

The Dying Agent

A 'small story' narrative analysis of the television documentary

My last words – Viimeiset sanani

Niina Moilanen
Master's Thesis
Spring of 2019
Department of Social Work
Faculty of Social Sciences
University of Lapland

University of Lapland, Faculty of Social Sciences

The title of the pro gradu thesis: The Dying Agent. A 'small story' narrative analysis of the television documentary *My last words – Viimeiset sanani*.

Author(s): Niina Moilanen

Degree programme / subject: Social Work

The type of the work: Master's thesis x laudatur thesis

Number of pages: 76

Year: 2019

Summary:

In Western societies today, the process of dying may extend for a period of years, even decades. Traditionally death was managed through community, ritual and religion, whereas death is now personal and private. As the authority of medicine over death is being challenged, there is a growing demand for a modern *ars moriendi*, an art of dying.

The topic of good death is both political and personal. A critical analysis of the concept reveals the professional imprint on the ideal. A medical philosophy promotes choice and control in end-of-life care, while palliative and hospice philosophies value the awareness and acceptance of death by the patient. A review of good death research literature demonstrates, however, the differing ideals of patients, professionals and caretakers.

The multifaceted body of research into the good death is largely based on specific, focused inquiries into the topic. Assuming an alternative approach, the current research design is based on examining the 'practice' of dying. The aim is therefore to explore the good death ideal through a narrative analysis of the television documentary *My last words (Viimeiset sanani)* of incurably ill persons facing the last months of their lives. In the episodes addressed, three 'small stories' are selected for closer analysis: the stories portray an encounter with death, living with death and addressing the consequences of death.

The analysis applies William Labov's theory of narrative structure and positioning analysis of Michael Bamberg. Through narrative performance, the small stories yield an account of dying agency. While the initial encounter with death produces a 'chaos narrative', the speakers return to reclaim their agency through the 'quest narrative'. The good death emerges as a struggle against social adversity – from chaos of illness to quest for agency – pursuing reconciliation between the individual and the social.

The aim of dying agency is in establishing dying as 'normal'. As representatives of illness narratives, the small stories of *My last words* appear as alternative to the modernist 'restitution narrative' which finds resolution in medical cure. Thus, resisting sequestration of death and instead calling for a growing awareness and tolerance of death and dying, the speakers seek to repair the relationship between individual and society by asserting death back into the realm of social.

The study demonstrates the value of the television documentary as empirical material for social research. The documentary is considered a site of contestation and negotiation between social and individual conceptions and ideals, potentially shaping social reality and personal experience of illness and dying.

Keywords: narrative analysis, small stories, television documentary, agency, dying, death, good death

Lapin yliopisto, yhteiskuntatieteiden tiedekunta

Työn nimi: The Dying Agent. A 'small story' narrative analysis of the television documentary *My last words – Viimeiset sanani*.

Tekijä: Niina Moilanen

Koulutusohjelma/oppiaine: Sosiaalityö

Työn laji: Pro gradu -työ_x_Sivulaudaturtyö__Lisensiaatintyö__

Sivumäärä: 76

Vuosi: 2019

Tiivistelmä:

Länsimaisissa yhteiskunnissa kuoleamisen kokemus pitkittyy usein vuosia kestäväksi elämänvaiheeksi. Kulttuurihistoriallisesti tarkasteltuna traditionaalinen kuolema kohdattiin yhteisön ja uskonnon kontekstissa, kun modernia kuolemaa ovat hallinneet lääketieteen arvot ja käytännöt. Nykyinen, postmoderniksi kutsuttu kuolema on yksilöllinen ja yksityinen. Kuoleman kokemusta suuntaavien auktoriteettien puuttuessa etsinnässä on uusi *ars moriendi*, kuoleamisen taito.

Hyvän kuoleman käsite on poliittinen ja henkilökohtainen. Kriittisesti tarkasteltuna hyvän kuoleman määritelmässä näyttäytyy asiantuntijavalta: elämän loppuvaiheen hoito perustuu valinnanvapauden ja itsemääräämisoikeuden arvoille. Palliatiivisen- ja saattohoidon ammattilaisten näkemyksissä hyvä kuolema liittyy kuoleman tiedostamiseen ja hyväksymiseen. Eri viiteryhmien käsityksiä selvittäneistä tutkimuksista ilmenee, että potilaiden, ammattilaisten ja omaisten näkökulmat hyvästä kuolemasta eroavat.

Hyvän kuoleman kansainvälinen tutkimus koostuu pääasiassa nimenomaisesti hyvän kuoleman määritelmiä ja tekijöitä tarkastelevista haastattelututkimuksista. Tässä tutkimuksessa tarkastellaan sen sijaan kuoleamisen 'käytäntöä'. Tutkimuksen kohteena on televisiodokumentti *Viimeiset sanani*, jossa parantumattomasti sairaat ihmiset jättävät läheisilleen hyvästit videoviestin muodossa. Hyvän kuoleman ideaalia lähestytään narratiivisen analyysin keinoin: tutkimukseen valituista dokumenttisarjan jaksoista poimitaan kustakin kolme 'pienää kertomusta', jotka kuvaavat päähenkilöiden kohtaamista kuoleman kanssa, elämää kuoleman kanssa ja kuoleman seurauksien kohtaamista.

Tutkimuksessa tarkastellaan kertomusten narratiivista rakennetta William Labovin narratiivisen analyysin kautta sekä kertojien omaksumia positioita Michael Bambergin kerronnallisen asemoinnin menetelmää hyödyntäen. Kuoleman kohtaaminen näyttäytyy kaaosnarratiivina, jonka jälkeen kertojat pyrkivät palauttamaan toimijuutensa. Hyvää kuolemaa tavoitellaan vastustamalla sosiaalista epäoikeudenmukaisuutta: kuolevan toimijuus tähtää kertomuksissa kuoleman normalisointiin, ja siten kuolevan yksilön ja yhteiskunnan välisen suhteen korjaamiseen. Samalla kuolema positioidaan sosiaalisen ytimeen. Narratiivit haastavat modernin parantumistarinan aseman vastustamalla kuoleman hiljentämistä yhteiskunnassa ja peräänkuuluttavat tietoisuuden lisääntymistä ja suvaitsevaisuutta kuolemaa ja kuolevia kohtaan.

Tutkimus puoltaa media-aineistojen hyödyntämistä empiirisenä aineistona sosiaalisten ilmiöiden tutkimuksessa: tässä tutkimuksessa aineistona käytetty televisiodokumentti näyttää yksilöllisten ja sosiaalisten ideaalien aktiivisena neuvotteluna. Julkisilla sairauskertomuksilla voi olla merkittävä ideologinen vaikutus sairauden ja kuoleman kohtaamiselle sekä yksilölliselle kokemukselle.

Avainsanat: narratiivinen analyysi, pienet kertomukset, televisiodokumentti, toimijuus, kuolema, hyvä kuolema

CONTENTS

1 INTRODUCTION.....	1
2 PREVIOUS RESEARCH AND CURRENT APPROACH.....	6
2.1 The good death.....	6
2.2 Sequestered or celebrated?.....	9
2.3 Research questions.....	12
3 AGENCY: A REFLEXIVE PROJECT.....	13
3.1 Self and Modernity.....	13
3.2 Fateful moments.....	15
3.3 Narratives of illness.....	16
4. EXPLORING <i>MY LAST WORDS</i>	20
4.1 Narrative analysis: Labovian structure and Bambergian agency.....	20
4.2 From ‘small’ to ‘Big’.....	21
4.3 Research design, data and methodology.....	24
5 SMALL STORIES OF DYING AGENCY.....	27
5.1 Maria.....	27
5.2 Manta.....	33
5.3 Raimo.....	42
5.4 Sirkka.....	48
6 NARRATIVES OF GOOD DEATH.....	55
6.1 From fateful moments to resolutions.....	55
6.2 Conflicting positions.....	58
6.3 Dying agency: through resistance to normalcy.....	63
7 DISCUSSION.....	67
REFERENCES.....	73

1 INTRODUCTION

When we, as children, first become aware of death, the notion of everything ending for us and for those we care most about seems unbearable. Imagining how it feels to be dead as the opposite to all we have come to know is beyond compare. Naturally, in these moments, we look to the adults for reassurance and security. However, adults may feel none the wiser: how to speak of death – to provide comfort in the face of the ultimate question?

An awareness of death is considered a unique, even defining, dimension of humanity. Yet we put a lot of effort into building the kinds of bonds with the world that would hold – we look to the future through upbringing, education, relationships, personal goals and various acquisitions – to the extent that after those early moments of existential distress, mortality is forgotten – sometimes actively, other times without effort. Any disruption in our oblivion thus usually comes a shock.

The Latin phrase “*memento mori*”, “*remember you will die*” instructs us to contemplate our mortality, acknowledging the inevitability of death and the importance of maintaining its connection to life. It seems, however, that our relationship to death follows our lifestyle, which has evolved from an essentially communal undertaking into an individual project. Similarly, the traditional death was based in community and encountered in the context of religion, whereas modern death has replaced ritual by privacy and the priest with the doctor (Walter 1994, 185).

Until the late 19th century, notes Tony Walter (2015), death was common at any age, even in infancy, whereas today it is mostly linked with degenerative diseases in a phase of life where the main life tasks and roles have been completed. Thus, says Walter, death is disconnected from life. Similarly, constructing an entire history of death, Philippé Aries (1974) argues that a major shift occurred in the middle of the 19th century in the social treatment of death, “*a complete reversal of customs*”: death was concealed, physically and conceptually, in the privacy of hospitals.

According to Walter (2015), as more people began to die in hospitals, the medical perspective, focusing on cure, has left the dead ‘lonely’. In response, the hospice and palliative care movement originated in the perspective that dying was overly medicalized. The

hospice movement has thus attempted to humanize dying by emphasizing the emotional and spiritual dimensions of the process.

In a similar vein, end-of-life policy has interpreted dissatisfaction with how death is handled today as a form of 'social death', a loss of personhood. Modern policy guidelines are thus congruent with the consumerist health care philosophy and hospice philosophy, emphasizing a person-centered care, autonomy and agency. (Borgstrom 2015.) However, the humanistic critique of the prevailing professionalism has now turned against the palliative and hospice ideology: the Right to Die movement demands restoring control back to the dying, proclaiming that each person has a right to die with 'dignity', on their own terms. Furthermore, academic voices have also suggested alternative models for end-of-life care based on community care (Brown & Walter 2014; Becker et al. 2014; Poroch 2012; Horsfall et al. 2012).

For the arguments that, as a result of medicalization, death has been denied and sequestered (Gorer 1965; Illich 1976; Aries 1974; Elias 1985; Mellor & Shilling 1993) the common view is that people have been deprived of agency when it comes to death (Hockey 2007). Similarly, Anthony Giddens (1991) discusses a 'scientific out-look' permeating into the personal of human self-identity, containing and limiting the free mode of thought and experience. Science, technology and expertise dominate over existential questions and dilemmas, a trend which Giddens calls the sequestration of experience (1991, 8). For Giddens, modernity is in fact essentially about excluding existential issues from social life. At the same time, he believes that late modernity creates an unprecedented context for novel efforts of self-development: individuals are required to answer huge existential questions without the support of traditional moral and social frameworks (Tucker 1998, 205). Rather than the subject becoming frail and decentred, finding "*its identity in the fragments of language and discourse*" as postmodernists would have it, Giddens claims that the reflexive project is, in fact, energized against a backdrop of moral impoverishment (Tucker 1998, 169-170).

As an integral part of this reflexivity, death seems to have indeed shed the cloth of taboo: death and dying have regained a growing social and cultural interest, calling forth political, professional, academic and civic positions as to the idea of 'good death'. In fact, it is the concept of 'good death' which underpins the continuing critique of the medical management of death and dying (Hart, Sainsbury & Short 1998). The discussion involving

rights, social context and culture of death certainly represent a change in paradigm for the biomedical model of death and a continuing effort to reclaim death from the field of professionalism. In fact, claim Hart, Sainsbury & Short (1998), the ‘good death’ is the last attempt to empower people in the project of individualism.

The public death in 2009 of a young British celebrity, Jade Goody, is an extreme example of a high-profile exposure of the last weeks of life. The media coverage in Britain was met with mixed reactions, including criticism of public dying and of reality television in general (Walter 2009). Jade expressed that her motive to signing the media deals was raising funds for her sons’ future education and encouraging women to have cervical cancer smear tests (ibid.). The newspaper accounts produced a heroic and intimate account of Jade’s death, with Jade breaking taboos by openly acknowledging her dying as fact and contextualizing her death as ‘the end of a life well lived’. By constructing this type of biographical continuity and agency through Jade’s efforts and perspective on death, the media in fact assumed the role of education rather than exploitation, and a moral stance that is compatible with that of palliative care. (Frith, Raisborough & Klein 2013.)

In focusing on the experience, choice and social aspects of a good death, these perspectives propose a model of agency – one that is empowering for the patient, the caregivers as well as society. Socially and culturally, observes Walter (2015), “[...] *we are witnessing the development of a new art of dying, with hospices, journalists and the dying people themselves writing the scripts for a new heroism in the face of the old Grim Reaper.*”

Reflecting on Giddens and the current cultural craving for an art of death (Walter 2015), it could be deduced that a cultural obsession with death (Hawkins, 1991) is an ongoing reflexive project – derived from the deterioration of myth, tradition and ritual. For Anne Hunsaker Hawkins (1991), the arduous task of confronting death calls for a cultural paradigm – a network of values, beliefs, and practices – for dying persons to negotiate this difficult rite of passage. However, a culture based on individuality, relativism and plurality compels people not only to confront, but to create death from whatever fragments of ideology and religion are still available. (Hawkins 1991.)

In Finland, the reality and intimacy of dying was made public through a Dutch-Finnish television documentary *My last words* (Mijn Laatste Woorden – Viimeiset sanani) (Iso-talo 2013), which first aired in Finland in 2013. In both countries the initial idea was met

with definite public suspicion, even resentment. The Dutch viewers were appalled and shocked by the personal accounts of the dying, even though euthanasia is legalized in the Netherlands (Yle uutiset 2008). Commenting the public outrage in Britain related to Jade Goody's death, Walter (2009) contends that the sequestration thesis still applies, implicating a continuing social need to compartmentalize death out of sight. For Jade Goody, as well as the representatives and the main characters of *My last words* however, the aim appears to be the opposite.

In keeping with Hawkins' hypothesis, *My last words* presents multiple accounts of illness: those of the ten main characters and that of the media format. As narratives of illness meet our needs to reconstruct discontinuities in an imagined biography, seeking purpose and meaning (Williams 1984) and since telling a story is inevitably about taking a moral stance (Bruner 1990, 51), so are the narrators of *My last words* ultimately exploring the concept of 'good death'. After all, making meaning of death is not only about the experience of dying, since considering death as good or bad has implications for professionals, for carers as well as the dying persons themselves: dying places an obligation on others to ensure that the death is good (Firth, Raisborough & Klein 2013).

The question of death thus poses a responsibility that is both personal and social, bearing on the professional as well as the individual. The motivation behind this study is thus in keeping with the medieval maxim to engage in self-examination on the meaning of death and dying. In this aim, the study at hand examines the dialogue on death between society and the individual which unfolds in the Finnish episodes of the documentary *My last words*. What follows is therefore one view into the current Western approach to dying, contemplating on whether death remains sequestered or whether, through such public media coverage, death is revived.

Chapter 2 offers a review into the 'good death' research and then into the academic discussion on the social and cultural context of death. At the end of chapter 2, the current research design is compared to the previous efforts of discussing the good death. Chapter 3 undertakes a theoretical discussion on the problem of human agency and takes notice of Giddens' account of 'the reflexive project' as the aim and means of modern agency. Next, agency is considered through the reverse angle, in Giddens' terms the 'faithful moment', which enforces the existential and the inevitable upon the modern agent. As one possible route forward, narratives of illness are discussed as a form of narrative agency.

Chapter 4 describes the documentary *My last words* as a source for empirical analysis and the methodology based on the narrative analysis of William Labov and Michael Bamberg. In chapter 5, the documentary is analysed through the ‘small stories’ of confronting death, living with death and leaving farewells to loved ones. The findings of narrative analysis are taken together in chapter 6 and finally, we return to a discussion on the ethics of some of the major themes explored: the effect of the public stories of illness, the authority of television and the nature of the mediated experience, and the television documentary as an empirical source for social research.

2 PREVIOUS RESEARCH AND CURRENT APPROACH

2.1 The good death

The topic of good death is both political and personal. A critical analysis of the concept reveals the professional imprint on defining the ideal. For instance, Walter (2015) assumes an essentially cultural perspective, claiming that modern Western individuals value personal autonomy and thus fear ceasing to be a social actor – and to mitigate this fear, medical philosophy promotes choice and control in end-of-life care. The good death has further been discussed through the current practices related to death and dying, and the consequent institutionalisation of death under medical practice (Whitney & Smith 2010). Empirical studies aiming to delineate the elements of good death for different reference groups have demonstrated the differing ideals of the patients, professionals and caretakers (Payne et al. 1996; Hughes et al. 2008; Meier et al. 2016).

In a landmark study in the sociology of death, observing the process of dying in six hospitals, Barney Glaser & Anselm Strauss (1965) identified four levels of awareness upon impending death. The staff played a crucial role in this regard, controlling information shared with the patients and thus their level of awareness. The ‘dying trajectory’, introduced by Glaser and Strauss, implied the schema of an ‘appropriate’ death, offering for all concerned the time for interaction and for a shared awareness to form.

In another extensive study, Allan Kellehear (1990) focused on the social lives of the dying in hospital context. As a starting point for his study, Kellehear noted the lack of attention in research to the fact that the social experience of dying may extend for a period of weeks, months, even years – thus turning dying into an actual phase of life which needs to be organized like any other. As such, he criticized the work of Glaser & Strauss as more of a description of caretaker activity than of the behaviour of the dying person (1990, 19). Applying the concept of ‘good death’ as a theoretical framework, Kellehear recalled the roots of the concept in phenomenological research, emphasizing the social processes involved in dying from the viewpoint of the dying person (ibid., 28). Kellehear’s definition of ‘good death’ as “*the social life of the dying person who is aware that he or she is dying*” (ibid., 32) underscored the interaction between the person and the social institutions of the wider society. Drawing from historical and cross-cultural cases, Kellehear divided a ‘good death’ into five categories: an awareness of dying, adjustments

and preparations to death, relinquishing roles, responsibilities and duties, and the making of farewells with others (ibid., 33-34).

In his analysis, Kellehear perceived the dying as active in the social management of life's final chapter. He proposed that what he observed was a culturally sanctioned behaviour which made death more meaningful for all concerned. However, he emphasized the ideological purposes of the good death: on one hand, it served the individual psychologically, offering opportunities for order and control. For some of Kellehear's interviewees, this meant the making of material preparations for family members or remaining in working life despite the illness, for instance. On the societal level, the good death justified the roles of professional power and expertise (medicine, law, funeral industry) in participating in the process of dying. He concluded that social ideals produce social pressures to achieve a Good Death (Kellehear 1990, 194), and death thus remains socially controlled.

