

X - n. 1/2011

Salute e Società

The pre-chosen death
End of life arrangements
and instructions

edited by

Carmine Clemente
Giuseppina Cersosimo



FrancoAngeli

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The journal is published on behalf of Università degli Studi di Bologna



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Autorizzazione del Tribunale di Milano n. 137 del 6 marzo 2002 - Quadrimestrale - Direttore responsabile: Stefano Angeli - Poste Italiane Spa - Sped. in Abb. Post. - D.L. 353/2003 (conv. in L. 27/02/2004 n. 46) art. 1, comma 1, DCB Milano - Copyright 2010 by FrancoAngeli srl - Stampa: Tipomozza, via Merano 18, Milano.

Terms I 2011 - English Italian Version - Printed in april 2011

Copy Editing by Fausta Martino

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EDITORIAL

Tullio Seppilli*

An anthropological approach (and for this reason trans cultural) about death is based on an idea: death, an absolutely biological event, is very influenced, in its creation and in its specific modalities, by the *historic-social* context in which it exists, producing many cultural elaborations in different contexts, many individual and collective experiences, many behavioural and organizational answers.

For people, the biological event of death acquires at the same time strong socio-cultural dimensions, being very differentiated in civilization contexts (and in the same heterogeneous contexts of stratified societies).

From this perspective, the idea of *death anthropology* should be addressed towards three big kinds of processes, crossing to image, meaning and consequences of death in different social contexts.

1. *Death socially rendered*, based on a process with representations, learning and practices linked to impressive cultural construction designed, in every society, to give to the death a field of specific interpretations, of definite meanings, and potentially, of possible perspectives.
2. *Death socially thwarted*, related to that group of representations, learning and practices linked to all actions, with heterogeneous approach, realized in every society to prevent or to fight risk elements considered afoot of death, or of hidden dangers for human life. This process, creating in socio-cultural area, gets over biological notions of so-called “survival instinct” and of “natural” processes of body defense (from immune answers to “spontaneous” behaviour). For these reasons it is possible considering specific research area of *medical anthropology* (different medical systems as “dykes against death”).
3. *Death socially produced*, related to all representations, learning and practices linked to big range of operations producing, in every society, for different aims, with most conflicting excuses and in various forms,

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Translation is by Lucia Mautone.

directly or indirectly, consciously or unconsciously, intentionally or not and with several kinds of emotions and of embedding in primary aggressiveness processes, impressive number of single or diffused death effects. This “production of death” is influenced, in each culture, by power systems, by hierarchic structure of values and by individual or collective destination, by aims followed in “giving death” and by life’s value – and to human life – in different status and contexts. Death is often *a biological event socially produced*.

These notes intend to propose and structure some topics about research referred to *the first of these three kinds of processes*, summarizing as *the interpreted death*, that is the wide transcultural area of representations surveys, individual and collective experiences about death and rituals and social practices in different historical-social contexts: defined as *death culturalization*, with its attitudes and consequences.

Inside this wide and multiform research issue, it seems to be possible finding at least three important and distinguishable scouting guidelines.

The “first guideline” concerns representations, experiences, rituals and practices as “answer” to basic element of human condition. For man, at different level among various cultures, acquired self-consciousness and own individual being, produces a more or less aware representation of his life as a path, or better as a “project”, assuming meaning in reaching steps and destinations subjectively important. Death, before being a real event, predates its presence during human life, as frequent and threatening image of unrelenting and unexpected “end of every project” (and of every achievement).

- This “beforehand” awareness, certainly producing anxiety, of unavailability and unpredictability of death, and so of next certain loss of personal identity and of every “good”, even hardly achieved during life, is seems to be “typically” and “universally” human; the result of a complicated identity, unifying in its memory long periods of life and projecting next steps and aims.
- Talking about death as a long development, as the end of an existence daily built towards small and big plans, as complete ending of own life’s project, increases “affection to the life”, with foundations in biological nature of all living beings. The creation, in every society, of knowledge and different “medical” practices in order to fight with physical traumas and diseases their possible mortal result, is a clear token.
- However, this anguish of death, appearing as an “universal being”, shows clear individual and cultural differences. Individual differences, coming for everyone, from our quality of life, from evaluation of successes and failures, from persisting or not of expectations for the future, and so of objectives to reach, from a personal balance, summarizing impartial circumstances and subjective evaluations and experiences, influenced by different personalities. Many people,

because of a strong loss, “give into death”: an unhappy case history less evaluated by human sciences and anthropology, leaving to popular common sense this issue, while it is a basic crux for examination of controversial link “mind-body”. Up till revocation of every adherence to the life, rather its negation, in total renunciation, represented by suicide.

