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Life at the end of life: beliefs about individual life after death and "good death" models - a qualitative study

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Abstract

Background: Different ideas of "good death" may influence the effectiveness of end-of-life care in patients with different ethos. This study aimed to identify the influence of believing in individual life after death on "good death" models.

Methods: Semi structured-interview to 8 persons, 4 believers and 4 non-believers in individual life after death from the general Italian population. Analysis of the transcribed text according to the method suggested by Mc Cracken.

Results: The analysis has shown a diverse and coherent conceptualization of death according to whether the subjects believe or not in individual life after death. Believers, for whom death marks the passage to a new dimension, prefer to be unaware of dying, while non-believers, for whom death is the end of the individual, prefer to be conscious until the very end of life. However some important aspects in common have been identified, i.e. having close people nearby, receiving assistance from experts, or the preference for a soft atmosphere around the dying person.

Conclusion: There are aspects in common and aspects in contrast between believers and non-believers in individual life after death: while sharing many aspects of what a "good death" ought to be, they have opposite stands on being aware of dying. A plurality of models should be foreseen, accepting, in this case, their practical and theoretical implications.

Introduction

Death and culture

Death is "good" when it fits with the role given, acknowledged and accepted by the dying person [1]. One of the main objectives of a culture is re-orienting death towards life: each person's death threatens society's cohesion by casting a shadow on the feelings of safety and continuity

on which every human being bases his/her life and finds support and consolation [1].

The dying person is assigned a role – the role of dying – that reflects beliefs and values. The ways, signs, rites, symbols and meanings that societies implicitly or explicitly express in order to face this problem are as many and

distinctive as are the cultures, and they change and evolve with them [2].

The "role of dying" and the belief in Everlasting Life

In the past, the acceptance of the role of dying was probably easier [3]. The "good death" was a part of a religious *ethos*, and the dying person was placed into a socially shared scenario, where it was possible to find a meaning, and to acknowledge death as a necessary and welcomed transformation process (re-birth to True Life), which was provided with a wide set of rites, shared behaviour, and socially significant acts [4].

The shifting to a progressive secularization of modern western society involves both non-believers and believers, and seems to create an irremediable split in the re-orientation process of death towards life [1]. The loss of value of intrinsically unpleasant events such as pain, suffering, regret, death itself, and the replacement of old metaphysical certainties with new relativity and doubt, of eternity with finiteness of time, are not counterbalanced with equivalent consolations. It is likely that the extinction of the once most feared Judgment and of Eternal Punishment do not compensate for the loss of meaning of death – whatever meaning it has. Today the model of "good death" accepted in the past is probably no longer good, and has been fragmented on several counts, sometimes worrying and threatening, perhaps because lacking in the certainty of a superior design.

Death and medicine

In the Western world the process of individualization (i.e. the definition of all elements that constitute individuality) has most likely driven the cultural elaboration of individual death, and consequently, of end-of-life and bereavement care – which are 'individual oriented' – towards new and post-modern models [5,6].

This event is developing symmetrically with the ever more intrusive presence of medical technology, specially when life is seriously threatened, and the more and more turning of people to a medicine which has grown into a total institution [7]. Doctors can better foresee the imminence of one's death, which today is mostly a consequence of chronic degenerative diseases. However, this fact does not help in understanding death. Medicine is defining for, and unwittingly imposing on the dying a new role, and understanding this is crucial to correctly and coherently provide that end-of-life assistance that medicine today is called to do [1]. The attempt to re-orient death toward life, in order to mitigate the dying anguish and the relatives' grief, is recognizable in the widespread disposition to encourage terminal patients to feed on their expectation of recovery, and to hide or even deny the irreversibility of their disease [8,9].

This attitude, however, is actually paternalistic and it is hardly acceptable since it conflicts with the duty to respect one's autonomy. The social and individual affirmation of autonomy as a founding value, and of self-determination as a right [10] has created an ideal character of self-control [11], empathy and critical (and serene) evaluation, which likely, openly or unconsciously, people refer to.

