ORIGINAL ARTICLE: BIOETHICS

Killing or allowing someone to die: a difference defined exclusively by the criteria of "terminal"? Making decisions regarding a patient's death.

Federico Nicoli, Mario Picozzi Center for Clinical Ethics, Insubria University, Varese, Italy

Abstract. The aim of this research is to reply to some of the most important moral question: Is it "good" to hasten the patient's death? In a situation of terminal illness the principle of proportionality seems too biased in favor of clinical data, but at the same time, the criterion of terminal represents a clinical condition which is necessary, but not sufficient to determine whether to withdraw or to withhold treatment. "Terminal" acquires a predominant position in the definition of the principle of proportionality: one wonders whether and under which conditions its definition is taken for granted. "Terminal" seems to be a diagnosis that offers certain guarantees, but which must not to be considered as final, since it can violate the patient's right to autonomy. The question regarding good actions is substantial when one takes part in a relationship with a patient at the end of his life.

Key words: terminally ill, end of life, therapeutic alliance, proportionality, irreversibility.

Introduction

What are the criteria used by physicians in order to make decisions regarding the treatment of patients at the end of their lives? Can *terminal illness* still be considered as the *only* condition where some therapeutic choices seem to be justified?

The mere fact that we possess the ability to operate on patients opens the door to important questions regarding the ways of ending life that require an analysis and a response from a moral point of view. The problem comes at a time when therapies and medical instruments offer the terminally ill patient the possibility of anticipating or postponing the end of his life.

The theme of hastened death seems destined to bring into play a series of rights and responsibilities of decisive importance for moral philosophy. The difficulty in identifying one common certainty which can take on the role of general guidance, depends on the fact that the map of moral values in the contemporary world has been defined on one hand by an aspect of the concept of the defense of life, which presents the concept of "good", towards which each individual tends by nature; and on the other hand by the principle of protection of human dignity, understood as the right to self-determination by the individual. Each of these two principles must be taken into close consideration in order to analyze the question of the end of life, because they are values experienced both by the caregiver and by patients. The meaning of actions can be identified by the gestures involved in those actions.

42 F. Nicoli, M. Picozzi

The question regarding good actions is substantial when one relates with a patient at the end of his life. This question concerns themes regarding the tutelage and preservation of the human life. The notion of proportionality has been developing throughout the history of Catholic moral theology.

The concept of proportionality: a historical development.

A sound medical approach considers how both clinical and living conditions affect the patient's quality of life. Proportioned treatment originates from a precise evaluation of both clinical conditions and personal history, and is developed through the specific relationship between patient and physician (the so called "therapeutic alliance") in which the significance of every choice is identified. Proportionality must be evaluated for each single patient, considering his/her particular clinical history, objective state of health, needs, psychological resources, and personal values (ascertained through careful listening, open dialogue, and with sufficient time) (1). The concept of proportionality is related to the concept of ordinary and extraordinary means of conserving human life, which has been developing in philosophical and theological moral traditions since XVI century. Only since 1980 this set of terms has been changed to proportionate and disproportionate means. This latter set of terms better interprets the relationship with the concept of person (2). Caring for the person is the center of the question regarding whether a clinical choice is "good". Moral tradition started to look at this question addressing the issue of suicide, thanks to St. Thomas: «a man has the obligation to sustain his body, otherwise he would be a killer of himself [...] by precept, therefore, he is bound to nourish his body and likewise, we are bound to all the other items without which the body cannot live» (3). No theologians immediately following St. Thomas developed a position which differed from his regarding suicide.

In the Catholic moral tradition, after St Thomas, three fields concerning the difference between ordinary and extraordinary means of conserving human life can be identified (4). 1- In the XVI-XVII centuries the main factors used to explain the difference between the ordinary and extraordinary means are related to food and drugs.

