GROUP 3. Interdisciplinary perspectives on death, the dead and dying in the context of medicine and healthcare

Foreword

This summary document is the result of an interdisciplinary discussion on death (the relationship with the phenomenon itself), the dead (the relationship with the deceased) and dying (the relationship with the stages in the process), both in general and in the particular context of medicine and healthcare.

1. Introduction: death concerns the living

We should immediately note that death also, and perhaps especially, concerns the living. Ways of thinking and talking about (or not talking about) death and ways of ritualising it and experiencing it give us a more general insight into the ways societies organise how they live together and how they think about and define the social connections within them. Through attitudes to death, we can understand our beliefs, our representations, our behaviours, our ideals, our fears and our taboos. That being the case, we are presented with several general avenues for reflection. Those outlined here relate to modern western society, but we are of course aware that a diversity of approaches and ways of experiencing death coexists within western society and, especially so, within human societies.
1.1. Modern-day death separate from any temporality?

Nowadays, death seems to have less of a connection with temporality than it did in the past where it was part of a long timeframe, a timeframe that connected a past and a future. Death thus becomes an example of presentism, i.e. the belief that the relationship with the past and the future is no longer central or necessary to the social and individual management of death. In this context, it is as if the present were an end in itself, as if the present would never end, as if it were detached from any temporality and therefore from any idea of eternity.

As far as death is concerned, such a perception seems to be reinforced by progress in medical techniques that have perfected predictions and prognostics of dying. We are therefore witnessing the emergence of a new figure, that of the dying person. This new figure poses intellectual, moral and practical difficulties for medical and healthcare professionals whose ideal aim is increasingly to "postpone death" as long as possible and, in so doing, to consider it a failure when death becomes inevitable.

1.2. Lack of shared transcendence and troubled identities?

The trend for individualism and an obsession with the present that characterises most of our society seems to go hand in hand with an erosion of a relationship with a shared transcendence: extra-human protective figures (as in traditional religions), as well as secular protective figures (the Nation, the Homeland, the Party, etc.). The individual dimension of death is highlighted and the collective dimension diminished.

Several phenomena flow from this: on the one hand, difficulties talking about real and specific death – including a sense of a chasm that it is difficult to bridge, a frustration, even, that it is difficult to suppress – and, on the other hand, a trend towards an internalisation and privatisation of death. Such a situation can cause identity problems due to the fact that death appears to be a radical otherness (mysterious, unconceivable, inexpressible) – an otherness all the more incomprehensible because it is experienced alongside anxiety and embarrassment. This crippling attitude perhaps goes hand in hand with the significance accorded to the biomedical definition of death and the technical management of end-of-life which seem to do away with the very notion of a "natural death".

1.3. Diversity of practices and attitudes surrounding death?

One might wonder whether the plethora of representations and practices associated with death that we see today – both in terms of social groups and individuals – is linked to a double phenomenon: on the one hand, the sometimes extreme reduction of an awareness of temporality and, on the other hand, the erosion of unifying representations of death. This singling out seems to go hand in hand with a reinvention of rituals observed by healthcare and funeral professionals such as, for example, the often "improvised" or "DIY" ceremonies that we have witnessed in the medical establishment – which tends to tolerate them benevolently. Here too, the

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33 Alain Plattet reports on his experience of this in the context of his work with "Quartiers Solidaires": out of 150 neighbourhood meetings of elderly people, the question of death has never been raised as part of discussions about quality of life. People at the meetings would say to him: "We don't talk about death."
diversity of attempts to give meaning to death – that of the relative or of the patient – is evidence of the difficulty of coming to a collective agreement about shared values and a shared meaning of death.

1.4. New political ethics of death?

These modern western reconfigurations also relate to the question of responsibility in the face of death – i.e. its ethical aspects. In so-called "traditional" contexts, it is primarily the collective that has this responsibility, especially in relation to the taboo surrounding death and the stigmatisation of suicide. Today, in so-called "modern" societies, this ethical concern for people's death tends to take the form of policies on death, which then becomes regulated through laws. But these policies are still affected by moral difficulties and conflicts of perception and representation.

