“I will not die that way. Why should I be forced to?”

Brittany Maynard’s story in the campaign for assisted dying, a narrative perspective

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Physician-assisted dying in the United States, where a terminally ill person that fulfils certain criteria can be prescribed a substance to end their life, is legal in eight states as well as in Washington D.C. Advocacy organizations have played a central role in getting legislation passed. The state of Oregon, where the practice has been legal for over 20 years, serves as a model for legislation that is being proposed in other states. The advocacy organization Compassion & Choices, based in Portland, Oregon has been central in framing the issue of assisted dying in the United States.

In 2014, Compassion & Choices released a video featuring the story of a young woman named Brittany Maynard who was dying of brain cancer. The video went viral and was viewed over 9 million times in the month after being released, making Maynard the face of assisted dying in the United States. In this thesis I examine her story through narrative analysis as it is told in the campaign video and in three other videos released after the first one. Two of the videos in the material were released after Maynard's death and in them the story is told by Maynard's husband Dan Diaz, who has actively continued campaigning for assisted dying.

The aim of this thesis is to examine how advocacy organizations such as Compassion & Choices use personal stories to get attention for their cause and try to influence policy. The content of Maynard's personal story, how it is told, and how the story is connected to arguments for assisted dying is analyzed through narrative methods.

The results show that family values and an active lifestyle are emphasized in the narrative. The story alternates between statements presented as facts and personal experiences that are more emotional. The main arguments for legalization that are made in the videos are related to autonomy and personal choice and to avoiding unnecessary suffering. The personal experiences of Maynard are related to these arguments through how the story is told through speech, text and pictures. Strategies to frame the policy issue in a certain way and get the audience to identify with Maynard are also employed.

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Assisterad död (eng. assisted dying) i USA, där en döende person som uppfyller vissa kriterier kan få ett recept på läkemedel för att avsluta sitt liv, är lagligt i åtta delstater samt i Washington D.C. Intresseorganisationer har spelat en central roll i lagstiftningen relaterad till dödshjälp. Oregon, där dödshjälp varit lagligt över 20 år, har fungerat som en modell för lagstiftningen i andra delstater. Intresseorganisationen Compassion & Choices som har sitt huvudkontor i Portland, Oregon, har lyckats väl med att influera hur assisterad död uppfattas i USA.

År 2014 publicerade Compassion & Choices en video där en ung kvinna som var döende i cancer, Brittany Maynard, delade sin historia. Videon fick stor uppmärksamhet och sågs inom en månad över 9 millioner gånger. Maynard blev känd i hela USA som en representant för assisterad död. I den här avhandlingen undersöker jag hennes historia genom narrativ analys. Materialet består utöver kampanjvideon av tre andra videon där Maynards historia berättas. Två av dessa videor publicerades efter Maynards död och i dem är det hennes man, Dan Diaz, som berättar hennes historia. Diaz har aktivt efter Maynards bortgång fortsatt kampanjen för att assisterad död ska legaliseras.

Målet med denna avhandling är att undersöka hur organisationer som Compassion & Choices använder sig av personliga historier för att skapa uppmärksamhet för sin sak och för att försöka påverka politiskt beslutsfattande. I centrum för analysen, som görs genom narrativa metoder, står innehållet i Maynards historia samt hur historien berättas och hur narrativet anknyts till argument som stöder legalisering.

Resultaten visar att familjevärderingar och värderingar om en aktiv livsstil understryks i narrativet. Berättelsen växlar mellan fakta och personliga upplevelser som är mer emotionella. De huvudargument för legalisering som presenteras är argument relaterade till autonomi och rätten att välja samt argument om att undvika onödigt lidande. Maynards personliga upplevelser kopplas till dessa argument genom hur historien berättas i tal, text och bilder. Materialet innehåller också strategier för att framställa den politiska frågan på ett visst sätt och få publiken att känna solidaritet med Maynard.

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1. Introduction

In January 2014, a young woman in California named Brittany Maynard was diagnosed with brain cancer. A couple of months later, the cancer was found to be both terminal and very aggressive and her doctors gave her a diagnosis of six months to live. After considering her options, Maynard decided to move with her family from California to Oregon to be able to die an assisted death, which was then legal in Oregon but not in California. She also got in touch with the advocacy organization Compassion & Choices to ask if she could help them campaign for legalizing physician-assisted dying in other states. An advocacy organization, or advocacy group, according to Collins dictionary is "an organization that campaigns on a particular issue".[1] In the case of Compassion & Choices, the organization aims to "improve[s] care, expand[s] options and empower[s] everyone to […] choose end-of-life care that reflects their values, priorities, and beliefs."[2] The organizations uses a "comprehensive strategy including legislative advocacy, grassroots organizing, media outreach and litigation" to reach these aims.[3] Maynard's cooperation with Compassion & Choices was realized through the Brittany Fund. They made a video about Maynard's story that spread quickly and got a lot of attention (9 million views in the first month after being published), making Maynard the face of the assisted dying debate in the United States.[4]

The debate about physician-assisted death is actively going on in many states and in April 2019, New Jersey became the eighth[5] state in the U.S. to make it legal. When Colorado did so in 2016, Dan Diaz, the husband of the late Brittany Maynard, took part in the campaign and there was even a new video featuring Maynard released for the campaign. When the discussion was going on in Hawaii in 2018, Maynard was mentioned in some of the news coverage, although it had been over three years since she died. When the California End of Life Option Act was under threat from the courts in 2018, the campaign to defend it #IWantTheOptionCA featured videos of both Maynard and Diaz.[6] Maynard and her story remain relevant in the debate years after she died, despite the fact that she only took part in it for a month before she died. This can be attributed in part to her husband, who still actively takes part in the campaign through interviews and talks at different events, and also to the organization Compassion & Choices that keeps bringing up her story. But if her story had not gotten

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[1] *Collins Dictionary*, s.v. "Advocacy group."
[2] Compassion & Choices. "About Us."
[3] Compassion & Choices. "Our Accomplishments."
[4] Coombs Lee 2015.
[5] In addition to these eight states, Washington D.C. has also legalized assisted dying and bills have been introduced in several other states. According to Sofka (2017, 116), as many as twenty states considered assisted dying legislation in 2016.
[6] See for example Brown 2016; Stewart 2016; Mataconis 2018; Calfas 2018. See also the #IWantTheOptionCA videos on the CompassionChoices YouTube channel.

the visibility it first did when Maynard's video was released, it would not be relevant in the policy debate about assisted dying today.

Assisted dying is something that is currently under debate not only in the United States but in many other parts of the world as well. Medical and technical advances have made it possible to keep people alive for longer and longer, raising questions about quality of life and what constitutes a "good death". Although several Western countries have ongoing political discussions about euthanasia and assisted dying, it is still illegal in most jurisdictions.[7] Euthanasia is legal under certain specified conditions in a handful of countries in Europe and in Canada, and assisted dying is legal in parts of the United States, also under specific conditions.[8] In the United States, the question has been left to the state legislature, making for an interesting situation where assisted dying is either legal or illegal, depending on which state you live in. This makes the American campaign for legalization interesting to examine. Because there are already examples and data on how the legislation works in other states, the campaigns both for and against legalization can use these numbers and examples in their advocacy work. Assisted dying has been legal in Oregon for over 20 years, but the legalization in other states has been more recent. This has made Oregon a model for the legalization in other parts of the United States, and the two big advocacy organizations promoting legalization (Compassion & Choices and Death with Dignity) both operate out of Oregon. Because the advocacy organizations play an important part in forming the legislation in the matter of assisted dying, it is important to examine not only the legal language itself, but also the organizations and campaigns that have a role in making legislation happen. This thesis focuses on Maynard's story and on how it is being told and used in the campaign by the organization Compassion & Choices to legalize assisted dying in the United States.

1.1 Research questions

Compassion & Choices uses personal stories in their campaigns to connect with the public and to depoliticize the issue of assisted dying by making it personal.[9] When people identify with the personal stories, they are more likely to care about the policy issue. This makes stories a powerful tool in advocacy work, and Maynard's story is an exceptional example of how a personal story can make a policy issue visible and interesting to the media and the public, and through that to legislators. Advocacy organizations in the United States are central actors in policy-making, which

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[7] Johnstone 2013, 66.

[8] Euthanasia here refers to practice where the physician administers a substance to end the life of a patient and assisted dying refers to legalization that allows a physician to prescribe a substance that the patient self-administers. For example the Netherlands and Canada allow both euthanasia and assisted dying. Further distinctions and questions related to the language of medical aid in dying are discussed in chapter 2.1.

[9] CompassionChoices, January 2017 NY Volunteer Training, 1:28:00.

makes it important to study the means through which they try to influence policy. Using personal stories can be an effective way to get attention and make policy understandable. However, because the demands on supporting arguments with evidence or facts are different for personal stories than for many other ways of sharing information, stories can be misguiding and too much emphasis risks being put on personal experience.

As Maynard's is one of the most known stories related to right to die legislation in the United States, I am interested in the way Maynard presents herself, and is represented by her family, when her story is shared in the campaign videos. Because Maynard's campaign for assisted dying is strongly connected to her personal life, it is interesting to examine what kind of personal traits and parts of her life are brought into the campaign and how these elements are used to support the arguments for legalizing assisted dying.

The questions in focus here are: How are stories used by advocacy organizations such as Compassion & Choices to gain visibility and explain their point of view to the larger public? How do Maynard and her family tell the story about her life and death in the campaign? How does the way the story is told reflect the debate on assisted dying and the arguments used for legalizing assisted dying?

By examining these questions, I aim to answer the broader question about what advocacy organizations gain by sharing personal stories related to policy issues. The questions are examined through narrative analysis of Maynard's campaign videos with Compassion & Choices, and two videos where her husband Dan Diaz tells her story after her death. The content of the story shared in the videos is examined, but also how and in which context the story about Maynard's life and death is told.

1.2 Outline

To contextualize the issue of assisted dying in the United States and get a clearer picture of what Maynard's campaign with the organization Compassion & Choices is about, it is useful to start with a short overview of how the question has been addressed in the past. Chapter two starts with an introduction to the language and terms used in the debate. Language is not neutral, and especially when moral issues are being debated the terms preferred by different actors usually include some indication of their policy preferences. After the discussion about the language related to assisted dying, there is a short history of how the laws came to be, followed by a presentation of the Oregon act on assisted death. The chapter ends with a section on previous research on the subjects that are treated in this thesis. The next chapter gives the theoretical and methodological framework for this thesis. The chapter includes discussion about narrative analysis, how organizations use stories to help their cause, and about the communication strategies that are often used by organizations in the debate about euthanasia and assisted dying. The fourth chapter turns to the analysis that is the focus of this thesis, presenting the material and methods used. The following two chapters discuss the results. The first one of these chapters is focused on the portrayal of Brittany Maynard in videos that are part of her campaign and the second analysis chapter is about how different arguments and strategies are used in the material and how Maynard’s story is used to advance these arguments.

The aim of this thesis is to show how personal stories are used to support policy arguments in the campaign for assisted dying through what is told, and how it is told. The content of the stories frame the issue through both actual arguments and other communication strategies. The main arguments given by Maynard and her family are similar to arguments seen in other debates about assisted dying and euthanasia and mostly related to autonomy and avoiding unnecessary suffering. In this particular case, the original storyteller is no longer alive and it is interesting to see how little this affects the way the story is told. The same parts of the story are being told in a similar way both before and after Maynard’s death.

2. Background and context

This chapter introduces the issue of assisted dying in the United States, starting with a discussion about the terms used in the debate. Language is never neutral, and the debate about assisted dying also includes discussion and disagreement about which terms to use. There have been accusations about use of euphemisms and terms that are deliberately confusing on the one hand, and on the other hand, there is criticism that language is used to deliberately spread fear and misunderstanding about what is really going on.[10]

Advocacy organizations have been important in shaping the way legalization looks today in patients' rights at the end of life. The second part of this chapter is about the history of assisted dying in the United States, focusing on the most important actors and organizations as well as landmark court cases that are relevant to the issue, including the right to refuse treatment. After the historical overview on how the legalization related to assisted dying came about, it is also worth taking a closer look at the laws on assisted dying that currently exist in the United States. The laws in place in different states, as well as the new propositions that have been introduced, are very similar. They are based on the Death with Dignity Act that was passed in Oregon over ten years before assisted dying was made legal anywhere else in the United States and it is the model that is being advocated by the biggest organizations for assisted dying, including Compassion & Choices. The last part of this chapter is about previous research related to the thesis topic. I will shortly introduce and discuss research on assisted dying in the United States, the main arguments that are being used for and against legislation, the narrative turn in social sciences and how narratives are being examined in health an illness research as well as in research about social movements.

2.1 Assisted dying terms and concepts

There are quite a few different terms in use for medically assisted dying. Sometimes the use of different terms is meant to distinguish between different ways of assisting someone to die, but the choice of a certain term is also often a political one. As in many complex questions facing society, it is hard to come up with neutral language describing the phenomenon. According to Megan-Jane Johnstone, linguistic framing devices are used actively on both sides of the debate as a tactic to shape how the issue and concepts related to it are defined.[11]

A distinction is often made between *euthanasia* and (*physician-*)*assisted death* (also known as *assisted suicide*). Merriam-Webster defines euthanasia as the "act or practice of killing or permitting

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[10] See for example Saunders 2018; Brehl 2016; Harvey 2014; Compassion & Choices, "End-of-Life Care: Commonly Used Terms"; Death with Dignity, "Terminology."
[11] Johnstone 2013, 90–91.

the death of hopelessly sick or injured individuals (as persons or domestic animals) in a relatively painless way for reasons of mercy".[12] In the debate about legalizing euthanasia, it is often assumed that it would be performed by a doctor and as an active and intentional act, for example by injecting the patient with something that will kill him or her. Physician-assisted death is often distinguished from euthanasia as an act that is performed by the patient him/herself. The doctor prescribes the drugs, but does not otherwise take part in the act. Active euthanasia is also sometimes distinguished from *passive euthanasia*, which refers to stopping treatment (or never starting it in the first place). Refusing treatment is legal everywhere in the United States if it is the wish of the patient, but the term euthanasia is seldom used in this context and the practice is mostly left out of the debate on assisted dying. Refusing treatment can be for example removing, or deciding not to start, life support. Some might like to make a distinction between stopping treatment and never starting it in the first place, but mostly stopping treatment seems to be included under the term passive euthanasia even if it can be seen as an active act. Some would also make a distinction between stopping hydration and nutrition versus stopping other treatments, but the courts have not seen a legal difference in most cases.[13]

Physician-assisted death is often called (and perhaps better known as) physician-assisted suicide, but its proponents reject this term because of the word suicide. For example, Compassion & Choices on their webpage find that there is a clear difference between wanting to take your own life (e.g. not live anymore) and to want to choose how you die when you are already dying. They argue that the term suicide is inaccurate and used by opponents to scare people as well as "hurtful and offensive"[14] to patients and families. Physician-assisted suicide is still widely in use, for example by many journalists, and recommended by the Associated Press.[15] It is also the term used by the American Medical Association. The main advocacy organizations for assisted dying in the United States make it clear that they do not support euthanasia, which they define more narrowly than Merriam-Webster as the intentional killing of a patient by a physician, for example by administrating a lethal dose of medication.[16]

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[12] *Merriam-Webster*, s.v. "Euthanasia."

[13] Keown 2002, 4; Louhiala 2017; Kay 2006, 266.

[14] Compassion & Choices, "End-of-Life Care: Commonly Used Terms".

[15] See for example Associated Press, "Maine to again consider "death with dignity" bill"; Associated Press, "Murphy to sign bill allowing medically assisted suicide"; Tarinelli 2019. Assisted suicide is also the term used by the American Medical Association, see AMA Statements, "Physicians to continue examination of physician-assisted suicide."

[16] Death with Dignity, "Terminology"; Compassion & Choices, "End-of-Life Care: Commonly Used Terms". For further discussion of different terms, see for example Gilbert 2015; Butler 2015; Harvey 2014.

Some of the opponents to assisted dying legislation (and even some who support the practice) mean that avoiding the word suicide is just a way to euphemize what is really going on.[17] There has also been similar criticism toward vague terms like death with dignity, medical aid in dying, end of life choices or etc. Especially death with dignity is a contested term as dignity can mean very different things for different people. According to Johnstone, dignity is often presented as a core value by organizations supporting euthanasia and assisted dying legislation, but in reality it is used as more of a euphemism for assisted dying in for example the use of phrases such as dying with dignity. Montero points out that feelings and images of dignity are affected by both those surrounding the person who is dying and by society as a whole. Some of the proponents of legalization have reacted to the criticism around the use of the term dignity in this context and for example Compassion & Choices recommend that their volunteers do not use the phrase dying with dignity when talking about physician-assisted dying. This is discussed in a training video for volunteers in the New York campaign from 2017. It is explained in the video that although the movement has become known as the death-with-dignity movement they do not want to suggest that the only way to die a dignified death is through medical aid in dying so they recommend avoiding using the two as synonyms. Even though some organizations are moving toward calling it medical aid in dying, the phrase dying with dignity is still strongly associated with physician-assisted dying. The other big advocacy organization in this matter in the U.S. is called Death with Dignity, and the laws instated in Oregon and Washington are named Death with Dignity. The newer laws have names that do not mention dignity, without that necessarily meaning that their names are any clearer in stating what the law is about. The laws that have been introduced in different states have the following names: the *Death with Dignity Act* in Oregon, Washington and Washington D.C., the *Patient Choice and Control at End of Life Act* in Vermont, the *End of Life Option Act* in California and *End of Life Options Act* in Colorado, the *Our Care, Our Choice Act* in Hawaii and finally, the *Aid in Dying for the Terminally Ill Act* in New Jersey. This might be a result of the fact that the laws have been developed in cooperation with the advocacy organizations, as the two big ones Death with Dignity and Compassion & Choices use very similar language, underlining patient options, choices and control at the end of life.[18]

Hillyard and Dombrink suggest that changes in the language related to assisted dying has been a way to resolve cultural and ethical conflict in medicine and redefine how issues are understood. The term *mercy killing* is no longer used, because the act of killing does not fit into the cultural and social role

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[17] See for example Saunders 2018; Harvey 2014.

[18] Johnstone 2013, 131; Montero 2004, 169; CompassionChoices, January 2017 NY Volunteer Training, 46:10.

of physicians. Euthanasia is problematic because it brings to mind the mass murders of Nazi Germany. Changing the language has been a way to legitimate practices.[19]

One last term that I want to mention here is the right to die. Right to die is the concept that humans have the right to end their own life if they are suffering from a terminal illness, or in some cases, simply because they no longer wish to live. Assisted dying proponents are often referred to as right-to-die organizations or the right-to-die movement. Opponents on the other hand are, like in the case of abortion, often called the right-to-life movement. The term right to die is widely used and can refer to different practices. For example, the earlier court cases about the right to refuse treatment are often referred to as right-to-die cases, although the Supreme Court has not seen a constitutional right to die and the cases have been decided on other matters.

In this thesis, I use the term (physician-)assisted death or dying, which is, in my opinion, the most descriptive and neutral term that I have come across. By assisted dying, I refer to the practice as it exists in the United States. There are slight differences in the laws between different states, but the differences are small enough that I think they can be treated as the same law for the purposes of this analysis, which is not focused on the technical aspects of the laws. All the laws are based on the Oregon law that will be discussed later in this chapter. Before discussing the particulars of the legislation in place in Oregon, it makes sense to shortly introduce the history of assisted dying in the United States. The organizations and court cases that are discussed next have been central in forming what assisted dying laws in the U.S. look like today.

2.2 A short history of assisted dying in the U.S.

Assisting someone to die for compassionate reasons is something about which almost every state in the United States has their own laws. Aiding someone to die is illegal in many states, but it varies how much the law is enforced. Richard Kay estimates that there might be hundreds or thousands of cases every year where a physician helps a patient die through assisted death or active euthanasia.[20] Kay suggests that when all parties involved are agreed, cases are unlikely to come to the attention of law enforcement and even when they do, there has not been an eagerness to prosecute. In cases that have made it to trial, juries have been understanding and if there has been a conviction the sentences have not been harsh.[21] To better understand the practice of assisted dying in the U.S., it might be useful to take a look at the history leading up to the situation today, where several states have recently legalized physician-assisted dying or seem to be in the process of doing so.

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[19] Hillyard and Dombrink 2001, 7.

[20] This was written when the practice of assisted dying was still only legal in Oregon.

[21] Kay 2006, 258.

Suicide was long illegal in the United States, and although punishing people who succeeded in taking their own life (e.g. by burying them at a crossroad with a stake through their body and confiscating their personal property) was largely abandoned by the end of the 18th century, attempting suicide remained punishable into the 20th century in at least some states. As suicide and its attempt became de-criminalized, because of objections relating to mental health issues as well as the fact that if the offender succeeded he or she was already dead, assisting someone to commit suicide was no longer covered under laws about aiding and abetting crimes. Many states made separate laws making assisting suicide a crime, putting it in a different class than homicide and often with lighter punishments, although courts have generally made a difference between actively participating in the suicide and helping someone do it on their own.[22]

The first propositions in the United States for making euthanasia legal under some specific circumstances were drafted in 1906 in Iowa and in Ohio, but neither bill passed. In 1938, the Euthanasia Society of America was founded and support was growing, but when World War II ended and information about the Nazi euthanasia programs came to light, support for the issue dwindled quickly and advocacy campaigns in the United States came to focus on the right to refuse care or request the withdrawal of treatment instead.[23]

In the 1950s and 1960s, medical and technological advances made it possible to keep people alive for much longer periods of time, even in situations where they were terminally ill or in a vegetative state. The death process changed as people started dying in hospitals instead of at home to a larger extent than before. Ethical, economic, social and legal questions connected to the development of what Hillyard and Dombrink call *institutionalized dying* gave birth to influential social movements in patients' rights and medical politics in the 1960s and 1970s. In 1967, the first *living will* was developed by the Euthanasia Society of America. It was a legally binding document you could make in advance to influence the choices made at the end of your life. The debate had shifted from euthanasia toward advance directives and the right to refuse treatment, and in 1974 the Euthanasia Society of America changed its name to the Society for the Right to Die.[24]

Since then, the right-to-die organizations in the United States have gone through many name changes and mergers. The Society for the Right to Die changed its name again in 1991 to Choice in Dying. During the early years of the 21st century it changed names and merged with other

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[22] Kay 2006, 258−260.

[23] Ferguson 2007, 12−13; Scherer and Simon 1999, 27−28. In these euthanasia programs, mentally and physically disabled people were killed using gas, lethal medication and starvation, and the practice was at least partly rationalized through medical arguments. For more on the euthanasia programs in Germany during the National Socialist regime, see for example Burleigh 1994.

