

# The Quest for a Perfect Death. Thoughts on Death and Dying in the Future

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## Abstract

From the title of the conference I'd like to call my essay *The quest for a perfect death. Thoughts on death and dying in the future*. I've divided my text into three parts: In the first almost descriptive and hermeneutical part I give some insights into present social developments concerning death and dying in our high income societies. Inspired by the guiding questions in the program of the Conference I sketch two extreme future scenarios in the second part: the *assisted suicide scenario* and the "*palliative care*" *scenario*. As the labeling of the two outlines already reveals I presuppose value judgments, respectively assumptions, about a good and bad death without opening them up to discussion. In the third part I try to outline a *desirable future scenario* with regard to recent developments. That third part is normative since I draft some moral arguments concerning death and dying in the near future. The central idea of my vision of the future is centered on the assumption that an art of dying (*ars moriendi*) is identical to an art of living (*ars vivendi*). Because an over-planned life could end up in a state of self-blockade, we should envision the rediscovering of acceptance of what once was called "fate".

**Keywords:** Good death, dying well, finitude of life, assisted suicide, palliative care, self-determination, *ars moriendi*, *ars vivendi*.

## Current Developments

In the last twenty years death and dying have become issues of enormous public interest. While Elisabeth Kübler-Ross with her famous book “On death and Dying” touched a social taboo at the end of the nineteen-sixties [1], today death and dying have become subjects of ordinary and common discourses. While this change is normally traced to the popular studies of Elisabeth Kübler-Ross, important academic work has already been done by well known sociologists, as Allan Kellehear stresses in his amazing and helpful overview of death-studies published during the last 40 years [1].

There was the public dying of Pope John Paul II in 2005, the stories about Terry Schiavo in the US, Diane Pretty in the UK, Eluana Englaro and Piergiorgio Welby in Italy, Vincent Humbert and Chantal Sebire in France, Noël Martin in Germany, Gunter Sachs in Switzerland. These are just a few important examples, which only touch the tip of the iceberg of public interest for death and dying.

To demonstrate this new interest – which indeed contradicts the often repeated and nevertheless false *thesis of death denial* in our societies – further examples are easy to find: We know assisted suicide and euthanasia as issues in famous films like “Mar adentro” of Alejandro Amenábar or Clint Eastwood’s “Million dollar baby”, there are not only cyber cemeteries, scientific interest in near death-experiences, but also special homepages like [www.sterbehilfedeutschland.de](http://www.sterbehilfedeutschland.de) bringing up daily news about death and dying, there are unending talk-shows with personal testimonies on dying experiences, there is the famous exhibition “*Noch mal leben vor dem Tod*” (“Live once more before death”) shown in Germany, Switzerland, Austria, Israel and the UK with larger than life-portraits of dying and dead people, there are legal, ethical, political discussions about good dying in parliaments, courts, scientific settings etc. Because of the emergence of new institutions like hospices, palliative care institutions, new professions, legal regulations like the laws on advance directives, euthanasia or assisted suicide makes sociologists today talk about

- an institutionalization of death and dying,
- the *discovery of dying* (as the Swiss sociologist Ursula Streckeisen does, referring to the “discovery of childhood” in the well known book “Centuries of childhood” written by Philippe Ariès),
- the *new visibility of death* (die “Neue Sichtbarkeit des Todes”, as Thomas Macho and Kristin Marek do in a recent book title [2]), or even
- the *loquaciousness of death* (die “Geschwätzigkeit des Todes”), as the German sociologist Armin Nassehi does [3],

indicating processes of scientification, politicization, economization, medicalization and juridification of dying in our modern societies. For non sociologists the book of Reimer Gronemeyer called “Sterben in Deutschland“ is more readable while describing the same tendencies [4].

Nevertheless all these changes are marked by a deep ambivalence: While nearly all people would like to know more about dying processes, about experiences and possibilities to intervene or to make provisions for their own death, most of them have never had the real

experience with death or dying in their daily life (perhaps apart from car accidents or risky sports). Death and dying are happening in special institutions like nursing homes, hospitals or hospices. According to the German sociologist Werner Schneider these developments indicate a new arrangement or a re-arrangement of the last phase of life in our western societies: The modern idea of understanding death as “the enemy of life” is disappearing, the discourse doesn’t pronounce both the struggle for life and the struggle against death any more, while stressing new forms of social and cultural securing (“Sicherstellung“) of death and dying [5]. Death is no more something we have to prevent under all circumstances, but something we should control according to our own ideas and ideals. Apparently these developments bear new ideals and norms about good and bad dying (a late modern age *ars moriendi*, so to say): Central norms are doubtless self-determination, the ideal of dying as a self-controlled, conscious and active act, and the importance of retaining a good quality of life until the last hours of life. Both assisted suicide and palliative care fit in this “new” concept, although they are often confronted with one another: “For both, the worst evil is a poor quality of life.”[6]