Despite the attention which Kellehear accorded to an ideal death, Bethne Hart, Peter Sainsbury & Stephanie Short (1998) maintain that the goal of death with acceptance should be approached with more criticism. Particularly, they point out that Kellehear's sample did not include patients who were perceived to be in denial or in distress regarding their diagnosis. In addition to Kellehear, other studies have linked the level of awareness to the ideal of the good death in ways which continue to speak of conforming to expert pressure and control. Beverley McNamara (1995) observed in hospice setting how the good death ideology, based on open communication and an acceptance of death, was actively pursued in the work of the hospice staff, and significantly shaped the experience of dying (see also Semino, Demjén & Koller 2014; Goldsteen et al. 2006).

A comparison of studies reveals an obvious diversity in patients' definition and preference of a good death, which may arise from culture and reference group. Ronit D. Leichtentritt & Kathryn D. Rettig (2000) for instance, interviewing elderly Israelis, discovered that death was not perceived as "good" at all, but rather an inevitable completion of life. For their informants, a good life was a prerequisite for a good death, and a good death was consistent with the life lived. Second, death was underlain with a hope of a continuance of one's identity through future generations. On the other hand, Glennys Howarth (1998) discovered in her study with the elderly in North London that good death connoted, above all, ease, speed and unawareness – although some of her informants recognised the value of knowledge of impending death in making preparations.

For Swedish terminally ill cancer patients, a good death was conceived of as a process, including living with imminent death, preparing for death and dying comfortably, i.e. quickly, with independence, diminished suffering and social relations intact (Kastbom, Milberg & Karlsson 2017). A study focusing on patients with advanced AIDS (Pierson, Curtis & Patrick 2002) delineated altogether 12 different categories pertaining to good death, where pain control, quality of life and the presence of loved ones were among the top three. Finally, a focus group consisting of homeless older adults, in turn, considered ‘dying in sleep’ as the optimal death, in conjunction with diminished suffering, experiencing a spiritual connection and making amends with significant others (Ko, Kwak & Nelson-Becker 2015).

Recognising the many sources of potential difference in preference for good death, such as gender (Lawton 2000, 168) and social status (Howarth 2007), Broom & Cavenagh (2010) explored the experience of being cared for from the perspective of contemporary masculinity. Interviewing patients (11 male and 9 female) receiving in-patient hospice care, Alex Broom & John Cavenagh found significant variation in participants’ accounts of death, involving on the one hand, ‘struggle talk’ and on the other, a desire ‘for an end’. In contrast, the unanimity in the participants’ discussion of good death produced a moral framing of dying, centering on the idea of “*rising to the occasion*”. Significantly, however, this unanimity in conception of a good death became tensioned as the participants both embraced and resisted these expectations; Broom & Cavenagh (2010) conclude that the good death emerged as a site of contestation between the needs and desires of the dying person, and those of the carers, family and hospice staff.

The hospice ideology, signifying an awareness and acceptance of death, is suggested to imprint a powerful ideological model on both staff and patients (McNamara 1995; Hart, Sainsbury & Short 1998) and is thus criticised as a form of social control. These concerns are indeed amplified by the recognition of diversity in patient perspectives related to good death. In this regard, the most commonly sited (although rather dated) study eliciting this issue is by Sheila Payne, Alison Langley-Evans & Richard Hillier (1996). They focused on the tensions related to the different conceptions of good death between patients and staff, and demonstrated how patients preferred dying in one’s sleep, quietly, with dignity, pain-free and suddenly, while nurses emphasised symptom control, family involvement and peacefulness – whereas a ‘lack of acceptance’ was underscored by the nurses as a form of ‘bad death’.

Regarding the hospice philosophy, representing a holistic approach to care of the dying, Payne, Langley-Evans & Hillier (1996) further paid attention to the fact that in their study the nurses pronouncedly placed symptom control as a priority in good death, a finding which they attributed to the influence of the medical model upon the hospice context. Later, McNamara (2004) noted how the consumerist approach to patient autonomy no longer served the hospice philosophy of the good death: emphasizing the patient's choice prohibited the active attempts of the staff in facilitating the ideal death. As a result, claims McNamara, the hospice ideology has been replaced by a 'good enough death', aiming at alleviating physical symptoms and therefore potentially neglecting other forms of care. Similarly, Walter (1994, 144) observed that a central value of care for hospice workers was actually control: the staff was able to focus on practicing basic skills of care, since dying patients lose functionality and since there is no longer a need to determine diagnosis.

2.2 Sequestered or celebrated?

There is ambivalence, both academically and socially, as to whether death remains sequestered or whether it is in fact celebrated. Hugh Willmott (2000) argues that death is unrecognised as a source of motivation for human action and points to the significance of the sequestration thesis for sociological theory. In effect, claims Willmott, theories of sequestration, such as that of Giddens, perceive human action as powered by the very element it is set in opposition with. As such, the projects of modernity and self-identity are "[...] conditional upon a suspension or sequestration of our knowledge of mortality" (Willmott 2000). However, Willmott puts forth a counterargument, insisting that the fear of death is a social construct, rather than an innate human condition – and that in analysing the methods of coping with a fear of death, also research is contributing to its sequestration.

The sheer volume of death conveyed through the media, however, will not go unnoticed. Willmott, nevertheless, contends that these representations of death remain fixed in the logic of modern sequestration – for instance by discussing death in terms of its causes (see also Giddens 1991, 204) – cancer, AIDS, cardiovascular disease – thus distancing the audience from the question of mortality itself. For Willmott, the proliferating

discussion of death grows in a type of existential void in which death is simply viewed as an end to self-identity, while dying in fact becomes lonelier.

Similarly, Walter (1996) discusses the topic of loneliness in a modern/postmodern framework. As medical expertise controlled the process of dying, the modern death witnessed the exclusion of the patient in the role of an object – the funeral presented a polished, neutral confiscation of death – and the bereaved family members were expected to handle their grief since death had been ‘abolished’ (ibid., 196). In contrast, the postmodern version shifts the focus back to the experience of the individual, whereby the private now informs the public. Here, Walter observes two strands: the radical approach accords the autonomy of experience to the individual who, as a consumer picks and chooses the preferable deathway or the forum for grief, while the expert approach views death as a highly traumatic experience, and therefore “*replaces priests and doctors with counsellors and therapists*” to alleviate the passage through the difficult experience. In the former strand, the authority remains with the individual, whereas in the second, with the experts.

In both cases described by Walter, however, the postmodern relationship between death and the individual seems, importantly, *removed from the social*. While society dismantles the taboo of death, the individual remains the autonomous realm where the reality of dying is encountered. In addition, this reality of dying in the postmodern age is dramatically different compared to traditional deaths, which were both unexpected and relatively quick. The process of dying may now extend for a period of years, even decades – thus also calling into question the notion of ‘fateful moments’. The effect is, claims Walter (1996), that people are seeking and building a ‘craft of dying’, and the craftsmen and -women are the dying themselves.

A solution of the ‘radical strand’ is to call upon traditional rites of passages (Walter 1996), connecting the individual and the existential (Giddens 1991, 204). This is an effort of the new social movements to counter the medical monopoly of death– the notable difference to traditional deaths being, however, that whereas the ritual itself formed the script of death in which the dying person obviously played the main role, the postmodern ritual is selectively and actively constructed by the dying themselves (Walter 1996). What emerges, in effect, is the dying or the bereaved drawing upon, not surrendering to ritual.

Alternatively, the 'expert strand' (Walter 1996) relies on knowledge of death and dying. In the wake of fateful moments, as Giddens explains, seeking information becomes urgent (1991, 141-142). The postmodern consumer is immersed in accounts and guidelines for a good death. Not only do people dying or grieving look to help from the experts, but modern palliative and hospice services actively teach ideals of the 'good death' and healthy grieving (Walter 1996, 200). In fact, Walter notes how even in the vast research literature on death the discussion on traditional death is not analytical but rather ideological (ibid., 197), the aim being to challenge the modern institutionalized approach to death (see e.g. O'Gorman 1998). What thus appears as freedom and abundance of choice, is in fact expert influence on what is 'good' in the selection of facilities, tradition and resource (Walter 1996, 198).

Similarly to Walter (1996), Fortuin, Schilderman & Venbrux (2017) recognize the 'radical' and 'expert strand' as contemporary approaches to death, terming them the 'canonical niche' (drawing on religious authority and established tradition) and the 'utilitarian niche' (grounded in rational and utilitarian reasoning). In addition, they identify a third option, called the 'expressive niche' (grounded in authentic self-expression). They connect the problem of dying agency explicitly to cultural opportunities for action and perception, 'affordances'. They conclude that applying different cultural niches in efforts to derive meaning in the face of death may lead to personal conceptions of death that are incompatible. Remaining sensitive to these various cultural affordances is essential for researchers in determining the role of individual characteristics on one hand and culturally embedded values and meanings on the other, in relating to death.

The good death has become the topic of research, the problem on the political agenda and paradoxically, a catch phrase for both the new social movements as well as the hospice philosophy they criticize. As Walter (1996) describes, the fragmented and contested nature of the ideal deathway indicates that death is negotiated by each person individually. Good death should therefore be treated, above all, as an ideal.

2.3 Research questions

Despite the multifaceted body of research into the good death, the perspectives captured in the aforementioned studies are based on specific, focused inquiries into the topic. However, as Giddens explains about the reflexive agent, the reasons and intentions behind actions are not those specifically articulated, as much of human agency is based on what Giddens calls 'practical knowledge'.

Examining this 'practice' of dying, then, forms the backbone of the current research design. In this design, dying agency is identified as living with the knowledge, the everyday reality, and the consequences of one's death. The narratives related to these aspects of the experience of dying are thus considered the sites actual agency, since language is the point of entry into the reflexive project of the self (Giddens 1991, 51). It is suggested that the agency of dying, represented in these narratives, is informed by ideals of good death upheld by each of the main characters in the documentary.

The study of narratives combines classic Labovian analysis of narrative structure to Bamberg's positioning analysis. The analysis focuses on a number of 'small stories' (Bamberg 2010), acknowledging the embeddedness of the narratives within the framework of interviews and scenes which make up the documentary.

The research questions are:

- 1) How is agency represented in the small stories perceived through the Labovian narrative structure?
- 2) How is agency portrayed as positions and interaction through storytelling?
- 3) What are the elements of the 'good death' narrative in *My last words*?

3 AGENCY: A REFLEXIVE PROJECT

3.1 Self and Modernity

An intimate, personal perspective into human existence, a perspective Giddens refers to as ‘self-identity’, emerges through an analysis of modernity itself. Social is not separate from personal, nor is it external: through their intimate struggles, individuals actively help in reconstructing the social around them (1991, 12). However, this is also because the ‘world’ of modernity is profoundly distinct from that of previous periods of history: in many ways it is a single world, based on new forms of mediated experience and thus having a unitary framework of experience (ibid., 5).

High modernity involves the dismantling of the traditional reference points of identity – the social institutions of community and family, and the elements of time and place (Giddens 1991, 16-17) – along with the concomitant process of negotiating one’s place in the world. The human experience, the self-identity, thus becomes the core of agency, in both content and aim. ‘Finding oneself’, says Giddens, is something that the social conditions of modernity enforce upon us (1991, 12). This process of being and becoming, ‘the reflexive project of the self’, consists in “*sustaining coherent, yet continuously revised, biographical narratives*” (ibid., 5). Each of us *lives* a biography reflexively organized with respect to social and psychological information about possible lifestyles (ibid., 14). Not only is self-identity thus ambivalent, so is the world with which it converses. This is because modern institutions, rather than providing a basis for identity, fragment and dissociate authority and knowledge.

Rejecting a postmodern analysis, however, Giddens points to the simultaneously unifying characteristics of modernity. Although the essential reflexivity of modernity undermines the certainty of knowledge (Giddens 1991, 21), the mass media creates an a shared, ‘mediated experience’ – the intrusion of distant events into everyday consciousness (ibid., 27). The mediated experience elevates the sphere of experience from immediate to universal. For Giddens, this ultimately means a situation where there is a ‘we’, as humanity, and no ‘others’.

In high modernity, the reflexive agent faces the major ontological task of composing her very self. The multitude and plurality of choice that exists at her disposal through the mediated experience indicates both a vast context of social awareness and a tremendous resource. However, Giddens states that an adequate analysis of agency must situate the agent in time and space (1987, 60), which means that Giddens' agency remains firmly linked to social structure (Tucker 1998, 80). The tacit knowledge of how to operate in the day-to-day of their lives is called 'practical consciousness' by Giddens (1979, 55; 1984, xxiii) and is imperative in the process of reflexive monitoring tied to specific social conditions. The actions taken within the social structures serve as the very means through which individuals express themselves (1984, 2-3). The creative capacity of the individual is thus limited by the social knowledge that creates routine, significant in reproducing social reality. Although the agent is reflexive and knowledgeable, free action occurs in the context of social rules – because human social activities are, importantly, recursive (ibid., 2).

The post-traditional social order offers the individual choices and alternatives which turn into personal lifestyles. Lifestyles, in turn, represent the routinised character of social life, a set of habits and modes of acting which Giddens perceives as the material form of the individually constructed self-narrative. (Giddens 1991, 80-81.) The patterns of life choices are thus a result of both the freedom of choice and the need to create logic and predictability out of endless possibility. The room for manoeuvre available to the individual is in fact narrowed down by the very lifestyle choices she makes: choice creates the concomitant urgency to choose (ibid., 81) and to relate each choice into the project of the self.

The presence of choice which turns into the need to participate in life planning is, for Giddens, an example of a more encompassing theme which he terms the 'colonisation of future'. The flip side of the dismantled and fragmented social experience in late modernity is the awareness and calculation of risk which is necessarily interwoven into each individual lifestyle choice and self-narrative. Giddens describes the 'protective cocoon' which is formed by 'bracketing out' potential eventualities in everyday life, necessary for agency and for social life (1991, 3). The performances individuals put on in specific social contexts (ibid., 58), the established routine of social institutions and individual lifestyles create and reproduce trust in the normalcy of daily life.

3.2 Fateful moments

Crucial for practical consciousness and for the social agent is the development of trust, a sense of ontological security, through which the individual is able to have an experience of self in relation to a world (Giddens 1991, 45). Ontological security is a belief in the continuity of self-identity and, on the other hand, in the reliability of social life (Tucker 1998, 83). Maintaining this sense of security becomes, therefore, a basic driving force for action – particularly for the modern individual faced with the fragmentation of the self and of experience. Following the logic of structuration, which states that structures are both the medium for social action and their outcome (1979, 69), so is trust both a generalized attitude underlying agentive decisions (*ibid.*, 19) and sustained in the daily, routinised activities of social life (Giddens 1984, xxiii).

An examination of routinisation, claims Giddens (1984, 60), is essential to understanding the role of ontological security in the reflexive character of social life. Such an examination, paradoxically, involves critical situations, typically marked by rites of passage, notes Giddens. To put it differently, “*We can learn a good deal about day-to-day life in routine settings from analysing the circumstances in which those settings are radically disturbed*” (1979, 123). Although these critical situations represent discontinuities, Giddens observes that they form an intrinsic part of the continuity of social life, having “*a definitely routinised character*” (1984, 61).

The dialectic between stability and crisis from the individual perspective is, in fact, also essential to an analysis of social reproduction – stability and change in society – and thus to a theory of agency. Blending psychological and social elements of analysis, Giddens explains how the routinisation of social relations importantly manages the layers of individual history, even the potentially problematic dimensions surfacing as feelings of anxiety. “*The familiar is reassuring*”, states Giddens, and thus the routine of structure becomes an aim of human action: after all, “[...] *the familiar in social settings is created and recreated through human agency itself, in the duality of structure*” (1979, 128).

Much of human action, and of social interaction is founded, therefore, on basic trust, which in turn is built on the ‘bracketing-out’ (1991, 127) of all the possible eventualities which might form a threat to daily life. Regardless, there are moments and events which

call the very existence of the individual into question. These ‘fateful moments’, according to Giddens, are instances which are particularly related to risk (1991, 113) and call for individuals to make decisions “[...] *that are particularly consequential for their ambitions, or more generally for their future lives*” (ibid., 112). Fateful moments, such as becoming aware of a serious illness, are transition points that call into question not only future plans-of-action, but the entire self-identity (Giddens 1991, 143). Since in the conditions of high modernity no overarching authority exists, fateful moments may also introduce the need for seeking out information. Giddens calls this empowerment through reskilling (1991, 141-142).

For Janet Holland & Rachel Thomson (2009, 454), the ‘fateful moment’ provides the point of entry into the very instantiation, and therefore empirical study, of agency: “[*the fateful moment*] *requires that the individual considers the consequences of choices and action, and assesses the risks of those outcomes*”. In other words, the nature of the fateful moment as potentially dramatic and profoundly disarranging *presumes* taking action. In fact, claim Holland & Thomson, “[...] *it is taking control in the fateful moment and exercising agency that is crucial in the definition*” (2009, 455). ”

3.3 Narratives of illness

Giddens argues that the linguistic turn in social theory, exploring the intersection between language and the constitution of social practices (1987, 78) is unable to provide insight into agency or social structures (ibid., 80) because language itself resides in social practices, not outside of it. Language thus appears as the *medium of social practice* (Giddens 1979, 40). At a first reading, language is indeed positioned in a minor role in Giddens’ theory of agency. The acting subject is described essentially through the ‘reflexive monitoring of conduct’ (1979, 39). This reflexivity, however, pointing to reasons and intentions behind actions should not to be considered as something specifically articulated, nor as a separate conscious deliberation preceding actions, but as a continuous state or a characteristic of human agency (ibid., 40).

The flow of social life, consisting of individual acts, operates to a large extent based on practical consciousness – drawing on ‘tacit’ knowledge, which can only partially be

expressed through discourse, says Giddens (ibid.). In fact, the reasons actors expressly supply for their actions appear somewhat contradictory to their rationalization which is revealed in the stream of conduct of the agent (ibid., 57). This reflexive state is a chronic feature of the human subject – and thus anchored in all action as part of the logic of producing and reproducing behaviour (Giddens 1991, 63).

Even though reason behind action bears mostly on the non-discursive level of reflection, language is the point of entry into the reflexive process of self, which after all is at the heart of agency in late modernity. Whereas the articulate consciousness of reasons for action is not the dominant mode of agency, agency nevertheless presumes self-consciousness. For Giddens, self-consciousness is not separate from, nor even primary compared to an awareness of others, “[...] *since language – which is intrinsically public – is the means of access to both*” (1991, 51). In other words, intersubjectivity does not derive from subjectivity, but vice versa (ibid.). The ‘self’, being inherently social in nature, develops and is constructed, through language.