During the XVI century the main commentary on Secunda Secundae of St. Thomas is the Relectiones Theologicae by the Spanish Dominican F. de Vitoria (†1546). Vitoria explains his position on the relationship between a patient's life and the questions regarding administering food and drugs. He writes in the chapter Relectio de Temperantia: «If one uses foods which men commonly use and in the quantity which customarily suffices for the conservation of strength, even though from this his life is shortened, even notably and this is noticed, he would not sin... From this, the corollary follows that one is not held to use medicines to prolong his life even where the danger of death is probable, for example to take for some years a drug to avoid fevers or anything of this sort» (4). For F. de Vitoria there is no obligation to use all means available to conserve one's own life: it is morally admissible to use only the proportioned mean designated to this end (5).

This omission is not equivalent to a suicide, but to living using only the ordinary means possible to put off imminent death. In general only food is recognized as an ordinary means, but not in every instance - a sick person is excused from taking food only when there is limited or no hope of life - (6).

2- In the XVII-XX centuries another study-question emerged: can the mutilation of a limb or an essential part of the body be evaluated as an extraordinary means to conserve the human life?

The Jesuit Francisco Suarez (†1617) in his *Opera Omnia* asserts that the mutilation of «a principal member is almost equivalent to death, for this reason a man is not bound to undergo it in order to save his life» (7). Regarding amputation, Suarez explains that the reasons for differentiating ordinary means from extraordinary means are related to pain: no one has the duty to conserve his life if suffering is tremendous and the result is uncertain. The exception, as Cardinal De Lugo (†1660) writes, concerns a person *whose life is very necessary for the public good* (8). A person can accept the order to be operated (mutilated) but only on the condition that the outcome will be safe and certain.

N. Mazzotta (†1746) in his Theologia Moralis explains

the features of the extraordinary means (therefore not mandatory): 1- there is no hope of recovery, 2- great horror or torment, 3- extraordinary expenditure. These would excuse a person from employing these means (9).

3- Moral reflection changes with the introduction of the modern use of Anesthesia (from the XIX century to 1957).

The physician C. Capellmann applies traditional moral theological principles to modern medical science. In his opus De Operationibus Vitae Periculum Afferentibus he mentions the obligation of conserving one's life and the duty to submit to treatment, now considered safer, if one's life is at risk. Pain is no more the criteria which justifies the withholding of a surgical operation. But anesthesia doesn't necessary remove the concept of extraordinary means regarding a difficult surgical operation. This clinical data made a significant impact on choices of treatment, given the new, more readily available resources. As A. Lanza and P. Palazzini write in their Theologia Moralis (1955), the extraordinary means should be decided in individual cases, in which no one has the duty to undergo a grave incommodum serious impediment – to conserve his life (10).

4- Since 1957 there have been some important pronouncements by the Catholic Church, in which the notion of proportionality is related to the criteria regarding the terminally ill and to end-of-life issues. In a famous document, entitled *An address of Pope Pius XII to an International Congress of Anesthesiologists*, published in *Osservatore Romano*, November 25-26, 1957, the *Pope* considers objective ethical aspects (clinical condition) related to subjective ethical patient and familial aspects (existential condition) (11). The difference between "right" and "obligation" opens up the question of the relationship between two free wills: those of the patient or his family and those of the physician; who together must arrive, as closely as possible, at a mutually consensual therapeutic choice.

Only in 1980 the terms "ordinary" and "extraordinary" come to signify change in "proportionate" and "disproportionate" means of conserving life. The new terminology is mentioned in the document *Iura et Bona* (1980) published by the Sacred Congregation for the Doctrine of the Faith (12).

Pope John Paul II, in the Encyclical *Evangelium Vitae*, explains the difference between killing and allowing someone to die, referring to the notion of the proportionality of care (13).

From a historical point of view, it can be deduced that the notion of proportionality is relevant in every clinical choice regarding patient care, both on the part of the patient and the physician, and the freedom of choice is only applicable to extraordinary circumstances and means, which, as they are considered extraordinary, are therefore not obligatory.

