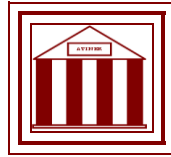


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**A Modern Variant of Justice:
The Right over One's Own Body in Time
of Disease**

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**A Modern Variant of Justice:
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Abstract

The growth in biomedical knowledge and technology has expanded not only the possibilities to *survive* to serious illnesses and accidents when it is desired to live, but also, in the opposite direction, the impossibility *to die* when it is desired to die. In the last cases self-determination over one's own body is not allowed when the goal or the result of it is death. Nevertheless, a more coherent interpretation of the right over one's own body should lead to break this last limit and accomplish a dramatic last desire "Do not cling to me" (*Μή μου ἄπτου*)¹, let me go.

Keywords: Euthanasia, self-determination, suffering, Protestantism

¹Gospel of John 20: 17.

Euthanasia is the bioethical issue that currently calls for an urgent moral and legal reflection. It is, in fact, a modern variant of the classic theme of justice. What answer ought the legal system give to the seriously or terminally ill that ask to die? The legal systems have to wonder about the possibility to apply self-determination even for euthanasia, since they recognize it yet in other aspects of living. Can we choose to die in these terrible situations or the *when* and the *how* of our death should depend on the nature? The aim of this paper is to search good reasons to support the idea that self-determination should apply also for the decision concerning death.

Very often euthanasia is misinterpreted as an issue of mercy. It is instead a matter of rights and justice. Taking seriously the possibility of our death is not, of course, an easy choice. In *The Examined life* Robert Nozick wonders, among others meditations, if one were able to take seriously the possibility of his or her own death¹.

Under normal conditions of health we are reluctant even to imagine that what we are will be deleted by the *last wave* of our breath as an inscription on the shore of the sea. In fact, «we seem to ourselves deeper than the mere stoppage of life can reach»² because hoping to do many other things, achieve new goals, averts the dismay of “there is nothing more that can be done”. Usually “when life runs quietly human beings have more other interesting things to do rather than thinking to death”³.

Hope is nourished by thoughts; the ones we formulate observing that our strengths are quite conspicuous reserves to do what we wish in life. We do not think about death and the reason is simple. We are so busy to live that dying doesn't reasonably find even a line in the pages of our agenda, also because since we do not live in a cloistered reality, no one remembers us that sooner or later we will have to do. In normal health conditions, death is our worst enemy. We fear it and we escape from its thought. It is something we eventually think about when it lightly touches us beating others around us, but not us yet.

On the contrary, it is completely different the perception of death by those who lost a good health condition for a serious illness or an injury. For them, normal life is, sadly, by now just a memory, like a discolored painting of an author condemned in the role of background actor in the bustling world of the living people. In these cases death becomes a daily thought, the one cherished more, the sweetest during the same days spent motionless in a bed or during the endless nights in which, in the silence of the healthy people, the end of life is the most needed rest. For them, in the saddest cases, self-determination and the sense of dignity can be hollow words and the thought of death reveals itself as the end of the torments.

It comes to face the worst dilemma that life can submit: *to survive* or to die? I choose on purpose the verb *to survive* because who decide to continue to live after a severe disabling accident or after a major illness, “builds” his days *on* the life once he had, on the past experience, or better said, on the memories

¹Nozick, R., 2006. *The Examined life*, Simon & Schuster Paperbacks, New York, 20.

²*Op. cit.*, p. 23.

³Mancuso, V., 2007. *L'anima e il suo destino*, Cortina editore, Milano, 5.

of the past. Today is based on yesterday. Tomorrow is like today, a sad *eternal recurrence of the same* on the skin of the same person. For a sound subject today is made partially by the experience of the past but it is already bound a step forward in the future.

The Importance of Choice

Everyone's life is full of small and big dilemmas as: "to go up to Law or Medicine School, to study in Rome or in Milan, to become barrister or judge, to adopt a child or not; to lie or to tell the truth, to be generous or selfish, dating this or that boy, to forgive or to hold a grudge, to give up or to press on, Kafka o Dostoevskij, coffee with or without sugar". Choices like these are more or less important and some of those are also ordinary or even trivial but nevertheless they give meaning to our life, the one that from time to time is the result of *our* deliberation and we often regret for those times in which we followed the advice of others instead of ours.

