

Striving for normalcy: Analysis on narrative, positioning and agency in incurable illness

ARTICLE

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ISSN 2242-6280
<https://doi.org/10.5774/thanatos.156508>

Abstract

This paper explores the agency of incurably ill persons, through a narrative analysis of the Dutch-Finnish television documentary *My last words*, which follows incurably ill persons facing the last months of their lives. The analysis is based on William Labov's theory of narrative structure and Michael Bamberg's positioning analysis. Through narrative performance, the stories of Maria and Raimo offer an account of dying agency. While the initial encounter with death produces a "chaos narrative", the speakers gradually reclaim their agency through the "quest narrative". From the chaos of illness to the quest for agency, there emerges a struggle against social adversity – a pursuit of reconciliation between the individual and the social. The aim of dying agency is to establish dying as normal.

Keywords: narrative analysis, positioning analysis, television documentary, agency, incurable illness

Introduction

Agency in death is a political, social, and personal matter. The 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. Empirical studies of death have also demonstrated the differing ideals of patients, professionals and caretakers (Hughes *et al.*, 2008; Meier *et al.*, 2016; Krikorian *et al.*, 2020). Acknowledging this need to address the heterogeneity of death and dying as a cultural and personal experience, the topic of agency in death has been discussed in connection to the institutionalisation of death under medical practice (Whitney and Smith, 2010). As more people have begun to die in hospitals (Forma *et al.*, 2020) the medical perspective, focusing on cure, has left the dead 'lonely' (Walter, 2015). Thus, claims Walter (*ibid.*), by emphasising choice and control in end-of-life care, the medical philosophy aims to mitigate the modern Western individual's fear of losing autonomy and social agency (Caswell & O'Connor, 2015).

In the field of death studies, the idea that death has been denied and sequestered due to medicalization is widely accepted (Gorer, 1965; Illich, 1976; Ariés, 1974; Elias, 1985; Mellor & Shilling, 1993). Scholars have argued that this has resulted in the deprivation of individual agency in matters of dying and death (Hockey, 2007). These perspectives are echoed in Giddens' analysis, which describes modernity as essentially about excluding existential issues from social life. Giddens discusses a 'scientific outlook' 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 (Giddens, 1991, p. 8).

Giddens believes that late modernity creates an unprecedented context for novel efforts of self-development: individuals are faced with a reflexive project which compels them to confront and to answer huge existential questions without the support of traditional moral and social frameworks (Tucker, 1998, p. 205). Following Giddens' rationale, it appears that as an integral part of the reflexivity, death seems to have shed its cloth of taboo. Death and dying have regained a growing social and cultural interest (Walter, 2019). People give meaning to serious illness and death in different ways (Leung, 2010) and engage in various practical actions – e.g., burn candles to honour seriously ill loved one (van Dongen, 2008) or participate (even) in end-of-life documentaries (Hakola, 2024). These practices support dying persons' agency and social relationships (Leung, 2010).

In this article, we examine a dialogue on death between society and the individual as it unfolds in the television documentary *My Last Words*. Viewed through the theoretical framework of narrative agency, we consider the documentary a site of the reflexive project whereby individuals construct their (dying) identity. Specifically,

we analyse how agency is represented through the Labovian narrative structure. Our aim is to consider agency through storytelling: how agency is portrayed as positions and interaction through small stories of death in *My last words*.

Data

*My last words*¹ (Mijn Laatste Woorden – Viimeiset sanani) is a television documentary series consisting of Dutch and Finnish episodes, each introducing a single main character – incurably ill and facing the last months of their life. In Finland, the documentary first aired in 2009. *My last words* represent the first instance of the terminally ill stepping into the limelight on Finnish public television.

The documentary serves as an intriguing point of access into the discussion of agency in dying. As contemporary death is an experience that potentially lasts for years, we suggest that the topic of agency might be approached as a process, a practice and negotiation of dying, thus incorporating the personal, social and possibly even the societal factors. The documentary, as a public display of private experiences, offers a unique perspective into the intersection of personal strategies meeting social and societal ideals and expectations.

