggi tells Norma that now is the time for hard questions, and for making the best out of the time that is left. The patient hopes for a miracle all the same. Selvaggi confides in Gawande that medicine is the easy part of the equation. It is the discussions on hospice care that are harder. In Norma's case, the doctor slowly adds hospice care to the discussions and asks how Norma feels about her situation. 'I think we are coming close,' she says, to which the doctor replies: 'I worry about the same thing. We take care of you here.' Gawande learns from this that there are no natural moments for difficult conversations, but it is crucial to have them. If one waits until there is a crisis, it is too late, and the patient might end up in similar situations as in ICU documentaries where their own agency in decision-making is bypassed.

While both Norma and Bill struggle to accept they are dying, their final choices to accept comfort care is celebrated as person-oriented care, where the focus is on the person, not on the illness. This compares to Shlomith Rimmon-Kenan's discussion on illness narratives, where the medicalised approach turns the focus on 'case reports', where illness rather than the patient is assigned the role of the protagonist and where the story of illness is told through 'the voice of medicine' (Rimmon-Kenan 2002, 11). In other words, the decision to

demedicalise death turns the focus back onto the person and to their voice and experience.

This point is stressed in Gawande's last meeting with Doctor Robert Soiffer, who has a more traditional, treatment-oriented approach. However, one of his patients, Jeff, is clear about his priorities: after three years of treatments, he wants to die at his farm, surrounded by family and friends. On his deathbed, he tells the filmmaker that his final days have been 'some of the best days of my life'; even while his mind and body have rapidly declined, 'I'm still a happy guy' (Jennings 2015). Similarly, his wife witnesses that while Jeff's world is reduced to a bed by a window, his relationships grow deeper towards the end. With Jeff, the camera moves out of the hospital environment. The visual contrast is significant. Instead of reclining under harsh fluorescent lamps in an impersonal hospital room, Jeff watches his yard and natural light through the window. His death is framed by the cosy and comforting space and atmosphere. To Gawande, Jeff's case is a testimonial of the benefits of stopping medical interventions in time. Death acceptance and demedicalisation of death enable Jeff's agency, give him time with family and friends, and increase the quality of the end of life.

The documentary's narrative viewpoint remains institutional; it is about a doctor learning about end of life through (medical) case studies. In a podcast on the documentary, Gawande sees that his exploration changed him and made him a better physician. He learned to consider not only the benefits and risks of the medical treatments, but to discuss the patients' goals and values, and how these could be taken into consideration when treating terminal illnesses (Frontline, PBS, 2015). However, these experiences are intended to be more than a personal transformation story. The viewer is invited to change together with the physician, who admits that the medicalised vision obstructs accepting death as a part of life. The film invites the viewer to share the responsibility; the medicalised hopes and expectations are part of western culture, and the change of attitudes should not be limited to medical professionals. It should include everyone. If the demedicalisation narrative replaced medicalised practices, end-of-life experiences could improve both for the dying and their families.

The educational aspect is also noticeable in a short documentary *Dying in Your Mother's Arms*, which follows the work of children's palliative care doctor Nadia Tremonti. The film begins with an interview, Tremonti facing the camera. She had consulted her colleagues about a case where the family struggled to understand the situation of their child. Tremonti recalls asking the physicians who refused to use the word death: 'Do you think the reason the family is confused about how serious this is because you can't even say it?' (Beder 2020) The documentary places Dr Tremonti into a teacher's position. She is filmed giving lectures to other professionals, while in voiceover she explains the benefits of palliative practices. In addition, her compassionate

and open discussions with the mother of a dying baby provide an example of how to deal with difficult encounters and discussions. The structure of the film, similarly to *Being Mortal*, emphasises that other medical professionals, as well as the viewers, can and should learn from her expertise to understand the benefits of demedicalised death. Tremonti's work with the mother and her baby emotionally and affectively proves how focusing on loving touches and the intimacy of the last moments create a 'good death' in comparison to technological interventions.

Conclusion

Medical documentaries on the end of life reveal how all parties involved, the physicians, the patients and their families struggle with end-of-life care decisions. These struggles are traced back to medicalisation practices, where medical professionalism and technology, and their mediated representations, have created expectations that life-threatening and terminal illnesses can be cured. In their criticism of the omnipotence of the medical field, end-of-life documentaries appear to turn around the cinema's appreciative solidarity with modern medicine. Yet, it is not the patients but rather the physicians who recognise the disadvantages of overmedicalisation and call for a change of attitudes. Thus, these documentaries' institutionalised perspectives both renew and uphold the practices of medical documentaries and programming. They question the overtly technological aspects of end-of-life care (instead of acute care) but idealise the authority of medical professionals.

To refine their arguments in favour of a change in sociocultural attitudes and medical practices, these documentaries represent physicians' arguments for and against medicalisation. Despite the apparent balance of rhetorical and verbal arguments, the films' ethical claim is created on the affective and (audio) visual level of the narration. The viewers are scared by the affective visuals of medicalised images, where a person's autonomy is assumed by impersonal machines. The occasional positive image emphasises the benefits of demedicalisation, Jeff on his deathbed in the comfort of his home or the ability of the mother to hold a dying baby in her arms. These images build visual and affective comparisons between death acceptance or 'good death', and death denial or 'bad death'. Consequently, the documentaries suggest that death denial and medicalisation strengthen death anxiety, which decreases the potential for well-being.

The purposeful use of affective visuals also makes clear what Lisa Downing and Libby Saxton (2010) mean by visualised ethics. They argue that in a contemporary society saturated with images, ethics also functions more on the visual than the verbal level. For them, the question is not what ethics is, but what 'ethics does', which encourages us to study how films as visual

objects participate in making ethical statements. They also suggest that ethics is created in an encounter between the viewer and the film; the film can encourage the viewer to challenge the existing practices and norms when confronted with ethical questions (Downing and Saxton 2010, 1–3).

Medical end-of-life documentaries represent medicalised death as the main ethical question of which the viewer is expected to create an opinion. The most interesting ethical debate takes place on the visual level illustrating cautionary tales of medicalisation. These images urge the viewer to re-evaluate the benefits and limitations of medicalisation of death. As such, the visual ethics of these documentaries confront the viewer with 'behind the scenes' access to medical care, on which, as investigative approaches suggest, our values and attitudes need readjusting. Thus, the ethics of documentaries go beyond questions of objectivity or balance of spoken arguments, reaching out to engage the viewer towards attachment with represented images. Documentaries that advocate change show that ethics is only partially about whether filmmaker's creative processes create a reliable representation of the chosen topic. It also includes the viewer's responsibility to feel, think, evaluate and to be open to change.

References

Ariès, Philippe. 1975. *Western Attitudes toward Death: From the Middle Ages to the Present*. Translated by Patricia M. Ranum. First published 1974. Baltimore, MD: Johns Hopkins University Press.

Aufderheide, Patricia. 2008. *Documentary Film: A Very Short Introduction*. Oxford: Oxford University Press.

Austin, Thomas. 2012. *Watching the World: Screen Documentary and Audiences*. Manchester: Manchester University Press.

Bauman, Zygmunt. 1992. *Mortality, Immortality and Other Life Strategies*. Stanford, CA: Stanford University Press.

Beder, John. 2020. *Dying in Your Mother's Arms*. Documentary, Short. The New York Times.

Borum Chattoo, Caty. 2020. *Story Movements: How Documentaries Empower People and Inspire Social Change*. New York: Oxford University Press. https://doi.org/10.1093/oso/9780190943417.001.0001.

Brylla, Catalin, and Mette Kramer. 2018. 'A Pragmatic Framework for the Cognitive Study of Documentary'. *Projections* 12 (2): 159–80. https://doi.org/10.3167/proj.2018.120216.

Caronia, Letizia, and Luigina Mortari. 2015. 'The Agency of Things: How Spaces and Artefacts Organize the Moral Order of an Intensive Care Unit'. *Social Semiotics* 25 (4): 401–22. https://doi.org/10.1080/10350330.2015.1059576.

Charles, Mathew. 2013. 'News, Documentary and Advocacy Journalism'. In *Journalism: New Challenges*, edited by Karen Fowler-Watt and Stuart Allan, 384–92. Poole: CJCR: Centre for Journalism and Communication Research, Bournemouth University.

Conrad, Peter. 2007. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore, MD: Johns Hopkins University Press.

Cooren, François. 2010. *Action and Agency in Dialogue: Passion, Incarnation and Ventriloquism*. Amsterdam; Philadelphia: John Benjamins Publishing Company.
Dijck, José van. 2005. *The Transparent Body: A Cultural Analysis of Medical Imaging*. Seattle; London: University of Washington Press.
Downing, Lisa, and Libby Saxton. 2010. *Film and Ethics: Foreclosed Encounters*. London; New York: Routledge.
Drukarczyk, Laura, Carsten Klein, Christoph Ostgathe, and Stephanie Stiel. 2014. 'Life Threatening Illness in Popular Movies-a First Descriptive Analysis'. *SpringerPlus* 3 (1): 411. https://doi.org/10.1186/2193-1801-3-411.
Eitzen, Dick. 2007. 'Documentary's Peculiar Appeals'. In *Moving Image Theory: Ecological Considerations*, edited by Barbara Fisher Anderson and Joseph Anderson, 183–99. Carbondale: Southern Illinois University Press.
Elias, Norbert. 2001. *The Loneliness of the Dying*. First published 1985. New York: Continuum.
Field, David. 1994. 'Palliative Medicine and the Medicalization of Death'. *European Journal of Cancer Care* 3 (2): 58–62. https://doi.org/10.1111/j.1365-2354.1994.tb00014.x.
Freytag, Jennifer, and Srividya Ramasubramanian. 2019. 'Are Television Deaths Good Deaths? A Narrative Analysis of Hospital Death and Dying in Popular Medical Dramas'. *Health Communication* 34 (7): 747–54. https://doi.org/10.1080/10410236.2018.1434735.
Froemke, Susan, and Matthew Heineman. 2012. *Escape Fire: The Fight to Rescue American Healthcare*. Documentary. Aisle C Productions, Our Time Projects.
Frontline, PBS. n.d. 'Inside "Being Mortal" with Atul Gawande and Tom Jennings'. Frontline. Film Audio Track. https://soundcloud.com/frontlinepbs/inside-being-mortal?utm_source=www.pbs.org&utm_campaign=wtshare&utm_medium=widget&utm_content=https%253A%252F%252Fsoundcloud.com%252Ffrontlinepbs%252Finside-being-mortal. Last accessed 7 November 2022.
GBH. 2018. 'FRONTLINE Journalism Fund'. WGBH Educational Foundation. 13 April 2018. https://www.wgbh.org/support/directed-giving/frontline-journalism-fund. Last accessed 20 May 2022.
Giddens, Anthony, and Philip W. Sutton. 2017. *Essential Concepts in Sociology*. Second edition. Malden, MA: Polity.
Hakola, Outi. 2022. 'Breathing in Mortality: Demedicalization of Death in Documentary Films'. *Journal of Somaesthetics* 8 (1): 30–44.
Hall, Jeanne. 1991. 'Realism as a Style in Cinema Verite: A Critical Analysis of "Primary"'. *Cinema Journal* 30 (4): 24. https://doi.org/10.2307/1224885.
Harrison, Natalie. 2014. 'Life and Death in Hollywood'. *The Lancet Oncology* 15 (6): 568. https://doi.org/10.1016/S1470-2045(14)70210-4.
Heineman, Matthew. 2021. *The First Wave*. Documentary. National Geographic Documentary Films, Participant, Our Time Projects.
Henderson, Lesley. 2010. 'Medical TV Dramas: Health Care as Soap Opera'. *Socialist Register* 46: 198–215.
Hetzler, Peter T., and Lydia S. Dugdale. 2018. 'How Do Medicalization and Rescue Fantasy Prevent Healthy Dying?' *AMA Journal of Ethics* 20 (8): E766-773. https://doi.org/10.1001/amajethics.2018.766.
Houben, Carmen H. M., Martijn A. Spruit, Emiel F. M. Wouters, and Daisy J. A. Janssen. 2016. '"Am I Dying Doctor?": How End-Of-Life Care Is Portrayed in Television Medical Dramas'. *Journal of Palliative Care & Medicine* 6 (1). https://doi.org/10.4172/2165-7386.1000247.
Jennings, Thomas. 2015. *Being Mortal*. Documentary. Frontline, PBS.

Kemmitt, Alicia. 2007. 'Documentary Stories for Change: Viewing and Producing Immigrant Narratives as Social Documents'. *The Velvet Light Trap* 60 (1): 25–36. https://doi.org/10.1353/vlt.2007.0018.

Krauss, Dan. 2016. *Extremis*. Documentary. Netflix.

Laerkner, Eva, Ingrid Egerod, Finn Olesen, and Helle Ploug Hansen. 2017. 'A Sense of Agency: An Ethnographic Exploration of Being Awake during Mechanical Ventilation in the Intensive Care Unit'. *International Journal of Nursing Studies* 75 (October): 1–9. https://doi.org/10.1016/j.ijnurstu.2017.06.016.

Latour, Bruno. 1996. 'On Interobjectivity'. *Mind, Culture, and Activity* 3 (4): 228–45. https://doi.org/10.1207/s15327884mca0304_2.

Lofland, Lyn H. 1978. *The Craft of Dying: The Modern Face of Death*. Beverly Hills, CA: SAGE Publications.

Luers, Erik. 2021. '"Burnout and Fatigue and a Loss of Sanity": Matthew Heineman on Making COVID-19 Documentary "The First Wave"'. *Filmmaker Magazine* (blog). 13 December 2021. https://filmmakermagazine.com/112666-matthew-heineman-covid-19-documentary-first-wave/. Last accessed 28 June 2023.

Lupton, Deborah. 1995. '*G.P.*: A Postmodern Medical Drama?' *Australian Journal of Communication* 22 (2): 108–20. https://www.researchgate.net/publication/28634 6215_GP_A_Postmodern_Medical_Drama. Last accessed 31 August 2023.

MacDougall, David. 2018. 'Observational Cinema'. In *The International Encyclopedia of Anthropology*, edited by Hilary Callan, 1–10. Oxford: John Wiley & Sons, Ltd. https://doi.org/10.1002/9781118924396.wbiea1535.

Nash, Kate, and John Corner. 2016. 'Strategic Impact Documentary: Contexts of Production and Social Intervention'. *European Journal of Communication* 31 (3): 227–42. https://doi.org/10.1177/0267323116635831.

Navasky, Miri, and Karen O'Connor. 2010. *Facing Death*. Documentary Frontline, PBS.

Nichols, Bill. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.

Ostherr, Kirsten. 2013. *Medical Visions: Producing the Patient Through Film, Television, and Imaging Technologies*. Oxford; New York: Oxford University Press.

Painter, David Lynn, Alison Kubala, and Sarah Parsloe. 2020. 'Playing Doctor on TV: Physician Portrayals and Interactions on Medical Drama, Comedy, and Reality Shows'. *Atlantic Journal of Communication* 28 (5): 322–36. https://doi.org/10.1080/ 15456870.2020.1691002.

Plantinga, Carl. 2013. '"I'll Believe It When I Trust the Source": Documentary Images and Visual Evidence'. In *The Documentary Film Book*, edited by Brian Winston, 40–7. London: British Film Institute.

Quinlan, Christina. 2009. 'Media Discourses on Autonomy in Dying and Death'. *Irish Communication Review* 11 (1). https://doi.org/10.21427/D7XM8T.

Rimmon-Kenan, Shlomith. 2002. 'The Story of "I": Illness and Narrative Identity'. *Narrative* 10 (1): 9–27.

Sadler, John Z., Fabrice Jotterand, Simon Craddock Lee, and Stephen Inrig. 2009. 'Can Medicalization Be Good? Situating Medicalization within Bioethics'. *Theoretical Medicine and Bioethics* 30 (6): 411–25. https://doi.org/10.1007/s11017-009-9122-4.

Saito, Stephen. 2017. 'Interview: Director Dan Krauss on the Difficult Decisions Behind "Extremis"'. The Moveable Fest. 4 January 2017. https://moveablefest.com/dan-krauss-extremis/. Last accessed 19 May 2022.

Semino, Elena, Zsófia Demjén, and Jane Demmen. 2018. 'An Integrated Approach to Metaphor and Framing in Cognition, Discourse, and Practice, with an Application to Metaphors for Cancer'. *Applied Linguistics* 39 (5): 625–45. https://doi.org/10.1093/ applin/amw028.

Semino, Elena, Zsófia Demjén, Jane Demmen, Veronika Koller, Sheila Payne, Andrew Hardie, and Paul Rayson. 2017. 'The Online Use of Violence and Journey Metaphors by Patients with Cancer, as Compared with Health Professionals: A Mixed Methods Study'. *BMJ Supportive & Palliative Care* 7 (1): 60–6. https://doi.org/10.1136/bmjspcare-2014-000785.

Styles, Ruth. 2014. '22-Year-Old Man Who Overcame Traumatic Brain Damage'. *Daily Mail*, 28 March 2014, sec. Femail. https://www.dailymail.co.uk/femail/article-2591559/Incredible-story-22-year-old-man-odds-MILLION-one-revealed-heart-warming-Louis-Theroux-film.html. Last accessed 3 November 2022.

Tabernero, Carlos. 2018. 'The Changing Nature of Modernization Discourses in Documentary Films'. *Science in Context* 31 (1): 61–83. https://doi.org/10.1017/S0269889718000066.

Theroux, Louis. 2014a. *Edge of Life*. Documentary. BBC.

———. 2014b. 'Q&A with Louis Theroux on "Edge of Life"'. Facebook Event. https://m.facebook.com/LouisTheroux/photos/qa-with-louis-theroux-on-edge-of-life1-edge-of-life-is-a-very-emotive-film-why-d/530128420438345/. Last accessed 4 November 2022.

Walter, Tony. 2020. *Death in the Modern World*. London: SAGE Publications.

White, Tom. 2017. '"Extremis" Takes an Emotional Journey Through the End of Life'. International Documentary Association. 14 February 2017. https://www.documentary.org/online-feature/extremis-takes-emotional-journey-through-end-life. Last accessed 19 May 2022.

Wiseman, Frederick. 1970. *Hospital*. Documentary. Osti Films.

Zimmermann, Camilla, and Gary Rodin. 2004. 'The Denial of Death Thesis: Sociological Critique and Implications for Palliative Care'. *Palliative Medicine* 18 (2): 121–8. https://doi.org/10.1191/0269216304pm858oa.

3. HOSPICE DOCUMENTARIES

Responsibility to Care

In 1965 Cicely Saunders, founder of the modern hospice movement, wrote: 'I am sure the most important foundation stone we could have comes from the summing up of all the needs of the dying which was made for us in the Garden of Gethsemane in the simple words "Watch with me"' (Saunders 2005, 1). Saunders refers to the hospice movement philosophy of holistic care for the terminally ill, shifting the focus from finding a cure to supporting the patient physically, emotionally, spiritually and socially.

For a film scholar, the phrase 'watch with me' offers an entry to hospice documentaries, which are commissioned by, or produced in collaboration with, the hospice organisations. In these documentary films, 'watch with me' turns into an invitation to enter the hospice spaces and the stories of dying people. In the western countries, these are often deemed to belong to the private sphere. The documentary camera allows the viewer to join the watch and to learn from these encounters. As many viewers have little experience of hospices in their everyday lives, watching also turns towards the hospices' daily practices. This direction of gaze is purposeful; through these films, hospices raise awareness of their work and of mortality. 'Watch', thus, summons the viewer's activity, and the agency of 'with me' refers to the hospice's institutional framing of end of life.

