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Balance Sheets of Suffering in End-of-Life Care

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Abstract

Drawing on recent work in cognitive linguistics and social studies of knowledge practices, this chapter explores the various ways in which the figure of a *balance sheet* frames arguments and positions in end-of-life care. Across arguments and positions, there are substantial differences in the kinds of matter that are balanced against each other and the values attributed to them, and which items are allowed as entries on the balance sheet and which are not. A common currency on the balance sheets is human suffering. Comparing Norwegian and Dutch end-of-life care practices, the argument is elaborated by looking at (a) the personal balance sheets of cancer patients, (b) the balance sheets of euthanasia, assisted suicide, and palliative sedation, and (c) the balance sheets that set patient's right to self-determination up against health professional's right to conscience. Finally, the different ways in which the balance sheets are operated are considered with regard to their impact on the level of constraints that the different end-of-life care policies put on patients and health professionals, and how these shape the material conditions of our dying.

Keywords: balance sheets of suffering, conceptual blending, modes of ordering, end-of-life care, palliative care, euthanasia, assisted suicide, palliative sedation

1. Introduction

Every argument must generate a space in which it can be persuasive, valid, true, or right—a space in which it can be represented. These abstract *spaces of representation* [1] comprise a framing logic, produced data, conceptual structure, and explicit or implicit onto-epistemological and moral positions. They constitute, to use Mark Turner's phrase, comprehensive *hyper-blends* [2], or to use Annemarie Mol and John Law's expression, *modes of ordering* [3]. Several such comprehensive hyper-blends or modes of ordering may exist simultaneously, generating lines of friction, contention, and disagreement [3]. These spaces do not have to be

invented *de novo* every time an argument is made. They are available as cultural, narrative, or discursive resources, that is, as collective templates that can be recruited and operated through blending with the particulars of situated arguments at hand.

Drawing on the recent work in cognitive linguistics [2, 4–8] and social studies of knowledge practices [1, 3], in this chapter, the various ways in which the figure of a *balance sheet* and its associated *calculative devices* frames arguments and positions in end-of-life care will be explored. Across arguments and positions, there are substantial differences in the kinds of matter that are balanced against each other and the values attributed to them, and which items are allowed as entries on the balance sheet and which are not.

The arguments about the balance sheets of suffering in end-of-life care that are being developed here are no exception to the requirement that they too need a space in which they can be persuasive, valid, or right. An important feature of “my space” is that it moves away from the long-held assumption that ontology, epistemology, and ethics constitute separate domains, toward a view that takes notions of embodied cognition and the performative nature of discursive-material practices as its point of departure. In the next section, we will make that “move” explicit, before introducing the notions of *conceptual blending* and *modes of ordering*. Following these introductory sections, the figure of the balance sheet as a space in which moral arguments are presented and weighed against each other is introduced. The most common currency on the balance sheets is human suffering. Comparing Norwegian and Dutch end-of-life care practices, the argument elaborates by looking at (a) the personal balance sheets of cancer patients, (b) the balance sheets of euthanasia, assisted suicide, and palliative sedation, and (c) the balance sheets that set patient’s right to self-determination up against health professional’s right to conscience. Finally, how the different ways in which the balance sheets are operated impact the level of constraints that the different end-of-life care policies put on patients and health professionals, and how they shape the material conditions of our dying are shown.

2. From disembodied to embodied cognition and discursive-material practices

We still struggle with the legacy of long-held assumptions about the separateness of question of ontology, epistemology, and ethics. These assumptions operate through a range of fundamental distinctions, like the ones between body and mind, object and subject, is and ought, fact and value, and nature and culture. Science, often written in the singular, is about discovering matters of fact about a preexistent, natural, and material world, about which entities exist in the world, how they relate to each other, and how we can intervene to bring about change. On the other side of the divide, we locate the seat of self-governing (autonomous) subjects in the deep internal space of the human mind. Although we know from elementary human anatomy that there is no empty space in the skull, we have come to understand ourselves as inhabiting this private internal space. This nonmaterial space of the mind is coextensive with autobiographical consciousness and shaped by biography and experience [9]. This