The self becomes problematic particularly in late modernity – a problem which Giddens calls ‘living in the world’. As discussed, selves are confronted with the plurality of choice as the traditional sources of identification and obligation have become obsolete. The individual is presented with a multitude of alternative lifestyle choices, authorities and sources of community. The dilemma emerges, as modernity fragments the human experience. For Giddens, the problem of unification for the self is essentially related to preserving the ‘narrative of self-identity’ (1991, 189). Here, the dual nature of modernity as both unifying and fragmenting (ibid.) is apparent: not only widening the domain of experience and identification, bringing the distant within reach of anyone, anywhere, the mediated experience also offers narratives specifically developed to create narrative coherence with which the reader can identify (ibid., 199).

Considering, once again, Giddens’ theory of agency, as the production and reproduction of social practice as a reflexive and ongoing process, the central task of maintaining the narrative of self-identity should be perceived as both practical and discursive. The self-identity of the modern individual, “*constituted by the reflexive ordering of self-narratives*” (Giddens 1991, 244) relies on a ‘discursive consciousness’ (1979, 73) of agency. Thus, reducing Giddens to a mere “*theorist of practice*” who considers human agency as “*habitual, repetitive, and taken for granted*” (Emirbayer & Mische 1998) overlooks the

ever-prevalent effort of monitoring, unifying and constructing of the modern *self vis-à-vis* social practice and others.

A critique, reminiscent of Giddens' analysis of agency, is put forth by Paul Atkinson (1997; Atkinson & Delamont 2006) who considers the narrative turn as a new wave of Romanticism, where the atomised subject, thoroughly individual and personal, is speaking in social vacuum. What is lost in narrative in many of these approaches, is a context and an analysis. For Atkinson (2009), a social analysis in narrativity should consider that the right to talk, the permissible topics of talk, and the conventions of participation in speech events are all constitutive of social position. In fact, taking as a case in point the illness narrative, which has claimed unprecedented attention in narrative analysis, is a distinctively Anglo, middle-class mode of expression, claims Atkinson (*ibid.*). Like Giddens, Atkinson thus rejects an autonomous talking subject.

Constructing a life story, write Amia Lieblich, Rivka Tuval-Mashiach & Tamar Zilber (2008), requires the narrator to fulfil two tasks: telling a story of their being and development, and providing an explanation for how they reached their present situation or identity. If possible, this task becomes even more urgent once told upon impending death. Illness narratives are thus considered attempts at biographical reconstitution and identity work (Atkinson 2009). Chronic illness disrupts the relationship between the self, the body, and the surrounding world: illness can be experienced as an external event, yet through narrative, it can be integrated into the life story (Hydén 1997, 51-53). Gareth Williams' (1984) analysis of illness narratives' etiology indicates that persons afflicted by arthritis offer not only causal explanations for the onset of the disease, but also interpretive: for Williams, these explanations are narrative reconstructions for the disruptions of illness in daily life.

Narrative theory has increasingly become aware that situational factors play a crucial role in the construction of narratives, and of the different possible narratives arising from different situations, particularly from the interaction of the narrator and the listener (Hydén 1997, 52). As far as a healing or a restorative function, illness stories represent the opportunity of looking into the past, the present, and the imagined future, all important dimensions of identity construction, accomplished performatively. This is not to suggest that the identities are inauthentic, rather that identities are accomplished and positioned with an audience in mind. (Riessman 2003, 7.)

Illness narratives are of interest to social research particularly as they are conceived as resistance to the authoritative role of medicine in explaining illness (Hydén 1997; Atkinson 2009). When a distinction was made between illness and disease, the possibility opened up for the study of the patient's speech acts as an integral and important part of the course of illness, and once attention shifted from illness to suffering, these speech acts formed a voice that was strong enough to resist the medical authority (Hydén 1997, 49).

Arthur W. Frank (1995) laid the groundwork for a theory of illness narratives. The first category is the *restitution narrative*, a recovery from illness by the grace of a medicine, a medical expert or a technical solution. The *chaos narrative*, on the other hand, represents the opposite, where the narration is unable to express nor repair the damage of illness. Third, a *quest narrative* accounts for the agency that is formed as a result of illness: at first, illness leads in a disarray and despair, then, through transformation, to reclaiming a novel form of subjectivity. These narratives, to put it in Williams' (1984) terms, including those depicting the good death – strive to re-establish order by reconstructing the broken relationship between the body, self and society.

4 EXPLORING *MY LAST WORDS*

4.1 Narrative analysis: Labovian structure and Bambergian agency

There are many points of entry into reading a narrative. An analytical framework might focus on a textual or rhetorical (Burke 1969), a psychological (Lieblich, Tuval-Mashiach & Zilber 1998), or a social and political (Williams 1984) logic of narrative. The overarching question for these different approaches is whether the chosen framework gives precedence to the internal world of the narrator or whether the narrative is treated as the outcome, to a lesser or greater degree, of various structures, discursive, cultural or social, for instance.

Unlike structuralists and post-structuralists, who perceive the construction of reality through and in language, Giddens (1987, 91) contends that meaning does not originate within language, but at the intersection of applying signifiers with “*objects and events of the world, focused an organized via the acting individual*”. This context of social conduct, in narrative analysis, is narrative structure, which is recognizable to various audiences. The stories told may be unique, but they are composed by adapting and combining narrative structures which cultures make available (Frank 1995, 75).

A classic theory of narrative structure is put forth by William Labov and Joshua Waletzky (1967; Labov 2006) in the form of an analytic framework of how people convey past *personal experiences* in narrative form. This model became paradigmatic for narrative research, usually applied or at least referred to by any narrative study (Riessman 2008, 81). Studying the vernacular use of language within street culture, Labov and Waletzky (1967, 13) stated as their aim to find correlations of the narrator’s social characteristics with the structure of their narratives, in the effort to discuss problems of effective communication. They defined narrative in general as “*a particular way of reporting past events*” where the temporal order of clauses represents the temporal sequence of events (Labov 2006).

A complete narrative in the classic Labovian model includes six elements:

- an abstract (a summary or a ‘title’ of the story);

- orientation (the context of events, including the who, where, when and why of the story);
- complicating action (an event or action, possibly indicating conflict);
- evaluation (the narrator's point of view); resolution (how the complication ends or what it leads to); and
- coda (connecting the narrative to the moment of telling the story).

Michael Bamberg (1997; 2005; 2010) builds on Labov's approach, which he considers has two possible readings. The first focuses on what is said and how it is said, to work out the reason for why the narrative is put forth. The second takes the narrative form as a means of performance – considering the narrative as an act – where the audience bears a greater role in how the narrative is constructed and performed. (Bamberg 1997.) Bamberg thus develops an approach to narrative analysis called *positioning analysis*, which, in addition to considering what is actually said, explores the narrative as an interactional event. Positioning analysis considers how the characters, as well as the participants to the act of storytelling, assume positions in relation to one another.

Thus, following concepts familiar from Giddens' analysis of agency, also narrative analysis can be considered an interplay between structure and performance. The study of the textual and structural properties of narratives analyses themes and the ways characters are presented in the narrative, assumed to aim at coherence in producing a representation of an experience or an event for the listener. Instead, narrative-as-practice considers the *process* of negotiating identity claims in social contexts: participants are seen to constantly reflect on and adjust their choices with respect to what they jointly create in the moment (Bamberg 2005, 223).

4.2 From 'small' to 'Big'

Positioning theory was initially developed within the context of psychology of personhood – linked to a person's conceptions of what he or she is as an individual, and how they are connected to the positions available to that person in the collectivities he/she attends to (Harré 2010, 51). Positioning analysis acknowledges, in the framework of agency, the role of the local context, the normative constraints and opportunities for action in narrative performance (ibid.). In other words, positioning theory perceives the

framework for action as not determined by competence alone but also as rights and duties with respect to the social context (ibid.,) – much like Giddens, for whom free action occurs in the context of social rules (1984, 2).

Positions, then, are clusters of normative beliefs pertaining to a particular episode of social interaction – “*features of the local moral landscape*” – to which people are assigned to, or assign themselves via a variety of implicit and explicit acts. These positions are local and may even be momentary, which is why any positioning act can also be challenged. (Harré 2010, 53.) However, positions form the fundamental source of meaning in narratives as they determine the ‘act-force’ of speaking and acting (ibid., 54), delineating the meaning of those actions. In fact, states Rom Harré (ibid.), what you *are* is partly determined by the roles you have.

Building on Harré, Bamberg (1997) accentuates the purpose of the narrative itself as an act – perhaps of claiming positions and of positioning others – where the role of the audience plays a crucial role. Bamberg (2006) argues that studies in narrative identity should include the referential level of meaning – that is, analysis should investigate how the use of linguistic devices (i.e. what textual narrative analysis is traditionally about) is contextualized. Compared to Labovian approach, Bamberg (1997) therefore suggests a broader consideration of the narrative, one where the discursive situation and discursive purpose – the pragmatics of narrating – are united with the linguistic (structural) analysis.

The ‘narrative turn’ in social science presented narratives as one of the main forms through which we perceive, experience and judge our actions – the very medium for how we make sense of the world (Hydén 1997, 49-50). Positioning theory, then, represents a rift within the narrative theory pertaining to the role of narrative as source of empirical knowledge. The ‘narrative turn’, after all, has been criticized for claiming narrative itself as the independent site of research. Atkinson’s (2009) critique, for instance, relates to the lack of context in the treatment of narratives: narratives are celebrated as privileged phenomena in their own right, devoid of cultural or social life. In the same vein, claims Atkinson, contemporary social science research, in search of an ‘interior biographical life’ draws on explanatory models which are non-, or even anti-sociological, investigating a subconscious and private experience (ibid.).

Bamberg notes, similarly, that the narrative turn in social sciences was largely built on ‘big story’ research (Bamberg & Georgakapoulou 2008), investigating life stories as manifestations of identities. The ‘big story’ approach starts from the first-person perspective, a self-oriented, self-reflective and rational individual – and importantly, locates the source of meaning within that person. In contrast, an interest in ‘small stories’ (Bamberg 2006; Bamberg & Georgakapoulou 2008; Bamberg 2011) takes identity as a process of construction, profoundly situational and social. The small story approach views the individual as socially and interactionally constituted, while agentive and “*occasionally strategic*.” Meaning thus originates in the social interaction (Bamberg 2011.)

Whereas the ‘big story’ approach tends to essentialize self and identity (Bamberg 2008, 184), a focus on small stories views the relationship between identity and narrative more as aim than fact. The small story perspective represents a markedly different analysis into the relationship between the social and the individual compared to the ‘biographical turn’ of social science. The paradigm of narrative and identity as an ongoing process of social negotiation resonates with that of Giddens (1979, 43): he perceives the production of a text – parallel to the production of a social practice – not the outcome of intention or a ‘fixed form’, but “*a concrete medium and outcome of a process of production, reflexively monitored by its author or reader*”. Furthermore, for Giddens (ibid., 43-44), considering the text presumes considering who the author is as an acting subject:

“An author is neither a bundle of intentions, nor on the other hand a series of ‘traces’ somehow deposited within the text. [...] But to study a text is at the same time in a definite sense to study the production of its author. The author is not simply ‘subject’ and the text ‘object’; the ‘author’ helps constitute him- or herself through the text, via the very process of production of that text.”

Rather than a deposit of meaning planted and to be discovered, positioning theory and a focus on ‘small stories’ take narrative as an act of meaning construction – a joint effort of the speaker and audience, bound by the social context which inevitably is part of the very aim of the narrative.

Narrative positioning analysis proceeds on three levels, formulated into three positioning questions (Bamberg 1997; Bamberg and Georgakapoulou 2008):

- 1) How characters are positioned within the story (level 1)

- 2) How the speaker/narrator positions him/herself (and is positioned) within the interactive situation (level 2)
 - a. Analysing the interactional accomplishment of *narrating* as the activity under construction in the excerpt
 - b. Analysing the research setting in which the interviewer has asked a question, how it was answered in the form of telling a story and what can be concluded from that.
 - c. Analysing the joint interactional engagement between participants.
- 3) How the speaker/narrator positions a sense of self/identity with regard to dominant discourses or master narratives (level 3)

4.3 Research design, data and methodology

My last words (Mijn Laatste Woorden – Viimeiset sanani) is a television documentary series¹ consisting of four Dutch episodes and five Finnish ones, each introducing a single main character – incurably ill and facing the last months of their life. Each episode ends in a farewell video message by the main character to his or her loved ones. In Finland, the documentary first aired in 2013, and was described by YLE (Yleisradio, The Finnish Broadcasting Company) in the following way:

*“Death, like birth, is a part of life. The documentary series My last words offers a platform for the incurably ill persons and their loved ones. The documentary makes you think but does not cause fear or anguish. The topics dealt with are addressed directly, not through euphemisms. The five Finnish episodes are followed by four Dutch ones.”*²

My last words represents the first instance of the terminally ill stepping into the limelight in the Finnish public television. The news of the upcoming series was met with mixed reactions in social media. The Dutch roots of the format raised suspicions in some commentators, who suggested that the purpose of the show was nothing more than to advertise euthanasia which is legal in the Netherlands. Other comments expressed that “*feeding off*” death and the private suffering of people was “*tacky*”. Those in opposition considered

¹ The documentary is based on the format of the Dutch production company Palm Plus. The Finnish episodes are produced by Sari Isotalo, Susamuru Ltd. Palm Plus won the Golden Rose festival award for *My last words* in Switzerland in 2007.

² YLE, <https://areena.yle.fi/1-1930625>, accessed March 2nd, 2019.

death a valuable topic for public discussion, noting that death had become too distant and abstract a topic for the contemporary person. (Uusi Suomi 2008.)

For the purposes of exploring the discussion of good death, the documentary appears as an intriguing point of access into the topic. Based on a review of research literature on the constituents of good death, the obvious differences, even contradictions, in the ideals expressed by various reference groups are clear. Considering the experience of dying as one that potentially lasts for years, it appears, that the topic might be approached differently. Rather than as definitions and preferences, the good death could be identified in the practice and process of dying, thus incorporating the personal, social and possibly even the societal factors at play in the individual experience. As the empirical material for this study, the documentary as a public display of private experiences appears to offer the unique perspective into the intersection of personal strategies meeting social and societal ideals and expectations.

Considering the narrative structure of *My last words*, each episode represents a collage of perspectives into the experience of dying. First, the visual storyline forms through the lens of the camera. What is seen by the viewers appears, at times, in partnership with what is said, accentuating and explaining the topic at hand – while at other times the camera footage appears in contrast, even in contradiction to the expressed emotions. This contrast is particularly clear in the Dutch episodes of the documentary, which feature lots of rhythmic music, voice narrating and editing to present the main characters as courageous and energetic in the midst of their final moments.

The main character is presented in conjunction with his or her family members, each offering their personal angle into the experience. Importantly, the interviewer also plays an active role in choosing and delimiting the topics of discussion. Through the interviews and the social network, the documentary assembles a life story of the main character from the vantage point of the approaching death.

Since an analysis of all ten episodes would have been beyond the scope of this thesis, it is confined to the Finnish episodes. After transcribing the episodes, including both the textual and the visual material in each of them, my focus further narrowed down to consider how the characters were portrayed in the documentary. In considering the narrative structure of the format, the many narratives *within* each episode, performed by the main

characters themselves stood out. Beneath the main storyline, multiple small stories are heard, occasionally appearing as autonomous first-person narratives, while others jointly produced by a number of characters, sometimes including the interviewer. In order to entrench beyond the script and structure of the documentary, these small stories appeared as the points of entry into the narrative voice of the main characters themselves.

I attempted to identify comparable narratives for analysis: one related to the initial experience of receiving diagnosis and facing the possibility of death; another related to living with death; and finally one related to facing the consequences of death, i.e. leaving farewells. As the number of narratives accumulated, it became clear that four (out of the five Finnish) main characters was the maximum I could include in the analysis. Although the sample is not large, and is demarcated by the Finnish context, choosing commensurate small stories allows for comparisons to be made.

5 SMALL STORIES OF DYING AGENCY

5.1 Maria

Maria – small story 1

1 I've worked on a cruise ship for 25 years as a croupier at a gambling table.
 2 In 2008, when I got the diagnosis,
 3 that summer I was working on a ship on the Turku-Stockholm route.
 4 I took the train to Turku,
 5 and went to work,
 6 stayed there for two days.
 7 The pain was too much
 8 so I couldn't stay any longer,
 9 so I came to Helsinki by ship.
 10 Then the doctor gives you three days of sick leave,
 11 then you return,
 12 stay a couple of days,
 13 and come back.
 14 It was just horrible. Horrible, in the beginning.
 15 But then suddenly, I remember it was a Tuesday,
 16 the phone rang in the morning:
 17 "Will you come right away to hear the results."
 18 So, naturally I was amazed,
 19 and anticipated
 20 that there had to be something there,
 21 since the results came back so quickly.
 22 And so there was a young female doctor
 23 who said,
 24 you have multiple myeloma,
 25 explaining it is bone marrow cancer.
 26 And there it was.
 27 I was horrified,
 28 I went straight to the ladies' room, crying and confounded.

Maria's story of illness follows the classic Labovian (1967; 2006) narrative structure, beginning with an abstract which recognizes the background of her 25-year career on a cruise ship. The complication is the climax of the narrative, marked off by the speaker dramatically shifting from past to present tense, inviting the audience to join the urgency of the experience of falling ill and enduring the pain of illness (lines 10-13): "*The doctor gives you three days of sick leave, then you return, stay a couple of days and come back*".

Maria's story could be considered two separate stories, the first one (lines 1-14) describing the illness experience and the second (lines 15-28) receiving the diagnosis. The second story, whether treated as a continuance of the first part or an independent narrative, begins, regardless, with an orientation "*But then suddenly, I remember it was a Tuesday*". A (further) complicating action follows: "[...] *the phone rang in the morning*". Her evaluation "*So, naturally I was amazed*" emphasizes her position as the object of these rather impersonal events. Finally, the resolution of the story is underlain with Maria's anticipation "[...] *there had to be something there*", thus importantly including her as an actor in the unfolding of events.

Receiving the news of her diagnosis (lines 22-26) is a miniature narrative itself: "*And so there was a young female doctor (orientation) who said, you have multiple myeloma, (complication) explaining it is bone marrow cancer (resolution). And there it was (coda).*" However, considering the entire segment as a complicating action leaves room for the last two lines (27-28) as resolution of the larger narrative. Without the last two lines "*I was horrified. I went straight to the ladies' room, crying and confounded*", the narrative of receiving diagnosis would resemble a report of a distant, almost random event, lacking a human face. In fact, the resolution of Maria's story also counts as evaluation ("*I was horrified*"). In the Labovian model of narrative inquiry, which explicitly explores the format of accounting for personal experiences, evaluation is considered essential, since an experiential narrative would be pointless without evaluation (Labov 1997).