Hospices are not a new idea. While many churches, for example, have a long history of caring for the sick and dying (Tatko 2017; Miličević 2002), the modern hospice movement has branded this form of care. Saunders, a nurse,

social worker and physician, actively advocated holistic care for the terminally ill in the 1960s, and in 1967 established St Christopher's hospice in London to develop treatments of dying patients (Clark 2005, viii). These practices turned into a movement that spread quickly around the world (Bennahum 2003, 3–7; Kim 2019; Zeugin 2021, 98; Centeno and Rhee 2019). From the beginning, the hospice movement has presented itself as an alternative to medicalised death by offering a human-centred, 'natural' death (Hall 2017, 232–5).

Since the 1990s, the hospice movement has institutionalised: hospice practices and management as well as palliative medicine have been standardised. Institutionalisation has helped to raise resources and political acceptance, but has also burdened the movement with a stigma of its own (Abel 1986; James and Field 1992; Zeugin 2021, 98; Graven and Timm 2021). Alongside medicalisation, the institutionalisation and professionalisation of death, confining death to specialised institutions to be dealt with by professionals, have been blamed for the modern subjects' assumed alienation from death and dying (Elias 2001; Ariès 1975; Bauman 1992). While death awareness movements, and by extension the hospice movement, oppose this alienation, the institutionalisation turns into a paradox. Camilla Zimmerman and Gary Rodin (2004) describe this as a cultural struggle on whether hospices are seen as distancing institutions or society's way to prepare for death in ways that allow a 'natural' dying process, reduce suffering and provide quality of life. The hospice documentaries' invitation to watch provides an interesting outlook to the paradox of institutionalisation. The viewers are invited to see for themselves whether hospices reproduce negative connotations related to institutionalised death or whether they embrace the awareness of mortality and provide an alternative for the care of the dying.

This chapter is dedicated to documentaries produced by hospice institutions, such as *Except for Six* (Burnell 2008), which was commissioned by the Hospice of Michigan in the United States, and *The Light Inside* (Hicks 2015), a commission by Hospice Peterborough, Canada. In addition, I will discuss films produced in close collaboration with hospices. These films, which tell the story of the hospices, include *Last Days of Life* (Persson 2013), a documentary of a hospice in Uppsala, Sweden; *End Game* (R. Epstein and Friedman 2018) filmed in collaboration with the Buddhist Zen Caregiving Project (also known as the Zen Hospice Center) and the palliative ward at the University of California Medical Center in San Francisco (UCSF), and produced by Dr Shoshana Ungerleider, a hospice and palliative care physician and advocate (Sidewinder Films); *Here & Now* (Banci 2018), a short documentary filmed in collaboration with La Casa di Iris hospice in Italy; and *Les Pal·liatives* (Gispert and Valls 2018), a documentary about the Catalonian PADES (home hospice programme) team in Barcelona's Nou Barris district. What is shared by each of these documentaries is the institutional framing, the perspective of the hospices

and their staff, accompanied by the stories of the dying patients. I argue that the movement between these perspectives – institutional and personal – creates an image of hospice as a form of care that can become institutionalised without losing compassion, responsibility and value of individual autonomy.

Ethics of Care

'Hospice philosophy' is often construed as differentiating hospices from other medical care institutions. The philosophy stems from Cicely Saunders's understanding of 'good care' for the dying patients, where the patients' individual needs are met with compassion (Saunders 2005; Graven and Timm 2021, 326; Clark 1999). The short documentary *Here & Now* emphasises this philosophy, finishing with these words on a black screen:

> La Casa di Iris is an Italian hospice that provides help to terminally ill people and their families through palliative care, compassion and love. Day after day this little community brings dignity, respect and peace to one of the most natural aspects of life: death. (Banci 2018)

This description sums up the previous scenes of daily life at the hospice – families visiting the patients with their pets, the staff getting ice cream for a patient outside mealtimes, and a staff member and patients playing cards together. The documentary portrays hospice as a form of care and a philosophy rather than a bureaucratic institution. The scenes contrast hospice with Max Weber's influential ideas of institutions as part of bureaucratic states with formalised, normative and hierarchical processes that aim for efficiency and order. In the Weberian tradition, the idealisation of efficiency has left little room for individual desires or emotions (Weber 2013). When hospices are portrayed as places where the staff have time to 'waste' with patients, efficiency is replaced by affective relationships, and this, in turn, creates an image of a unique institution with a unique ethical approach to care.

In the context of hospice and palliative care, the 'ethics of care' approach builds on this contradiction between hospices and traditional medical institutions. Ethics of care is a feminist approach to moral theories, an alternative to classical theories that emphasise (male) rational reasoning and universal, objective rules for an unemotional agent who makes moral decisions based on logic (Gilligan 1982; Noddings 1984, 1–6; Tronto 2020, 25–60). The unemotional moral agent aligns with Weberian institutions and with the four principles of traditional medical ethics: beneficence, non-maleficence, autonomy and justice (Lawrence 2007). In comparison, ethics of care builds on a (feminine) approach that emphasises context and takes compassionate practices (care) and emotions (compassion) as its moral guideline. Here, 'care' includes two

connotations of the verb – care as an act and as a value, an emotion. In the context of caring for the elderly and terminally ill, the benefits of the ethics of care approach have been recognised (De Panfilis et al. 2019; de Vries and Leget 2012). Ludovica De Panfilis and others argue that the values in the ethics of care approach, such as compassion, trust and responsibility, the context and quality of the caring relationship and respect of individuality meet the needs of the dying people who often struggle with quality of life, dignity, emotions and existential issues (De Panfilis et al. 2019, 2–3).

Ethics of care discussions involve various traditions, and here I turn to the question of responsibility, which is contrasted with obligation. Carol Gilligan, an influential figure in the ethics of care approach, sees that the expression of care is 'fulfilment of moral responsibility'. This responsibility directs itself towards relationships and embraces reciprocity (Gilligan 1982, 73). Whereas traditional ethics treats moral choices as obligation, assuming separation between individuals, Steven Edwards contends that Gilligan's demand for responsibility-based ethics expects involvement with others. He exemplifies the difference: 'Instead of asking, "what, if any, obligations do I have to help that person?" one asks "How can I help?"' (Edwards 2009, 234). Thus, ethics of care builds on interpersonal relationships, acts of communication and a sense of responsibility towards others.

These principles are exemplified by the documentary *Here & Now* on La Casa di Iris in Italy. The hospice staff go beyond the roles of providing physical care and answering the needs of the patients. A staff member talks about Carlo, an artist and a patient. While others continue to play cards, Carlo is wheeled into the common room, and the camera moves to follow his encounter with the hospice staff. Three staff members come to see his pictures being hung on the bulletin board. Together, the staff members examine the pictures, compliment them and ask Carlo to paint more of them. Carlo smiles and laughs with them (Figure 3.1). The moment communicates warm and reciprocal relationships. There is value in the emotional support whereas the efficiency of care acts is not even hinted at.

In the context of documentary film, ethics of care has meanings beyond mediating hospice care practices for the viewer. The ethics of care approach shares key elements with Vivian Sobchack's (2004) thoughts about aesthetics and ethics as ethical care, which builds on the viewer's responsibility and reciprocal relationship with the film. For Sobchack, the film-viewing experience is grounded in senses, where the aesthetics evokes the viewer's 'sense-ability', a corporeal connection to the materiality of film as an object. These sense-making capabilities require the viewer's response (to feel, to embody, to think) to the images, and this corporeal and cognitive 'response-ability' also includes ethical aspects. The viewer's responses to a film's materiality can evoke 'ethical care and consciousness and, perhaps, responsible behaviour' (Sobchack 2004,

Figure 3.1 Staff members complimenting Carlo on his pictures in *Here & Now* (Banci 2018)

227, 241, quote from 135). Thus, by arguing that the viewer's ability to respond to the aesthetics is ethically charged, Sobchack connects ethics to responsibility, a theme familiar from the ethics of care approach. The connection between these approaches is further deepened by highlighting the role of relationships. Ethics of care emphasises intersubjectivity, whereas Sobchack (2004, 232–4) prefers the neologism of interobjectivity, which tempts us to recognise that connections are created not only to other people, but also to material objects (such as films).

The similarities between ethics of care as a moral theory and ethical care as the viewer's connection to a film's materiality bring us back to 'watch with me'. Hospice documentaries invite the viewer to witness hospice care and the patients' dying experiences, and by doing so, they can prompt ethical responses in the viewer. The reciprocity in the relationship between the film and the viewer ties ethics both to the filmed content and to the viewer's (responsible) responses to this content.

The connection between aesthetics and ethical approaches – both at the level of hospice work and the level of the viewer's experience – is visible in the Swedish documentary *Last Days of Life* (Persson 2013), based on the practice of ethics of care in a hospice in Uppsala. The opening scenes capture glimpses of patients in their rooms with their families, staff members walking in the corridors, a nurse lighting a candle (signifying someone's death) and a body being transported from the hospice. After the credits, action starts by introducing Kerstin, a patient. She is standing in the social space of the hospice,

and is supported by two nurses, one on each side. Kerstin complains about the pain she is in, and a nurse leaves to get her pain medication. The short interaction refers to the importance of pain relief (whether physical or emotional pain) in the hospice practices, which allows the bodies to become social again (Graven and Timm 2021, 330). The benefit of this practice is visible in the image of Kerstin and a nurse on the sofa, waiting for the medication, amiably chatting and laughing. The help with the pain enables Kerstin to make the best use of social spaces and activities at the hospice.

After Kerstin is escorted to her room, the editor cuts to a close-up of clasped hands, old and young. The image of 'holding hands' has become symbolic of caring for the elderly and terminally ill, signifying as it does intersubjective connection and comfort. In cinema, as Emma Wilson (2012, 111–12) points out, comforting touches are powerful means to express unspoken meanings and emotions because these kinds of haptic images of mortality can convey love and compassion, or in other words, ethics of care. The camera framing expands, revealing the context as the nurse massages Kerstin's hands while having a conversation. This moment of chatter and laughter builds everyday interaction, but also shows that the nurse has the time and the willingness to be present at the patient's side. This highlights another element that Graven and Timm (2021, 331) recognise from hospice practices – the importance of being present and caring according to 'hospice time', instead of institutional time. The care is paced in such a way that nurses have time for patients without appearing busy. Indeed, the moment between the nurse and Kerstin avoids any sense of rushing; it is presented as a meeting of two people. The connotation is enhanced by an image where the two sit next to each other on a bed, instead of the patient being on the bed and the nurse in a visitor's chair. The two share more than a space in the hospice room, they share an intimate piece of furniture.

Kerstin confirms the meaning of this moment when she starts talking about her emotions. The camera records a close-up of her face, highlighting the sincerity of her emotions when she tells the nurse that 'it's nice to have someone to talk to. You're very good at that here. That's the truth.' Kerstin emphasises the support provided by the hospice, and the camera pans out from a close-up to a mid-shot that includes the nurse in the framing. The viewer witnesses the two looking at each other, sharing a moment. The moment communicates a feeling of 'being safe', or a feeling of being looked after, a third aspect of Graven's and Timm's (2021, 302) understanding of how the hospice philosophy translates into care practices. Kerstin's positive feedback is a sign of her feeling safe to talk about emotions. These subtle ways in which the film reflects the ethics of care through aesthetics build a warm and welcoming atmosphere for the viewer. While dealing with a challenging topic (death), the documentary creates a safe and caring space to connect with the filmed subjects, the images

and the hospice. This ethos prevails throughout the film. The staff are present and interact with the patients. The care takes place in everyday encounters of shared moments and support. Medical treatment is almost absent; the focus is on the affective nature of care. The decision to bypass physical and medical care is a conscious choice that directs the attention to reciprocal relationships.

From the perspective of carers, ethics of care connects with affective labour. This term, popularised by Michael Hardt (1999), translates into non-material work that produces or manipulates affects, such as well-being, comfort and excitement. Johanna Oksala (2016, 290–1) argues that affective labour takes place in un-commodified work, such as taking care of the terminally ill at home, and in commodified work, such as nursing. Due to the affective labour's connotations with domestic work, traditionally performed by women, this often-invisible work has been seen as feminised and underappreciated. Nowadays, affective labour is recognised as a productive part of social reality, and as such, the emotional capacities of the carers are recognised along with their technical skills (Oksala 2016, 285–91). At the core of affective labour is hospice and palliative care that asks the carers to be present, support and comfort, to provide human contact and interaction, and to produce relationships and emotional responses. Thus, similarly to ethics of care, affective labour does not magically or 'naturally' appear, and as such, it has become a marketed product of the hospice institutions (Hakola 2021).

While they approach the end of life from an institutional perspective, hospice documentaries also shed light on the practices of affective labour. In *Last Days of Life*, Anne, a nurse, keeps the patients company, helps them to have a bath, eat and take their medications, but also just sits with them. There is warmth in her presence, and she either smiles or looks supportively at the patients. Outside the patients' rooms, the viewer is privileged to her thoughts and feelings. In a scene, she exits the room of a withdrawn patient. In the corridor, she faces the camera and reflects on her experiences:

> First, I go into one room and see someone who's not doing well, who's in pain, maybe someone who's closer to death than someone else, and then I have to go to the next room and talk about something different. Then I have to take a few deep breaths before I go in. But it's important to show these patients that might not need me that much and can take care of themselves that I'm still here and I'm interested. (Persson 2013)

While talking, Anne gazes slightly off the camera, but when she assesses someone being close to death she looks directly at the camera. The difference is striking. She is comfortable in recognising the situation of the patients, but reflecting her own thoughts and feelings requires a distance from the viewer. When she starts to speak about the importance of being present, the framing

changes from medium close-up to a mid-shot. This slight distancing highlights the institutional reflection of the situation – the hospice philosophy. In this case, she also gazes towards the camera, showing her acknowledgement of the expectations and importance of the job. The personal and hospice philosophy mix, creating both institutional expectations and individual experiences.

By being able to follow Anne's (and other hospice staff's) work and feelings and see how positively their care is received by the patients, the viewer can be impressed by the benefits of ethics of care. The inclusion of the staff perspective helps the viewer to understand what ethics of care means in practice. In addition to the staff's affective labour, the documentary also produces affective labour, because the film's materiality has a similar ability to produce and manipulate emotions. The careful planning of the images that mediate and communicate compassion, responsibility and reciprocal relationships extends the ethics of care towards the viewer. The created aesthetic is comforting, supportive and peaceful; the images create a safe and caring space for the viewer's responses. In a reciprocal relationship, the viewer is requested to care, to 'watch with me' and respond to the represented images in a responsible way.

In the ethical processing of film's materiality, Sobchack gives a specific role to documentary expressions. She argues that documentary images that are 'charged with real' make the viewer conscious of extra-cinematic social and cultural aspects, where previous knowledge and experiences inform the viewer's relationship with the images, and prompts not only aesthetic evaluation, but ethical judgment, or 'ethical care of knowledge'. In other words, documentary spaces are ethically invested and request response-ability and responsibility (Sobchack 2004, 222). By inviting the viewer into the everyday lives of hospices, their staff and patients, the hospice documentaries request ethical responsibility over witnessing, but also responsibility to become aware (and appreciate) the work that hospices do.

Raising Awareness of Hospice Care

Hospice documentaries, by definition, desire to raise awareness of hospice care work, practices and philosophy, underpinned by and culminating in the ethics of care approach. The hospice movement's roots are in social activism that strives for public, legislative and political recognition (Bennahum 2003). This is where storytelling by audiovisual materials can serve to increase public visibility. For example, a representative of the Hospice of Michigan sees their film *Except for Six* as a tool to 'tell our story better' (Serba 2008), and the Spanish documentary, *Les Pal·liatives* was supported by 'la Caixa' Foundation's social programme of promoting and raising awareness of the meaning of palliative care (CCMA 2018). In the case of *The Light Inside*, a documentary commissioned by Hospice Peterborough in Canada, I had a chance to interview

David Kennedy, bereavement coordinator at the hospice who also appears in the film, and the film's director Neil Hicks. Both highlight the film's importance as an awareness tool. The film was connected to the hospice's fundraising goals, but instead of just asking people for money, the hospice team wanted the film to show what they do and what their work means. Hicks, for example, wanted 'to tell their story in such a way that allowed the community to understand, number one, hey, we are here, hospice exists, and hey, number two, we play an important role in the community' (Hicks 2019).

Hospice documentaries raise awareness by balancing the aims of not wanting to be seen as an institution and the desire to manage public relations in favour of the hospice movement. This struggle turns into another balancing act of weighing the documentaries' informational and affective aspects. The informative aspects seek to increase the public understanding of hospice work and to decrease negative connotations and misunderstandings. Particularly, the hospices have struggled with a reputation of being 'places to die'. While death often causes anxiety, many people avoid thinking about it, and by extension, they have not wanted to learn about hospice work (Hickey and Quinn 2012; Friedman, Harwood, and Shields 2002). To alleviate such hospice-related fears, the documentaries have become tools to open the doors symbolically and literally to the hospice and welcome the public to follow the daily activities that aim to support quality of life. Here, the opening of the doors and allowing the camera inside becomes an informative act, yet the meanings attached to these places emphasise affects in which the viewer can hopefully find comfort.

Thus, the first balancing act between being informative and affective negotiates the uses of place and space. Place can be seen as locations and sites that are defined by human experiences, whereas spaces are more abstract and occur in time as part of human activities (Seamon and Sowers 2008). In hospice documentaries, hospices are described as spaces for ethics of care. The actual place does not matter, and often the buildings are not filmed from the outside. This is highlighted in the Spanish documentary *Les Pal·liatives*, which introduces the 'Catalonian model' for home hospice care. The care workers visit hospice patients, and between meetings, they talk about their own experiences of hospice care. The camera follows them through the doors to a new home where the care workers chat with the patients and their families. These chats include checking up on the patients' physical state, but also their emotional and social well-being. Furthermore, the visits build relationships and create a sense of being taken care of by a community. The presence of the hospice workers carries a sense of safe space and ethics of care, and thus extend hospice space to the personal spaces of the patients. Instead of a physical place, what matters are the activities, the care that these spaces enable and offer.

Given that hospice homes can convey a sense of infrastructure, the documentaries shot in them have the added struggle of dealing with the stigma

of institutionalisation. Research has highlighted that hospice buildings wish to communicate hospice philosophy, including 'homeliness' and community aspects where people can spend time together with their families, friends, other patients and staff members, and to provide access to nature, such as gardens and natural light. Both outside and inside spaces balance privacy and ideals of community to avoid a sense of institutionalisation, or as McGann articulates, 'incarceration' (McGann 2016; Graven and Timm 2021, 333). In *The Light Inside*, for example, the camera visits different rooms at the hospice and shows spaces for community, such as a room for group meetings and sitting rooms. The homelike furniture, with plush sofas, chairs, curtains and fireplaces create a space that brings elements from private spaces (home) and public spaces (community) together. By inviting the viewer to cinematically visit these spaces, the informative yet affective spatial descriptions familiarise and normalise hospice spaces, and consequently, hospice as a form of care.