[24] Scherer and Simon 1999, 28; Hillyard and Dombrink 2001, 5−9; Ferguson 2007, 14.

organizations until it was dissolved in 2004 making the remaining organizations on the West coast and Portland, Oregon the center of the national campaign for assisted dying. In 1980 the Hemlock Society was founded in California and became an influential actor in many state campaigns for legalizing assisted dying. It later relocated to Oregon and in 2003 it changed its name to End-of-Life Choices. In 1993 Compassion in Dying was founded in Washington to advocate for assisted dying there. The two organizations merged in 2004 into Compassion & Choices, which is now one of the most influential advocacy organizations concerned with this issue. The other large organization Death with Dignity supports the same kind of Oregon model assisted dying as Compassion & Choices, but at least according to their own webpage they do this in a more behind-the-scenes way that is more focused on lobbying than drawing attention to their organization. Death with Dignity has its origins in the political action committee that successfully campaigned to get the Oregon Death with Dignity Act passed in 1994.[25]

These name changes and mergers are interesting for a couple of different reasons. There is a trend in the name changes to emphasize words like choice and dignity. Johnstone notes similar name changes in both pro-life and right-to-die organizations in Australia to underline the key messages and signature terms of the organizations. These name changes are connected to presenting the organizations’ message in a certain way and also to contrast their message from other advocacy groups. An example is Compassion & Choices, which is not the only “descendant” of the Hemlock Society. In 2003, as the Hemlock Society changed its name to End-of-Life Choices (which would later through mergers become Compassion & Choices) some of its advocates founded a new organization called the Final Exit Network. This organization does not promote the Oregon model of restricting assisted dying to the terminally ill with less than six months left to live, but advocates for a more broad right to end one’s life for people who are suffering from “intolerable medical circumstances”. Their main focus is also not on changing legislation, but instead to support “those who are suffering *now*”. In contrast, Compassion & Choices makes it clear that they do support the Oregon model, policy work, and cooperation with hospice care facilities, as does Death with Dignity. The merging of organizations has also led to Portland, Oregon and the Oregon type of legislation becoming central in the national campaign for assisted dying as both Compassion & Choices and Death with Dignity have their headquarters in Portland. In addition to these two big organizations, there are a number of smaller ones all over the United States.[26]

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[25] Death with Dignity. “History”; Compassion & Choices, “Washington”; Death with Dignity, “About Us”; American Life League, “Euthanasia History”; Patients Rights Council, “Assisted Suicide & Death with Dignity: Past, Present & Future – Part I”; Death with Dignity, “History”.

[26] Johnstone 2013, 128−131, 134; Final Exit Network, “History of Final Exit Network”; Final Exit Network, “Our Exit Guides - a compassionate presence”.

As technology could keep people breathing and nourished under more and more extreme circumstances, the line between life and death became more fluid and the need arose to construct new legal and medical criteria related to determining when someone is considered dead. In addition to these legal criteria of death, patients and advocacy groups brought attention to the issue of quality of life. In the later decades of the 20th century there were several landmark court decisions related to patients' right to die or to refuse or stop treatment. *In re Quinlan* (1976)[27] was a landmark case in the New Jersey Supreme Court, about a young woman named Karen Ann Quinlan, who had fallen into a coma after incidents at a party. After she was declared to be in a persistent vegetative state, her family wanted to have her ventilator removed, but the hospital refused for reasons of fear of prosecution. The case was brought to court and the lawyers tried several arguments including free exercise of religion, cruel and unusual punishment and Quinlan's right to privacy. The case made it to the New Jersey Supreme Court, which granted the right to remove the ventilator and ruled that state intervention violated Quinlan's right to privacy. Quinlan still continued breathing on her own and died ten years later but the decision influenced other cases, and privacy is still very much at the center of the discussion. *In re Quinlan* only went as far as the state court, but the decision still had an influence on legislation in the late 1970s and 1980s as several states passed laws or decided in courts about advance directives, proxy decision-making, and the right of the patient to refuse treatment as well as nutrition and hydration.[28] The case also gained a lot of media attention and made the issue known to the public, much like Maynard's story did almost forty years later with assisted dying. The Quinlan case and other cases made the right-to-die movement and its objectives known and the movement gathered a great deal of public support in the 1980s and 1990s.[29]

In 1990, a case[30] made it as far as to the U.S. Supreme Court. Nancy Cruzan had been in a car accident 1983 and when it was clear she would not wake up, her parents wanted to withdraw life supporting nutrition, but according to Missouri law they needed a court order. It was granted, but the state appealed and the state supreme court decided that there was no "clear and convincing evidence" that Cruzan would have wanted the feeding tube removed. The U.S. Supreme Court

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[27] *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (NJ 1976).

[28] Cases that clarified the opinion of the courts on the right to refuse treatment or nutrition and hydration include: *Bouvia v. Superior Court*, 179 Cal.App.3d 1127, 1138-39 (1986) where the court held that competent adults have the right to refuse any kind of treatment, including feeding through tubes even if not terminally ill, as well as several cases about the rights of incompetent patients to refuse treatment and how decisions can be made for them: *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (1977); *In re Storar* 420 N.E.2d 64 (1981); *In re Eichner* 420 N.E.2d 64 (1981); *In re Conroy*, 486 A.2d 1209 (1985); *Brophy v. New England Sinai Hospital, Inc.* 398 Mass. 417 (1986); *In re Jobes*, 529 A.2d 434 (1987). For more on these cases and the right to refuse treatment, see for example Liang and Lin 2005; Lynn 1989; Flynn 1990, chapter 2; Makdisi 1990; Paola, Walker and Nixon 2010, 324.

[29] Hillyard and Dombrink 2001, 6−13; Ferguson 2007, 15−16; Scherer and Simon 1999, 28.

[30] *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990).

decided to hear the case and, in a 5−4 decision, ruled that a state has the right to decide which criteria must be met for there to be "clear and convincing evidence" that an incompetent person would want to stop lifesaving treatment, but it was not a united court and five different opinions were written. As the first right-to-die case in the Supreme Court, the Cruzan case set important precedent for cases to come: The Supreme Court did not recognize a constitutional right to die, but they did recognize the right to refuse treatment (also for incompetent persons) if it had been clearly stated when the person was competent. The court ruled that informed consent trumped the right to privacy. It clarified the rules around the rights of incompetent persons and their families. And finally, it did not set federal rules for the right to die, but decided to leave the question up to the states.[31]

Following the Cruzan decision, Congress passed the Patient Self-Determination Act[32] in 1990, which was the first legislation at the federal level about living wills and refusal of treatment. The act requires health care providers to inform patients of their choices and rights regarding health care directives made in advance. The Cruzan decision and Patient Self-Determination Act established the right to refuse treatment in all of the United States in cases when it can be clearly proven that it is the will of a competent adult person, even if this might shorten his or her life. Problems arise mainly in cases where it is unclear what the patient would have wanted, for example when the patient is in a vegetative state.[33]

The right-to-die movement had gained a lot of supporters, and in 1991 and 1992, first Washington and then California voted on ballot initiatives about medically assisted death for terminally ill patients. Both initiatives were rejected with around 53−54% no-votes, but were central in gaining visibility for the national campaign. The Washington initiative, Initiative 119, got more than half of its financing from outside the state. The Hemlock Society was a top contributor, with many of its members and local chapters donating to the campaign in Washington, making it the state initiative with the most fundraising since 1975 when information about the financing of initiatives had started being collected. Advocacy organizations continue to be central contributors in the campaigns for legalization through financing as well as through their events, information campaigns and lobbying. The latest assisted dying law to be approved through a citizen ballot campaign was 2016 in Colorado

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[31] Ferguson 2007, 16−18.

[32] Patient Self-Determination Act, 42 U.S.C. § 1395 et seq. (1990).

[33] Kay 2006, 262.

and the campaign was supported by Compassion & Choices with more than 650 000 dollars in donations and non-monetary support.[34]

In 1994, Oregon became the first state to approve assisted dying through a ballot vote with 51 % support. The Death with Dignity Act was challenged in courts and did not come into affect straight away. In 1997, there was another ballot vote about rejecting the act, but it failed to pass (this time the vote was 60−40 %) and physician-assisted death became legal in Oregon in 1997. The Oregon act has served as a model for assisted dying acts in other states.[35]

Meanwhile, the question of a right to die kept coming back to the courts. In 1997, the Supreme Court decided on two cases *Washington v. Glucksberg* and *Vacco v. Quill*[36] that challenged the laws forbidding physician-assisted dying in Washington and New York. The Supreme Court did not recognize a right to die as constitutional and state bans were not overturned. However, that same year the Supreme Court refused to hear a case, *Lee v. Oregon*[37], which was a challenge to the Oregon Death with Dignity Act from a lower court that had been overturned by the Court of Appeals. Because the Supreme Court did not hear the case, the Oregon act that had passed in 1994 was instated. The decisions in these three cases were signaling that the court would leave this question for the states to decide. One case that is not important because of precedence but because it gained a significant amount of attention for the right to die movement as well as for opposing views, is the case of Terri Schiavo. Schiavo had fallen into a coma after her heart stopped in 1990 and was in a persistent vegetative state. In 1998, her husband requested that her feeding tube would be removed but her parents opposed. Because the wishes of Schiavo were unclear, a lengthy court battle followed, during which the feeding tube was removed and put back several times and organizations, activists and even Congress and President George W. Bush as well as the Vatican got involved before the final decision to remove the feeding tube in 2005. President Bush opposed assisted dying and also tried to block the Oregon Death with Dignity Act. In 2006, the Supreme Court heard the case *Gonzales v. Oregon*[38] where the Bush administration tried to use federal drug law, the Controlled Substances Act, to prosecute doctors who had prescribed drugs for medically assisted dying according to the Oregon law. The Supreme Court decided that the Attorney General of the United States is not given the right by to the federal drug law made by Congress to overrule state law on how to use medications. The decision confirmed the intent of the court to let the states decide. Since

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[34] Hillyard and Dombrink 2001, 34; Colorado Campaign Finance Disclosure Website, search word "Compassion & Choices". The whole budget for the campaign was over 5 million dollars. For more information on the financing of the campaign, see Yes on Colorado End of Life Options financial summary.

[35] Oregon Health Authority, "Death with Dignity Act History."

[36] *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793 (1997).

[37] *Lee v. State of Oregon*, 107 F.3d 1382 (1997).

[38] *Gonzales v. Oregon*, 546 U.S. 243 (2006).

then, seven other states as well as Washington D.C. have legalized assisted dying through ballot initiatives (Washington 2008, Colorado 2016) or decisions by legislators (Vermont 2013, California 2015, Washington D.C. 2015/2017, Hawaii 2018, New Jersey 2019), and in the case of Montana in court (*Baxter v. Montana*[39], 2009).[40]

2.3 The Oregon model

The key role of advocacy organizations, such as Compassion & Choices and its partners, in consulting on safeguards and restrictions as well as legal language has made the laws in different states very similar to the one in Oregon. This is the case for all the other states listed at the end of the previous chapter that have assisted dying laws, but not for Montana where assisted dying is legal because of a court ruling that only stated that state law does not prohibit the practice. Proposed legislation to make the rules clear has not gained enough support to pass in Montana. The rest of the 52 states prohibit assisted dying through state law or common law, or have an unclear situation due to lack of legislation on the issue, but there are ongoing campaigns in many states to introduce legislation. Since the Oregon model for assisted dying legislation is so dominant, it makes sense to look a bit more closely at what the act entails and at some statistics on how it is used in practice. This is also the legal and practical framework within which Maynard took part in assisted dying and what she and her family advocated for in other states.

The Oregon Death with Dignity Act states that an adult, who is a resident of Oregon and has been given a diagnosis of a terminal disease (from which it is estimated that the patient would die within six months) can request medication to end his or her life. The law includes safeguards and restrictions: the diagnosis must be confirmed by a second physician, and the patient might need to undergo counseling to determine that he or she is capable and not suffering from a psychiatric or psychological disorder or depression that would affect his or her judgment. The physician also has to tell the patient all the facts about the diagnosis and alternative ways to manage the dying process.[41]

It is also separately stated that old age or disability cannot by themselves meet the criteria for illness to qualify for assisted dying. The request needs to be made in writing, through a certain form, and witnessed by two people, one of whom cannot be related to the patient or might otherwise benefit from his or her death in any way. The physician is supposed to make sure that the law is followed by the patient before prescribing the drugs and there are time limits and waiting periods between the different steps in the procedures. The different steps need to be documented and the cases reported

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[39] *Baxter v. Montana*, 354 Mont. 234 (2009).

[40] CBS, ”A look back: The Terri Schiavo case”; Lagorio 2004.

[41] *Oregon Death with Dignity Act* Or. Rev. Stat. § 127.800 et seq.; Oregon Health Authority, “Death with Dignity Act Requirements.”

to the state, which produces an annual statistical report. Wills, insurance policies or any other contracts cannot include language that would affect the patient’s decision.[42]

The Oregon Death with Dignity Act does not, in contrast to the acts in many of the other states, state how the cause of death should be written on the death certificate, but apparently, they follow the same practice as in the other states, where the underlying cause of death is stated on the death certificate. The act includes clauses of protection for physicians and people present at the time of death, as well as penalties if the rules are not followed. One interesting aspect in relation to the chapter on language, is that the act specifically states that the act shall not be interpreted as making assisted suicide legal, but it does not define what is meant by assisted suicide. It might refer to other types of assistance that do not follow the rules set out in the act. The act is mainly about the responsibilities and rights of physicians, not really focused on the right to die, but the right to assist, even though there are also clauses about relatives and insurance companies. The campaigning for these laws on the other hand is much more focused on patient rights than about protecting the legal rights of physicians.[43]

The Death with Dignity Act has been in place in Oregon for more than 20 years and statistics about its use have been collected since the beginning. Some of these statistics are presented in table 2.1, which is based on the yearly report from 2017 about the Oregon Death with Dignity Act. A similar report is published every year by the Oregon Health Authority. The table includes data from 20 years on who has died by taking advantage of the Oregon Death with Dignity Act. This table only includes data on the patients who died through ingesting assisted dying medication. Prescriptions that were not used by the patient are not included here, but will be discussed later in this chapter. The table includes some data on demographics as well as data on the underlying illness of the patients and the situation in which they died. The total number of patients who died over the 20 year period is 1 275.

The division between sexes among the patients who died is around half male and half female, with slightly more men dying from the medication. Statistics on how the sexes were divided between people asking for and getting the prescription is not available. The people who died from the medication were mostly elderly. More than 70 percent were over 65 years old. Less than 3 percent were 44 years old or younger. The median age of the people who died over the 20 year period was 72 years old (with an age range of 25−102).

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[42] *Oregon Death with Dignity Act* Or. Rev. Stat. § 127.800 et seq.

[43] *Oregon Death with Dignity Act* Or. Rev. Stat. § 127.800 et seq.

Table 2.1 Oregon Death with Dignity Characteristics, 1998–2017

Characteristics of Oregon DWDA deaths*	1998–2017 Total (N=1 275)	1998–2017 Percentage
Sex		
Female	607	47.6 %
Male	668	52.4 %
Age		
18–44 years	35	2.7 %
45–64 years	321	25.2 %
65–84 years	723	56.7 %
85+ years	196	15.4 %
Race**		
White	1 223	96.3 %
Asian	19	1.5 %
Hispanic	15	1.2 %
Other or unknown	18	–
HEALTHCARE AND ILLNESS		
Hospice care**		
Enrolled in hospice care	1 119	90.2 %
Not enrolled in hospice	122	9.8 %
Unknown	34	–
Underlying illness		
Cancer	993	77.9 %
Neurological diseases (most commonly ALS)	134	10.5 %
Respiratory diseases	61	4.8 %
Heart/circulatory diseases	49	3.8 %
Other illnesses	38	3.0 %
Patient died at**		
Home (of patient, family or friend)	1 181	93.1 %
Long term care, assisted living or foster care facility	68	5.4 %
Hospital	4	0.3 %
Other or unknown	22	–

*adapted from Table 1 in the Annual Statistical report about the Oregon Death with Dignity Act for 2017[44]
** “unknown” cases were excluded when counting the percentages in the original table, and because the categories other and unknown were combined here, the percentages do not add up to 100.

The patients who died within the program were overwhelmingly white (more than 96 %). The only other racial or ethnic groups that represented more than 1 percent of the people who died were Asians and Hispanics, both representing fewer than 2 percent. Only one African American person died in accordance with the Death with Dignity Act over the whole 20 year period. Compared with the demographics of the state, 76.4 percent of the population in Oregon is white, 12.8 percent Hispanic, 4.7 percent Asian or Pacific Islander and 1.9 percent African American according to the

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[44] Oregon Health Authority, Public Health Division, Center for Health Statistics 2018, 8–11.

2016 census. Other states have had assisted dying laws in place for a shorter period of time, which means that there is not yet data available for more than a few years, but the statistics in for example Washington and California seem to point in a similar direction. Well over 90 percent of the people who died assisted deaths in Washington were white in the last three reported years 2015−2017 and almost 90 percent in California in 2017. The percentage seems especially high in California, where non-Hispanic whites make up only 37.2 percent of the population according to the U.S. Census Bureau. The law has been in place in California only a few years, so it might yet be early to draw very far-reaching conclusions, but there might also be barriers in access to assisted dying that favor some groups over others. Buchbinder has found, in her study of assisted dying in Vermont, that there are barriers in access to assisted dying that have to do with access to physicians, the cost of the medication and access to information. Similar patterns have also been found in research about the use of hospice care among ethnic and racial minority groups.[45]

Some other characteristics of the patients that was not included in this table, but are still worth mentioning here, is that a majority (46.5 %) were married, but many were also divorced (23.9 %) or widowed (22.4 %). Most were highly educated, with over 90 percent having graduated high school, over 70 percent having attended some college and over 45 percent having completed a Bachelor's degree or higher. This supports Buchbinder's assessment that assisted dying might be more accessible to patients of a higher socioeconomic level.[46]

A majority (90 %) of the patients were enrolled in hospice care at the end of life. Cancer was the most common illness for which people sought assistance in dying (over 77 %). The safeguards in the act make the program accessible especially for patients with aggressive cancers where the diagnosis is often less than six months to live. Many other diseases kill more slowly and less predictably, or affect the competence of the patient, so that the patients do not qualify for assisted dying according to the Oregon act. The second most common illness after various forms of cancer was neurological diseases, in this case mostly ALS. Few of the patients were referred to psychic evaluation (only 4.9 %) but this is the statistic of those who died and therefore only includes those who were approved for Death with Dignity so this figure might be misleading. More than 90 percent of the patients reported having informed their family of their decision. The majority died at home (more than 90 %), some in care facilities and only a few in a hospital.

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[45] Office of Economic Analysis 2017; Washington State Department of Health 2018; California Department of Public Health 2018; United States Census, California, Table "Race and Hispanic Origin"; Buchbinder 2018a. For ethnic and minority differences in hospice usage see for example Cicolello and Anandarajah 2017; Noh and Schroepfer 2014; Connor et al. 2008.

[46] Buchbinder 2018a.

Table 2.2 presents the number of people who received a prescription for assisted dying in the 20 years that the Oregon Death with Dignity Act has been in use. The table includes the number of people who got a prescription and the number of people who died from the medication each year. Roughly two thirds of the amount of people who got a prescription died from taking medications prescribed according to the Death with Dignity Act. Although the total number of patients who are given a prescription for a substance to end their life has increased, the percentage of patients who end up taking the medication has stayed roughly the same.[47] The table also includes the percentage of Death with Dignity deaths of all the people who died in Oregon that year, and for comparison, the percentages of deaths by homicide and suicide.

Table 2.2 Oregon Death with Dignity prescriptions and deaths 1998–2017

Year	Prescription recipients*	DWDA Deaths*	Percentage DWDA deaths**	Percentage homicide deaths **	Percentage suicide deaths**
1998	24	16	0.05 %	0.45 %	1.86 %
1999	33	27	0.09 %	0.37 %	1.70 %
2000	39	27	0.09 %	0.29 %	1.67 %
2001	44	21	0.07 %	0.34 %	1.70 %
2002	58	38	0.12 %	0.34 %	1.66 %
2003	68	42	0.14 %	0.30 %	1.91 %
2004	60	37	0.12 %	0.37 %	1.84 %
2005	65	38	0.12 %	0.33 %	1.81 %
2006	65	46	0.15 %	0.35 %	1.83 %
2007	85	49	0.16 %	0.25 %	1.92 %
2008	88	60	0.19 %	0.31 %	1.81 %
2009	95	59	0.19 %	0.32 %	2.03 %
2010	97	65	0.20 %	0.36 %	2.15 %
2011	114	71	0.22 %	0.33 %	1.95 %
2012	116	85	0.26 %	0.34 %	2.21 %
2013	121	73	0.22 %	0.27 %	2.05 %
2014	155	105	0.31 %	0.29 %	2.29 %
2015	218	135	0.37 %	0.39 %	2.13 %
2016	204	138	0.39 %	0.36 %	2.15 %
2017	218	143	0.39 %	0.35 %	2.25 %

*Numbers according to Table 2 in the Annual Statistical report about the Oregon DWDA for 2017.[48]
** Based on the statistics in Table 2 in the DWDA report and the yearly reports about manner of death for the people who died in Oregon.[49]

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[47] The relation varies between years, but for the yearly numbers it has to be taken into account that some people who died that year got the medication prescribed in previous years and some who got the prescription take it in another year. It is also worth pointing out that the numbers are small enough, especially for the first years, that the decisions of individuals have a lot of influence on the numbers.

[48] Oregon Health Authority, "Oregon Death with Dignity Act: 2017 Data Summary" 2018, 12.

[49] Oregon Health Authority, "Oregon Death with Dignity Act: 2017 Data Summary" 2018, 12; Oregon Death Data, Manner of Death by County of Residence, yearly tables for the years 1998–2017.

A little less than 0.4 percent of all deaths in Oregon in 2017 were caused by the ingestion of substances prescribed in accordance with the Death with Dignity Act. There has been a slight rise in the percentage of assisted deaths since the first years since the act was passed. As the practice has become more known, more people have some knowledge about the act when they find themselves in a situation where they have the choice of using it, and the better it is known there is probably a larger amount of people willing to use it. The percentage of total assisted deaths is now at about the same level as the percentage of homicides in Oregon. The suicide rate is higher that the percentage of DWDA deaths and has been rising as well. Some opponents to assisted dying claim that the rise in suicides is caused by the fact that the Death with Dignity Act normalizes suicide, while proponents point to other factors to explain the rise in suicides.[50]

In Oregon, patients taking part in the Death with Dignity program are asked about what concerns they have related to the end of life. The three most common concerns both in 2017 and over the 20 year period were losing autonomy (90.9 % over the 20 year period), being less able to engage in activities making life enjoyable (89.5 %) and loss of dignity (75.7 %)[51]. Other concerns included in the questionnaire are losing control over bodily functions (45.7 %) and being a burden on family, friends or caregivers (43.7 %). Less common concerns were concerns about inadequate pain control (25.8 %) and the financial implications of treatment (3.7 %).[52]

The reasons patients request aid in dying has also been investigated in a couple of studies. Ganzini et al. asked nurses and social workers who work in hospice in Oregon in 2001 about their experiences with patients that request assisted dying.[53] According to both the nurses and the social workers, the most important reasons for patients who requested assisted dying were about controlling the circumstances of death and the desire to die at home. Depression, lack of support or fear of being a burden were not seen as important reasons. Although pain, and fear of pain, was seen as an important reason for the requests, the nurses in general did not think that the patients who requested assisted dying were in more pain than patients who did not. A survey sent to patients gave similar results. Ganzini, Goy and Dobscha did a study where they interviewed people in Oregon that had either requested physician assistance in dying or were contemplating to do so, about their reasons for being interested in assisted dying. They found that the most common reasons were loss of independence, wanting to control the time and manner of death and die at home, and the

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[50] See Ingraham 2018. Some explanations listed in this article that examines the rising suicide rates at the national level are access to firearms, high rates of drinking and drug abuse, economic factors and a culture of self-reliance.

[51] Loss of dignity was added as a question in 2003.