The speaker's position in this illness narrative resembles that of a puppet, first thrust back and forth between work and the doctor's office in unbearable pain, then specifically called to see the doctor and finally fleeing from the scene upon receiving the diagnosis. Although the narrative is full of motion, the speaker only begins to verge on the speed of events as she 'anticipates', after the phone call, what is about to unveil. The agency in this narrative is represented by the doctor and the diagnosis. Their agency is first concealed and evasive, yet as the story unfolds, these agents are revealed: a voice at the end of a phone turns into a 'young female doctor' giving the news, and the pain which drove the speaker back and forth is identified and revealed for what it is. The speaker, on the other hand, establishes her agency only through her evaluation of the experience, stating "*I was horrified*". Because of her escape, the narrative ends without coda, which would take audience back to the here-and-now (Bamberg 2006), explaining the story's relevance in the current moment. Ending in the past therefore signals the independence of the

narrative from other contexts. The experience of receiving the diagnosis is described as total – the reaction of the speaker cannot be moderated or softened by any temporal or conceptual point of reference.

Maria – small story 2

- 1 *I: What in concrete terms has changed in your life after falling ill?*
- 2 The most concrete thing has of course been gaining weight.
- 3 I have to consume such large doses of cortisone
- 4 which cause enormous swelling of the body.
- 5 So, looking in the mirror,
- 6 I don't see me,
- 7 there is someone else looking back.
- 8 I normally dress sort of funny
- 9 and I wear lots of different kinds of hats
- 10 – I'm a bit of a hat freak –
- 11 but those hats make people smile.
- 12 So, I think it's wonderful to go out for walks and to meet people, to smile at them and to get a smile back.
- 13 It's like, you turn your life into an enjoyment.
- 14 Nowadays, walking around town [Maria filmed trying on different kinds of hats for the camera], smiling at people, you don't receive the kind of feedback anymore,
- 15 and I feel
- 16 they're looking and thinking
- 17 "there goes some drunkard, swollen and sweating,
- 18 and who knows what".
- 19 So, when I meet people,
- 20 the first thing I tell them
- 21 is that I have to take cortisone
- 22 and that's why I'm so chubby
- 23 and that's why I'm sweating.
- 24 Because that's how much it bothers me –
- 25 I mean,
- 26 I can drink alcohol and especially in the summer,
- 27 when you can have white a wine and smoke outside,
- 28 it's quite delightful. [Lighting up a cigarette during the interview]

Maria's second small story depicts the reality of living with cancer. The question put to her by the interviewer emphasizes the concrete effects on her life, and Maria replies with a narrative of physical transformation due to medication. The first part of her reply (lines

3-7) form a narrative of physical transformation: she takes cortisone (orientation) which causes swelling of the body (complication) and thus looking in the mirror, she has turned into someone she does not recognize (resolution). In Labovian inquiry, the key to a narrative structure lies in temporal juncture: the organization of narrative clauses in temporal form, so that changing the order of the clauses would in fact change the logic of the narrative. Since Maria's story of transformation takes place in present tense, the causal sequence of her account forms the base for a Labovian analysis.

In fact, Maria's narrative remains in present tense throughout. The blurring of the time frame in which she was healthy, then falls ill and undergoes the changes caused by her medication creates an impression of a spiral of events, whereby her 'normal' self is shredded by the hurricane of cancer. Thus, her rather concise narrative of physical transformation abruptly unfolds into a story of social experience of shame. The resolution of looking at a stranger in the mirror is followed by the speaker setting up another baseline for her story: "*I normally dress sort of funny*". Here, the word 'normally' also indicates 'before', referring to a time before illness. The narrative has therefore moved back in time, albeit syntactically remains in the present.

This 'normal' (lines 8-11) establishes the orientation for another narrative, and is followed by an evaluation by the speaker, explaining her motivation to make people smile. The complication (lines 14-18) ties the narrative to the original theme of physical transformation, describing and imagining other people's reaction to the speaker's changed appearance. The speaker's agency, aiming to re-establish her position as the old self (lines 19-23) finally offers resolution, giving voice to both her own experience of the loss of her familiar looks, as well as to the imagined criticisms of the people she meets. The closing segment (lines 24-28) beginning with "*Because that's how much it bothers me*" represents a coda, continuing with the speaker's evaluative position vis-à-vis her transformation, the missing smiles as well as her interpretation of the social reactions to her looks.

Beginning as a story of physical metamorphosis and turning into a tale of social rejection and loneliness, the narrative finds resolution in the active stance assumed by the narrator to her changed situation. Her effort to communicate with her surroundings, creating smiles and enjoyment, has turned into a strategy of blunt openness about her medical situation. However, the coda (lines 24-28), an evaluative position related to the imagined social disapproval, ties the problem of enjoyment and being mislabelled to the present

here-and-now. In fact, the coda is actually an evaluation of her agency in the clench of her illness and of social rejection. What first perhaps appears as a footnote in the main story, with the narrator clearly stepping outside the temporal structure of the plot, the coda actually adds a powerful comment on the narrator's rights and ability to remain the normative, independent voice in her life, regardless of the change, both physical and social, to her normal experience.

Maria – small story 3

1 Now it has happened.
 2 I hope
 3 my death was beautiful
 4 so that it leaves a beautiful memory.
 5 I know
 6 you are all sad
 7 and miss me,
 8 so grieve for a while,
 9 but after that forget about it,
 10 and remember something every now and then, both the good and the unpleasant.
 11 To my siblings, especially to Jämä, I've been a rather tiresome little sister.
 12 Remember,
 13 when you think about something for a while,
 14 you will find the answer
 15 and you will know
 16 what I would've said about it.
 17 I hope
 18 that before I died
 19 I could've made
 20 the Cancer Society and other people to realise
 21 that there are more and more people
 22 who share my destiny, living for years incurably ill.
 23 In a situation like this, when future is uncertain,
 24 you cannot predict your time of death.
 25 I thought
 26 I would live for five, six months,
 27 and I've lived for seven years now,
 28 and I'm puzzled about
 29 how to handle another seven years,
 30 if that should be the case.
 31 Death is not a bad thing,
 32 death is a happy concept, at least for me.
 33 Life is wonderful for as long as it lasts,
 34 but the calm of death, what could be a better source of serenity.
 35 But enjoy life for as long as it lasts,

- 36 and under no circumstances fear death nor dying people.
 37 Death is not contagious. Cheers!

In the first segment of Maria's farewell message (lines 1-10), death is approached temporally. Death is both as an immediate event "*Now it has happened*" (line 1) and an occasion which already belongs in the past "*I hope my death was beautiful so that it leaves a beautiful memory*" (lines 2-4). The speaker then addresses her bereaved family, in their present, and moves into their future, instructing them both to forget and to remember, in moderation.

The first segment is characterised by dualities. It treats death as something almost independent, a process following its own rules: "*it has happened*". The speaker therefore appears impartial to the event; she can only hope for the process to have been beautiful. Furthermore, her position as the bystander is underscored by her recognition of the impact of her death on her family. The speaker's position as a bystander is also reflected through the notion that her death is not for her: death will pass on as a memory to the living.

Next, the speaker continues to assume the perspective of her audience, expressing their grief, "*I know you are all sad and miss me*" (lines 5-10), and instructing them on how she would like to be remembered by them. Thus, mapping the experience of the audience, the speaker follows two separate, yet parallel trails: one addressing death itself, the other addressing grief. The former, in which she is but the object of death, she wishes turns into a beautiful memory. This memory she appears to grant a sovereign position. In contrast, the latter, where she is the object of grief, she accords a relative position – to be remembered in proportion, and to be allowed to contain both the good and the bad.

The second segment (lines 11-16) addresses the family members individually. Here, the speaker shortly comments on her relationship to her siblings. What follows is a guideline for future, which simultaneously appears to extend the connection between the siblings beyond the speaker's death: "*Remember, when you think about something for a while, you will find the answer and you will know what I would've said about it.*" The reality of the shared bond between the siblings turns into an understanding, an internalised

knowledge of the other. The speaker's position, through this bond, continues as the siblings' internal dialogue.

The third segment (lines 17-30) expresses a wish, situated both in the past as well as the future, of the growing social recognition of the people living with an incurable illness. This portion of the message verges on a statement for the larger audience. It begins with a general acknowledgement of the prevalence of the experience of living with an indefinite prognosis (lines 21-24) and continues as a personal account of dealing with the uncertainty of time left.

The last segment (lines 31-37) closes the circle, returning to where the message began: this time, death is addressed as the counterpart to life. The message, starting off as a personal address to the speaker's immediate family, and continuing as social and political commentary, ends in a universal reflection on the topic of death. Here, the speaker appears to be standing on the dividing line between two ultimate realms, able to make claims to both. This binary position is reflected in approaching the topic – "*Death is not a bad thing, death is a happy concept*" (lines 31-32), she declares. This logic continues into the juxtaposition with life, which in fact appears to diminish the contrast: "*Life is wonderful for as long as it lasts, but the calm of death, what could be a better source of serenity*" (lines 33-34). The message ends in maxim to enjoy life and not to fear death. Significantly, the humorous ending of the message again separates death and life via the remark "*Death is not contagious*" (line 37). This juxtaposition does not set the two in opposition but treats them as counterparts – death as a comfort, rather than a threat to life.

5.2 Manta

Manta – small story 1

- 1 I have diabetes and all possible complications
- 2 that may result from it:
- 3 my eye has been surgically removed,
- 4 my kidneys do not work,
- 5 and my peripheral blood flow is so poor
- 6 that my fingers and my leg have been amputated.
- 7 Now it's about trying to get by on dialysis.
- 8 In January it will be nine years like this.

- 9 I have never met anyone
 10 who had been on dialysis for more than ten years,
 11 so, this is verging on the maximum period
 12 a body can take.

Manta's story of illness is a physical one; it could be said that the very scene in which the story is embedded is the human body. The story develops as a map, locating the various body parts which are failing and causing problems for the narrator. Emphasizing the quantity and breadth of the problem is how the first segment of the story (lines 1-6) lists the problem areas and combines with the second segment (lines 8-12), describing the temporal margins of the situation. Although the body is the object operated on, expressed in passive tense (eye removed, fingers amputated), reciting all the dysfunctions of the body in fact turns into a process of active deterioration. Meanwhile, the narrator appears both as the context of this activity as well as the spectator of the chain of events. The story, beginning "*I have diabetes*", ends with "*...a body can take*", emphasises how the speaker is reduced into physical body.

The temporal flow of the story starts off in the present, then recalls the past problems of the body (lines 6-9), and again returns to the present (lines 7-9), as the narrator slightly reclaims her position. The speaker behind the bodily scene is, however, pale and fragile, appearing in passive subject position: "*Now it's about trying to get by*". Finally, the story sets off to the future, while transcending the contours of the narrator's individual body (lines 9-10). The complicating action of the narrative is in fact a general statement, shifting the perspective radically from the particular to the universal: "*I have never met anyone who had been on dialysis for more than ten years*". The narrator, thus far appearing only through the body, reappears as the 'I' of the story, identifying the limits to her agency and to her life.

The intimate list of her body's lost battles has, for the time being, find truce under "*getting by on dialysis*". By setting the timeframe, however, the narrator positions herself parallel to others dependent on dialysis, and thus concedes the scene back to the body. The alternating perspectives between the 'I' and 'body' set them apart, almost portraying the body fighting its own battle, while the 'I' appears as the commentator, viewing the action from the side lines.

Manta - small story 2

1 [Interviewer]: *What is the role of religion in Manta's life?*
2 [Daughter:] I think
3 religion has helped mother
4 to deal with her own death
5 and on the other hand it has provided her with a community and the kind of people
6 who accept her as she is.
7 They have this kind of group or a circle
8 that spends a lot of time together
9 and talks about religion and life and everything.
10 [Interviewer]: *What does faith offer you in life?*
11 [Manta:] It is sort of refuge there, after all,
12 and at least right now it is easy
13 to think
14 that after this one will end up some place good.
15 [Interviewer]: *Has church been able to fulfil your needs?*
16 I must say
17 that up until the last few days, yes,
18 but now something has caused a kind of indecision,
19 whether, like, I believe in the church or in God.
20 [Interviewer]: *Has something happened*
21 *which has made you doubt the church?*
22 Well, it was precisely
23 when this documentary was being made,
24 when they had this attitude
25 that talking about death is allowed but only privately,
26 while disturbing other people with such severe topics is not allowed. [Manta is
lifted inside the taxi in her wheelchair]
27 [Interviewer]: *Did you feel like*
28 *you weren't accepted as you are?*
29 Yes, and I thought
30 whether there's any point in me going there
31 if I'm not allowed
32 to be myself.
33 If I'm supposed
34 to think..
35 If I'm supposed to censor myself all the time.
36 And it is now so strongly a part of oneself after all,
37 because this disease is getting worse all the time,
38 and day by day it gets sort of bigger and closer, so...
39 I'll have to see
40 what the final result is. [Taxi takes off].

The role of religion in Manta's life unfolds as a double narrative: the same question is first posed to Manta's daughter, and then to Manta herself. Manta's daughter (lines 2-9)

considers the importance of religion for her mother in a narrative in which there are three agents: religion, Manta, and the religious community. Religion is formulated in agentive terms, appearing in the subject position “*religion has helped mother..*”; “*religion has provided her with a community*”. On the other hand, working in conjunction with religion Manta is able to “*deal with her own death*”. As the characters of the story, religion and Manta are thus positioned as partners.

Delineating main from secondary characters (Bamberg 2012) in the daughter’s story is not straightforward: religion is described as a precondition for the agency of both Manta and the community. Religion is therefore referred to in present perfect tense (“*has helped*”, “*has provided*”) whereas the ensuing actions of Manta and the community appear in present tense (“*accept her as she is*”, “*spends a lot of time together*”, “*talks about religion and life*”). The story thus unfolds in temporal sequence, from past to present, overcoming the complication, dealing with death and looking for a community, to resolution (Labov 2006): the group has attained, if not control, at least a collective approach to ‘everything’.

The narrator (Manta’s daughter), at first emphasizing her evaluative position (“*I think*”) puts herself outside the narrative. Much like the intertwining of the main and secondary characters (religion, Manta and the community), also the position of the detached narrator begins to shift into that of a participant. The daughter’s understanding of both the private needs of her mother in dealing with death as well as the functioning of the community, implies rather an ‘inside’ position into the story. Through her account of the relationship between the community members and of their acceptance of Manta as she is, her daughter conveys a rather universal story of love and friendship – one she can identify with. Considering Bamberg’s (1997) thesis that the speaker, through the narrative, is ultimately answering the question ‘Who am I?’, it could be concluded that the daughter’s narrative is not only, or even mostly, about Manta’s identity, but indeed her daughter’s testimony to the basic human needs and of their fulfilment. It is as though she is including herself within the circle that finds acceptance and solace through religion and togetherness.

Manta’s response (lines 11-14) “*It is sort of a refuge there, after all*” describes faith metaphorically through another term, ‘refuge’. Faith becomes almost a negation – an escape or an asylum from something. After all, ‘refuge’ could not exist without its counterpart.

Furthermore, ‘refuge’ is followed by the spatial attribute ‘there’, implying distance and distinction.

What is more, defining ‘faith’ in spatial terms is linked to the second part of the reply (lines 12-14): “[...] *and at least now it’s easy to think that after this one will end up some place good*”. The “*refuge, there*” and “*some place good*” become parallel, connecting Manta’s present to that which she anticipates after death.

Similarly to her daughter’s narrative, Manta’s agency in her own account is carried by a vehicle – her faith. In both narratives, the characters are ambivalent, nearly replaced by ‘faith’ and ‘refuge’. For Manta, faith seems to connect with a universal agent who is referred to in passive terms – “*it is easy to think*” and “*one will end up*”. Although anonymous and passive, Manta’s agency finds a powerful vessel in faith. It provides Manta with space to think and allows her to connect with a future that transcends the present. Defined as an antithesis to ‘all this’, faith contains the resolution to her narrative, and to her life.

In her reply, Manta describes a level of immunity from life’s struggles, and a peace of mind secured in faith. However, the interview reinstates her in the current circumstances. Now replacing ‘faith’ with ‘church’, the interviewer is asking whether the church has been able to fulfil her needs. The question establishes Manta’s needs as self-evident and the church as responsible for matching those needs.

Manta’s reply reciprocates the hypothesis embedded in the question. Following the explicit positioning of Manta vis-à-vis the church by the interviewer, Manta adopts an active stance more distinctly: “*I must say*”, she begins her comment, emphasizing her evaluative position. She then proceeds to ponder a juxtaposition of her own, whereby she positions the church and God vis-à-vis one another. Her own position appears as the deciding factor in solving this equation.

Asking to clarify the details behind Manta’s hesitation, the interviewer poses the following question in even more agentive terms, thus offering Manta a clearly adversarial position: “*Has something happened which has made you doubt the church?*”

In her reply, Manta describes a particular event (lines 22-26) related to the filming of *My last words*, which also represents the complicating action in this small story. Again, her own role in the story is effaced, although she is a central participant in the documentary project. Instead, she focuses on the church's actions, and indeed assumes a disengaged position, referring to the church as 'they'. Furthermore, in Manta's account, the conflict between her and the church is pronounced by the identification of the specific moment in which the rift was formed: "*Well, it was precisely when...*" forms the platform for the story of the church's stance on discussing death. In Manta's narrative, the church appears as a normative agent, having the power to 'allow' and 'not allow'. Although Manta herself does not make a visible appearance in this segment, she navigates her own agency via the perspective of the opponent: her dying is privatized and considered too 'severe' a topic for others.

Following this logic, and further tracking Manta's personal experience in the narrative, the interviewer moves the focus from the church back to Manta: "*Did you feel like you weren't accepted as you are?*".

Answering "Yes", again confirming the interviewer's hypothesis, Manta indeed appears onto the stage, continuing the story begun by the interviewer "[...] and I thought", visibly reassuming her position as the agent. She continues with the juxtaposition between her and the church by pointing to a difference both in location and in quality: "[...]whether there's any point in me going there if I'm not allowed to be myself". The previous segment, where "[...]disturbing other people with such severe topics [as death] is not allowed", finds its counterpart here, when Manta is "not allowed" to be herself. With the aid of the interviewer, Manta thus creates a parallel between the two.

Paradoxically, Manta finds her voice as the agent of her story through a juxtaposition with the church. She continues with her position as the object of church's manipulation: "*If I'm supposed to think... If I'm supposed to censor myself all the time.*" Thus, the negative terms with which she described her subjugated agency 'not allowed to be' turns into the positive form 'supposed to', indicating what is expected of her. The political and social critique of her account is embodied in the word 'censor', expressing the normative pressure to behave and speak as though she was not dying.

Next, Manta introduces another character – death (lines 36-38). “*And it is now so strongly a part of oneself after all*”, she begins, much like stating a fact: “*it is [...] after all*”. This segment appears as a brute affirmation to Manta’s attempt to express her need to “*be herself*” (lines 29-35): death is a ‘part of oneself’, undeniable and real, getting ‘bigger’, ‘closer’. Yet it is not specifically Manta who is affected by death: her choice of words ‘part of oneself’ could also be read universally as ‘part of being human’.