The ultimate institutional place/space comparison happens between hospitals and hospices. The patients, such as Ron in *Except for Six*, visit hospitals to receive medical care, but these are short and efficient visits that focus on medical aspects. The hospice as a space for care, in comparison, builds on compassion, company and lack of urgency. This distinction corresponds to the description of medical documentaries (Chapter 2), where the sense of authenticity and space for medicalised death were generated by hurrying doctors and medical technology. Christina Quinlan, similarly, has noted that public images, such as media representations, deal with institutionalised death by contrasting hospital and hospice deaths. The hospitals are pictured as places where technical and institutional approaches take precedence, whereas hospice space is seen as dedicated to the personal (Quinlan 2009). In *Except for Six*, for example, Professor Henry Holstege finds the main difference in the hospices' human-centred approach:

> You have people here who understand the dying process, you have people who are very empathetic, you have people who take their time to try to bring out the emotions. You have people to dialogue and talk. That's why hospice is such a wonderful advancement in regard to palliative care and the dying process. (Burnell 2008)

Here, hospice becomes 'a good institution' because it openly acknowledges death, opposing its medicalisation. Also, the human-centred approach, where caring takes place in reciprocal relationships, defies the Weberian understanding of institutionalism. Consequently, the documentaries tend to promise that if the viewer becomes aware of this 'good institution', more people could benefit from these services.

The second balancing act between informative and affective approaches takes place through the narrative perspective, where the institutional perspective is balanced by the hospice patients' personal stories. This sequence is especially visible in *Except for Six*, a film commissioned by the Hospice of Michigan. The film has a dialogical structure: interdisciplinary hospice experts explain what a hospice is, followed by the hospice patients' experience. The expert interviews have an educational tone, which is stressed in the spatial aspects. The experts are interviewed in their offices, or, in the case of physician Robert J. Zalenski, in his classroom at Wayne State University. In her interview, National Hospice leader Dottie Deremo describes hospice as a supportive model with well-toned structures and practices that aim for holistic and affective care. The patients' perspectives complement the institutional message by representing the lived experiences of care. Ron, a 69-year-old cancer patient, becomes the main filmed subject, whose journey from day twenty-seven at the hospice is followed until his death. In an interview for the Michigan Live news site, the film's director Matthew Burnell declares that in their desire to raise awareness of end-of-life care, they 'decided to follow elderly people through hospice care to help people better understand the process' (Serba 2008). This comment supports the perspective that while Ron's story adds emotional depth to the story, Ron becomes an example in a story about hospice, not the other way around.

In setting the scene, the experts agree that hospice care is not to be feared. This care helps terminally ill people to live their remaining lives to the fullest. From this philosophical perspective, the film moves towards practices, where Deremo explains the role of each interdisciplinary staff member – physicians, nurses, social workers, spiritual care providers and volunteers. In each case, Deremo's talk is given a rhythm with scenes of staff members meeting with Ron and other patients. The staff help Ron to take his medication, converse with him and follow his physical condition. Their work represents ethics of care in practice, and includes comforting touches, hugs and caresses, as well as laughing, storytelling and reciprocal relationships. Deremo's abstract description about creating a 'sacred space' for the dying and their families is seconded by Ron, who admits that at first, he resented the idea of hospice, because it is 'not for the living', but he reconsidered after realising that hospice helped him to live with his diagnosis and enabled him to stay at home. Indeed, Ron is shown working with his cars and playing with his grandchildren. The film uses Ron's affective experiences to support the institutional and informative message of the hospice experts that hospice is about improving the quality of life.

In the case of *The Light Inside*, director Neil Hicks emphasises that to support the film's message it was extremely important to have real people tell their stories and voice their support for their local hospice. Hicks argues that finding these people also gave them an opportunity to give back to the hospice,

to show how meaningful this form of care had been for them (Hicks 2019). The film tells the stories of two families battling with end-of-life issues. First, cancer patient Patti and her husband are trying to deal with the life-threatening illness. Second, parents Kathy and Gregg are mourning the sudden loss of their child. The structure of the film presents hospice as a support in this struggle. At the beginning of the documentary, both families share on camera their battle and need for help. Both are filmed in their homes, and Patti is also filmed in hospital receiving chemotherapy. The section ends with Kathy and Gregg narrating how overwhelming it was to lose their son and to deal with everyday life, and how that feeling of disconnection was 'an ugly place to be, because we did not know what to do'. From the home interview, the scene fades to black, and an intertitle appears on the screen: 'A place to turn to'.

The second section starts by introducing the local hospice. The camera travels through the streets of Peterborough, making the physical and geographical places familiar to the community a meaningful part of the narration. The gaze turns from the main street to a church tower, and from there to the driveway of the hospice building. The door opens, both literally and symbolically, and the viewer is allowed into the hospice. Here, the viewer also meets the staff of the hospice. A volunteer coordinator talks about the philosophy and values of care and how these, together with the people working there, make the place special and real. David Kennedy, the hospice's bereavement coordinator, promises that they help people struggling with death and dying, and while they cannot give any ultimate answers, they provide support so that 'you don't have to feel alone'.

Through Patti and Kathy and Gregg, the viewer visits the support groups and witnesses the help the hospice staff provide. This section alternates between the testimonial aspects and the institutional explanations of how the hospice helps. Patti's husband laments that not many people understand what they are going through, but the hospice helps to ensure that there is still life left. Both Kathy and Gregg say how important it was to know that they were not alone, and how the hospice gives them tools to help with the grief. These testimonials are supported by David's narration of how one needs to learn to live with grief, how death and dying cannot be put aside. One can find ways to deal with them and see how encountering death can make people appreciate life more. The film ends with Kathy and Gregg confirming that they have learned how their loss and sorrow can include life that honours their son. From this interview, filmed outdoors where the family is enjoying winter activities, the screen fades to black with the words, 'When the unthinkable happens, you are not alone.' In this video, the educational aspects are carefully woven together with the message that hospice provides tools and hope in difficult situations.

In a way, the structure of this short documentary conveys a sense of rescue. Hicks, the film's director, recognises the dual structure of the film (from

problem to solution), but instead of straightforward rescue, he sees it as a message of support:

> One of the concerns we had was making sure that to be honest about the story and to be honest about the role that hospice plays is to celebrate the role that they do play, but to not overstate it to the extent that it becomes inauthentic. Hospice didn't fix these problems, nor did it fix these brutal situations that these families were in, but hospice did provide a support structure that was very important during these moments in time. (Hicks 2019)

Here, Hicks's insight into the planning of the film shows how affective storytelling elements add value to the informational needs related to awareness. Indeed, according to research done on social issue documentaries, human-centred stories are less likely to create rejection or counter-arguments than are informational or educational rhetoric, not least because these stories are seen as more engaging, less ideological, easier to comprehend, better at addressing emotional or existential issues, and are better remembered than informational messages (Borum Chattoo and Jenkins 2019; D. Epstein, Farina, and Heidt 2014; Hoeken and den Ouden 2019). In addition to raising awareness more effectively, balancing the information with stories allows hospice documentaries to focus on hospice philosophy without emphasising institutional aspects. The informative aspects easily connect to the sense of institution, whereas affective elements mediate a public image of hospices as spaces for care. At best, the message of care communicated by these documentaries invite interpretations that serve to alleviate the fears and negative connotations that the viewer might have about hospices.

Raising Awareness of Mortality

While hospice documentaries aim to increase awareness of the hospice movement, this aim intertwines with a wider context, the death awareness movement. Indeed, in their empirical work with hospices, Graven and Timm (2021, 329) found that the death awareness serves as a significant philosophical support for hospice staff. Similarly, while making hospice care visible, hospice documentaries also raise death and dying into the public discussion. This is visible in the closing words of the Netflix-distributed *End Game* (R. Epstein and Friedman 2018), a documentary that was nominated for an Academy Award in the category of Best Documentary (Short Subject). The film closes with the words of palliative care physician B. J. Miller: 'We are wired to run away from death. But dying is a part of life.' As such, the documentary aims to normalise death alongside hospice care. In an interview for an international

documentary association, directors Rob Epstein and Jeffrey Friedman continue with this theme. Epstein argues that making the film was important because people do not want to think about death:

> It's a very hard thing to wrap your mind around. It's too scary. That was one of the reasons why we wanted to make this film—to make it less so. And that's what we were experiencing as we were doing the research and conceptualizing the project—witnessing these people whose job it is to alleviate suffering and to make death less scary. (Kurie 2019)

This film also builds from an institutional perspective. Epstein says that they shadowed the two doctors and met all the patients in the film through them (Kurie 2019). Thus, while the patients' stories are heartfelt, their stories are framed by the work of the care teams, who do their best to help them to deal with difficult situations. Epstein also considers that the patients and their families wanted to be part of the film because of their appreciation for end-of-life care: 'They were so appreciative of the palliative care that they were getting and understanding its value, that they wanted to be part of demystifying and educating others through their experience to help alleviate the suffering of others' (Kurie 2019).

The filmmakers follow two palliative care teams. One is led by Dr B. J. Miller, a palliative care physician at the Buddhist Zen Caregiving Project (also known as the Zen Hospice Center) in San Francisco. The other is Dr Steven Pantilat at the University of California San Francisco Medical Center, a hospital-based palliative ward. In this film, the hospital and hospice environments are set next to one another, but unlike in many hospice documentaries, the hospital institution is not demonised, but appreciated. In fact, the film starts from a scene where Pantilat discusses one of the main characters, 45-year-old Iranian-American Mitra, who is dying but whose family struggles to accept the situation. With his palliative team, Pantilat wonders if the family would be open for a hospice referral, but the chaplain of the team comments that the family equates hospice with death, which they are not ready to accept. Thus, the team continues to treat Mitra and the family at the hospital, and they do this with similar ethics of care as in the hospice institutions. Here, palliative care within a hospital creates a similar space for care as do hospices.

End Game acknowledges the difficult emotions of the patients and their families and observes staff trying to help patients and families deal with these difficult emotions. This follows from what Graven and Timm have found in the rhetoric of hospice workers. At first glance, the hospices' desire to avoid the stigma of being 'places' for death but wanting to be open about death can appear contradictory. However, as Graven and Timm argue, for hospice workers the openness refers to the emotional aspects of the dying process, not

about being dead. Hospice staff create opportunities 'for patients to express emotions such as grief, anxiety, and to share memories and thoughts about what is important at the end of life' (Graven and Timm 2021, 329). Awareness of death thus translates into being allowed to experience complex emotions.

This is evident in a dialogue that Miller has with Thekla, one of the patients. In their previous meeting, Miller had asked Thekla to think about dying, to try to make death a bit less unknown. Thekla says that she has failed the assignment. Because she loves to live, accepting dying or death feels impossible and scary. Miller is understanding, yet continues to encourage Thekla to acknowledge her situation, and that perhaps it might be better to get used to the idea of death at some level. If nothing else, Thekla could hold onto an idea that one does not know what death is. Perhaps it would not be as bad as Thekla imagines. Thekla thinks about this, and admits: 'It could be terrible, but it could be wonderful.' Miller takes this as a cue to continue and argues that based on his experience, whatever we encounter after death, it will not be too horrible. When Thekla questions this, Miller turns to near-death experiences which people have described in positive terms. Thekla concedes that there might be some truth to these experiences (R. Epstein and Friedman 2018). In this exchange, Thekla does not experience sudden enlightenment. Her fears are heard and taken seriously, and at the same time, Miller tries to suggest ways to alleviate them.

Similar encounters between hospice and palliative care experts and patients structure the narration. The staff allow patients to feel mixed emotions and are not afraid to have difficult discussions. They offer the patients support to deal with the emotional upheaval of, and difficulty accepting, forthcoming death. Their expertise makes hospice and palliative care specialist work, something that separates commodified affective labour from non-commodified care work. For example, in the case of Mitra, the viewer witnesses a scene where she is anxious and struggling. She cries and shouts, letting out her frustrations, fears and anxiety. The family members start crying because they are upset about Mitra's uncontrollable responses and suffering. Mitra cries that she does not even know what she is anxious about. There is no clear problem that could be solved. Mitra's mother admits on camera that this causes anxiety in her as well and she feels that she is suffering and at the limits of her ability to cope. In situations like this, ethics of care is offered as additional support, something that can be managed by professionals rather than on your own.

In their desire to alleviate fears, hospice documentaries encounter both emotional and physical aspects of dying. During the filming, the patients get weaker and more fragile. While these films do not show moments of death, they include scenes both before and after. The final section of *Last Days of Life*, for example, shows Kerstin struggling to sit up and stand up, yet her desire to do so has not vanished. From these struggles, the film cuts to a shot in the hospice

corridor. A nurse exits the room and lights a candle. The camera moves closer and records from the doorway Kerstin's family standing by her bed before they collect their belongings and leave. The camera follows their quiet parade, while Cornelis Vreeswijk's ballad about a beautiful dance between a young, vibrant woman and an older man plays in the background (Vreeswijk 1986). The camera then moves into the room and stays at Kerstin's bedside. Her now still body – an opposite to her vibrant personality – and flowers in her hand create a peaceful, yet sad image that remains until the film closes.

This, and similar scenes in other hospice documentaries, are reminders of the destination of the hospice journey. Such scenes also require the viewer's 'response-ability'. Sobchack argues that the viewers have a responsibility to justify why they watch real events, those in particular that are about death and dying. Based on her own reactions to seeing a rabbit's death on-screen, Sobchack views these on-screen images of dying as material reminders of being both a mortal and a moral being. In other words, watching requires responsibility, which includes becoming aware of one's own mortality (Sobchack 2004, 222–3). Thus, while hospice documentaries build understanding and awareness of what hospices do, they also demand that the viewers acknowledge mortality instead of running away from it. These documentaries build an image where death and dying is everybody's business, and that hospices refuse to be institutions where death can be hidden away.

Conclusion

Hospice documentaries approach end of life through the care provided by hospice and palliative care institutions. By giving examples of everyday work and life at the hospices and by opening the hospice doors, the documentaries make it known that these are welcoming and communal places which embrace life. Raising awareness is a reciprocal relationship. The hospices have a responsibility to care for the dying, and the viewer is invited to share this by watching and becoming aware of their work, and consequently, by wanting to support this form of care. In the context of end-of-life documentary films, Anna Elsner (2020, 2) argues that the process of dying is always 'inseparable from the question of how we care for the dying'. This, for Elsner, includes the staff and the filmmakers, but in ethical film viewing, it needs to extend to the viewer as well. Caring for the dying is everybody's responsibility.

When the viewers are included in ethics of care, hospice documentaries provide the ultimate reasoning to why hospices are 'good' institutions; as spaces for ethics of care, they should not be seen as 'traditional' institutions, but as alternative societal structures that include everyone in society, a way for the community to manage supporting the dying. Thus, request for responsibility turns into a promise. When hospice documentaries promise to support the

dying person and their families, they promise that one day the viewer may be on the receiving end of ethics of care. By watching with the filmmakers, the viewer is promised that good end-of-life care can be one reason why one should not be so afraid of dying and death.

References

Abel, Emily K. 1986. 'The Hospice Movement: Institutionalizing Innovation'. *International Journal of Health Services* 16 (1): 71–85. https://doi.org/10.2190/RQBV-J2PG-VFNM-1H97.

Ariès, Philippe. 1975. *Western Attitudes toward Death: From the Middle Ages to the Present*. Translated by Patricia M. Ranum. First published 1974. Baltimore, MD: Johns Hopkins University Press.

Banci, Virginia. 2018. *Here & Now*. Documentary, Short. Bournemouth Film School.

Bauman, Zygmunt. 1992. *Mortality, Immortality and Other Life Strategies*. Stanford, CA: Stanford University Press.

Bennahum, David. 2003. 'The Historical Development of Hospice and Palliative Care'. In *Hospice and Palliative Care: Concepts and Practice*, 1–11. Boston, MA: Jones and Bartlett.

Borum Chattoo, Caty, and Will Jenkins. 2019. 'From Reel Life to Real Social Change: The Role of Contemporary Social-Issue Documentary in U.S. Public Policy'. *Media, Culture & Society* 41 (8): 1107–24. https://doi.org/10.1177/0163443718823145.

Burnell, Matthew. 2008. *Except for Six*. Documentary. Hospice of Michigan; Visioneer Films.

CCMA. 2018. 'S'estrena la coproducció de TV3 "Les pal·liatives", a "Sense ficció"'. CCMA. 29 October 2018. https://www.ccma.cat/premsa/sestrena-la-coproduccio-de-tv3-les-palliatives-a-sense-ficcio/nota-de-premsa/2883690/. Last accessed 19 November 2022.

Centeno, Carlos, and John Y. Rhee. 2019. 'Organization of Palliative Care in Different Parts of the World'. In *Textbook of Palliative Care*, edited by Roderick Duncan MacLeod and Lieve Van den Block, 37–75. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-77740-5_6.

Clark, David. 1999. '"Total Pain", Disciplinary Power and the Body in the Work of Cicely Saunders, 1958–1967'. *Social Science & Medicine* 49 (6): 727–36. https://doi.org/10.1016/s0277-9536(99)00098-2.

———. 2005. 'Foreword'. In *Watch with Me: Inspiration for a Life in Hospice Care*, edited by Cicely M. Saunders, vii–xii. Lancaster: Observatory Publications.

De Panfilis, Ludovica, Silvia Di Leo, Carlo Peruselli, Luca Ghirotto, and Silvia Tanzi. 2019. '"I Go into Crisis When …": Ethics of Care and Moral Dilemmas in Palliative Care'. *BMC Palliative Care* 18 (1): 1–8. https://doi.org/10.1186/s12904-019-0453-2.

Edwards, Steven D. 2009. 'Three Versions of an Ethics of Care'. *Nursing Philosophy* 10 (4): 231–40. https://doi.org/10.1111/j.1466-769X.2009.00415.x.

Elias, Norbert. 2001. *The Loneliness of the Dying*. First published 1985. New York: Continuum.

Elsner, Anna Magdalena. 2020. 'Landscapes of Care and the Enchantment of Dying in Edwin Beeler's *Die Weisse Arche* (2016)'. *Studies in Documentary Film* 14 (2): 147–60. https://doi.org/10.1080/17503280.2020.1725994.

Epstein, Dmitry, Cynthia Farina, and Josiah Heidt. 2014. 'The Value of Words: Narrative as Evidence in Policy Making'. *Evidence & Policy: A Journal of Research, Debate and Practice* 10 (2): 243–58. https://doi.org/10.1332/174426514X13990325021128.

Epstein, Rob, and Jeffrey Friedman. 2018. *End Game*. Documentary. Netflix.