All above mentioned can certainly be applied to terminally ill patient. In these particular clinical situations the physician has the right to intervene with all the means at his/her disposal, but does not have the obligation to intervene (this position was held until the middle of the last century).

Could be the notion of proportionality only determined by the criteria of "terminal"?

The notion of "terminal" is one of the parameters which make it possible to choose the most appropriate therapy for a better quality of life during the end-of-life process (14).

The criteria of "terminal" renders ethically reasonable the possibility – but not necessarily the obligation – of withdrawing or withholding a clinically configured treatment as non-proportionate. The patient always has the last word regarding this choice, but, as we shall see later, not the only one. In literature there is one substantial study on the historical development about the definition of terminally ill: it is a paper by D. Hui, which offers a synchronic elaboration of the different definitions of "terminal" from various sources from 1984 to 2012 (15).

In this paper Mc Cusker's definition in the matter of the *terminal care period* is cited. He writes: "The period during which there is evidence of progressive malignancy, and in which therapy cannot realistically be expected to prolong survival significantly. Patients enter this period either at time of diagnosis, or following a period of active treatment. The onset of the terminal care period should not be confused with the point at

F. Nicoli, M. Picozzi

which life-expectation is estimated to be short. A patient might be expected to die within a few months, but have a treatable malignancy. This patient would still be in the active treatment period" (16). In another paper by D. Hui, the life-span of the *terminally ill* is so defined: "a life expectancy of six months or less" (17). On the contrary in The Hastings Center Guidelines the term *Terminally Ill* means "having an incurable or irreversible condition that has a high probability of causing death within a relatively short time with or without treatment" (18).

The definition of the Hastings Center Guidelines underlines the time limit without a precise edge.

The term "terminal" can't be considered univocal in all fields of medicine. In oncology "terminal" is a clinical criterion used to make a prognosis (19). In neurology (in particular in Alzheimer disease), "terminal" corresponds to the most acute phase of the disease (20). In all of these definitions an important aspect is the clinical factor, which defines life expectancy. This element may be considered to be more important than the more ample criteria of "terminal", because it seems to play a relevant role in the patient's quality of life and in his/her possible future choices.

Generally speaking when a patient is terminal each treatment can be evaluated as disproportionate. The criterion of "Terminal" acquires a predominant position in the definition of the principle of proportionality. J. Capasso et al. write: "The goal at this point [terminal phase] is mainly supportive: to ensure the most comfort for the patient and the people providing care. Other goals at this point include symptom management, emotional and spiritual support, assistance with personal care, transportation assistance, and improving communication with health care providers" (21). The life expectancy of less than six months results as a sufficiently shared criterion for the approval of the suspension of treatments, including lifesaving ones, save hydration and nutrition. D. F. Kelly writes: "Treatments are morally extraordinary when their burdens outweigh their benefits" (22).

"Terminal" seems to be a diagnosis (in oncological diseases) that offers certain guarantees; it is often used to define a specific clinical condition (as shown previously by the definitions): it seems to offer more security regarding choices about withholding or withdrawing

treatment. These choices should be shared as much as possible so as not to violate the patient's right to autonomy.

In literature the criterion of "terminal" is at the core of intensive research activity. Where there are no treatments which can cure or block the progression of the disease, the cause of death is strongly (although not exclusively) connected to the disease itself and not to the discontinuation of treatment. According to the principle of double effect, D.F Kelly writes: "the direct killing of an innocent person is never morally right, but allowing a person to die is sometimes morally right" (12). Noteworthy are the considerations regarding the role of the double effect in end of life decision making by T.E. Quill et al. because they emphasize the clinician's intent. They write: "This principle is often cited to explain why certain forms of care at the end of life that result in death are morally permissible and others are not. [...] The rule of double effect is a conceptually and psychologically complex doctrine that distinguishes between permissible and prohibited actions by relying heavily on the clinician's intent" (23).