idea underlies the important humanist notions of personhood and human agency. I have called both psychology's internal space of the human mind and the modern notion of the autonomous, human subject for *irreal* to express the ambiguousness in two senses in which we think about ourselves: (1) the sense that we are coextensive with our body, with the entailment that the "I" or "Self" ends with the disintegration of the body/brain, and (2) the sense that there is something more, something that is separate and distinct from our body/brain, an immaterial entity (soul?) that we perhaps hope will live on after death [10]. Obviously, this notion of the human subject is also a key concept in ethical reasoning. Autobiographical consciousness is the defining feature of what makes us living human beings. It is called *autobiographical* because it locates the current self in a temporal continuum of a lived past (memory functions) and an anticipated but open future (functions of planning and evaluation of alternative courses of action) [11]. The evolutionary emergence of autobiographical consciousness produced, most notably in humans, the awareness that we all, at some future time, will die. *Memento mori!* It also produced the anticipation of suffering that has not yet come to pass. Entities that have developed or have the *potential* to develop an autobiographical consciousness in their deep internal space are the subjects of ethical care, worthy of ethical and legal protection without discrimination by other human beings and society. The possession of that potential capacity is, in an essentialist understanding of medical ethics, necessary and sufficient to qualify for ethical and legal protection. A fully developed autobiographical consciousness provides its owner with the possibility of choice, subject to its own and society's laws instead of the deterministic laws of nature. The laws of nature and the laws of man are separate matters.

Hence, we conceive of the deep, internal, private space of the individual mind as being coextensive with consciousness and with the operative agent doing the intending, willing, emoting, conceptualizing, and associating of concepts to language that we associate with thinking. It is the thinking that we do in this internal space, and of which we are consciously aware, that we have come to define reductively as human cognition. To define something is a process or activity of *delineating*, of tracing a boundary that simultaneously produces an inside and an outside, that what belongs and that which is excluded. Although produced in real time in the same brain, emotions and feelings have no place in what has become the epitome of human cognition: rational thinking and reasoning. This conception of the rational human subject not only disembodied cognition, displacing the body but also displaced emotions as a form of cognition, that is, as the human body's principal biological valuation system. It is in such a "space of representation," featuring a fundamental distinction between objective facts and subjective values, between reasoning and feeling, that traditional forms of medical-ethical reasoning gain traction; get the facts straight before moving on to sorting out the moral quandaries and dilemmas. It is such a space that makes the idea that end-of-life decision-making should be informed by medical knowledge about a patient's disease, treatment possibilities, results, and prognoses seem persuasive and right.

Recent work in the neurosciences challenges the distinction between detached, rational reasoning occurring in the bark of the cerebral hemispheres (higher brain functions) and emotions generated in specialized, lower areas of the midbrain. Effectively, this work reclaims emotions for the appropriate understanding of all forms of biological, embodied cognition

[11–13]. Embodied cognition biologists argue that cognition is a fundamental feature of biological life [14–16]. Cognition is a function that emerges with the formation of a living organism. Cognition is coextensive with the recursive sensorimotor loops of the embodied activity of living organisms. Life = embodied action = cognition. The repeated, recursive cycles of action and perception constitute an intentional arc. Intentionality is here conceived as an organism's orientedness toward its socio-natural environment. The Self is, in this view, the result of ongoing, here-and-now dynamic biological processes in a brain that is in continuous interaction with the body in which it is embedded and with the body's physical and social environment. This is also the pre-position on which my own arguments in this paper are built: all judgments about the world, about human nature, and core human values are the products of *cognitive* recursive processes embedded in the bodies, brains, and activities of individuals and the recursive interactions among and practices of members of *collectives*. Damasio argues that the cognizing Self is "a perpetually recreated neurobiological state" [17]. Arguing along the same lines, we could say that the worlds of cognizing, meaning-making collectives are the emergent outcomes of perpetually recreated discursive-material practices [18]. Another way of saying this is that sciences do not *represent* a separate, pre-existent world, but that sciences conceived as collective sociomaterial practices *perform* the phenomena that make up the world we live and die in. They form, to use Latour's term, our "modes of existence" [19]. Within such formations, there is no a priori separation between what is, what we know about what is, and what we value and care about. If there seem to be such fundamental distinctions, then they are the result of the work of philosophers (of science, of mind, etc.) being appropriated by scientists into the onto-epistemological foundation of their science. These processes can and should be studied empirically. The social study of "knowledge practices" is concerned with the ways sociomaterial "modes of ordering" come into being and with the power involved in that process. Multiple modes of ordering (plural) exist simultaneously; sometimes going comfortably together, giving rise to frictions and oppositions at other times and places [3].