Friedman, Betsy T., M. Kay Harwood, and Matthew Shields. 2002. 'Barriers and Enablers to Hospice Referrals: An Expert Overview'. *Journal of Palliative Medicine* 5 (1): 73–84. https://doi.org/10.1089/10966210252785033.
Gilligan, Carol. 1982. *In a Different Voice: Psychological Theory and Women's Development*. Cambridge, MA: Harvard University Press.
Gispert, Oriol, and Marta Valls. 2018. *Les Pal·liatives*. Documentary. La Lupa Producciones.
Graven, Vibeke, and Helle Timm. 2021. 'Hospice Philosophy in Practice—Toward an Authentic Death'. *OMEGA – Journal of Death and Dying* 83 (2): 325–42. https://doi.org/10.1177/0030222819852850.
Hakola, Outi. 2021. 'Advertising Hospice Care Services'. *Death Studies* 45 (9): 726–34. https://doi.org/10.1080/07481187.2019.1686089.
Hall, Lauren K. 2017. 'Rehumanizing Birth and Death in America'. *Society* 54 (3): 226–37. https://doi.org/10.1007/s12115-017-0129-6.
Hardt, Michael. 1999. 'Affective Labor'. *Boundary 2* 26 (2): 89–100.
Hickey, Deb, and Sharon Quinn. 2012. '"I Don't Want to Talk about It." Raising Public Awareness of End-of-Life Care Planning in Your Locality'. *International Journal of Palliative Nursing* 18 (5): 241–7. https://doi.org/10.12968/ijpn.2012.18.5.241.
Hicks, Neal. 2015. *The Light Inside*. Documentary, Short. Hospice Peterborough.
———. 2019. Personal interview by Outi Hakola.
Hoeken, Hans, and J. N. den Ouden. 2019. 'Narrative Health Communication'. In *Narratives in Research and Interventions on Cyberbullying among Young People*, edited by Heidi Vandebosch and Lelia Green, 61–74. Cham: Springer.
James, Nicky, and David Field. 1992. 'The Routinization of Hospice: Charisma and Bureaucratization'. *Social Science & Medicine* 34 (12): 1363–75. https://doi.org/10.1016/0277-9536(92)90145-G.
Kim, Chang Gon. 2019. 'The History of Hospice and Palliative Care in Korea'. *The Korean Journal of Hospice and Palliative Care* 22 (1): 1–7. https://doi.org/10.14475/kjhpc.2019.22.1.1.
Kurie, Peter. 2019. 'The Final Passage: "End Game" Offers a Lesson on Death and Dying'. International Documentary Association. 12 February 2019. https://www.documentary.org/online-feature/final-passage-end-game-offers-lesson-death-and-dying. Last accessed 10 January 2022.
Lawrence, Dana J. 2007. 'The Four Principles of Biomedical Ethics: A Foundation for Current Bioethical Debate'. *Journal of Chiropractic Humanities* 14 (January): 34–40. https://doi.org/10.1016/S1556-3499(13)60161-8.
McGann, Sarah. 2016. *The Production of Hospice Space*. London: Routledge. https://doi.org/10.4324/9781315553870.
Miličević, Nataša. 2002. 'The Hospice Movement: History and Current Worldwide Situation'. *Archive of Oncology* 10 (1): 29–31.
Noddings, Nel. 1984. *Caring, a Feminine Approach to Ethics & Moral Education*. Berkeley: University of California Press.
Oksala, Johanna. 2016. 'Affective Labor and Feminist Politics'. *Signs: Journal of Women in Culture and Society* 41 (2): 281–303. https://doi.org/10.1086/682920.
Persson, Nahid. 2013. *Last Days of Life* (*I Livets Slutskede*). Documentary. Sveriges Television AB; Real Reel Docs AB.
Quinlan, Christina. 2009. 'Media Discourses on Autonomy in Dying and Death'. *Irish Communication Review* 11 (1). https://doi.org/10.21427/D7XM8T.
Saunders, Cicely M. 2005. *Watch with Me: Inspiration for a Life in Hospice Care*. Lancaster: Observatory Publications.
Seamon, David, and Jacob Sowers. 2008. 'Place, and Placelessness, Edward Relph.' In *Key Texts in Human Geography*, edited by Phil Hubbard, Rob Kitchin, and Gill Valentine, 43–51. London: SAGE Publications.

Serba, John. 2008. 'Hospice Intends Film to Be "Awareness Tool"'. MLive. 1 September 2008. https://www.mlive.com/movies/2008/09/hospice_intends_film_to_be_awa.html. Last accessed 19 November 2022.
Sobchack, Vivian. 2004. *Carnal Thoughts: Embodiment and Moving Image Culture*. Los Angeles: University of California Press.
Tatko, Aleksandra. 2017. 'The Origins and Development of the Modern Hospice Movement in the Context of Ongoing Demographic and Social Changes in the World'. *Praca Socjalna* 2 (33): 155–74.
Tronto, Joan C. 2020. *Moral Boundaries: A Political Argument for an Ethic of Care*. First published 1993. New York; London: Routledge. https://doi.org/10.4324/9781003070672.
Vreeswijk, Cornelis. 1986. *Balladen Om Herr Fredrik Åkare Och Den Söta Fröken Cecilia Lind*. Vol. I Elfte Timmen. Max Records.
Vries, Maruscha de, and Carlo J. W. Leget. 2012. 'Ethical Dilemmas in Elderly Cancer Patients: A Perspective from the Ethics of Care'. *Clinics in Geriatric Medicine* 28 (1): 93–104. https://doi.org/10.1016/j.cger.2011.10.004.
Weber, Max. 2013. *Economy and Society: An Outline of Interpretive Sociology, Volume 2*, edited by Guenther Roth and Claus Wittich. First published 1922. Berkeley; Los Angeles; London: University of California Press.
Wilson, Emma. 2012. *Love, Mortality and the Moving Image*. London: Palgrave Macmillan. https://doi.org/10.1057/9780230367708.
Zeugin, Barbara. 2021. 'The Hospice Movement, Palliative Care, and Anthroposophy in Europe'. In *The Routledge Handbook of Religion, Medicine, and Health*, edited by Dorothea Lüddeckens, Philipp Hetmanczyk, Pamela E. Klassen, and Justin B. Stein, 98–112. London: Routledge. https://doi.org/10.4324/9781315207964-9.
Zimmermann, Camilla, and Gary Rodin. 2004. 'The Denial of Death Thesis: Sociological Critique and Implications for Palliative Care'. *Palliative Medicine* 18 (2): 121–8. https://doi.org/10.1191/0269216304pm858oa.

4. SPIRITUAL DOCUMENTARIES

Making Death Meaningful

> It *is* hard to die, and it will always be so, even when we have learned to accept death as an integral part of life, because dying means giving up life on this earth. But if we can learn to view death from a different perspective, to reintroduce it into our lives so that it comes not as a dreaded stranger but as an expected companion to our life, then we can also learn to live our lives with meaning. (Kübler-Ross 1975, 6)

The quote comes from psychiatrist Elizabeth Kübler-Ross, who was a driving force behind developing the international death awareness movement. In 1969, her classic book *On Death and Dying* (Kübler-Ross 2009) spoke against the medicalisation of death and approached death and dying through everyday experiences. The book gave visibility to death as a societal topic both among academics and the public. In this book, Kübler-Ross introduced her grief-stage theory according to which people adjust to terminal illness through five stages – denial, anger, bargaining, depression and acceptance. The model emphasises the importance of death acceptance in easing the emotional burden of everyone involved. Her later book, *Death: The Final Stage of Growth* (1975), from where the above quote is from, symbolically adds another stage to this personal growth. The book itself is a collection of essays by writers who discuss the ways in which different cultures, religions and philosophies have negotiated death acceptance, dealt with death anxiety and established the meaning of life and death. In this collection,

Kübler-Ross argues for the importance of creating a meaningful relationship with death.

In the field of psychology, Kübler-Ross's grief theory has become increasingly criticised. New grief theories do not consider death and loss to evolve in stages that lead to acceptance and personal growth, but place emphasis on individually varied emotional responses (McCabe 2003). Yet, the acceptance narrative continues to exert cultural influence. For example, Kübler-Ross's influence remains strong in spiritual approaches to the end of life. In this context, spirituality is an individual concept, which does not necessarily mean being part of an established religion, but it can be a philosophical approach to existential questions. Spirituality often becomes significant for the terminally ill and those approaching death. Studies have shown that it can help people to cope with end of life and add to their sense of quality of life (Stephenson, Draucker, and Martsolf 2003; Bovero et al. 2016), whereas some other studies have found that spirituality does not appear to diminish fears (Kates 2020). In the hospice movement, spiritual care is part of holistic care along with physical, psychological and social care. In practice, spiritual care includes supporting a person's religious beliefs and rituals, and it also recognises the individuals' desire to find meaning and purpose for life and death, validation for lived lives and ways to make suffering and pain understandable (Ferrell 2017).

The search for a meaning of life and death has also been contemplated in some end-of-life documentaries, which prioritise questions of how we should understand death's role in our lives. These documentaries suggest that anyone would benefit from thinking about the meaning of death, because the meaning-making process may alleviate death anxiety and encourage one to live more fully. In contrast to medical and hospice documentaries, which give institutional viewpoints on end-of-life care, spiritual documentaries adopt an institutional voice in guiding the viewer towards a meaningful death. In this chapter, I start by discussing the educational tone of spiritual documentaries with the help of two short films, *Lessons for the Living* (Henderson 2010), an American film, and *For One More Moment* (Timonen 2017), a Finnish documentary. I will then move to a close analysis of two American documentaries – *Solace: Wisdom of the Dying* (Adair 2008) and *Living Your Dying* (Pennybacker 2003) – and one from Switzerland, *Die Weisse Arche* (Beeler 2016). My argument is that these documentaries aim to transform spirituality from being a question of belief to a sphere of knowledge or truth which would endow spirituality with equal cultural appreciation bestowed upon the medical understanding of death. Because spirituality has the potential of alleviating death anxiety, these documentaries suggest that such cultural appreciation could benefit everyone, not only those in the midst of a dying process.

Searching for Spiritual Knowledge

The Finnish documentary *For One More Moment* centres on the interviews of three nurses of a hospice home in the Tampere region. Instead of introducing any patients, the documentary highlights the nurses' experiences of how their job has normalised death for them. The message is emphasised in the imagery of the scenes. While a few scenes are filmed in the hospice home, most take place outdoors. There is a scene of one of the nurses painting a picture by a lake, another saddling a horse, and the third sitting in a gazebo surrounded by trees. This symbolism serves as a testimony to how the nurses have learned to accept death as a natural part of life. Consequently, they have learned to appreciate the beauty of the last moments, and most importantly, to appreciate life.

In a review, film critic Pauliina Savola argues that this film's meaning is bigger than the thirteen minutes of its length. In that time, the film manages to crystallise images of life and death that have been shaped by decades of staff members' experience. These images, Savola writes, are not 'dark or gloomy, but full of warmth and hope. The message is important: before we die, it would be good to live. Today, not tomorrow' (Savola 2019, translated from Finnish). This reading relates to what director Jenny Timonen thinks about the tone of her film. In an interview for a local newspaper, Timonen says she wants the film to be hopeful, and that the viewer would 'sit quietly and think for a while when the film ends … and when they leave, they would think about their own lives' (Kuusela 2017, translated from Finnish). The wisdom and experience of the hospice nurses teach the viewer to appreciate life and to respect death.

This is typical of spiritual end-of-life documentaries. The film has an existential message and something to teach. In many ways, these documentaries follow the same logic as Kübler-Ross's *Death: The Final Stage of Growth*. In the foreword the editors Joseph Braga and Laurie Braga frame the book as a tool to help the reader to 'learn' to 'find peace in life and death' through examining their emotional responses to others' knowledge and stories. By doing so, the readers might allow death to help them to find meaning for life and to become who they 'truly' are (Braga and Braga 1975, x–xii). In this framing, meaning-making connects to 'truth' as something that can be found. This chapter keeps returning to the word 'truth', mostly because it is repeatedly used in the context of spiritual and existential documentaries. 'Truth' appears to legitimate the factual claims that spirituality has an important role in everyday lives. Thus, I use 'truth' to accentuate the context of these arguments, while in my argumentation I prefer the terms 'knowledge' and 'testimony'. For me, 'truth' assumes an absoluteness, whereas knowledge refers to either practical or theoretical understanding of an issue and allows room for adjustments (Merriam-Webster n.d.), and testimony combines meanings

of witnessing, 'firsthand authentication of a fact' and even 'public profession of religious experience' (Merriam-Webster n.d.). Both these terms emphasise lived experience and constructed viewpoint instead of assuming absolutes, and as such they are more in line with my understanding of documentary as an ethical space to explore mortality.

Yet, the idea that 'truth' is something to be found, remains well rehearsed in documentary contexts. Justin Wells, who works as a camera crew member in Hollywood productions and has studied both philosophy and fine arts, and has written about spirituality in documentary filmmaking. He argues that the 'truth' about the world and ourselves is always suppressed, something that remains in the margins of hectic everyday life. However, at their best, documentaries can offer a journey to explore the mysteries of life and the world, and as such, to reveal some parts of the philosophical, existential or spiritual 'truth' to the filmmaker and, in turn, to the viewer (Wells 2018). Here, documentary filmmaking is given a revealing role in the human enquiry to learn the 'truth' about meaning of life and humanity.

Many spiritual end-of-life documentaries, as the above example of *For One More Moment* shows, turn to the experts to find answers about life and death. This documentary was inspired by the filmmaker's encounter with hospice staff when her mother was dying. Awed by the staff's experience, she wanted to make a film about their expertise (Kuusela 2017). Similar experiences have inspired other spiritual documentaries as well. Lily Henderson, the director of *Lessons for the Living*, wanted to film hospice volunteers after her own experiences as a volunteer provided her with a transcendental experience on life and death. Thus, Henderson gives visibility to volunteering but her film also shows how death can ground a person, provide a holistic understanding of life and become a meaningful part of it (Henderson 2019).

Similar to *For One More Moment*, *Lessons for the Living* assumes that those who witness a lot of death and dying can gain knowledge that goes beyond everyday understandings of death and life. This is knowledge that has accumulated over the years and is based on experienced evidence. Documentary filmmaking can provide space for these testimonies in a way that enables the viewer to learn about death and dying. Even the name of the film reveals the importance of teaching potential, which is further highlighted by the opening quote from Kübler-Ross: 'We run after values that, at death, become zero … That's what dying patients teach you' (Henderson 2010).

The short documentary is a collection of interviews of hospice volunteers in New York. They testify what they have learned from the dying people and how the volunteering has changed their thinking about life, death and dying. One of the lessons is to learn how to be in the presence of a dying person. The volunteers assure that these are meaningful and beautiful encounters, where they have learned to be present, to be compassionate and to prioritise the other

over their own needs. Other lessons are related to the meaningfulness of death. As such, death encourages one to appreciate life and to find recognition for each individual existence. Says one of the volunteers: 'I think at the end people are who they are. All the masks are down. And they really are extraordinary.' In other words, by accepting that your life is limited, you can focus on being true to yourself.

Many volunteers in this documentary emphasise spirituality, even though they understand spirituality differently. The documentary introduces a priest, a shamanic healer and a follower of Buddhist religion, for example. Henderson, the director of the documentary, recognised that while she did not set out to make a spiritual film, many of her filmed subjects 'had this mystical tone', which 'sets into that world where everything is positive and light'. Thus, for her, the spiritual undertones of the interviews added 'polish' to the subject of death and dying, and therefore, the closing of the documentary provided a necessary balance to the testimonies of the meaning of death (Henderson 2019). The last person to be interviewed is Kathleen, a former volunteer, now a patient at a hospice ward. Unlike many others, she wants to avoid mystery. She argues that volunteering took the mystery out of death, and forced her to focus on the moment, the physical process, on something that is inevitable. For her, this matter-of-fact way of dealing with death encourages her to 'live today, as fully as I am able'. While Kathleen adds practical and physical aspects to accompany the mystical interpretations of death, even this practical view endorses the idea that death makes life meaningful.

In their desire to teach the viewer with their testimonies about the meaning of life and death, many spiritual end-of-life documentaries tend to follow the practices of expository documentary-making. Bill Nichols sees this as one of the oldest and still most prominent ways of creating non-fiction stories. The expository mode builds cognitive knowledge and rhetorical argumentation for a certain concept or perspective. In order to do so, these documentaries use voiceovers and interviews and list the experts' titles and affiliations to construct information that aims to reveal the 'truth' (Nichols 2017, 107–8). Similarly, spiritual documentaries use plenty of interviews, where the experts are given time and space to talk about their notions of death without interruption. This gives didactic importance to the spoken word. Images perform a supportive role, providing evidence (Nichols 2016, 75). The early documentary theorist John Grierson argues that while these kinds of documentaries would rather not be called lecture films, this is what they are. They rarely dramatise or aesthetically reveal. They describe and even expose. He gives these films value in education (and in propaganda), even if he finds that they do not make considerable contributions to the 'fuller art' of the documentary (Grierson 1966, 20). Due to such criticism, expository filmmaking has been partially displaced in the documentary field, whereas the observatory mode has increased its popularity

(Martin-Stone 2013). However, even the most speech-oriented documentaries express meanings on multiple levels and build meanings beyond what is said.

The tried and tested solution of spiritual end-of-life documentaries to use an expository mode further highlights these films' tendency to search for the meaningfulness of death. They suggest that there exists a 'truth' about death which needs to be discovered by careful examination to increase the quality of life. In this task, experts who have dedicated their professional and personal lives to these issues can help others to gain spiritual knowledge about life and death. Thus, the documentary films both showcase spiritual testimonies and participate in creating them.

In terms of showcasing spiritual knowledge, documentaries represent death and dying as transcendental themes. Erik Knudsen argues that documentaries can offer 'transcendental realism' by readjusting the focus from scientific, rational or material knowledge towards a holistic understanding of the world and its realities. He argues that because human experience has always included 'infinite, eternal, mystical and unconscious movements in existence', documentaries should also try to reach 'the very heart and soul of who we are and what we are' (Knudsen 2008, 3–4). Spiritual end-of-life documentaries rise to their transcendental challenge by exploring the meanings of life and death.

In terms of creating spiritual testimonies, documentaries can search for knowledge by various strategies. Sybille Krämer, for example, recognises a discursive and existential 'truth' from documentary expressions. The discursive approach highlights that the subjective 'truth' is not enough, but arguments need to be valid from a third-person perspective as well, and this validation is gained by careful rhetorical argumentation. Existential 'truth', then, has a performative dimension, where someone's personal experience or expertise (second-person perspective) can validate the 'truth' if the viewer believes in this authority (Krämer 2016, 30–2). Krämer only recognises these two ways of exploring 'truth' and does not consider whether there could be a first-person approach to 'truth'. Perhaps the first-person approach appears too subjective for a concept such as 'truth', whereas the concept of testimony gives more flexibility to explore this option as well. To continue from Krämer's dichotomy, I call this transcendental testimony (or 'truth', if this is what one prefers). In this argumentation, the viewer's personal experience with the film transforms their understanding of life and death, and the potential for this transcendental knowledge can be suggested through the film's aesthetics and narration. In the following analysis, I explore the different understandings of how the viewer's knowledge on spirituality of death is built through discursive (third-person), existential (second-person) and transcendental (first-person) narrative structures.

Discursive Testimony about Death

Solace: Wisdom of the Dying (2008) is created by Camille Adair, a hospice nurse, who felt that the end of life needed to be integrated into the healthcare field as a 'natural and sacred human process' (Camille Adair/Sacredigm Alliances, Llc n.d.). In an interview, Adair highlights the spiritual aspects as necessary for moving away from the medicalised, or 'pharmaceutical', approach to death and dying that has made western societies 'soulless'. Instead, she seeks elements from 'ancient traditions and ancient wisdom' that can bring attention back to the human experience and open our minds to 'the other realm' (Sitar 2012). The documentary-making inspired Adair to move into end-of-life and caregiving counselling, education and patient advocacy. She has produced an eleven-part video and multimedia project, the Solace Teaching Program, that discusses hospice and palliative care, aging, illness and dying, and is aimed primarily for people involved in caregiving or working in healthcare. In the programme, spirituality plays a prominent role in Adair's attempt to make healthcare more humane. These starting points show how spiritual knowledge is presented as an equal alternative to medical knowledge on death.