We therefore come face to face with the difficulty of considering and assessing the legal and legitimate nature of the "request to die" from those who are suffering. And we have to address the difficult question of knowing how to reconcile individual choice with the collective norm – respect for the autonomy of the individual and an ethical and political concern for people's lives.

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These four general avenues of reflection are found to varying degrees in the five specific discussion points drawn up by the group.

A. Death decided in a medical context

Today, people only rarely die in their own homes (in France, 58% of deaths occur in hospital). The majority of people therefore die in a medicalised environment (hospital, long-stay institution) and no longer in their private, personal, domestic and social environment. This situation has consequences for when death happens.

In recent years, medicine has made extraordinary technical leaps forward. These advances have contributed to medicine being perceived and practised according to an ideal of "postponing death" as long as possible. This is of course connected to the relatively new technical ability to maintain vital functions longer than ever and therefore to maintain life "artificially". In this medical context, death tends to be seen as a failure, both by patients and relatives on the one hand and by professionals on the other.

This development has an important consequence: it is when medicine can do no more that it is "decided" to let death "come". Death is often, therefore, the result of a medical decision (discontinuation of care, non-intervention or withdrawal of therapy, discontinuation of chemotherapy, turning off machines, non-resuscitation, non-treatment, etc.).

This situation raises several significant problems: the risk of abandoning patients who are in the process of dying or unable to survive in spite of medical technology; poor self-image on the part of carers who have not "succeeded" in effecting a cure or prolonging life. These problems can lead to a breakdown in trust between the person who is dying and his/her carers, who are encouraged to direct the patient to other players for end-of-life support. In these circumstances, it becomes difficult for carers to maintain or assign any meaning to what they do, especially when it more or less amounts to admitting to therapeutic defeat. This difficulty can be the cause of
conflicts among healthcare professionals, who are to some degree forced to try to reconstruct a positive image of themselves, including when the patient dies.

Carers therefore find it difficult to talk about the "decision for death", as if it were "unthinkable" in a healthcare environment – some kind of "institutional taboo". However, this in no way prevents the search for meaning outside the medical context in the form of minor-key rituals – generally informal and often spontaneous and based on a DIY approach – which develop in parallel to the care activities (debriefing, meditation, candles, souvenirs, etc.). These rituals, and, therefore, these moments of searching for meaning, are established outside of the healthcare context, even if they are benevolently tolerated by institutions.

This situation raises not only the question of support for the person who is dying, but also support for those witnessing the death – both the patient's relatives and the professionals involved.

Discussion Points

We would like to discuss and reflect on some essential and additional questions.

How do we morally and spiritually accept the known but rarely openly-stated fact that death – including when and how it happens – is decided in a medical institutional setting?

How can we consider resolving the tension experienced by carers between, on the one hand, the duty to offer relief and to try to cure and, on the other hand, the need to give meaning to death in an institutional setting, while avoiding a feeling of failure and guilt?

How might we resolve the tension between some patients' desire to die – or to give meaning to their death in an institutional setting – and the great difficulties medicine has in accepting death34?

B. The figure of the dying person

Throughout history and across different countries, there has always been an abundance of tales telling of heroic, worthy deaths, or deaths that can offer a useful lesson to the living. Numerous figures owe their heroic status not only to what they accomplished on earth but also to the way they perished, sacrificing their life to an ideal. This pattern is found in numerous ancient tales – the Iliad, the Odyssey, etc. – and one might also say that it is at the heart of Christianity. Alongside this notion of death there have always been models for "dying well". While different in certain respects, these models are based on an equation that supposes that one's life can be evaluated against the yardstick of its end. Death therefore gives meaning to life.

We find this parallel between life and death on a more everyday level. It is embodied, in particular, in the way individuals in a society tend to gather around the same ideal of death. For example, by the Middle Ages, the clergy had ensured their presence at the centre of society by taking charge of the ill and the dying in hospices or leper colonies, and through funeral services. This central presence meant that a

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34 Some patients express this fear: "Medicine will not know what to do when I am about to die".
sudden death tended to be more terrifying that a slow death that would give the patient time to prepare for the last judgement through extreme unction and the absolution of sins.