[52] Oregon Health Authority, "Oregon Death with Dignity Act: 2017 Data Summary" 2018, 10.

[53] Ganzini et al. 2002.

prospect of worsening pain or quality of life and the inability to care for themselves. The researchers found that the current situation of the participants did not affect their reasoning to an equal extent as worries about future suffering.[54] These results show that the reasons that patients consider assisted dying is not so much about inadequate pain managing or absolute pain, but instead about the meaning of pain and its effects on the sense of self. Autonomy and fear of future suffering are themes that are very present in both studies as well as in the Oregon statistics.

Assisted dying is still quite new in the United States, and although it has been legal in Oregon a while longer than in other states, more research is still needed on how the law works in practice and how it is perceived by the public. This thesis focuses on the role of organizations and how they get their message across through personal stories. The last part of this chapter presents previous research that is relevant to the thesis topic.

2.4 Previous research

There has been a lot of research on assisted dying and euthanasia, and a great part of it focuses on the moral issues and arguments related to assisted death and on the legal implications of specific legislation.[55] According to Megan-Jane Johnstone, most of the literature on euthanasia and assisted dying is principally focused on "making a case" for legalization or on challenging opposing views.[56] Although I think Johnstone in this statement overlooks the literature arguing against legalization, which is also significant, I share Johnstone's view that more attention should be devoted to the interest groups and social movements involved in forming public opinion and influencing political action in this issue. If Johnstone is accurate in her claims that most of the literature concerned with euthanasia and assisted dying has political motivations, there is also a great need for more research on the topic done by researchers who do not have a political agenda.[57]

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[54] Ganzini, Goy and Dobscha 2009. Contemplating assisted dying in this case means that the participants had contacted the organization Compassion & Choices to get information about assisted. The researchers also collaborated with ethics consultants and specialists at medical centers to get participants for their study that had formally requested physician assisted dying.

[55] See for example Dworkin, Frey and Bok 1998; Keown (ed.) 1995; Keown 2002; Ferguson 2007; Smith 2012; Ars and Montero (eds.) 2004; Rachels 1986. Some works take a comparative view of different legislations; see for example Groenhuijsen and van Laanen (eds.) 2006, while others such as Johnstone 2013 focus on examining the questions within a specific legal framework. Several of the works mentioned here include at least some level of comparison between the systems in the Netherlands and Oregon, which have perhaps become the two most known models for assisted dying.

[56] Johnstone 2013, 78.

[57] In the field of bioethics, prominent opponents of assisted dying are for example John Keown and Margaret Somerville, who have both been discussing questions related to euthanasia and assisted dying for decades. See for example Keown 1995 (ed.); 2002; Somerville 1993; 2013; 2014. Important proponents include legal philosophers Ronald Dworkin and Gerald Dworkin. See for example Dworkin, R. 1993; Dworkin, Frey and Bok 1998; Dworkin, G. 2009.

In the United States, physician-assisted dying is still new, and the research has been focused on legal language and its implications. Recently, as the issue has gotten more attention, there has been more research devoted to public opinion, and the opinions of medical professionals and other actors involved. Most of the articles so far have been published in either medical or law journals, but the issue is gaining more attention in social science as well. Mara Buchbinder is a medical anthropologist, who in recent years has written a couple of articles on assisted dying laws and access, saying that the existence of such laws does not make them equally accessible to all people in the states that have legalized medical aid in dying. She has also in earlier works dealt with similar questions in regard to abortion. A couple of her articles are particularly relevant here. Buchbinder is working on a project studying the Patient Choice and Control at End of Life Act in Vermont. Within this project she has together with three other researchers interviewed people close to those requesting assisted dying, with a focus on the death experience. In other articles she discusses the duty of physicians to inform their patients about assisted dying, access and barriers that restrict access to assisted dying, and how the law in Vermont enables and restricts patient control. This is very interesting because control over the death process is one of the arguments frequently used for instating assisted dying laws and one of the motivations most used by patients as a reason for wanting assisted dying.[58]

The visibility and impact of Maynard's story in the campaign for assisted dying are sometimes mentioned in articles about assisted dying legislation, but her campaign, or the role of the interest organizations involved, have not been the main focus of the academic debate despite their central position in the media debate. Carla Sofka includes Maynard's story in an article on digital survivor advocacy, where Dan Diaz' campaign after Maynard's death is one of the cases studied. Her results, however, are presented in general terms, and she does not in her article explicitly discuss Diaz' advocacy involvement. Sofka observes that getting involved with a cause, such as campaigning for assisted dying legalization, can help victims and survivors find meaning in difficult situations.[59] This can be applied to both Maynard's reasons for getting involved and her husband's choice to continue campaigning with Compassion & Choices after her death. Strate and Zalman discuss lobbying and interests in relation to assisted dying in Michigan after the well-publicized court cases against Dr. Jack Kevorkian, a retired doctor who assisted in more than 120 suicides. Their study is relevant here, mostly because of their discussion on lobbying on morality issues, but since their research is focused on lobbying legislators and not connected to any type of referendum, their case study is quite different from this one. It is, however, worth mentioning that the groups that were particularly active in Strate and Zalman's study are the same and/or similar ones to the ones involved in the issue today

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[58] Buchbinder et al. 2018; Buchbinder 2017; Buchbinder 2018a; Buchbinder 2018b.

[59] Sofka 2017.

more than 20 years later.[60] Tatum also writes about advocacy organizations in the criminal trial of Dr. Kevorkian. He takes a narrative perspective to examine how the assisted dying movement used stories in the trial to persuade the judge and jury.[61] Tatum's research shows that organizations like Compassion & Choices have used stories for a long time to further their cause and in that way Maynard's story is not unique. On the other hand, the attention Maynard's story got was immense, which is interesting as the story in itself is similar to numbers of other stories related to the same issue. This makes it important to examine the communication strategies employed by Maynard and Compassion & Choices to spread her story, which is the aim of this thesis.

Megan-Jane Johnstone's book on the media representations connecting euthanasia and Alzheimer's disease is worth mentioning here. This is one of the few works related to this issue that includes a larger scale analysis of how media and public opinion are used in the debate and what kind of communication strategies are used by the advocacy organizations to promote their viewpoints and keep the issue on the agenda.[62] Johnstone is from Australia and her book focuses mostly on the debate there and to some extent in Europe. In the assisted dying discussion in the United States, Alzheimer's disease is not that much in focus, because of the restrictions in the laws. Patients with Alzheimer's disease do not qualify for medical aid in dying because of the less than six months to live and competence safeguards. The big organizations promoting the Oregon model largely control the agenda and they do not support widening the laws, because they promote patient control. Alzheimer's disease is sometimes mentioned in arguments by opponents to legalization, who fear that legalizing assisted dying could escalate into killing the old and disabled. That the debate looks so different in different countries is a result of the fact that the legal language and practices related to existing and proposed legislation affect the debate. This also underlines that this is hardly a simple question of supporting or opposing legalization. Johnstone discusses several themes that are also relevant to the debate in the United States. These include the arguments and communication strategies used by the organizations and how stories are used in the campaigns. Some of the more common arguments in the assisted dying debate will be presented next and the political use of stories and the communication strategies of advocacy organizations will be discussed in the next chapter.[63]

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[60] The three most active groups in Strate and Zalman's study were the Hemlock Society (now called Compassion & Choices), the Michigan State Medical Society and the anti-abortion group Right to Life. Strate and Zalman 2003, 331–334.

[61] Tatum 2002.

[62] Johnstone 2013.

[63] Johnstone 2013.

According to Johnstone, debates about euthanasia and physician assisted dying commonly recycle the same or similar arguments on both sides of the debate. Hillyard and Dombrink also see similarities between arguments used in assisted dying debate and in connection to criminal law reform and regulation of gambling, drugs, prostitution and abortion.[64] Johnstone has identified five arguments that are often used to argue for legalizing euthanasia and physician assisted dying: *autonomy*, *dignity*, *relief of pain and suffering*, *justice and equity*, and *altruism*. Arguments about autonomy are often phrased as the right to choose, including not only the right to die, but also control over when and how it happens. Arguments about dying with dignity and avoiding an undignified life as well as pain and unnecessary suffering at the end of life are also common. Less commonly used arguments are arguments about justice and fairness (from the perspective that some endure more suffering and that others would not be prepared to do so in the same situation) and arguments about altruism and a “duty to die” when one becomes a burden to caregivers.[65]

Similarly, Hillyard and Dombrink find that the two major themes in arguments by those supporting legalization are compassion and autonomy. They also conclude that arguments against legalization often have to do with fear that the laws will be used for the wrong reasons or that people will be pressured to use them or that more restrictive laws will be expanded to other forms of euthanasia. Hillyard and Dombrink also identify the argument that introducing assisted dying legalization might harm the medical profession and trust between patients and doctors.[66] Johnstone presents seven arguments that are commonly used against legalizing euthanasia and physician-assisted dying. She lists the following arguments: *sanctity of life*, *slippery slope*, *discrimination*, *clinical uncertainty and possibility of recovery*, *mistaken, irrational or imprudent choice*, *risk of abuse*, and *non-necessity*. The sanctity of life is the argument that human life is sacred and taking it is simply wrong. This is an argument that is often used by religious and right-to-life organizations. The slippery slope argument assumes that once we allow taking human life, even if the law is very restricted, this will loosen moral standards and lead to a development into other forms of killing. Discrimination in Johnstone’s list refers to that some lives are treated as less worthy than others. The argument about medical uncertainty deals with more practical issues such as misdiagnosis and the facts that doctors make mistakes, treatments are constantly evolving and people can have unexplained and unexpected remissions. The irrational choice argument states that wishing for death is irrational and that people can be misguided and wrong in their requests. Requests for euthanasia and assisted dying should therefore be seen as a plea for help and care. The more practical arguments also include the risk of abuse by relatives or other caregivers that might manipulate patients because of their own interests.

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[64] Hillyard and Dombrink 2001, 4.
[65] Johnstone 2013, 69–72.
[66] Hillyard and Dombrink 2001, 3–4.

The last argument in Johnstone's list is that assisted dying is not necessary as the symptoms can be managed through good palliative care. Of the arguments against legalization Johnstone has found that the sanctity-of life, slippery slope and non-necessity arguments are the most common.[67]

According to Johnstone, the debate has followed a back and forth pattern typical of philosophical debate with arguments, objections and counter-objections to those objections. She adds that most debaters approach the issue with their minds made up and ready to attack opposing views and defend their own.[68] Although it has often been approached as a for-or-against issue, this kind of debating might not actually suit the issue of assisted death very well. I assume that few of those that support euthanasia or physician-assisted dying in certain restricted circumstances would allow it freely to all without restrictions. On the other hand, many opponents support the right to refuse or end treatment, which is sometimes called passive euthanasia and is legal in all of the United States.[69] It is also legal to administer high doses of pain relief medication even when it is known that it will shorten the patient's life, although it cannot be done for the reason of hastening death. Hillyard and Dombrink are of the opinion that some of the procedures in end-of-life care are already as invasive as assisted dying.[70] Since assisted death exists in different forms, legal language shapes the issue and frames what is being debated. Even when there is legislation in place, there are dividing and linguistic lines and for example Compassion & Choices makes it very clear that they do not support euthanasia, defined as death by direct intervention by a physician, in any form.

The reasons for supporting assisted dying that appear in the material for this thesis are, like in Johnstone's research and the two Oregon studies,[71] most frequently arguments related to autonomy. This includes arguments about the choices of patients and wanting to control the circumstances of death. Another reason that appears frequently in the narratives told by Maynard and Diaz is the wish to avoid (unnecessary) pain and suffering. The arguments that are featured in the stories by Maynard and her family are discussed further in chapter 6.1.

Stories as research material were present in qualitative social science research before narrative analysis had its breakthrough toward the later parts of the 20th century, studied for example through ethnographic methods in sociology and other fields. According to Riessman, the difference between ethnographic analysis and narrative theory is that traditional ethnographic research treats the material as realistic descriptions of events, whereas narrative theory is part of the "interpretive turn"

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[67] Johnstone 2013, 69−72.
[68] Johnstone 2013, 69.
[69] See for example Montero 2004, 165.
[70] Hillyard and Dombrink 2001, 3−4; Montero 2004, 165.
[71] Johnstone 2013, 71; Ganzini et al. 2002; Ganzini, Goy and Dobscha 2009.

in social sciences that questions concepts such as objective truth and language as a neutral medium for conveying information. There is no consensus among researchers on exactly when, and in which discipline, the interest for narrative methods outside of literary study began, but similar critique of positivist and realist theories introduced narrative analysis in many fields. Today, narrative methods are used in social and human sciences like history, psychology and sociolinguistics as well as in professions such as law, medicine, psychiatry and education. One important element of the development of narrative inquiry was cross-disciplinarity, and the more fluid boundaries between different disciplines broke with earlier realist traditions. Different accounts connect this narrative turn to phenomena such as the identity movements of the 1960s, 20th century developments in psychology and therapy culture which raised interest in exploring personal life and the unconscious, and trends and theories that brought interest in researching language and the power relationship between researcher and subject. Riessman points out that one reason that is often overlooked is the developments in technology in the 20th century. Better and more available recording technology brought first person accounts that could be analyzed and transcribed word for word. Cheaper cameras and video cameras have also made visual narrative accessible for researchers.[72]

According to Hydén and Brockmeier, the field of narrative in research about illness, disability, health and medicine has been expanding since the 1980s. This narrative turn is connected to the other nonliterary narrative research boom in the social sciences and humanities, which was affected by more focus on interdisciplinarity, but in the cultural study of health it also coincided with changes in medical research toward more focus on chronic illness.[73] Narrative methods are often used in research related to topics of health and illness in society. According to Hydén and Brockmeier, this multidisciplinary field is often concerned with meaning-making processes that take a narrative form, for example patients' illness accounts, and narrative analysis has brought new methods to the research of illness, health and culture. Narrative analysis is being used for analyzing illness narratives in interview settings such as doctor−patient discourse, but also in researching other health-related communication in society.[74] There are studies about for example narrative in health care reform, the reception of narratives in medical drama series on TV, and how cancer risk information in narrative form influence listeners.[75]

According to Mattingly, narrative has the potential to give meaning and build personal identity in illness and other situations that disrupt "normal life". She finds that stories provide healing in ways

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[72] Riessman 1993, 1−6; Riessman 2008, 14−16.

[73] Hydén and Brockmeier 2008, 3.

[74] Hydén and Brockmeier 2008, 1−2, 7−8.

[75] Hodgetts and Chamberlain 2004; Davin 2004; Janssen et al. 2013. Janssen et al. do not actually use narrative methods in their study, but the impact of narrative is the focus of their article.

that biomedicine cannot. Storytelling transforms identity, interprets meanings in the past, and help patients imagine possible futures. Narratives frames experiences and can affect how a patient experiences suffering. According to Hydén and Brockmeier, people experiencing illness, injuries or disability tell stories to reach out to other people to make them understand, help, or recognize the suffering, as well as to come to terms with the situation themselves. Narrative is therefore not only about making sense of the situation but also about communicating and expressing the suffering. In doctor−patient relations research focuses on how doctors listen to and take narratives into account and how doctor−patient communication works for example in cases where the patient is not able to communicate coherently.[76]

Within health and medical narratives, there is also some research concerning death narratives. Frank makes an interesting point about narratives about death as the ultimate narrative, because the ending is final as far as we know. According to him, this puts pressure on dying people and those surrounding them to get it right. The death narrative is the end to the life story and people may be inclined to hasten death not to have an ending that contradicts their values. Another interesting aspect about death narratives, which is pointed out by Catherine Belling, is that you cannot tell the ending to your own, someone else has to give the story closure.[77]

There is a fair amount of research on social movements and advocacy organizations and the strategies they employ to get their message across and influence causes. Narrative in social movements has been examined by for example Polletta and Davies. Francesca Polletta has focused some of her research on social movements on the role that storytelling plays in the work of advocacy organizations to mobilize support and influence decision-making.[78] Davis writes about narrative and the cultural change in social movement research, discussing, among other things, the power of stories to challenge and to interact with broader society.[79]

Illness, storytelling and their relation to activism and social movements has been addressed by several researchers focusing on women’s experiences with and accounts of breast cancer. This includes studies on how cancer affects identity and group belonging[80], whose voices get heard, how breast cancer victims and survivors are represented and the differences between “mainstream” and alternative activism[81], and how social movements such as the pink ribbon movement have

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[76] Mattingly 2008, 73; Hydén and Brockmeier 2008, 1−2, 7−8.

[77] Frank 2004, 132−133; Belling 2004, 146−155.

[78] See for example Polletta 2006; Polletta 2009; Polletta and Gardner 2014−2015.

[79] Davis 2002.

[80] Cartwright 2000; Langellier 2001; Thomas-Maclean 2004; Davis 2008; De Boer and Slatman 2014; Coll-Planas and Visa 2016.

[81] Nielsen 2014; Cartwright 2000; DeShazer 2013.

successfully employed different communication strategies to get support for their cause[82]. Especially interesting in the context of this thesis are questions about who is represented in the media or in information campaigns as the face or voice of breast cancer and what groups or narratives might be left out. Cartwright has found that the public images of breast cancer in popular media as well as awareness and fundraising campaigns often feature young, thin and white women. Older women are rarely featured, although a majority of breast cancer patients are in their fifties, sixties, or older. Cartwright points out that questions about representation are not straightforward as for example older women might not identify more with pictures of older women than they do with pictures of younger women.[83] The communication strategies of both individuals and organizations are also worth discussing. The pink ribbon movement has been very successful in raising awareness and the symbol has become well-known through the work of advocacy organizations aided by mass media and corporations. Through awareness campaigns, the pink ribbon has become a strong brand as well as an awareness symbol. Sulik finds that because breast cancer is largely defined through the pink ribbon (mass) culture, issues tend to be simplified for the public and profit motives play a big role for involved parties such as pharmaceutical, medical and technological industries, large breast cancer organizations, and sponsoring companies. The pink ribbon culture also excludes illness narratives of women who do not identify with the pink ribbon message of femininity, positivity and fighting and overcoming the illness.[84] In a similar way, the big assisted dying organizations set the agenda and define what assisted dying advocacy looks like and aims for.

While the legal and ethical aspects of assisted dying have been well covered, there is a need for more research on the organizations involved in the debate for legalization and on how these organizations use different communication strategies to frame the issue. Both Johnstone and Tatum show that personal stories play an important role in how these advocacy organizations get their message across. This thesis examines the story of Brittany Maynard, who succeeded in getting an unprecedented amount of attention, enough to have an impact on legalization in California and other states. I analyze the strategies employed in the telling of her story to frame the issue of assisted dying.

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[82] Sulik 2011; Mcqueen et al. 2011.
[83] Cartwright 2000, 123–132.
[84] Sulik 2011, 9, 12–17.

3. Theoretical and methodological framework

This chapter introduces narrative analysis as a methodological and theoretical field within social and cultural studies and discusses some theories and concepts that are central to narrative inquiry. This is followed by a discussion on why and how organizations and social movements make use of stories in a deliberate way to get their message across. The chapter ends with a discussion about some of the communication strategies used by these organizations to make their narratives, and the (policy) goals they relate to, gain visibility and acceptance among the general public.

3.1 Narrative analysis

Narrative analysis is a group of related theories and methods that interpret texts that take a storied form. The emphasis is put on the story, who tells it, how it is told, the audience for whom it is told, and so on. There are different approaches and perspectives, and there is disagreement between researchers about what a narrative is and how it should be analyzed. Elements that are analyzed have to do with how the speaker or writer constructs events and uses language and/or visual means to convey meaning. This can include analysis of why incidents are told as stories, for whom and what purpose the story is told, why it is told in a certain way (for example placing events in a certain order), what cultural factors and power structures are included or taken for granted, how the story is received and what it accomplishes, and what is left out of the story or could be interpreted in another way than the narrator does. There are differences between how much different researchers focus on structure and language, social and cultural context, and audience and reception.[85]

Using the word *story* here does not suggest that the content is made up and not dealing with facts, although narrative theory does question realist theories that assume that there is such a thing as objective truth separate from interpretation by humans. Story refers to what is told when people apply meaning to those facts. Through storytelling, people construct personal and group identity and stories can serve many purposes. Stories are used when trying to remember the past, to argue and convince, to engage and convey emotions, to entertain, to mislead and to mobilize support.[86]

Although – or maybe because of the fact that – narrative research is expanding in many disciplines, there is no consensus among researchers about what constitutes a narrative. Definitions range from

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[85] Prince 2008, 115–117; Riessman 2008, 11–12. Prince talks about classical and postclassical narratology, whose origins he places in French and Francophone linguistics and Saussure's structuralism. According to him classical narratology is focused on which elements give a narrative meaning more than what a particular narrative means while postclassical narratology takes a broader view. Riessman sees a similar development from the structural analysis of the American linguist William Labov, toward a wider approach to meaning-making of and in narratives. See also Davis 2002, 10–12.

[86] Gabriel 2004, 169; Riessman 2008, 8–9.

the broad to the narrow and from practical descriptions to abstract ones. William Labov, whose work has had a great impact on narrative analysis, defines narrative as the personal experience (of the narrator) of a specific event that happened in the past. Arthur Frank, at the other end of the spectrum, considers narrative too wide a concept to define, but finds a metaphor by literary critic Frank Kermode helpful in understanding narrative. Kermode compares narrative to the ticking of a clock where the “tick” begins the narrative and creates expectations that are answered by the “tock”. The “tock” is expected to give meaning to the “tick” and waiting for the “tock” gives significance to what happens between the “tick” and the “tock”. Frank continues the metaphor in his reasoning about death stories and observes that death is the “ultimate tock”, because unlike many other “tocks” that start a new “tick” this one is final and that puts pressure on the dying and those close to them to doing it the right way.[87]

Riessman points out that in the case of life narratives, and other very broadly defined narratives, methods and systematic analysis become difficult. Narratives often include narrative elements such as telling the audience that the story is beginning and ending, for example by starting a fairytale with “Once upon a time”. A similar example from the material in focus here, is when an interviewer asks Dan Diaz to “tell [...] Brittany’s story real quick”, although here it is not the storyteller who tells us that the narrative is beginning. The narrative typically includes context and sentences about meaning and values in addition to the events.[88]

For the purposes of this thesis, narrative can be defined as Maynard’s life, illness and death story as it is told within the context of the campaign to legalize assisted dying. How the story is told is affected by the campaign context (getting the message through and presenting the narrative in such a way that the story ending in Maynard’s (assisted) death “makes sense”) but also by the cultural and political context of the United States (or more narrowly California and Oregon), the institutional and legal context of assisted dying laws and advocacy organizations and by the personal values, beliefs and experiences of Maynard and the other people involved in telling the story.

One difference between narrative methods of analysis and many other forms of qualitative research is that narrative analysis focuses not only on what is said, but also on how it is said. Different types of narrative inquiry focus on different aspects of the story, but narrative analysis can include for example how things are said (which words are chosen to describe events, how different parts of the

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[87] Labov’s definition of narrative and his method is discussed in Wells 2011, 63−68 and in Patterson 2008. See also Riessman 1993, 17−24. Labov’s method for structural analysis of narratives was introduced in Labov and Waletzky 1967 and Labov 1972. Kermode’s definition of narrative is discussed by Frank in Frank 2004, 132. See also Kermode 2000, 44−46, 192−193.