In the narrative structure of *My last words*, each episode represents a collage of perspectives into the experience of dying. 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. Each episode builds into a life story which is viewed from the vantage point of the approaching death.

We have chosen to focus this article on the Finnish episodes. After transcribing and translating the episodes into English, we narrowed down our focus to how the characters were portrayed in the documentary. Out of four TV episodes analysed, we chose two episodes for this article. We chose the two episodes to include both female and male stories. Beneath the main storyline, we heard multiple small stories, occasionally appearing as autonomous first-person narratives, while others were jointly produced by multiple characters, sometimes including the interviewer. To go beyond the script and production of the documentary, we used these small stories as points of entry into the narrative voices of the main characters themselves. The cases selected for this article serve as examples through which we interpret positions and agency across the dataset.

The documentary material as research data is specific. Hakola (2024), who has studied death documentaries, approaches end-of-life documentaries through a metaphor of space. Documentary films create a space where the social issue occurs in

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

time and place and is framed by evolving activities and meaning-making. She notes that documentary films tell personal stories as part of social issue argumentation. Although positioned within broader social and political movements, the personal stories in these documentaries can be understood not merely as ideological expressions, but rather as genuine meaning-making by the individuals involved.

For the purposes of this paper, we consider two narratives: one related to the initial experience of receiving diagnosis and facing the possibility of death, and another related to living with death.

Analysis and conceptual framework

We applied William Labov's theory of narrative structure (2006) and Michael Bamberg's positioning analysis (1997) in our analysis of the narratives. A classic theory of narrative structure was put forth by Labov and Waletzky (1967; Labov, 2006) on how people convey past personal experiences in a narrative form. 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, and resolution; how the complication ends or what it leads to and
- a coda; connecting the narrative to the moment of telling the story.

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

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

- How are characters positioned within the story? (level 1)
- How does the speaker/narrator position him/herself (and is positioned) within the interactive situation? (level 2)
- How does the speaker/narrator position a sense of self/identity with regard to dominant discourses or master narratives? (level 3)

Bamberg and Georgakopoulou (2008) describe their narrative approach as a departure from the 'narrative canon' which takes narrative as a representation of the narrator's personal subjectivity. Instead, they identify small stories as sites of interest, where people use stories in mundane, conversational, everyday situations and thus practice their identity in interaction with others. The small story approach focuses on under-represented narrative activities, such as tellings of ongoing events, future or hypothetical events, shared (known) events, but also allusions to (previous) tellings, deferrals of tellings, and refusals to tell. An interest in small stories (Bamberg, 2006; Bamberg & Georgakopoulou, 2008; Bamberg, 2011) takes identity as a process of construction, profoundly situational and social.

As theoretical tools alongside narrative analysis, we use Anthony Giddens' ideas of self-identity, fateful moments and agency. Giddens' ideas have also been applied in e.g. Kao (2017) from the viewpoint of agency in the study of suicide as a political site and in Ahmed et al. (2022) in the study of social and cultural dimensions of death. According to Giddens, high modernity calls for a "reflexive project of the self", which consists in the sustaining of coherent, yet continuously revised, biographical narratives" (1991, pp. 12, 5). Self-identity has become the core of agency, in both content and aim. In high modernity this reflexive agent faces the ontological task of composing her/his very self in the context of post-traditional social order that offers individual choices and alternatives. Fateful moments, such as becoming aware of a serious illness, are transition points that call into question one's entire self-identity (Giddens, 1991, p. 143). According to Giddens, the self-identity of the modern individual "constituted by the reflexive ordering of self-narratives" (1991, p. 244) relies on a discursive consciousness (1979, p. 73) of agency. Illness narratives can thus be understood as attempts at biographical reconstruction and identity work (Atkinson, 2009) when there is a threat of losing one's self-identity and agency.