At this point a possible dichotomy arises: the clinical data and consequently the terminal prognosis seem to have a direct influence on the moral question, i.e. *questions of conscience*, inherent in the decision to withdraw or to withhold treatment; withholding treatment may help to provide a higher quality of life during the patient's last moments, although it may accelerate the dying process.

There are three ethically relevant aspects that may help to explain why terminal illness is a key criterion in end of life issues. They are:

1. Is the criterion of terminal illness only clinical data? In a situation of terminal illness the principle of proportionality seems too biased towards the clinical data, but at the same time, the criterion of terminal represents a sufficient but not necessary clinical condition to determine whether to withdraw or to withhold treatment. There are therefore other factors, which can come into play, which influence decisions regarding good therapeutic choices. R.P. Hamel and J.J. Walter write about the intentions involved in ending treatment: "Life is something more than biological existence. Life is a conditional value which couples biological exis-

tence with social, spiritual and human activities such as loving, praying, remembering, forgiving and experiencing. Life is all these things. Consequently, when these activities can no longer be realized, there is no moral obligation to continue medical treatment, unless to relieve suffering. The conclusion that treatment can stop does not mean that the person is worthless, but that the person has activated all human potential" (24).

2. Can the criterion of terminal illness influence the policies of rationalizing about the use of economic resources in the health care field?

J.W. Finn writes: "Patients with inadequate social support, and patients who are impoverished or poorly adherent to prescribed regimens, may have shorter life expectancies. Unresolved relationship issues or existential distress may prolong the dying process (25). If true, this allows us to underscore both the ethical issues relating to the burdens of health care, and the inherent question of whether terminal patients should have the possibility of obtaining life-sustaining care" (26).

3. Does the criterion of "terminal" respond to a specific moral issue? If so, which one?

It defines the difference between directly causing death and letting someone die. This difference seems to be the most important feature in justifying the substantive meaning of "terminal": the cause of death is related to the irreversibility of the terminal disease and not to the suspension of treatments. With reference to the patient's death and from a Catholic perspective, the difference between letting someone die and killing them excludes the *immediate and mediate material cooperation* with evil (27).

J.P. Bishop writes about the distinction between killing and allowing a patient to die: "In the traditional formulation, there is thus no distinction between acts of commission and acts of omission, but there is a morally important distinction that remains helpful for the care of the dying; that distinction is between directly and indirectly causing death. Today, directly causing death is often seen as parallel with acts of commission; indirectly causing death is commonly confused with acts of omission. But nothing could be further from the case in the older formulation. Acts of commission and acts of omission are

both forms of directly causing death for both entail the direct action of the will" (28).

Based on the above-mentioned critical analysis one can identify the key factors regarding what is really crucial about end-of life decisions in near death situations: a) the relationship between persons (patient, physician, family), b) the dialectic between resistance to and surrender to a terminal disease.

All these three aspects have important ethical implications but the third aspect seems to be the most relevant moral criterion for those who must decide. This last feature turns out to be the most significant, irrespective of who will have the last word (patient, family member or legal guardian).

The criterion of "terminal" maintains its specific ethical and clinical value, given the difference between directly causing death and letting someone die.

Can the difference between killing and allowing someone to die be understood only through the criterion of terminal illness?

The criterion of "terminal" provides guidelines to establish the difference between killing and allowing someone to die, but this difference may not be comprehensible only by using this criterion.

Is this criterion really nullifying? Or do we take it for granted that just because it reassures, it eases the consciences of those who should decide? Perhaps it is useful to take time to think. From the ethical point of view, in the case of a patient with a non-terminal incurable disease the suspension of treatments is in any case a choice: "there is a grey zone of physician complicity" (29). On the other hand if the patient is terminal the suspension appears to be "always" more clear and morally licit.

The decision to withdraw treatment is taken considering the clinical data, but this may not be the only factor. In a quality care situation, the clinical reality which can best justify the idea of conditioned and shared surrendering to the disease is the irreversibility factor.