[88] Riessman 1993, 17−20; Brittany Maynard's Husband Speaks Out, 1:42.

story are related to each other in the telling, or structural linguistic analysis), and in what context it is said (to whom, by whom, in what physical and/or cultural circumstances including historical, racial, class, gender, institutional and political context).[89]

According to Riessman, one of the features that most clearly distinguish narrative analysis from other similar methods is that longer accounts are treated as one unit and not picked apart and fragmented when they are coded into categories. Single words and themes are not grouped and analyzed out of context, which is customary in other similar forms of qualitative analysis. What is said is analyzed as a whole, and other parts of the story gives context to what is said and how it is interpreted. This makes it less useful for making general statements, but it helps preserving information about the intentions of the narrator.[90]

Narrative research interprets the interpretations of narrators and admits that stories are told in a specific time and place and are affected by the personal experiences of both narrator and researcher. Some researchers also focus on powers structures and cultural elements that affect the narrative in question. With the strong focus on the subject and subjective, narrative analysis is more suitable for some types of research questions than others. Narrative methods generally work well for case-centered research that interprets oral, written or visual text. Even though a particular case is often the focus of narrative inquiry, as is the case in this thesis, Riessman states that it is still possible to make generalizations much like some theories in for example physics, psychology or medicine are born through the study of an interesting case. She believes that human behavior can be studied in similar ways within the social sciences. The cases in focus can include everything from individual narratives to group and organization narratives, even state narratives on the national level. However, context is important and the case is situated in a certain place and time, which gives context and frames that guide the interpretation of meanings.[91]

Because the researcher does not have the same experiences as the narrator, the time, place and experiences of the researcher also affects the interpretation of the narrative. Riessman identifies five levels of the research process where interpretation and subjective representations of events take place. She underlines that the borders between the different levels are porous and should not be interpreted too strictly. The five levels of interpretation happen when something takes place, when

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[89] Squire, Andrews and Tamboukou 2008, 4−12; Riessman 1993, 20; Wells 2011, 5−9.

[90] Riessman 1993, vi; Riessman 2008, 12. See also Wells 2011, 7.

[91] Riessman 1993, 4−5; Riessman 2008, 11−13, 18; Prince 2008, 118−120.

the experience is told, when the story is transcribed, when the transcription is analyzed and finally when the results are read.[92]

Riessman calls the first level *attending* by which she means experiencing the event that will be represented. This first level is when certain elements are noticed or made meaningful in someone's mind and includes interpretations of experiences of different senses such as hearing, seeing, feeling etc. According to Riessman, we actively construct reality and what we (choose to) notice is affected by our abilities, knowledge, values and interests.[93] In the case of Maynard's story, this is for example her experiences with her illness and diagnosis, moving to Oregon and getting the prescription for ending her life. Because the narrative in this case is defined so broadly, the experiences and events at this level of interpretation are many. Riessman probably had more narrowly defined narratives in mind when constructing her model.

The next level is *telling* about the experience, which is when the narrative is performed. At this level it is affected by the cultural context of the narrator and his or her ability to put the experiences into words (for narratives in spoken or written form). According to Ricœur, telling a story distances the teller from the narrative as he or she interprets experience and makes choices on how to tell it.[94] Narratives can also include pictures in photograph or video form, but in that case similar choices are made, for example in editing, that affect the narrative. The story is also affected by the audience through reactions and follow-up questions, or simply because the narrator adapts the story to who is listening, or assumed to be listening in case of for example broadcasted stories. When telling a story the narrator is inevitably representing him- or herself in addition to the events experienced. The means through which the story is told affects the narrative as well; a story told to friends at a dinner party takes a different form than an interview, or for example a policy video like Maynard's. Language and words also cannot completely and perfectly represent reality as it was experienced.[95] On the relationship between narrator and audience, Davis points out that there is a balance to telling a story. For the narrator to engage the audience, he needs to make connections and fill in meanings, but it is important not to say too much. What is left out of the story is also significant, because it makes the audience engage to fill in the gaps.[96]

The third level in Riessman's stages of the research process is *transcribing* the experience which fixates it in written form (or audio/video). Like at the earlier levels, the transcription is an incomplete,

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[92] Riessman 1993, 8−15.
[93] Riessman 1993, 8−9.
[94] Ricœur 1990, 61.
[95] Riessman 1993, 9−11; Riessman 2008, 145−153.
[96] Davis 2002, 16.

partial and selective representation. Choices about how much detail to include (for example pauses, tone and how fast the narrator is speaking), where to begin, and what to leave out affects the representation. Different choices can lead to different results when the transcript is *analyzed* at the fourth level. At this level the investigator tries to make sense of the narrative and makes choices about what to include, what to leave out, how to present and arrange the content and through this process edits and reshapes what was told. Values, interests and the theoretical background of the researcher affect these choices, and additionally they might also be affected by rules and suggestions by editors and publishers.[97] In the case of this thesis, the choices related to recording the narratives in video form were not done by me, so the choices affecting the interpretation on the third level were partly made by the narrators. Although the videos, and not a transcription of them, were mainly used for the analysis, some of the choices related to transcription described by Riessman apply here in how I have chosen to present the quotes and examples given in the text. Since the analysis in this thesis is not focused on linguistic detail and structure, readability was prioritized over more exact representation when writing out the quotes.

The final level of representation happens when the experience is *read*, where the reader's time, place, experiences etc. affect the interpretation of the narrative. The agency of the storyteller is important, but as Riessman shows in her account of the levels of representation, the actions of other people also affect the narrative, which is imperfectly and selectively represented. As mentioned above, how narratives are constructed, told and heard is affected by previous experiences and cultural context as well as interests and values. These make the framework through which experiences and stories are constructed and given meanings. According to Frank, frames refer to the things that are presupposed in the narrative about for example reality or life goals. These frameworks are applied to specific situations and form and define the narrative about those situations. At the same time the frames are influenced by experiences and narratives. According to Johnstone, social movements try to frame issues through language as well as other strategies to affect how the public thinks about a certain issue.[98]

There are several ways to distinguish between different types of narrative analysis. Squire, Andrews and Tamboukou divide approaches into work that is focused on *events* and work focused on *experience*. Event narratives are about specific events that happened to the narrator in the past while experience-centered narratives can be more broadly defined when it comes to the length of the experience and in what form it is shared. Riessman identifies a couple of different forms of narrative analysis, the main ones being *thematic analysis* and *structural analysis*. Of these two,

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[97] Riessman 1993, 11−14.

[98] Riessman 1993, 14−15; Frank 2004, 139; Johnstone 2013, 81−82.

thematic analysis focuses more on what is spoken, what the narrative means, what information is communicated and less on how, to whom and for what purpose the story is told. The focus is on the told, more than the telling of the story. In contrast, structural analysis is focused on how the narrative is constructed. Content is included in the analysis, but the focus is on how the story is told. There is variation in how much context is included. In later works, Riessman also adds *dialogic or performative analysis* as well as visual narratives as a new type of narrative. Performative analysis is more varied and broadly defined and uses elements of the other two approaches and also adds to them. These approaches are focused on how speech is produced interactively through discussion and dialogue or how stories are created and heard in contexts. Stories tell us about society and culture as well as about the person or group who tells them. Cultural aspects might be things that the narrator is not aware of or takes for granted, meaning that the narrator is not seen as the only, or final, authority on the content of the story. This approach emphasizes interaction, whether through dialogue or as an imagined audience. Riessman points out that the approaches are not mutually exclusive, but can be combined and adapted. Squire, Andrews and Tamboukou refer instead to *structural*, *content*- and *context-based* approaches, but they find the divide between events and experiences more theoretically important.[99]

In this thesis, the material is analyzed as to its content and some structural elements are also included. Context is a very important part of the analysis, with imagined audiences and the ongoing policy debate affecting the contents. As mentioned above, the narrative is defined broadly as a story of experience rather than a particular event. Now that narrative analysis has been introduced, it makes sense to look closer at how organizations use stories to advance their policy goals.

3.2 The political use of stories

Riessman writes that individuals often have different purposes than organizations when telling stories, although purposes also overlap. Stories are used by individuals to remember, argue, justify, persuade, engage, entertain, and even mislead, while organizations use stories more to mobilize and create and keep up a sense of belonging. For organizations and political campaigns and causes, stories can help construct group identities and inspire others to join. According to Paul Bate, this is because people get to know each other through stories and that is how group formation happens when individuals find common ground. Language is a part of this as well. When individuals in groups share the same language they start sharing the same meanings and understandings of concepts. This

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[99] Squire, Andrews and Tamboukou 2008, 8, 5; Riessman 2008, 17−19, 53−54, 77−80, 105−106, 178−181. See also Davis 2002, 10. See Riessman 1993 for a thorough presentation of structural and thematic approaches and how to apply them in different ways. In Riessman 2008 a dialogic/performative approach as well as visual narrative analysis are added. Patterson 2008 writes about Labovian approaches to event-centered and structural analysis. See also Labov and Waletzky 1967; Labov 1972.

is also how belonging to an organization and sharing stories might affect how individuals tell and make sense of their own story. They "learn" to understand their experiences in a certain way.[100]

Polletta and Gardner make several points about the use of stories by social movements to achieve different aims such as mobilizing supporters, get new members to join their cause, and influence policy through lawmakers. They point out that sometimes gaining enough visibility for a story is already "winning" as that frames the issue in a certain way and makes it harder for competing narratives to get heard. Research has shown that stories can affect opinions especially in situations where the audience does not already have strong opinions on the issue. Stories make people treat information less critically, especially if they align with their values.[101] Tatum points out that stories can be a way to simplify complex issues, because stories are not bound by strict expectations to present rational reasoning or support arguments. Stories are also a powerful way to evoke emotions, both positive and negative ones.[102]

Human rights organizations often use personal stories as testimonies, where the story of an individual represents the experiences (often traumatic ones) of the whole group. In Latin America *testimonio* has served this kind of purpose for movements against military dictatorships. Similarly testimonies of Holocaust survivors are used for memorialization. Polletta points out that because everyone can tell his own story, storytelling can be a way of challenging official narratives. Testimony and the use of personal stories can be a way for the less powerful to get heard. It can also "illustrate" an issue for the public. In the U.S. this strategy has been used successfully by AIDS activists, the women's movement, sexual minority movements, Occupy Wall Street and many others. This is what Compassion & Choices does as well, and with Maynard's story they were successful in getting public attention. In the case of Compassion & Choices, they are not fighting oppression from other people, although the right to die has sometimes been presented as a human rights issue. Compassion & Choices also has a good relationship with lawmakers in many states and have been successful in getting their legislative testimonies heard before state legislatures.[103]

Plummer warns that the use of testimonies is not completely unproblematic as powerful stories can be used both to exploit and to distract. Johnstone finds it highly problematic when conclusions are drawn from personal stories that might not be representative. Personal experiences are often

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[100] Riessman 1993, 8−9; Riessman 2008, 8; Bate 2004, 336−337, 346. See also Polletta 2006. Cain 1991 has written an interesting article on how members in Alcoholics Anonymous adapt to an existing "story model" when sharing their experiences, and how the sharing of these similarly constructed narratives creates and upholds group and personal identity of members in the organization.

[101] Polletta and Gardner 2014−2015, 534−535, 538−539. For deeper analysis and various examples of the impact of public narratives, see Brock, Strange and Green (eds.) 2011. See also Kreiswirth 2000.

[102] Tatum 2002, 182−183.

[103] Gready 138−139; Polletta 2006, 3−4; Polletta and Gardner 2014−2015, 542; Squire 2008, 55.

treated as being true for the general public and not only the person that had the experience. In fact the explanation for "going public" is often that it is done to help others. Johnstone believes that this is misleading, because every life and every story is different.[104]

Compassion & Choices, the organization with which Maynard cooperated to share her story, discusses their reasons for using stories in their advocacy work in a training video for volunteers in the New York campaign for the Medical Aid in Dying Act. The video was posted on the Compassion & Choices YouTube account in January 2017. The video is aimed at volunteers and includes points about how to approach the issue and how volunteers can get involved in the Compassion & Choices campaign. One of the ways to get involved suggested in the presentation is for volunteers to share their story. In the training video, the Compassion & Choices representative explains the reasons for using personal stories in the campaign. She explains that stories "speak to people's hearts and to shared values", humanizes information and help people understand concepts. In other words, Compassion & Choices uses storytelling to make the issue of assisted dying easier to relate to. In the video, the Brittany Maynard story is used as an example of how stories can be used to effectively advance the campaign. They credit Maynard for initiatives being started by lawmakers to legalize assisted dying in many states, and for making the movement grow by sharing her story and inspiring others to tell their own stories. These two reasons fit well with the observations made by Riessman, Bate, and Poletta and Gardner that are discussed above about how organizations use storytelling to mobilize support and create and keep up common objectives. The video includes a couple of related but slightly different reasons. Compassion & Choice encourages the use of stories as a way to depolitize the issue and as a way of starting a dialog. By this they mean that stories relate the issue to a specific story or make it about helping a specific person that would be affected by the law, instead of framing it as a broad policy issue. The idea of using stories as a way to "open doors" for discussion is also interesting. By using stories, debaters evoke reactions among both supporters and opponents and introduce the issue in a certain context to those who are unsure or undecided. Finally, the video underlines that stories are important because people remember stories, not facts and figures.[105]

It often makes sense for organizations to use many tactics and ways to try to influence policy from different directions at the same time. Organizations try to gain visibility in the media, contact policy-makers, influence public opinion, and so on. It is important to critically examine the communication strategies used by advocacy organizations to affect policy. Examining how stories are used by

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[104] Plummer 2001, 237; Johnstone 2013, 96. 99.

[105] CompassionChoices, January 2017 NY Volunteer Training, 1:27:50-1:29:47; Tatum 2002; For example Janssen et al. 2013 found, in their study of different ways of conveying information about cancer risk, that study participants who got the information in narrative form instead of "just the facts" were more affected by the information.

organizations like Compassion & Choices to advocate for their causes can help gain an understanding of how organizations aim to affect public opinion using personal stories. Some of the ways that organizations use communication strategies to affect the public's reactions and opinions will be discussed next.

3.3 Communication strategies of advocacy organizations

Organizations use a number of different strategies to advance their policy goals. Using personal stories was discussed above, and some other strategies will be discussed here. The strategies discussed here are not only used by proponents of assisted dying but also by the organizations opposing legalization as well as by many other advocacy groups.

Advocacy organizations are often interested in gaining both political and public support. Political support is important for passing legislation, but politicians might be unwilling to support propositions that do not have the support of the public. Johnstone notes that the movements for assisted dying and euthanasia have successfully brought their issue to the attention of the public and gained more visibility than many other advocates for legislation on social matters. The effects on legislation and the political level have so far been less potent, but Johnstone points out that the cultural change has been substantial with opinion polls done both at the local level and globally showing majority support.[106]

The right-to-die organizations have been good at making their case to the public by using different communication strategies and framing devices such as appealing to emotions and presenting information in a certain way. Johnstone, who is quite critical toward the way these organizations communicate their cause, calls it propaganda. Johnstone lists a lot of different strategies used by the organizations.[107] Some strategies that will be discussed in more detail here are common sense and normalization strategies, framing strategies, and public opinion and media strategies. They differ from the arguments presented in chapter 2.4, because they are mostly not arguments supported by facts or logical reasoning. Instead these strategies are more about how information is presented. This does not necessarily mean that the information is false, but it is framed and interpreted in certain ways.

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[106] Johnstone 2013, 77. I assume that Johnstone by "local" refers to polls in Australia, where she has conducted her research, but the same is true for polls in the United States.

[107] Johnstone 2013, 89−90. For a full account of the different strategies that Johnstone identifies in the Australian debate, see Johnstone 2013, 89−126. I have only included the ones that are most relevant to the case being discussed here. As mentioned previously, the debate and organizations involved in the issue in the United States and Australia differ in some important ways.

One strategy that falls into what I call common sense arguments, is presenting statements as information that "everybody knows" instead of presenting facts to support the argument in question. For example, it is often presented as a given and kind of argument for assisted death that palliative care cannot relieve all suffering. However, the argument usually is not developed into how assisted dying is a good solution to the problem, according to Johnstone. "Everybody knows" and common sense strategies are based on social identification. As a similar tactic, authority figures such as for example politicians or religious leaders are included in the debate, because it is assumed that people want to identify with them. A closely related normalization tactic in the assisted dying debate is the "it's already happening" argument. The argument is that assisted deaths are already happening in secret, and that it would be safer if the practice was legal and regulated. Sometimes this is combined with the argument that the laws criminalizing assisted dying are not being enforced. In response to this argument, Montero points out that law is not about what is, but rules about what should be and that if the law was adapted to everything that is, then it would lose its normative function. He admits that there might be situations when it would be legitimate to adapt the law to existing circumstances, if the facts of these circumstances could be precisely determined, but finds that the argument in this case lacks foundation. The reasons he gives for this is that it is not possible to know how frequently euthanasia is performed in secret and that the motives for not enforcing laws are often unclear. He is of the opinion that many people confuse euthanasia with legal interventions such as stopping treatment. Montero admits that the laws are not perfect, but contests that this could be used as justification for decriminalization. He also disagrees with the claim that legalizing would put an end to the cases of secretly performed euthanasia.[108]

One normalization or framing strategy used by assisted dying advocates is to present assisted dying as medical treatment. This frames it as normal, and part of medicine and/or palliative care instead of opposed to it. In making palliative care not an alternative to assisted dying, but connected to it, they are portrayed as part of the same dying process. This is also related to language. The organizations in the United States do not use the words euthanasia or suicide. Instead they use terms like medical aid in dying or end-of-life options. Hillyard and Dombrink call this kind of framing through language and phrases semantic arguments and find that it is done especially through the debate around the use of the word suicide. Both proponents and opponents have strong feelings about the use of the word suicide in relation to assisted dying.[109]

Another strategy that is related to language is branding. According to Johnstone, right-to-die organizations use certain language and signature terms to help their brand stand out. She lists using

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[108] Johnstone 2013, 92, 98, 108−109; Montero 2004, 178−179.

[109] Johnstone 2013, 127−129, 132; Hillyard and Dombrink 2001, 4.

the same words, such as choice, control, dignity etc. as well as logos and other visible branding. Sulik has found similar patterns in the “pink ribbon culture” of the breast cancer movement. According to her the pink ribbon brand carefully combines stories and information to create associations that support the brand. In the right-to-die movement choice, in particular, stands out in presenting euthanasia as a product on the market that can be chosen, according to Johnstone. Emphasizing choice also promotes individualism. Johnstone also suggests that some of the name changes in right-to-die organizations have to do with re-making their brand and distancing themselves from more extreme organizations with different objectives, such as the Final Exit Network.[110]

One way for organizations to try and influence public opinion is getting visibility in the media. According to Somerville, sharing personal stories is a good way to get visibility in the media. She believes that people identify with the stories and the people telling them. Somerville also argues that if the issue is intensively covered in the media, people react to it more than if they are simply aware of it. According to Polletta and Gardner, social movements have difficulties getting the media to cover causes, because mainstream media focuses on people and events. Personal stories might then be a way to get issues on the agenda.[111]

Johnstone observes that new media provides new ways for the public to interact with advocacy organizations and to share content and pictures. New media also makes it possible for organizations to organize in new ways and overcome geographic boundaries. In addition, new media is useful for organizations, because they offer a way to influence and access more traditional media. Maynard’s story is a good example of this. It was published on YouTube and linked to the website of People magazine, from where it spread to other news on the web, papers and television. According to Polletta and Gardner, media visibility is important also because politicians follow news sources for information about the news as well as about public opinion.[112]

Johnstone suggests that the visibility of the debate about how to die makes people aware of their own mortality and makes them feel helpless and uncertain and that euthanasia or assisted dying becomes a solution and protection from concerns about having a bad death. She is basing this on the works of the anthropologist Ernest Becker’s thoughts on “mortality saliency” and Greenberg, Solomon and Pyszczynski’s terror management theory that is a social psychology theory that has been developed based on Becker’s work. Reminding people of death increases their need for protection and affects their behavior and beliefs. Johnstone argues that the euthanasia debate is a catalyst for feelings of helplessness and uncertainty, while it is at the same time bringing reassurance

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[110] Johnstone 2013, 128−129, 134; Sulik 2011, 133.
[111] Somerville 1997; Polletta and Gardner 2014−2015, 541.
[112] Johnstone 2013, 136−138; Polletta and Gardner 2014−2015, 540.

to those feeling vulnerable by suggesting that they can have control, choice and dignity in death. Johnstone believes that any sense of control, choice and dignity is illusory, but that the need for protection from anxiety over their mortality makes people want to believe these illusions, which explains why legalization of euthanasia and physician-assisted dying enjoys large public support.[113]

This chapter presents narrative analysis as a theoretical and methodological field and discusses some of the strategies used by organizations to get the attention of the public and frame issues to advance their policy goals. Narrative analysis, at least in the way it is understood and used in this thesis, emphasizes the context of stories; and meanings are interpreted in relation to the goals of the narrators and the organization that they are affiliated with. Organizations use stories to explain meanings but also to get people involved and to raise interest for their causes. In the next chapter, the videos that are the focus of the analysis in this thesis are presented alongside some aspects of how the analysis was conducted and choices and features that influence the interpretations of the material.

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[113] Johnstone 2013, 148−152, 166−167. For more on Becker’s theories about mortality salience, see Becker 1973. For more on terror management theory, see Greenberg, Solomon and Pyszczynski 2015.

4. Materials and methods

The material in this thesis consists of four videos that were published on YouTube and are related to the Maynard campaign with Compassion & Choices for legalizing assisted dying. The content of the videos was analyzed from a narrative perspective with focus on how Maynard's story is told and connected to arguments and communication strategies related to the campaign for assisted dying. The four videos, a description of the methods and research process as well as some remarks on the nature and limits of this kind of inquiry will be discussed in this chapter.

4.1 Material

The material includes two videos where Maynard herself tells her story, with the help of her mother and husband, and two videos where her husband Dan Diaz tells the story after her death. The first part of the material consists of two videos titled *The Brittany Maynard Story*[114] and *A Video for All My Friends*[115], which are directed and edited videos that were published on the YouTube channel of Compassion & Choices, which has 216 videos in total. Many of the videos are stories by patients and their close ones, but there are also educational videos about the organization and how to do advocacy work, and videos of physicians, politicians and religious leaders talking about the issue.[116]

Of the videos on the Compassion & Choices YouTube channel, eight videos are about Maynard (see Table 4.1). The first five ones were released in 2014 or 2015, before or within a year after Maynard's death. They stand out on the YouTube channel because of their number of views and are the five most watched videos on the channel. *The Brittany Maynard Story* and *A Video for All My Friends* both have millions of views and the other three also have more than a hundred thousand views on a channel where most videos get a couple of thousand or hundreds of views.[117] The high number of views suggests that many followed links from other sources to watch the videos on the YouTube

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[114] The Brittany Maynard Story, published October 6, 2014. https://www.youtube.com/watch?v=yPfe3rCcUeQ&t=140s. The video was directed by Allie Hoffman, who has made a name for herself in marketing and fundraising for NGO campaigns in social issues and development work.

[115] A Video for All My Friends, published October 29, 2014. https://www.youtube.com/watch?v=1lHXH0Zb2QI&t=166s. For this second video, information about the director is not mentioned, but the video is very similar in style to the first one and has been edited by someone in a similar way to include video shots, text panels, and pictures.

[116] CompassionChoices, YouTube channel. The number of videos on the channel is from February 3, 2019.