Next, we will consider Maria's and Raimo's stories through William Labov's theory of narrative structure and Michael Bamberg's positioning analysis. Then, we discuss the narratives of agency in conjunction with Giddens' theoretical concepts. We also utilize Frank's (1995) typology in the analysis of empirical data. Frank identifies three basic narratives of illness: restitution, chaos, and quest. Restitution narratives anticipate getting well again and emphasize the technology of cure. However, in chaos

narratives, illness seems to stretch on forever, with no respite or redeeming insights. The concept of chaos in Frank's framework typically refers to moments of unforeseen disruption, a fateful moment, as the trajectory of life shifts unexpectedly. Yet in the context of this analysis, it also encompasses the process of transformation and reinterpretation of these moments over time.

Quest narratives are about finding insight as illness is transformed into a means for the ill person to become someone new. Our analysis primarily focuses on chaos and quest narratives.

Results: dying agency

Our first research question focuses on how we perceive agency in the small stories 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.

Small stories of dying agency

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 her illness follows the classic Labovian (Labov & Waletzky, 1967; Labov, 2006) narrative structure, beginning with an abstract describing the background of her 25-year career. 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 caused by it (lines 10–13): "The doctor gives you three days of sick leave, then you return, stay a couple of days and come back."

Then (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 by Maria's anticipation "[...] there had to be something there", thus importantly including her as an actor in the unfolding of events.

In this illness narrative, the speaker appears as a puppet-like figure, moved by external forces beyond their control – from work to the doctor's office and, finally, out of the scene altogether after receiving the diagnosis. Although the narrative is full of motion, the speaker only begins to catch up with the speed of events as she 'anticipates', after receiving the phone call, what is about to unfold. Agency in this narrative is represented by the doctor and the diagnosis. Their agency is first concealed and evasive, yet over the course of the narrative, these agents become increasingly visible: a voice on the phone turns into a 'young female doctor' breaking the news, and that had driven the speaker back and forth is finally identified and revealed for what it truly 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 Maria's illness narrative ends without a definitive coda, which would take the audience back to the here-and-now (Bamberg, 2006), explaining the story's relevance in the current moment. Ending in the past 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 Interviewer: 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 causes 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.

Maria's second narrative depicts the reality of living with cancer. 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). A narrative of physical transformation abruptly unfolds into a story of a 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 time before illness. The narrative has therefore moved back in time, albeit syntactically remains in the present.

The narrative finds a resolution in the active stance assumed by the narrator to her changed situation. The speaker's agency aims to re-establish her position as the old self. Her effort to communicate with her surroundings, creating smiles and enjoyment, has turned into a strategy of blunt openness about her illness. She calls for her right and ability to remain the normative, independent voice in her life, regardless of the physical and social change to her normal experience.

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 first segment of the narrative (lines 1–6), the orientation “It was in 1998” is followed by the complicating action “when this cancer was diagnosed”. The speaker then steps outside the temporal structure into present tense, assuming the medical perspective to offer an objective evaluation (3–5). The narrative reaches a relative resolution (6–7), in the passive voice, “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 of isolation and submission for the overall theme of cancer diagnosis.

The second segment (lines 8–13) begins with a somewhat brusque evaluation (lines 8–9) related to receiving the diagnosis: “Of course, the first thing was – ‘So, is this it?’”. Lines 10–11 form an orientation, “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.”

Perceived as two short narratives, the position of the passive-voice-narrator of the first one could be characterized as that of a victim. In the second narrative, the speaker discovers agency through his position of submission – he actively prepares to die. Furthermore, the speaker adds an evaluative position, saying that he managed to prepare for it quite well. What follows is that cancer, as the complicating action of the first narrative, loses momentum. In fact, the real complication represents somewhat of an anomaly in the cancer script: the diagnosis 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 relates to the personal experience of the narrator, and the present to the general context, the medical status quo. The use of present tense also demonstrates the potential of the medical story for being anyone’s story. Lines 5–6 in fact produce such a synthesis, presenting the situation impersonally by 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, and comparable to ‘anyone’: whoever would appear as the main character in this narrative is defined by that position and, 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 on 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 set off 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 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 Helinä as they always have
 43 and not avoid her,
 44 just approach her fair and square.
 45 [Wife:] People start avoiding places where someone has died.
 46 It was different before:
 47 people came for a visit after someone's death.
 48 I'd like to be treated the same way as always,
 59 that's what I'd like at least.
 50 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].