3. Conceptual blending and modes of ordering

Cognitive linguists George Lakoff and Mark Johnson have long recognized the embodied nature of cognition [20–22]. Studying everyday and scientific language, they demonstrated that our understanding of the world, as it is expressed through language, is imbued with metaphorical imagery inferred from our embodied experience. The basic idea is that our embodied being and acting in the world provides the metaphorical schemas that constitute language and human understanding. An example is our basic understanding of causal relationships and human agency rooted in our embodied experience of pushing or moving objects around and observing the effects of that action. In a similar sense, our understanding of being emotionally moved is rooted in the experience of an outside force being applied to our bodies. We understand the passage of time metaphorically as a movement through space, a notion that is materially anchored in analogue clocks [23]. We may understand dying, a passage from one state into another, as involving a passage through space, a journey across the water and into the west, to undying lands, or from this earthly place full of suffering

to a sacred, heavenly place of peace and tranquility where we will meet again those loved ones that passed before us. Death itself is often understood through militant metaphors as an enemy that must be fought off. But death may also be understood metaphorically as a welcome friend that saves us from further suffering in this world, or as a pre-emptive escape from the intolerable, meaningless, empty days ahead. The basic operation that a metaphor performs is one of mapping, of the transfer or projection of entities, processes and structure from a *source* domain to a *target* domain. Metaphorical schemas combine to build complex and abstract conceptual understandings.

Gilles Fauconnier and Mark Turner take Lakoff and Johnson's work further and develop it into a theory of conceptual blending [2, 4–7]. Metaphorical mapping is only one form of conceptual blending. There are several more. Conceptual blending can be schematically presented by way of a minimal network that comprises at least three mental spaces: at least two input mental spaces and the blending space [2]. The input spaces selectively contribute or project structure and elements to the blended space in which these are integrated. Structure and elements that occupy analogous positions in the two input spaces, which in other words map between domains, may be compressed into identity and human scale. Conceptual blends can be elaborated by further blending with input spaces that already are blends. Biologists, for example, have blended the evolutionary history of life on earth with the developmental history of an individual from conception to birth and into adulthood, giving rise to the (problematic) idea that ontogeny recapitulates phylogeny [24]. Neuroscientists have blended the sequential emergence in biological organisms of what Damasio calls a proto-, core- and autobiographical-consciousness with the macroanatomy of the brain, associating proto-consciousness with the brainstem—that we share with animals, core consciousness with the mid-brain—that we share with closer animal relatives that we assume not to be self-conscious yet, and specifically human autobiographical consciousness with the phylogenetically newest neocortex of the large hemispheres [10, 11].

In many instances of conceptual blending, one or more of the input spaces is already a blended space. Mark Turner calls the blends that result from blending spaces that already are blends for *hyper-blends*. Many of our most treasured ideas concerning human beings are hyper-blends, like the notion of an autonomous human agent inhabiting a nonmaterial deep internal space inside our skull. In conceptual blending theory, it is not only analogies and similarities that matter, but dis-analogies are also important, including their either problematic or productive entailments. The notion of brain death, for example, is a hyper-blend, blending the idea of the legally certified death of a person with diagnostic procedures proving in a warm, breathing, and heart-beating body that the brain is irreversibly damaged. The dis-analogies between common notions and experiences of a dead person (as cold, nonbreathing, and with no puls) and the warm, heart-beating brain dead patient can be hard to accommodate for next of kin. The productive entailment of the brain death hyper-blend is that good quality donor-organs can legally be extirpated for transplantation purposes without running the risk of being prosecuted for murder.

Furthermore, conceptual blending is conducive to counterfactual reasoning. The input spaces to a blend do not have to factually exist. They may be counterfactual. In some cases, the

counterfactual space does not even carry with it the suggestion that it might be possible. In many other cases, the counterfactual space implies a state or a scenario that may be possible but that has not yet come to pass. In the chronological/biological age hyper-blend, the discrepancy between a person's biological age—calculated by measuring biological indicators of aging—and chronological age entails a counterfactual scenario of premature death. The responsible self-management of modifiable risk factors can prevent this scenario. The premature death scenario will remain counterfactual unless you take care, take responsibility for your own health. The point is not that the blend is a “possible world” or a true representation of the world, but that the blend suggests alternative ways of engaging with the world, and whose primary responsibility that is.

The power a particular hyper-blend can hold over people, fueling its own protection and the rejection of alternatives, should not be underestimated. Apparently, this is the case when deeply engrained beliefs about our own human nature, living and dying are challenged. Conceptual blending is not just some language game that we can enter into and get out of at will. Conceptual blending is part and parcel of the discursive-material practices that are constitutive for and order the world in which we live. We live in the blend! But neither should we neglect the contingency, multiplicity, diversity, and simultaneous coexistence of different modes of ordering life and the world, and how they relate to and interfere with each other. “For,” Mol and Law argue, “the various modes of ordering, logics, styles, practices, and the realities they perform do not exist in isolation from one another ... They are not islands unto themselves, closed cultures, self-contained paradigms, or bubbles. [T]hey interfere with one another and reveal ... partial connections.” “Often,” Mol and Law continue, “it is not so much a matter of living in a single mode of ordering or of ‘choosing’ between them. Rather it is that we find ourselves at places where these modes join. Somewhere in the interferences something crucial happens ... complexity is created, emerging where various modes of ordering (styles, logics) come together and add up comfortably or in tension, or both” [3].