[117] The video *Take Action for Brittany* was published weeks after her death for what would have been her 30th birthday on November 19, 2014. This is a kind of In Memoriam style video with pictures and quotes, which ends by asking people to join the cause. *Brittany Maynard Legislative Testimony*, published March 31, 2015, is a legislative testimony that was presented to the California legislature before they voted on the assisted dying law in California in 2015. See Dockterman 2015. The video *Brittany Maynard's Legacy: One Year Later* was published one year after *The Brittany Maynard Story* on October 5, 2015. In the video, Diaz, Barbara Coombs Lee, who is the President of Compassion & Choices, and others discuss Maynard's message and impact.

channel. The last three videos of Maynard were released in 2018 as part of a campaign to defend the California End of Life Option Act, when three years after the law was passed a judge declared it unconstitutional because it was passed in a special legislative session[118]. These last three videos of Maynard have only around a hundred views on the YouTube channel, which is still more than most of the other #IWantTheOptionCA videos that were released as part of the same campaign. The three videos are short clips and might have been distributed mainly through other channels, for example as TV advertisements. They do not include any new material and are part of interviews that are included in the earlier videos.

Table 4.1 The Brittany Maynard videos on the Compassion & Choices channel

Title	**Release date**	**Length**	**Views***
The Brittany Maynard Story	October 6, 2014	6:30 min	12 million
A Video For All My Friends	October 29, 2014	5:58 min	5,3 million
Take Action for Brittany	November 19, 2014	3:13 min	250 000
Brittany Maynard Legislative Testimony	March 31, 2015	6:33 min	177 000
Brittany Maynard's Legacy: One Year Later	October 5, 2015	6:21 min	220 000
#IWantTheOptionCA Brittany and Dan	May 17, 2018	0:46 min	120
#IWantTheOptionCA Brittany Maynard Testimony	May 17, 2018	0:43 min	110
#IWantTheOptionCA Brittany Maynard Video for My Friends	May 17, 2018	0:26 min	100

*rounded number of views, describing the situation on October 9, 2018.

My analysis includes the first two of these videos, both released in October 2014 when Maynard was still alive. In these two videos Maynard herself talks about the issue of assisted dying and, even though the videos have been directed and cut, it is her version of her story that is being told in the context in which she chose to present it. The other six videos partly use the same material as the first two videos and either do not introduce much new content, or in the case of the legacy video, focuses more on the campaign than on the content of Maynard's story, which is why they were left out of the material. The legislative testimony and legacy videos are both interesting, but as they tell the story with a slightly different focus than the first two videos, I chose to include later videos of Diaz telling Maynard's story "from the beginning" instead.

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[118] See Romero and Associated Press 2018. The State Appeals Court later reinstated the law; see Associated Press, "Court reinstates doctor-assisted suicide in California."

The Brittany Maynard Story introduces Brittany Maynard as a person, her illness and her choice to move to Oregon where she will have access to assisted dying. The comment section for the video is turned off on YouTube, but elsewhere in the media and online the issue got a lot of attention and Maynard became known as "the face of assisted dying". *A Video for All My Friends* is in part a response to this attention and indirectly addresses some of the comments she received after posting the first video.

The second part of the material consists of two videos that feature Maynard's husband Dan Diaz telling her story. They were both filmed after Maynard's death. The first one, *Brittany Maynard's Husband Speaks Out On Death w/Dignity,*[119] is a clip from 2015 from the news program *The Big Picture* on the RT Network in which the host of the program interviews Diaz on the assisted dying legalization that at the time had just been introduced in California. The clip is published on the YouTube channel of The Big Picture RT. The second video of Diaz, *Dan Diaz and Brittany Maynard: The end-of-life conversation*[120], is from a presentation that he held in 2018 at a discussion event by the Commonwealth Club of California. The event took place after the End of Life Option Act in California had been challenged and reinstated. The two videos are presented in Table 4.2. In contrast to the Maynard videos, videos of Diaz are not collected by for example Compassion & Choices so I have included only the two videos that are part of the material for this thesis in the table. In addition to the information included for the Maynard videos, information about where the videos were released is included.

Table 4.2 The Dan Diaz videos

Title	Brittany Maynard's Husband Speaks Out On Death w/Dignity	Dan Diaz and Brittany Maynard: The end-of-life conversation
Release date	February 6, 2015	September 5, 2018
Length	8:51 min	1h 07:04 min (Diaz' presentation 2:06–15:51)
Views*	2 900	456
Released on	The Big Picture RT YouTube channel	Commonwealth Club YouTube channel

* number of views, describing the situation on January 28, 2019

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[119] Brittany Maynard's Husband Speaks Out On Death w/Dignity, published February 6, 2015. https://www.youtube.com/watch?v=X1WDTvByLxQ

[120] Dan Diaz and Brittany Maynard: The end-of-life conversation, published September 5, 2018. https://www.youtube.com/watch?v=55240s0QdQg. The event was held on August 29, 2018 and included Diaz' presentation and a discussion between him and Dawn Gross who is the host of the radio show "Dying To Talk" and end-of life care activist.

Over the years, Diaz has appeared on a number of talk shows, interviews in different media, events, social media posts and podcasts, where he has talked about assisted dying legislation and shared Maynard's story. These particular two videos were chosen for this analysis for a couple of reasons. Firstly, I wanted the material included to be in video format for it to be more comparable to the Maynard videos. Secondly, even though the format is slightly different to the first two videos in the material, the story is told in a similar way in all four videos and they also include photos in a similar fashion. All four videos also relate to getting the legislation passed in California, while at the same time addressing the larger national scale and situation in the whole United States.

In the videos, Diaz tells Maynard's story in much the same way as it is told in the earlier videos, meaning largely from Maynard's point of view. Diaz does not share his own story, so although the narrator changes, the story being told is still the same one. The biggest difference is that, as Belling points out[121], you cannot tell the story of your own death. The story of Maynard's death can of course only be told after it has occurred.

In the video *Brittany Maynard's Husband Speaks Out On Death w/Dignity*, Dan Diaz tells the story in an interview so the discussion format is different from both Maynard's videos and from the later presentation by Diaz. However, compared to a lot of the other interviews with Diaz, this one has long answers to the questions and he tells the story without being interrupted. We also do not know the production context for the first two videos with Maynard because the videos have been edited. It is quite possible that they were also filmed as interviews even though the questions are not included in the videos. In the video with Diaz from 2018, he tells the story as a presentation so there are no interruptions.

The second video of Dan Diaz is from a talk on August 29, 2018 at the Commonwealth Club of California, which is a public affairs forum that arranges events on current topics. The video, *Dan Diaz and Brittany Maynard: The end-of-life conversation*, starts with a presentation by Diaz on Maynard's story. Although it is a PowerPoint presentation, it is similar in form to the videos where Maynard tells the story in the aspect that the same parts of the story are told. Pictures are also included to support the story in a similar way to the other videos. The talk goes on with a discussion between Diaz and Dawn Gross, who is the host of the radio show "Dying to Talk", which is trying to break the taboo of talking about death and dying. Gross is an active advocate for hospice care. Diaz' presentation (minutes 2:06−15:51 of the video) is what is mainly included in the analysis here. This is where he tells Maynard's story and this part is comparable with the other parts of the material. This fourth video in the material was filmed almost four years after Maynard's first video and Diaz has told the

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[121] Belling 2004, 146−155. See also chapter 2.4.

story in many different forums over the years at events related to legalizing assisted dying. I wanted to include this video because it ties together the beginnings of the campaign with how the campaign looks four years later and it is interesting to see whether and how the story has developed over time.

Now follows a description of how the analysis was done, before a discussion about some points relating to the material and methods that are good to keep in mind when looking at the results of the analysis.

4.2 Methods

The analysis is conducted as narrative analysis, which is a method that is centered on the material. The analysis focuses on how Maynard's story is told by herself and her family and how the arguments for assisted dying are presented and related to Maynard's story. The videos tell the story about her illness and death as well as her life before getting ill. The story is told in slightly different versions in four videos that both say the same things in different ways and add to the story. I primarily treat the material as the same story told several times by many people. In some aspects it is interesting to compare differences between different tellings of the story; other elements are discussed without much comparison.

The analysis was conducted in several steps. First, I analyzed each of the four videos separately to get a sense of which themes were the most central in the material. It was important for me to analyze all of the videos from this point of view and separately from each other so that the analysis would not be too guided by the first video, which might make it easier to miss themes and sentiments in the later half of the material. After analyzing the four videos, I chose the themes that seemed most relevant, and did a second analysis of all the four videos from the point of view of each of these themes. In this second part of the analysis, I paid closer attention to the relations between the videos, comparing points of views of the different narrators, as well as to chronology and how the story developed over time.

After the thematic analysis, I took a closer look at some of the structural features of how the story is told. In this part of the analysis, the focus is on how things are said, paying closer attention to the elements included in telling the story and who speaks about what kind of issues. In the first two videos this means mostly which one of the three narrators talks about something in a certain way. In the last two videos there is only one narrator (excluding the interviewer in the third video and the host and discussion in the fourth video), but here it is interesting to note which parts of the story is told in Maynard's voice and which parts of the story from Diaz' own point of view.

Context is an important part of both analysis chapters, but especially the second of the two chapters focuses mainly on how the context in which the videos were made is connected to the content. The videos are influenced by the debate on assisted dying in the United States and the organization Compassion & Choices and its policy goals. In addition, the content is influenced by the personal experiences and situation of Maynard and her family and, on a larger scale, the political and cultural aspects of society in California, Oregon and the United States. The audience, or expected audience, for the videos is also part of the context. The story is told to call attention to the issue among "the American public", but other important audiences are the mainstream media as well as policy-makers, as discussed in chapter 3 by Johnstone and Polletta and Gardner in relation to communication strategies by organizations.

4.3 Validity in narrative analysis

The theoretical points of view of narrative analysis affect how questions of validity are approached. Riessman points out that the concept of verification, and many of the procedures in use for determining validity, largely rely on realist concepts of truth or reality as something that exists "out there" independently from human interpretation. Validity in that case would mean trying to ensure that the results from the research process correspond with this external reality. This is not what validation in narrative research is about, because the narrative is not studied as evidence of what happened. According to Gabriel, facts do not speak for themselves and even if they could, it would not be without context. Narratives make sense of facts, give them significance and purpose. Something is always left out and simplified and different people tell the same event in different ways even if they genuinely aim to tell the objective truth. Most narrative scholars agree that narrative is not only about the story of the truth, but on telling the story from a point of view and trying to persuade others to see events in the same way. Meanings and meaning-making are also in focus.[122]

Since narrative analysis is not focused on finding absolute or objective factual truths, Riessman prefers to use the term trustworthiness as something the researcher should aim for. According to Riessman, there are two levels of validity in narrative research – the validity of the story told by the narrators and the validity of the analysis done by the researcher. Striving for trustworthiness can be done through paying close attention to methods, and data collection and analysis, and through considering ethical and theoretical factors. The researcher should make sure that the interpretation is reasonable and convincing, that claims are supported by the material and that alternative interpretations are considered.[123]

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[122] Riessman 2008, 187−188; Gabriel 2004, 169.

[123] Riessman 2008, 184−186. See also Greenhalgh, Hurwitz & Skultans 2004, 14; Wells 2011, chapter 8.

The material used here is what Riessman calls “found”, meaning that the material being analyzed was not created for the purpose of the analysis, but made by someone else and found by the researcher. In this case, it means that I have no insight into the production process of the videos. Questions, comments and directions given to the people talking in the videos, which might affect the content, are not known. On the other hand, because the material is “independent”, the content was not influenced by preferences and expectations of the researcher during the production stage. Decisions about the process and how the videos were made are especially relevant for the first two videos, which are edited. The video cuts between different speakers, and text, pictures, and video clips have been added, creating connections that were not there at the time of filming. Local context and structures within the video, meaning for example why one thing is mentioned before something else, is as a consequence of this not decided only by the person speaking, but also the people involved in editing the video. The same is true for comments, clarifications and opinions that might have been left out of the videos. Because Maynard and Diaz are telling the story within the context of an advocacy group, even the videos that are not edited are probably influenced by the objectives of the campaign and the organization Compassion & Choices. It is important to keep in mind that the content of the videos is affected not only by the opinions of the people speaking to the camera, but also by decisions and perspectives of other people working in the background. The different people on and off camera might also not share the exact same meanings, which means that while they might use the same words or concepts they can interpret them in slightly different ways. In addition, meanings might change over time, which is especially relevant for the last video that was posted almost four years after the first one, and after Diaz has spent years involved with the issue. While I am acknowledging this, and try to take it into account by keeping the four videos separate in the analysis, it is also a point of narrative analysis that there is always context influencing what is said and how it is said. There are also things left out of the narrative and the same story told by the same person might be told differently under different circumstances. Because narrative theory does not assume that there is such a thing as objective truth, it works well for this kind of material.[124]

In terms of definitions and content, it is also important to point out that a part of the literature referenced in this work, does not necessarily specify how they define assisted dying and euthanasia. As has already been discussed, this is not a simple yes or no issue and details in legalization or proposals define what assisted dying in a particular context means. Since some authors do not specify what form of euthanasia they are talking about, there is room for misunderstandings and misinterpretation. A scholar might for example oppose euthanasia if the drugs are administered by a

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[124] See Riessman 2008, 144 on found and made research material. Riessman is talking about photographs, but I think the concept can be applied to videos as well.

physician, but be more neutral toward legislation that requires the patient to self-administer. This is especially relevant in the discussion about arguments and strategies, where research about Europe or Australia have a different context than works commenting on assisted dying in the U.S. context. Differences in definitions are something that might affect the results, but I try to always include more than one point of view and in any case the main focus is on how arguments are included in the material in focus of the analysis. In the larger debate however, this is something that should be addressed more often than is currently the case.

The next couple of chapters turn to the results of the analysis of the videos telling Maynard’s story. The first of the analysis chapters is focused on how the story is told and how Maynard is portrayed as a person. The following chapter is about how the videos deal with arguments and discusses some communication strategies that can be found in the material.

5. Maynard's life (and death) story

As discussed in the theory chapter, organizations like Compassion & Choices that are advocating for social issues use personal stories to inspire others to join their cause and to create a shared sense of belonging among supporters. Stories are used to make issues easier to relate to. Brittany Maynard's story got a lot of visibility and therefore it makes sense to take a closer look at how Maynard is presented as a person in the advocacy work of Compassion & Choices. This chapter takes a look at how Maynard's personality, interests and values are represented in the narrative told about her by herself and her family, both before and after her death. The results are divided into three sections. The first two sections, family values, and personality, interests and beliefs, focus on some of the themes related to Maynard's character and values that are emphasized in the narratives. The third section is more concerned with the context and structure of the narratives, discussing communication aspects as well as how text panels, pictures and other components are being used in the different videos.

5.1 Family values

When analyzing the videos, the theme that rose most clearly from the material was statements related to family. Family is mentioned frequently as part of Maynard's personal story, especially in the first two videos. In fact, it is how the whole story is started and the first thing that is mentioned in the first video. Before it is even introduced what *The Brittany Maynard Story* is about, the video starts with the following sentence: "The thoughts that go through your mind when you find out you have so little time is everything that you need to say to everyone that you love."[125] In addition to bringing the focus to loved ones, this opening, that is presented in general terms, is a way to address the audience and ask them to imagine being in Maynard's situation. Tatum found similar rhetorical ways in personal stories used in the trial of Dr. Kevorkian to make the jury identify with the stories.[126] Only after the sentence about family, information about the context is introduced such as the name of the person speaking and a timeframe of her illness and diagnosis. This information is given as a text panel and after that Maynard continues the story of when she first started getting symptoms. The focus in this section is only partly on the illness, which is told in the context of her relationship with her husband. Maynard says that the symptoms started just "after she got married"[127] and while she is talking, photos from her wedding day are shown. While her wedding ring is being filmed, she goes on to talk about that when she was diagnosed she and her husband were "actively trying for a

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[125] The Brittany Maynard Story, 0:01.
[126] Tatum 2002, 194.
[127] The Brittany Maynard Story, 0:23.

family”[128]. Having the video start like this, introduces assisted dying as a family issue and from the beginning, and throughout the whole video the focus is not only on Maynard but also how her illness as well as her choices affect those around her. The video features not only Maynard, but also her mother and her husband.

Later in the first video, when Maynard talks about how she plans to die, she starts with who she wants to be there: her husband, mother, stepfather and best friend. She goes on saying that she wants it to be in her bedroom that she “share[s] with her husband”[129] and repeating that her mother and husband will be by her side. The last two and half minutes of the first video are mostly focused on Maynard’s interest and her family, talking about what she will do with her time left and what is important in life. Maynard talks about how she has been spending time with and travelling with the people she loves. This section will be explored in more detail in the next part where Maynard’s interests and how they are presented in the videos are discussed.

The second video, *A Video for All My Friends*, completes the story told in the first video and addresses some questions that got a lot of attention in the public discussion after the first video was released. It starts slightly more politically than the first video with a city view of Portland, Oregon and Maynard talking about her passing and her choice. The family context is still very present in this video already in the first sentence, because she frames the issue like this:

> So if November 2nd comes along and I’ve passed, I hope my family is still proud of me and the choices I’ve made. And if November 2nd comes along and I’m still alive, I know that we will just still be moving forward as a family like, out of love for each other and that that decision will come later.[130]

The second video is more focused on Maynard herself and on her illness and choices and slightly less on family than the first video. In the first video, family seems to be the main focus at the expense of explaining or justifying the decisions taken by Maynard and this second video includes more explanations. However, the family angle is never forgotten and in most of these explanations family is somehow included or mentioned. An example of this is when Maynard explains that she is afraid of waiting too long and the choice of assisted dying being taken away from her because she would get too sick to be able to take the medication. She talks about one of her seizures after which she could not say her husband’s name.[131] While Maynard talks there is also footage of her and her family both through video clips where they are doing things together like having dinner or walking in the woods

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[128] The Brittany Maynard Story, 0:35.

[129] The Brittany Maynard Story, 2:48.

[130] A Video for All My Friends, 0:01.

[131] A Video for All My Friends, 2:45.

and through footage of photo frames of Maynard and her family. So even when Maynard is not talking about family, they are often present in the visual part of the video.

As in the first video, the last part of the second video is dedicated to Maynard's family and future plans. Since the video was released days before her death, the part about future plans focuses on Maynard's wishes to spend her last days with her loved ones and for her family to be able to move on after her death. Here the importance of family is again underlined, when Maynard not only wishes that they will get over her death, but expresses that she wishes that her husband moves on and becomes a father. This part of the video is quite emotional, but her policy goal of getting legislation passed is also mentioned in this section.

In general, the first two videos are both more emotional and more focused on family than the later ones. The story told is the same, but the main person telling the story changes. The context is also different; the first two videos are edited, with music playing in the background and filmed in Maynard's home. The two later videos are in the format of a news story and a presentation at an event and more clearly focused on policy in addition to sharing the personal story of Maynard. The first video where Dan Diaz tells the story, *Brittany Maynard's Husband Speaks Out On Death w/Dignity*, is an interview with the Big Picture program and the journalist frames the question in more outspokenly political terms when introducing the topic:

> If you knew that you were gonna die. And that before your death, you or your family would face unimaginable pain and suffering. Wouldn't you want the option to end that pain and suffering? A majority of Americans say they would. A HealthDay/ Harris Poll found that 74 percent of Americans believe that terminally ill individuals should have the choice to end their lives with dignity. Now lawmakers across America are listening to the American people. Last month California lawmakers introduced new death with dignity legislation, largely in response to the passing of 29-year-old Brittany Maynard, who became an advocate for death with dignity laws before she died with dignity under Oregon's Death with Dignity Act.[132]

Family is mentioned in this video as well, but the main focus is on the legislation that at the time of the interview had just been introduced in California. When Diaz is asked by the interviewer to tell Maynard's story, he does so by going through the facts including medical facts and emphasizing the timeline by including dates. The family angle is present throughout the telling of these facts by the pictures being shown on camera, but Diaz mentions family notably less than Maynard does in the earlier videos. The pictures shown in the video are the same or similar to those used in the earlier videos. In addition, one picture is included that was used frequently in the media, taken of Maynard

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[132] Brittany Maynard's Husband Speaks Out, 0:14.

before getting ill holding one of their dogs as a puppy in her lap. The interview is more focused on political arguments and processes than on family. If this is the decision of the journalist and network and their framing of the issue, or if Diaz himself is focusing mainly on facts rather than emotions and personal angles, is not clear. The main topic for the interview is the legislation being introduced in California. But this is also quite soon after Maynard's death and Diaz might not be comfortable with talking about more personal stuff so soon after his wife's death.

The last video, *Dan Diaz and Brittany Maynard: The end-of-life conversation*, is not an interview, so we hear the story more clearly in Diaz' own words without questions determining the direction the story takes. The video starts with an introduction of Diaz by Rebecca Frankfurt from Northern California Grantmakers so, like in the previous video, the issue is framed before Diaz tells the story, but after that it is his presentation without interruptions by questions. Diaz starts the presentation in a similar way to how he told it in the interview from 2015. He starts by the statement "Brittany died November 1st, 2014"[133] and then tells the audience that he will share some background to make the "reality of what Brittany was facing" understandable. After this he goes through the events in chronological order, mentioning many dates and medical details. Chronologically, he starts a little bit before the other tellings with meeting Maynard in 2007, but the focus is on the illness. He does bring up their wedding in relation to how the illness started in a similar way that Maynard does in the first video: "A few months after our wedding Brittany started having headaches that would wake her up in the middle of the night."[134] Like in the first video, wedding pictures are included in the presentation.

Diaz talks about family less than Maynard does. In the interview from 2015 he mentions family mostly in general terms and in relation to how the legislation is written in a way to protect family members from criminal charges, and patients from possible influence or coercion in their decision. Maynard is of course mentioned several times in the interview, but mostly as the main character of the story. Her role as Diaz' family, or his role as her husband, is not discussed by Diaz himself. The interviewer, in contrast, underlines family in his introduction to the topic and introduces Diaz as Maynard's "widower and husband"[135]. Diaz does refer to Maynard as "my wife" twice in the interview, but this is done in sentences that are not otherwise about family connections: "On January 1st, 2014, we found out that my wife had a brain tumor." and "We had to, in a sense, establish

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[133] The end-of-life conversation, 2:05.
[134] The end-of-life conversation, 2:40.
[135] Brittany Maynard's Husband Speaks Out, 1:22.

ourselves in Oregon, simply so that my wife could pass away peacefully, without suffering the way she would have if we'd stayed in California."[136]

Diaz does not talk about family from his own point of view, and his parents or siblings are not mentioned in any of the videos. There are a couple of "we" phrases, but otherwise he is mainly sharing Maynard's story, not his own. In the presentation from 2018, Diaz mentions their friends and family a couple of times. Maynard's best friend is mentioned, and he also talks about how both he and Maynard had seen what dying from a brain tumor looks like, through the experiences of parents of friends. Family comes up mostly at the end of the presentation when Diaz shows a clip of Maynard.[137] The clip is the end of the first video that was released by Maynard and in it she talks about how she will spend her last time surrounded by those she loves. After this, Diaz ends the presentation with how much Maynard loved life and her family. Diaz does not mention anything about what family means to him, but like in the previous video, he is not telling his own but Maynard's story. It is interesting that after the clip where Maynard talks about family, Diaz' presentation is closer to the way Maynard talks about the issue and more focused on life and love and less focused on the medical facts and political issue.