The narration of *Solace: Wisdom of the Dying* is framed by Adair's own voiceover. She uses voiceover moments to express her desire to manage the human suffering and grief that she encountered in hospice work. Her practice echoes Nichols's (2016, 59) argumentation that voiceover serves as 'moralising center around which a particular view of the world revolve[s]'. Similarly, Adair's voice guides us through the film. In her exploration of mortality, she supports her argumentation through interviews of various experts on the spiritual aspects of death. These professionals represent religious authorities, people working in healthcare fields, and various spiritual guides, such as end-of-life coaches. These people have been chosen to be interviewed due to Adair's recognition of their expertise in the field. Many have published books on end-of-life spirituality and have built companies or advocacy programmes to help dying people and their families.

For example, a major role in the film is given to Larry Dossey, a physician who praises the impact of spirituality on well-being and healing. In his book *Healing Words: The Power of Prayer and the Practice of Medicine* (Dossey 1993), he testifies that there is evidence of prayer's healing potential and it should be included in medical practices, a view that has faced considerable criticism for the way it takes a stand against science-based medicine (e.g. Baker 1994; Roberts 1995). In the documentary, Dossey talks about non-local consciousness, which makes all people connected, and how this consciousness ensures that death is a part of life, and that human consciousness continues after death. He claims that if science could accept this idea of continuing and

flowing consciousness, the medical institutes could better approach questions of death and dying in patient encounters.

Religious authorities, such as Roshi Joan Halifax, founder of the Buddhist Upaya Zen Centre (Santa Fe, New Mexico), highlight natural death, but also discuss death's meaning in an individual's life. Halifax's book *Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death* seeks to help people to encounter death with courage, without fear, mainly by using their inner strength (Halifax 2009). In the documentary, she continues to discuss fear of death, which in the worst case can turn into morbid anxiety, but which, when prepared for, can turn into thrilling anticipation of what is to come. She also foregrounds the transformative role of suffering, which is seen as redemptive. Spiritual end-of-life coaches, such as Stephen Levine and Ondrea Levine, add to this view of seeing death as a rewarding experience: being conscious of our mortality can be gratifying and prepare us for dying. Death, they testify, can inspire people to look inwards and envision a greater reality after death; self-reflection can help us find the humanness and sacredness of end of life.

All the interviews focus on the teachable spiritual testimony that experts share and the viewer can absorb through speech acts delivered in front of the camera. The experts face the camera directly, their titles indicating the professional roles and institutions they represent and the books they have written. Their expertise is established through external validation, and their direct speech to the viewer emphasises that they are worth listening to. This narrative approach fits Krämer's understanding of validating testimony through discourse. For Krämer, discursive 'truth' requires outer validation, which is recognisable to a third person and which is typically located in a speech act. In other words, discursive 'truth' is rationally known and can be taught and learned (Krämer 2016, 30). The film's testimony is provided through 'talking heads', which turns spiritual knowledge into rational and cognitive argumentation. However, according to Catalin Brylla and Mette Kramer (2018), cognitive approaches to documentary viewing invite evaluation where the viewer assesses the film's truth claims by appraising whether the documentary appears trustworthy and whether the arguments resonate with their personal, cultural and societal understanding of the topic. This process, indeed, emphasises third-person validation in that the viewer becomes the third person to decide whether they can cognitively accept the testimony and whether they find these voices believable.

While the film is built around the experts' argumentative lessons, some personal experiences about death and dying are included. These snippets follow the experts' discursive testimonies to give them further validation. These subjective testimonies focus on personal growth and how suffering has helped people to find authenticity in life and their 'true selves'. Chris Calloway, a

singer diagnosed with breast cancer, shares her experience of receiving help from chanting at the altar for hours at a time. It helped her to encounter her life situation, find wisdom in her own energy field and to gain a 'higher life condition'. Later, she also talks animatedly about finding power in spirituality (as opposed to materialism), where facing death is a way to find one's 'authentic' self and to appreciate each moment in life. Her words play at the very end of the film, when she cheerfully declares that death is a take-off to a new experience, and as such, death is framed as a transformative and positive experience, something to be looked forward to. Through these assurances, the documentary builds an image of death as a teacher in life; painful experiences make us better people, cultivate us. For that reason, suffering and pain also have a meaning. Through death acceptance, one can move beyond fear and emotional pain, and start enjoying the transformative passage to another existence, energy or consciousness.

While most of the film is based on rhetorical argumentation, the soundscape and imagery involved add a spiritual dimension to the film. By conceiving meditation and self-reflections as tools to gaining death acceptance, *Solace: Wisdom of the Dying* presents mindfulness practices as spiritual tools. Mindfulness can be seen as a theory and/or practice of a present-centred awareness that helps to manage anxiety, depression and stress. It has a background in Buddhism and meditation traditions, and is often used as a therapeutical application in the spiritual care provided in hospice and palliative care (Bruce and Davies 2005; Mcgrath 1998; Johns 2004; Lee et al. 2021). The chosen imagery of the documentary supports the mindfulness approach. Buddhist objects, such as statues of Buddha and Ganesha, a Hindu god of beginnings, and sometimes also such Christian symbols as crosses and rosaries, create the background of the interviews. The aural world of singing bowls adds to the spiritual atmosphere. The vibrating and harmonious sounds of the bowls connect to the Tibetan Buddhist canon for spiritual, medicinal and musical purposes. In the United States, in particular, the bowls have become a part of mindfulness commodities (Brown 2020). The bowls' connection to both spirituality and healing has been recognised in some medical studies (Stanhope and Weinstein 2020), and as such they serve a purpose in the documentary to further emphasise the healing aspects of spiritual knowledge that can be found and explored.

However, the use of mindfulness as part of spiritual care has also been questioned, not because of its potential to alleviate anxiety, but *how* it is used in hospice contexts. In an ethnographic study, John Eric Baugher found that when mindfulness was adopted by hospice volunteers, it guided them to pay attention to those patients that wanted to review their lives and have deep and meaningful discussions. While doing this, they tended to ignore the patients who did not or could not engage in such processes (Baugher 2008). Similar criticism is often directed towards expository documentaries that are seen to

choose editing that supports the main message and leaves other interpretations in the margins. In *Solace: Wisdom of the Dying*, the benefits of the spiritual approach to end of life are supported by overwhelmingly positive tones and stories. When the narration focuses on interviews, the imagery excludes all references to physical aspects of dying. All interviewed people appear to be in a good condition, and thus, the attention is guided towards their rhetorical and discursive argumentation. Whether viewers find this positivity comforting depends on whether they accept the discursive testimony of the documentary narrator.

Existential Testimony about Death

Krämer counters discursive 'truth' with existential 'truth' in documentary narration. She draws this concept from Søren Kierkegaard's (1991, 205–7) dichotomy between 'knowing a truth' and 'being a truth', where knowing is language-based and being has a performative dimension. So, an existential approach to 'truth' becomes experienced by someone, and when shared with others, they need to believe in it (Krämer 2016, 32–3). In this process of believing, Krämer continues to draw from Kierkegaard's existential philosophy, where authority makes it possible to distinguish between truth and belief. These authorities do not speak in their own name, but in the name of what they represent, such as religion, and their embodied experience of this higher construct turns into 'being a truth' (Kierkegaard 1991, 227). While Krämer recognises that Kierkegaard's authority-based approach to knowledge can be frustrating, she argues that the same logic is often used in documentary films where trust and belief in the authorities serve to 'generate a form of *knowledge*'. She calls this a second-person model of witnessing; the trust in the message is based on interaction between the film and the viewer. The authority serves as eyewitness and takes responsibility for the message, and if the viewers accept this guarantee, they can also accept this testimony as 'truth' (Krämer 2016, 33–4). What is interesting in Krämer's argument is that whereas discursive 'truth' is always language-oriented, images can serve as existential testimonies. In other words, if the viewer trusts the authority of the image, it can offer a way to explore existential 'truth'.

Here, I turn to *Living Your Dying* (2003), because this documentary combines expert and image authority in its desire to assure the viewer of the benefits of a spiritual approach to death and dying. The documentary was directed by Robert Pennybacker and commissioned by the Mits Aoki Legacy Foundation, which honours the work of Reverend Mits Aoki and promotes and teaches a holistic approach to healing and death. Aoki was a theologian and founder of the University of Hawaii's Department of Religion. His work centred on spirituality in the transition to death, where his aim was 'conscious

dying': people should be 'living their dying' (Tasaka 2014). The film builds on the experiences and viewpoints of Aoki, who becomes the documentary's main source of expertise and authority on knowledge about death.

The film starts with images of nature, instrumental background music and a voiceover that defines birth as a beginning, death as a destination and life as a sacred journey between these. Images of floating memorial lanterns on water fill the screen, when Aoki starts talking:

> This is a realm of mystery. And I tell you when I work with dying people, so many times the dying person manifests to me something of the sense of mystery. I don't see this as a problem or something to cure but something to really experience in such a way that it can enlarge a person. It can make a person more authentic, more real. (Pennybacker 2003)

The camera cuts to a close-up of Aoki who speaks directly to the camera. After this initial interview, nature images return, and the voiceover promises the viewer 'an extraordinary journey into the mystery of death'. The following section alternates between voiceover and Aoki's own voice, which together build an image of Aoki's life and interest in death and dying. This section shows that Aoki has become 'being a truth' by virtue of his dedication to study death and dying, his witnessing and helping thousands of people to die, and his encounters with death and dying in his personal life. Aoki is presented as an embodiment and personification of spiritual knowledge. After this introduction, the film moves on to show through images what Aoki's knowledge means in practice.

In what follows, Aoki describes his wife's death, and the viewer meets three terminally ill people, Mike, Fay and Ululani. In a voiceover introduction, they are each given a spiritual theme to represent in the narration: individual journey, significance of community and meaningfulness of nature. The scenes include meetings between the patients and Aoki, who helps the dying and their families to work through whatever issues they may face. Aoki encourages them to live as fully as possible until the end, emphasising the meaning of family, community and relationships until the very end. By showing glimpses of these individuals' lives, their stories turn into testimonials of Aoki's spiritual knowledge. We meet these people when they are calm and peaceful even when discussing negative experiences and emotions. The calmness of the images speaks for existential evidence in accepting death as a part of life. The spiritual message is created through Aoki's authority and testimonial imagery.

Mike serves as an example of the individual journey towards himself. He says, while playing with his grandchildren, that his cancer has made everything in his life more poignant. The colours, sounds and smiles have become more vivid, and life has more meaning. The garden where they play is awash

with lush green scenery, and blue skies add to the vivid view. Fay, in turn, is an example of the importance of community and relationships. After seeing the smiling images from her daughter's graduation party, Fay shares in an interview that reaching her goal to see her daughter graduate has made her ready to die, 'because I've done what I wanted to do, and that's enough'. Aoki confirms this experience by assuring Fay that her ability to accept death has made her more open to her dying. In the last example, Ululani testifies for a transition towards the sacred. Aoki helps this native Hawaiian to draw support both from Christianity and the Hula tradition, a Hawaiian dance with religious meanings. Aoki enables Ululani to use visualisations and meditation to be comforted by sacred and spiritual aspects of nature. Beautiful and vivid images of nature and the Hula traditions enhance Aoki's words that if Ululani learns to draw power from these spiritual experiences, healing can take place.

Spirituality supports the dying people, but instead of framing their experiences as merely peaceful journeys, the film does not shy away from the fears and negative emotions that these people have. Aoki does not deny these emotions, but uses meditation and religion to alleviate them. The film also portrays the physical transition of the dying people into growing frailty. The viewer is invited to their deathbeds, even if the exact moment of death is excluded from the scenes. The deathbed scenes serve as final evidence of Aoki's message that life is a journey to a transformative horizon, a journey that one does not need to be afraid of. The dying are surrounded by their loved ones, who are leaving their goodbyes, and by Aoki who encourages the dying to go on in their journey. The scenes are peaceful and comforting, and as such, these images become performed testimonials of existential knowledge.

Whereas *Solace: Wisdom of the Dying* trusted a (third-person) talking-heads approach without death-related imagery, *Living Your Dying* combines Reverend Aoki's authority with testimonial use of images of the dying people. By inviting the viewer to witness Aoki in action – providing spiritual care for the terminally ill – the film embodies spiritual testimony. In Krämer's terms, Aoki performs second-person knowledge for the viewer, and the image testimonials invite the viewer to trust Aoki's expertise. In turn, this existential approach to knowing about death assures the viewer that death should be understood as the ultimate transformation. Death can thus give meaning to life long before the actual dying process.

Transcendental Testimony about Death

The last documentary discussed in this chapter is *Die Weisse Arche* (2016), a Swiss documentary directed by Edwin Beeler, who has adopted a spiritual approach to searching for the meaning and values of life. Similar to other documentaries in this chapter, these questions are explored together with

individuals dealing with death and dying in their professional and personal lives. The film introduces a hospice nurse, Monika, whose near-death experience has removed her fear of death, the mystic Sam who banishes ghosts from people's homes, cattle herder Alfons (a former Carthusian), who has a strong connection with nature and earth, and a group of Benedictine and Capuchin monks. Beeler says that he 'was interested in how different people live spirituality in their own lives personally and how they deal with death and the certainty that like everyone else they have to die' (Biasio 2017, translated from German). This quote reveals the main difference from the earlier films; while the documentary shows that the filmed subjects have special knowledge and expertise, these are framed through subjective experience instead of a universally applied 'truth'.

In this documentary, too, the experts talk to the camera, and occasionally we see them in sit-down interviews. However, most often the interview material is used as voiceovers while the camera films the subjects in their daily activities. While travelling through the Alps by train, Monika talks about her own near-death experience after getting caught in an avalanche. The monastery gardener, filmed arranging funeral wreaths, talks about helping to organise funerals, while the monastery painter, filmed painting angels on canvas, shares with the viewer his experiences of working with dying people. Combined, the spoken words and the images of the interviewees' activities diminish a sense of lecturing. The documentary brings together observatory aspects and the expository elements of searching for knowledge about death.

The use of everyday activities connects these subjects' knowledge to their lived experience instead of producing a universal 'truth'. In addition, the observatory aspects of narration invite the viewer to witness first-person argumentation instead of third- or second-person perspectives. In this process, the viewer's attention shifts from evaluating the spoken truth claims to witnessing whether these people follow through their values and attitudes. This is what happens, for example, when Monika confesses that she used to be afraid of death and was uncomfortable to be with dying people. However, her own positive experience of dying, where she experienced that her consciousness continued to exist, has made death her friend, which has enabled her to comfort the dying and their families. In the images, the viewer sees her taking care of patients with compassion. Monika's actions embody her spiritual knowledge and assures the viewer that death acceptance has become a lived experience for Monika. The viewer no longer experiences the testimonies through an authority, instead the viewer is expected to be the first-hand witness. This witnessing offers the viewer the potential to experience the realities of the other and to embody this experience.

Knudsen argues that when dealing with transcendental topics, documentary expressions should not be limited to rational or rhetoric argumentation.

To process the holistic view of life and death, one should search for emotions and feelings that both prompt the documentary-making and result from the viewing of the documentary. He claims that to widen our understanding of realities, documentaries need to find ways to 'move the viewer in such a way as to also address their spiritual and transcendental reality'. Knudsen claims that we are less dominated by our intellect than by our embodied emotions, and thus, the transcendental in documentaries should be searched through emotional stimuli (Knudsen 2008, 8–12, quote from 10). This argumentation shows the potential of first-person approach, where the viewer is invited to be the first-person whose first task is to experience the argumentation, not to evaluate its factual validity.

The reception of *Die Weisse Arche* recognises the transcendental potential of the film. According to Rolf Breiner, a film critic, Beeler combines human experience and knowledge about death with sublime images of mountains and monastic life. These images grant the documentary grandeur and represent dying as a transition to another dimension (Breiner 2016). Breiner's words translate the viewing into a transcendental experience. The viewer is encouraged to experience the sense of awe and spirituality that the filmed subjects are living with, whereby spiritual argumentation transforms into a spiritual experience that can become subjective knowledge for the viewer as well.

Knudsen finds that 'transcendental realism' in documentaries involves inaction and stillness (instead of dramatic events), which encourage the viewers to internalise the themes and engage with their inner thoughts and emotions. The transcendental is further created by reducing rational reasoning and scientific explanation while giving mystical experiences a central role. The documentaries should therefore try to reach beyond the material world to immaterial or existential questions, and by doing so, 'transcend attachment to the physical world' (Knudsen 2008, 13–22). The documentaries could thus distance themselves from trying to make sense of the world, and pay attention to what moves the viewer, as the focus on emotions and the mystical allows transcendental ways of knowing.

Die Weisse Arche utilises many of these expressive options. The daily activities do not build on any dramatic turn of events but rather on quiet moments of walking in nature, being present for the dying people, participating in religious rituals, and, for example, baking an apple pie. These scenes are edited to intertwine with images of nature, particularly the spectacular images of the Alps, or snow falling quietly on a monastery. Anna Elsner argues that the documentary's natural and grand landscapes support the film's spiritual argumentation that death is beyond any scientific understanding. In addition, the aesthetic use of landscape and the accompanying sounds of instrumental music and chanting familiar from the Catholic tradition gain a spiritual role in themselves, because they construct a transcendental experience for the viewer and 'reinforce the sense of indomitability' (Elsner 2020, 3–5, quote from 5).

A shot with Alfons the cattle herder emphasises the transcendental testimony of nature imagery. Previously, Alfons has told he left his Carthusian community, because he found that his inner voice and divine nature connection resonated better with his illness. What follows is sixty-eight seconds of a long-shot. The shot starts with tranquillity and focuses on a majestic wintery scene, where Alfons wades slowly through the snow (Figure 4.1).

Alfons appears a small figure amid the mountains. Quiet instrumental music adds a few chords to the shot before Alfons's calm and soft voiceover describes:

> For me, there is no spirituality without the relationship with earth. And there's no bread of life without earth. And of course, there is no earth, and no growth on earth without heaven, without everything surrounding this earth, surrounding this table. The earth as a table. For me, earth is a table. (Beeler 2016)

Alfons's voice fades away, and by the end of the shot, he has waded through the image. This single shot from the documentary emphasises the transcendental connection that Alfons experiences between earth and heaven, and between life and death. The aesthetics of the image creates the same sense of connection with nature, and a sense of the majesty of nature for the viewer. In her analysis of the film, Elsner connects *Die Weisse Arche*'s sense of transcendence as an alternative to the disillusionment produced by secularisation and modernisation. While disillusionment, or disenchantment, can lead to a sense

Figure 4.1 A wintery landscape and Alfons in *Die Weisse Arche* (Beeler 2016).

of alienation from the natural world and its mysteries, the transcendental images enable the revival of enchantment (Elsner 2020, 3). *Die Weisse Arche* does not lecture about spirituality, but invites the viewer to experience spirituality and form first-person testimony about it. In other words, while the film is a testimony to spiritual knowledge and the filmed subjects testify to the meaningfulness of death awareness, the viewer can embody spiritual testimony through affective witnessing.

As part of her argument, Elsner refers to Jane Bennett's discussion on enchantment. Bennett (2001, 4) defines this experience as '[t]o be enchanted is to be struck and shaken by the extraordinary that lives amid the familiar and the everyday'. Enchantment appears as another way to describe a transcendental experience, but Bennett's argument gains significance through its connection to ethical thinking. For Bennett, a sense of enchantment is crucial to ethical experiences. She emphasises that ethics should not be seen as an obligation to do something, but as affective aspirations, as a capability to be moved, surprised and challenged through experience (Bennett 2001, 3–4). This view resonates with the phenomenological discussions within cinema studies about ethical experience, which reaches beyond rational evaluation towards utilising the viewer's affective and embodied reactions to filmed materials. Jane Stadler (2008, 2), for example, argues that at best, films have an afterlife, or in other words, 'influence what remains with us when we are affected by the sensory impacts of the films, captivated by story, character, and conflict, and left wondering about the issues they raise'. When the viewer is left wondering, transformations in thinking and experiencing may emerge. Thus, embodied and affective cinematic experiences can create ethical space to encounter new ideas, to search for potential realities and to understand others' experiences. These can nurture care, compassion and responsibility towards others (Raviv 2021, 2, 7; Stadler 2008, 6, 38). Thus, the transcendental way of knowing in documentary films have similarities with ethical experiences.