4. A blended space for moral arguments: the balance sheet

As an embodied cognitive operation, *judging* is a matter of *balancing* and of weighing one against the other. Take one object in your left hand and a second object in your right hand: Which one weighs the most? This idea of judgment as a balancing act is materially anchored in the weighing instrument called a *balance*. We also use *balancing* in the sense of *re-balancing*, of re-establishing equality of “weight” between two entities when that balance has been disturbed. An eye for an eye, a tooth for a tooth! The proportional retribution balances the harm received. Justice is done. Justice is re-established. The image of the *balance* has been blended into the iconography of our legal system, together with the blindfold (impartiality) and the sword (punishment, retribution).

In economic practices, the blend of the *balance* has been elaborated with calculative features. The *balance sheet* is an archetypical space designed for the display and calculation of *proportional* relationships between costs and benefits, gains and losses, debts and possessions, and debit and credit. Balance sheets allow for forms of what Winther-Jørgensen calls for *strong*

calculation, that is, forms of calculation where the end result can be expressed as a numerical number [25]. The numerical values in which judgments based on strong calculations are expressed have strong appeal for policy makers and politicians. However, not all forms of balance sheet calculation are strong. Many are weak. Moral judgments are often of this kind. The familiar expression “on the balance of it” —followed by a decision or conclusion, that is a judgment—is a marker of some form of preceding calculation, strong or weak, that involves the weighing of factual states and counterfactual possibilities, probabilities, and proportions, against each other.

Foster provides a telling example of how the balance sheet is used in moral reasoning and judgment [26]. The case is one in which there is a dispute about what is in the patient’s best interest. Some cases go to court. In a legal setting, Foster explains: “If it is to mean anything – if it is to be real – it has to be procedurally entrenched” [26]. The reasoning goes like this:

- a. Human life is sacred. A corollary of that is that it must be a presumption that it is in the patient’s best interest to continue to live.
- b. The presumption can be rebutted.
- c. What is required to rebut is evidence that continued existence would be intolerable (the so-called intolerability test).

An appellate court judge explains how such an *intolerability test* should be executed.

The first instance judge with the responsibility to make an evaluation of the best interest of the claimant lacking capacity should draw up a *balance sheet*. The first entrance should be any factor or factors of actual benefit. Then on the other sheet, the judge should write any counter-balancing dis-benefits to the applicant. Then the judge should enter on each sheet the potential gains and losses in each instance making some estimate of the extent of the possibility that the gain or loss might accrue. At the end of the exercise the judge should be better placed to *strike a balance* between the sum of the certain and possible gains against the sum of the certain and possible losses. Obviously, only if the *account* is in relatively significant credit will the judge conclude that the application is likely to advance the best interest of the claimant [26] (my italics).

In the case of the intolerability test, the judge who performs the calculations in the balance sheet cannot do this on the basis of events that have already been experienced, but he must to a large extent rely on estimates of counterfactual events and experiences that have not yet come to pass. Furthermore, there may be limitations on what kinds of suffering or relief can enter the calculation.

5. Suffering as the common currency on personal end-of-life balance sheets

Suffering is a common currency on the costs side of end-of-life balance sheets. On the other benefits side of the balance sheet, suffering is balanced by more time of life, but not at any cost. The balance sheet can be a seriously ill or dying person’s personal dilemma to figure

out what to do and how to proceed. Think of a patient with an advanced form of cancer. This is the familiar quandary that follows from the uncertainty that you cannot know in advance whether the extra time of life that life-prolonging treatment will give has a quality of life that is worth living. Do the good days on which you have time to live outweigh the bad days that are filled with suffering? Shall I accept the offer of life-prolonging treatment at the cost of prolonged suffering? Or shall I accept that death is imminent and use the time left to settle my affairs and say farewell to next of kin and loved ones?

One gets the impression that the expected answer is obvious: Of course, you must choose for more time of life, to be with your partner, to see your children grow up and hold a newborn grandchild in your arms. But is this choice so obvious?

