

## **Risky Dying – How to Address End of Life Issues as Scientists in Reflexive Modernity?**

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Ladies and Gentlemen,

I am very pleased to be invited to this meeting of the NRP 67 and would like to thank the organizers for giving me the opportunity to speak here.

If I could make just one short comment at the beginning: In my talk today I will not spend a lot of time on concrete empirical data and data analysis; I will focus instead on theoretical and methodological notes and considerations, since I am sure there will be many opportunities to discuss empirical projects later on today.

I would like to start with a specific date – my own personal ‘date of death’: I will die on Thursday, September 7<sup>th</sup>, 2034, seven weeks before my 74<sup>th</sup> birthday. How do I know this? As you may already know, anyone can find out his or her date of death on the internet. Simply fill out a short questionnaire with some general information (such as age, gender, or Body-mass-index) and information about your lifestyle (do you smoke and drink?, are you physically active and keep a healthy diet?, are you married or single?, etc.). Based on this data, the website will instantly calculate your average life expectancy by using current mortality databases. The statistical elements are completely hidden from view, of course, since that is entirely the point. The result is presented as an individual, personalized prediction of the date of your demise. I wouldn’t be surprised if it was automatically synchronized with my Google calendar. But on closer inspection, the specific WHEN of my death does not seem so significant – more important, more interesting would be to know HOW I will die, the minutes, hours, weeks, months before my actual death.

Since humans are aware of their own mortality, the questions we ask ourselves about the end of life, individually and collectively as a society, and the way we process dying and death culturally are, on the one hand, a part of the human condition. The development of human culture is a phenomenon that, simply put, cannot be understood without recognizing the importance of human’s awareness of their mortality. On the other hand, it is remarkable that our Western way of thinking – in which the idea that we will experience a natural, preferably healthy death, guaranteed to us by the health society after a prolonged life, is dominant – has led us to believe that we can actually calculate the end of our lives using ostensibly objective data regarding our physical fitness and lifestyle and expect a truthful answer, at least in the sense of statistical probability.

In the following, I am interested in exactly these kinds of questions about the transformation of how we think about and act regarding dying and death in society. I’m a sociological observer who, since the mid-1990s, has been monitoring how societies have radically changed the way they deal with death and especially with dying. Why I chose “risky dying” for the title of my talk today, to describe some of these changes, will hopefully become clear during the course of my speech.

Accordingly, I would like to shed some light on the following issues

- the distinguishing features of this transformed, new way of dealing with dying and dying persons in society, which I will interpret in the context of reflexive modernisation as a conceptual framework (2);
- before this, I will briefly explain what 'dying' means from a sociological perspective (1);
- and finally, I would like to point out the resulting implications for methodologies and methods, that is, how forms of 'risky dying' in reflexive modernity can be studied empirically (3).

### **(1) The end of life from a sociological perspective: Dying as a social process**

What is dying in a sociological sense? Here is a short quote from sociologist Klaus Feldmann: "In earlier times, Orthodox Jews declared community members who had married non-Jews as dead and carried out a symbolic burial for these people."

(Feldmann, Klaus: Tod und Gesellschaft. Sozialwissenschaftliche Thanatologie im Überblick. Wiesbaden: VS 2010, S.126)

This quote shows us an example of what is called social death: A member of a group is defined as irrelevant, as no longer existent, as 'dead', metaphorically speaking. In small, closed-off groups this may even lead to the member's physical death without showing any 'objective' medical symptoms. This is sometimes misleadingly called 'psychogenic death', even though it is actually about social exclusion that is so strong that it puts someone's physical existence into question. When we look at it the other way around, we see that when there is a fatal diagnosis, it is important to what extent an illness and the physical process of dying is accompanied by exclusion, meaning that social exclusion precedes a person's physical demise. This was true, for example, for HIV-patients in the 1980s, for which the stigma of an AIDS diagnosis was also a social death penalty. It is no accident that the hospice movement can trace its roots in part to the care for these afflicted persons, who in this time were excluded from society due to their stigmatization as being 'infected'.