But being consistent with this character, i.e. being free to make choices, and at the same time being protected by the presence of death sound as contradictory. An explicit good death model actually doesn't exist but the medical (namely palliative care) literature converges towards some specific aspects that contribute to define a death as a good one: symptoms control, careful consideration for the social and relational context, preparation to die, and existential well-being [12,13]. Such elements of good death do not overlap completely between operators and patients [14,15]. The health professionals, in fact, highlight the conception of dying as a process which implies a graduality in end of life. This gradualness is not welcomed as much by patients who seem to prefer a sudden death [16].

Aims of the study

This study, in order to bring elements together for a more general debate on this subject, aims to: 1. examine the influence of believing in individual life after death on "good death models"; 2. identify how the main connotations of dying are organized in "good death" models. The identification of possible different ideas of good death could be useful for providing the patient with correct end-of-life care.

Methods

A qualitative study was carried out using the long interview method devised by Mc Cracken [17].

Sampling Criteria

1) Exclusion

- patients affected by life-threatening disease and/or their relatives: both direct experience of the disease and emotional involvement probably attenuates the cultural specifics of the subject involved, thus inducing an "appropriate-to-the-situation" behavior, which could be implicitly suggested by the carers;

- palliative care professionals: they could be influenced by constant confrontation with death, and by the "good death model" of their discipline.

2) Forecasting

possibility of having information-rich cases, i.e. people we assumed to have sufficient insight to deal with the issue

Table 1: Interviewees characteristics.

Code	Sex	Age	Working activity	Education	Children	Individual life after death
(B1)	Woman	69	teacher	Univ.degree	no	believer
(B2)	Woman	55	researcher	Univ.degree	yes	believer
(B3)	Woman	43	teacher	Univ.degree	yes	believer
(B4)	Woman	25	white collar	Univ.degree	no	believer
(NB1)	Man	44	blue collar	Lower secondary school	yes	non-believer
(NB2)	Man	67	antique dealer	Univ.degree	yes	non-believer
(NB3)	Man	74	top manager	Univ.degree	yes	non-believer
(NB4)	Man	63	building contractor	High School Diploma	yes	non-believer

Table 2: Categories which define a "good death" in medical (palliative care) literature.

a) Care:

- Symptoms' control (pain, diarrhea, vomiting, breathlessness, etc.)
- Avoiding a useless prolongation of the process of dying
- Control of anxiety and other psychological symptoms (not dying with fear)
- Being assisted by a staff in order to make the process of dying more comfortable

b) Relational and social aspects:

- Respect of cultural diversity
- Respect and acknowledgment of the cultural rules of dying (a death that happens within the current rituals of the cultural environment of reference)
- Emotional support provided to patients, their families and close friends
- Good communication between patient/family/close friends/caring staff
- Having close people nearby
- Family acceptance of the patient's condition
- Not feeling a burden for family and friends

c) Preparation:

- Awareness of diagnosis and prognosis (awareness of dying)
- Choice of where to die
- Maintaining a sense of control (possibility of controlling relevant aspects of one's own existence and/or deciding what and when to delegate to others)
- Maintaining a dimension of continuity of life right to the end

d) Existential aspects:

- Being at peace with oneself
- Religious or spiritual practices

we were interested in, and an educational level adequate to allow them to express accurately their opinions [18].

3) Believers/Non-believers

in this paper the distinction between believers (B) and non-believers (NB) refers mainly to maintenance/loss of individuality after death.

The characteristics of interviewees are shown in table 1 (in brackets is the coding utilized for identifying citations

reported in this paper). All the subjects were known by at least one of the researchers but not at all by the interviewer.

Phases of the study

1) Identification of the categories that define the object of investigation

As well as the categories derived from literature [11,13,14,19-37], other categories have been considered

Table 3: The interview**Free association of the term: "death".****Images of life and images of death.**

(What makes you think of life and death?)

The presence of death in your history: when, on what occasion, did it occur in your life?

On these occasions what made you feel good and what made you feel bad?

Why?

What positive or negative elements characterized those circumstances?

Why?

What do you understand by a good or bad death? (just/unjust – sensible/senseless – dignified/undignified – attractive/ugly)

What can you do or need to avoid doing in order to die 'well' or 'badly'?

Can you give real or hypothetical examples?

What do you think a person who is dying needs?

What would this person like in the form of a gesture of attention or respect from others?