In affluent countries with advanced health care systems, cancer treatment has been centralized in cancer clinics associated with university hospitals, combining research and teaching with treatment and patient care. In these hospitals, clinicians also hold research and teaching positions in the associated university. Through their professional organizations, these professors in oncology may be involved in the elaboration of professional guidelines for the diagnosis and treatment of particular forms of cancer. Many patients attending the clinic for diagnostics and treatment are enrolled in research protocols that are part of international, collaborative multicenter studies [27]. Today, these studies do not compare cancer treatment with the natural course of the disease under nontreatment. They compare slightly different multimodal treatment options with already existing ones. The by far most important effect variable is *survival* in one or other form, as duration of remission, mean time to relapse, or mean time to death. In these centers, quite aggressive treatments of even advanced stages of cancer have become the default treatment option offered to patients. "We will fight together!" one patient information brochure exclaims, suggesting simultaneously an expectation that the patient also fights her cancer [28]. There is a particular notion of *courage* here. The kind of courage the patient must muster to suffer through the ordeals of surgical, radiation, and chemotherapy to win more time of life to spend with her children and spouse, and to help medicine become better at treating cancer and, hence, save future lives. Cancer centers are in the business of adding and maximizing survival. Perhaps it should come as no surprise that the alternative, accepting that death is imminent and entering into a palliative trajectory, requiring a different kind of courage, is not always offered to patients in these centers [28].

Aggressive treatment and refusing life-prolonging treatment are two different trajectories that exhibit path dependency. Once you have entered into one or the other, it is difficult to go back. The suffering endured under treatment is the investment a patient must make to gain more time of life. To make it worthwhile, the good days must balance the bad days. When bad days outnumber good days, counting and summarizing days of each kind will not be sufficient. It may be necessary to increase the value of each good day, of each moment with your children or grandchildren to make the sum of them balance out and surpass the costs.

We should, furthermore, consider to what extent the treatment regime contributes to an increase of suffering. As diagnostic technologies make it possible to achieve the goal of early and even presymptomatic diagnosis of cancers, the suffering a patient endures is induced to an increasing degree by the treatment. Much of the suffering is iatrogenic and not caused by the disease.

Keating and Cambrioso argue that the evolution and history of cancer after the Second World War is the evolution of the disease under specific treatment regimens. It is a treatment history rather than a “natural history” [27]. Systemic cancer treatment intervenes in the biology of the disease. Today, it is more apparent than ever that cancer is not only a *clonal* disease, meaning that the origin of cancer cells can be traced back to a first, single cancerous ancestral cell that, having acquired the capacity of limitless cell division, gives rise to limitless numbers of descendants. Cancer is also *adaptive*. Or as Mukherjee puts it, cancer is a clonally *evolving* disease [29]. Due to some degree of genetic instability, every generation of cancer cells creates a small number of cells that are genetically different from their parents. With each volley of chemotherapeutic drugs that does not kill all cancer cells, a few mutant clones that can resist the assault grow out. In Mukherjee’s *clonal selection cancer blend*, blending the course of a disease in a patient with the evolutionary history of life forms on earth, “[t]his mirthless, relentless cycle of mutation, selection and overgrowth generates cells that are more and more adapted to survival and growth ... Cancer thus exploits the fundamental logic of evolution unlike any other illness. If we, as a species, are the ultimate product of Darwinian selection, then so, too, is this incredible disease that lurks inside us” [29]. In a sense, the “war on cancer” is a war on life itself.

Cancer treatment regimens *coproduce* the disease phases of *remission* and *relapse*. As the apparatus of collaborative groups matured, clinical trials targeted specific disease phases: trials for initial treatment, trials for first remission, trials for relapse, and so on. The disease at relapse was no longer the same as the disease initially diagnosed, requiring new drugs or new drug combinations. Without chemotherapeutic treatment regimens, these phases would not exist.

For the individual patient, cancer treatment regimens produce the protracted courses of disease, including the harm done to patients as a result of the “all-out assault” nature of the treatment that so many present-day cancer patients go through. The suffering caused by the treatment can be far greater and protracted than the suffering caused by the disease itself. It is a high price patients pay.

6. The balance sheets of euthanasia and palliative sedation

The figure of the balance sheet of suffering is also apparent in arguments policing the distinction between euthanasia and assisted suicide on one hand and palliative sedation on the other [30]. These are arguments not only about the implications of the intolerability of suffering but also about what kind of items are allowed onto the balance sheet and which are not.

Palliative sedation is described as the intentional pharmacological reduction of the patient’s consciousness with the aim to reduce intolerable suffering from intractable physical symptoms that cannot be managed otherwise. Palliative sedation until death is considered to be a last-resort option. Proponents of palliative sedation in end-of-life care take great care to present palliative sedation as an ordinary, medical treatment that is different in kind from euthanasia.

Palliative sedation is provided with the intention to relieve suffering, with an explicit focus on the *intention* with which the treatment is given. Often within the same sentence, under the same breath, it is added that the *intention* is not to hasten death. We encounter this figure in many variations. Of course, in this blend, the intent to hasten death would be equivalent to euthanasia or physician assisted suicide. The blend is further elaborated by blending with moral or legal positions. Depending on one's moral conviction or on the jurisdiction in which one works, hastening a patient's death would be equivalent with murder. An international panel of expert clinicians reviewing the literature on palliative sedation in the last weeks of life concluded that

The decision to offer sedation to relieve intolerable suffering during the last weeks of life presents no distinct ethical problem, provided that there is *no intention to hasten death*. It is distinct from euthanasia because (a) it has the *intention to provide symptom relief*, (b) it is a proportionate intervention and (c) the death of the patient is not a criterion for the success of the treatment [31] (my *emphasis*).