Raimo's second narrative unfolds as a two-person interview with both Raimo and his wife, Helinä. There is also an additional voice, Raimo's brother-in-law, complementing their account. This story thus bears multiple narrators, including the interviewer. Through her involvement, the narrative is anchored by both an abstract and a coda, thus planting a particular incidence from the past into the 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. It is followed by an orientation, in which Raimo's wife is joined by Raimo's brother-in-law as co-narrator. The orientation describes a chain of events leading to the complication (lines 24–25) of how a rumour about Raimo's demise starts to spread. The complication is followed by a 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 comes close to a farce depicting the process of a rumour spreading of Raimo's death. Raimo himself expands on the main narrative through an intimate perspective, demonstrating how death influences individual perceptions and choices. The joint response of Raimo and his wife to the false rumour reclaims Raimo's position as part of the community. The narrative is returned by the interviewer to the present from whence it began via the 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 a past cultural custom as an alternative to avoiding bereaved family members.

The temporal arch of the narrative is initiated in the present tense, when Raimo and his wife discuss the contemporary taboo related to death. It then reverts to past tense 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 of the main character of their story.

Narratives of agency in death

From fateful moments to resolutions

A Labovian perspective on the illness narratives highlights the fateful moment, the disruption in agency. In the narrative structure, the fateful moment is the complicating action, which is significantly different for Maria and Raimo. In Maria's story, the fateful moment occurs as the doctor finally delivers the bad news. Raimo's story relates the complication not to the possibility of dying, but to *not* dying – and thus being left waiting for death.

Consequently, the Labovian analysis of these illness stories also reveals different forms of agency upon the fateful moment. In Maria's case, the speaker is overwhelmed by the reality of the situation: Maria experiences an emotional blow upon receiving the news of her medical condition. Her narrative builds on the shock which drives her to escape into the ladies' room in the last scene. In contrast, Raimo describes an active stance on dying, which could even be viewed as an attempt at matching death. However, his attempt ends in ambivalence and disappointment.

In the second story told by both Maria and Raimo, Labov's instruments of analysis highlight the conflict and tension in living with death. Identifying the complicating action is particularly useful in delineating the elements of agency, which usually emerge in the story's resolution. In Maria's second narrative, the orientation – enjoying the social reaction to funny hats and smiles – is contrasted with the complicating action of not receiving the feedback anymore. Maria'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 a proactive stance in social situations by telling others about her illness and medication.

Raimo's story about the false rumours of his death also finds complication in the experience of social exclusion. This story is conveyed through multiple voices, which is also reflected in the resolution: Raimo and his wife confront the rumours together.

The Labovian analysis demonstrates a juxtaposition inherent in the stories of agency. Agency is portrayed through conflicts caused by a lack of understanding in society of the experience of living with an incurable illness. Both Maria and Raimo describe social exclusion following an unwanted social reaction, an uncomfortable social demeanour or as an outright rejection of the topic of death.

Essentially, the resolutions of the narratives describe agency as reactions to these conflicts. For both Raimo and Maria, agency is justified by ethical claims: Maria argues that she has the right to continue enjoying life without social prejudice, while Raimo calls for more public discussion on death in order to integrate death back into the realms of the 'normal' and life. Both speak for the normalcy of dying. As such, agency in these narratives aims at the social inclusion of the dying.

Comparing the first and second small stories offers insight into the development of agency following the fateful moment. For Maria, the initial reaction of fleeing the doctor's office turns into a proactive approach to social situations. By explaining about her medical condition to people she meets, she aims to establish social acceptance. The claim in her narrative is that she continues to have a right to be included among those who enjoy life.