How would you like to live the last week of your life? (knowing or not, what would you eventually change?)**Three things that you would like to happen to you in the last week of your life.****Three things that you would like to avoid doing or happening to you.****Are life and death two independent events?****Is there anything a person must never do in their life considering the existence of death?**

Is it possible to do something in life which would assure a good death?

Death: an event or a process?

If it is a process, when does one begin dying?

Can anybody consider him/herself ready for dying?

If so, when and why?

When does one feel 'ready for dying' (if this is possible)? (**How do you think one feels 'inside'? What is the mood? What would be the attitudes towards the life one is leaving and towards what is eventually expected?)**

Does someone leave something of him/herself to others when he/she dies?

What would you like to leave and what would you like to take with you?

Would it be a consolation knowing that the others are still around?

In an important relationship what is more acceptable: the suffering of seeing the other dying; or the suffering of dying knowing that the other is left alone?**In your opinion, what is meant by death "occurring in a natural way"?****Why do people have to die?**

Do you believe in fate?

How would you imagine life to be if there was no death? Would something change?

What?**Do you think there is anything after death?**

Does this shape the way you live and the way you die?

Do death rituals have any meaning to you?

What should we do with our corpse? (donation of organs, cremation, burial, etc.)

In case the following points haven't already emerged:

Is the place where one dies important?

Where would you like to die?

Is it important to have someone near you?

Could dependence on others ("being a burden") make death good or bad?

Is it important to be aware of being on the point of dying?

Would you like to be aware of it?

What value and meaning does hope have in facing death?

Is there anything which you think has contributed in shaping your ideas on the themes we have dealt with during the interview?

from conceptualizations of good death taken from the authors' reflections and experience (Table 2).

2) Construction of the lay out of the interviews

A semi-structured interview of twenty main questions was carried out, and, in some cases, of some secondary questions in order to go into the matter in more depth (Table 3). All interviewees gave written informed consent. Given

the sensitivity of the issues involved, the interviews were conducted by two clinical psychologists. The interviews lasted for about two hours, were tape-recorded, and transcribed by the interviewers themselves.

Analysis of the interviews

For a stronger validity of the analytic process, the analysis of the text was carried out autonomously by each author

Table 4: Good death models

Good Death for 'non-believers'	Good Death for 'believers'
Loss of individuality	Permanence of individuality
End of subjective life	Passage to another life
Being aware of dying	Dying unaware
Not losing control of the situation	Hope in miracles and in eternal life
Attention given to scene of death	Decorum in dying
Importance of living well in the "here and now"	Importance of getting to heaven
Little importance given to mortal remains	Importance given to mortal remains
Search for a secular modality of dying	Adherence to prevalent cultural rules

Elements shared by believers and non-believers

- 1) Trying to prepare for death without expecting to feel absolutely ready when death arrives;
- 2) Having close people nearby and receiving assistance from experts;
- 3) Having a soft atmosphere around the dying person.

in five successive steps, each of which represents an increasing level of generalization [17]. By this way each author identified some main categories referring to key elements of good death. A further level of analysis, was then carried out, comparing among the researchers their analytic processes, and achieving a consensus on what ought to be held as representative of the interviewees' points of view and beliefs. According to usual qualitative methodology, the analysis was performed after each interview, allowing us to decide to interrupt the accrual when we considered the constitutive elements of the main distinction (believer/non-believer) sufficiently defined.

Results

All B declared to be Roman Catholics. The interviewees showed a high compliance. Sometimes a strong emotive involvement emerged when the interviewee took on the point of view of the dying patient. In no case was an escape into rationalization perceived. Out of 11 thematic areas constitutive of a "good death" identified, 8 show important differences between B and NB (table 4).

1) Individual life after death

For the B, the individual dimension is permanent, consistent, reflected in Eternity and subject to a final judgment.

"I believe in life after death. Dante Alighieri was certainly one of the most concerned with this problem, creating all that opera, but the best thing he said is that all the dead would have wanted to meet, and realize what that new world was like, and, above all, would have wished to meet again with their moms" (B1)

"The end of life on Earth is the beginning of life beyond Earth (...)" (B3)

"If there is nothing beyond, what sense is there in dying?" (B4)

For the NB dying means losing one's own identity in a definitive way.