The ending of Manta’s story, “*I’ll have to see what the final result is*” (lines 39-40) is ambiguous in terms of agency. On the one hand, the story began as a comment to a juxtaposition between her and the church, and through further inquiries by the interviewer, Manta adopts a visible, agentive role. In the last segment (29-40) she delineates her position as suppressed by the church’s attitude, and of her speculation on whether she should stop going there. On the other hand, Manta then describes herself as intertwined with death, with the disease engulfing a larger portion of her in a steady fashion. The story does not end in resolution, for any of the agents – not for church, not for Manta, and not even for death.

Manta – small story 3

1 Now we have reached the hardest part of making this documentary,
 2 so when you watch this film,
 3 I’m no longer there.
 4 But first of all I want to say to the kids
 5 that I’m not afraid at all,
 6 and the only concern for me is how you will get by here.
 7 You know that I love you
 8 even though I’m no longer around,
 9 and a part of me is nevertheless with you here always.
 10 I’ve come to the conclusion
 11 that if there is a heaven somewhere,
 12 that’s where I belong.
 13 And every day I will be up there,
 14 watching what you get up to here.
 15 You have probably had a very tough time these last fifteen years,
 16 since at least once a year we’ve had difficult situations,
 17 wondering whether something will happen
 18 or whether anything will happen..
 19 You have been living with fear
 20 and I understand well

21 that you have had a it very hard.
 22 I hope that it won't leave too big a shadow over you
 23 so that you will get to live here like every other person.
 24 One important thing is for you to take care of each other,
 25 since siblinghood is one of the longest of relationships
 26 we have in life.
 27 Relationships to your parents or to your spouse are not as long as that
 between a brother and a sister, nor any other.
 28 I've written a letter to my sister Taina,
 29 who has seven children,
 30 leaving you two to her in addition to those seven.
 31 So, Taina will be a grandmother to your children
 32 when you get around to having kids.
 33 Hopefully you will have kids,
 34 of course it is up to you,
 35 but I reckon
 36 at some point people do start wanting to have kids.
 37 And Maria – when I moved here a year and a half ago
 38 and knew Maria only by appearance,
 39 she came up to me already on the first or the second day,
 40 asking if she could be of help somehow,
 41 taking out the trash
 42 or getting the mail or something,
 43 and that's how it all started.
 44 It hasn't been a day since
 45 that we wouldn't have seen each other
 46 or asked how the other was doing.
 47 I just want to say to her
 48 that it is very rare in today's world to behave like that and to help un-
 conditionally. So for that, many thanks. So there.

Manta begins her farewell message by situating the audience and herself temporally apart. Her way of addressing her death is acknowledging how the moment of viewing the message – the 'when' or 'now' for the audience – signifies that for the speaker, time has effectively stopped. Right after stating the fact, the borderline anomaly – "*I'm no longer there*" (line 3), the speaker resumes her position as the narrator of her death. Continuing the course where she appears to deny death, first through the euphemism "*I'm no longer there*", the speaker then addresses her children, telling them what she could actually be telling death itself: "*I'm not afraid at all*" (line 5). Death, thus far, has been referred to implicitly, through the notions of non-existence, and fear. This fearlessness in the face of death is then juxtaposed with a concern for life – specifically, that of her children: "[...] *the only concern for me is how you will get by here*". In the first segment (lines 1-6) of

the message, then, the speaker effectively substitutes death for an absence, and immediately reinstates her position as the 'I', anchoring herself to the lives of her children.

The second segment (lines 7-14) further consolidates the speaker's association with her children, continuing as a direct and personal address to them. The speaker purports herself as love that remains and endures even though she herself does not, and she also indicates her interconnectedness with her children, continuing to live as part of them. The speaker's metamorphosis into timeless and immaterial elements is elaborated in the small story (lines 10-14) describing her life in heaven. The speaker assumes the role of the analyst, declaring her conclusion to her life's mystery in her final moments. The conclusion is related to her true self, "*where I belong*", whereby she identifies with a dimension, or as it appears, a location. In the small story, the orientation continues "[...] *if there is a heaven somewhere*" (line 11) and is followed by the complicating action, or climax, "[...] *that's where I belong*" (line 12). Importantly, this is the complicating action of the entire farewell message. This segment seals her process of preparing for and contemplating death, and through this account of heaven, she effectively sets herself apart from both life and death. As such, she remains connected to her children, enduring as an 'I' who is "*watching you what you get up to here*" (line 14).

The future, present and partly eternal tense of the first two segments is next replaced by reviewing the past (lines 15-21). The perspective now focuses on the children and their experience of living in quandary with their mother's illness. The children are positioned as bystanders to the inescapable reality of illness. The following segment (lines 22-36), however, describes what appears almost as a plan-of-action for the children and their future. The speaker positions the children as a team, taking care of each other, equipped to do so naturally through the unique bond of siblinghood. The speaker also presents a type of will, in which she leaves her children to her sister, and her sister as the grandmother to her children's children. In the end of this segment (lines 33-36) the speaker repeats her attempt to position the children next to "*every other person*" (line 23). "[...] *[A]t some point people do start wanting to have kids*" (line 36) is presented both as a wish and a prediction on the children's future.

The last segment (lines 37-48) introduces Maria, a friend and a neighbour. This small story recalls the friendship from its beginning and continues to the present. The private

experience is turned by the narrator into a universal account of the selfless and unconditional will to help.

5.3 Raimo

Raimo – small story 1

1 It was in 1998
 2 when this cancer was diagnosed.
 3 It is officially called sarcoma,
 4 and for the time being it is an incurable disease,
 5 since there is no treatment.
 6 So, one has to get by,
 7 as long as one does, on one's own.

 8 Of course the first thing was -
 9 so, is this it?
 10 And so I prepared to die, and I think
 11 I managed to process the whole thing quite well.
 12 And then, as I didn't die right there,
 13 it was sort of a disappointment to me.

In the documentary, Raimo's first story of illness appears in two separate episodes, although together they form a logical pair. They are separated both temporally in the episode and by the scene of filming. The first part is filmed at the garage, where Raimo is repairing a table for her daughter. After the succinct narrative of receiving the diagnosis, which also serves as an orientation to the entire documentary episode, the interview focuses on Raimo's current project at the garage, and his hobby related to woodwork.

The topic of diagnosis is revisited in the next scene. In the first narrative (1-6), right after the orientation "*It was in 1998*" follows the complicating action "[...] *when this cancer was diagnosed*". Next, the speaker steps outside the temporal structure into present tense, assuming the medical perspective to offer objective evaluation. The narrative reaches a relative resolution (lines 6-7), in passive form, to the complication caused by the diagnosis: "*So, one has to get by, as long as one does, on one's own.*" The impersonal form of the narrative creates a tragic frame for the overall theme of cancer diagnosis. The story,

expressed in passive voice, appears to represent an experience of isolation and submission.

Treating the first narrative in conjunction with the second (lines 8-13), the latter seems to tie directly with the previous narrative. It begins with a somewhat brusque evaluation (lines 8-9) related to hearing the diagnosis, “*Of course, the first thing was - so, is this it?*”. Lines 10-11 form an orientation to the narrative, “*And so I prepared to die [...]*”, which is followed by the complicating action (line 12) “*And then, as I didn’t die right there*” and resolution (line 13) “*it was sort of a disappointment to me.*”

Looking at these narratives separately, the position assumed by the narrator through the passive voice in the first one could be characterized as that of a victim of cancer. However, connected to the second, the speaker discovers agency in his position of submission – he actively prepares to die. Furthermore, the speaker adds an evaluative position, saying that he managed to prepare quite well. Taken together, the complicating action of the first narrative, of receiving diagnosis, loses momentum: the diagnosis in Raimo’s story of illness is in fact *not* the primary complication. Rather, the complication follows from the anomaly in the cancer script – an inescapable reality, described in first narrative in medical terms, does not hold its promise after all, causing an emotional anti-climax for the narrator.

Here, the temporal layout of the narrative is set on two levels – the past relating to the personal experience of the narrator, and the present tense to the general context, the medical status quo. The use of present tense in describing the facts also emphasizes the potential of this story to being anyone’s story. Lines 5-6 in fact produce such as synthesis, presenting the situation impersonally, using the indefinite pronoun ‘one’: “*So, one has to get by, as long as one does, on one’s own*”. Here, the narrator positions himself at an impasse, with no choice, and comparable to ‘anyone’: whoever appears as the main character of this particular narrative is, in effect, defined by that position, and as such, ultimately alone.

Raimo – small story 2

- 1 [Interviewer:] *Should people talk more about death?*
 2 [Raimo]: Yes, it is a topic
 3 that is talked about far too little,
 4 it really should be talked about more.
 5 [Wife]: If you think
 6 that it is a part of life, like death and birth.
 7 [Raimo]: Yes, everyone dies, after all,
 8 and it is considered taboo, so..
 9 [Wife]: Probably not a lot of people think about it, being younger and healthier,
 only when it is right in front of you.
 10 [Raimo]: It is too hard for many people
 11 when someone dies,
 12 because it has not been talked about at all.
 13 [Interviewer:] *You once found yourselves in a bit of a funny situation when...*
 14 [Wife]: My brother came by, driving the funeral coach, transporting a deceased,
 15 and the flags were pulled up in the car and...
 16 He came to ask Raimo to help him out with some chore.
 17 [Wife's brother]: I went off to see Raimo
 18 and by mistake drove the funeral coach there in front of their house,
 19 stayed there probably 2 or 3 minutes,
 20 Raimo hopped aboard.
 21 We finished the chore
 22 and then I drove Raimo back home,
 23 and a couple of people happened to pass by,
 24 well, of course it started a rumour
 25 that Raimo had died.
 26 That finished off Helinä's customers for two whole months.
 27 And someone had apparently even seen an ambulance visit their house before I
 did.
 28 [Raimo]: There was this one man
 29 who was on his way to our house for a haircut,
 30 and he had met another man
 31 who asked where he was going,
 32 and so the first man replied: "To get a haircut at the Leppälä barbershop",
 33 and this other guy said,
 34 "Don't go there,
 35 because Raimo has died."
 36 [Wife]: Yes, and then the very next day we went out cycling
 37 just so that people would see for themselves
 38 that he was still alive.
 39 [Interviewer:] *How do you think people should behave*
 40 *once Raimo has died?*
 41 [Raimo]: I think

- 42 they should visit Helinā as they always have
 43 and not avoid her,
 44 just approach her fair and square.
 45 [A cat enters the interview situation] [Raimo:] This is our, yes, this is our lifeline
 and my sick buddy, she sleeps beside me and takes good care of me. There are
 two, Helinā takes care of me and Pupuli does. The cat is called Pupuli.
 46 [Family photos] [Wife:] People start avoiding places where someone has died.
 47 It was different before:
 48 people came to visit after someone's death.
 49 I'd like to be treated the same way as always,
 50 that's what I'd like at least.
 51 It's not like you have to say anything special, just to act normally, and not to be,
 like, pushing away [indicates a sign of rejection with her hand].

Another small story in Raimo's documentary the social reaction to death. The narrative unfolds as a two-person-interview of both Raimo and his wife, and is interrupted by an additional voice, Raimo's brother-in-law, complementing their account. This story thus bears multiple narrators, one of which is, significantly, the interviewer: through her construction, the narrative is anchored by both abstract and coda, thus planting a particular incidence from the past into a current, normative framework.

The abstract to the narrative is set by the interviewer asking Raimo and his wife to comment on death as a topic on the social agenda. They take turns in explaining the logic and the need for discussing death: first, Raimo confirms: "*Yes, it is a topic that is talked about far too little*", thus adopting the stance implied in the question. Next, his wife offers a justification for the argument: "*If you think that it is a part of life, like death and birth...*" Raimo, commenting on his wife's perspective, continues: "*Yes, everyone dies, after all [...]*". Their response (lines 2-12), discussing the role of death as a natural part of life, while socially still a taboo, ends with the interviewer asking them to share a personal story. The link between the story and previous question is implied by the unbroken sequence of these topics, and indeed Raimo's wife instantaneously picks up on the interviewer's logic before she has even finished the question.

The narrative begins with an orientation which replaces Raimo's wife as the narrator of the story with the actual main character, Raimo's brother-in-law, as the speaker. The orientation describes a chain of events leading to the complication (lines 24-25) of a rumour starting that Raimo had died. The complication is followed by resolution (line 26) "*That*

finished off Helinä's customers for two whole months." For the latter part of the story, Raimo assumes the role of narrator. His perspective, however, remains that of an object to the story's events, as he produces a vivid account of an encounter between two men on the street, discussing the rumour.

Raimo's miniature narrative resembles a farce on the process of a rumour spreading. Although his account also follows the Labovian narrative structure, progressing from complication to resolution, it also forms a segment within the larger story: it repeats the complication of the rumour spreading of his brother-in-law's narrative. Raimo thus expands on the main narrative through an intimate perspective, demonstrating how death influences individual perceptions and choices. Both narratives are finally completed by Raimo's wife as the narrator. Resolution (lines 36-38) comprises a counter-attack by Raimo and his wife, challenging the rumour by going out cycling together the next day. Their collective and visible response to the false rumour reclaims Raimo's position as part of the community.

The narrative is returned by the interviewer in the present context from whence it began via abstract: the story's instructional purpose is enforced as the interviewer asks Raimo and his wife how people should behave after Raimo's death. Here, Raimo and his wife offer, in effect, an alternative ending to the story (lines 41-51). Raimo's wife, who in fact is positioned as the main character of the coda, draws on past cultural customs as an alternative norm to avoiding the bereaved family members. The temporal arch of the narrative is initiated in the present, when Raimo and his wife discuss the contemporary taboo related to death, and then reverts to the past through the peculiar incident of Raimo's alleged death, and finally, through the here-and now of the coda, proceeds to the indefinite future. In this closing scenario, Raimo is no longer a part of the narrative, and his wife claims the position as the main character of their story.

Raimo – small story 3

- 1 Now you are four.
- 2 This is surely a sad moment
- 3 but grieving should not take too long.
- 4 After all, this is just life
- 5 and every person must leave here eventually.

6 To Helinä: I had to take a job in the south to find my wife right here in
 my hometown.
 7 It added up to 500 kilometres of courting distance in one direction.
 8 In due time, it all led to marriage and three wonderful children.
 9 Now you have to go on with your own life without me.
 10 If you're lucky,
 11 you will find yourself a new man,
 12 but a good man it must be. No drinking nor mucking about.
 13 To Carita: You are my first kid,
 14 I've spent a lot of time with you.
 15 I guess I was not able to find you a man,
 16 but hopefully a good man will walk into your life
 17 and understand
 18 what a good woman you are.
 19 I'm proud of you,
 20 you have always been my beloved daughter.
 21 To Marika: We have always gotten along, perhaps best of all.
 22 We have fought, but then made up.
 23 In you I see my best qualities, wonderfully refined [smiles jokingly].
 24 I'm proud of your accomplishments,
 25 you are a very beloved daughter to me.
 26 To Sussu: I've waited a long time for a grandchild,
 27 and because of you my wish will be fulfilled.
 28 This makes me very happy and proud.
 29 You have inherited my stubbornness,
 30 which is probably why we have fought hard but always made up.
 31 To my grandchildren: Grandpa is a man
 32 who would have loved you very much.
 33 Grandpa hopes all of you well, and sweet dreams in the orange, magnif-
 icent crib of the Leppälä family.
 34 That's it.

In the first segment (lines 1-5) of Raimo's farewell message the speaker expresses his death through those who remain: "*Now you are four*". The speaker then immediately offers instructions on not to spend time grieving; death is a part of life and furthermore, part of being human. By the same token, the speaker thus parallels himself to 'everyman', and by extension, his audience to himself.

The second segment (lines 6-12) produces a small story of the life of the speaker and his wife, beginning with how they met. The complicating action (line 9) then accounts for the death of the speaker – "*Now you have to go on with your own life without me*" – thus making a full circle and returning both to their initial positions, separate from one another. Resolution (lines 10-12) then follows in the form of a suggestion that his wife might find another life partner.

In the following segments (lines 13-30) the speaker addresses his daughters individually, commenting on their childhood and his relationship to each of them, and expressing his love and admiration. Finally, the last segment (lines 31-34) is situated in the future, presented in conditional form. This, in effect, produces an imagined account of the speaker's relationship to his future grandchildren. Assuming the role of their grandfather, the speaker wishes the children sweet dreams in the family crib. Through this particular artefact, the story of the speaker and that of the future generation intersect; the orange crib appears as the epitome of life's continuance.

5.4 Sirkka

Sirkka – small story 1

- 1 [Interviewer:] *What did you think when you heard of the stomach cancer?*
 2 I was told
 3 that there is no treatment, no operation and no cure.
 4 That it would be possible to try out some kind of medication,
 5 but I said
 6 “In no circumstances will I take anti-cancer drugs,
 7 and I would not like to be operated on,
 8 so, what you have told me
 9 is for the best”.
 10 Since it had been examined
 11 and metastatic tumours had been found,
 12 I did know
 13 that it was cancer.
 14 And so it was like,
 15 I didn't have to be cut up nor treated with toxins.
 16 So I said...
 17 “What I'm afraid of
 18 is the pain”,
 19 but the doctor said
 20 that pain can be treated nowadays.
 21 The senior physician said at the following appointment:
 22 “You are indeed an amazing person,
 23 there are not many people like you.”
 24 And I replied:
 25 “I thought
 26 that everyone confronts death straight up.”

Sirkka's story of receiving diagnosis is a narrative performed mainly as dialogue. The first half of the narrative portrays Sirkka as the active voice in the story, confronted by an anonymous figure giving the bad news: "*I was told that there is no treatment, no operation and no cure.*" The speaker quotes herself in the situation, reporting her response even though the other participant in the dialogue remains abstract. Through her reply (lines 6-9) she refers to 'you', the person she is conversing with in the story. Since that person appears only a bearer of bad news, the conversation could be considered one between the speaker and her diagnosis.

The speaker's voice remains active through evaluation (lines 10-15), when, referring to 'it' she describes the discovery of cancer. "*Since it had been examined and metastatic tumors had been found, [...]*" (lines 10-12) begins the account of a process that appears disconnected from her. Reviewing the process, however, she states: "*[...] I did know that it was cancer*" (line 12-13), thus returning in equal position with respect to her diagnosis.

The complicating action (lines 16-18) relates to the sole point in her attitude where she experiences fear: "*So I said.. What I'm afraid of is the pain.*" Even here, the speaker is the talking subject of the narrative: she describes her internal experience through quotation marks, a voice with which she navigates through the entire ordeal. Resolution (lines 19-20) follows immediately via the doctor's promise of pain management. It is here, in resolution, where the doctor becomes visible for the first time - as the partner in dialogue and in death.