In the case of non-terminally ill patients with incurable diseases suspension of treatment is debatable from an ethical point of view, while it is "always" licit to withdraw treatment if the patient is a terminally ill.

There are some valid reasons for discussion regarding the suspension of treatment in patients af-

46 F. Nicoli, M. Picozzi

flicted with incurable but non-terminal diseases. They are at least three: 1. If the criterion of proportionality originates from a dialectic relationship between clinical conditions and the existential status of a specific patient, terminal status leans strongly and inevitably towards the clinic condition; 2. Today "terminal" appears to be too restrictive as clinical criterion; technology prolongs difficult and painful clinical situations indefinitely, and often patients do not have the additional financial resources necessary to continue treatment; 3. It is essential to consider the complicated situations of the patients' families or loved ones. They are often required to attend to their loved ones for prolonged periods of time.

The criterion of irreversibility has not only a clinical but also an ethical value. Only through a good physician-patient relationship the criterion of irreversibility may help to decide about the suspension of the treatment. And this is true not only when the patient is terminally ill. The act of surrender seems to be justified when disease is irreversible. This clinical data must be related to both patient's quality of life and patient's therapeutic history.

Why does irreversibility better correspond to the difference between killing and allowing someone to die than the "terminal" factor?

Both irreversible and "terminal" conditions oblige us to recognize that there are limits to which a sick person must surrender. But the irreversibility factor leaves room for the power of choice of the sick person or of the proxy. The criterion of irreversibility can be fully included in the notion of proportionality, through which it is possible to arrive at a morally "good" choice regarding suspension of treatment (30).

The elements that make it ethically acceptable to the situation are:

- 1. if the disease which the subject is afflicted with is irreversible, the prognosis is poor, and his/her condition is worsening; i.e. there are no scientifically valid therapies and his/her condition is doomed to continuous deterioration over time:
- 2. if the subject has manifested forms of resistance to the diseases. From this point of view, having had the experience of the treatment, and it is to be suspended is a meaningful aspect (and indirect experience cannot be excluded from the equation, i.e. hav-

ing witnessed a loved one suffering from the same disease). In some cases this is the only possibility – vegetative states come to mind, of which of course one cannot have direct experience);

- 3. if suspension is gradual: it is not about "pulling the plug", but suspending things before more invasive treatments begin, then slowly progressing towards more traditional treatments (this allows time to contemplate mixed solutions);
- 4. if it acknowledges the value of the underlying symbolic gestures of care: this allows us to focus attention on the methods by which treatments are administered and meaning connected to said methods.

These factors are not meant to eliminate the criteria regarding terminal states, but to render ethically acceptable both the suspension of treatment (on certain conditions) and also the continuation of treatment for patients in their dying moments (who should Not be obliged to suspend it).

References

- 1. Giannini A, Messeri A, Aprile A, Casalone C, Jankovic M, Scarani R, Viafora C. End-of-life decisions in pediatric intensive care. Recommendations of the Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (SARNePI). Pediatric Anesthesia 2008; 18: 1089-95.
- 2. Spaemann R. Persone. Roma Bari: Laterza; 2007; 31.
- 3. Thomas S. Super Epistolas S. Pauli. Taurini-Romae: Marietti; 1953, II thess, lec. 11, n. 77.
- Smith RE. Conserving Human Life. Massachusetts: Pope John XXIII. Medical-Moral Research and Educational Center 1989; 32-76.
- 5. Vittoria F. Relectiones Theologicae. Lugduni, Relectio de Temperantia; 1587, n.1.
- 6. Sayrus G. Clavis Regia Casuum Conscientiae. Lib. VII, Cap. IX, n.38.
- 7. Suarez F. Opera Omnia. Paris: Berton, Vives; 1858, tom. XII, disp. 9, sect. 3, concl. 5.
- 8. De Lugo J. De Justitia et Jure. disp. 10, Sect. I, n. 21.
- 9. Mazzotta N. Theologia Moralis. Venetiis; 1760, tom I, tract. II, disp. II, quaest. I, cap.I.
- Lanza A, Palazzini P. Theologia Moralis II. Taurini-Romae: Marietti; 1955; 125.
- Smith RE. Conserving Human Life. Massachusetts: Pope John XXIII. Medical-Moral Research and Educational Center 1989; 316.
- 12. Martini CM. Dichiarazione Iura et Bona sull'eutanasia, IV.
- 13. Giovanni Paolo II. Enciclica: Evangelium Vitae. 1995; 65.