Each of us daily experience the importance of the simplest choices. Directing to our bookshelf and take from it our favorite novel, to sit on our armchair and drink coffee without sugar can give us a pleasant hour of relax as well as deciding the marry the one we love can make us definitively happier. The flavor of our existence is made, for this reason, by little and big choices.

But we could wonder if they are really for each of us little, unimportant choices. The coffee we drink very quickly is for some of us an unimportant gesture that does not deserve to be remembered at the end of the day. Some of us do not even count how many coffees we drank for so many they are. But for other people, the coffee they drink thanks to the help of a nurse or a relative is a very important moment of an entire day. It is a refreshment for taste buds that forgot many other flavors.

Let's make this idea clearer by an example of two places: a park and a clinic. Imagine to go in a park. It is a sunny Sunday of spring. Many families are there to enjoy the first warm rays of the new season. We are there too. The park is teeming with life, colors, sounds, scents, games, chats among friends and hugs of lovers. That is *life* that with a triumphant joy passes through the hours of the day until the sunset. Let's go now to the clinic. We enter the room 14 where there is a lady, mute, unable to move, who can communicate thanks to a monitor on which turns her gaze on the letters of the alphabet. She is suffering from Amyotrophic lateral sclerosis (Als). We arrive when the nurse hands her a bit of coffee. She cannot even swallow properly and she gets dirty, wetting the collar that holds her neck. Probably also someone in the park got dirty drinking coffee too and getting angry for the new shirt spoiled. The woman in the clinic does not pay attention to the "disaster of the laundry" because it is the only way to taste, once more, the drink that she likes a lot. In this case we face a dramatic reality in which the banality of a cup of coffee is the most enjoyable thing that one, in that situation, could hope to experience.

Life in that room loses its triumphant feature, its colors, the variety of flavors, and sounds. It sits silent at the bedside.

A Matter of Interpretation and Justice

After this last comparison between the two places, the park and the clinic, it seems to be clearly unjust to interpret the meaning of life in the same way. Those places are, at the same time, the symbol of two possible meanings of life. In one case life is a good to be protected and in the other case it is an evil to escape from. More precisely, what makes the difference is not life in itself but what accompanies life. Hope accompanies life in the park while despair and anguish accompany it in the clinic. Hope, queen of the park is transformed into pain at the entrance of the clinic. If the woman in the clinic asked for euthanasia we could not deny the dramatic nature of her request and consequently we have to reply seriously. Euthanasia is, in fact, as pointed out above, a modern variant of justice that according to the classical paradigm requires to give *to each his own*. In this case, *his own* is the right over one's own body¹ that is expressed in the autonomy of the subject to decide what to do of his own existence when unfortunate circumstances force it to an unbearable condition.

It is a subjective point of view on which it is possible to form a rational consensus.

None of us would like to be in the same situation of the woman in the clinic of which we perceive how odd it is if it is compared to what life should be. How blaming the woman who asks for death. It is only she that can decide what is right to do in that situation. The subjective evaluation is crucial. In that kind of situation we could also find other people who desire to live despite illness but there is also who just wants to leave this world that stole him even one of the simplest gesture of autonomy: for example, the one of wiping up a tear².

¹Cfr. Meulders-Klein, M. T. 1983. *The Right Over One's Own Body: Its Scope and Limits in Comparative Law*, in 6 B.C. Int'l & Comp. L. Rev. 29 (1983) 29 ff.; Griffiths, J., Weyers, H. 2008. *Euthanasia and Law in Europe*, Hart Publishing, Oxford; Marzocco, V. 2012. «*Dominium sui*». *Il corpo tra proprietà e personalità*, Editoriale Scientifica, Napoli; Ansuátegui Roig, F.J. 2007. *Eutanasia*, in *Questioni di vita o morte*, La Torre M., Lalatta Costerbosa, M., Scerbo, A. (eds.) 2007. Giappichelli, Torino, 191 ff.; Falzea, P. (ed.) 2009. *Thanatos e Nomos. Questioni bioetiche e giuridiche di fine vita*, Jovene; Galletti, M., Zullo, S. (eds.) 2010. *La vita prima della fine: lo stato vegetativo tra etica, religione e diritto*, Firenze University Press, Firenze; Faralli C., Zullo S., 2008. *Questioni di fine vita. Riflessioni bioetiche al femminile*, Bononia University Perss, Bologna.