The speaker, positioning herself as the independent actor in the narrative facing a desolate medical reality, is in resolution finally joined by the doctor, mending her only source of fear. The coda then displays a scene at the following appointment, again through dialogue between the speaker and a doctor. This time, the interlocutor is identified as the senior physician, and both are quoted word-for-word. Based on the authority and assuming the voice of the medical expert, the coda positions the speaker as unique. In response, the speaker somewhat ironically compares herself to 'everyone', through an adverse angle: "*I thought that everyone confronts death straight up*" (lines 25-26). This final remark establishes a universal reference point, both implying that 'confronting death straight up' is a task, both mandatory and possible, for all human beings – while also positioning the speaker as unique in having accomplished this task.

Sirkka – small story 2

- 1 [Interviewer]: *When you took ill,*
 2 *did it come up with your children or did it occur to you*
 3 *that you might move in with one of your daughters?*
 4 No, I was,
 5 I said right away:
 6 “Don’t you ever take me in to take care of me
 7 and don’t take care of me,
 8 no-one is responsible for taking care of their mother and father.”
 9 Nursing homes are so important,
 10 people should want to stay there more.
 11 Especially homey nursing homes like this one,
 12 this is good.
- 13 [Interviewer]: *Is a person who is incurably ill allowed to live more independently*
 14 *in a nursing home like this*
 15 *than if they stayed with their family members?*
 16 Yes, I’m in fact sometimes scared
 17 when my girls come to visit
 18 and they say
 19 “Don’t get up, don’t get up”.
 20 I say:
 21 “I will get up
 22 only when I have the strength.”
 23 Here the nurses don’t fuss like that over nothing,
 24 they know what kind of taking care of a person needs.
 25 They are used to it,
 26 so there is no such dreading and fussing over all the time.
 27 And since it’s not about worrying for someone as important as a member of your
 28 family,
 29 you don’t fuss over nothing.
 30 But they are good nurses,
 31 I’m not saying
 32 that they wouldn’t take care of you.

Sirkka’s second small story of illness addresses the moral and practical issues surrounding end-of-life care. The narrative unfolds as an interview, consisting of two parts. The first one (lines 1-11), following the Labovian narrative structure, is built on orientation (lines 1-3) “*When you took ill, did it come up with your children or did it occur to you that you might move in with one of your daughters?*”. The speaker replies, through complication (lines 4-8), in which she sets herself in a hypothetical dialogue with her children, rejecting the proposition.

The speaker’s response, along with the rest of the first narrative (lines 5-11), is set in present tense, emphasizing a shift from a particular event to a general perspective, through

which the narrative again assumes a universal position. In fact, the last portion of her reply (line 7) to her children is an inclusive statement: “[...] *no-one is responsible for taking care of their mother and father.*” Reclaiming the dialogue all to herself, she remains the acting agent even as negotiating her end-of-life care. Concomitantly, the speaker’s remarks, originally aimed at her family, now encompass parents and children in general as well as their respective responsibilities.

Finally, the resolution (lines 9-12) arrives through an alternative to family care at the end of life. Settling the dilemma between the individual needs and responsibilities between ‘you’, ‘me’, children and parents, the nursing home represents the solution for ‘people’ in general: “[...] *people should want to live there more*”. Next, describing her own nursing home as ‘good’, the speaker’s personal experience is elevated, as an example, onto the level of an ideal.

The resolution of the first story finds correlate in the interviewer’s next question (lines 12-13). Unlike the previous question, this one is phrased in universal terms, mirroring the speaker’s narrative tone: “*Is a person who is incurably ill allowed to live more independently in a nursing home like this than if they stayed with their family members?*” Again, the question provides an orientation to the narrative, picked up by the speaker. The complication (lines 14-17) is based on the dynamic between the speaker and her daughters visiting the nursing home: the daughters are quoted, repeating somewhat paradoxically, “*Don’t get up, don’t get up*”. The speaker’s reply (lines 19-20) forms the resolution, and a contrast, to the hasty mantra of her daughters: “*I say, I will get up only when I have the strength*”.

The dialogue of this narrative positions the speaker, individually, vis-à-vis her daughters, in the plural. Once again, the speaker claims her independence, as suggested by the interviewer’s orientation. Her response in the dialogue implicitly confirms the daughters’ approach yet defies their attempt to instruct her. More than this, the speaker resigns from instruction, claiming autonomy based on a balance of her own will and her physical condition.

In coda (lines 21-29), the speaker’s position is enforced and justified by reference to the nurses, who are similarly juxtaposed with the behaviour of the speaker’s daughters. Furthermore, through communion with the nurses, the speaker assumes the universal position

(line 22): “[...] *they know the kind of care a person needs*”. These two kinds of relationships, one between a mother and her daughters, and the other between the nurses and ‘a person in need of care’, are established as the difference between ‘fussing’ as opposed to having basic human needs met.

The speaker’s positions as the client of the nursing home is described as, on one hand, not ‘as someone as important as a member of your family’, yet as freedom from ‘fussing over nothing’. This balance is settled in the closing remark of the narrative (lines 28-30), which is a response and a clarification to a potential misconception by the audience that the quality of care at the nursing home would not meet a high enough standard. The narrative therefore illustrates the proposition of the interviewer’s orientation in narrative form, describing the independence of someone incurably ill as a right to express one’s own terms. The ‘nursing home’ appears, then, as the intersection between maintaining quality of life and retaining relative autonomy.

Sirkka – small story 3

1 To you, my offspring, who are now close to forty altogether,
 2 I want to leave this voice message and to remind you
 3 what I think
 4 is important while living here on Earth.
 5 You know, my children,
 6 how you have treated me with love,
 7 and to live that way with every person as you have treated me,
 8 it would be good.
 9 I’m crying
 10 but I have no reason to cry,
 11 I am just happy
 12 and this is
 13 what I hope for all you young, even little Eero:
 14 that you could go forward
 15 so that you looked for the good here on Earth,
 16 and not complain all the time.
 17 It is important
 18 not to carry a grumbling attitude.
 19 I hope
 20 that you, my offspring, have learned
 21 how to live here, most of you,

22 so that you love the environment and each other,
 23 and that you would find this kind of nest
 24 where you can lay down your sorrows, sharing with your siblings and
 children whatever troubles you.
 25 I want simply
 26 to say to you:
 27 love, thank and love, and if possible, believe in the God I believe in –
 28 but everyone is free to choose
 29 how they live,
 30 I will not force this upon anyone.
 31 God bless all of you.

The first segment of Sirkka's farewell message (lines 1-8) orients the audience to the purpose of the message. Her role as a forebear, even forerunner for the family, forms the content and tone of the message. The first segment, then, draws a parallel between the speaker, her children and all people, as the speaker encourages her children to treat every person with the same love as she has received from them. This chain of love, therefore, extends from the private to the universal, as part of the speaker's message of "[...] *what I think is important while living here on Earth.*"

In terms of the private/universal dynamic, the second segment (lines 9-18) is compatible with the previous one. The speaker remarks, paradoxically: "*I'm crying but I have no reason to cry, I'm just happy*" (lines 9-11), and continues to apply the logic in the form of a maxim – of the importance of focusing on the good and not on complaining. The maxim continues in the next segment (lines 19-24), with an instruction to create a 'nest' for sorrows through sharing them with others. The speaker sets herself as an example for others to follow, emphasizing the ability to choose the positive over the negative. Implicitly alluding to her soon absence, she enforces the idea of the collectivity of siblings and children as a source of comfort in difficult times.

The message focuses on life: the life the speaker and her children have shared together, and the principles they have followed during their mutual journey. The speaker, accounting for the past, orients the audience toward the future. The speaker's death is referred to only in passing, upon the sentiment she expresses, yet commenting that her tears are not tears of sadness (lines 9-11). Her position with respect to the audience is characterized by universality, commenting on what is 'good', 'important' and 'simple' about life. At the

same time, this position is built on the speaker drawing on relationships – those between her and her children, those based on love and sharing, and those to be valued – a person's link to every other person and to the environment. Ultimately, the elements of the farewell message are presented as the foundation of a good life, surpassing even death.

6 NARRATIVES OF GOOD DEATH

6.1 From fateful moments to resolutions

The first research question focused on how agency is represented in the small stories as perceived through the Labovian narrative structure. A Labovian perspective into the illness narratives provides us with a description of the *fateful moment*, the disruption in agency, which shatters the day-to-day experience. In these stories, the illness merges with the medical professional, or more generally with the language of medicine, as the informant on the cold facts. Each of the stories are therefore either performed as dialogue between patient and doctor, or as a dynamic between the person and the illness.

However, the complicating action, the fateful moment, as it were, is crucially different for all four accounts. In Maria's story, the fateful moment occurs as the doctor finally delivers her the bad news. This complication is the climax that follows a prolonged confusion where Maria experiences sudden, severe pain and travels back and forth in search for answers. For Manta on the other hand, the complicating action relates not to diagnosis as such, but to her body fighting a losing battle with the illness. In Manta's story, the fateful moment is in fact an anti-climax – an acknowledgement of the fact that the battle is already lost. In contrast to both these accounts, Raimo's story relates the complication not to the possibility of dying, but to *not* dying – and thus being left waiting for death. Similarly, in Sirkka's account, the complication relates not to falling ill or facing death, but to her fear of pain.

Consequently, the Labovian analysis of these illness stories also reveals four different forms of agency upon the fateful moment. For Maria and Manta, the speaker is overwhelmed by the reality of their situation: Maria experiences an emotional blow upon receiving the news of her medical condition, while Manta's story focuses on the physical deterioration. Whereas Maria's narrative builds on the shock which drives her to the ladies' room in the last scene, Manta's story appears to begin close to its actual end: the diagnosis itself no longer represents a novelty and surprise but rather assumes the position of the main character in the narrative. The speaker herself remains a voice in the background, a reporter of events and an analyst of eventualities. This style of reporting the facts resembles a testimony, and is apparent also in the story of Raimo, who explains how he received his diagnosis years ago.

However, whereas Manta's story is a battle of the body, Raimo describes how his active and compliant stance in dying is replaced by a feeling of disappointment and disorientation. In contrast, Sirkka's story reports her active stance to death, only interrupted by her fear of pain, and ends in her receiving appraisal for her courageous attitude. It is precisely here, in the relationship of the speaker to the complicating action, which informs the audience of the type of agency assumed upon the faithful moment. For Maria, confronting the illness is followed by her symbolic escape; Manta is already approaching the final moments of her countdown, Raimo's attempt at matching death ends in a sort of limbo of ambivalence, whereas Sirkka is empowered by her discussion with the doctor.

In the second small stories, Labov's instruments of analysis highlight the conflict and tension that is present in living with death. Identifying the complicating action – the cause for a disruption in the flow of events – is particularly useful in delineating the elements of agency, which usually emerge in the story's resolution. In Maria's second small story, the difference between orientation – enjoying the social reaction to funny hats and smiles – is contrasted with the complicating action of not receiving the feedback anymore. The speaker's evaluation of the complicating action is that she is misjudged as an alcoholic because of her changed appearance. Maria's response – the resolution, in Labov's terms – is to assume the proactive stance in social situations by telling of her illness and of medication.

Similarly, Manta discusses the role of faith and of church in her coping with illness, and once she reaches the complication – the church forbidding her to discuss death with other members of the congregation – she identifies clearly the contradiction between her own needs and the church's policy. Manta's stance on the church's policy is sharpened in the course of the interview, yet the narrative appears to lack a resolution. Manta clearly states the contradiction between her and the church's positions but rather than making a unilateral decision on the matter, she assumes an ambivalent stance to settling the dispute.

The story of the false rumours of Raimo's death finds complication in the social exclusion of Raimo's family. This story is conveyed through multiple voices, which is also reflected in the resolution: Raimo and his wife confront the rumours by going out cycling together. Sirkka's complication is similarly related to the social demeanour of people with respect to the dying person. Sirkka describes how her daughters excessively fuss over her during visits to hospice where she has decided to stay after receiving diagnosis. Sirkka's response

is the unequivocal “*I will get up only when I have the strength*”, reserving her the autonomy of making decisions about her care and of her social conduct.

The Labovian analysis demonstrates the juxtaposition inherent in the stories of agency. Agency is portrayed through conflicts arising in the social lives of the main characters, based on a lack of understanding in society of the experience of living with an incurable illness. In each of the small stories the speaker describes a form of social exclusion, coming across either as unwanted social reaction, an uncomfortable social demeanour or as an outright rejection of the topic of death.

The resolutions of the narratives, depicting agency essentially as reaction to these conflicts, are justified by ethical claims. Maria argues that she has the right to continue enjoying life without social prejudice, while Manta critiques the censorship by the church, as death is the growing part of her very being that is being silenced. Similarly, Raimo calls for more public discussion on death in order to integrate death back into the realm of ‘normal’ and of life. In contrast, Sirkka’s decision to move into a hospice is based on her view of the irreplaceable rift between her individual experience as a dying person and the behaviour of her family members. Each of the narratives speak for the ‘normalcy’ of dying on the one hand, and of the frustrating social reactions they meet, on the other. As such, the agency in these narratives aims, in various ways, to the social inclusion of the dying.

Comparing the first and the second small story for each of the main characters offers insight into the development of agency following the fateful moment. For Maria, the initial reaction of fleeing from the doctor’s office turns into a proactive approach to social situations. Explaining about her medical condition to people she meets for the first time aims to establish social acceptance. The claim embedded in the evaluation of her narrative is that she has a right to enjoy life like everyone else. Manta, captive to her body’s deterioration, aims to find a spiritual and social venue for reflecting on death. Her motive for approaching the church, and simultaneously her ethical claim, is her need to be accepted as she is. In his first story, Raimo, on the other hand, describes the inevitable loneliness related to receiving diagnosis: “*So, one has to get by, as long as one does, on one’s own*”. This solitary notion, as well as the ambivalence and disappointment which Raimo feels initially for not dying, turn into a collective outlook into confronting death. Raimo calls for a growing awareness and acceptance of death as a natural part of life, and for life to

continue as usual upon the death of a member of the community. In contrast, Sirkka considers hospice the proper venue for life's end, as the experience and needs of the dying differ from those of others. For her, hospice also represents autonomy which she regards her prerogative as the dying person.

The Labovian analysis of these small stories effectively reveals the obstacles to dying agency, and the subsequent social resistance upheld by those living with an incurable illness. Through their aims of defending the right to be seen, heard, included and respected, the narratives of dying agency connect to the sequestration thesis. For Giddens, the sequestration of existential questions in society forms the basis for agency, which is essentially a reproductive practice between individuals and social structures. In the small stories of *My last words*, the fateful moment finds a variety of responses, from astonishment to serene acceptance. However, the agency that follows in the second small stories speaks of the aim to navigate back into the routine of social life – to receive customary feedback in random encounters, to be allowed to share thoughts and experiences with others, to maintain a normal contact with other members of the community, and to continue as the autonomous individual in charge of one's needs of care. The speakers in these narratives thus struggle to re-create the *routinised character* (Giddens 1984, 61) in their social lives in order to salvage a sense of agency.

6.2 Conflicting positions

The second research question aimed to investigate how agency is portrayed as positions and interaction through storytelling. As Giddens (1991, 5) explains, the dissolution of the traditional sources of authority and identity create the need for the reflexive project of the modern self, sometimes interrupted by fateful moments which remind us of the urgency to maintain a biographical continuity. In this effort, stories of illness may be viewed as a form of meta-control of the contingency related to the human body, which represents a major source of risk to the human existence (Frank 1995, 32).

The small story approach (Bamberg 2006; 2011; Georgakopoulou 2006) does not deny the possibility of reconstructing a more coherent life story from the analysis of narrative fragments (Bamberg 2004) but is however more interested in discovering the various

ways of speakers attempting to bring themselves forth in an interactive context. As Alexandra Georgakopoulou puts it, the small story approach represents a shift from investigating narratives as sites of constructing of self to narratives as sites of *doing* self (and other) in various social contexts – thus allowing for the analysis of ephemeral and multiple selves (Georgakopoulou 2006). The argument is that people are not just assigned positions deterministically, based for instance on personal characteristics, but may grasp, negotiate and resist different positions in local conversations (Georgakopoulou 2013).

Giddens (1984, 61) points to how critical situations in human life, such as birth and death, acquire a routinised character as they turn into rites of passage, essentially upholding the continuity of social life. Walter (1996), in contrast, identifies the role of ritual as something for the dying or the bereaved to draw upon, but claims that ritual has lost its position as the intrinsic part of the social cohesive. Instead, ritual is placed by Walter beside expert knowledge and individual testimonies which act as resource and guideline for the dying.

Looking at the small stories in *My last words*, many of them are performed in response to questions put to the main character by the interviewer. For the storytellers, the interviewer therefore represents a large number of people – an anonymous audience of television viewers, possibly in many different countries. Through the documentary, the speakers engage in dialogue with the social conceptions, values and ideals related to death and dying. Their stories represent both the ‘expert strand’, offering medical and social information based on their experience, as well as the postmodern relationship to death of the ‘radical strand’, which posits the individual as the sovereign and unique realm of the dying experience (see Walter 1996). Simultaneously, their participation in this dialogue could also be considered an active effort to remain in the *longue durée* of institutions (Giddens 1984, 61) – producing and reproducing the social structure, an instrument of which is the media and the mediated experience.

In keeping with Walter’s (1996) thesis of the ‘radical strand’ approach to dying, whereby the private experience satisfies the growing public thirst for knowledge, Clive Seale (1995) discusses the need in late modernity to imbue death with meaning. Seale counters the sequestration thesis that death in society must be denied given the lack of protection by religion and traditional social structures from existential moments. In fact, Seale’s study deciphers a heroic script for dying, based on open awareness and an acknowledgement of death. The heroic script involves the choice to withstand the strain of knowing

about the approaching death, the absence of negative emotions and reaching acceptance. However, the script also includes what Seale calls feminine aspects of the heroic death, namely the emotional accompaniment in close relationships. An open awareness allows for the emotional accompaniment – the sharing of care, support and attachment – prior to death.

The script for *My last words* follows that observed by Seale. The stories of receiving diagnosis and facing the reality of death remain pronouncedly fixed in the perspective of the main character. These stories of illness are not performed as dialogue with the interviewer, nor are family members, spouses or friends included in these narratives. As small stories, these narratives appear independently, as monologues, assigning the speaker a sovereign position.

In each of these accounts, the knowledge of illness is presented either as a shock or an overwhelming circumstance. The stories end either in horror and paralysis or alternatively in acceptance and compliance by the speaker. However, even the stories which present the speaker as submissive and passive in the face of death, are followed by accounts of empowered, active agents, enjoying and even embracing their final moments. In fact, the first small stories serve as the complicating action in the overall narrative structure of the documentary: the initial devastation finds balance through the resolution of the second small stories.