In medical treatment, there is always a risk of detrimental effects, but these are unintended side effects. In one general medical or pharmacological sense, *proportionality* refers to the due care requirement that the level of sedation should not be deeper than is necessary to alleviate distress and suffering. When mild sedation (somnolence; a form of reduction of consciousness from which one can be aroused through appropriate forms of stimulation) achieves the intended result, then one should not aim for deep sedation (from which one cannot be aroused) [31]. In end-of-life care, severe anxiety is treated with sedatives from the same family of substances as those used in palliative sedation. *Proportionality* of anxiety treatment may require a dosage to be increased to levels where reduction of consciousness occurs as an *unintended side effect*. However, when the intention was not to expressly produce unconsciousness, or so the argument goes, this would not constitute palliative sedation.

When intentions *cause* actions, the reverse should also apply, that is, that intentions can be backtracked from the records in which action patterns and the traces that these leave behind are documented.

The *intention* of PST [= Palliative Sedation Treatment] can be *assessed by the proportionality ... of the action*. *Intent may be judged* by looking at the drug record. Repeated doses, titrated to ease an individual's distress, are the *mark* of proportionated sedation. Single large doses are the *mark* of ignorance and intentional harm [31] (my *emphasis*).

Cases in which there is a covert intention to hasten death through high dosages of sedatives constitute "covert euthanasia" or "euthanasia by stealth" (relief of suffering *by* death). The words "covert" and "stealth" place these ways of doing end-of-life care on the wrong side of the border, morally and legally. Future suffering relieved or prevented *by* death is not allowed on the benefit side of this balance sheet of suffering.

The Norwegian guidelines for palliative sedation to the dying, published in 2001 by the Norwegian Medical Association, provide a telling example of how suffering relieved by death is excluded from the balance sheet [32]. Against the claim that euthanasia contributes to the relief of suffering, the Norwegian guidelines for palliative sedation to the dying argue that suffering belongs to life and life experience.

Talk about the absence or relief of something that belongs to life is meaningless when the patient is dead. ... A sedated patient is without suffering, but simultaneously with life experience. Yet, it makes sense to say that suffering has been relieved, because the patient still lives and can be woken again. [32]

At least the potential for life experience is still present. The Norwegian guidelines dismiss the counterfactual argument that says that “not-living-anymore” will stop further suffering from occurring, although this is, in another blend, obviously true.

In Norway, suffering that has been prevented by the patient’s death is inadmissible as an entry into the balance sheet of human suffering. Positions on ethical, legal, and medical issues, on probabilities and causal relationships have been crafted together in a coherent framework that both shapes and restricts choices available to dying patients and next-of-kin?

Contrary to Norway, the Netherlands have carved out another path that goes deeper into the borderland of life and death. Historically, the Dutch physicians who, together with their patients, pioneered the practice of euthanasia in the Netherlands defended their actions with an appeal to the patients’ suffering made on their moral duty to not abandon but to help them [33]. The Netherlands allow patients to ask for more active termination of life to prevent suffering, simultaneously allowing physicians to grant such a request when they perceive it their never easy duty to provide assistance in dying when life can no longer be saved or prolonged. *Suffering prevented by death* is allowed as an entry on the benefit side of the end-of-life balance sheet. Safeguards marking that path, that is subject to the Dutch Penal Code, in the form of due care requirements, are consequently tougher than those for palliative sedation. These due care requirements include a second opinion by another physician, compulsory notification of each case to a review committee, and in each case a decision of exemption from prosecution and punishment. “The offence ... shall not be punishable if it has been committed by a physician who has met the requirements of due care ...” (Article 293 of the Dutch Penal Code, as amended by the law of 2001) [33].

7. Suffering from life

It is possible to specify the differences between items allowed to be entered on the balance sheet even further. In Norway, euthanasia and assisted suicide are illegal. But even in its guidelines for palliative sedation in end-of-life care the Norwegian Medical Association is very restrictive. In its 2001 guidelines, it is only intolerable and refractory *physical* symptoms that can provide a proper medical indication for the intended, proportional pharmaceutical reduction of the patient’s consciousness, and therewith life experience. Mental symptoms are not allowed on that balance sheet [32]. The Norwegian Medical Association revised its guidelines for palliative sedation in 2014 [34]. It maintains its position that palliative sedation is a last-resort option; a treatment that, although ordinary and legal, should only be given in exceptional cases of intolerable suffering resulting from or dominated by physical symptoms. However, the 2014 guidelines provide a small opening toward mental suffering by stating that “psychological symptoms alone are only in rare cases indication for palliative sedation” [34]. In a paper in

the Medical Association's journal, these psychological symptoms are specified as "serious and treatment refractory psychological symptoms and delirium with extreme unrest and confusion, provided that first an attempt has been made to correct pathophysiological causes" [35]. These are mental symptoms associated with the process of dying.