²The metaphor of the two place originates from a personal experience in a local clinic. In this occasion I would like to remember Umberto, a man so ill that he could not wipe his own tears. Umberto after a long agony died some months later. Consider also the cases of the loss of cognitive life when remains only the vegetative life; cfr. Faralli, C., *Premessa* in M. Galletti, S. Zullo (eds.), *La vita prima della fine: lo stato vegetativo tra etica, religione e diritto*, cit., p. VII.

No one, a part of the subject who is facing that terrible situation, can decide what is right to do. We could not reply to his request saying that: “for how sad your life is, you have to live”, because saying this poses a question: who or what can deny euthanasia? God, the creator of the Universe, or the value of life in itself regardless of its concrete feature?

Regarding to the first reason, the existence of God, creator and author of life, may be true only in the circle of believers, but it is not, for sure, an argument that can be presented to an agnostic or an atheist. Moreover, even the believer himself seriously ill in desperate condition of life could think that surviving thanks to mechanical or medical aids is an instrument of the evil that separates him from God who had decided for him an anticipate time to die that is postponed due to medical science. Contrariwise, it may be the case that the believer does not choose to die and considers the medical aids a blessing. None in this case could intervene suspending them.

Especially for a Christian perspective the value of the choice should be stressed. It is possible to think that the omniscient God since the moment of the creation knew that the nature of man, for how He created it, were essentially made to carry out choices. God knew that Adam and Eve would not have comply the prohibition not to eat the fruit of the tree of life. And yet, from that choice, as wrong it could be, derived the life as we know. Adam and Eve are therefore the symbol of the freedom of choice notwithstanding the prohibition of God. If Adam, the progenitor of the Christians, assumed the responsibility of the choice knowing that death would have be consequence, all the more the Christians should not take position against those who invoke euthanasia.

Regarding the second reason about the value of life in itself regardless of the possible specific characteristics it could assume, we can affirm that the legal systems consider it as an undeniable *ought to be*.

But it is important to understand the meaning of the value of life in itself. It consists in the impossibility to define the value of the lives of the others. No one indeed could say that the life's value of a sick person is lower than that of a healthy subject, nor it would be the case of the life's value of an homosexual in comparison to an heterosexual, and not even that of ethnic and linguistic minorities from which to conclude that they should die. In these as in many others cases, the value of life imposes itself in a universalistic sense and then it is given to each subject the right to direct their own existence towards values that can make sense of it. Over one's own life the legal system has to guarantee a fuller self-determination.

An Incomplete Self-determination

With reference to euthanasia, the concept of self-determination is considered not applicable to it because the time and the mode of death should be subtracted to the will of the subject. Therefore, it is believed that we can use law in order to apply self-determination about our body in many possible ways, except for death.

Nowadays self-determination is pivotal in the medical field in the cases of medical care and surgery. Today is even possible to change one's own sex in order to adequate the biological nature to the inner feeling of being a man or a woman. Let's consider also the cosmetic surgery aimed to correct defects of the body that are considered inadequate to a particular ideal of beauty. Also vast is the field of self-determination about heritage. According to the legal systems is considered worthy of protection the interest to decide what it will be of one's own goods. But, at this point we could say that the body unlike of economical assets, is not a mere thing.

Actually the body is a *thing*, it is substance, it is something that belongs to us. Since it is a very important *thing* for a human being, the possibility to decide what to do of it when it does no longer respond to the motives of one's own soul is a proof of the fact that we are not made only by the body but also by the body. When the equilibrium between soul and body is broken following ways that become unbearable, it is necessary a solution.

It is true that in these cases, their high level of "drama destabilize the legal and moral categories, because such extreme situations dissolve the boundary between life and death and the power relations that cross society"¹.

There is at stake the decision to apply self-determination also in case of illness without fear of being blasphemous and trying to be coherent with a series of many other activities that are allowed by law and that can be very dangerous for the life of man. Let's thing about boxing. It is a dangerous sport if we consider the damages to the retina and to the nervous system, but a boxer is aware of all them when he climbs the ring and yet law allows it. For a boxer his body has value in the perspective of the fight and in order to win the opponent. He agrees to take the risk of losing health because the value of fighting is greater than his physical integrity. On the contrary, when the physical integrity of the subject is lost by accidents and illnesses, self-determination is forbidden.