Maria's heroic script involves overcoming the distress caused by her physical transformation. She describes the transformed self as unrecognizable to herself when looking in the mirror. Figuratively speaking, she then holds up this mirror in social situations to observe how she no longer receives the normal feedback, and consequently positions herself a freak in other people's eyes. She breaks out of this position, however, through a proactive strategy of openly communicating her story to the people she meets. Frank (1995) discusses the roles assumed by people with illness as 'body-selves', suggesting that the identity of a person becomes tangled in the body's problems and limitations. Body-selves reflect the moral problem of the individual who is responsible for making choices as to how to react to illness. Maria's account of how illness changed her life is compatible with Frank's 'mirroring body'. The mirroring body focuses on acts of consumption: feeding it, clothing it, grooming it, and through consuming medical services, curing it – in the attempt to re-create the body similar to other bodies (Frank 1995, 43).

When outfits and smiles fail, Maria addresses the physical difference between her body and those of others by explaining the reasons behind her changed appearance.

Maria's story of overcoming the physical transformation partly resembles, in Frank's typology of illness narratives, the restitution story. The plot of this story type progresses from health to illness, and back to health, through a remedy. Obviously, Maria does not find cure, nor does she look for one, but her story nevertheless accounts for the return to her normal self after a temporary setback due to her medication. The restitution story reflects Zygmunt Bauman's (1992, 130-131) observation that the modernist aim is to slice mortality into smaller puzzles – diseases – and to create a sense of manageability through potential technical solutions to these individual problems. The restitution narrative of beating illness upholds this possibility of outwitting disease and suffering (Frank 1995, 97). However, Maria's story of transformation does not attempt to treat illness as transitory (Frank 1995, 115). Instead, reiterating the elements of a true 'quest story', the speaker searches for alternative ways of being ill – the moral obligation of telling the story lies, in fact, in the responsibility to convey a personal transformation (ibid., 117-118). Maria's transformation might begin as a physical one, but she discovers an alternative basis through open communication to maintaining her sociable manner. She returns, although marked by illness, in her original position.

Manta, on the other hand, is not interrupted by a sudden shock of illness, but conveys rather a life-long story of accumulating physical setbacks. Her small stories represent the division between the realm of the body and of the spirit: the former being a classic 'chaos story' (Frank 1995) of an overwhelming surge of problems suppressing the speaker, the latter a 'quest story', establishing the speaker's faith as her refuge from the somber circumstances of life. The bodily chaos story is characterized by immediacy: chaos generates a recurring crisis of survival (Frank 1995, 109) and as such, the narrative finds no purpose. The 'quest' of the second small story is therefore closely entangled with the chaos, yet it has to form an antithesis to the horror. Survival presumes the speaker dissociating from the body (ibid., 103), and thus, through faith, Manta effectively transgresses the question of death as well as her experience of being rejected by the church.

Raimo's chaos story – "*So, one has to get by, as long as one does, on one's own*" produces what Frank terms the 'monadic body', considering itself existentially separate and alone (1995, 36), essentially dependent on an outside cure (ibid., 85) which in Raimo's case

does not exist. Raimo's victory over chaos through acceptance of death is followed, ironically, by yet another contingency: Raimo is essentially abandoned by death. A double chaos story envelopes: even though the crisis of cancer diagnosis is overcome, the speaker ends the story in protest. The speaker's "*world is so unmade*" by chaos (Frank 1995, 104) that he cannot accept the gift of life.

The monadic body is compatible with the figure of the modern autonomous individual (Frank 1995, 85). It is somewhat paradoxical then, that this sovereignty with which the speaker sets to confront death, is in the second small story – the quest story – dissolved into a pronouncedly collective, even communal approach to death. Raimo's position in the quest story is notably equal to the other voices, Raimo's wife and his brother-in-law, taking turns in narrating. What is more, the moral of the quest story centres on life, which ought to continue after Raimo's death. In fact, Raimo's quest narrative represents a social *manifesto* (Frank 1995, 120) by the storyteller returned from the gates of death. In a sense, then, the autonomous, monadic position of the speaker of the chaos story carries over to the quest story, which is told collectively, but is actually fixed in the perspective of those around the dying person. Raimo himself is considered through his death, a dichotomy of presence/absence – a *position* more than anything else – having an effect on the social system.

Sirkka's stories of illness do not proceed from disruption to balance, but rather present the cancer diagnosis as an expected and appropriate development in her life story. Sirkka immediately assumes the position which is in agreement with death. In effect, she remains equal, even dominant, to her diagnosis in the first small story, speaking in a distinct voice throughout the encounter with cancer and with the medical experts, who remain in awe of her.

Rather than a narrative recounting triumph over chaos, Sirkka's narrative of illness is a story of continuity. Illness does not take anything away from her; in fact, her end-of-life arrangements in hospice accord her a special context of autonomy. This autonomy she describes as a position based on responsibility, knowledge and needs that separate her from the rest of her family. Sirkka positions herself in opposition to her family and social expectations, stating "*no-one is responsible for taking care of their mother and father*". Furthermore, she acknowledges the correct understanding by the hospice staff of her needs and of the appropriate manner of behaving around her. Her illness and the fact that

she is dying set her apart from other people, but not as something *less* than the average person – rather she rises above the mundane and the ordinary. This change, which is connected to the physical and professional space she now requires for herself, is also something her quest story presents as a universal moral duty. “*Nursing homes are so important, people should want to stay there more*” is the key statement of the narrative which positions the speaker in the realm of individuality and autonomy. By the same token, however, the story is placed in the universal canon of illness narratives: the justification for autonomy lies in the experience of dying which, the story claims, is universal and underlain with certain ground rules. Thus the speaker addresses, via her own experience, everyone.

6.3 Dying agency: through resistance to normalcy

The third research question set out to determine the elements of a ‘good death’ narrative in *My last words*. The small stories addressed in this study form unique, yet comparable scripts for dying. Following the narrative structure of the documentary, each character offers a story of their first encounter with death, living with death, and farewells to loved ones. Assuming the small story perspective allows for the scrutiny of agency in narrative performance – the active negotiation of positions which the speaker engages in the social context of storytelling.

As mentioned, the first small story in which the reality of illness is confronted, represents a classic chaos story for Maria, Manta and Raimo, whose lives are effectively interrupted by illness. In contrast, Sirkka considers illness as fitting in the overall scheme of her life story. All four main characters, however, assume an active stance to dying, and it is the purpose of this agency which presents itself as the narrative of good death.

Each episode ends in the *last words* by the main characters, delivered posthumously as a video message. Although personal and heavy with private memories, instructions and wishes, they are nevertheless incremental to the idea of good death: in these messages, the main characters consciously adopt a position standing on the dividing line between life and death, thus *actively performing the good death* through a narrative reconstruction of their life stories, relationships as well as the continued lives of their loved ones.

There is a significant divide among Maria's small stories in terms of her relationship to death. The chaos in the first small story appears total, whereas the second story already describes the people she meets as having more of a problem with her illness than she does. In other words, the divide between life and death becomes pronounced as the perspective in the quest story remains fixed on life. Here, she aims to *re-establish her normal social position* regardless the illness. Her mirroring body resorts to communicating her illness openly and proactively in order to avoid being outcasted, and to maintain the capacity and the right to continue enjoying life. Furthermore, in her farewell message, Maria expresses the wish to become a beautiful memory and thus a harmonious element in the lives of her family members. This memory should, however, be placed in a minor position within the course of life, and Maria instructs her family to enjoy life rather than fear death. A good death thus manifests as an idea of being included and belonging in life, even in illness and even after death.

The tragedy in Manta's chaos story is conveyed physically rather than emotionally. It is her quest story, however, which highlights the dissociated approach she assumes to death. Her aim in this quest is in *dealing with death*, reflecting on and confronting the process of dying as part of a spiritual effort. Death represents release from life's pain, yet importantly, death represents a promise of life: through death, Manta conceives a passage to Heaven, while still retaining connection to life through her children. In her farewell message, Manta expresses the future of her children as her only concern. Securing her children's ability to continue a normal life appears as the prerequisite for Manta's good death.

In Raimo's narratives the roles are switched: the centre stage is occupied by Life and Death, whereas Raimo himself is seated in the audience along with the viewers of the documentary. Raimo's chaos story involves the disempowerment he experiences in attempting to confront death through acceptance. The aim he assumes in the second small story is thus in the *assimilation of death into life*: he wishes to dismantle the emotional and social patterns of behaviour which he considers are based on a false fear of death. If death became a topic of public discussion, facing one's mortality would not appear such a shock, nor would a community member's passing be met with avoidance and silence. Raimo's own position in the quest narrative thus remains partly impersonal, as his manifesto portrays him through the categories of presence and absence. In contrast, Raimo's good death narrative positions life as the imperative, downplaying both personal and social tragedy in order to allow for life to continue.

Maria, Manta and Raimo describe a prolonged period of living with the knowledge of death, striving to break the barrier between the normalcy of life and the anomaly of death and illness. Sirkka, on the other hand, considers her diagnosis as appropriate to her phase of life and settles herself in her deathbed. Sirkka's autonomous and accepting approach to death mirrors the idea of a good death as a natural developmental task of old age with other life tasks complete (Röcke & Cherry 2002). She actively assumes the role of the dying person, which, however, appears in her account at odds with the needs and ideas of the people around her. In contrast to Raimo's account of the tragedy of social disengagement that follows his alleged death, Sirkka herself makes the choice to settle herself in hospice.

Much like her autonomous approach to preparing for death, Sirkka's farewell message focuses on life, treating the two as distinct realms in her story. On one hand, hospice offers both Sirkka and her family the mutual liberation by securing Sirkka's end-of-life care. On the other, Sirkka's farewell message to her children essentially establishes a life strategy based on human relationships, of finding solace and support in life's troubles in other family members. The process of dying, therefore, appears as *a process of voluntary disengagement* from life to be embarked upon decidedly and alone. The means of disengagement appear practical, while the principles applying to the process are ethical and universal. A good death follows adapting and dedicating oneself to the process of dying, which, by its very nature, renders autonomy upon the dying person.

One of the conclusions by Michael Young and Lesley Cullen (1996, 181), searching for a concept of good death through conversations with patients in East London is that a good death emerges from a good life. This appears also the chief argument in the narratives produced by Maria, Manta, Raimo and Sirkka: whether a life interrupted or completed by illness, through and in their narrative reconstructions, they aim to *position themselves as part of the social paradigm*. In fact, by positioning illness and death as 'normal' they make a claim on behalf of their agency. Whether a plea to enjoy social life, to feel free to discuss the approaching death, not to be treated as taboo or to remain in charge of their end-of-life arrangements, the speakers in these narratives attempt to establish death as relevant in the social arena.

This effort of reclaiming agency translates into a need to preserve narrative self-identity upon the faithful moment (Giddens 1991, 189). To achieve this goal, the speakers produce

narratives of social conflict arising out of their encounters with social expectations, fears and reactions, which they meet with active resistance. Through these attempts in resisting and claiming positions as narrative performance, agency appears crucial to the experience of good life, and consequently to experience of good death.

7 DISCUSSION

My interest in the topic of dying as an individual and social experience is, perhaps, related to the prevalence of death in both fact and fiction in its many cultural forms. Our everyday awareness is imbued with images and stories of death, consumed as newsfeed as well as popular entertainment. Or perhaps the widespread deliberation on death is in fact the consequence – of the evolution of Giddens' reflexive, reskilling individual, defying sequestration and aiming at a sustainable idea of her mortal self? Whether it be the cause or the effect of culture, an awareness of death is a dimension which pertains to most of my everyday contemplations. It involves the recognition of life's temporality on one hand, and the absolute of human mortality on the other, a juxtaposition which in fact connects us to each other and to our common humanity more powerfully than anything else. The publicly voiced accounts of dying in *My last words* therefore appeared to me as a step in the right direction, offering an opportunity to consider death in plain, through real-life stories.

The aim of this study was to retrace the intention and means of dying agency as it appears in and through the narrative. As an empirical source, the personal accounts of dying in the television documentary *My last words* offered a publicly contested site for discussing death. Representing the mediated experience which is a significant resource for the reflexive project of the modern self, the documentary is another response to the growing interest in death and dying in society. It intersects the public/private domain, and thus represents the counter-trend to sequestration of death in society. Indeed, the personal narratives of dying proved highly tensioned, revealing both individual struggles to maintain a sense of agency and critique of individual and social standards based on prejudice, sequestration and oppression which the speakers are faced with.

Choosing the small story approach, the question of agency came to be considered as interaction – that between storyteller and audience, agent and structure. These small stories were further conceived of as sites of cultural performance, where the ideals of good death were negotiated. The alternative strategy would have involved looking at the 'big story' of the self in each episode, drawing on life history and carving out the individual behind dying agency. However, as *My last words* reflects both the documentarist as well as the main character, looking at the small stories allowed for the study of the respective positions of the two narrators in interaction. Furthermore, choosing small stories as the focus of attention aimed at

dismounting the grand narrative of self to approach instead the stories told in actual encounters, which Bamberg (2017) calls the ‘*real*’ stories of our *lived* lives.

The ‘big story’ of self is presumed to aim at biographical coherence and authenticity (Bamberg 2017), which is also what narratives of illness are considered to represent. Choosing the alternative approach aims to reveal identity claims, too, but is set on investigating the potential multiple and multifaceted positions of a single subject in various interactive contexts. It is thus worth noting that the premise of locating the dying voice through positions assumed through the small stories is reflected in the results of narrative analysis. Dying agency, as perceived through the Labovian narrative inquiry and Bamberg’s positioning analysis is identified as one based on a high social awareness and even pushing a political agenda.

Particularly, the concept of good death was considered a motif for agency per se – a social norm in the making – which presumes the agentic response aimed at producing/reproducing the social structure. Therefore, although the good death was not discursively addressed by these agents, we may recall Giddens’ emphasis on the tacit knowledge of social rules which form the basis for action. The reflexivity of the agent, her reasons and intentions behind actions, are rarely specifically articulated (Giddens 1979, 40) but rather observed in the flow of social conduct. Through the documentary, the main characters participate in the negotiation of their social and cultural position, and thus the position death.

Agency must include not only the capacity to resist or ‘act otherwise’ but also the possibility of ‘making a difference’ (Giddens 1984, 14). *My last words* appears as the final chapter in lives which aim to establish their position in the world of living one last time. The participation in the modern reflexive project before a wide audience represents the process of structuration – acting in congruence with social structures. At the same time, this participation is an act *against* the culture that excludes and silences the dying.

The ‘good’ death as a normative question is narratively addressed *as* and *through* agency. The chaos of death is met by each main character through the aim of *constructing a shell of normalcy around the dying experience*. For Maria, this agency involves open communication and the attempt to continue her social lifestyle as usual. Manta’s aim, in turn, is in finding acceptance and acknowledgement of her dying experience through the community of the church. Raimo’s narrative unfolds, essentially, into an account of social death, whereby an

individual is no longer considered an active member of the social world (Caswell & O'Connor 2015). In Raimo's story, the entire family is treated as taboo, a household to be avoided. In an effort to reinstate himself as a member of the community of the living, Raimo joins his wife in making a joint public appearance, cycling together and defying the social silence. Sirkka, on the other hand, prepares for death somewhat detached from her family. The hospice, for her, is the venue for death to be approached as 'normal'. The good death thus appears a specific project to be individually executed by the dying as an active social strategy, yet highly normative in character, to be socially recognised and embraced.

Importantly, the good death emerges through a struggle against social adversity – from chaos of illness to quest for agency – and ending in a reconciliation of the individual and the social. A reconciliation calls for social awareness both of the dying, in their particular circumstances, and of death in its universality. Here, the good death appears in contrast to Walter's (1996) account of the postmodern death as following either the 'radical strand' (death as the autonomous and private territory of the dying person) or the 'expert strand' (death as mastered only with the aid of doctors and counsellors). In the narratives of *My last words*, death is not removed from social, rather, the agents of good death insist on reinstating themselves, *in conjunction with death*, into social.

Therefore, although through contestation, positioning and conflict, what ultimately emerges through the small story analysis of *My last words* is an aim to repair the relationship between the body, self and society, and thus to re-create order (Williams 1984). These narratives of good death represent an alternative to the modern restitution narrative, upheld by the philosophy and language of medicine. Whereas the patient of the restitution narrative plays the sick role, dependent on the expertise of the doctor (Frank 1995, 83), the agents of *My last words* reclaim their position as the authors of their body's story.

The small stories of *My last words* produce a portrait of the process of dying which covers a long period of time. In Kellehear's (1990) study, to achieve a good death, the patients met this period with awareness and attempted to organise it to lead a meaningful social life. The good death also involved adjustments and preparations to death, relinquishing roles, responsibilities and duties, and the making of farewells with others. Compared to Kellehear's observations in the hospital context, the stories of *My last words* are glimpses into the reality of dying, filmed, edited and produced for the general public, with the main characters consciously prepared to address their audience. Their process of relinquishing roles and

preparing for death are not presented in full before the camera; instead, it appears that through the documentary, Maria, Manta, Raimo and Sirkka express the terms under which they succumb to finally resigning their full agency in the final phase of their lives.

Adding to Kellehear's dimensions of good death, *My last words* represents the general aim by the participants of being helpful to others (see also Steinhauser et al. 2000). The reason for storytelling is not only in negotiating one's own position through narrative performance – it is, by implication, an invitation to a mutual reflexive process of constructing the self. The cultural relevance of the quest story is in helping the listener in contemplating on the contingency of life – not by way of rescuing the other from this contingency, but by sharing the perspective which the wounded storyteller has gained through illness (Frank 1995, 126-127). In fact, parallel to the aspiration to normalcy and social inclusion is the transformative aim of dying agency which is transmitted by every participant in the documentary. As they prepare to die, they call for an evolution in the world they are about to leave behind – a call for more sensitivity, awareness and courage in confronting death and the dying.

Finally, the good death narrative is based on contemplations on death itself. The chaos of the first small stories represent an unyielding encounter, where the only route forward for the agent is through surrender. Beyond this fateful moment, the second small stories describe the efforts of the narrators to navigate back into social existence. Through their claim for inclusion, they ask for death to be allowed to blend in life. Thus, as dying agents, they succumb to that imperative of life which *includes* death.

As a documentary, *My last words* is not what could be called an impartial medium for the stories of the dying. The aim of countering the sequestration of death is prevalent in the themes and topics raised in both Finnish and Dutch episodes. The main characters themselves obviously enrolled for the documentary with a personal and social agenda in mind. For instance, Maria states that one of her motifs for participation is to give a face to the reality of living, for many years, with the knowledge of dying. However, many also merely express their wish to leave a memory of themselves for their loved ones through the documentary.

Whether intentional or not, the participants convey a consequential model of dying. In considering the mediated experience as a significant resource in the reflexive project of the self, Giddens points to the profound effect which newspapers and television have both on our

experience and the public opinion – not only on our attitudes, but importantly, as access to knowledge which is the foundation of social action (Giddens 1997, 364). Pierre Bourdieu (1996) also warns against the influence of television on political and cultural life. In Bourdieu's view, journalists choose to see certain things and not others (1996, 19), looking for the spectacular and the drama. Paradoxically, even when attempting to capture the ordinary without an added interpretation, the very act of presenting an image or a report on television, "*implies a social construction of reality that can mobilize (or demobilize) individuals and groups*" (ibid., 21).