If something of me survives after death, I could return and see the people who are dead before me: if all this were true, then may be that someone would like to come back...I feel more comfortable thinking that there is nothing. I feel this is a more coherent way (NB1)

Nothing exists in our life without a beginning and an end. Even the simplest and minimal things are part of a cycle.(NB3)

2) The very moment of death

For B death is a passage, a crossing, a dimension-jump which definitively fixes the quality of that immaterial element that deeply defines each individual – the soul. Death is a fracture in personal evolution, but, at the same time, it is something which also brings the hope of both the continuation of existing individually and the personal meeting with (not the "melting" into) God.

".. to have this great meeting with God, to have a place at the great supper, this is hope (B1)

"I am not such a materialist to think that death is the natural succession of life. I think it is a fracture in it. This is how I feel" (B2)

On the contrary the individual dimension for NB is defined by temporal limits, therefore transitory and precarious, precious and unrepeatable. Individuality becomes completely nullified in death, either as a return (re-absorption) into the biological cycle of life, or as a

melting into a sort of 'universal soul': two very different interpretations, but reaching the same conclusion.

"One will leave only a trace of his/her life. However, of what he/she really was, I don't think he will leave anything. What one is, is an absolutely personal thing, unique and unrepeatable and nobody really knows what it is since everybody sees it in different ways, so, one cannot leave his/her own essence." (NB1)

"It is better to evaporate and lose oneself in nothingness" (NB2)

3) Awareness of dying

Being conscious and aware of the moment of death is not fully welcomed by believers. Death is a passage, a fact of which the individual does have an experience, a mysterious experience not subject to either direct or referred empirical knowledge, which could also be dreadful and scary, and which is foreseen to have a tremendous impact on whoever has experience of it.

"Naturally I'm a little afraid of it, in the sense that it will have a tremendous impact (...). [A recently deceased relative] sent everybody out and said: "So, I must die". This I think is a very intense moment, but also a terrible awareness. I think that she felt a chill going up her spine. It's better to be asleep." (B1)

"I have no personal experience of death and dying...but sometimes it's said: "he died but did not realize it", and this fact makes me comfortable." (B2)

Staying fully aware right up to the last instant, allows one to safeguard his/her own identity right to the end, and this characterizes the ideal way to die for NB.

"I would like to "live" that experience totally aware. It would give more sense to my life in the same way as the choices I made in my life. Perhaps death is the most important moment of life and I would like to "be there" as much as possible" (NB1)

"It is important to be aware [of dying] because [it] is part of life and it is an event that, in my opinion, everybody would want see what it's like. One ought to be aware, and even... describe it to others"(NB2)

4) The hope and the control of the dying process

The way of conceiving hope is, obviously, different between B and NB, but it is also somehow conflictual among B.

On the one hand, for B there are "unsayable" things (the hope of his/her meeting with God), unpredictable and therefore not fully controllable, but also the hope of being able to postpone this meeting, of being able to benefit from a miracle and, still, be healed again and survive.

"For me it is the Christian hope, in the sense that everything does not end at the moment when I die." (B1)

"I can say that there is hope for another life; but I can also say that there is the hope not to die right now...to postpone death... I believe that everybody has the hope of recovery; believing in miracles lies in everybody. So, there is the hope of a miracle also in someone who knows that he will never recover...saying "let's bet"..."(B3)

On the other hand there is the absence of hope in NB, the tranquility of knowing that 'afterwards' there is nothing, which leads one to focus on the control of the situation preceding death itself.

"I don't think I have any hope beyond death. I hope I'm well until that exact moment when I have to go. Not believing in anything else beyond life and not knowing anything, I don't have any hope either. I think that hope does help believers, but if someone isn't a believer, hope is not important." (NB2)

5) What "good life" is

The B lives in the expectation of a passage to another existence in which he/she will receive a prize or a punishment proportional to his/her specific and individual merits or demerits.

"I mean I will have prizes that others will not have, in the reckoning of accounts I will have a little more merit." (B3)

The NB focuses only on the quality of her/his life, without any further expectation.