Even though family is one of the most central themes in the videos, it is restricted to a couple of people. As discussed above, Maynard's mother and husband take part in the videos and in addition to them her best friend and stepfather are mentioned. Maynard's biological father is not mentioned anywhere in the material, nor is any other family members such as grandparents or Diaz' family. Maynard does mention that she is her mother's only child.[138] One reason for restricting the number of people included in the videos is probably lack of time. The first two videos counted together consist of 12:28 minutes of material, which is not a lot of time to tell a story and it makes sense to leave out information. More people would also have made the story more complicated and a factor might also be that the videos were filmed in a different state from where Maynard lived most of her life. Maynard also explicitly says that no one else will be present at her death "I plan to be surrounded by my immediate family, which is my husband and my mother and my stepfather and my best friend, who is also a physician. And probably not much more people."[139] But this can be seen as a reference to dying at home with her family instead of surrounded by doctors and nurses in a hospital.

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[136] Brittany Maynard's Husband Speaks Out, 1:48; Brittany Maynard's Husband Speaks Out, 3:21.
[137] The end-of-life conversation, 14:34.
[138] A Video For All My Friends, 4:30.
[139] The Brittany Maynard Story, 2:31.

There are many reasons to emphasize the role of family in personal stories shared by advocacy organizations. Love for family members is something that a big part of the public can identify with. Many people can imagine the difficulty of saying goodbye to your loved ones. Talking about family makes Maynard and her family easy to relate to and creates emotion and drama in the story. It is also something that can be seen in other similar videos, for example many other videos on the Compassion & Choices channel also include family members. It has become part of the story model of how stories like this "should be told". This can be compared to Cain's study of stories told in Alcoholics Anonymous, where she found that the personal stories told followed a certain pattern or "model".[140] Related to this is the fact that the videos in general promote American middle class values, of which family is a big part. Cartwright found that similar values are emphasized in representations of breast cancer patients.[141] Emphasizing Maynard's love of life and her family is also connected in several instances to the fact that she does not want to die. Family love is in a way presented as "proof" that Maynard is not suicidal. For example, in *A Video for All My Friends* Maynard talks about that if her dreams came true she would get better, but because that is unlikely her biggest dream is that her mother and husband are able to move on with their lives and be happy.[142] Finally, it should also be mentioned that Maynard and her family might emphasize family love in their stories because they really are close and want to talk about it.

5.2 Interests, personality traits and beliefs

Details about Brittany Maynard's personality and interests are conveyed in the videos through what her family and she herself say about her and her life as well as through pictures − both photographs and in video form. How she is presented as a person is relevant, because of how she has become a front figure for the assisted dying movement in the United States and it is interesting to see what sort of personality traits are included and emphasized in connection to the campaign.

Maynard's personality and interests in the first two videos are conveyed through pictures, comments by her mother, and through how she tells her own story. In the later material, Maynard's personality and interests are discussed by Diaz and also shown through picture material included as photos and video clips in the interview from 2015 and presentation from 2018. Some aspects of her personality or person that are either discussed or shown in the material and will be discussed here are personality traits that are being used to describe Maynard, Maynard's age, and her interests. Some aspects of Maynard's life that are not mentioned in the material will also be discussed from the point

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[140] See Cain 1991.
[141] See Cartwright 2000.
[142] A Video for All My Friends, 4:09.

of view of why they might have been left out. In the first video, Maynard is described by her mother Debbie Ziegler in the following way:

> Brittany has always been, kind of, bigger than life. She has kind of a wanderlust and she's always liked exciting things, adrenaline rush. She's like, travelling, she's always been precocious and very, very bright and anything she set her mind to, she did.[143]

This quite neatly sums up how Maynard is presented in all the accounts. She is described – and shown – as someone who loves life, is physically active, outdoorsy and loves to travel, and is independent and knows what she wants. These are also personality traits that fit well into the presentation of her as an advocate for assisted dying. An argument for assisted dying that is used frequently in the debate in general and also in this material, is that the process gives dying patients' *choice* and *control*. In this context, it makes sense to emphasize personality traits that show Maynard as a person who is independent (from the influence of others), knows what she wants, and is willing to fight and sacrifice to get it. That she values activeness and being in good shape contrasts with the fact that she is dying and makes it relatable to viewers that she does not want to end up without control while her body is failing.[144]

Maynard is presented as a very active person both in the sense that she likes to be outdoors and doing athletic activities and in the sense that she takes charge of her own life and that autonomy is important to her. It is also visible in the picture material, which apart from the wedding pictures mostly consists of Maynard visiting exotic places such as Machu Picchu, and doing activities like hiking, climbing mountains, skiing, and kayaking. These pictures are probably mostly taken before her diagnosis, but some are also taken after, underlining the fact that Maynard did not want to stop living and experiencing things just because of her illness. In the second video, the level of activity and adventure is lower, but the video includes footage of Maynard and her husband walking in the woods and Maynard talks about how she enjoys going outside:

> I still get out and do what I can, I walk with my husband, I walk with my family and my dog. And things like that bring me the greatest feelings of health that I have these days.[145]

When Diaz talks about Maynard's interests in 2018, he connects this love for an active lifestyle with loving life and wanting to live and fight the disease:

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[143] The Brittany Maynard Story, 3:48.

[144] The arguments about choice and control are discussed in chapter 2.4. See also Johnstone 2013, 155–164. Autonomy arguments and how they figure in this material will be discussed in more detail in chapter 6.

[145] A Video for All My Friends, 1:25.

> She put the medication in the cupboard and she focused on living life. Brittany's passion was being outdoors in nature. So we went to Yellowstone National Park. She hiked glaciers in Alaska with her friend, a physician, we went to Olympic national park in Washington, Hood River in Oregon, and we took a helicopter tour of the Grand Canyon. And in addition, and in addition to focusing on living life and doing the things that mattered to her, we also sent her packet of medical information to all of the clinical trials that offered any glimmer of hope. When you have cancer, you fight.[146]

This way of relating activity and autonomy with enjoying life and not wanting to die can be connected to the arguments about why assisted dying is acceptable, because the person does not actually want to die. It is similar to the discussion about not relating it to suicide. At the same time, this might say something about modern life and the pressure to perform, have fun, and experience new things. It can put a lot of pressure on people if you are supposed to be climbing glaciers even when you are dying. On a personal level for Maynard, being used to being active and in control might contribute to the feeling that not being able to control death is unacceptable and that the option of hastening death is preferable. Both Maynard and Diaz talk about the fear of losing control on several occasions in the material.

Maynard's age is something that got a lot of focus in the media and she is often presented as "a 29-year-old woman".[147] In the videos, age is mentioned by Maynard when she talks about when she got the first diagnosis that she had a brain tumor and "three, maybe five, up to ten years to live". She continues, "I have to tell you, when you're 29 years old, being told you have that kind of timeline still feels like you're being told that you're gonna die tomorrow."[148] Her age is also mentioned in text panels in both the first and second video when Maynard is introduced. In both videos, the text panel with her age is combined with the fact that she has six months or less left to live, explicitly connecting her age to the concept of dying young.[149] In the two later videos, Maynard's age is mentioned by the people introducing the topic, before giving the floor to Dan Diaz. Otherwise the narrators do not really talk about age, but there is no need to. It is clear from the pictures, video clips and stories that Maynard is young.

That Maynard is young is important, because at least age-wise she is not representative of patients that qualify for assisted dying as a large majority of the patients are over 65 years old.[150] That might be part of why her story got so much attention among people of all ages, but it hides factors of aging

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[146] The end-of-life conversation, 9:02.

[147] See for example Weisensee Egan 2016 ("Terminally Ill 29-Year-Old Woman: Why I'm Choosing to Die on My Own Terms"); Bever 2014 ("Brittany Maynard, as promised, ends her life at 29"); Maynard 2014 ("My right to death with dignity at 29"); Slotnik 2014 ("Brittany Maynard, 'Death With Dignity' Ally, Dies at 29").

[148] The Brittany Maynard Story, 1:11.

[149] The Brittany Maynard Story, 0:16; A Video for All My Friends, 0:29.

[150] The statistics about who uses the Death with Dignity Act in Oregon are presented in chapter 2.3.

and the connection between old age and assisted dying from the public view. Cartwright has found similar patterns in how women with breast cancer are portrayed. Maynard fits the same profile of young, white, straight, upper and middle class, well educated, urban person that Cartwright finds is often how breast cancer patients are shown in the media as well. At the same time, Cartwright points out, audience members might not always identify with "people like themselves". An older woman does not necessarily identify more with a picture of someone her own age than with the picture of a younger person.[151]

It is worth pointing out that many of the landmark cases (and other cases that have gotten publicity) about the right to die have been cases featuring young, white, middle class women. This is the case with for example the Quinlan, Cruzan and Schiavo cases that all got a lot of attention.[152] It is important to keep in mind that often cases do not just happen to end up in the Supreme Court. Cases that are brought to court with the support of advocacy organizations are carefully chosen so that the facts suit the issue on which the organization wants to influence legislation. When cases are chosen, the profile of the person at the center of the case is one consideration affecting the choice. According to Hillyard and Dombrink, the Quinlan case brought to the attention of the public the point that a situation concerning the right to die could happen to anyone.[153] Maynard's youth and active lifestyle similarly underline the fact that assisted dying could concern anyone.

It is also interesting to note that some aspects of Maynard's life are not included in the videos. Her education, or if she has a job, is not discussed and neither are the education or careers of her family and friends, except for her best friend being a physician and that Diaz took a leave of absence from his job when they moved to Oregon. It is not specified where or with what Diaz works. Although it is not mentioned, the family's socioeconomic level is still present in the material. They talk about travelling all over the world, expensive hobbies such as rock climbing, and they were able to move their lives to Oregon for months and get a second home there. It is true that work, education or socioeconomic status does not relate to having brain cancer, but these aspects might also have been left out to make the family appeal to a wider audience. It is also possible that these were things that the family wanted to keep private or that they were thought to be less relevant than other things that were included in the videos.

Religion is not discussed by Maynard, but Diaz, who is a Catholic, mentions it in the later videos. He focuses mostly on the Catholic Church as one of the big organizations that are opposing assisted dying and not on his own religious views. He does not, for example, explain how supporting assisted

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[151] Cartwright 2000, 124–126.
[152] These cases are discussed in more detail in chapter 2.2.
[153] Hillyard and Dombrink 2001, 13.

dying fits into his faith. In the interview from 2015, it is the journalist who brings up the Catholic Church:

> Interviewer: I'm just curious, I lived in Oregon when that law was passed and it was a voter-run issue actually, the legislation didn't have the courage to do it. And the main push-back was coming from the Catholic Church and some Evangelicals who were basically recycling abortion arguments in a way, you know they called themselves right to life. Are you getting this same sort of blowback or has that died down now that people are more familiar with this and, it's been a few years in Oregon and Washington State has done it.[154]

According to Montero, supporters of the legalization of euthanasia often frame it as an issue about religion to advance their own arguments. If the opponents are assumed to believe that the power to make decisions about death belongs to God, it can be argued that legislators should not favor religious opinions that are held by only a part of the population. Then the argument follows that euthanasia should be legalized to give the option to those who want it, and those who do not can leave that option unused.[155] This is close to how it is framed in the material by Diaz. He mentions that Maynard was not very religious, but that she also did not see the question of assisted dying as a religious issue:

> Brittany and I talked through it and she wasn't terribly religious so for her this is a moral, this is an ethical decision that a church official really shouldn't be… It should be the patient deciding.[156]

Montero's objection to this type of reasoning is that it frames the issue as a purely private choice, ignoring its larger impact on culture and society. Montero believes that the legal and political point of view, not ethical or philosophical viewpoints, should be in focus in the debate on this issue.[157]

Diaz responds to the question about the Catholic Church posed by the interviewer that they[158] expect opposition from the church. But he does not elaborate further on the question of religion. The framing of the Catholic Church as the main opponent to legislation fits into Montero's arguments on how religion more generally, and the Catholic Church in particular, are being framed as the main opponents to assisted dying. But in this case the Catholic Church also actively involved itself in the issue. Father Ignacio Carrasco de Paula, who is the president of the Pontifical Academy for Life at the Vatican, which is an academic honorary society responsible for questions concerning ethics,

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[154] Brittany Maynard's Husband Speaks Out, 7:26.

[155] Montero 2004, 163−164.

[156] Brittany Maynard's Husband Speaks Out, 8:30.

[157] Montero 2004, 163−164.

[158] Diaz uses the phrase "we expect…". Presumably he is talking about those involved in the Compassion & Choices campaign and/or the legislators who were at the time trying to get the legislation passed in California.

condemned assisted dying and commented directly on the Maynard case days after Maynard's death. He said that ending your life is not an act of dignity.[159] A couple of weeks later the Pope commented in general terms on the death-with-dignity movement calling it "playing with life" and "a sin against God".[160] This is not the first time the Vatican gets involved in a right to die case in the United States as they also commented on the Schiavo case.

What especially stands out in the descriptions of Maynard's personality is that she loved travelling, adventure, and being outdoors. These are all very active personality traits which fit into the picture of someone who knows her mind and can make rational and smart choices for her life (and death). Maynard's young age makes her case stand out and it was one of the features about her case that was most underlined in the media. Despite this being a controversial issue, Maynard and her family mainly represent traditional values. Before examining some of the arguments and communication strategies used in the videos, there are some points to be made about how the story is told.

5.3 How is the story told

In addition to speech, information in the videos is given through text and pictures. In the first two videos, *The Brittany Maynard Story* and *A Video for All My Friends*, the text panels have the same format: simple white text on a black background inserted into the video like intertitles. In the news story, the logo of the show is visible at the bottom of the page and when Diaz first appears his name is shown on a text panel along with the title "Death with Dignity Advocate" in a way typical of news stories. Later in the interview the text panel shows the text "Terminal Illness: Right to Choose" as sort of a title for what the discussion is about. At the bottom of the page, other news headlines are rolling by. In the last video, a similar panel with Diaz' name and title, this time the title is "Patients' Rights Advocate, Widower of Brittany Maynard", has been added to the video when Diaz first appears. In addition, his presentation includes a couple of quotes on fear and wisdom that are shown on-screen.

Both pictures and text inserts are sometimes shown with only music in the background and sometimes with someone talking in voiceover. The discussion that follows here will focus on how the text segments are used in the first two videos, because in that case they have their own "role" in providing information in the story. If you wanted to simplify, you could say that the photographs bring emotions and the text panels rational facts to the videos. The photographs included in the videos are mostly taken before Maynard got sick and in most of them she is portrayed smiling and looking happy with her husband, mother or best friend. Adventure and activity is also shown through

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[159] McKenna 2014a.

[160] McKenna 2014b.

these photos, which are often taken during activities such as skiing, kayaking or rock climbing. There are also quite a few pictures from Maynard and Diaz' wedding included.

In contrast, the texts in the videos provide background commentary and information that frame the story. This is how more "technical" information is included in the videos. For example, the text inserts near the beginning of the first video tell the viewers that:

> In January 2014, after years of suffering from debilitating headaches, Brittany Maynard found out she has brain cancer. She was given a prognosis of six months left to live. She had recently turned 29.[161]

And a bit later in the same video there is a text panel explaining the type of brain tumor that Maynard had:

> Glioblastoma multiforme is the most aggressive and lethal form of brain cancer. It grows and spreads to other parts of the brain quickly. Studies show that few patients survive beyond three years, regardless of the treatment course they receive.[162]

In addition to medical information, policy is another thing that is included through text panels, although they are also mentioned by Maynard and Diaz in speech. For example, *The Brittany Maynard Story* ends on a political note with the following quote:

> At present, only 5 U.S. states allow terminally ill patients the right to die with dignity. A movement is underway to expand access, so that no American has to endure prolonged pain and suffering. Join us: www.thebrittanyfund.org.[163]

In a similar way, text panels in *A Video for All My Friends* tell the audience that Maynard's story has gone viral and how the Oregon Death with Dignity Act works. The texts and pictures also relate to local context in the videos. For example, when Maynard talks about her decision, a text panel follows explaining the Oregon law. This is even more visible with the picture material, when wedding pictures are shown when Maynard talks about her wedding, when her wedding ring is filmed when she talks about trying to have a baby, or when she is talking about dying upstairs in her own bed and the bed is filmed.

The people included in the first two videos are Maynard, her husband Dan Diaz and her mother Debbie Ziegler. No one is filmed talking together, but there is background footage where they set the table and walk in the woods together. They all talk in slightly different ways about different topics. Maynard talks the most on both videos and she talks a lot about her love for her family but also tells

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[161] The Brittany Maynard Story, 0:08.
[162] The Brittany Maynard Story, 1:03.
[163] The Brittany Maynard Story, 6:17.

her illness story and how she plans to die. Ziegler talks the most about emotions of the three people in the video. She talks about how the diagnosis was a shock to her and about her reaction to it and having false hope. She also talks about Maynard's personality, describing what Maynard is like. Otherwise Maynard's personality is mostly conveyed through how she talks about things or through pictures where she is often smiling and doing active things. Of the three, Diaz talks the least about feelings, although he does mention that it brings him relief that Maynard will not have to suffer. This might be related to gender, both in the sense of what Diaz feels comfortable discussing or what is "appropriate" to discuss and on the other hand how the director and Compassion & Choices think he should be represented. Riessman has found in her research with divorced couples that men talk less about feeling than women do. She finds that men avoid talking about feelings and instead emphasize action and doing in their narratives.[164] A reason for the different ways of talking might be that Compassion & Choices wanted to give the three people slightly different profiles to resonate with more people. With such a small sample where everyone is part of the same family, family culture might also affect what roles they take on and off camera.[165]

In the later videos filmed after Maynard's death, only Diaz is present of the three, but Maynard's influence on the videos happens in other ways. It is interesting in this last video how Diaz not only tells Maynard's story instead of his own, but at times also does it in her words. He quotes her a couple of times, about things that he says that she said to him. The first quote by Maynard that Diaz cites is after telling the audience why chemotherapy was not an option as the side effects would make the suffering worse and it would not cure her. The way he tells it has narrative elements and evaluative clauses[166], making it sounds almost like lines in a storybook:

> "I'm not afraid to die," Brittany said to me one day, "I'm not afraid of death. Death does not have that power over me anymore." Those words were not just lip service; I knew Brittany truly meant that. She did not fear death. "But I am afraid of suffering," she said. "Especially since I will die anyway. I would prefer to die gently. Not struggling and in pain."[167]

The story goes on with how Maynard had brought up medical aid in dying. The quote explains her reasoning and Diaz' "verification" of her words when he says "I knew Brittany truly meant that." is interesting. A similar type of quote is introduced by Diaz later in the story. After he has described the process of dying from a brain tumor and how it affects, or risks affecting, the motor function and

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[164] Riessman 1990 as discussed in Riessman 2008, 100.

[165] The Brittany Maynard Story, 3:00.

[166] Labov found evaluation to be one of the key elements of narrative. Evaluative clauses explain the point of the narrative. See for example Patterson 2008, 26–27.

[167] The end-of-life conversation, 4:40.

communication abilities of the patient. He again lets Maynard comment: "Brittany said, 'I will not die that way. Why should I be forced to?'"[168]

Diaz uses a couple of other ways to give Maynard an active part in the story after her death. Both the presentation from 2018 and the interview from 2015 include a short clip from different parts of the video released by Maynard before her death. In the interview from 2015, Maynard's clip is played as part of the introduction before the interview with Diaz. She talks about how the medication brings her relief because she will not have to suffer. In the presentation from 2017 the clip is played at the end and Maynard talks about what is important in life.[169] This way she is part of the discussion and the audience hears her message in her own words. In the presentation from 2018 Diaz also uses a third way of "letting Maynard have her say". On the issue of palliative and hospice care, he underlines that Maynard wanted it to be said that they are not at odds with assisted dying. This is an issue that has sometimes been brought up as part of the debate on assisted dying and euthanasia and will be discussed further in chapter 6. When talking in general terms about the laws or safeguards or something related to "the patient", Diaz uses the pronoun "she" a couple of times, linking what he is saying to Maynard's story.

In this chapter Maynard's personal story and themes related to Maynard's personal life and character have been discussed. The main theme that stands out in the content of the narratives is the central role that family is given in the story. Maynard relates most of her thoughts and feelings to family in some way. In the later videos, Diaz is more clearly focused on policy, but because he is not telling his own story, but Maynard's, their relationship is still present in the story at all times. The other theme that stands out the most in these descriptions of personality and personal life is Maynard's interest in travelling and adventure. The next chapter examines how these personality traits are connected to the policy arguments included in the story.

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[168] The end-of-life conversation, 7:50.

[169] Brittany Maynard's Husband Speaks Out, 1:00; The end-of-life conversation, 14:34.

6. Arguments, counter-arguments and communication strategies

This second part of the analysis focuses on the arguments and communication strategies used in the videos to support the aims of the campaign to legalize assisted dying. The arguments and strategies are grouped in three subchapters. The first part is focused on actual arguments and counter-arguments for supporting legalization that can be found in the material. But they are only part of the ways used to argue for the issue. The next part focuses on the normalizations and framing strategies used in the videos to make a case for assisted dying. The third part focuses on the communication strategies employed to keep the issue on the agenda or influence public opinion. These strategies and arguments are not clearly separated from each other and are often used together to support each other and to make a point.

6.1 Arguments

Most of the arguments used in the videos relate to either autonomy or suffering. This is similar to what Johnstone found in her research that arguments about autonomy, pain and suffering, and dignity are the arguments most commonly used for legalizing assisted dying and euthanasia. Tatum, in his study of arguments used in narratives about assisted dying cases in trial, also found the main arguments to be related to autonomy and compassion for suffering.[170] In contrast to Johnstone's results, dignity is not used much as an argument by Maynard and her family, at least not in that wording. This might be because dignity as a term has become somewhat controversial. Dignity still features in the videos and will be discussed further below; it is for example used frequently by the interviewer in the 2015 video. The arguments used in the videos are not presented as policy arguments but rather included as part of the story and Maynard's personal experience. When Maynard talks about the medication and choosing what her death will look like the point of view is personal and the description practical:

> I don't wake up every day and look at it [the medication]. It's in a safe spot and I know that it's there when I need it. I plan to be surrounded by my immediate family, which is my husband, and my mother, and my stepfather, and my best friend, who is also a physician. And probably not much more people. And I will die upstairs in my bedroom that I share with my husband. With my mother and husband by my side. And pass peacefully, with some music that I like in the background.[171]

While Maynard talks, first the medicine bottle, and then the bedroom is filmed, adding to the practically oriented description by showing the things she is talking about. Especially in the first two videos, the content is presented as Brittany Maynard's personal story and opposing views or

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[170] Johnstone 2013, 71; Tatum 2002. See also Hillyard and Dombrink 2001.