From this point of view euthanasia is a matter of justice and coherence of the legal system.

If we agree thinking that life in itself is a pivotal value of the system we have to specify that no one consider his life simply *in itself*, but because of its relations and experiences that allow to distinguish ourselves from the others and from the biological existences in nature. Every man is not a number and the Mr. Smith we use in the example is nowhere, but "there are we", with our names and surnames, with our faces and voices, our hands and legs. Tragic circumstances of life can make the subject to regress in a condition in which the richness of life's forms is reduced to a meager assets that can't give anymore a meaning to life. Certainly from the outside it is important to support emotionally and psychologically the person who is in those conditions and to affirm that his life has value even in the saddest situation. But if that person, from his inner point of view, refuses the value of life in *itself* because he would

¹In particular in the case of persistent vegetative state see: Zullo S., *Introduzione*, in Galletti, M., Zullo, S. (eds.), *La vita prima della fine: lo stato vegetativo tra etica, religione e diritto*, cit., p. XII.

like to give it the value according to *himself*, we could not contradict him and euthanasia cannot be denied. As Grossman said in *Everything flows*¹ for a bleeding heart all is strange and terrible.

In this sense, the capability to act according to our decisions and to interact communicatively with others defines our identity. In fact, «Speech and action reveal this unique distinctness. Through them, men distinguish themselves instead of being merely distinct; they are the modes in which human beings appear to each other, not indeed as physical object, but *qua* men. This appearance, as distinguished from mere bodily existence, rests on initiative, but it is an initiative from which no human being can refrain and still be human. [...] A life without speech and without action [...] is literally dead to the world; it has ceased to be a human life because it is no longer lived among men»².

Two Meanings of Suffering According to the Christian Tradition

The two big spheres of Christianity, Catholicism and Protestantism have different positions about the bioethical issues and it is due to many reasons. Protestantism despite the plurality of its denominations, is characterized by a common element: the defense of the principle of self-determination. This fact does not lead it to a contradiction even if it is based on a set of beliefs founded on the idea of a God creator and author of life. There is no contradiction because of the different ideas about the authority, the responsibility of each man before God and the meaning of suffering.

Protestantism has not the presence of a teaching alike the Catholic one. There is not an authority like the Pope and the college of Cardinals. In Protestantism the holy synods give some guidelines and suggestions. They express them in proactive and not in prescriptive terms. The concept of responsibility is based on the idea that each man has to replay personally to the call of God and to do so it is not necessary the mediation of the church. Besides this, it is added the admission of the possibility of error on the part of the church. As the French Protestant Federation said, the Church can make mistakes even when it invokes the Holy Spirit³. So the church does not consider itself as the location of the teaching but as a place for discussion. This vision could be interpreted as the result of the anti-priestly position of Christ himself who demonstrated, in many occasions, that wisdom is not the private heritage of the priestly class. He rejoiced recognizing that the Father had

¹Grossman, V. 2009. *Everything flows*, NYRB, New York.

²Arendt, H. 1998. *The human condition*, 2nd ed. Introduction by M. Canovan, The University of Chicago Press, Chicago-London, 176.

³Aramini, M. 2007. *Bioetica e religioni*, Paoline, Milano, 68. See also, Savarino, L. 2013. *Bioetica cristiana e società secolare. Una lettura protestante delle questioni di fine vita*, Claudiana, Torino; Bognardi, D., Ibarra, M. (eds.) 2005. *L'inizio e la fine della vita. Le sfide della bioetica*, Claudiana, Torino.

hidden “these things from the wise and the intelligent and had revealed them to infants”¹.