"I think that the fuller someone lives, the better he is able to die...If someone has done many things in his life, and had many experiences, he feels his time has not been wasted"(NB4)

"I like very much a sentence by (I think) Heraclitus: "When I'm dead, let my corpse be given to the dogs". It shows a vision-of-life that gives more importance to the things one does in his life"(NB1)

6) Aesthetics of death

All the interviewees paid particular attention to the scene of death with an emphasis on visual perception, suggesting and highlighting an aesthetic dimension of dying. The scene of death determines the quality of the memory that the deceased leaves to the living. Slovenliness, squalor, exhibition of one's own degradation constitute elements of a bad death. Also emotions, including those of the dying, should be controlled, in a sort of discreet way in exposing one's intimacy.

"I can remember my Mum's pain, my own Mum... I remember her being beautiful, dressed in black, that she came back with this image of pain." (B1)

"...What I associate with death is the sense of shame which I also associate with illness. I think that when someone is ill, he has the tendency to be ashamed. Maybe "shame" is an exaggerated word, but in illness one is also very bashful, and so tends not to have contacts with others " (B2)

Particularly for NB, death should not only be "proper", but also "beautiful". The solemnity and uniqueness of the event demands an adequate script and ritual, where aesthetic canons are elevated compared to everyday standards; an aesthetics that is supposed has been expressed in times and cultures of the past, but that today is lacking.

"If one is conscious, he should be in a nice bed with perfumed sheets, with people who are participating in this event; or, if possible, should be placed in a nice panoramic spot where one can see pleasant things just for one more time, and not in a hospital room. I think this has a certain significance, for I think the place can condition the way of dying" (NB2)

"I would like to go back and live in my countryside, also to go back to my small village. I was taken away from my village in Sardinia when I was a child but now I feel that is my true home. The first things I saw were there, the first scents, the first tastes, the earth, the wheat fields..., the idea of going back to the place from where you left off, to return to your mother's lap. So, from nowhere I found myself there, and it's from there that I wish to return to nothingness." (NB1)

7) Mortal remains

The attitudes regarding the corpse's treatment (cremation or deposition/conservation in a coffin) suggest an intention to witness either the disappearance or the permanence of the individuality of the deceased. The B stand regarding cremation relates to their need to maintain individuality after death.

"I'm not for cremation.... I feel that a person who dies loses something at the moment in which nothing individual remains; the person's identity even after death." (B2)

"I'm not for cremation (...) It was important knowing that [the deceased] was there...because he was there also physically (...). It serves the deceased because it leaves something of that person, and it serves the living in that they can remember that person forever." (B3)

"For cremation I have a problem, it seems to me that it cancels out the physical identity of the person" (B4)

For NB it is less important to preserve mortal remains.

'As Hamlet says 'It would be better to evaporate and lose oneself in nothingness"; that would be good stuff.' (NB2)

"The right thing to do is to burn corpses: become ashes. As Christian religion says: "Ashes you were, and ashes you will be" (NB1)

8) Cultural rules

For B a meaning of death does exist, and is 'already given'. It was revealed *ab origine*, and successively handed down from generation to generation. It was not possible to identify in their interviews neither an effort to construct a socially shared meaning to attribute to death, nor the mere possibility of alternative conceptions.

"I always make reference to Faith. I think, however, that if everything has a purpose, that there is an established plan, this helps to accept [death]. I also think that a person with faith is privileged compared to a person without. This certainty is comforting." (B3)

The meaning of death, handed down by past generations through religion is not satisfactory for NB, but they also feel that a secular approach to dying and a matured tradition outside a religious conception of life, is lacking.

"We are unprepared, but I think this is a subject that needs to be dealt with more deeply; also apart from the arguments held by religions. Except for religious environments, it is spoken little of. It seems to me no one is battling to speak about it more. If they did, this could help people be more prepared outside of religious environments." (NB4)

Some elements of good death, largely shared by palliative care literature are emphasized by both B and NB (table 4).

9) Preparation to dying

All interviewees agreed on the possibility and opportunity of a preparation for death, but they also agreed that there is no case in which it is possible to be ready to die. It is desirable to be *always* ready to die, not to be ready to die at a specific moment.