- This need of making projects, of caring of life’s spaces still open, “safe from death”, has increased and increases never-ended trials to know in advance the future, and increases fears conducting these efforts: from every ritual prediction, often based on question to higher powers mediated by specific ministries, on interpretation of dreams, up till anxious giving to the diagnosis and prognosis of professional resources of present medicine. There is a wide literature about, of heterogeneous disciplinary origin.
- But diversity of actions about own death is related to the difference in cultural backgrounds, or anyway to specific cultural knots, because reduction of death’s fear, or load of values and representations that forbid this fear, appears as the result of one or a group of circumstances: (a) an acceptance of death as only way compatible with a personal coherence or a public token of loyalty to specific ethic individual or collective rules (moral, ideological-political, religious), (b) an acceptance of death risks, or at the limit, research of death as personal contribution to prevailing of a collective cause, and (c) a deep belief in afterlife existence, where everyone will find redemption from iniquities and sufferings received and from prices paid for personal moral integrity – maybe a prize for sacrifices and a support for suffering –, or could reach loved people dead before him: an idea related to a vision of life as flow of generations, in which everyone takes up solidly and responsibly a position and a role in a continuous chain of human being.

A “second guideline” concerns representations, experiences, rituals and practices consequent upon the basic element of human condition (beyond its historical form), that is man, from the beginning of his evolution, lived in social contexts where answers to problems of his life get through to mediation of inter-individual relations. Everyone project onto other people around him a more or less deep emotional investment (involving moreover his safety processes), such as death of these people, and their loss, is understood as severe mutilation: mutilation of personal existential structure, mutilation of possible sharing of memories, mutilation of personal projects about the future and of hope that the life will go on (from here the meaning of mourning and its “elaboration”).

In this guideline, in the field of human sciences, subjects “psi” have to be analyzed. On the other hand, in the third guideline, describing specifically now, empirical surveys and theoretical consideration have to be conducted more into perspective of anthropological subjects (and of

similar subjects as history of religions). This guideline is the most observed by anthropological research.

A “third guideline” analyzes representations, experiences, rituals and practices related to universal cultural production of certainty of afterlife “continuity of life”, that is some horizon “beyond the death”.

In every known society, indeed, idea about afterlife existence and about places that died people have to reach are confirmed, through complicated *passage ritual*, in order to lead a new and specific life. In every known society two worlds – of alive or dead people – seem to be sometimes open to particular contacts, and sometimes to dramatic interference forms. This idea of a life after death is moreover documented since higher Paleolithic.

- Several societies think that particular characters (shamans, demigods, or others) are capable of entering into the world of dead through paths and specific rituals, assuring not only access to that world, but also the following return among alive people (compare to Greek myth of Orfeo and Euridice, or *psicopompa function* to going with dead people into their final house, assigned to Asian shamans).
- Dead can “come back”, and in its new condition (phantom, ghost, soul, breath, “double”) is impure, pollutant, dangerous, at times threatening. He can “come back” in order to earn something from alive people, a revenge towards his killer, for example, or ritual burial denied, being in half between two worlds, without life but unable to cross the threshold of underworld.
- There are proofs of fear of a “return” of dead since Higher Paleolithic: in rituals of *double burial* – in which after digging up of the body now reduced to skeleton, dead was again and permanently buried – are sometimes evident specific praxis addressed to thwart for dead way back, for example changing the place of two thighbones, in order to prevent him from walking. Ethnological proofs: dead is picked up from his hut, cutting a temporary exit in the wall, right away closed, so that he can’t find the way to come back among alive people (remember the debate about so-called *doors of dead*, located near the main entrance in many medieval houses in central Italy). Moreover, among us also, it is very widespread, and widely used in literary and motion-picture storylines, “terror” caused, especially during the night, by cemeteries.
- Sometimes people think that dead “comes back” in order to help who is considered near: he watches over alive people, keeping on protecting loved people, because he “knows” things that human beings can’t know (dead husband indicating in advance winning numbers of lotto to his widow in financial straits, in popular culture from the region of Campania). Often people think that for this aim dead appears through dreams, that is in a *oneiric dimension*, “other” compared to that of “normalcy”, and that uses, to communicate, a symbolic language to decode: a difficult operation, involving specific knowledge and skills.