- 14. Picozzi M, Consolandi V, Siano S. Fino a quando? Milano: San Paolo; 2012; 132.
- 15. Hui D, Nooruddin Z, Didwaniya N, Deu R, De La Cruz M, Kim SH, Kwon JH, Hutchins R, Liem C, Bruera E. Concepts and Definitions for 'Actively Dying', 'End of Life', 'Terminally Ill', 'Terminal Care' and 'Transition of Care': A Systematic Review. Journal of Pain and Symptom Management 2014; 47(1): 77-89.
- Mc Cusker J. The terminal period of cancer: definition and descriptive epidemiology. Journal of Chronic Disease 1984; 37: 377-85.
- 17. Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, Bruera E. The lack of standard definitions in the supportive and palliative oncology literature. Journal of Pain and Symptom Manage 2012; 43: 582-92.
- Berlinger N, Jennins B, Wolf SM. The Hastings Center Guidelines for Decision on Life-Sustaining Treatment and Care Near the End of Life. New York: Oxford University Press; 2013; 205.
- 19. Mc Cusker J. Mentions the three criteria for a terminal diagnosis: 1) firm evidence of progressive disease, 2) termination of active cancer therapies, and 3) "death is not far off". In: Hui D, Nooruddin Z, Didwaniya N, Deu R, De La Cruz M, Kim SH, Kwon JH, Hutchins R, Liem C, Bruera E. Concepts and Definitions for 'Actively Dying', 'End of Life', 'Terminally Ill', 'Terminal Care' and 'Transition of Care': A Systematic Review. Journal of Pain and Symptom Management 2014; 47(1):86.
- Loeb C, Favale E. Neurologia. Roma: Società Editrice Universo; 2003; 1047.
- 21. Vadivelu N, Kaye AD, Berger JM. Essentials of Palliative Care. New York: Springer 2013; 58.

- 22. Kelly DF. Medical Care at the end of life. Washington D.C.: Georgetown University Press 2006; 103.
- 23. Quill TE, Dresser R, Brock DW. The Rule of Double Effect
 A Critique of Its Role in End-of- Life Decision Making.
 New England journal of medicine 1977; 337(24): 1768-71.
- 24. Hamel RP, Walter JJ. Artificial Nutrition and Hydration and the Permanently Unconscious Patient, The Catholic Debate. Washington D.C.: Georgetown University Press 2007; 151.
- 25. Finn JW. Determining prognoses for patients with terminal illnesses, American Family Physician 2006; 73(11):2062-7.
- 26. Berlinger N, Jennins B, Wolf SM. The Hastings Center Guidelines for Decision on Life-Sustaining Treatment and Care Near the End of Life. New York: Oxford University Press 2013; 28.
- 27. Ashley BM, Deblois J, O'Rourke KD. Health Care Ethics: A Catholic Theological Analysis. Washington, D.C.: Georgetown University Press; 2006; 56.
- Bishop JP. Euthanasia, efficiency, and the historical distinction between killing a patient and allowing a patient to die. J Med Ethics 2006; 32:220-4.
- 29. Duffy TP. Physician Assistance in Dying, A Subtler Slippery Slope. Hast Center Report 2014; 44(2): 49.
- 30. Picozzi M, Consolandi V, Siano S. Fino a quando?. Milano: San Paolo; 2012; 133-4.

Correspondence:

Federico Nicoli

Center for Clinical Ethics, Insubria University, Varese, Italy E-mail: federico.nicoli82@gmail.com