The way in which *Die Weisse Arche* creates enchantment through sublime aesthetics together with the filmed subject's embodied spiritual knowledge also creates potential for a transcendental and ethical experience. Here, the viewer can construct first-person knowledge about spiritual aspects of death and dying. Instead of suggesting a universal or an objective 'truth', the film suggests that there are empowering aspects in subjective knowledge. The documentary questions the exact limits between life and death. These people, the nurse with a near-death experience, the healer/mystic who banishes ghosts, and the Catholic monks, are united in their conviction that there is an afterlife, a continuation of consciousness. According to their transcendental testimony, there is no need to fear death as an end.

Conclusion

Spiritual end-of-life documentaries argue that death is a more complex question than scientific understanding allows room for. Death is also a source for existential and transcendental questions and experiences. These films highlight death acceptance narratives, and they do so by providing teachable interviews and moments for the viewer. In their desire to expose or reveal the benefits of spirituality, these documentaries portray death as a meaningful part of life, and by acknowledging this, one can focus on living and experience less death anxiety. These documentaries do not discuss how death should (or should not) be approached from a medical perspective or how dying should be cared for, but they focus on how making death meaningful could add quality to everyone's lives.

Spiritual end-of-life documentaries tend to explore their topic with the help of people who deal with death and dying in their professional lives. These films prioritise expertise and institutional views on spiritual aspects of death and dying. However, the ways in which this knowledge is built vary. To build a more factual validation of the benefits of spiritual care, some documentaries, such as *Solace: Wisdom of the Dying*, *Lessons for the Living* and *For One More Moment* use the discursive knowledge of experts teaching and transforming their knowledge for the viewer. Other films, such as *Living Your Dying*, use expert knowledge and testimonial images to build a second-person aspect where truth can become existentially known. And *Die Weisse Arche* invites the viewer to build first-person testimony by providing transcendental experiences.

In all these approaches, we can recognise different epistemological paths to how we can know about the world. Both third- and second-person approaches want to validate spiritual knowledge by presenting it educationally through discursive testimonial evidence. Their approach conforms with the traditions of early modern western philosophy. These philosophical discussions have framed subjective knowledge as a secondary, and potentially a misleading, way of knowing. Empirical knowledge is the primary way of knowing because it can be detected in the physical and empirical world (Bolton 2022). Thus, when spiritual knowledge is represented as part of something that professionals have empirically gained and observed, this knowledge gains cultural and societal validation. It should therefore be given a position equal to that of medical knowledge in western countries' understanding about death. And consequently, the subjective way of knowing would limit spirituality to the sphere of belief.

However, when these goals of emphasising the spiritual aspects of death are brought to documentary-making, the roles of both subjective and empirical ways of knowing turn around. The subjective approach of *Die Weisse Arche* invites the viewer to experience the argumentation in first-person. In this

process, the viewers become witnesses of others' experiences and can create their own empirical views on the topic. In comparison, universal argumentation about spirituality makes the viewer dependent on the experts' views, and the viewers need to evaluate whether their knowledge appears as trustworthy or too subjective and conditional. As such, in the documentary context, the transcendental testimonies can offer subjective and affective, yet empirical, ways of knowing, and this internalised mode can provide an ethical space to explore the mysteries of death and life.

References

Adair, Camille. 2008. *Solace: Wisdom of the Dying*. Documentary. Point of Light Productions.

———/Sacredigm Alliances, Llc. n.d. 'About | Meet Camille'. Camille Adair. https://camilleadair.com/camille/. Last accessed 4 January 2022.

Baker, Robert. 1994. 'If Looks Could Kill and Words Could Heal'. *Skeptical Inquirer*, A Skeptic's Notebook, 4 (3). https://skepticalinquirer.org/newsletter/if-looks-could-kill-and-words-could-heal/. Last accessed 27 June 2023.

Baugher, John Eric. 2008. 'Facing Death: Buddhist and Western Hospice Approaches'. *Symbolic Interaction* 31 (3): 259–84. https://doi.org/10.1525/si.2008.31.3.259.

Beeler, Edwin. 2016. *Die Weisse Arche*. Documentary. Calypso Film AG.

Bennett, Jane. 2001. *The Enchantment of Modern Life: Attachments, Crossings, and Ethics*. Princeton, NJ: Princeton University Press.

Biasio, Fabian. 2017. 'Die Weisse Arche: Interview Mit Filmemacher Edwin Beeler'. Letzte Reise. 17 January 2017. https://geschichten.letztereise.ch/beitraege/2017/die-weisse-arche/index.html. Last accessed 12 December 2022.

Bolton, Martha. 2022. 'Primary and Secondary Qualities in Early Modern Philosophy'. In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta and Uri Nodelman. Stanford, CA: Metaphysics Research Lab, Stanford University. https://plato.stanford.edu/archives/fall2022/entries/qualities-prim-sec/.

Bovero, A., P. Leombruni, M. Miniotti, G. Rocca, and R. Torta. 2016. 'Spirituality, Quality of Life, Psychological Adjustment in Terminal Cancer Patients in Hospice'. *European Journal of Cancer Care* 25 (6): 961–9. https://doi.org/10.1111/ecc.12360.

Braga, Joseph L., and Laurie D. Braga. 1975. 'Foreword'. In *Death: The Final Stage of Growth*, edited by Elisabeth Kübler-Ross, i–xiii. New York: Touchstone.

Breiner, Rolf. 2016. 'Dem Tode ganz nah'. Cineman. 2 July 2016. https://www.cineman.ch/movie/2016/DieWeisseArche/review.html. Last accessed 12 December 2022.

Brown, Candy Gunther. 2020. 'Tibetan Singing Bowls – Los Cuencos Cantores Tibetanos'. *American Religion* 1 (2): 52–73. https://doi.org/10.2979/amerreli.1.2.03.

Bruce, Anne, and Betty Davies. 2005. 'Mindfulness in Hospice Care: Practicing Meditation-in-Action'. *Qualitative Health Research* 15 (10): 1329–44. https://doi.org/10.1177/1049732305281657.

Brylla, Catalin, and Mette Kramer. 2018. 'A Pragmatic Framework for the Cognitive Study of Documentary'. *Projections* 12 (2): 159–80. https://doi.org/10.3167/proj.2018.120216.

Dossey, Larry. 1993. *Healing Words: The Power of Prayer and the Practice of Medicine*. San Francisco, CA: HarperSanFrancisco.

Elsner, Anna Magdalena. 2020. 'Landscapes of Care and the Enchantment of Dying in Edwin Beeler's *Die Weisse Arche* (2016)'. *Studies in Documentary Film* 14 (2): 147–60. https://doi.org/10.1080/17503280.2020.1725994.

Ferrell, Betty R. 2017. 'Spiritual Care in Hospice and Palliative Care'. *The Korean Journal of Hospice and Palliative Care* 20 (4): 215–20. https://doi.org/10.14475/kjhpc.2017.20.4.215.
Grierson, John. 1966. *Grierson on Documentary*, edited by Forsyth Hardy. Berkeley; Los Angeles: University of California Press.
Halifax, Joan. 2009. *Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death*. Boston, MA: Shambhala Publications, Inc.
Henderson, Lily. 2010. *Lessons for the Living*. Documentary. ThinPlace Pictures.
———. 2019. Personal interview by Outi Hakola.
Johns, Christopher. 2004. *Being Mindful, Easing Suffering: Reflections on Palliative Care*. London; New York: J. Kingsley Publishers.
Kates, Jeannette. 2020. 'Self-Reported Fears by Hospice Patients at the End of Life'. *Innovation in Aging* 4 (Suppl. 1): 246–7. https://doi.org/10.1093/geroni/igaa057.795.
Kierkegaard, Søren Aabye. 1991. *Practice in Christianity: Kierkegaard's Writings, Vol. 20*. First published 1850. Princeton, NJ: Princeton University Press.
Knudsen, Erik. 2008. 'Transcendental Realism in Documentary'. In *Rethinking the Documentary: New Perspectives, New Practices*, edited by W. De Jong and T. R. Austin, 108–20. Berkshire; New York: Open University Press. https://eprints.bournemouth.ac.uk/21857/.
Krämer, Sybille. 2016. 'Truth in Testimony: Or Can a Documentary Film "Bear Witness"? Some Reflections on the Difference between Discursive and Existential Truth'. In *In the Beginning Was the Image: The Omnipresence of Pictures*, edited by András Benedek and Ágnes Veszelszki, 29–40. Frankfurt am Main: Peter Lang AG. https://www.jstor.org/stable/j.ctv2t4cns.5.
Kübler-Ross, Elisabeth. 1975. *Death: The Final Stage of Growth*. New York: Touchstone.
———. 2009. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. London: Routledge.
Kuusela, Matti. 2017. '23-vuotias Jenny Timonen esitti vaikean kysymyksen äitinsä kuolinvuoteen äärellä – Hoitajan rohkea vastaus sai hänet tarttumaan vaikeaan aiheeseen'. *Aamulehti*, 12 October 2017. https://www.aamulehti.fi/kulttuuri/art-2000007276575.html. Last accessed 8 December 2022.
Lee, Jihyun, Kwan Hoon Kim, Craig S. Webster, and Marcus A. Henning. 2021. 'The Evolution of Mindfulness from 1916 to 2019'. *Mindfulness* 12 (8): 1849–59. https://doi.org/10.1007/s12671-021-01603-x.
McCabe, Marilyn. 2003. *The Paradox of Loss: Toward a Relational Theory of Grief*. Westport, CT: Praeger.
Mcgrath, Pam. 1998. 'Buddhist Spirituality—a Compassionate Perspective on Hospice Care'. *Mortality* 3 (3): 251–63. https://doi.org/10.1080/713685956.
Martin-Stone, Karen. 2013. 'The Ethics of Television Archaeology.' In *World Archaeological Congress (WAC7)*. Jordan.
Merriam-Webster. n.d. 'Knowledge'. In *Merriam-Webster.com Dictionary*. https://www.merriam-webster.com/dictionary/knowledge. Last accessed 27 June 2023.
———. n.d. 'Testimony'. In *Merriam-Webster.com Dictionary*. https://www.merriam-webster.com/dictionary/testimony. Last accessed 27 June 2023.
Nichols, Bill. 2016. *Speaking Truths with Film: Evidence, Ethics, Politics in Documentary*. Oakland: University of California Press. https://www.jstor.org/stable/10.1525/j.ctv1wxtcp.
———. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.
Pennybacker, Robert. 2003. *Living Your Dying*. Documentary. Lotus Film Productions.

Raviv, Orna. 2021. *Ethics of Cinematic Experience: Screens of Alterity*. New York: Routledge.
Roberts, John. 1995. 'Healing Words: The Power of Prayer and the Practice of Medicine'. *BMJ* 311 (7013): 1174. https://doi.org/10.1136/bmj.311.7013.1174.
Savola, Pauliina. 2019. 'Vielä pienen hetken vierelläsi, arvostelu'. Film-O-Holic.com. 8 February 2019. http://www.film-o-holic.com/dvd-arvostelut/viela-pienen-hetken-vierellasi/. Last accessed 8 December 2022.
Sitar, Dana. 2012. 'What Is the SOLACE Project? – An Interview with Camille Adair'. *SevenPonds* (blog). 4 August 2012. https://blog.sevenponds.com/professional-advice/an-interview-with-camille-adair. Last accessed 11 January 2022.
Stadler, Jane. 2008. *Pulling Focus: Intersubjective Experience, Narrative Film, and Ethics*. New York: Continuum.
Stanhope, Jessica, and Philip Weinstein. 2020. 'The Human Health Effects of Singing Bowls: A Systematic Review'. *Complementary Therapies in Medicine* 51 (June): 102412. https://doi.org/10.1016/j.ctim.2020.102412.
Stephenson, Pamela L., Claire B. Draucker, and Donna S. Martsolf. 2003. 'The Experience of Spirituality in the Lives of Hospice Patients'. *Journal of Hospice & Palliative Nursing* 5 (1): 51–8.
Tasaka, David. 2014. '"Light, Love and Wisdom" Live On'. Mits Aoki Legacy Foundation. 6 December 2014. https://mitsaoki.com/. Last accessed 13 January 2022.
Timonen, Jenny. 2017. *For One More Moment* (*Vielä Pienen Hetken Vierelläsi*). Documentary, Short. Elokuvapalvelu J. Suomalainen.
Wells, Justin. 2018. *How to Film Truth: The Story of Documentary Film as a Spiritual Journey*. Eugene: Cascade Books.

5. ADVOCACY DOCUMENTARIES

Investigating the Legalisation of Assisted Dying

End Credits (Decommere 2013), a Belgian documentary on assisted dying, opens with a scene from Frans Buyens's autobiographical film *Less Dead than the Others* (1992). The featured scene portrays Irma before her assisted death. She smiles sweetly, declares that her time has come and thanks the man holding her hands. In *End Credits*, twenty years later, Frank Buyens's life partner recalls how the film influenced the debates on assisted dying in Belgium, and how Buyens, similarly to this scene, mumbled his own thank you at the moment of his assisted death. In *Fatal Flaws: Legalising Assisted Death* (2018), another documentary on assisted dying, a Dutch journalist complains to Canadian filmmaker Kevin Dunn that several new documentaries portray euthanasia in a favourable light. Dunn asks another journalist if this is propaganda, and gets a decidedly affirmative answer. Both documentaries recognise and acknowledge the influence that cinematic narratives have on public debates about assisted dying.

Consequently, many assisted dying documentaries follow advocacy practices. Advocacy documentaries play a role in civil society by using strategic communication to engage the viewer in civic participation, to promote a certain perspective and to mobilise action (Aufderheide 2008). Advocacy films openly embrace their drive for social change and push the boundaries of social issue documentaries. Diana Barrett and Sheila Leddy categorise the potential impact of advocacy documentaries and recognise that films can aim for (1) individual responses to the film, (2) public awareness on issue, (3) public engagement

that mobilises audiences, (4) social movement that mobilises groups of people to commit to campaigning, and (5) social change that provides long-term change, such as policy or legislative changes (Barrett and Leddy 2008, 16–19). Documentaries on assisted dying tend to aim higher than raising awareness. Often they openly desire to influence legislative issues related to end of life. Documentaries provide accessible narratives on the issues, and as Nina Zeldis (2005, 131–3) argues, they take assisted dying debates outside courtrooms by adding the appeal of personal stories to legal debates.

Documentaries about assisted dying have been popular in the twenty-first century when the legal aspects of assisted dying have been in flux in western countries. While most western countries allow some form of passive euthanasia (refusal or withdrawal of treatment and life support), active euthanasia remains illegal in most places. These laws, however, are under debate, and an increasing number of countries and areas have legalised some form of assisted dying over the past twenty to twenty-five years. Switzerland does not criminalise supplying means for suicide, and non-profit organisations have since the 1980s helped those wanting to end their lives. Oregon, a state in the north-west of the United States, started assisted dying practices in 1997, and other states have slowly started to follow its lead: Washington (2008), Montana (2009), Vermont (2013), California (2016), Colorado (2016), District of Columbia (2017), New Jersey (2019), Hawaii (2019), Maine (2020) and New Mexico (2021). In Europe, assisted dying is legal in the Netherlands (2001), Belgium (2002), Luxembourg (2009) and Spain (2021). Canada legalised assisted dying in 2016, Australian states and territories passed legislation between 2017 and 2022, and New Zealand changed its laws in 2021. Several documentary films have been dedicated to the debates related to these changes in attitudes and legislation.

Jan Grue (2022, 2) argues that documentaries on assisted dying participate in creating these changes. He explains the processes with the Foucauldian concept of biopolitics. Biopolitics describes the processes where a state's power intersects with body management, such as reproductive practices and health management (Foucault 1990, 133–59). In the context of death, biopolitics often functions in a negative context. For example, the term necropolitics coined by Achille Mbembe (2019) refers to the state's authoritative use of power in causing death through war and capital punishments or by exploiting natural resources. Grue argues that a state's politics could also approach death in a positive, productive and collaborative manner. In the positive 'thanatopolitics', a term borrowed from S. J. Murray (2018, 718–19), the state could aim to ensure a good or meaningful death for its citizens (Grue 2022, 4–6). The biopolitics of death, indeed, revolves around society's understanding of a 'good death'. For some, it refers to the so-called natural death supported by comfort care. For others, 'good death' refers to the ability to

control the manner and time of one's own death. In the documentaries, this tension transforms into a debate over the ethics of the state's normative death-related biopolitics. The documentaries often serve assisted dying as a moral dilemma that needs to be investigated. Daniel Shaw (2012, 2) argues that the cinema tends to explore ethical concepts, exemplify ethical theories and thought experiments or discuss various perspectives on moral issues, such as assisted dying. In documentary films, similarly, the filmmakers investigate this controversial topic, and the viewer is given the position of a critical evaluator, and consequently, the role of an active agent in the processes of social change.

In this chapter, I analyse the ways in which the documentary films participate in the biopolitics of death. I will start by briefly reviewing the expository approach of the documentaries on assisted dying, and will then move on to study three independent documentary films. I analyse the abovementioned Belgian documentary *End Credits* (Decommere 2013), which takes an evaluative stance on existing practices of assisted death. I will then discuss the other film mentioned above, the Canadian documentary *Fatal Flaws: Legalising Assisted Death* (Dunn 2018), where the filmmaker Kevin Dunn visits the Netherlands, Belgium, the United States and Canada to discuss the problematic aspects of legalising assisted dying, and an Australian documentary, *Fade to Black* (Ervine 2017), which supports the right-to-die campaign in Victoria, Australia. My analysis shows that these documentaries have different understandings of the relationship between the state and the individual. The films that are critical on the issue advocate the state's responsibility to protect (vulnerable) citizens, whereas documentaries favouring the legalisation emphasise the individual's right to choose. These two perspectives relate to different ethical principles about right and wrong. Supporting human rights and avoidance of causing harm are both considered ethical acts (Velasquez et al. 2010), but in the documentaries about assisted dying, they are often contradicted. The opponents of assisted dying consider death assistance to be an unethical practice because it harms human lives, whereas advocates for the legalisation frame assisted dying as an ethical issue of human rights.

Investigative and Evaluative Approaches

Media stories on assisted dying, in general, use social, cultural and political power in generating and guiding the public discussions (Winnington 2021, 177; Grue 2022, 2, 6–7; Booth and Blake 2022, 107; Johnstone 2013). Several studies show that media coverage on assisted dying has been unbalanced and has favoured the legalisation arguments in the twenty-first century (Johnstone 2013; Kis-Rigo et al. 2021; Booth and Blake 2022, 110–12). In the case of documentary films, Peter Saunders (2022, 11) explains the bias with the media

tendency to prioritise 'new' topics and social change stories. He accuses the BBC of failing as a public broadcaster to represent a proper cross-examination of assisted dying and for focusing on documentaries that portray assisted dying in a positive light (Saunders 2011, 244–50). These kinds of positive portrayals, Megan-Jane Johnstone (2013) argues, normalise assisted dying and, consequently, shift the public opinion.