Raimo, on the other hand, first describes the inevitable loneliness related to receiving the 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 for not dying, turn into a collective outlook on 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.

The Labovian analysis reveals the obstacles to agency in dying, and the subsequent social resistance experienced by those living with an incurable illness. Through their aims of defending the right to be seen, heard, included and respected, the speakers connect to the sequestration thesis. For Giddens (1984), the sequestration of existential questions in society forms the basis for agency, which is essentially a reproductive practice between individuals and social structures. Sequestration, which is part of ontological security, involves excluding death and other existential questions from routine interaction and social consciousness, thus creating a sense of certainty and continuity in daily life.

In the small stories of *My last words*, the fateful moment finds diverse responses, from astonishment to serene acceptance. However, the agency that emerges in the

second stories of Maria and Raimo speaks of an 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 and to maintain a normal contact with other members of the community. The speakers struggle to re-create the routinized character (Giddens 1984, p. 61) of their social lives in order to salvage a sense of agency.

This effort of reclaiming agency is a process of regaining control over one's narrative self-identity upon the faithful moment (Giddens, 1991, p. 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.

Conflicting positions

Walter has described the postmodern relationship to death as the sovereign authority of the individual to 'write their own script' of the dying experience (see Walter 1996). In keeping with Walter's (1996) thesis that the private experience satisfies the growing public thirst for knowledge, Seale (1995) discusses the need in late modernity to imbue death with meaning. Seale's study portrays a heroic script for dying, based on open awareness and an acknowledgement of death. The heroic script entails the choice to withstand the knowledge of the approaching death, the absence of negative emotions and reaching acceptance. However, the script also incorporates 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* is built on the elements described by Seale. In the small stories of Maria and Raimo, the knowledge of illness is presented as an initial shock, only to be followed by the accounts of empowered agents enjoying and even embracing their final moments. Maria's heroic script involves overcoming the distress caused by her physical transformation. When outfits and smiles fail, Maria addresses the issue by explaining the reasons behind her changed appearance. Within Frank's (1995) typology of illness narratives, Maria's resembles 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 a cure, nor does she look for one, but her story nevertheless accounts for her attempt to return to her normal self. Maria's transformation might begin as a physical one, but through open communication she discovers an alternative basis for maintaining her sociable manner. She returns, although marked by illness, to her original position.

Still following Frank's (1995) typology, 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 (cf. 1995, p. 36). The monadic body is compatible with the figure of the modern autonomous individual (Frank 1995, p. 85). However, as illustrated in Raimo's story, a moment that initially appeared as "fateful"

evolves over time. His narrative is not merely a response to a “disappointment” of not dying, but rather a reflection on how perspectives on such moments change over time. The sovereign position with which the speaker sets out to confront death is gradually transformed as Raimo reinterprets the meaning of his experience. Somewhat paradoxically, this sovereignty with which the speaker sets out to confront death, is dissolved in the second narrative – the quest story – into a pronouncedly collective, even communal approach to death. The autonomous, monadic position of the speaker of the chaos story carries over to the quest story, which is told collectively, but already fixed in the perspective of the living. The moral of the quest story centres on life, which Raimo says ought to continue after his death. In fact, Raimo’s quest narrative resembles a social manifesto (cf. Frank, 1995, p. 120) by the storyteller returned from the gates of death. Raimo himself is considered as a dichotomy of presence/absence – as a position more than anything else – and as having an effect on the continuance of the social system.

Dying agency: through resistance to normalcy

There is a significant divide between Maria’s small stories in terms of her relationship to death. The chaos in the first story appears total, whereas the second one already describes the people she meets as having a greater 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 of the illness.

In Raimo’s narratives the roles are switched: the centre stage is occupied by 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 as a ‘living dead’. His aim, however, in the second narrative is to assimilate death into life: He wishes to dismantle the very social structure which makes his life with death unbearable. If death became a topic of public discussion, facing one’s mortality would be less lonely, as would the experience of bereavement. Both Maria 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.