[171] The Brittany Maynard Story, 2:23.

arguments about policy are mostly not discussed. The two later videos are more clearly framed as part of the policy campaign. The arguments about autonomy and suffering that feature in the videos are not discussed in detail in a legal or philosophical context; the discussion stays mostly at the personal level. The policy goal is often phrased as wanting all Americans to have the choice to control their death and avoid suffering. In the two later videos the context is slightly more political and generalizing and less personal. There might be several reasons for this. The context of the later videos is clearly focused on campaigning; and since Maynard's death, Diaz has also been sharing her story in campaign context for years, which affects how he tells it. The fact that Diaz is not sharing his own story also affects the content. Maynard's story is used as an example of how the act works in practice and Diaz talks about Maynard's choices, emotions and decisions while also arguing for why assisted dying should be legalized. These same reasons might explain why many of the communication strategies figure more in the later videos, the first two videos are more focused on the personal story, but the two main arguments autonomy and unnecessary suffering are the same in all four videos. In the first video, Diaz is the first one to mention suffering, and it is also the first argument presented by any of the narrators:

> Between, you know, suffering or being allowed to decide when enough is enough. It just, to me […] it provides a lot of relief and comfort that, okay, that option is there if and when we decide, or she decides, that it's time.
>
> […]
>
> Death with dignity allows for people who are in the predicament of facing a lot of suffering that they can decide when enough is enough.[172]

The video is edited here so that it cuts to Maynard talking about suffering between Diaz' lines. She repeats the sentiment about feeling relief over not having to suffer. Diaz, in this quote, is also the first to bring up the political side of things, which is interesting as Maynard is otherwise presented as active and independent and the one who takes charge and makes decisions. This might have to do with the tactic discussed above of how stories are used politically by Compassion & Choices, where different people are giving different roles in the campaign so that one for example shares her personal story and someone else focuses more on "the facts".

According to Johnstone, there is strong cultural belief in western liberal democracies that competent adults have the right to autonomy. In health care, this can be seen in bills about patients' rights, laws about privacy and consent and court decisions on the right to refuse care and make advance directives. There is an overview in chapter 2.2 of how these laws and decisions developed in the

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[172] The Brittany Maynard Story, 3:00; The Brittany Maynard Story, 3:35.

United States. The right-to-die movement often makes the argument that the right to self-determining choices in life should also be respected in choices concerning death. These choices include choices about where, when, how and under what circumstances a person's death should take place. According to Johnstone, the rhetoric of choice is problematic because it is assumed, without backing up the claim, that choice is fundamentally important and that authentic choice is possible and occurs in this context.[173]

Johnstone finds that the risk and fear of losing control in death is often emphasized in narratives and real life case scenarios related to assisted dying. Johnstone thinks that any sense of control or choice brought by assisted dying legalization is an illusion, because the choice would only be meaningful if humans could live forever and had a genuine choice between that and dying. She continues that even if a person's death is carried out according to their plan and they feel in control, they have in reality abdicated that control to the person assisting them to die. Catherine Belling, on the other hand, finds that planning our death and telling the story of how we want it to look can bring a sense of control that helps patients deal with the fact that they are dying. Belling does not suggest that we can fully control everything, but that an element of control over the details can help bring closure and meaning. She thinks that this can explain why people choose to hasten their death, but also thinks that similar death plans in narrative form could help bring a sense of control for other patients as well, who do not choose assisted dying. Compared to Johnstone, Belling is focused less on who has the actual control in terms of power relations and instead on how to bring terminally ill patients a sense of control and comfort through preparing for death.[174]

How Maynard is described as an active person who loves travelling is connected to the question of control. For example in the first video Maynard's mother talks about how since she was little Maynard has always done anything that she set her mind to. In the video this is connected to her love for travelling and being active in pursuing her goals even though she is dying and also, a bit less directly, to controlling her own death and making her own decisions. Ziegler connects it to choice and autonomy in the following way: "It's not my job to tell her how to live, and it's not my job to tell her how to die. It's my job to love her through it."[175]

When Maynard and her family talk about control and choice, they seem to be closer to Belling than Johnstone in their meanings. Maynard talks about who she wants to be present at her death, where she wants it to happen, and that she wants to choose what music is playing it is more a question of a sense of control. She also talks about things she wants to do before she dies:

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[173] Johnstone 2013, 157.
[174] Johnstone 2013, 155−156; Belling 2004, 146−153.
[175] A Video For All My Friends, 3:58.

> Before I pass, I hope to make it to the Grand Canyon. And that's all I can do – set little goals like that. And all those things make every day worthwhile.[176]

Although it could be argued that for someone very sick making it to the Grand Canyon is actually a quite big goal, this underlines that the things she aims to control are concrete and limited and practical and not big philosophical questions. Johnstone claims these kinds of choices are meaningless[177], but if the only choices that are meaningful are life-altering choices, then can we really be said to control any aspect of our lives? When Maynard and her family talk about controlling death it is more about dying at home and deciding when it happens. They also mention the feeling of control several times and how that has brought them relief and strength:

> I cannot even tell you the amount of relief that it provides me to know that I do not have to die the way that it's been described to me that my brain tumor would take me on its own.[178]
>
> And having this medication emboldened her to fight. Up until Brittany received the medication she could not escape the torture that the brain tumor could exact upon her. But all of the sudden, because of simply having the medication, that fear vanished. Brittany had taken control back from the tumor.[179]

In the case of the assisted dying acts in the United States, there are safeguards that both add and diminish patient control. Self-administration is the biggest safeguard against the influence of others. The patient has to take the medication him- or herself so in that sense control is not given to any other person. The requirements of a diagnosis of less than six months to live and mental capability give physicians control over who gets a prescription, but Johnstone's argument discussed above about giving over control to physicians is perhaps more relevant in cases where drugs are administered by the physician than in cases where the patient takes the medication.

is also underlined in the material that Maynard is not choosing to die, but how to die, because if she could, she would like to live. Diaz and Maynard make clear that in their opinion it is not a choice between living and dying, which is why, in their opinion, this cannot be described as suicide:

> The term suicide is neither applicable nor appropriate in describing this medical practice. My wife Brittany wanted to live. A suicidal person wants to die. Brittany wasn't depressed, despondent or making irrational decisions. All of those being characteristics of an individual that is suicidal. A terminally ill individual that applies for this program isn't choosing between living and dying. The living part, that option is no longer on the

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[176] The Brittany Maynard Story, 4:42.
[177] Johnstone 2013, 158–160.
[178] The Brittany Maynard Story, 3:25.
[179] The end-of-life conversation, 10:04.

> table. She is only choosing between two different methods of dying. One is gentle, peaceful. The other would be struggle.[180]

Johnstone discusses if choice is desirable in this kind of situation and if it is, then if the choice in question is a meaningful one as we would die eventually anyway. I think that much like the discussion about control, Maynard and Johnstone talk about different things when they talk about the choice to die. Maynard underlines when telling her story that the choice is not between living and dying, but about how to die. Maynard and Diaz also talk about how having the option is important and that having the medication brings a sense of control whether the patient takes it or not. Johnstone does, however, pose another interesting question about choice. She discusses how much humans are in charge of the choices we make and how much they happen subconsciously and we rationalize our decisions afterwards. This is a really interesting point about choice in general and does relate to the question about how much advocacy organizations are truly able to influence opinion and thoughts. However, that argument could be applied to all healthcare decisions made by patients or even all decisions made by anyone. It does connect to the argument against legalization of euthanasia that people might change their minds.[181] This argument is not addressed by Maynard and Diaz. They seem to assume that people do know their own minds and are able to make this kind of choice rationally. In general, autonomy is an important value in the United States, and I have not come across the argument that people would not be able to make rational choices at the end of life by those in the United States who oppose legalization either. The U.S. legislation has safeguards in place that try to deal with the fact that someone might change their mind. These safeguards include waiting periods and the fact that the patient has to take the medication him/herself. But if Johnstone is correct and we rationalize our choices to ourselves this might not have much effect. I find this discussion about choice interesting but as an argument against legalization it is problematic because of the fact that it relates to all choice and could similarly be used against all autonomy. However, this underlines that the argument for legalization for reasons of autonomy and choice is not straightforward either.

Montero is also critical toward the choice rhetoric, but he uses different reasoning. Montero argues that framing euthanasia as a question of autonomy and private choice, and that this right should triumph over moral convictions, is misleading. He emphasizes that the law is connected to a host of social, moral and cultural values that affect everyone in the society. The right to end or help end someone’s life, if given to medical professionals, would change the medical profession and by extension affect society as a whole. Montero makes his argument about euthanasia, where the

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[180] The end-of-life conversation, 12:34.
[181] Johnstone 2013, 157−164.

physician administers the drugs to end someone's life and does not mention assisted dying in the form that it exists in the United States where the patient self-administers. However, he also underlines that although suicide is not explicitly illegal (for reasons discussed in chapter 2.2), it is still ethically questionable to take one's own life and has never been recognized as a right. Montero argues that euthanasia is not only an ethical question and personal choice but also a question of sociopolitical ethics, which is why it can be forbidden in accordance with the public interest to protect all patients, the integrity of the medical profession and the foundation of the legal system.[182]

Like with the autonomy arguments, pain and suffering are discussed in the videos at the personal level and made part of the illness narrative rather than discussed explicitly as an argument for legalization. In this case it becomes even more personalized than with the autonomy arguments, because many of the symptoms described are connected to brain tumors and Maynard's personal suffering and symptoms. Diaz talks quite a lot about suffering in the later videos and he is the first one to bring it up in the first video. The language he uses about pain and suffering is quite violent:

> So those are the parameters of the program. But what might be some of the reasons for pursuing it? The fear of being tortured to death, if the brain tumor was allowed to run its course. That was the one thing that terrified Brittany. It had already been explained to us by her medical team, and a simple search on the internet will give you the list of horrific symptoms that a person with a brain tumor might endure as they are dying. But on top of that both of Brittany and I each had a friend whose parent died. One of a GBM, the other of a stage three brain cancer, so we knew what was coming firsthand.[183]

In addition to the violence described, this quote also includes common sense strategies such as referring to both experts and personal experience. Diaz continues with describing some of the symptoms that are associated with brain tumors:

> And that included pain that could not be alleviated with morphine. Dilaudid is four times stronger than morphine and Brittany was on some hefty doses of Dilaudid. Personality changes where one minute the individual seems normal, the next minute they might be agitated, cruel or violent. Seizures that become increasingly frequent and severe. The mild seizures would leave her unable to speak for 20 to 30 minutes. The grand mal seizures, when she had those, those would leave her exhausted, typically throughout the following day, sometimes with blood coming out of her mouth because she's bitten through part of her tongue. That's just the reality of what she was dealing with.[184]
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> The probability that she would go blind as the tumor grows and puts pressure on different parts of the brain, the likelihood that she would lose the ability to speak and

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[182] Montero 2004, 177.
[183] The end-of-life conversation, 5:58.
[184] The end-of-life conversation, 6:40.

> communicate altogether. It’s not uncommon for a brain tumor to cause a stroke and depending on what part of the brain is damaged due to the lack of oxygen during the stroke she could lose motor function, the ability to stand, walk, swallow, partial paralysis with likely complete paralysis a possibility.[185]

This account of symptoms is interesting for a couple of reasons. Firstly, like in the previous quote, the description is quite violent and interestingly enough, Diaz uses similar “common sense” strategies in this part of the story. Between the horrifying descriptions he uses phrases like “That’s just the reality of what she was dealing with.” or “It’s not uncommon…”[186] Another interesting point about this account is that it mixes symptoms that Maynard was already having with possible scenarios that might occur in the future. The reason that Diaz talks about suffering more than the others might be that different people in the video talk about slightly different themes. It might also be that the people involved in making the videos (including Maynard and her family) thought that it “looks better” and is perceived more as facts and less as complaining if someone else mentions the suffering, because there is more of a distance when you talk about someone else’s suffering. It probably also affected him a lot to watch from the side as some of the symptoms described above occurred. He has also been involved in the campaign for years so he has had time to reflect on his experiences and research possible symptoms and possible scenarios.

As mentioned above, dignity, the third of the most common arguments for legalization according to Johnstone, and one that also came up frequently in the research about reasons for assisted dying in Oregon, is not often used as an argument in this material.[187] An exception is the interviewer in the video from 2015, *Brittany Maynard’s Husband Speaks Out On Death w/Dignity*, who uses the phrase “dying with dignity”. Otherwise it is mostly used when referring to the name of the legislation in Oregon, which is called the Death with Dignity Act. According to one of their training videos[188], Compassion & Choices no longer recommends using this phrase because there has been some critique that there are many other ways than assisted dying to die ”with dignity”.[189] However, the fact that the word dignity is no longer used that much by Compassion & Choices, or Dan Diaz, does not mean that they do not use any arguments related to dignity in their campaigning. When talking about her seizures, Maynard speaks about not being able to say her husband’s name after a strong seizure. In the last video, Diaz lists some symptoms that Maynard had or were likely to get at a later stage if she would have died from the tumor. These include symptoms related to other than physical pain and suffering such as personality changes and not being able to speak or communicate in any

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[185] The end-of-life conversation, 7:20.

[186] This kind of common sense clauses will be discussed in more detail in chapter 6.2.

[187] Johnstone 2013, 71; Ganzini et al. 2002; Ganzini, Goy and Dobscha 2009.

[188] CompassionChoices, January 2017 NY Volunteer Training, 46:14.

[189] For more discussion on the term dignity in the context of assisted dying, see chapter 2.1.

way.[190] The fear of this kind of symptoms connected to other than physical suffering can be interpreted as referring to the same kind of fears felt by the people who list dignity as a reason for wanting assisted dying.

A concept that is related both to autonomy arguments and arguments about pain and suffering is risk. The videos include a significant amount of talk about risk. Autonomy is mentioned both in a negative and a positive sense in the videos. The positive way of discussing autonomy includes for example Maynard talking about how just having the medicine brings relief and comfort, because she "know[s] that it's there" when she "need[s] it".[191] Diaz also talks about feeling relief over having the option if the suffering becomes too much.[192] Having the option of ending your life is treated as comforting to both the person that is dying and to her family who does not want to see her suffer. On the other hand, autonomy is also talked about in a more negative context related to fear:

> When people criticize me for not, not like, waiting longer or, you know whatever they've decided is best for me, it hurts because really I risk it, I risk it every day, every day that I wake up.[193]
>
> So the worst thing that could happen to me is that I wait too long because I'm trying to seize each day, but that I somehow have my autonomy taken away from me by my disease because of the nature of my cancer.[194]

Maynard talks about fear and risk strongly in connection with autonomy. What she fears is losing control, and losing the option to die the way she wants to. Both ways of expressing fear and risk, whether in a more positive or negative tone, make a strong connection between assisted dying and a sense of security. This fits well with Johnstone's claim that assisted dying works as a sort of protection and solution against a bad death, but at the same time thinking about it also increases the feelings that protection is needed.[195] The quotes above also underline that choice in this context is not only about whether to get the medication or not. After you do, you still have to keep making the choice of whether or not, and when, to take it. Around two thirds of the patients who receive a prescription in accordance with the Death with Dignity Act in Oregon die from ingesting the medication.[196]

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[190] A Video for All My Friends, 2:36; The end-of-life conversation, 6:50.
[191] The Brittany Maynard Story, 2:25; The Brittany Maynard Story, 3:23.
[192] The Brittany Maynard Story, 3:00.
[193] A Video for All My Friends, 0:45.
[194] A Video for All My Friends, 2:16.
[195] See chapter 3.3 and Johnstone 2013, 148–152.
[196] For statistics over the usage of the Oregon Death with Dignity Act for the 20 years it has been in place, see chapter 2.3.

More ethical or philosophical arguments such as arguments about fairness are not brought up much in the videos. Fairness and justice arguments figure in the debate about euthanasia in the context that some people have to endure more suffering than others and that it is unfair to ask them to endure what others who are not suffering would not be prepared to endure.[197] Unfairness is hinted at when Maynard talks about how people have decided what they think would be best for her or Diaz mentions that some people think applying for assisted dying is to give up. Arguments about altruism, or a "duty to die", which are discussed in chapter 2, do not figure in the videos. I'm assuming this argument is quite rare in debates and not agreed with by most supporters of legalization.

By not discussing the ethical aspects at the society level and instead focusing on personal stories, the issue of assisted dying is personalized. If the debate is mainly focused on the individual's rights, or on the opposing side, on the wrongness of ending a life, important structural and cultural effects on society caused by the legislation might be ignored. The narratives of personal stories frame the issue as a personal choice that should be given to anyone that wants it and can be ignored by anyone who does not want it. Another way to frame the issue in terms of rationality is by normalization and common sense strategies, which will be discussed next.

6.2 Common sense, framing, and normalization strategies

There are different kinds of statements used in the debate that are not exactly arguments for or against legalization, but are used to argue the case in a similar way. These are statements aimed at either normalizing the issue or framing it in a certain way. These statements are often presented as common sense and something that is obvious, but evidence supporting the claims is rarely presented. Some examples of normalization and common sense strategies that will be discussed here are: framing assisted dying as medical practice and part of other end-of-life care, discussion about legalization and safeguards, and using certain language and phrases.

According to Johnstone, one of the normalization techniques used by the right-to-die movement is to present assisted dying and euthanasia as a normal medical procedure or part of palliative care.[198] Usually in the euthanasia debate it is assumed that the procedure would be performed by a physician, but there has been some discussion about this not being compatible with the aims of that profession and if it, in case it was legalized should be performed by someone else. This discussion is not that central to the debate in the United States, because one of the most important features of the laws in place about assisted dying is that the patient has to take the drugs without help. The

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[197] Johnstone 2013, 70.
[198] Johnstone 2013, 132.

assistance from the physician is related to writing the prescription. Still, it is not accepted by everyone that this role is compatible with the medical profession.

There are a couple of instances where assisted dying is connected to medical practice in the last video, but this connection is not made in the other ones. The reason for this might be that Diaz at the time the last video was filmed had been involved with Compassion & Choices for nearly four years and has been influenced by their rhetoric and arguments. It might also be that the presentation or lecture form of the event and having more time to talk freely affects the content. There is also no footage or pictures of doctors, nurses or medical equipment, except for filming the medicine bottle in *The Brittany Maynard Story* when Maynard talks about how having the medication brings her comfort.[199] The video also shows an MRI scan of her brain where the tumor is marked. Diaz includes the same picture in his presentation in *The end-of-life conversation*.[200] In this presentation there are a couple of other ways as well where medical practice is referred to in relation to assisted dying in a way that could be seen as framing the issue as medical practice. In the video, Diaz talks about the Oregon Death with Dignity Act as a program, which could be a way of associating it with medical treatment programs. For example:

> Brittany died gently on November 1st, 2014. Within five minutes of taking the medication she fell asleep very peacefully. Within thirty minutes her breathing slowed to the point where she passed away. That was the gentle dying process that this program afforded her.[201]
>
> A terminally ill individual that applies for this program is not choosing between living and dying. This program is very narrowly focused and it affords a very small number of individuals like Brittany that find themselves in this predicament.[202]

In one instance Diaz does make the direct connection to assisted dying as medical practice. This is done when he is discussing language, and how this is not suicide. Here he explicitly states that it is a medical practice:

> A quick side note regarding words and terminology; medical aid in dying is the term that you'll hear me use. There are those that attempt to apply the term suicide, euthanasia, physician-assisted suicide. The term suicide is neither applicable nor appropriate in describing this medical practice.[203]

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[199] The Brittany Maynard Story, 2:27. Maynard also mentions in the same video that her best friend who will be present at her death is a physician. This is also mentioned by Diaz in The end-of-life conversation.

[200] The Brittany Maynard Story, 1:24; The end-of-life conversation, 3:45.

[201] The end-of-life conversation, 11:43.

[202] The end-of-life conversation, 12:56.

[203] The end-of-life conversation, 12:12.

This is the only clear statement in the material that assisted dying is medical practice and the statement is underlined because it is being contrasted with suicide. There is also one instance related to medicine and common sense strategies where Diaz explains the medication that Maynard used, to "demystify" the practice.

> Just to demystify the medication; because over the past three years I've heard all kinds of crazy things. The prescription is a sleeping medicine. Secobarbital is the name. It's been around for over 80 years. So long before there was Ambien − a person had difficulties sleeping; you might get a prescription for Secobarbital. I'm careful to explain this, because I've heard people refer to it as a singular black pill or that it's an injection into a person's IV. The biggest safeguard is that the terminally ill individual has to able to take the medication on her own. Brittany has to be able to consume that Secobarbital. It's a regular prescription. There's a hundred capsules. Those capsules have to be opened; their powders emptied into a glass. It's mixed with four or five ounces of water. It's a whole process.[204]

All of this is said in a slightly amused tone, supporting the idea in the beginning of the quote that opponents and critics of assisted dying believe "crazy things" about how assisted dying works in practice. This paints opponents as irrational and suggests that if they only understood what it is really about, they would not oppose assisted dying. While the claim is not false − there probably are a lot of untrue beliefs in relation to assisted dying and there are blogs and articles claiming all sorts of things, including that Maynard is not really dead and was played by an actress in the videos – it suggests that many opponents are simply misinformed and in opposition because they do not know better. Diaz on the other hand, by using medical terms, knowing the names of medications, and explaining how the medicine or safeguards in the act work − sounds like an expert.

Johnstone also discusses the relationship between assisted dying and palliative care. She finds that there in Australia, has been a re-branding of the right-to-die groups where assisted dying is presented as a choice alongside other alternatives in end-of-life care, including hospice and palliative care. It is often presented in a context of choice and having more alternatives to offer. But she sees this as a linguistic device to frame assisted dying in a certain way to guide people to think of it as part of medical and hospice care and affect how people think about assisted dying.[205]

The connection to hospice and palliative care is a phenomenon that can also be seen in a lot of the information material produced by Compassion & Choices, which on its webpage has information about different options at the end of life, including different alternative for hospice care. There is, however, not much talk about hospice care in the material. It is only mentioned in the last video:

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[204] The end-of-life conversation, 10:53.

[205] Johnstone 2013, 130−135.

> One last note, and this comes directly from Brittany, medical aid in dying is not at odds with hospice and palliative care. Brittany had a wonderful palliative care team at OHSU, Oregon's Health and Science University, and the support we received from the hospice facility was immeasurable.[206]

This is similar reasoning to what Johnstone is talking about, but it is not made into a central issue in these videos. It is still something that is very present in some of the other communication by Compassion & Choices so its absence here does not mean that this technique is not used in the debate in the United States. Assisted dying and palliative care are also sometimes seen as opposed to one another. Diaz hints at palliative care in another comment in the same video, and in this comment assisted dying is posed as a complement, or next step, to palliative care. Diaz indirectly presents a counter-argument to the suggestion that there is no need for physician assisted dying, because hospice care and palliative sedation[207] can make patients comfortable enough at the end of life.

> Any assertion made that in a hundred percent of the cases we can control a terminally ill individual's pain and suffering at the end of life. It's simply not true. There are certain cases when an individual still does suffer.[208]

This "counter-argument" is interesting for several reasons. Firstly, it is unclear if and likely improbable that anyone has claimed that it is possible to control suffering at the end of life in a hundred percent of cases. Diaz is not saying who has claimed that it is. In fact, when examining the statement closely he does not even say that someone has said this. What he actually says is something along the lines of that "if someone said this, it would not be true". This is a counter-argument without an actual argument, but this might not be how this is heard since it is phrased like a counter-argument. This might lead to the assumption that this is said in answer to claims about palliative care being a hundred percent effective. Another point about the effectiveness of palliative care is that it is not necessarily accessible to everyone. This is something that is not discussed in the material, but there is an ongoing debate about improving the accessibility and usage of hospice care in the United States. The argument has been made that many bad dying experiences could be avoided by better and more accessible hospice care. The place of assisted dying in relation to hospice care is also under debate. Compassion & Choices sees them as complementary choices in end-of-life care, while some fear that legalizing assisted dying will be seen as a solution to the problems in hospice care. It is not sure that assisted dying could be a solution to bad death experiences because

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[206] The end-of-life conversation, 13:41.