Television documentaries, particularly, explore the topic through the international legalisation context. Film crews travel to countries where assisted dying is legal to investigate their practices. For example, in *Live and Let Die* (SBS Australia 2002), the film crew heads to the Netherlands to find out 'why the Dutch tolerate euthanasia', while in *Choosing Death* (Fellows 2018), an episode in the BBC documentary series *Altered States*, Louis Theroux travels to the United States to meet with people preparing for assisted dying. One of the most popular destinations is Switzerland, where a non-citizen can receive death assistance; Frontline documentary *The Suicide Tourist* (Zaritsky 2010) follows a Chicago native to clinic in Switzerland. Swiss assisted death practitioners are interviewed in several documentaries. For example, Dr Erika Preisig, president of Lifecircle, an organisation for assisted suicide, appears in such documentaries as *Terry Pratchett: Choosing to Die* (C. Russell 2011), *Final Exit* (2014) and *The Good Death* (Krupa 2018). Travelling allows the documentary makers to research the practices of assisted dying, including the acceptance process, use of lethal drugs, and the environments where deaths take place. For example, the French documentary *Dignitas – la mort sur ordonnance* (Menoud 2010) and the (Swedish-language) Finnish documentary series *Med rätt att dö* (Svarvar and Holmberg 2020) explore how assisted dying works as a practice and as an industry. The documentary crews talk with physicians, representatives of advocacy groups, lawyers, politicians and researchers. Such institutional and authoritative perspectives turn the focus towards rational argumentation related to both critical and positive aspects of assisted dying.

It is difficult unequivocally to define whether assisted dying is treated negatively or positively in the television documentaries, although the latter appears to be more common. The inclusion of personal stories of those seeking assisted dying creates understanding towards their decisions, and many of these protagonists want to act as examples and contribute to the legalisation of assisted dying in their home countries. For example, the Australian television documentary *My Own Choice* (Jackson 2013) introduces 35-year-old Jay who is severely, but not terminally, ill. He campaigns publicly, not only to change Australian laws, but to raise funds to travel to Switzerland for assisted dying. Similarly, in *Allow Me to Die* (Mason and Weitenberg 2015), an Australian journalist explores how assisted dying functions in Belgium, and alongside with physicians and politicians, two patients, Peter and Simona have

an important role. These patients represent the individual need and desire for assisted dying, while the authorities voice both negative and positive aspects of death assistance. Once again, embodied personal stories place a strong emphasis on feelings and seem to add emotive persuasion to what is otherwise presented as rational argumentation for and against assisted dying.

The investigative approach encourages the viewer to cognitively evaluate the credibility and reliability of the claims that these documentaries create. The theories of reception of documentary film emphasise that the viewers have responsibility to use their earlier knowledge to evaluate whether a documentary's content seems reliable. Yet, how the issues are represented and argued for the viewers influences their evaluation and interpretation (Eitzen 2007, 185; Austin 2012; Nichols 2017, 33; Brylla and Kramer 2018). Carl Plantinga (2013, 44–5), for example, argues that the viewers trust the content if they can assume that the filmmakers are handling the topic with respect. This respect, however, does not translate into objectivity or a neutral perspective; instead the creative non-fiction storytelling provides viewpoints that can help the viewer to understand life and people (Borum Chattoo 2020, 15). Thus, the viewing experience is influenced by the need to evaluate both the reliability of the content and the ethical practices related to its representation.

The Belgian film *End Credits* (Decommere 2013) engages the viewer to evaluate the moral complexity of assisted dying. The film, released ten years after the legalisation of assisted dying in Belgium, aims to study those aspects of the law that have remained questioned. To do this, the film director Alexander Decommere introduces two ethically challenging cases. First, the filmmaker follows 83-year-old Adelin's life in a care facility. Adelin has dementia and years ago, before he became ill, filed for assisted dying in case he would no longer be himself. In the care facility, Adelin tells the nurses that it is difficult to find meaning in life, and he occasionally repeats his plea for help to die. However, when discussing this request with his physician, Adelin gets angry and offended and accuses the doctor of wanting to get rid of him. One of the nurses admits to the camera that Adelin's changing moods are disturbing. While the staff want to support Adelin's choice, his memory problems make it difficult to know whether his choice is still the same as it was when he was healthy.

The second case introduces Eva and her physician. In an interview, Eva faces the camera calmly and explains that she suffers from psychiatric issues and that nothing has helped her suffering. Thus, she seeks assisted dying as a young person. Eva wishes to donate her organs, because helping others would give meaning to her otherwise miserable life. The physician supports her wishes, and after evaluation, Eva's request is accepted. Yet, Eva's own hospital cannot benefit from her death, and they need to seek approval from another hospital to receive Eva's organ donation. The receiving hospital's ethical committee,

however, rejects Eva's request for assisted dying and suggests further treatment options.

These two introductory sequences pose dementia and mental health as morally problematic cases of assisted dying. Both stories view death assistance as a situational and a societal question. According to C. H. Whiteley (2022, 21–5), 'moral' as a concept has two sides: a sociological aspect that refers to communal moral beliefs and a psychological side that refers to the inner morality of person. In advocacy documentaries, the two aspects intertwine. The shared moral values guide what kind of choices are available for the individual, and individual cases require society and its institutions to evaluate their normative practices. In *End Credits* the viewer is invited to participate in the evaluation of these practices, along with various professionals. After introducing these cases, the filmmaker adds another evaluative level to the narration. He shows the filmed material, for example, to professors of ethical medicine and medical law, psychiatrists and members of ethical committees. The specialists are shown to watch the same footage that viewer has just seen on Decommere's laptop before offering their evaluation of the cases.

In Eva's case, most professionals argue that she conveys her desires clearly and she should be granted permission for assisted dying. They argue that the new committee should not intervene with the decision made by another committee. One enraged expert blames the other hospital for undermining Eva's autonomy. Few question Eva's young age, and only one professional claims that if even one ethical committee sees problems in this case, 'we as a society should accept' their decision. Here, the majority defend individual choice, and the minority vote for society's responsibility to protect its citizens. In Adelin's case, most experts hesitate to follow through with an assisted death. The debate focuses on whether Adelin is the same person as before, and whether we should honour his earlier wishes or respect the person he has become and, thus, refrain from hastening death. The memory problems suggest that Adelin's autonomous subjectivity and capability to make choices are compromised. Whereas the views vary on his current capability to make rational choices, most of the professionals would follow the guideline of 'when in doubt, we should do nothing'.

These varied professional viewpoints serve to emphasise the complexity of evaluation of ethical principles related to assisted dying. The viewers have been able to first evaluate the cases based on their values about what is right and wrong, and then, experts provide additional ethical argumentation into the mix. Finally, the filmmaker reveals how Adelin's and Eva's cases are resolved. Eva opts out of organ donation in favour of keeping her date for assisted dying. The filmmaker witnesses Eva's final moments, when she settles on the couch and the physician administers the medication. The doctor watches over Eva when she turns sleepy, starts to breathe heavily and finally stops breathing.

Her death is quick, peaceful and takes place in the comfort of her own home. In Adelin's case, the physician decides on comfort care instead of assisted death. Adelin quickly becomes fragile and his breathing turns laboured. The care facility invites people to join Adelin during his last moments, and while his death takes long and is physically demanding, he is surrounded by those who love and support him.

According to Jennifer Malkowski, both these cinematic deaths could come under the modern category of a 'good death', because the representations offer customised and unique deaths which continue their lifestyles and life stories. Consequently, a good death also becomes a personal responsibility that is constructed through action, such as making an active choice about end of life. At the same time, individualism allows distance between the dying person and the viewer because uniqueness promises that your death will be different. Therefore you do not need to care so deeply (Malkowski 2017, 73–86, 104). Grue, similarly, argues that documentary portrayals of assisted death frame death as someone else's rational choice, and as such, the death of others escapes identification and invites evaluative practices (Grue 2022, 17–18). As such, while *End Credits* offers two death scenes, these scenes become part of an investigative approach where the viewer can evaluate the consequences of Eva's and Adelin's choices.

Neither of the cases offers an absolute answer to when assisted dying should be permitted. Instead, both cases encourage the viewer to participate in ethical evaluation of whether the vulnerable person should be protected or whether they have agency to make an informed choice. These debates have often been seen as relating to neoliberalism. Neoliberalism is a controversial and incoherent term, which often refers to extending the use of competitive market logic in all areas of life, including subject making (Springer, Birch, and MacLeavy 2016, 1–3). Liz Bondi (2005, 499), for example, argues that a neoliberal subject is 'an autonomous, individualized, self-directing, decision-making agent at the heart of policy-making'. Grue contends that neoliberalism also explains recent changes in end-of-life biopolitics. In neoliberal states, death becomes freely chosen, an individual's rational decision allowed by the state (Grue 2022, 4–5, 8). Consequently, public debates on assisted dying revolve around such themes as individual autonomy, choice and rights, which are contrasted to society's duty to protect vulnerable people and the sanctity of human life (Inthorn 2017, 159–64; Rawlings et al. 2023, 8–13; van Wijngaarden and Sanders 2022; Burlone 2020; Booth and Blake 2022, 110–15). Thus, the debate over the morality of assisted dying is also a debate over modern subjectivity and responsibility.

Amanda Booth and Denise Blake (2022), for example, argue that in the New Zealand media stories on assisted dying, the subject could take a position of 'my choice', or they could recognise the vulnerability of disabled and

elderly people. In the first case, the (neoliberal) subject is loaded with positive terms, such as autonomy and individuality. In the second case, neoliberalism is seen as a dangerous choice for society because it makes it difficult to protect vulnerable people. These discourses, according to Booth and Blake, also create different stories of protection. In the first case, the focus is on protecting the human rights of an autonomous individual, while in the second case, society or individuals with a moral sense protect those who cannot protect themselves (Booth and Blake 2022, 110–15). *End Credits* repeats both these narratives where Eva is seen as autonomous decision-maker and Adelin is a vulnerable person needing protection. From these two positions, the film asks the viewer to evaluate how far we can take being respectful of individual choices while also being responsible for the decisions to administer lethal drugs.

Protecting the Vulnerable

The Canadian film *Fatal Flaws*, unlike *End Credits*, openly celebrates its advocacy function, while still using a similar evaluative and investigative style. It is produced in association with the North American advocate organisation The Euthanasia Prevention Coalition that aims 'to preserve and enforce legal prohibitions and ethical guidelines prohibiting "mercy killing"' (Euthanasia Prevention Coalition n.d.). In Canada, assisted suicide was legalised for terminally ill adults in 2016. The film was released in 2018, when the discussions to extend the law were underway. In 2021, Canadian legislation was amended to allow assisted dying in more varied situations. *Fatal Flaws* appears as a counter-argument to such demands, and the context explains the documentary's focus on the dangers of the 'slippery slope', the theory that argues that if assisted dying is accepted in any form, it inevitably leads to killing the citizens who have become a burden on society. On the film's website, director Kevin Dunn writes that 'it's impossible to ignore the cultural shift in attitude towards euthanasia and assisted suicide. What was once considered murder under the law is now being accepted as medical "treatment" in many countries' (Dunn 2017). To investigate these dangers, the filmmaker visits the Netherlands, Belgium and the United States to study the undesirable consequences of legalisation processes.

The documentary is a collection of interviews framed by Dunn's voiceover and questions. He interviews people on both sides of the argument, yet his style creates a narrative of 'us' versus 'them'. For example, his voiceover opens the film:

> They call it with a lot of different things. Death with Dignity, Doctor Assisted Death, medical aid in dying. Those are all pretty turns of the phrase. […] The ugly truth is we are talking about giving doctors the legal right to kill their patients. (Dunn 2018)

Here, Dunn positions those supporting assisted dying as 'them', whereas 'we' are the critical voices who have a moral duty to oppose assisted dying.

Repeatedly, Dunn declares a need to protect the vulnerable, particularly those who are elderly, who have memory issues, who are depressed, disabled or young. These are the people, he argues, that will be collateral damage in the slippery-slope practices of assisted dying. Dunn accompanies the slippery-slope argument with strong emotional reactions that add a sense of threat to the narration. In these contexts, Dunn uses the first-person 'I' narration. For example, when discussing the expansion in the Netherlands to include those suffering from psychiatric and existential suffering to assisted dying practices, Dunn responds with a personal statement that it scares him.

Personal testimonials also have their expository role in the narration. These are stories of vulnerable people, such as disabled and elderly people, to whom assisted dying was offered as a humane treatment option. In almost all these cases, a family member speaks for the vulnerable person needing protection from ill-advised healthcare personnel. A mother talks about being asked to consider assisted suicide for her disabled daughter who was given no hope of recovery. The mother, sitting next to her daughter, is offended by the suggestion, and the recollection makes both of them cry. In another case, a daughter shares her story of having had to fight to get medical care for her elderly mother when the care staff were ready to give up. And a physician recalls convincing one of his cancer patients that there is something worth waiting for after the aggressive and invasive treatments. Years later, the patient thanked him for saving her life. These testimonials expose problems with healthcare and argue repeatedly that with proper care and protection, assisted dying is an unnecessary alternative.

While testimonials add emotional persuasion to the narration, the interviews with authorities and professionals take the main stage. By focusing on rhetorical arguments, *Fatal Flaws* takes cues from expository documentary mode, where argumentation builds with expert interviews, but from a certain perspective, including propagandist approach (Grierson 1966; Nichols 2017, 107–8). Particularly, Dunn makes use of evidentiary editing, where continuity is built not on the continuous use of time or place, but on the cohesion of argumentation or perspective (Nichols 2017, 121–3). For example, when Dunn asks a journalist whether this is propaganda, the viewer assumes that the question is related to the previous comment on documentary films' influence. Yet, the interviewees change between the shots making it unclear whether the person responds to the same claim or not. This type of presentation has raised ethical concerns. Kate Nash (2011, 227), for example, argues that due to their rhetorical structure, expository documents tend to speak 'on behalf of others, placing them within the documentary's argumentative structure'. As such, individual views may become secondary to the narrator's argument. Nichols

goes as far as labelling expository films as using a 'Voice of God' commentary, where the film's narrator decides how the argumentation is presented (Nichols 2016, 75–6; 2017, 121–3).

Dunn uses the interviews as conveying a seemingly balanced debate. In the early scenes of the film, for example, he uses a split-screen scene where different authorities appear on-screen one after another. Each interview was filmed separately, but on the split-screen they appear to be talking at once and in relation to each other. Even when their voices are muted, the authorities' hand movements add a debating feel to the scenes. Dunn's voiceover explains the meaning of the split-screen: 'Proponents argue that people should have the right to choose the way they die. Critics say that choice is an illusion, and a recipe for elder abuse and coercion when people are at their most vulnerable' (Dunn 2018).

After setting the tone for debate, the documentary focuses on tearing down arguments that are often used in support of legalisation of assisted dying. Dunn introduces five main claims in title cards along the film. In all these, the viewer first sees the original argument before the text transforms into a counter-argument:

1. 'It's about choice' vs. 'It's *not* about choice'
2. 'It is about terminal illness' vs. 'It is *not* about terminal illness'
3. 'It's about suffering and pain' vs. 'It's *not* about suffering and pain'
4. 'It isn't suicide' vs. 'It *is* suicide'
5. 'This is caring' vs. 'This is *killing*, *not* caring' (Dunn 2018)

One of the key questions in *Fatal Flaws* is the potential abuse of assisted dying in healthcare. With the help of personal testimonials, Dunn raises fears that

Figure 5.1 Split-screen image of interviewed authorities in *Fatal Flaws* (Dunn 2018).

healthcare professionals will pressure vulnerable people who are a (financial) burden on society to agree to kill themselves. William, a paralysed professor, blames healthcare professionals for pressuring him to refuse treatment which is expensive and uncertain. These requests to consider alternatives for treatments undermine his value and make him feel that he is not treated with similar seriousness as other patients due to his disabilities. Similar concerns are voiced by advocacy groups that oppose assisted dying. They argue that politicians put pressure on doctors to learn how to kill their patients, instead of how to care for them. Dunn also meets with physicians who argue that they do not want to be put in a position where they are expected to harm their patients. These doctors see themselves as protectors of the vulnerable, as the last line of defence – and suspect that their profession in general will not be able to live up to these high moral standards.

Dunn uses this framing to censure the arguments of the advocacy group Death with Dignity. He has a long conversation with the group representative, who assures Dunn that the organisation wants assisted dying to take place in a legal and supervised context. The representative places responsibility on the physicians because their role involves ethical standards and professional integrity. If doctors are the ones to prescribe medication for assisted dying, it is better that they should consider their responsibilities in the evaluation of each individual case. The representative of Death and Dignity aims this argument to be reassuring – one cannot just ask for assisted dying and expect to be able to die tomorrow – but the doubts that Dunn presents on the ethical integrity of the profession eat away at this assertion.

When an individual might not be able to sustain their moral and ethical integrity, Dunn demands that the state's biopolitics should provide protective guidelines. A member of the Dutch parliament, for example, argues that the state has a responsibility to protect its citizens, including those who are medically or socially vulnerable. According to a researcher interviewed by Dunn, people who want to die because they are tired of life have given up hope of a better life and feel like a burden. From this, Dunn concludes that society fails those who need support, and with better support there would be no need for assisted dying. During his journey, the filmmaker meets Aurelia, a young woman with psychiatric problems who fights for her right to die. In his interview with Aurelia, Dunn argues that she seems happy enough, and finds it difficult to understand that she wants to die. After the interview, Dunn talks to the camera in the corner of the lobby. He looks directly at the camera and the viewer, and emotions fill his voice when he asks who has let her down. He blames society and the healthcare system for failing to take good care of the citizens.

Dunn also attacks the argument that assisted dying aims to relieve suffering. He argues that there are competent ways to eliminate pain and suffering, and

even more importantly, according to a survey in Oregon, current pain and suffering are not decisive factors among those requesting assisted dying, which renders the premises for assisted dying false. The rational argumentation, supported by scientific evidence adds authority to Dunn's on-camera presence: he faces the camera, holds the viewer's gaze and explains things clearly and convincingly. Dunn also introduces further survey results which show that the biggest concerns for those opting for assisted death are loss of dignity, quality of life, ability to take care of oneself and controlling the circumstances of death. He therefore argues that people are afraid of potential future suffering, which could be avoided. However, Dunn omits to mention the rest of the survey results. According to these, a lack of social, financial and emotional support was not among the significant factors for requesting assisted dying (Ganzini, Goy, and Dobscha 2008). Fears about losing control over one's life might not be solved with a better support system.

Throughout the film, Dunn makes clear arguments that assisted dying can take advantage of those in a vulnerable position. They need to be protected, and the best protection is to refuse any form of assisted dying that can be misused to get rid of those who are not considered worthy of living. Dunn also places a heavy responsibility on society to take better care of its citizens, because better care and compassion could erase the need for assisted dying. At the end of the film, Dunn returns to Aurelia's story. In a video call, Aurelia is excited to introduce the drugs she was prescribed for assisted dying. During a walk in nature, which is a thinly veiled reference to the preference of natural death, Dunn describes begging Aurelia to choose differently – to no avail. While he does not know what Aurelia has gone through, he is convinced that there is always hope for a better tomorrow. He revisits his other testimonial stories to uphold the narrative of hope, support and protection. The mother is able to take care of her disabled, yet happy daughter at home. The grandmother lived for another year and met the newborn baby of the family. Dunn's own father survived cancer. There is always hope, Dunn maintains, and while life may seem difficult, it is not a reason to give up. Dunn finishes the story by demanding that is up to each of us to enable each other's lives in a way that we maintain hope and do not fear of being a burden.