With the spread of secularisation in the West, this trend has increasingly become reversed, to the point where sudden death (painless and without knowing anything about it) has become the ideal. Such a U-turn is also related to the rapid development in medicine immediately after the second-world war. This period saw the medical establishment embark on a quest to cure everything and to eliminate all trace of failure, starting with incurable patients. The abandonment or marginalisation of patients; forgetting to include a morgue when building a new hospital; academic courses that contain no training linked to death: these are all signs that the medical establishment had forgotten about death during this period.

This forgetfulness and its consequences are at the root of the boom in palliative care. In the 1960s, Elisabeth Kübler-Ross, a Swiss psychiatrist living in the United States, set out the moral contours: the definition of death as the final stage of development, or a way of discovering oneself and opening oneself up to others. In the 1970s, the British doctor, Cicely Saunders, added to this, at the same time as developing a clinic specialising in palliative care (use of opiates, pain relief, etc.) The emergence of palliative care had the effect of creating a new category, that of the dying person: the person who, progressively, knows that his or her life expectancy is decreasing and that he or she is going to die.

In caring for the dying, palliative care providers appeal to self-discovery: faced with death, patients must open up to themselves and their relatives. By extension, those supporting the patient are liable to undergo the same process of self-discovery and to learn from it about life and human existence. According to this approach, death is supposed to remind everyone of their uniqueness and the "essence" of their existence. It is interesting to compare this model with that of extreme unction. In the latter case, patients prepare for another, eternal, life, full of heavenly aspirations. In the "good death" model that has emerged from palliative care, patients are oriented more towards their past, so as to put a full-stop to what will soon no longer be.

Analyses differ as to the status to be accorded to these models, over and above their various differences. Some would highlight the enchantment of the world of which they are proponents, while others would stress their disenchanted nature: by leaving care to the clerical or medical establishment – by handing over to them, as it were, the definition of what is "good" or "ideal" for the dying person – one places oneself under their control.

**Discussion Points**

Ultimately, this difference in point of view relates to a fundamental tension for the being between autonomy and alienation. Any model of a "good death" can help to calm the anxiety implicit in death and the unknown that is contains. Alongside this, however, these models require intermediaries – on the one hand, priests or ministers and, on the other hand, doctors or psychologists – able to guide and subjugate individuals in accordance with divergent interests. Following on from this, without a point of reference (and therefore without a model), individuals may find themselves autonomous, but at the same time crippled, not knowing where to focus...
We would like to propose for discussion and reflection: is there a solution to this dilemma?

We would also like to hear His Holiness' opinion on medical interventions that aim to prolong life\textsuperscript{35}.

The Buddhist tradition has also developed an art of observation and a "semiology" of the approach of death. How would His Holiness respond faced with a patient who was dying in a palliative care setting?

C. The experience of someone else dying

These observations relate to the experience of an "expected" death in the context of an incurable disease. It is very different from sudden death, such as during resuscitation, for example.

Being with somebody during their last moments and their death has a deep and lasting impact on the relatives who have been in this situation. It is not uncommon for relatives to be able to relate the events that took place and the conversations they had with carers in great detail, even several years later. Such an experience is likely to affect significantly the way they view their life and their own death: "I reconciled myself with this moment" or "I am going to sign up to EXIT". Many of the fears expressed by patients are rooted in the difficult last moments that they have witnessed.

Aside from these general points, the experience of someone else dying can take various forms:

**Experiencing dying as strange, troubling, unknown**

Few people, including healthcare professionals, are familiar with the experience of dying. However, in our society there is no shortage of opportunities to "experience the death of someone else" through fiction (cinema, games, the news, etc.). One might even talk of the "pornography of death" in the sense of "complacent even obscene representation". This fictional familiarity is in contrast to the real-life strangeness. The unknown gives rise to fantasies, fears and erroneous interpretations (or subjective reappropriations) of events taking place.\textsuperscript{36}

**Experiencing dying as "unbearable suffering"**

Nearly half of patients fall into a coma before dying. This period resembles a more or less peaceful sleep in which the patient may sometimes move or speak, as if dreaming. Professionals are very alert to possible signs of suffering (groans, agitation, facial twitches) so that they can adjust the pain relief. For many relatives the end of life, especially when it is protracted, becomes painful to the point of

\textsuperscript{35} A recent study compared the attitude of American Christians (very inclined to accept measures to prolong life compared to atheists) with the attitude of European Christians (much less inclined).