The Dutch law regulating euthanasia and assisted suicide makes no distinction between physical and mental suffering, including suffering from psychiatric conditions like schizophrenia or bipolar disease. There is recognition that the mental suffering from psychiatric conditions over long time, and without the prospect of improvement, can induce in patients the wish to die. Dutch law has made it possible for these patients to ask for and receive professional help in ending their lives on request, provided proper procedures and due care requirements are followed.

Starting in the early 1990s, in the Netherlands, there is currently an ongoing discussion about the question whether the kind of suffering that should be allowed as entries on the balance sheet should be expanded beyond psychiatric conditions to include *suffering from life*. In 2010, a group of publicly well-known former politicians, physicians, university professors, journalists, and artists established the Out of Free Will civil initiative, *Uit Vrije Wil*, working toward the legalization of professional help to die for people of old age who consider their life *completed* [36]. The people this concerns are people who have reached respectable ages of 75 or older and who have developed a sustained wish to die. They do not want to have to keep on living a life that has become meaningless and without prospect. They may or may not suffer from the accumulated physical symptoms of common ailments that come with old age, but that is not the source of their wish to die. The reasons they give for their wish to die vary but have often to do with the loss of next of kin and spouses; the feeling of not being needed anymore after having lived an active and fruitful life, of being sidelined by society; a fear of losing their independence; of becoming dependent on others; the lack of meaningful everyday life activities. Life itself, or better, the prospect of living through the many empty and meaningless days ahead has become the source of a kind of existential suffering [37]. Some of them still have a partner they live with or adult children with families, and they enjoy spending time with them. But on the balance of it, these moments do not outweigh the burden they suffer from having lost the prospect of a meaningful future. They are, to use Wijngaarden's phrase, "incurably old."

The issue of legalization of professional help to die to old age people who consider their life completed was brought up in parliament during the 2014 evaluation of the Dutch law on euthanasia and assisted suicide. The government commissioned an advisory report on the issue from a group of experts. The committee concluded that the extant legal framework already provides sufficient possibilities for this presumably small group of people. Hence, it is not advisable to allow, with regard to assisted suicide, more freedom to emerge than is already provided by the current legal framework [38]. Despite this conclusion, in the year preceding the parliamentary elections of March 2017, several liberal parties expressed their support for an expansion of the law and include the suffering from having to live on as a legitimate ground for asking but also receiving professional help in ending one's life. In 2016, member of parliament for the liberal democratic party D'66, Pia Dijkstra, prepared and submitted a bill to this effect, arguing that the freedom of every citizen to shape and live their lives in accordance

with their own preferences also includes decisions concerning the final phase and the end of life. Everyone has the right to leave this life, or conversely, no one is obliged to keep on living [39]. Forcing someone to continue living a life that has become meaningless not only violates this person's right to self-determination, but it also constitutes a form of harm. It should not be a crime to help!

It is uncertain whether the bill will pass the next parliament, and of course, there is an opposition, not only from religious parties in parliament but also from mental health professionals, arguing that these people are mentally ill, suffering from a detachment syndrome. They should receive treatment not be given assistance to die.

8. Human rights as currency on end-of-life balance sheets: patient autonomy vs. professional conscience

In the previous sections, a different type of balance sheet has been lurking: the balance sheet that sets up and weighs the patient's right to self-determination against health professional's right to conscience.

The Norwegian 2001 guidelines on palliative sedation to the dying explicitly require *proportionality* between the severity of the patient's suffering and the moral gravity of the demand put to a physician. To ask a physician to collaborate in the permanent reduction of a patient's consciousness, and therewith life experience, is of such significance that this can only be requested in cases where the patient's suffering is of equal magnitude [30, 32].