Therefore, dying has always been more than a primarily physiologically determined process – dying is always and above all a social process. In a sociological sense, dying is considered to be a complex process of discharging members of a community – please note, discharging, not excluding(!) – a process which leads to a comprehensive transformation, a fundamental re-interpretation and re-definition of the shared reality of all participants that surround the dying process. In this way, the community makes itself aware of the fact that one of its members will be leaving them forever, keeping in mind that all the surviving members must undergo a meaningful transition into a new reality of everyday life without the deceased other. Thus, from a sociological point of view, it is not(!) the dying person him- or herself who is positioned at the centre of the social configuration of dying, as might be expected. Instead, this arrangement is about those who are still living and the way they cope with the experience of the dying of another person that is significant to them: Practically, in their actual everyday lives, and in the way they order their world and assign meaning to this order.

The community or the society of those who continue on living usually cares for the dying person in a way that allows its members to keep on living as well as possible after experiencing this departure – that is, allowing themselves to keep the belief intact that their life is still meaningful, despite having to experience death through the dying of another. Therefore, how a human being dies is always determined by the society they live in and configured along the following lines:

1. Predominant core principles, applicable norms and values that provide templates and orientation for action,
2. the existing institutional references in which dying is situated in space and time (for example, in the clinic, palliative care unit, hospice, or at home, including the definitions of social roles that are associated with them), and
3. the corresponding social relations between the dying, their relatives, and the volunteer or full-time end-of-life workers.

In short: We do not die just like that, our dying is carefully made: is like 'making to die'!

## **(2) The modernisation of modern end-of-life: The ,good' way to die**

But this social 'doing dying' has undergone fundamental transformations since the 1970s. At the same time, for about the last 30 to 40 years, our society has taken part in an enormous laboratory experiment that has attempted to carry out the modernisation of modern end-of-life – an experiment whose outcome, in my opinion, remains quite uncertain. For this, I propose three possible explanations:

1. We live in a society whose public and normatively effective discourses are supposed to constantly familiarize us with the 'right' way to handle the experience of dying and death, the right way to deal with dying people and dead people.
2. The awareness of one's own end-of-life, the anticipation of dying at some point in the future, the concern for one's own death has become an 'individual project', a final life project which must be planned carefully in advance and is self-determined, that is, individually and purposefully designed.
3. In this respect, a 'final care culture' geared towards an 'individually tailored' end-of-life experience, with organizational fields of activity of providing for, assisting, and supporting the dying and their loved ones. These organizational fields of activity institutionalize a 'good way to die' as the last phase of life for the modern individual.

In practice, this means that individuals must consider how they imagine their own dying should be like (such as creating a living will, patient's provision, or health care proxy). They must have conversations with their family, with doctors, and with others close to them. When the time comes, reliable networks of care and support must be put in place, treatment options must be reviewed, the preferred extent of assistance must be clarified: Are there any relatives available to help, is there a family doctor, a home care hospice service? Is there a palliative care ward at the nearby clinic or hospital, or is there a dedicated hospice close by? When the time comes, these decisions have to be made, and effective treatment of pain and psychosocial support must be implemented. Alternatively, the best thing would be to have the opportunity to end it all in a self-determined way, according to one's own free will and at the appropriate time... And it's not just about the big decisions concerning life and death that must be made, it is in particular the many small and practical processes of everyday customs at the end of life that are important. It's about realizing what is needed 'more' or 'less' or 'never' in everyday life during this extra-ordinary crisis situation that is an illness that threatens your very existence.

All of this means that in our perception: Dying doesn't just happen anymore, dying is an increasingly risky thing to do! You have only one shot, nothing can be undone or tried again. You can soften the effects of a wrong career decision by additional training or retraining for a new vocation, a second marriage can be followed by a third marriage if necessary. However, the afflicted cannot learn from their experience of dying if it doesn't work out the way they thought the first time.

This new, risky way of 'doing dying' is a significant contrast to the social treatment of dying as was characteristic for the so called first modernity of the 20<sup>th</sup> century, using the terminology established by the theory of reflexive modernization developed by Ulrich Beck, among others. Today, we do not have to deal just with the medical aspect of caring for the dying, and it is certainly no longer a hidden, isolated, and lonely process of being-made-dead behind the scenes, which the modern clinic of the 1950s and 60s was accused of. Instead, since its onset at the beginning of the 20<sup>th</sup> century, it is clearly recognizable that modernization of end-of-life continues to radicalize the normative idea of the "unique personal life", a life which the modern individual, now thoroughly individualized in every part of life, is tasked with planning and actively shaping until their last breath.