Fatal Flaws, thus, considers that the fierce protecting of the vulnerable carries ethical practices. In this approach, the people are divided in three categories: the vulnerable who are victims and who cannot act on their own behalf, but need protection; the opponents, who are ill-advised in their attempts to relieve potential future suffering, or who immorally attempt to save resources; and the protectors who morally defend the vulnerable. The protectors, here, are often moral individuals, but preferably, the state should assume this role and create biopolitics that protects the lives of the citizens instead of judging which lives are worthy of living.

Protecting Individual Rights

In comparison to *Fatal Flaws*, *Fade to Black* builds an alternative narrative of heroes and protectors. This documentary, directed by Jeremy Ervine, introduces Peter Short, a CEO, who after a cancer recurrence joins the campaign for legalising assisted dying in his home state of Victoria, the first Australian state to permit assisted dying. In this story, Peter gains the status of a hero for protecting and battling the right to choose one's own manner of dying. In an interview for the podcast *Euthanasia: Pro and Con*, Ervine argues that he wanted to represent both sides of the argument. Yet, the film started when Peter was looking for someone to help him spread the advocacy message. After meeting Peter, Ervine suggested that a documentary about his life and campaign would be more effective and interesting than any advertisement (J. N. Russell 2016). Through Peter, the documentary embraces an advocacy role, recognised by the organisation of Dying with Dignity. On their website, the advocacy organisation celebrates that the documentary 'sends a strong message to politicians that Australians care passionately about choice at end of life. With law reform now on the national agenda, the time is right for *Fade to Black* to be a powerful force for change' (Dying with Dignity 2017).

The documentary includes scenes of Peter's life, home and family as they struggle to cope with his terminal diagnosis. Some years earlier, Peter had been diagnosed with cancer, but the treatment had worked, and he went into remission. Peter says it felt amazing to get his life back. When the cancer returned, the prognosis was not as optimistic, and Peter got scared about pain and suffering that would follow. At first, he searched the web for effective ways to kill himself. However, after consideration, he decided to deal with the situation and joined a campaign that advocated for legalising assisted dying. While the personal aspects and family reactions give rhythm to the documentary, the main content focuses on the campaign. Ervine portrays Peter giving speeches at public events, talking to media outlets and reaching out to politicians. In the campaign, Peter embodies those terminally ill people whose lives would be affected by the bill. He gives voice to fears of suffering and pain and to the desire to die in a manner and time of his own choosing. He becomes an example of what Grue (2022, 10, 16) calls a cultural narrative of celebratory rhetoric, where death-seeking characters become the protagonists the viewer is expected to root for.

Ervine, however, introduces plenty of other voices from this campaign and from its counter-campaign, such as representatives of advocacy groups, physicians and Australian politicians. Both sides of the argument are thus represented, but Ervine's representation is the result of similar evidentiary editing that was used in *Fatal Flaws*. Selective use of scenes is emphasised in two longer sequences of political debate. First, Peter is invited to Canberra to

talk to select members from the House of Representatives at the Parliament House. Second, he is invited to a hearing with the senators. On both occasions, Ervine edits together scenes from the hearings and the expert interviews. The scenes from both hearings focus on the arguments of proposed legislation, as well as how the politicians challenge these views. The interview scenes deepen these perspectives, but also situate and comment on the arguments. Here, evidentiary editing favours the right-to-die campaign.

For example, as a part of these hearing sequences, the filmmaker introduces Margaret Tighe, a representative for Right to Life Australia. Tighe opposes the bill and often uses religious reasoning to support her arguments. Her main argument, however, is that palliative care proves that there are viable care options to assisted dying. The editing focuses on undermining Tighe's arguments, in a manner rather similar to the editing decisions of *Fatal Flaws*. Ervine cuts from Tighe's argumentation to an interview with Dr Richard Di Natale, senator and leader of the Australian Greens party, who campaign alongside Peter for the Right to Die Bill. Di Natale warns the viewer that counter-campaigns use scare techniques to turn people against assisted dying, for example by deliberately calling assisted dying 'killing people'. Then, Ervine cuts back to Tighe's interview just in time for the viewer to hear Tighe claiming that society should not 'legislate to kill people'. A similar warning of scare techniques is used with the slippery-slope argument, and this way, the viewer is prompted to be critical of the claims made by the counter-campaign.

Fade to Black also engages with rationalisation, another familiar technique from *Fatal Flaws*. The campaign for assisted dying uses Peter's story as empirical evidence, supported by rational arguments and scientific research that show that assisted dying laws could provide more control and less suffering for the terminally ill and prevent suicides, which are traumatic for family members. The opposing voices are framed as irrational and based on outdated values and conservative religious beliefs. For example, Peter reacts to religious arguments with passion and addresses the camera in the corridors of the Parliament House, annoyed that some people have lived so long in their 'bullshit' that they have not familiarised themselves with the reality. Di Natale, in a calm manner, explains that while there is a right to religious beliefs, the state and the church are separate for a reason and religious values should not define the values of all members of society. In these arguments, religious values and the realities that people live are seen to contradict each other. In addition, the counter-campaign is repeatedly asked to provide empirical support for their arguments, such as that assisted dying would encourage unnecessary killing and suicides. The camera captures any hesitation as proof of missing evidence, and celebrates a moment in the senator hearing, when one of the senators dismisses opposing arguments as personal views. In other words, the right to die is represented as a rational choice based on the lived realities of the citizens.

Thematically, Peter and his fellow campaigners systematically argue that everybody should have choice at the end of life. In addition, Dr Rodney Syme, who represents Dying with Dignity Victoria, paints assisted death as a dignified, peaceful and beautiful way of dying, which enables the person to leave goodbyes. He also argues that palliative care is not an answer for everyone, and the proposed bill targets those who suffer severe symptoms and will encounter difficult deaths regardless of comfort care. In these discussions, an option to end one's life becomes a human right, a right to choose for oneself.

The latter part of the documentary witnesses Peter's weakening condition. Peter and the family are devastated and discuss their options with Dr Syme, who talks to Peter about lethal medication as an alternative to palliative care. He also walks the family through the process of assisted death, stressing that it will create a positive memory that helps with the grief. The wife admits to the camera that having a choice is a comforting gift, but Peter is the one who makes the decision. In the end, Peter decides on palliative care, but points out that his whole motivation for campaigning was about having alternatives and being able to feel in control by choosing for oneself. The filmmaker follows Peter's declining health, his hospitalisation and eventually his death, his funeral and scattering of the ashes. In these last moments, the focus is on the family and their loving goodbyes to each other. In the end, Peter dies peacefully surrounded by his loved ones.

After Peter's death, the wife writes the final entry in Peter's blog. She tells about his passing and thanks everyone for their support. The message ends with a sentence, 'As a family we will continue to strive to achieve Peter's dream of seeing Senator Richard Di Natale's Dying with Dignity Bill become law.' The film closes with updates on the campaign. Di Natale promises that if the bill is passed, it will memorialise Peter. The very last screen has been added to the film after its initial release. This addition states that 'Victoria became the first Australian State to legalise assisted dying'. The positive result of Peter's campaign adds value to his efforts and to his story. It encourages the interpretation that Peter is a hero who successfully fought for individual autonomy and choice.

Conclusion

Western countries have increasingly debated the legalisation of assisted dying during the twenty-first century. In these debates of end-of-life biopolitics, political and ethical questions intertwine. Several documentary films take part in these debates, and while many filmmakers argue that they take both sides of the argument into consideration, the narrative decisions, particularly evidentiary editing, reveals the advocacy nature of these films. Most of these

documentaries, similarly to other media representations, tend to come out in favour of assisted dying, partly due to the novelty aspects of potential social change and partly due to compelling personal stories and engaging cultural discourses of individual choice, autonomy and agency. However, this does not mean that only one narrative is present in the documentary field. There are in fact two competing narratives, which openly address and oppose each other as in the case of *Fatal Flaws* and *Fade to Black*. Not only do these documentaries build their own perspective, they also commit to dismantling the counter-arguments of the competing narrative.

The two narratives emerge from a different understanding of the roles of the individual and the state or society. First, those against assisted dying subscribe to a state-led society where the state assumes responsibility for the citizens, ideally providing good care and support but at the very least protecting the lives of its citizens. Here, death becomes the ultimate threat, something to be feared and avoided. If the state fails in its role, morally strong citizens need to step up and recognise and protect the value of vulnerable people. Here, the protector of the vulnerable is the ethical hero of the narrative, and life in any form is the celebrated prize.

Second, those fighting for legalisation of assisted dying prioritise the individual over the state or society. Individuals have the right (and responsibility) to make their own informed decisions, and it is this human right that the state needs to protect and enable at the end of life too. In these stories, the human rights and individual autonomy are championed by those fighting for assisted dying. In particular, the people who fight for their own right to choose the manner of death are celebrated as warriors of the cause. In this narrative, death is not something to be feared, but there is concern over the manner of death, and potential pain, suffering or loss of dignity and personal autonomy. The coveted prize of this narrative is the good quality of life, followed by a controlled death.

Both narratives draw support from rational argumentation which is underpinned by empirical evidence (testimonials and personal life stories). Both sides also argue that the other side falls into emotional and purposeful argumentation that does not stand up to (scientific) scrutiny. In these debates, which take place both between and within the films, the filmmaker, who investigates and explores the topic also organises the arguments together and offers them as truth claims for the viewer. While the documentary viewer is always expected to evaluate the truth claims and reliability of the documentary content, the importance of evaluation is further highlighted in the case of advocacy films that openly take part in building the civic society. The discourses of such advocacy documentaries admit that there is no singular truth on the issue, which is why the viewer needs to consider the ethics related to the storytelling, but also the ethics related to the debated issue. The documentaries serve assisted dying

as a moral and ethical dilemma that must be explored. While the filmmakers have done their part of the investigation, the viewer is asked to do the same. This position implies that film is expected to do more than raise awareness, it is hoped to invite the viewer to be an active participant in society's biopolitics of death.

References

Aufderheide, Patricia. 2008. *Documentary Film: A Very Short Introduction*. Oxford: Oxford University Press.

Austin, Thomas. 2012. *Watching the World: Screen Documentary and Audiences*. Manchester: Manchester University Press.

Barrett, Diana, and Sheila Leddy. 2008. 'Assessing Creative Media's Social Impact'. The Fledgling Fund. 2008. https://mediaimpact.issuelab.org/resource/assessing-creative-media-s-social-impact.html. Last accessed 4 January 2022.

Bondi, Liz. 2005. 'Working the Spaces of Neoliberal Subjectivity: Psychotherapeutic Technologies, Professionalisation and Counselling'. *Antipode* 37 (3): 497–514. https://doi.org/10.1111/j.0066-4812.2005.00508.x.

Booth, Amanda, and Denise Blake. 2022. 'Assisted Dying in the Aotearoa New Zealand Media: A Critical Discourse Analysis'. *Mortality* 27 (1): 107–23. https://doi.org/10.1080/13576275.2020.1823355.

Borum Chattoo, Caty. 2020. *Story Movements: How Documentaries Empower People and Inspire Social Change*. New York: Oxford University Press. https://doi.org/10.1093/oso/9780190943417.001.0001.

Brylla, Catalin, and Mette Kramer. 2018. 'A Pragmatic Framework for the Cognitive Study of Documentary'. *Projections* 12 (2): 159–80. https://doi.org/10.3167/proj.2018.120216.

Burlone, Nathalie. 2020. 'Value-Based Issues and Policy Change: Medical Assistance in Dying in Four Narratives'. *Social Policy & Administration* 54 (7): 1096–109. https://doi.org/10.1111/spol.12587.

Buyens, Frans. 1992. *Less Dead than Others* (*Minder Dood Dan de Anderen*). Film. Films Lyda.

Decommere, Alexander. 2013. *End Credits*. Documentary. Recht op Waardig Sterven vzw.

Dunn, Kevin. 2017. 'From the Director'. Fatal Flaws - Film. 15 October 2017. https://fatalflawsfilm.com/2017/10/15/from-the-director/. Last accessed 13 February 2023.

———. 2018. *Fatal Flaws: Legalising Assisted Death*. Documentary. Sideways Film.

Dying with Dignity. 2017. 'Peter Short's Story Told in Fade to Black Film'. Dying with Dignity: New South Wales. 2017. https://dwdnsw.org.au/fade-to-black-film-peter-shorts-legacy/. Last accessed 14 February 2023.

Eitzen, Dick. 2007. 'Documentary's Peculiar Appeals'. In *Moving Image Theory: Ecological Considerations*, edited by Barbara Fisher Anderson and Joseph Anderson, 183–99. Carbondale: Southern Illinois University Press.

Ervine, Jeremy. 2017. *Fade to Black*. Documentary. Torrential Pictures.

Euthanasia Prevention Coalition. n.d. 'About'. Euthanasia Prevention Coalition. https://epcc.ca/about/. Last accessed 13 February 2023.

Fellows, Arron. 2018. 'Choosing Death'. *Louis Theroux's Altered States*. British Broadcasting Company (BBC).

Final Exit (*Notausgang*). 2014. Documentary. Medienproject Wuppertal.

Foucault, Michel. 1990. *The History of Sexuality. Vol. 1: An Introduction*. Translated by Michael Hurley. First published 1976. New York: Vintage.

Ganzini, Linda, Elizabeth R. Goy, and Steven K. Dobscha. 2008. 'Why Oregon Patients Request Assisted Death: Family Members' Views'. *Journal of General Internal Medicine* 23 (2): 154–7. https://doi.org/10.1007/s11606-007-0476-x.
Grierson, John. 1966. *Grierson on Documentary*, edited by Forsyth Hardy. Berkeley; Los Angeles: University of California Press.
Grue, Jan. 2022. 'The Death of Others. On the Narrative Rhetoric of Neoliberal Thanatopolitics'. *Disability Studies Quarterly* 42 (1). https://doi.org/10.18061/dsq.v42i1.7799.
Inthorn, Sanna. 2017. 'Audience Responses to Representations of Family-Assisted Suicide on British Television'. *Participations* 14 (2): 153–74.
Jackson, Liz. 2013. *My Own Choice*. Documentary. ABC Australia.
Johnstone, Megan-Jane. 2013. *Alzheimer's Disease, Media Representations, and the Politics of Euthanasia: Constructing Risk and Selling Death in an Ageing Society*. London; New York: Routledge.
Kis-Rigo, Andrew, Anna Collins, Stacey Panozzo, and Jennifer Philip. 2021. 'Negative Media Portrayal of Palliative Care: A Content Analysis of Print Media Prior to the Passage of Voluntary Assisted Dying Legislation in Victoria'. *Internal Medicine Journal* 51 (8): 1336–9. https://doi.org/10.1111/imj.15458.
Krupa, Tomáš. 2018. *The Good Death*. Documentary. ARTE; Czech Television; Golden Girls Filmproduktion.
Malkowski, Jennifer. 2017. *Dying in Full Detail: Mortality and Digital Documentary*. Durham, NC; London: Duke University Press. https://doi.org/10.1215/9780822373414.
Mason, Brett, and Calliste Weitenberg. 2015. 'Allow Me to Die'. *Dateline*. Special Broadcasting Service (SBS).
Mbembe, Achille. 2019. *Necropolitics*. Translated by Steve Corcoran. First published 2016. Durham, NC: Duke University Press.
Menoud, Jean-Bernard. 2010. *Dignitas – la mort sur ordonnance*. Documentary. RTS.
Murray, S. J. 2018. 'Thanatopolitics'. In *Bloomsbury Handbook to Literary and Cultural Theory*, edited by J. R. Di Leo, 718–19. London: Bloomsbury.
Nash, Kate. 2011. 'Documentary-for-the-Other: Relationships, Ethics and (Observational) Documentary'. *Journal of Mass Media Ethics* 26 (3): 224–39. https://doi.org/10.1080/08900523.2011.581971.
Nichols, Bill. 2016. *Speaking Truths with Film: Evidence, Ethics, Politics in Documentary*. Oakland: University of California Press.
———. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.
Plantinga, Carl. 2013. '"I'll Believe It When I Trust the Source": Documentary Images and Visual Evidence'. In *The Documentary Film Book*, edited by Brian Winston, 40–7. London: British Film Institute.
Rawlings, Deb, Megan Winsall, Lauren Miller-Lewis, and Jennifer Tieman. 2023. 'Natural Death Versus Known Date-Of-Death: A Qualitative Study of Views on Voluntary Assisted Dying in an Online Course About Death'. *OMEGA – Journal of Death and Dying* 86 (4): 1272–90. https://doi.org/10.1177/00302228211008771.
Russell, Charlie. 2011. *Terry Pratchett: Choosing to Die*. Documentary. BBC Two.
Russell, James N. 2016. 'Jeremy Ervine – Doc Filmmaker – Fade to Black'. *Euthanasia: Pro and Con* (podcast). Listen Notes. 20 October 2016. https://www.listennotes.com/podcasts/euthanasia-pro-and/jeremy-ervine-doc-filmmaker-sR0MwHXn4ui/. Last accessed 2 January 2023.
Saunders, Peter. 2011. 'The Role of the Media in Shaping the UK Debate on "Assisted Dying"'. *Medical Law International* 11 (3): 239–56. https://doi.org/10.1177/0968533211011003007.

SBS Australia. 2002. *Live and Let Die*. Documentary, Short. Journeyman Pictures.
Shaw, Daniel. 2012. *Morality and the Movies: Reading Ethics through Film*. New York: Continuum.
Springer, Simon, Kean Birch, and Julie MacLeavy, eds. 2016. 'An Introduction to Neoliberalism'. In *The Handbook of Neoliberalism*, 1–14. New York: Routledge, Taylor & Francis Group.
Svarvar, Jan-Olof, and Maria Holmberg. 2020. *Oikeus kuolla* (*Med rätt att dö*). Documentary. Yleisradio.
Velasquez, Manuel, Claire Andre, Tom Shanks, and Micheal J. Meyer. 2010. 'What Is Ethics? (Revised from an article that originally appeared in *Issues in Ethics* IIE V1 N1, Fall 1987)'. *Markkula Center for Applied Ethics at Santa Clara University* (blog). 2010. https://www.scu.edu/ethics/ethics-resources/ethical-decision-making/what-is-ethics/. Last accessed 1 January 2023.
Whiteley, C. H. 2022. 'On Defining "Moral"'. In *The Definition of Morality*, edited by G. Wallace and A. D. M. Walker. First published 1970. London; New York: Routledge.
Wijngaarden, Els van, and José Sanders. 2022. '"I Want to Die on My Own Terms": Dominant Interpretative Repertoires of "a Good Death" in Old Age in Dutch Newspapers'. *Social Science & Medicine* 311 (October): 115361. https://doi.org/10.1016/j.socscimed.2022.115361.
Winnington, Rhona. 2021. 'The Assisted Dying Movement: How Media Platforms Influence Our Response to Events That Challenge the Boundaries of Contemporary Social Control'. In *Death and Events: International Perspectives on Events Marking the End of Life*, edited by Ian R. Lamond and Lisa Dowson, 177–93. London; New York: Routledge.
Zaritsky, John. 2010. 'The Suicide Tourist'. *Frontline*. Public Broadcasting Service (PBS).
Zeldis, Nina. 2005. 'To Be or Not to Be: Terminal Illness in Film and in Life'. *Nursing Forum* 40 (4): 129–33. https://doi.org/10.1111/j.1744-6198.2005.00025.x.