As discussed, media and television indeed reserve a prominent role in celebrating 'ordinary heroes' and promoting the self-aware scripts of heroic dying (Walter 2009; Frith, Raisborough & Klein 2013; Seale 1995). This idealism is addressed by Armstrong-Coster (2001), who examined how people with cancer perceive and are influenced by the broadcast media cancer stories, and whether the final accounts are manipulated to meet the demands of the "market". In her study, a focus group of people with cancer viewed and commented on a documentary film depicting a cancer story, and strongly reacted to the film's portrayal of the cancer experience. The film represented a heroic journey with cancer, which the focus group experienced as highly shameful since they felt they had not themselves lived up to such a standard. In their view, the film was not representative of the reality of the experience, but at the same time, understood how such a truthful depiction might prove damaging to the public. Armstrong-Coster however concludes that her study with the focus group demonstrates how an idealized notion of dying conveyed by the media can, in fact, prove distressing to those 'fellow travelers' who live a different reality of fatal illness.

These heroic stories of illness could be considered modern attempts to re-create some of the ontological security which is lost in life's fateful moments. Silverstone (1993) explains how everyday life can be understood as a continual defence against disorder. According to Silverstone, television provides such continuity and familiarity which may be paralleled to a 'transitional object', sustaining ontological security. Since television has colonised social reality, we must attempt to understand it better, argues Silverstone.

It is precisely here that we should also consider the value of the television documentary as empirical material for social research. The value lies firstly in what has been discussed in this study as the nature of the documentary as a site of contestation and negotiation between social and individual conceptions and ideals. Secondly, it is in acknowledging the powerful

and normative role of television in shaping social reality and thus personal experience. As illness disrupts the individual's life trajectory and interferes in the relationship between the body, self and society, illness narratives are produced and consumed in order to retain a sense of agency and order. Upon reaching public fora, these narratives necessarily touch on social and cultural ideals.

Through the public narratives of illness and dying, the reflexive project of the self becomes a global and universal undertaking. The study of these public testimonies bears relevance for students of social science interested in the ethical and standardising repercussions of a provision where private informs the public (Walter 1996) – and significantly, in media age, where public informs the private. After all, suggest John Meyer and Ronald L. Jepperson (2000), in the modern society, individual agency is increasingly called upon as the authority of the state and church diminish. The authors even describe the modern individual as “*empowered with more and more godlike authority and vision*” (ibid., 105), an agent who may attain a sacral position as a representative of higher principles in the public domain. This empowerment of the individual in the end-of-life context is tangibly demonstrated by the euthanasia and ‘death with dignity’ movements as well as the personal narratives of good death.

The study at hand began as an effort to understand the experience of dying as an individual and social process through the concept of agency. In the course of analysis, it became apparent that the documentary in fact retained and enforced the perspective of agency – thus dismissing death itself. What is not shown in any of the episodes is the final phase of life, not to mention actual death. This begs the question whether death in society and in the media continues to be treated as the ‘point zero’ (Bauman 1992, 14), unintelligible and taboo. Partly to the negotiation of dying agency in which the main characters engaged through *My last words* is the public discussion related to the documentary. These voices on the public fora are important in deliberating the social response to what is a good death (Raisio, Vartiainen & Jekunen 2015). Furthermore, as discussed earlier, these cultural and social ideals also bear on the experience of dying in the privacy of hospitals, hospices and homes. Acknowledging the normative weight of television and of the good death ideal call for further attention to how, or whether, we choose to imagine our deaths through the collective mediated experience. Finally, the study at hand suggests that the sequestration thesis still requires continued academic self-examination and empirical effort in social research.

REFERENCES

- Ariés, Philippe 1974. *Western Attitudes toward Death from the Middle Ages to the Present*. London: Marion Boyars.
- Armstrong-Coster, Angela 2001. "In Morte Media Jubliante: An empirical study of cancer-related documentary film." In *Mortality*, 6 (3) 287-305.
- Atkinson, Paul 2009 "Illness narratives revisited: the failure of narrative reductionism." In *Sociological Research Online* 14(5)16.
- Atkinson, Paul 1997. "Narrative Turn or Blind Alley?" In *Qualitative Health Research*, 7 (3) 325-344.
- Atkinson, Paul, & Delamont, Sara 2006. "Rescuing Narrative from Qualitative Research." In *Narrative Inquiry*, 16 (1) 164-172.
- Bamberg, Michael 2011. "Who am I? Big or small - shallow or deep?" In *Theory & Psychology*, 21(1) 122-129.
- Bamberg, Michael 2010. "Blank Check for Biography? Openness and Ingenuity in the Management of the "Who-Am-I Question" and What Life Stories Actually May Not Be Good." In Schiffrin, Deborah, De Fina, Anna & Nylund, Anastasia (eds.): *Telling Stories: Language, Narrative and Social Life*. Washington, DC: Georgetown University Press.
- Bamberg, Michael 2008. "Twice-Told Tales: Small Story Analysis and the Process of Identity Formation." In Sugiman, Toshio, Gergen, Kenneth J., Wagner, Wolfgang & Yamada, Yoko (eds.): *Meaning in Action. Constructions, Actions and Representations*. Japan: Springer.
- Bamberg, Michael & Alexandra Georgakopoulou 2008. "Small stories as a new perspective in narrative and identity analysis." In *Text & Talk*, 28 (3) 377-396.
- Bamberg, Michael. 2006 "Stories - Big or Small. Why do we care?" In Bamberg, Michael (ed.): *Narrative - State of the Art*. Amsterdam/Philadelphia: John Benjamins Publishing Company.
- Bamberg, Michael 2005. "Narrative discourse and identity." In Meister, Ian Christoph (ed.): *Narratology beyond literary criticism*. New York: Walter de Gruyter.
- Bamberg, Michael 2004. "Talk, Small Stories, and Adolescent Identities." In *Human Development*, 47 (6) 366-369.
- Bamberg, Michael 1997. "Positioning Between Structure and Performance." In *Journal of Narrative and Life History* 335-342.
- Bauman, Zygmunt 1992. *Mortality, Immortality & Other Life Strategies*. Cambridge: Polity Press.
- Becker, Carl, Clark, Elisabeth, Despelder, Lynne Al, Dawes, John, Ellershaw, John, Howarth, Glennys & Kellehear, Allan 2014. "A Call to Action: An IWG Charter for a Public Health Approach to Dying, Death and Loss." In *Omega*, 69 (4) 401-420.
- Borgstrom, Erica 2015. "Social death in end-of-life care policy." In *Contemporary Social Science*, 10 (3) 272-283.
- Bourdieu, Pierre 1996. *On Television and Journalism*. London: Pluto Press.
- Broom, Alex & Cavenagh, John 2010. "Masculinity, moralities and being cared for: An exploration of experiences of living and dying in a hospice." In *Social Science & Medicine*, 71 869-876.
- Brown, Louise, & Walter, Tony 2014. "Towards a social model of end of life care." In *British Journal of Social Work*, 44 (8) 2375-2390.
- Bruner, Jerome 1990. *Acts of Meaning*. Cambridge, MA: Harvard University Press.
- Burke, Kenneth. 1969. *A Grammar of Motives*. Berkley and Los Angeles: University of California Press.

- Caswell, Glenys & O'Connor, Mórna 2015. "Agency in the context of social death: dying alone at home." In *Contemporary Social Science*, 10 (3) 249-261.
- Elias, Norbert 1985. *The loneliness of the dying*. Oxford: Blackwell.
- Emirbayer, Mustafa & Mische, Ann 1998. "What is Agency?" In *American Journal of Sociology*, 103 (4) 962-1023.
- Endacott, Ruth, Boyer, C., Benvenishty, Julie, Nunn, Ben M., Ryan, H., Chamberlain, W., Boulanger, Carole & Ganz, F.D. 2016. "Perceptions of a good death: A qualitative study in intensive care units in England and Israel." In *Intensive and Critical Care Nursing* 8-16.
- Fortuin, Nienke, Schilderman, Johannes & Venbrux, Eric 2017. "Death and the search for meaning: canonical, utilitarian and expressive thanatological cultural niches." In *Mortality*, 22(4) 339-355.
- Frank, Arthur W. 1995. *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Frith, Hannah, Raisborough, Jayne & Klein, Orly 2013. "Making death 'good': instructional tales for dying in newspaper accounts of Jade Goody's death." In *Sociology of Health and Illness*, 35 419-433.
- Georgakopoulou, Alexandra 2013. "Building iterativity into positioning analysis. A practice-based approach to small stories and self." In *Narrative Inquiry*, 23 (1) 89-110.
- Georgakopoulou, Alexandra 2006. "Thinking big with small stories in narrative and identity analysis." In *Narrative Inquiry*, 16 (1) 122-130.
- Giddens, Anthony 1991. *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.
- Giddens, Anthony 1987. *Social Theory and Modern Sociology*. Cambridge: Polity Press.
- Giddens, Anthony 1984. *The Constitution of Society. Outline of the Theory of Structuration*. Cambridge: Polity Press.
- Giddens, Anthony 1979. *Central Problems in Social Theory. Action, Structure and Contradiction in Social Analysis*. New York: MacMillan.
- Glaser, Barney & Strauss, Anselm 1965. *Awareness of Dying*. Chicago: Aldine.
- Goldsteen, Minke, Houtepen, Rob, Proot, Ireen M., Abu-Saad, Huda Huijer, Spreeuwenberg, Cor & Widdershoven, Guy 2006. "What is a good death? Terminally ill patients dealing with normative expectations around death and dying." In *Patient Education and Counselling*, 378-386.
- Gorer, Geoffrey. 1965. *Death, Grief and Mourning*. New York: Doubleday.
- Harré, Rom. 2010. "Positioning as a Metagrammar for Discursive Storylines." In Schiffrin, Deborah, De Fina, Anna & Nylund, Anastasia (eds.): *Telling Stories: Language, Narrative and Social Life*. Washington, DC: Georgetown University Press.
- Hart, Bethne, Sainsbury, Peter & Short, Stephanie 1998. "Whose dying? A sociological critique of the 'good death'." In *Mortality*, 3 (1) 65-77.
- Hawkins, Anne Hunsaker 1991. "Constructing death: three pathographies about dying." In *Omega*, 22 (4) 301-317.
- Hockey, Jenny 2007. "Closing in on death? Reflections on research and researchers in the field of death and dying." In *Health Sociology Review*, 16 (5) 436-446.
- Holland, Janet & Thomson, Rachel 2009. "Gaining perspective on choice and fate. Revisiting critical moments." In *European Societies*, 11(3) 451-469.
- Horsfall, Debbie, Noonan, Kerrie & Leonard, Rosemary 2012. "Bringing our dying home: How caring for someone at and of life builds social capital and develops compassionate communities." In *Health Sociology Review*, 21 (4) 373-382.
- Howarth, Glennys 1998. "'Just live for today'. Living, caring, ageing and dying." In *Ageing and Society*, 18, 673-689.
- Howarth, Glennys. 2007. "Whatever happened to social class? An examination of the neglect

- of working class cultures in the sociology of death." In *Health Sociology Review*, 425-435.
- Hughes, Travonia, Schumacher, Mitzi, Jacobs-Lawson, Joy M., & Arnold, Susanne 2008. "Confronting Death: Perceptions of a Good Death in Adults With Lung Cancer." In *American Journal of Hospice and Palliative Medicine* 39-44.
- Hydén, Lars-Christer. 1997. "Illness and narrative." In *Sociology of Health and Illness* 19(1) 48-69.
- Hyvärinen, Matti, & Löyttyniemi, Varpu 2005. "Kerronnallinen haastattelu." In Ruusu vuori, Johanna & Tiittula, Liisa (eds.): *Haastattelu. Tutkimus, tilanteet ja vuorovaikutus*. Tampere: Vastapaino.
- Illich, Ivan 1976. *Limits to medicine*. London: Marion Boyars.
- Isotalo, Sari 2013: *Viimeiset sanani (My last words.)* Susamuru Oy. A television documentary series. First aired by the Finnish Broadcasting Company, Yle TV1 on April 24, 2013. https://rtva.kavi.fi/cms/page/page/info_katselupisteet. Accessed: October 18, 2018.
- Kastbom, Lisa, Milberg, Anna & Karlsson, Marit 2017. "A good death from the perspective of palliative cancer patients." In *Supportive Care in Cancer* 933-939.
- Kellehear, Allan 1990. *Dying of cancer: the final year of life*. Melbourne: Harwood Academic Publishers.
- Ko, Eunjeong, Kwak, Jung & Nelson-Becker, Holly 2015. "What Constitutes A Good and Bad Death?: Perspectives of Homeless Older Adults." In *Death Studies* 422-432.
- Labov, William. 2006. "Narrative pre-construction." In *Narrative Inquiry* 16(1) 37-46.
- Labov, William. 1997. "Some Further Steps in Narrative Analysis." In *Journal of Narrative and Life History*, 7 (1-4) 395-415.
- Labov, William & Waletzky, Joshua 1967. "Narrative analysis: Oral versions of personal experience." In Helm, June (ed.): *Essays on the verbal and visual arts*. Seattle, WA: University of Washington Press.
- Lawton, Julia 2000. *The dying process: Patients' experiences of palliative care*. London: Routledge.
- Leichtentritt, Ronit D., & Rettig, Kathryn D. 2000. "The Good Death: Reaching an inductive understanding." In *Omega*, 41 (3) 221-248.
- Lieblich, Amia, Tuval-Mashiach, Rivka & Zilber, Tamar 1998. "Narrative Research. Reading, Analysis and Interpretation." In *Applied Social Research Methods, Volume 47*. London: Sage Publications.
- Lieblich, Amia, Zilber, Tamar B. & Tuval-Mashiach, Rivka 2008. "Narrating Human Actions. The Subjective Experience of Agency, Structure, Communion and Serendipity." In *Qualitative Inquiry* 14(4) 613-631.
- McNamara, Beverley 2004. "Good Enough Death: autonomy and choice in Australian palliative care." In *Social Science & Medicine*, 58, 929-938.
- McNamara, Beverley 1995. "Threats to the good death: the cultural context of stress and coping among hospice nurses." In *Sociology of Health and Illness*, 17 222-244.
- Meier, Emily A., Gallegos, Jarred V., Montross-Thomas, Lori P., Depp, Colin A., Irwin, Scott A. & Jeste, Dilip V. 2016. "Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue." In *American Journal of Geriatric Psychiatry* 261-271.
- Mellor, Philip A. & Schilling, Chris 1993. "Modernity, self-identity and the sequestration of death." In *Sociology* 27 411-431.
- Meyer, John W. & Jepperson, Ronald L. 2000. "The "Actors" of Modern Society: The Cultural Construction of Social Agency." In *Sociological Theory*, 18 (1) 100-120.
- O'Gorman, Stella Mary 1998. "Death and dying in contemporary society: an evaluation of

- the current attitudes and the rituals associated with death and dying and their relevance to recent understandings of health and healing ." In *Journal of Advanced Nursing*, 1127-1135.
- Payne, Sheila, Langley-Evans, Alison & Hillier, Richard 1996. "Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients." In *Palliative Medicine*, 10, 307-312.
- Pierson, C. M., Curtis, Randall, J. & Patrick, D. L. 2002. "A good death: A qualitative study of patients with advanced AIDS." In *AIDS Care*, 587-598.
- Poroch, Nerelle. 2012. "Kurunpa: Keeping Spirit on Country." In *Health Sociology Review*, 21 (4) 383-395.
- Raisio, Harri, Vartiainen, Pirkko & Jekunen, Antti 2015. "Defining a Good Death: A deliberative democratic view." In *Journal of Palliative Care*, 3, 158-166.
- Riessman, Katherine Kohler 2008. *Narrative Methods for the Human Sciences*. Los Angeles: Sage.
- Riessman, Katherine Kohler 2003. "Performing identities in illness narrative: masculinity and multiple sclerosis." In *Qualitative Research*, 3 (1) 5-33.
- Röcke, Christina & Cherry, Kelly E. 2002. "Death at the end of the 20th century. Individual processes and developmental tasks in old age" In *International Journal of Aging and Human Development*, 54 (4) 315-333.
- Seale, Clive 1995. "Heroic Death." In *Sociology*, 29 (4) 597-613.
- Segal, Judy 2000. "Constesting Death, Speaking of Dying." In *Journal of Medical Humanities* 21(1) 29-44.
- Semino, Elena, Demjén, Zsófia & Koller, Veronika. 2014. "'Good' and 'bad' deaths: Narratives and professional identities in interviews with hospice managers." In *Discourse Studies*, 16(5) 667-685.
- Silverstone, Roger 1993. "Television, ontological security and the transitional object." In *Media, Culture and Society*, 15 573-398.
- Steinhauser, Karen E., Clipp, Elisabeth C., McNeilly, Maya, Nicholson, Christakis, McIntyre, Lauren M. & Tulsky, James A. 2000. "In search of a Good Death: Observations of Patients, Families and Providers." In *Annals of International Medicine*, 122 (10) 825-832.
- Tucker, Kenneth H., Jr 1998. *Anthony Giddens and Modern Social Theory*. London: Sage.
- Uusi Suomi. 2008. *Yle: Kuolemaa hyvällä maulla*. <https://www.uusisuomi.fi/koti-maa/11287-yle-kuolemaa-hyvalla-maulla>. Accessed April 14, 2019.
- Yle uutiset 2008. Viimeiset sanani -tv-sarja käsittelee kuolemaa. *Yle uutiset* 16.1.2008. <https://yle.fi/uutiset/3-5818653>. Accessed December 12, 2018.
- Walter, Tony 2015. "Death and Dying, Sociology of." In Wright, James D (ed.): *International Encyclopedia of Social and Behavioural Sciences, Vol. 5*. Elsevier.
- Walter, Tony 2009. "Jade's Dying Body: The Ultimate Reality Show." In *Sociological Research Online*, 14 (5) 1-11.
- Walter, Tony 1996. "Facing Death without Tradition." In Jupp, Peter C. & Howarth, Glennys (eds.): *Contemporary issues in the sociology of death, dying and disposal*. Basingstoke: MacMillan.
- Walter, Tony 1994. *The Revival of death*. London and New York: Routledge.
- Whitney, Al & Smith, André 2010. "Exploring Death and Dying through Discourse." In *The Arbutus Review*, 1, 68-80.
- Williams, Gareth 1984. "The genesis of chronic illness: narrative re-construction." In *Sociology of Health and illness*, 6 (2) 175-200.
- Willmott, Hugh 2000. "Death: So What? Sociology and Sequestration." In *Sociological Review*, 48 (4) 649-665.
- Young, Michael & Cullen, Lesley 1996. *A Good Death. Conversations with East Londoners*. London and New York: Routledge.