\textsuperscript{36} An elderly woman, in a coma, was passing away slowly and peacefully, with her daughter and granddaughter present. The two women were cowering in the corner of the room opposite the bed, not daring to get closer for fear that at the moment of death the elderly woman might "scream or her body explode". After being reassured, they were able to get close to the elderly woman, hold her and talk to her.
being almost unbearable. The slightest movement or breathing noise can be interpreted as a sign of pain or suffering. This situation is well known in palliative care: carers know that in the final moments, it is often the relatives that need more attention than the patient. One might wonder whether the practice of palliative sedation (continuous anxiolytic treatment causing reduced consciousness in the patient, including deep sleep in some cases) that has developed in western countries has to some extent been influenced by the painful experience for the relatives.

Experiencing dying as "puzzlement – astonishment – a mystery"
Relatives often say that after keeping vigil over the body for several hours, they no longer feel the essence of the deceased person, as it if had magically "disappeared".37

Experiencing dying as a "sacred moment"
For the relatives, watching over a dying person often takes on a solemn, even sacred, character, which is unrelated to any religious belief. This is easily noticeable when one enters the room, as if one were entering a church. Even when the person is an a coma, the relatives present talk in low voices and express great respect towards him or her through their attitude, gestures and tone.

Experiencing dying as a "loss of meaning"
As already mentioned, when a person's end of life become protracted over several days and no communication is possible because the patient is in a coma, the situation can become very difficult for the relatives. They express their consternation as to "why it is taking so long? What is the point of all this waiting?". The lack of communication seems to play a significant role. This element of communication and of awareness that it includes also affects carers in the way they care for the patient. If there has been no verbal communication with the patient, for example if the patient is already comatose when admitted to hospital, he or she risks being treated more like an object than a person.

Experiencing dying and synchronicities
Synchronicity can be defined as the simultaneous occurrence of two or more events that do not have a causal link, but whose association appears meaningful to the person witnessing them. Synchronicities are not uncommon at the moment of or immediately after death. Witnessing such a phenomenon can be a source of calm and even hope for both relatives and carers.38

37 A young woman who had been with her father throughout his illness and final moments expressed astonishment on seeing her father's recently dead body. "Where is he?" she asked, "Where has my father gone? Where is his personality, his being?".

38 At the moment of her brother's death, a young woman ran out of the room, screaming in distress, summoning all the staff with her cries. The patient happened to love birds and had numerous ornaments and photos of birds in his room. He also had a twin brother that he had not seen for a long time following an argument. The sister's despair was linked to the fact that she had not been able to reconcile them. At that moment, all eyes were drawn to a sparrow banging into the walls of
Experiencing dying "after death"

On occasion, we observe that very soon after death, a change occurs in the face of the deceased: features relax and soften even when he or she has become very emaciated. Witnessing this can be extremely comforting to the relatives, especially if the end was a painful one.  

Reflections

In our modern society where death has become medicalised and religious beliefs (though not spirituality) have fallen away, dying seems like a "free zone" for ritualisation, both for the person who is dying and for the relatives and healthcare professionals in attendance. Dying seems like a strange, disconcerting, even frightening phenomenon. Paradoxically, it can also be a source of calm or even a new beginning.

Whatever the circumstances, for many relatives, confronting the experience of someone dying takes on an intensity characterised by "life". This marks them forever and profoundly influences the way they perceive their life and their own death. This experience can also be an opportunity for reflection for the carers and volunteers, usually in attendance at someone else's death, without our having to see in this any trace of "obscene" egotism. In other words, looking after a dying person well allows one to understand one's own existence better, give it some meaning and prepare for one's own death.

Discussion Points

If the experience of dying seems to be a key moment, a turning point in the life of those attending the dying person, could a "re-ritualisation" of these moments help them? Should it also help the dying person? How might we encourage it to become established in a society that is so diverse with respect to representations of life and where the taboo surrounding death is so strong?