"I think, for someone, yes, it could be possible to be ready to die. I've heard it said by a person and I think he was ready. It needs a long ascetic preparation, a strong faith, generosity – also for others, too. Someone I met needed a kind of training, a spiritual vigilance (...). People are ready to die in war. It is always a strong ideal that pushes you on, that moves you on. Young people are ready [to die] for ideals in all regions, in all states. There are people who sacrifice themselves: from Japanese Kamikaze to those Muslims who throw bombs; they know they are going to die." (B1)

"I don't think one feels 'ready to die' because everyone is attached to life, by instinct. I asked a person who has strong convictions.....an aunt who is a nun and she confessed to me, in spite of her faith, that: 'I also am afraid of dying.. Even me! I don't feel I'm ready'. I do not think anyone is ready to die. I would say that I am at peace with my conscience, but I feel, that ...I have still things to do!" (B3)

"I'm ready to die; I've accomplished my duties." These words express a very religious concept.A person who wants to commit suicide is a person who can claim he is ready to die. Nobody would say they are ready to die but people who want to commit suicide. Even those who are actually ready, and know very well what is going to happen, always hope they can live one more night. (.....) Preparation for death needs both strong introspection [...], and better medical care, more scientific knowledge in order to stop the suffering" (NB3)

For dying, each moment is good only if the spirit is right. If, however, you are not prepared, it will never go right." (NB1)

10) Close relationships and medical support

All interviewees affirm that one of the most important dying person's needs is the nearness of both the patient's loved ones, and of experts in end-of-life care. Dying at home is not crucial: the hospital could be as appropriate, if there are conditions allowing the presence of patient's dear ones. This presence, however, must in some way be regulated, organized, contained, so as not to generate suffering, so as not to be a source of 'ugliness', nor a waste of resources. However, the logic imposed upon hospitals today, where care is identified with technology and where emotional relationships end up being stifled, should be refuted.

"I also think that if a person is ill, a doctor, a person who is skilled and at hand, who would press urgently for the administration of a drug if he is really bad, is a consolation. It is just as important [...].having people near who love you, who do not commiserate you, but who are there to live this experience with you. Not pity, but sharing." (B3)

"What should never be done is abandon a person, or place her in institutions which are far away, and then wash your hands of her. [...] I wouldn't like to die alone in a hospital bed." (B4)

11) Emotions and atmosphere

Great importance was given to the atmosphere which should be created around the dying person. Preference was given to a soft atmosphere rather than to a strong emotional involvement with dramatic tones.

".. a dying person should realize that those people who are assisting him are not frightened, that they don't feel repugnance, they are not bothered by this..." (NB2)

"The sick must be respected not only if still competent: even when they are not conscious anymore they must be considered with respect, and if you are by them, your closeness must be sincere" (NB1)

"Dying where there is no attention, no silence, is bad" (B2)

"Even a soft atmosphere is good care" (NB3)

Discussion

This is a qualitative study. It does not aim to know the distribution of the two models in our general population, but to generate hypotheses and suggests issues to be dealt with by quantitative research. We recognize that the need to have information-rich cases led us to a sample characterized by high educational level. Therefore we can not exclude biases in the data based on the skew of the sample.

The answers show two different and coherent conceptualizations of death, according to whether the subjects believe or not in individual life after death. For NB death marks the end of the individual, while for B it marks the passage to a new dimension. Each of these assumptions determine two different models of 'good death'. The main difference between NB and B attitudes refers to being or not being conscious/aware of the moment of death. B prefer to be unconscious when death comes. They do not fear the next world, but rather the passage, the crossing over the boundary: a mysterious but actual process, that take place in time and space. This attitude coexists with the hope of a miraculous delay of death itself, which seems to conflict with the conviction of reaching the true, best and perfectly happy life in the union with God.

The Hebrew/Christian tradition, to which the B interviewed belong, does not provide instructions on how to face this very passage, nor does it describe the process, as it is done in other religions like, for example, Tibetan Buddhism or the ancient Egyptian religion [38]. What happens between the moment of death and the one of rebirth is obscure and, thus, generates anguish. The NB attitude seems, instead, to appeal to the epicurean sentence: "If I am, death is not; if death is, I am no longer: why, then, fear death?". NB reveal also a different aesthetics concerning death and dying. Things, objects, the environment become almost gifts that the dying person leaves to the living, gifts precious because intrinsically beautiful, thus assuming an autonomous importance. B, on the other hand, underline "decorum" as appropriate style of both the dying person and the bystanders. The NB interviewees, even if perfectly aware and proud of their own *ethos*, acutely felt the lack of a socially recognized and accepted secular way of dying. Secular rituals are lacking, and realizing scenes of death which contain and respect

their conception of life is difficult when not totally impossible.