A European study published by the National Institute for Demographic Studies in Paris 2007 came to a similar result: “The circumstances of death have changed over the last hundred years in Europe. Most people die at old or very old ages, often in a hospital or care home after a long chronic illness. A much wider range of medical treatments and palliative care has also become available. Patients, for their part, more often prefer to die peacefully rather than prolong life at all costs.” [7]

As the results of the EURELD-study have shown, more than 50% of all deaths in Switzerland are linked with medical decisions concerning the end of life [8]. If one subtracts deaths occurring in the streets or mountains without any possibility of medical intervention we have to face that in about three quarters of all deaths *Medical Decisions concerning the End of Life of the patients* (MDELs) were taken. In 28% of all deaths decisions are taken to withhold or withdraw treatments, and in 22% decisions about alleviation of pain and symptoms with possible life-shortening effects. Compared to the more controversial practices of killing on request (0.27%), assisted suicide (0.36%) and merci killing (0.42%), these two types of medical decisions concern comparatively a lot of cases.

In his overview of the social and behavioral studies on death Allan Kellehear, sociologist at the University of Bath in the UK, stresses the important fact that all we know about dying is mainly *through the lens of illness* [1, p. 19]. We still know very little about other forms of dying, especially about poverty experiences of dying, non-illness forms of dying, e.g. dying in prison, by suicide or war. He also indicates that there are sharp divisions in the literature between a material view of dying that emphasizes social and bodily decline (as Sherwin Nuland outlines in his book “How we die” [9]) and other literature that examines unusual psychological and social experiences associated with that bodily decline (like deathbed visions or near death experiences [10]).

## Two future scenarios

Inspired by the guiding questions in the program of the Conference I distinguish two extreme scenarios in order to work out some crucial points in a very simplistic manner. In the second volume of “The Principle of Hope” (first published as “Prinzip Hoffnung” in 1959), under the

title “Outlines of a better world”, Ernst Bloch has written a chapter on the struggle for health and medical utopias (chapter 35): Here he criticizes the absence of utopian thinking of physicians and (like Francis Bacon in the 17<sup>th</sup> century) conceives the importance of struggling for health and against death. He even dreamed about the abolition of death: “We may finally risk the proposition that precisely because the doctor, even at the individual sick-bed, has an *almost crazy* utopian plan latently in view, he ostensibly avoids it. This definitive plan, the final medical wishful dream, is nothing less than the *abolition of death*.” [11, p. 465] To reach that goal we have to fight against destiny. Ernst Bloch was convinced that this fight creates the link between medical and social utopias.

Imagine we woke up some morning realizing that we live in the year 2050. The crazy utopian plan of the doctors has not yet become fully true, but efforts in medicine and public health have led to a situation where a lot of dangerous illnesses have been eliminated and human enhancement technologies have been established, so that life expectancy could be extended to an average of more than 200 years. Chronic diseases, psychiatric disorders, overpopulation and longevity are now the most important problems of mankind, at least in the high-income countries.

In this situation a first scenario concerning death and dying could be an *assisted suicide-scenario*. Regarding the wording of the title I was inspired both by the actual practice in Switzerland and the metaphor of the last men in the Prologue of Friedrich Nietzsche’s Zarathustra. For Zarathustra the vision of the last men was a real “Dystopia”, but the people didn’t understand him (he, Friedrich Nietzsche alias Zarathustra, as the misunderstood prophet):

“The earth has then become small, and on it there hops the last man who makes everything small. His species is ineradicable like that of the ground-flea; the last man lives longest. (...) Turning ill and being distrustful, they consider sinful: they walk warily. (...) A little poison now and then: that makes pleasant dreams. And much poison at last for a pleasant death. (...) No shepherd, and one herd! Every one wants the same; every one is equal: he who has other sentiments goes voluntarily into the madhouse. (...) They have their little pleasures for the day, and their little pleasures for the night, but they have a regard for health. ‘We have discovered happiness’, say the last men, and blink thereby.” [12]<sup>1</sup>

Central issues for the last men in Nietzsche’s “Book for All and None” as in my *assisted suicide scenario* are the importance of health, the abolition of illnesses, the equality of all in the sense of indifference and apathy, longevity and the search for happiness. In this society a lot of possibilities to die after most illnesses were abolished and anti-aging measures were widely established do not remain. For a pleasant death people will need poison. That brings to mind what Thomas Morus had already written in his “Utopia” in 1518:

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<sup>1</sup> Im deutschsprachigen Original [12, 19–20]: „Die Erde ist dann klein geworden, und auf ihr hüpfet der letzte Mensch, der Alles klein macht. Sein Geschlecht ist unaustilgbar, wie der Erdflöh; der letzte Mensch lebt am längsten. (...) Krank-werden und Misstrauen-haben gilt ihnen sündhaft: man geht achtsam einher. (...) Ein wenig Gift ab und zu: das macht angenehme Träume. Und viel Gift zuletzt, zu einem angenehmen Sterben. (...) Kein Hirt und eine Herde! Jeder will das Gleiche, Jeder ist gleich: wer anders fühlt, geht freiwillig ins Irrenhaus. Man hat sein Lüstchen für den Tag und sein Lüstchen für die Nacht: aber man ehrt die Gesundheit. ‚Wir haben das Glück erfunden‘, sagen die letzten Menschen und blinzeln.”

“I have already told you with what care they look after their sick (...); but when any is taken with a torturing and lingering pain, so that there is no hope either of recovery or ease, the priests and magistrates come and exhort them, that, since they are now unable to go on with the business of life, are become a burden to themselves and to all about them, and they have really out-lived themselves, they should no longer nourish such a rooted distemper, but choose rather to die since they cannot live but in much misery (...); since, by their acting thus, they lose none of the pleasures, but only the troubles of life, they think they behave not only reasonably but in a manner consistent with religion and piety; because they follow the advice given them by their priests, who are the expounders of the will of God.” [13, p. 83]

These ideas also remind us of Michel Foucault’s system of bio-power as a new formation of power in western societies: The prerogative of the state – according to Thomas Morus, the priests and magistrates, in a future society perhaps public health experts or ethics committees – to decide on the life and death of its citizens. Besides chronic pain one major problem will be the state of boredom, indifference and coldness, as Bernard Williams stated in his often cited essay on the tedium of immortality [14]. “Everything is joyless”, he quotes the 342 year old Elina Makropulos, and the description of her experiences sounds like the feelings of the last men in Nietzsche’s Zarathustra. One major problem in these societies will be the isolation of their members and tiredness of life. If people do not remember their children because they are too old and there are too many descendants, they are isolated, without meaning in life and therefore ready to die by killing themselves, if there is no other possibility to die. In a world without “natural” death we will have the real problem with how and when to end the boring and indifferent life. A real dystopia!

A second future scenario I call the “*palliative care*” scenario, also conceived as a dystopian vision. In this scenario everyone dies without pain and having found meaning in their death [15]. “Palliative care” is written in quotation marks because it is meant in the sense of an overexaggerated care which bans or eliminates all kind of personal, especially negative experiences, like doubts, despair, hopelessness or unbearable suffering: Everybody is able to find meaning not only in pain, but also in suffering, dependence on others, finitude of life, death and dying. If someone doesn’t find a meaning, he or she has a problem which could be resolved with the help of professional care of social workers, psychologists, physicians, nurses or priests. The central idea is what Cicely Saunders once called *total patient care*. There are structures of all-embracing care with area-covering provision of hospices and palliative care teams, and a standardization of dying processes, as Stefan Dresske describes in his ethnographic studies made in German hospices today [16]. If someone gets too old and doesn’t want to live anymore, there are socially accepted ways of reducing eating and drinking without feeling pain or suffering until death. Everybody writes advanced directives to assure self-determination. The fight against fate is an important task, the quality of life to the last breath the central ideal, where everyone defines for themselves what quality means. Quality-adjusted dying and professionalism are important keywords. Finally: the costs for the caring at the end of life are low. If someone becomes a real burden for the society or if people have “out-lived themselves” (Thomas Morus), they decide on their own to die underlining the importance of the common good. There is no need for a governmental decision, because the people have internalized the ideals of a good life and death and decide on their own in the

correct manner. If patients have lost their decision making capacity, close friends or family members will decide for them in the normalized way.

## Desirable scenario for the near future

Neither the first nor the second scenario would be attractive or reasonable. I think a *desirable scenario for the near future* has to take into account some serious social problems like the financing of social security, the scarcity of physicians and nurses, the problem of isolation of old people, the increase of chronic diseases and dementia, longevity and last but not least the growing social inequalities with regard to welfare in general, access to health care and life expectancy in particular. While dying in high income countries is more and more expensive, millions of people in low income countries don't have access to basic health care and are dying without provision of professional care at the end of their life. From a moral point of view it is absolutely necessary to create new ways to enable access to basic health care and palliative care e.g. for people with AIDS in Africa, or the millions of people who are victims of migration forced by war, civil war, hunger and poverty. In a certain sense there is a necessity of a de-medicalization of dying in the high income countries, and an imperative to medicalise death and dying in the rest of the world.