The concern for health professionals' right to conscience is also evident in these and other guidelines' preoccupation with the *cause of death*. Or rather, their preoccupation with avoiding that a palliative intervention can be perceived as a contributing causal factor to the death of the patient. After the patient's death, it is the underlying disease that should stand alone as the cause of death. Graef and Dean wrote that "[t]he desired outcome of PST is symptom relief and a peaceful, quiet death *by the natural course of the disease*" [31] (my italics). Note that the causal relationship is signified by the word "by." The agent causing death is the disease. Note also that the quote ignores that modern medicine has transformed the courses of many diseases through myriad of interventions and attempts to cure or delay the disease so that it is no longer possible to talk about the *natural* course of a disease. To a large extent, modern medicine has *chronified* the diseases it cannot cure [40]. The word "natural" must here be understood in opposition to artificial or "caused by a medical intervention." On the question whether palliative sedation has an impact on the exact time of death, Dutch guidelines conclude that, when administered proportionally, palliative sedation does not hasten death. The Norwegian guidelines are not satisfied with the level of evidence for this conclusion and argue that "even though it is claimed that palliative sedation does not foreshorten life, it can never be completely ruled out that a patient dies as a result of the sedation." The risk of this happening increases *proportionally* with the time the patient spends in an unconscious or sedated condition [32].

Both the patient and the doctor or the nurse have a right to autonomy and self-determination that derives from the same Universal Declaration of Human Rights concerning the right to freedom of thought, conscience, and religion. So, on the balance of it, whose autonomy shall carry the most weight in end-of-life decision making?

9. Consequences of restrictive end-of-life care policies for the balance sheet of suffering

The same figure of the balance sheet of suffering and human rights is used in both countries, but it is operated quite differently. Norway is the more restrictive of the two countries, at least in its policy documents, laws, and professional guidelines. It puts more constraints on both dying patients and physicians and other health professionals. The Netherlands have developed more generous end-of-life care practices, allowing patients to ask for more active termination of life at the patient's explicit and sustained request.

The notion of constraints can be understood in two different ways. A common understanding of a constraint is that of a prohibition, an arrangement that aims to prevent something from happening. The other understanding of a constraint puts emphasis on the channeling effects of constraints, the way in which a dam in a river, for example, channels the water current into a tube to produce hydropower energy. Or the ways in which environmental constraints can channel the direction of emergent biological forms (volleys of chemotherapy impacting the biology of the cancer; the wide spread use of antibiotics producing multiresistant bacteria). Could the strong emphasis on the sanctity of life in palliative end-of-life care in fact increase the amount and duration of suffering in dying patients? Of course, this is a question that is difficult to answer. But, I will argue, there are indications that this might be the case.

One reason is apparent in the definitions that palliative sedation has received in Norwegian guidelines. As a last resort option, palliative sedation is defined as the intentional, pharmacological reduction of the patient's consciousness with the aim to reduce intolerable suffering from intractable *physical* symptoms that cannot be managed otherwise. Suffering from intractable physical symptoms is a proper medical indication. Suffering from psychiatric condition is not allowed onto the Norwegian balance sheet of suffering. Depending on the degree of physicians' compliance with these professional guidelines one can argue that there may be suffering that is addressed too late, and perhaps insufficiently out of fear for being accused of euthanasia.

When definitions of palliative care are provided, the definition is more often than not followed, under the same breath, by the reassurance that palliative care/palliation does not hasten death nor prolong it. As a factual statement, this must be false. Palliative treatment affects the temporal dimensions of dying. However, the evaluation of a palliative treatment's effect on the timing of death is different depending on its direction, whether the process of dying is accelerated or delayed. Even a small change toward an earlier death is viewed with suspicion, because the *intention* of palliative care is not to hasten death or relief suffering by death. At the end of the day, it is the underlying disease, and it alone, that must stand out as the agent responsible for the death of the patient. Unfortunately, this preoccupation with avoiding that

acts of care can be construed as causal co-factors to the death of a dying patient induces uncertainty, anxiety, and feelings of guilt in both health professionals and next of kin. A shift in the timing of death in the other direction, delaying the process of dying, is valued differently, because it gives the patient more time and more life experience. However, more time as a result of palliative treatment also allows the erosion of body and mind to become deeper before death finally arrives.

10. Conclusion

In many western countries with highly developed health care systems, the law of the land has delegated the *competence* to make end-of-life care decisions to physicians, based on the assumption that these are medical decisions that require knowledge and expertise about treatment possibilities, documented results, and prognosis. The medical-professional literature describes the point at which life-prolonging treatment is no longer possible and its transition into a palliative trajectory as a *medical assessment and decision*. Despite the fact that respect for the patient's autonomy is first among the four principles of medical ethics, in practice, our autonomy is constrained at a time when it perhaps matters most, at the time of our dying [10]. I am not advocating that patients facing death "put in the oars" —as the Norwegian saying goes—too early. When they do, they may spend a long time waiting for death. However, I would support people reclaiming important aspects of end-of-life decision making from medicine, give priority to their own versions of the balance sheet of their lives and values, and achieve or maintain a greater degree of direction over the manner, place, and timing of death.

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