- In order to interrogate dead people about future, about past or about condition of life, there are *evocation rituals*, realized usually through mediation of a “sensitive” actor (the *medium* in euro-american spiritualism).
- In many contexts people think that dead “come back” together, reaching world of alive people, in particular periods considered “breaks”, “final” moments of calendar cycle (so for example during *day of dead people*), or for specific rituals (*funeral of dead people* in European traditional culture).
- From general idea of a possible “return” of dead people and from heterogeneous meanings assigned, derives everywhere, especially towards “personal” dead people, an ambivalent behavior: of nostalgic affection and irrational fear, of ritual commitment and fear of repressions, of “*pietas*” and of horror. In every context developed heterogeneous but always important magic-religious forms of *offers to dead people* and of *cult of progenitors* (from thousand-year use of *altars of progenitors* in Chinese culture to particular “adoption of skulls” and their periodical “cleaning” in the *cult of physic souls*, realized in underground caves of Naples). From here a kind of contract, of “symbolic change” among dead people and alive people: offers, gifts, and other ritual functions realized by alive people towards dead people, in order to assure that dead people, from their parallel world, don’t “come back” to punish alive people for some wrong suffered, and, rather, to guarantee personal protection.
- The whole legendary and ritual spectrum going with person is deceasing and then with dead to his new life’s condition, is a strategic point in every culture, and in some societies, or about some social characters, adopts strong importance and a great articulation. In many contexts, moreover, during this “passage”, is supposed to be active a process, through a careful balance of life lived, and some higher entity decides which place dead is designated. It is a legendary and ritual spectrum addressed to “rebuild” social order broken by death, and only lately decreased more in “western society” (maybe since urban cemeteries become outlying, for lay-sanitary reasons, and so by ban of entombment in the church and in cemeteries near cleric buildings (remember contentious essay *Dei sepolcri* of Ugo Foscolo, 1807): from *prophecies of death* to complicated *limitations* and many *taboos* controlling the shake for dead, his home furniture, clothing, nutrition and behavior of kin and of neighborhood, up to notice of death and rituals related to the overtaking (*extreme unction*), to funeral rites and funeral honours (*funeral tears*, for example, or *funeral banquet*), to arrangement of body (burial, incineration, or other practices, everyone with its cosmovisions and philosophies of life), to destruction or allotment of all his goods, and then to forms of mourning and following commemorations, finally to cemetery structures and ways they are visited.

- There is anxiety that dead has not received basic ritual elements to enter in netherworld. In European folkloristic areas (for example in Italy and in France) people think that for children born dead or dead before baptism, “innocent” so but not yet “Christian”, is closed the door of Heaven: only now is disappearing common belief that priests of some cleric buildings (called churches *à répis*) have the power of raising for brief seconds from the dead the newborn in order to baptize before his final death.
- In some contexts – and in a very elaborated way in Indian subcontinent (Hinduism, Buddhism) – developed idea of *reincarnation*, after death, into an other being, human, animal or vegetable (*metempsychosis*), depending on behavior of the person during the life: is generated so a continuous cycle of livings, more or less extended, ending in a condition of total “rescue”. Maybe it is important remember now the recent creation of an psychotherapeutic address, in California and then in Brazil, called *past-life therapy* or *terapia de vida passada*, based on hypothesis that, through hypnosis, it is possible recalling in the conscience of the patient wounding events of previous lives and, through this bringing to mind, eliminate neurotic syndrome caused.
- Many cultures wonder about death, about its real “naturalness”, thinking that “at the beginning”, in a primordial “condition” death doesn’t exist: *legends of origin (or of creation) of death*, addressed to understand “when”, “why” and “how”, higher beings make man die, they are displayed in many populations, assigning this idea to punishment for violating a taboo or for a sin, or also to external events of human action.
- Is important, finally, affirming that centrality and plurality of social functions related to the death, and the same changeable but permanent degree of phenomenon, are in every society the matrix of a wide and very variegated elements of specific knowledge, specific activities and of specific careers, translating in meaningful corresponding organizational and financial dimensions. The phenomenon acquires a strong importance, especially in societies defined “complicated”, related also only to the first of three kinds of processes indicated at the beginning, about representations and experiences concerning death and its rituals and social practices: to issues tautly defined, so, as *death socially rendered*. But considering moreover the other two kinds of processes described at first, multiform and very wide activities, fixed or casual, about fight *to counter* death, and above all activities addressed to *produce* death of other people, in general the position of roles and figures revolving death, is very strong in every society.