Nevertheless, the two models have several points in common about what is indispensable for making the moment of death more comfortable. These elements are substantially consistent to clinical and organizational praxis of palliative care, i.e. the understanding and satisfaction of the dying person's needs (namely the control of suffering) carried out by a specific multidisciplinary staff, who accepts death as a 'natural' event, even welcomed as the end of all sufferings [11,39]. Despite B and NB agree on many elements (presence of friends, relations, competent and continuous care, pleasant environment, attention to details, respect for choices, etc.), it seems improbable that the ideal model of progressive acquisition of the role of the dying person implicit in the palliative care philosophy could fully satisfy both parties.

The palliative care aspiration to a death without delay and without anticipation demands the active participation of the dying person him/herself in order to get the social and biological death to coincide. This concept of coincidence between the social dimension and the biological one is crucial [1]. When the dying person before his/her decease loses what characterizes the social life of an individual, in particular consciousness and self-awareness, that lack of dignity, which common sense perceives as a negative value, does ensue. Thus, death becomes 'bad' [11]. In fact the intentional prolonging of this condition (the artificial prolongation of biological life at the end-of-life) is seen as an unjustifiable violence.

Assistance to the dying person has been understood, up to the present day, more as an act of charity rather than as a medical duty. It is not by chance that we will have to wait for the middle of the 20th Century before one speaks of palliative 'medicine' in hospices which had been created and mostly still managed as charities at a time when hospitals had long since been considered an expression of science and of the public health service.

The cultural model to which palliative care refers (be it implicit or explicit) makes reference to a style of good death which has its roots in the Christian tradition of caring. The Hospice can, in fact, be considered the belated fruit of the realization of that process of *charitas*, which a follower of St. Jerome, a matron of the *gens Fabia*, started in Rome in the IV century [40]. Such a model of good death, if acknowledged uncritically and if shared only by health professionals, could be inadequate to the sensibility and expectations of a population made up more and more of cultural and moral strangers. If this model were imposed on patients – even unwittingly – it could produce a gap between medicine and some patients, perhaps

resulting in a sharpening of that solitude which palliative care sets out to soothe.

Conclusions

This study highlighted the existence of some different constitutive features of "good death" focusing on the distinction between believer and non-believer in the maintenance of individuality after death, and we feel that this difference is a major one, at least in the Italian cultural context and deserves further research. The awareness of these differences may help palliative care professionals meet the real needs and expectations of terminal patients.

It would seem reasonable to conclude that today it is not possible, nor desirable, to assume a single specific model of good death, and that a plurality of models should be foreseen, accepting in this case, their practical and theoretical implications.

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References

1. Seale C: **Constructing death. The sociology of dying and bereavement.** Cambridge: Cambridge University Press; 1998.
2. Parkes CM, Laungani P and Young B: **Death and bereavement across cultures.** New York: Routledge; 1997.
3. Ariès P: **Western Attitude Toward Deats.** Transl. H. Weaver. New York: Knopf; 1981.
4. Di Nola MA: **La nera signora.** Roma: Newton Compton; 1995.
5. Walter T: **The revival of death.** New York: Routledge; 1994.
6. Elias N: **Über die Einsamkeit der Sternbänden in Unseren Tagen.** Frankfurt: Surkamp; 1982.
7. Callahan D: **The troubled dream of life. Living with mortality.** New York: Simon e Schuster; 1993.
8. Gordon DR and Paci E: **Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy.** *Soc Sci Med* 1997, **44**:1433-52.
9. Del Vecchio Good MJ, Munakata T, Kobayashi Y, Mattingly C and Good BJ: **Oncology and narrative time.** *Soc Sci Med* 1994, **38**:855-862.
10. Field D: **Awareness and the modern role of dying.** *Mortality* 1996, **1**:255-265.
11. Seale CF, Addington-Hall JM and McCarthy M: **Awareness of dying: prevalence, cause and consequences.** *Soc Sci Med* 1997, **45**:477-484.
12. Singer PA, Martin DK and Kelner M: **Quality end-of-life care: patients' perspectives.** *Jama* 1999, **281**:163-8.
13. Turner K, Chye R, Aggarwal G, Philip J, Skeels A and Lickiss JN: **Dignity in dying: a preliminary study of patients in the last three days of life.** *J Palliat Care* 1996, **12**:7-13.
14. Payne SA, Langley-Evans A and Hillier R: **Perceptions of a "Good" death: a comparative study of the views of hospice staff and patients.** *Palliat Med* 1996, **10**:307-312.
15. Payne S, Hillier R, Langley-Evans A and Roberts T: **Impact of witnessing death on hospice patients.** *Soc Sci Med* 1996, **43**:1785-94.
16. Toscani F, Cantoni L, Di Mola G, Mori M, Santosuosso A and Tamburini M: **Death and dying: perceptions and attitudes in Italy.** *Palliat Med* 1991, **5**:334-343.
17. Mc Cracken G: **The long interview.** London: Sage Publications; 1988.
18. Crabtree BF and Miller WL: **Doing qualitative research.** London: Sage Publications; 1992.
19. Speck P: **Spiritual issues in palliative care.** In *Oxford Textbook of palliative medicine* 11th edition. Edited by: Doyle D, Hanks GWC, Macdonald N. Oxford, New York, Tokyo: Oxford Med Publ; 1998:810-814.