Maria and Raimo aim to re-position themselves back into the social paradigm through and in their narratives. In fact, by positioning illness and death as normal they make a claim on behalf of their continued agency. Whether making a plea to enjoy social life, to feel free to discuss the approaching death, to not 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.

Discussion

Our aim in this study was to retrace the intention and means of agency in dying as they appear in the narratives of the television documentary *My Last Words*. As an

empirical source, the documentary represents the mediated experience (cf. Giddens, 1991) which is a significant resource for the reflexive project of the modern self. It intersects the public/private domain.

Agency in death is narratively addressed through the attempt *to construct a shell of normalcy around the dying experience*. This struggle emerges simultaneously against death and social adversity – from the chaos of illness to the quest for agency – and ends in a reconciliation of the individual and the social. In the narratives of *My Last Words*, the agents of dying insist on reinstating themselves, in conjunction with death, into the social. As a means of dying agency, the illness narratives ultimately aim to repair the relationship between the body, the self, and society, thereby re-creating order (cf. Williams, 1984).

My last words represents the need of the dying to being helpful to others (see also Steinhauser *et al.*, 2000; Hakola, 2021). 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 social relevance of the quest story is in helping the listener to contemplate 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, pp. 126–127). Thus, parallel to an aspiration to normalcy and social inclusion is the *transformative aim* of dying agency. As Maria and Raimo 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. They seek to repair the relationship between an individual and society by asserting death back into the realm of the social. Documentary projects can be seen as personal legacies for a wider audience, turning something personal into something public; they leave a mark on historical and social communities, transforming personal legacies into public narratives (Hakola, 2024).

Due to de-institutionalization and re-familiarization of care and ageing in place, the final stages of life and death could be expected to take place in homes and in familiar environments (Seppänen *et al.*, 2023). It is therefore important to identify the agency and position of incurably ill people in everyday life. This study stresses the importance of this by emphasizing the social and cultural aspects of being incurably ill and dying, alongside the well acknowledged importance of pain control, spiritual and emotional well-being and close relationships in a good death (Meier *et al.*, 2016, Krikorian *et al.*, 2020).

As a result of this study, we suggest that the agency and position of incurably ill persons need to be supported further to avoid reproducing marginalized social identities. The analysis presented in this article demonstrates the continued relevance of Elias's (1985) view of dying being pushed behind the social scene, away from everyday life, which still lacks expressions and practices that would help in dealing with end-of-life

issues. Although we have practices to address serious illness (e.g., van Dongen, 2008) and death (e.g., Hakola, 2024), the approach of death is still a situation that requires the handling and reassessment of agency. With this study we are contributing to the awareness of how incurably ill people experience social life (and death).

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Abstrakti

Tämä artikkeli tarkastelee parantumattomasti sairaiden ihmisten toimijuutta analysoimalla hollantilaissuomalaisista televisiodokumenttia *My Last Words* (Viimeiset sanani) narratiivisen analyysin avulla. Dokumentissa seurataan parantumattomasti sairaiden ihmisten elämän viimeisiä kuukausia. Analyysi pohjautuu William Labovin narratiivisen rakenteen teoriaan ja Michael Bambergin kerronnallisen asemoinnin teoriaan. Marian ja Raimon tarinoiden narratiiviset performanssit tarjoavat näkökulman kuolevan toimijuuden kysymyksiin. Vaikka kuoleman kohtaaminen aluksi tuottaa "kaaokertomuksen", puhujat vähitellen palauttavat toimijuuttaan "etsintäkertomuksen" avulla. Siirtymä sairauden kaaoksesta toimijuuden etsintään ilmenee kamppailuna sosiaalista vastoinikäymistä vastaan ja pyrkimyksenä sovittaa yhteen yksilöllinen ja sosiaalinen. Kuolevan toimijuuden tavoitteena on normalisoida kuolemista.

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