The period of industrialization and then of so-called society of consumption seem have introduced – in the frame of a wide process of cultural laicization, but also of a spreading individualism, of a increasing hedonism and of a wide development of values related to youth, presence

and health – an important scanning in western attitude towards death. Many authors report indeed, with different emphasis and from various disciplinary perspectives (anthropological, sociological, historiographical), sunset of a “traditional” idea of death. Beyond fear, in traditional idea, people built about death a vision of its continuous “cum-presence”. Its cultural description was represented by impressive ideological-religious horizons, by frequent verbal and iconic expressions, by centrality of places of burial and forms of cult annexed, by richness of rituals, of premonitions and of “experiences” of contact. There is idea, anyway, of “naturalness of death”, of its “obvious” presence, of its being, in a certain sense, part of life in cycle of generations (“last will and testament” and “death in the bed” domestic, with sons and grandchildren).

With regards to this question, frequency, in the past, in formulating as “when he understood it has arrived his last moment called his sons” gives maybe hypothesis of a bigger ability, in traditional societies, to “listen” to his body and to foreshadow and accept his end.

This idea seems to be replaced with an other, of “scotomization of death”: death, even exposed as show, but objectified and returned anonymous by mass media, is, in daily life, kept quiet, occulted, showed as inmost and private, “medicalized”, bare of public symbols, an “exceptional event”, something not good to speak about. In late-capitalist societies there is a collapse of almost all forms of collective and individual rituals, related to events of death and nearly of all forms of active and supportive participation of neighborhood networks towards survivors – from progressive marginalization and camouflage of funerals and of standardization of plants of burial, to the progressive departure of every form of symbolic presentation of mourning –.

Description of death in talks and in daily relations is widely banned (unsuitable and improper as in victorian age pornography, according to well-known metaphor of Geoffrey Gorer) and mourning is so more widely lived as individual feeling, protected by an implied and respected discretion.

In this frame of “rejection of death” is maybe important considering practice, developed especially in United States, of so-called *toilette of dead*, in order to, at the moment of his public display, he regains as much as possible features “as alive”.

Anthropological observation has as primary responsibility evaluation of effects of this scotomization, of this fall of collective rituals of death and of talks about death and “good death”, and results on emotional balance of human beings, on elaboration of mourning leaved to individual loneliness, and on social practices annexed at the end of life (think for example of several forms of “therapeutic persistence” and difficulties to describe “right to an happy death”), in order to create, in current historical circumstances, a balanced emotional and cultural link with biological and inescapable event of death.



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INTRODUCTION

Giuseppina Cersosimo and Carmine Clemente*

In most cases, the terms life and death cannot be considered separately, even if several prominent philosophers have tried to claim that one excludes the other and that if the paths of daily life are often kept rigidly apart, the two worlds are corollaries.

We shall start by considering several different views of life in order to have a greater understanding of how the issues relating to its interruption are still not easy to deal with, notwithstanding the cases of Welby and Englaro having made it possible to discuss them as well as consider what is being done in other countries.