20. Low JT and Payne S: **The good and bad perceptions of health professionals working in palliative care.** *Eur J Cancer Care* 1996, **5**:237-241.
21. Keizer MC, Kozak JF and Scott JF: **Primary care providers' perceptions of care.** *J Palliat Care* 1992, **8**:8-12.
22. Miller FG: **The good death, virtue and physician-assisted death: an examination of the hospice way of death.** *Cambridge Quarterly of Healthcare Ethics* 1995, **4**:92-97.
23. Wallston KA, Burger C, Smith RA and Baugher RJ: **Comparing the quality of death for hospice and non-hospice cancer patients.** *Med Care* 1988, **26**:177-82.
24. McNeil C: **A good death.** *J Palliat Care* 1998, **14**:5-6.
25. Vovelle M: **La Mort et l'Occident de 1300 à nos Jours.** Paris: Gallimard; 1983.
26. Emanuel EJ and Emanuel LL: **The promise of a good death.** *Lancet* 1998, **351 Suppl 2**:SII21-9.
27. Mc Namara B, Waddell C and Colvin M: **The institutionalization of the good death.** *Soc Sci Med* 1994, **39**:1501-1508.
28. Callahan D: **Pursuing a peaceful dea.** *Hasting Center Report* 1993.
29. Bertman SL: **Facing death: images, insights and interventions.** Washington D.C: Hemisphere Publishing Corporation; 1991.
30. Gilmore A and Gilmore S: **A Safer Death.** New York: Plenum Press; 1987.
31. Hart B, Sainsbury P and Short S: **Whose dying? A sociological critique of the "good death".** *Mortality* 1998, **3**:65-77.
32. Jomain CH: **Mourir dans la tendresse.** Paris: Le Centurion; 1986.
33. Baudry P: **La mort provoque la culture.** in: Augé M. *La mort et moi et nous* Paris: Le Penser-Vivre Textuel; 1995.
34. Brown M: **A good death. Principles of palliative care are yet to be applied in acute hospitals.** *Bmj* 2000, **320**:1206.
35. Thobaben M: **Helping terminally ill clients experience a "good death".** *Home Care Provid* 2000, **5**:202-203.
36. Patrick DL, Engelberg RA and Curtis JR: **Evaluating the quality of dying and death.** *J Pain Symptom Manage* 2001, **22**:717-26.
37. Saunders C: **The management of terminal malignant diseases.**, 11th edition. London: Arnold Publ. Ltd; 1984.
38. Eliade M: **Histoire Des Croyances Et Des idées Religieuses.** Paris: Payot; 1983.
39. De Hennezel M: **Mort intime: Ceux qui vont mourir nous apprennent à vivre.** Paris: Pocket Best; 1997.
40. Cosmacini G: **L'Arte lunga. Storia della medicina dall'antichità ad oggi.** Edited by: Laterza & Figli. Roma: Gius; 1997.

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