[207] Palliative sedation is when a patient is sedated to intentionally lower awareness or causing unconsciousness. It is sometimes used for patients near death when other pain relief does not work. It is legal in the United States and not seen as assisted dying. It is also legal to administer pain medication knowing that it will hasten the death of a patient (although the reason cannot be to hasten the death of the patient) See for example AMA Ethics; American Academy of Hospice and Palliative Medicine.

[208] The end-of-life conversation, 7:58.

of problems in palliative care. Buchbinder has found that some of the same problems of accessibility relate to assisted dying as well.[209]

Another interesting point related to the quote above is that even though palliative care in many or most cases probably can relieve physical pain, many of the reasons given in this material and seen in the Oregon statistics and studies as well[210] are not, or at least not solely, related to current physical pain and suffering. Fear of loss of autonomy, mobility, cognitive skills and so on play a big role in why assisted dying requests are made. It could be discussed if it is beneficial, or possible for that matter, to separate mental and physical suffering in situations like this. Diaz does not specify here if he is talking only about physical suffering, but elsewhere in the material when describing symptoms both he and Maynard do talk about both physical pain and other symptoms.

Similarly to the way that assisted dying is presented as medical practice, the discussion about safeguards in the Death with Dignity Act frames it as rational and safe from abuse. The safeguards included in the act are mentioned in all the four videos, but discussed more by Diaz in the later material. In the first video they are referred to in the text inserts in general terms: “She met the criteria, and received a prescription for medication that will end her life peacefully and painlessly, if she chooses to ingest it.”[211] Another text panel at the end of the video also mentions that the movement is about giving the terminally ill the right to die and this is how it is also expressed in *A Video for All My Friends*. The safeguards are otherwise not discussed in the first two videos. In contrast, Diaz takes some time in both videos to explain the safeguards:

> Brittany had looked into the laws in Oregon, which allow a mentally competent, terminally ill patient, a person that has been given six months or less to live, in Oregon they allow for the patient to receive a prescription so that they can decide, the patient can decide for herself, himself when their suffering gets too great, and so they can pass away peacefully.[212]
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> Early on, Brittany brought up the topic of medical aid in dying. At that time, it had been available in Oregon for sixteen years, but it was not available to her here in California. The parameters of this program, just to explain that: Two physicians, independent of one another, have to agree that this person is terminally ill with six months or less to live. That person has to be mentally competent, then make the request both verbally and in writing. There’s a fifteen day waiting period in between those requests, there are

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[209] Buchbinder 2018a. About reforming medical care, see Hillyard and Dombrink 2001, 4.

[210] See the statistics about the reasons for choosing assisted dying in chapter 2.3.

[211] The Brittany Maynard Story, 2:18.

[212] Brittany Maynard’s Husband Speaks Out, 2:36.

> witnesses involved… These are the safeguards that are in place and Brittany felt incredibly protected throughout the entire process.[213]

In addition to explaining the safeguards and how they protect the patient, both these quotes make it very clear that assisted dying and moving to Oregon was Maynard's idea. This supports the argument about patient autonomy and also underlines that there was no influence from anyone else.

Another technique of normalization is the "it's already happening" argument. This is used as a way of rationalizing why there should be legalization according to the Oregon model, arguing that at least in that way there are safeguards in place, and there will no longer be patients assisted in secret by their doctors and family members. Diaz makes this argument in the interview from 2015:

> […] but the wisdom of the legislation in Oregon where the patient gets to decide for himself or herself, it puts the power where it belongs, in the patient, with the patient, and takes away all of this kind of secrecy behind closed doors. Because it does happen in states like California and elsewhere, where a patient if they do ingest enough of certain medicines can in fact pass away.[214]
>
> The problem with that is that, I would say, that's where you run the risk of there being potentially family influence or coercion. Versus if there is legislation passed, it's in the books and the patient has to then pursue, apply for, be accepted, be granted the prescription. That is a much safer, a much more patient-focused scenario, where I think it eliminates the possibility of any coercion or family influence and it puts the patient in control.[215]

As discussed above, Montero argues that the fact that something is already going on, is not in itself a good argument for making it legal. He also states that it is impossible to know how frequently illegal assisted dying and euthanasia is performed. There is not really any way to know because, like Diaz mentions in the quote above, it is done in secret. Diaz also does not present any arguments for how legalizing assisted dying would stop illegal assisting, for example in cases when someone does not qualify for assisted dying according to the existing laws. It could be argued that illegal assisting would be more actively dealt with by the police and courts if there was a legal option that makes it clear what is not legal, but this is not discussed anywhere in the material. Montero does not think that legalization would necessarily put an end to illegal euthanasia.[216]

Language is also used to convey rationality and present arguments as common sense. In the interview from 2015 Diaz is positioned as an expert, invited to give insight on a legislative proposal which underlines him speaking with the voice of reason. The interviewer's way of asking the

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[213] The end-of-life conversation, 5:16.
[214] Brittany Maynard's Husband Speaks Out, 4:50.
[215] Brittany Maynard's Husband Speaks Out, 5:22.
[216] Montero 2004, 178–179.

questions supports this, for example pointing out that Diaz is involved in helping lawmakers make sure that the legal language in the California law proposal is appropriate.[217] In his 2018 presentation, Diaz also uses phrases that impart this sense of common sense or rationality:

> Tonight I'm gonna share with you a little bit more than the sound bites that were in the media so that you'll have an understanding of what, of the reality of what Brittany was facing.[218]

In the long account, discussed in connection to risk in chapter 6.1, of symptoms Maynard was having or would potentially get later, common sense phrases are inserted into the list of symptoms. This is especially interesting as the account includes both symptoms that Maynard was already having and symptoms that she would probably have gotten but might not have. Diaz does not claim that she would certainly have faced all the potential symptoms, but when they are listed quickly one after another mixed with phrases such as "That's just the reality of what she was dealing with." it might sound to the listener like it was all certain to happen. "The reality" that she was dealing with refers to the seizures and for example blindness, becoming paralyzed, and losing the ability to speak are potential effects of the brain cancer, but you have to listen closely to hear the difference. According to Davis, this is why stories are powerful. They give events meanings by framing them in a certain way and telling the listener how to understand what is told.[219] This type of "common sense" clauses evaluate what is told and tells the audience how Maynard's story should be interpreted.

The common sense phrases give an illusion of credibility to what is said. To clarify, I do not suggest that what they are saying is not true, but that the language and framing of these statements is relevant as well as the content of what is said. Sometimes this kind of comment happens in a side note that at the same time paradoxically seems to downplay the importance of what it is said while simultaneously being rationality or common sense language. It presents what is said as a fact that is not really under discussion. Some examples of these kinds of side notes from the last video are: "The parameters of this program, just to explain that, […]" and "Just to demystify the medication: […]".

Some of the strategies for framing the issue of assisted dying in a certain way or normalizing the practice have been discussed in this chapter. Many of these are what Hillyard and Dombrink call semantic arguments.[220] By defining assisted dying and related concepts in a certain way they are given certain meanings. Language and communication strategies are also used to get attention and acceptance among the public and these strategies will be discussed next. Some of the strategies presented here have many functions and fit into both categories.

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[217] Brittany Maynard's Husband Speaks Out, 6:01.
[218] The end-of-life conversation, 2:11.
[219] Davis 2002, 16.
[220] Hillyard and Dombrink 2001, 4

6.3 Public opinion and communication strategies

Other communication strategies used by advocacy organizations for assisted dying have to do with different ways of trying to catch the attention of and involve the public and the media. Getting public support and media attention is a way to get policy makers to listen and react. Public support, media and politics are all connected, because the media picks up what they think will interest the public and politicians follow the media closely.[221]

The material does not refer to public opinion much, even though quoting polls about the support for legislation is among the strategies often used to show that there is wide support for assisted dying. One explanation might be that the contents of the videos are not focused on statistics and facts but more on the personalization of the issue. What Maynard and Diaz bring to the campaign very successfully is primarily the personal point of view of Maynard's story so it might be that this is a strategic choice. Quoting polls and other more political rhetoric might take away attention from the personal story. This theory is supported by the fact that a lot of the information about the more "technical information" about the disease and legal aspects in the first two videos is provided in text panels and not through something anyone says. The people in the videos talk more about their own experiences and emotions. On the other hand, in the two later videos Diaz includes more of this kind of information. The reasons to bring up the rising support in polls for assisted dying is that it can be used as an argument that the public wants legislation.[222]

Majority support is brought up by the interviewer in the video with Diaz from 2015. He mentions that according to a HealthDay/ Harris Poll, 74 percent of Americans support "death with dignity".[223] The 74 percent is brought up by Diaz later in the same video in connection to getting the law passed in California:

> […] we are working towards getting legislation passed. And it will be challenging. We've tried previously in California. But I think what's different this time is we have Brittany's message and we have people that are thinking about it and as you mentioned in the introduction, 74 percent of Americans are actually in favor of it so hopefully this time people, and the legislators, recognize that, yeah, this is a law that makes sense, and get it passed.[224]

Here Diaz mentions the connection between public support and getting politicians to listen and react. This type of argument, but framed in a different way comes up a couple of times in the videos when they talk about the impact Maynard's story has had. Here it is not framed as about how many

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[221] Polletta and Gardner 2014−2015, 540; Johnstone 2013, 178.
[222] See Johnstone 2013, 178−180.
[223] Brittany Maynard's Husband Speaks Out, 0:27.
[224] Brittany Maynard's Husband Speaks Out, 6:50.

support the political goals of the campaign, but they talk about how many were affected by Maynard's story. This is of course not found in the first video, which is the reason Maynard's story got so much attention, but it is in some way mentioned in the other three videos. Near the end of the second video there is a text panel which reads: "In the past month, Brittany's story has gone viral. Millions have been inspired by her strength and bravery."[225]

"Millions" in this sentence presumably refers to the millions of people who watched the video, but it also paints the picture that millions of people are mobilizing and supporting the sentiment in the video, which is of course not something that can be determined simply from the number of YouTube views. Like the figures about a majority supporting legalization, this statement is a way to make people identify and feel that they are joining the majority if they support the campaign. The two Diaz videos are introduced (by the other speakers than Diaz himself) by referring to the media attention that Maynard's story got.

A bit contradictory, another argument that is made in the material is that the proposed law would affect a very small number of people. The safeguards limit access to people who have a diagnosis of less than six months to live and are mentally as well as physically capable to take the medication themselves. In *The end-of-life conversation* Diaz underlines that this makes only a small number of people qualify for the Oregon Death with Dignity program:

> This program is very narrowly focused and it affords a very small number of individuals like Brittany that find themselves in this predicament. In Oregon that number is 0.3 percent. It's a fraction of a percent over the past 20 years that have had to utilize this program.[226]

This is a different sort of argument, making the point that because this only concerns a small group of people (for whom it is very important) it is not something that the majority should be concerned about or fear and also not decide about for someone else. In their current form the laws directly concern only a small part of people, but unlike many other minorities anyone can become a part of that group. Identification through for example personal stories makes people consider the fact that they or their family could become part of that minority. Even if not everyone qualifies for the program, people do not know in advance if they will become part of that minority. There are some interesting language choices in the quote above as well. Firstly, the expression "having had to use the program" is interesting. It portrays the program as necessary, but also does not fit so well into the picture of autonomy and choice. Secondly, expressing that the percentage is 0.3 percent over the past 20 years is misleading because although Diaz is correct that the numbers are small, they have

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[225] A Video for All My Friends, 5:17.

[226] The end-of-life conversation, 14:04.

been rising almost every year. So if the percentage is 0.3 percent over 20 years it is likely to be higher for the past couple of years. In 2017, the percentage of Oregon deaths from assisted dying was just under 0.4 percent. See chapter 2.3 for more discussion on the statistics related to the Oregon Death with Dignity Act.

Branding is, according to Johnstone, done by right-to-die organizations through using certain words such as choice and dignity and also by using visual means such as logos.[227] Something that could be considered as part of branding the campaign is how the same photos of Maynard are used in the different videos and also elsewhere in for example news stories. Most of the pictures that figure in the videos are either pictures from Maynard's and Diaz' wedding or travel pictures of Maynard and her family and best friend performing different outdoor activities. There are also some other couple pictures of Maynard and Diaz as well as the picture of Maynard with her dog as a puppy that was mentioned before and was very much used in the media. By the use of the same set of pictures in the different videos and on news sites Maynard is made recognizable and known as herself and also as the face of assisted dying. Once people start recognizing the pictures, they become part of the brand of the organization and campaign. While this is probably done on purpose by the campaign for the reasons mentioned above, there might be other factors that affect using those same pictures as well. One such factor might be that Maynard and Diaz were willing to share a certain amount of pictures, but maybe not all parts of their life for the campaign. Another reason those pictures are used in news stories is that once there was an interest in Maynard's story and she was recognizable it makes sense for the media to use those pictures to get people to read or watch their stories. This is the same reason as the campaign has for branding the story through pictures to arouse interest, and is in line with the aims of Compassion & Choices, but the agency and decisions are those of news editors and journalists.

One of the most important strategies for organizations like Compassion & Choices is the topic for this thesis, the use of personal stories. Through the use of personal stories, the organizations simplify issues and make an emotional connection to the audience. Stories are important because they work through identification. When the audience identifies with the story or storyteller they are more likely to care about the issue. Stories are also used as a media strategy. Organizations have a hard time getting the media interested in causes and one way to raise interest in a cause is through personal stories. Tatum found in his study of narratives in the Kevorkian trial that the jurors at the trial were asked to imagine that they were in the situation of the patient wishing access to assisted dying.

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[227] Johnstone 2013, 128−135.

According to Tatum, this is a tactic that is meant to strengthen identification.[228] There are a couple of similar comments in the videos, for example when Maynard speaks directly to the audience at the end of the first video:

> The reason to consider life, and what's of value, is to make sure you're not missing out. Seize the day! What's important to you? And what do you care about? What matters? Pursue that. Forget the rest.[229]

Johnstone finds that social identification is appealed to by including for example nurses or mothers and similar figures that generally enjoy a lot of trust in the stories about assisted dying.[230] Maynard's mother is present in the first two videos where she talks about emotions and her relationship with her daughter. The statements are often about wanting Maynard to live the life she wants and support her, likely something that many parents can identify with:

> My hope now is that my daughter can live her life the way she wants to. That she can make the decisions that she wants to. That she can be who she is.[231]

Experts and authority figures are sometimes included in the campaigns because they bring authority through who they are.[232] This is not used much in this material, which is mostly focused on Maynard's personal story; although the fact that Diaz is still asked to campaign in other states to give visibility to the issue is related to this phenomenon. Because Maynard has become the face of the assisted dying movement, she, and through her Diaz, has become something of an authority figure in this issue. Other authority figures are more present in other material from Compassion & Choices. The main role of Maynard and her family is to share their personal story. Critics and opposition are not mentioned much either. In *A Video for All My Friends* critics are mentioned indirectly by Maynard and by her mother in relation to autonomy and that no one else knows what is better for Maynard than she herself does. The two quotes are phrased in the following way:

> When people criticize me for not, not like, waiting longer or you know whatever they've decided is best for me, it hurts because really I risk it, I risk it every day, every day that I wake up.[233]
>
> It's not my job to tell her how to live, and it's not my job to tell her how to die it's my job to love her through it.[234]

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[228] Tatum 2002, 194.
[229] The Brittany Maynard Story, 5:58.
[230] Johnstone 2013, 110–112.
[231] The Brittany Maynard Story, 4:54.
[232] Johnstone 2013, 108–110.
[233] A Video for All My Friends, 0:45.
[234] A Video for All My Friends, 3:58.

Neither of them names any critics specifically or what the critique is about, but they make their own position clear. Diaz in the later videos talks about having heard “crazy things” in a similar way, without calling out any specific group. He also, when talking about how this is not suicide or giving up, mentions opposing groups in the following vague way:

> And there are groups that seem to suggest that if a person applies for this, that they’ve somehow given up. That couldn’t be further from the truth.[235]

The only opponent that is named is the Catholic Church as well as more vaguely “some evangelicals”. As discussed in the previous chapter, the Catholic Church is often named as the main opposition to legislation, making the debate about religion. Disability organizations, which are one of the other big groups opposing legalization are not mentioned in the material at all.

Johnstone points out that the media is very important for advocacy organizations as a way to catch the attention of both the public and politicians. New media bring some new ways for the public to get involved and interact with the organizations. At the same time, if organizations are able to get enough attention on social media, the chance of more traditional media picking up the story is better, too.[236]

The one argument that really stands out in the material is the argument about autonomy. Maynard, Diaz, and Ziegler all talk about choice and control, which they relate to their own stories in different ways. This is also one of the most common arguments for legalizing assisted dying, and one that works well in American society, because it emphasizes individualism. As central as individual choice is to the assisted dying rhetoric, Maynard and her family still connects it strongly to family values and make it clear that they support each other’s choices. The other argument that stands out is the argument about suffering, and here, just like in some of the studies discussed in chapter 2, the focus is put more on the fear of future suffering than on the current situation. The arguments are often defined broadly and vaguely, like “wanting all Americans to have a choice” and opponents are not named. This keeps the discussion mostly at a general level, perhaps as a way to appeal to as large an audience as possible.

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[235] The end-of-life conversation, 9:55.

[236] Johnstone 2013, 136−137.

7. Conclusion

The objective of this thesis has been to examine how personal stories are used in the campaign to legalize physician-assisted dying in the United States to capture the public's attention and frame the issue in a desired way. Using stories for political aims is not a new phenomenon and it is done by a range of advocacy organizations, politicians and corporations to create and mobilize support. Stories help people make sense of the world and can be powerful tools in creating and upholding social structures or in changing them. Maynard's story got a significant amount of media attention and has become *the* story about assisted dying in the United States to the extent that her story is still used in current campaigns and discussed in the media several years after she died. This is why stories are important to the successes of organizations like Compassion & Choices. Maynard's personal story is strongly connected to the policy issue of assisted dying in the public's mind. Because of the fact that Maynard's story is so well known it might be harder for competing narratives to gain attention among the public and get heard by lawmakers.

Depolitizing issues through the use of personal stories, and on the other hand making the personal political, is a strategy often used by advocacy organizations to make people understand and relate to complicated issues. When people identify with a story they are more likely to care about a policy issue. Advocacy organizations in the United States play an important part in influencing decision-making through policy strategies and often work on many fronts to get their issue heard before lawmakers and in the courts. Using personal stories is a strategy that can be very effective, especially when the story gets as much attention as Maynard's did. Maynard's story is often credited with directly influencing legislation in several states, which shows the power of social media and a good story. At the same time every personal experience is different, and if one experience is being treated as representative for the whole society it might be misleading.

Maynard is hardly representative for the age group that is most affected by the assisted dying laws. Most patients that make use of the laws are over 65 years old and a significant part older than 85. Maynard's age adds to the tragedy of her story and is probably one of the reasons that her story gained so much attention. At the same time, the fact that Maynard is young hides the connection between old age and assisted dying from the public picture. On the other hand, representativeness is not a simple question and it could be argued that Maynard has more in common with someone older that is also dying from cancer than with a healthy 30-year-old woman who has decades left to live, or at least assumes that she does. The question about what constitutes a good death is relevant to most people at some point in life. This made Maynard's story resonate with the wider public as well as lawmakers in many states.

Maynard's "profile" as a white, young, athletic, well-educated, middle class woman fits into the image that Cartwright found in her research of the public image of breast cancer in awareness campaigns and popular media.[237] The patients at the center of the landmark court cases related to assisted dying and patient's rights to refuse treatment also for the most part fit this profile. Because the advocacy organizations choose carefully which cases to represent in court, or spend time and resources on promoting, this should not be seen as coincidence. Maynard's youth, healthy lifestyle and attitude make her someone people might want to identify with and corresponds to ideals represented elsewhere in the media in American and other Western culture. Her whiteness and socioeconomic status also makes her representative of "mainstream" popular culture and ideals. Someone from a different socioeconomic background or minority might not be seen as representative for everyone in the same way, or be able to underline the point that this could happen to anyone. While representativeness is not uncomplicated, it should also be asked if for example minorities identify with Maynard. It can be seen in the studies mentioned in chapter 2 about access to hospice care that minorities are underrepresented in usage of hospice care. The Oregon Death with Dignity statistics discussed in the same chapter show that this is true also for the Oregon act. Maynard and Diaz talk about expanding the right to assisted dying to all Americans, but Buchbinder has in her study of Vermont found barriers, including economic factors, to access in assisted dying.[238]

When Maynard's story is told, it is a mix of statements presented as facts and personal experiences that are more emotional. Maynard's personal relationships are at the center of the story, especially in the two videos that were released before Maynard's death. The story does not change much in the later videos when it is told by Diaz after Maynard's death, but the content is somewhat more political. Loving your family is something that many people can relate to and talking about spending your last time with your loved ones is something that will make many people react emotionally. Emphasizing family values in the story is a way to make people relate and imagine themselves in the same situation. The assisted dying message is powerful, because although it is a very small minority that find themselves in a situation where they can choose to make use of the law or not, anyone could end up in that situation. Maynard's story is easy to relate to because it is easy to imagine oneself or a family member in a similar situation.

As discussed in chapter 3.3, the ongoing discussion about assisted dying makes people think about their own mortality and euthanasia or assisted dying becomes a sort of protection from having a bad

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[237] Cartwright 2000.

[238] Buchbinder 2018a.

death.[239] This is supported by some of the studies presented in chapter 2 about why people choose assisted dying, although more research on the issue is needed. It seems that the fear of future pain and the desire to control death are more important factors than the actual pain or current situation of the patient. Maynard and her family also talk about risk and fear of losing autonomy and control on the one hand, and on the other hand about the sense of comfort it brings to have taken back control from the disease about how Maynard will die. The fear of losing control is the main explanation given in all of the videos for choosing assisted death. This is not presented as a policy argument, but instead as a personal choice. By focusing the debate on individual choice, the effects of assisted dying legislation on society in a larger sense might be ignored.

The personality traits that are emphasized when describing Maynard in the videos are activeness and independence. These personality traits fit well with the discussion about not wanting to lose autonomy. Diaz connects these traits with the will to fight the cancer and survive and, when it became clear that this was not an option, to control the circumstances of death. The story also makes it clear that assisted dying was Maynard's own choice and something she actively pursued by moving to another state to access the law in Oregon. Maynard's story is used as an example of how the Death with Dignity Act works in practice and the story emphasizes the safeguards included in the act. It is hard to question if they were enough to protect the interests of a patient like Maynard. It is made clear that she actively chose this by herself and that neither she nor her family wanted her to die. In cases like this, questions about representativeness come into question as the situation might be quite different for other patients. Stories about being active and grateful during the time you have left also might put pressure on other patients who have different experiences.

Narrative serves many different purposes in this thesis. Narrative theory and methods are central to the way the analysis was conducted and to the perspective from which the material was analyzed and which questions were posed. At the same time storytelling is used as a communications strategy by organizations like Compassion & Choices to gain visibility and make their message interesting to the larger public and the media. The material that is the focus of the analysis consists of accounts of Maynard's life and death story and they are told with certain policy aims in mind. Finally, it has been suggested that storytelling could play a part in making the death process easier for patients and their close ones as a way of articulating wishes and installing a sense of control. In this way stories help patients make sense of and deal with death process. When Maynard and her family tell their story there is a double purpose of explaining to others and making sense of it themselves. Both the listener and the narrator are affected by the stories that are told, which is what makes stories so powerful.

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[239] See also Johnstone 2013, 148–152, 166–167.

8. Bibliography

Research material

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