D. Avenues for reflection on the dead body

In our modern media-focused society, we are constantly exposed to the spectacle and the representation of the dead body. However, being in the physical presence of a corpse disconcerts and upsets us. Its material and symbolic destiny is the subject of four stages of ritual: social identification of the body, funeral rites, dealing with the corpse and eternalisation of the dead person. These stages allow us to understand how we try to come to terms with the materiality of death. In the context of these

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4 Recently, the wife of a young  patient who, during the last days of his life had suffered pain that was difficult to relieve, said: "He looked so handsome and smiling – even more handsome than when he was alive. It was a real gift." She went to fetch her two daughters who were asleep at home so that they could see their father and retain this memory of him.

40 This question may also appear in section D below in relation to rites.
stages, how can we comprehend the recent changes in the transactions surrounding the body?

1. **Social identification of the body**: once society has been made aware of the death, what becomes of the body? Is the whole of the body important? Is the body seen as potentially dangerous? This strangeness and the danger of the body mean that it must be "domesticated" through ritualisation.

2. **Funeral rites**: the body is looked after by funeral specialists who arrange the presentation of the body. New techniques mean the body can be prepared so as to appear paradoxically more alive than before death. We are witnessing the appearance of new practices that aim to prolong the presence of the body in the family, as if the body has become an object of veneration.

3. **Dealing with the corpse**: the dead body has to be dealt with in accordance with political, legal, environmental and economic regulations and requirements, and symbolism can be attached to all these levels. But at the same time, isn't the treatment of the body the most hidden component of our rituals? Isn't this concealment in line with the limitation of social spaces where the materiality of the body is tolerated?

4. **Eternalisation of the dead person**: from saints' relics to "avatarisation". While the keeping of saints' relics involves the preservation of the material body itself, we are now entering a new realm altogether with the virtualisation tools that we have at our disposal. We are now witnessing new phenomena: the preservation of the living body to whom we give things to see and to read: (the tomb, photos, videos, stories, etc.); the social life of the dead person can be prolonged on social network sites where the dead person remains connected to the living and can even acquire new "friends"; and, in the future, techniques that already exist in experimental form will make it possible to reincarnate the body through a process of "avatarisation" by bringing it to life through artificial intelligence. These developments again raise some fundamental questions for the whole of society about the presence and the forgetting of the dead. What sort of presence do we tend to give to the dead nowadays? Is the eternalisation of the dead in order to benefit the living a violation of the dead person – a stolen death? Is it, on the contrary, a new form of life for the dead person that is useful to the living?

**Discussion Points**

We would like to propose to His Holiness the following questions:

How can we understand and face up to the tension that exists between the need to dispose of the body and the desire to preserve it in various forms?

Is rediscovering the importance of the body part of re-linking the four stages of ritual that have nowadays become separated?

**E. Choosing to die**

Geriatric clinicians are increasing faced with patients' "requests to die", even when such requests are not really justified by a terminal state of health. This situation
raises problems both for healthcare professionals and for the medical establishment. Part of this problem is to do with the reasons that people who make such requests give. In particular, they say that they feel they have become a burden on society or on their families or the medical establishment. It is as if dying were an "altruistic" request. This situation raises at least two questions:

1. Should/can professionals see in this a symptom of real suffering disguised in the form of social justification?
2. Should we see in this a symptom of the social obligation placed on these vulnerable people, leading them to consider their "voluntary" disappearance.

These questions seem to belong to a dilemma:

Premise 1: if these requests are considered to have a genuine foundation, assisted suicide would become a form of suicide that is acceptable, legal and legitimate as far as society is concerned (e.g. the authorisation of organisations such as Exit or Dignitas), but unacceptable to professionals, health institutions and, indeed, all relatives.

Premise 2: if these "requests to die" are turned down by professionals or the medical establishment as being unfounded or through admission of failure, there is the risk of abandoning patients and relatives to their real suffering, even of driving patients to taking their own life, on their own, violently, i.e. in a way that is unacceptable to society.

This dilemma raises the question of the "politicisation of death", i.e. the norms and social measures that influence how people behave in relation to their own death. This politicisation verges on the impossible: the voluntary death of individuals who are suffering as a means of achieving collective good.

**Discussion Points**

More generally, the question is the following: is it morally legitimate to entrust the regulation of voluntary death to the authorities, i.e. the law and the State? Should we, on the contrary, take the view that voluntary death should not be regulated by the law and the State, without morally and socially abandoning it as a taboo or something unacceptable?