One major problem in our high income societies will certainly be the one-sided concentration of controlling the dying process and the idea of isolating or concentrating all negative aspects of human life (like pain, suffering, dependence on others, dementia, depression, impairments) in a very last period of life, which should be professionally controlled either by palliative care-experts or shortened by suicide. This worry doesn't concern in the first place normative aspects of duties and rights but ideals about a good or flourishing life. In this view assisted suicide should be the general solution to prevent, to eliminate or to ban pain, suffering, dependence, dementia and all the other negative experiences. The overseen fact is that all these aspects are part of our human condition and aren't preventable. Human life without suffering would no longer be human life. If we take a look at the real world there are more and more people suffering from chronic diseases, a lot of people dependent on others (not only disabled people) and an increase of depressions and other psychiatric disorders. The result of establishing this "misleading idea" (to place all the negative experiences in a very last phase of life) therefore could only end in deception or premature death. Certainly there are questions without answer, we can struggle against diverse forms of pain and suffering, but suffering as human condition will stay and is to be endured (even if there is no meaning). An idealization of dying-processes often called "natural dying", could collide with the common reality of alienations or inconsistencies during the dying process.

Epicurus said in his letter to Menoeceus: "The art of living well and dying well are one." [17, p. 45] In other words: An *ars moriendi* (art of dying) is identical to an *ars vivendi* (art of living), since in the last phase of life the very same aspects are of importance as during the whole life. From a Christian viewpoint I would underline the importance of the three divine virtues: belief, hope and love, furthermore the attitudes of forgiveness, acceptance of change and the fact that human life is *always* fragmentary and imperfect. In this view we should be at least skeptical regarding the idea of the "Ganzheitlichkeit" (totality or wholeness)

in palliative care, also about the idea of dying a perfect or mild death (“Sanftes Sterben” [18]). As Sherwin Nuland has pointed out, the material view of dying processes often shows neither a mild nor acceptable, but a tough and horrible picture.

In this view an *ars vivendi* should encompass the rediscovering of acceptance of “fate”, in the sense of accepting the fact of being determined by others or by unforeseen events in life. In our human destiny, birth and death are peaks of heteronomy. The German philosopher Martin Seel reminds us (like Harry Frankfurt) about the one-sidedness of the ideal of a rationally organized and planned life (I’d like to add: also about the one-sided idea of a so called “rational suicide”): “They will only live autonomously, if they let themselves be surprised by the world, by others, and all the more by themselves.” [19, p. 629]<sup>2</sup>

Furthermore an over-planned life could end up in a state of self-blockade. Even if advanced care can be useful we should accept that the final phase often can’t be completely controlled. A clenched orientation towards the planning and controlling of the dying process could end up in the opposite of a self determined death: in a rationally planned, socially enacted and for that deeply heteronomous dying, as Reimer Gronemeyer has stressed for years. He asks: „We have learned how to plan our lives. And now the planning of the dying comes along? Will modularization, standardization, quality check and evaluation be established in end of life care? Will we be delivered to a quality checked dying in the end?” [4, 22]<sup>3</sup>

Finally I think we should accept and be open-minded to different ideas of what is or could be a *good death*. We should not forget that neonates, little children or the elderly with dementia couldn’t live up to the ideal of a self determined, self controlled death and that there are a lot of people who don’t want to write advanced directives. Allen Kellehear describes different concepts, narratives or pathways, besides the idea of *dying as personal control*. As important examples he mentions the understanding of *dying as a journey*, *dying as oscillation* (fluctuating between decline and improvements), *dying as withdrawal* (a process of disengagement, a slow withdrawal of both bodily energies and social engagement and interest), *dying as physical collapse*, *disenfranchised dying* (entrechtetes Sterben, stressing the powerlessness of the dying e.g. in nursing homes, but also underlining the fact of unrecognized dying like dying in prison, of AIDS, poverty, coma etc., not recognized by the dying themselves or by the authorities responsible for them) and finally *dying as transformation* (deathbed visions, near death experience nearly always full of love and peace). The subtitle of his book “The study of dying” is interesting and inspiring, indicating a change “*From autonomy to transformation*”. The sociologist writes: “Dying, like life itself, can still surprise us with the unexpected and the positive, often even in what seems to be our darkest hour.” [1, p. 17]

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<sup>2</sup> Im deutschsprachigen Original: „Autonom lebt nur, wer frei dafür ist, sich von der Welt, von den anderen und erst **recht** von sich selbst *überraschen* zu lassen.“

<sup>3</sup> See also pp. 187–199: „Death Control. Von der Kunst des Sterbens zum verwalteten Abgang“: „Unser Leben zu planen, das haben wir gelernt. Kommt jetzt die Sterbeplanung dazu? Setzen sich in der Sterbebegleitung Modularisierung, Standardisierung, Qualitätskontrolle und Evaluation so durch, dass wir am Ende einem qualitätskontrollierten Sterben ausgeliefert sind?“

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