In general, writings did not include the word death, but rather the term end-of-life. However, it may be considered, the principle of life, with the characteristics of being a gift as well as *sacred* is the basis of the difficulties and misunderstandings between the various parties in accepting that an individual can choose when to die. In fact, the term life has a dual aspect. On the one hand, it reflects a particular dimension, highlighting its belonging to each of us as individuals, the essence of the self. While the other shows a universal aspect, corresponding its individuality to the social nature of each one of us. It is in relation to the second aspect of widespread subjectivity that thousands of questions, doubts and issues have been raised: can an ethic on the end-of-life be absolute and imposed on to everyone? Is it useful and necessary to set out advance directives in the eventuality of losing your own autonomy? Can advance directives be considered a new border of informed consent? Can the possible choices made in the present and in a state of consciousness be extended to the future?

The work in this volume through its multidisciplinary approach, aims at explaining how new technologies, associated to the end-of-life, create the dilemma of euthanasia: is it right, morally and legally, for a doctor to aid

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in an “assisted suicide”, if asked by the patient? Under what conditions and in what circumstances?

Answers to these dilemmas are considered from different moral perspectives and approaches. In fact, according to the moral approach of utilitarianism, the answer to the question whether it is more or less right to help a patient to die, can only be given by taking the consequences into consideration: if the person’s current situation is unbearable, thus allowing him to die reduces further suffering and increases serenity. Any resistance is only due to the legacy of our ethical traditions, which have been adapted to the problems posed by new medical and social contexts. Whereas, according to the moral approach of natural law, the gift of life is absolute and inviolable. Therefore, the desire to alleviate the patient’s suffering is considered a crime. On the other hand, according to a principlist approach, which has as the main aim of curing the sick people by providing them with autonomy and not causing them any harm, in order to respect autonomy and improve the quality of life of the patients, the end-of-life can be considered morally legitimate.

In fact, the issues of the end-of-life as well as any related definitions are still very unclear. Even the medical profession is uncertain and divided on issues such as the permanent vegetative state, as well as whether nutrition and hydration are to be considered medical treatments or not.

If the scientific debate in Italy has yet to find common points, politics on several occasions seems to avoid any further discussion. Without doubt, this legislative void is due to the total inadequacy and inertia of the Italian Parliament, when dealing with bioethical issues, to take a clear position on such delicate matters, which include fundamental rights such as life, health and human dignity.

The debate calls into question not only the medical and social sciences, as well as philosophy, but also the jurisprudence. At the end, politics has the responsibility to translate these issues into law. Otherwise, the resolution of tragic and real end-of-life situations will be entrusted to the courts. Will *Biolaw* replace *bioethics* (?) and law and politics replace constitutional jurisprudence?

Law might become biolaw. In a context characterized by the legislative monopoly, biolaw might become a technique of social control based on the neutrality and impersonality of technology.

The role of ethics is crucial when trying to deal with the adequacy (if not the restraint) of science, in relation to the subject studied as well as problems and reasons of existence.

The role of the courts when trying to fill the legislative void and deal with the end-of-life is likely to weaken the basic role of ethics in trying to address the adequacy of science in relation to the problems and reasons of existence.

It repro poses a dialectic between the natural sciences and the sciences of the artificial, which refers to that between nature and culture, including both the physical sciences as well as the humanities and social sciences. It has practical implications both in the field of medical knowledge as well as contemporary society in general.

Modern society, characterized by a great number of preferences, lifestyles, as well as social insecurities, could be the basis for a new subjectivity that claims on the basis of a new autonomistic rationalism, more individualism, more freedom as well as more self-determination in all spheres of life.

Modern rationalism tends to the affirmation of the individual over both social conscience as well as the sense of collective existence. Politics conflicts with different issues and pursues the possibility of finding solutions of “consensus”.

Faced with rapid scientific developments and their potential biotechnological applications, the conflicting responses derived from the various bioethical concepts, as well as traditional cultures and religions propose the need to develop a reasonable dialogue on both a moral level as well as by of a tolerant government, on a political level, of the various competing and conflicting proposals.

It therefore implies finding what is called the *reflective equilibrium*, i.e. the ability to modify our moral intuitions on the basis of what may be the practical consequences of our actions, following a continuous path of adjustment between principles and consequences, up to the point of obtaining an appreciable balance.