The individual organizes, masters, shapes their own day-to-day life in a self-determined way – believing that they themselves make decisions and perform actions. This belief, this basic attitude simply means: We want, should and must be the 'masters of our own destiny' in many areas of life, making all the major and minor decisions in life for ourselves, thereby trying to design our own lives to be as 'good' as possible. The "unique personal life" of the individualized individual in modern society is matched by the radicalized normativity of the actively self-determined and pre-emptively organized "unique, personal, good way to die", which should be as painless as possible and seems to be more dignified and successful the more self-determined it is.

This idea is the linchpin of several scientific and professional as well as political discourses on 'good ways to die', which have provided the institutional objectives of all newly developed and still-developing, as well as established and yet to be reformed organizations for dying. These organizations include the traditional retirement home or nursing home and the clinic or hospital ward, which now needs to develop a culture of hospice and a competency for palliative care, on the one hand; on the other hand the palliative care units and hospice services that have emerged since the 1980s; and last but not least dying at home with the family doctor, with a home care nursing service, or with volunteers or a mobile multi-professional palliative care team.

As late as the 1950s and 60s, dying was something to be concealed as an ultimately unavoidable 'workplace hazard' of the modern health care system, something to be postponed for as long as possible. The dying were shifted off to the station bathing room at the back of the clinic, where doctors took a wide berth and nurses hesitantly tried to find a way to deal with situation of people dying. All in all: Dying and death represented a disturbance in clinical procedure. Dying was considered to be an error in the system of modern medicine, for the great promise of modernity was to expel any suffering from people's lives that appeared in any way to be treatable by society. It is the great success story of modernity that more and more human suffering appeared to be avoidable and socially manageable for more and more people, and could be minimized or even circumvented entirely by modern institutions. Closely connected to this success story is the modern promise of 'dying naturally' at the end of life – meaning to make it possible for everyone to experience life until the end of its natural lifespan. Even this 'natural' lifespan could apparently be extended further and further – through better living conditions, diet, hygiene, medical care, and welfare.

This is the crucial difference to pre-modern, traditional societies, where human beings relentlessly shaped their existence in light of their looming mortality, which could manifest itself at any time, every day, at any hour. At the heart of this way of thinking is the organisation of everyday life in the face of 'death, the great equalizer', who would sooner or later come for every person, without discrimination, whether master or servant. On the other hand, there was a consciousness dominated by religion concepts that a person must be well-prepared to enter into eternal life in the hereafter at any time, be it in heaven or hell. By contrast, the modern promise of a 'natural death' today permits modern human beings to live their whole, prolonged life in a state of consciousness where they consider themselves to be 'potentially immortal'. Probably, very few of you left the bed this morning thinking about what affairs should be brought in order today in case you should not return at home this evening – or ever again.

Today, it is still valid to live everyday life with an attitude of potential immortality – meaning to cast out any uncertainty about continuing to be alive across an entire lifespan. And yet, at the same time, we are experiencing the slow decline of this sense of immortality, and a return of the consciousness of mortality, but in a very different form than the traditional context of its perception and interpretation that existed 500 years ago. In my opinion, it is misleading to speak of the return of an Ars Moriendi, even though it may be labelled as Ars Moriendi Nova, because it's not just about individual preparation in faith and the believer's ability to find the grace of God in his or her actions. Today, at the core of the modernisation of the end of life, there are discursive processes in connection with institutional and organisational structuring processes that are related to power, domination, and social inequality, as well as producing new expectations for social roles, new 'subjects'. One such subject is the active or activated 'good' or 'right' dying person, who dies well because of the provisions he or she has made, and because of their ability to act in a self-determined capacity. Also important are relatives that offer their assistance in whatever form, and different end-of-life workers from the family doctor to volunteers as well as many others who are involved with the 'final life project' and help to carry out the institutional management of the end of life.

To summarise briefly: Because our radically individualist view determines our perspective on everyday life as members of this society, it seems plausible for us to position the individualized individual who is completely self-determined and autonomous until their dying breath at the centre of our thinking in society. And it is for this reason that the idea of a long, self-determined, fulfilled, painless and 'immortal' life necessarily corresponds with a manageable, adaptable, and ideally pain-free way to die in reflexive modernity, in which the way the institutional order regarding the end of life has changed fundamentally.

Individualised dying is an increasingly risky activity as it becomes more reflexive. For whom, to what extent and with which consequences this best possible but risky way of dying becomes a realistic prospect – we do not yet know, because we are still missing the empirical data and are still right in the middle of this great social laboratory experiment of the new order of the end of life.

### **(3) Consequences for an empirical perspective on 'risky dying' in reflexive modernity**

In my third step I will try to outline a brief research program for an empirical perspective on 'risky dying' in reflexive modernity. As a sociologist who comes from the tradition of interpretive sociology and the theory of symbolic interactionism and who has concerned himself with the study of the

sociology of knowledge and especially with the ideas of Michel Foucault, I would like to emphasize that this outline is intended to stimulate discussion on what parts of this research program might be useful, interesting or entirely negligible from your point of view, drawing from the experience of your projects.

My research agenda is comprised of four points:

1. Which research strategy is right for studying the end of life?

Because we are in the middle of a social laboratory experiment, we are in need of comprehensive, often qualitative, exploratory empirical data – currently, we simply don't know what we are looking for, which categories, operationalizations and hypotheses are suitable for our studies. Dying has become a complex social process in reflexive modernity. Therefore we must be very careful with radical quantitative empiricism, and should first try to generate theories, since only an empirically supported construction of theory can adequately inform the practical side of things. Theory can help praxis to understand which convenient self-evident ideas and unquestioned convictions it clings to. For scientists, it is equally important to resist a premature methodological canonisation in the sense of a pseudo-objectivization of our methodical approach. From my point of view, the topic is less about dying as an objectively representable phenomenon and more about dying as a fundamental social process with an emphasis on aspects of knowledge and action regarding the social practice of 'doing dying'.

2. From discourse to dispositif: Discourses as generators of „true knowledge of dying“ and “doing dying” as a social practice

So the second step is to empirically reconstruct how and which general principles, values and norms of 'good ways to die' that inform the thoughts, perceptions and actions of people that emerge are enforced and processed as 'true knowledge'. The appropriate theoretical and methodological tools for reconstructing the discursive construction and assertion of 'true knowledge', that is knowledge that claims to be valid and by being 'accepted to be true' is true in its consequences, are discourse analyses on death and dying. We have to ask: What are the relevant politics of knowledge, and how do they function as 'politics of truth', what symbolic regimes of the end of life do they produce, and whom do these apply to?

So we have to look not only at general discourses but also at local knowledges and local cultures, at practice itself, an empirical and methodical way to access specific 'forms of doing dying' is needed. Thus, we must empirically reconstruct the institutional contexts in which risky dying is situated in space and time, equipped with dying-objects (from the nursing bed to the patient-controlled analgesia infusion pump) and practically implemented in specific forms of social relations with corresponding roles. We have to keep in mind that all institutional configurations of dying are 'becoming reflexive' in the sense of 'manufactured uncertainties', producing more and more unintended side effects in practice. So we have to ask, how actors try to restore certainty in the process of dying, and possibly how they, through these efforts themselves, disturb the whole process or cause it to hang in the balance, or how these attempts ultimately fail – and what are the institutional consequences and side effects of this?

This kind of glimpse at dying in practice, which is closely related to discourse analysis as mentioned earlier, can be theoretically substantiated by the concept of dispositif and methodologically and

methodically implemented using dispositif analysis. Which discourses of 'good ways to die' are related to which institutional practices of 'doing dying' and thereby transform the modern dispositif of dying and death into a 'reflexive dispositif' of dying and death?

### 3. Power and domination

Closely related to the question of social change along the discourse and dispositif concepts, focusing on the relationships between discourses, practices, their objectifications and the production of 'subjects' (the 'good' dying person, the family physician competent in palliative care, the companion volunteer), is the question of power. Who, and in which institutional settings, is afforded definitional and interpretational dominance of what constitutes good and successful ways of dying in contrast to bad ways of dying? Who, and in which space-time settings, has what kind of authority – authority over what kind of objects, over time, knowledge, authority over what actors involved in the process of dying, and so on – so that ultimately, the difference between, for example, a form of dying arranged by the dying person themselves and a dying arranged by others, for instance by relatives or 'end-of-life workers', becomes recognizable.

### 4. Finally: the question of social inequality

This leads us to the question of social inequality in the risk-charged field of 'good ways to die'. The more 'potential immortality' is replaced by the awareness of dying as a final life project to be arranged by the dying person themselves, and the more dying becomes a malleable, manageable, and risky process, then the more this form of dying becomes an unequal form of dying and a source of inequality in itself.

To date, our entire healthcare system has proven to be full of social inequality. Education, income, occupational status and professional prestige are significant determinants for the risk of disease throughout an individual's lifetime, as well as being the deciding factors in the average life expectancy. The higher you are positioned within the social structure of our society, the healthier and longer you will live. There is no empirical reason to assume that relations of inequality suddenly reverse or dissolve in the face of severe illness and dying at the end of life. It can therefore be assumed that, the more palliative care and hospice work are integrated into the health care system, the more they will reproduce and maybe even reinforce social inequality in the context of dying. This is a core question that needs to be substantiated empirically.

## **Conclusion**

Coming to the end of my talk: As I explained at the beginning when I told you my personal date of death, the WHEN of my death is not that interesting, it is the HOW of my dying that seems rather important. But I already know a couple of things about the HOW of my death, for I was born in 1960 and I know my generation: We, the Baby Boomers have always been too many. In kindergarten, in school, during the search for an apprenticeship or when applying for university, later during retirement it will be the same story. We have always been too many of us and will always be too many. We will also be too many at the end of our lives, in the hospitals, in the nursing homes, we will even get in each other's way at the graveyard, if not even the change of the funeral culture from a big coffin to a space-saving urn should have the desired effect. And this phenomenon of "too many and too much" will probably influence the prolonged process of our dying which, in all statistical likelihood, we will have to pass through in a multimorbid state, often alone, without much family

care, with too much solitude, too much of being dependent on strangers...- and for society it will be, above all, a matter of cost: a “too much” of costs! And how much this fate will affect me will be primarily a question of social status – as a Bavarian civil servant this may admittedly not be that alarming for me, as a sociologist who observes society, however, this perspective is extremely troubling.

How someone dies, whether or not receiving palliative care, whether being accompanied by volunteers or not, and so on, currently depends on that person's place of residence, on the surrounding institutional and organizational infrastructure and the available structure of social relationships (at the hospital, nursing home, at home, etc.). Furthermore: How much ‘capital’ do you need today and in the future to be able to die well in this society? For instance in the form of economic capital for choosing the right treatment and care options?; as social capital in the sense of having a support network social relationships at your disposal? The less ‘family’ is available, the more important other social networks will be, preferably with contacts to medical and care professionals, maybe you even know some volunteers or the coordinator of a hospice association...? How much cultural capital do you need in the sense of culturally specific knowledge about the functioning of our social support networks, where you should fill out which forms, where do you get important information...? Simply put: the poor not only have no money, but do not have access to networks and little trust in institutions. They will struggle with finding a ‘good way to die’.

Dying will continue to become an increasingly risky affair – but this also means: dying requires more trust than ever: in people as well as in institutions. The more people see themselves as integrated into a society, the more trust they can develop in the institutions and organizations which this society provides for the social process of ‘doing dying’. Can there be a good way to die for everyone? My answer is: No, it will not be possible for everyone to die in a ‘good way’!

The continuation of the social laboratory for the future concerned with ‘good’ dying will therefore be demanding and difficult, but in regard to my personal situation I feel quite optimistic for the moment. As a ‘young old person’, at the age of 50plus, as a ‘best ager’, I estimate that I have – despite this strange probability calculation – about forty to fifty years in ahead of me before the end comes. Which means I have a lot of time for preparing and organizing ‘my own’ risky dying, which – because this is the way the society of those who will live longer than me wants it to be – will be a good dying.

THANK YOU VERY MUCH!