Furthermore the Protestant vision put before the pre-eminent interest in the person rather than in systems, rules and traditional ethical principles². In this perspective it is interesting the declaration of the Bioethical Commission of the Waldesian and Methodist Churches in Italy. According to it “Christian Ethic and the Pastoral have to give credible answers to suffering and pain, they must take them all the way, without digressing, and without irresponsibly projecting them into a dimension of self-redemption”³. So this kind of Christian bioethics does not consist, as the Commission said, in the repetition of rules or premises to adapt to reality but it derives inductively by the respectful research of the data and animated by principles. This position is the result of the old tension between the respect of the *Shabbat* or the respect of life in its real needs, or better said, between ethics in the service of life or life in the service of ethics. In the preeminence of the first, as it happens to Protestantism, there are not absolute principles, and the sense of humanity is defended against strict law when the latter becomes an instrument of spiritual death. It is adopted a spirit of “constructing solidarity” aimed to overcome conflicts and find solutions trying not to be confined by rigid alternatives and accepting the fact that there are real situations not easy to be resolved. They invoke mercy in order to absorb contradictions and alleviate suffering.

Determinant for this different approach is also the concept of suffering. According to this tradition suffering has not value in itself. It is the case of the so called “uselessness of the pain”. It is not an instrument to purge the conscience even because the purification in this case would not be sincere or spontaneous. It would be commended by the suffering, it would be the result of a causal chain that origins not in the will but in the body.

Suffering has to be contrasted using medical remedies. It is unthinkable passing by suffering without offering relief in the name of moral absolutes that make irrelevant the situation in which the individual is found⁴. Suffering cuts our relation with the others. We found ourselves in a deep solitude because we cannot help but think to ourselves, to our hacking body, to the suffering that fights the body and we see it impotent against this enemy. Any other thing is irrelevant, no other thing can matter. There is just this body under attack and the soul and the spirit, believing or not in one or both of them, are hostage of it. In the well of disease, soul and spirit take the risk to be poisoned. It is not something that has to happen in each cases. In some of them it is possible to live disease with courage and the reaction of the inner part of a man can be a fortress in this time of need. But in other cases it can be exactly the opposite and we cannot ask men to be heroes if they do not have the strength. As Seneca

¹Matthew 11:25.

²Aramini, M. *Bioetica e religioni*, cit., 71.

³“Commissione sui problemi etici posti dalla scienza. Unione delle Chiese valdesi e metodiste in Italia”, *L'eutanasia ed il suicidio assistito*, February 1998.

⁴Extremely relevant are the words of Jesus in this bioethical issue: “I want mercy not sacrifice”. Matthew 12:7 with reference to Oseah 6:6.

said «I shall not avoid illness by seeking death, as long as the illness is curable and does not impede my soul. I shall not lay violent hands upon myself just because I am in pain; for death under such circumstances is defeat. But if I find out that the pain must always be endured, I shall depart, not because of the pain but because it will be a hindrance to me as regards all my reasons for living»¹.

We cannot deny the moral urgency of responding to a request from those who are in a state of need, even if it would mean to help them to die. Defense against natural suffering is a “noble and decisive task” that humanity entrusts to science. When the last one cannot fulfill it, it has no longer right to intervene on a human body.

In 1998, the Commission expressed a favorable opinion about the advance directives. It was the time in which there were not, at least in Italy, particularly famous cases that drew public and mediatic attention on them, so it is noteworthy the fact that the Commission expressed that position.

Thanks to the advance directives it is possible to spell out the decision about end of life care ahead of time. From this point of view, the body, as already outlined, is a thing, or better, the most important thing we can think about and consequently decide about. The advance directives are a concrete form to defend the individual body against possible abuses of medicine and its application². According to the Commission the request for euthanasia should not be denied or considered unacceptable in principle. On this matter, the only non-negotiable value is the conscience of the individual. In the most dramatic cases, life is a daily humiliation of hope. We are in the presence of a different conception of the sanctity of life. Life is sacred until it is possible to give it a human sense. It is a kind of *sanctity of a free life*³. It is true that life has a miraculous feature just because we had the chance to know how life is on earth, but it is also true that, risking to be insincere, we cannot convince to survive who does not feel anymore for this life a feeling of gratitude or a sense of wonder.

Conclusion

Opposing to the principle of self-determination is a form of oppression that has nothing to do with the imperative of love of the neighbor, because loving someone means to recognize that in those situations the decisive point of view is the one of the ill one. As we know, death is a subtractive event that in cases of illness or accidents starts when the physical integrity of the subject is

¹Seneca, *Letters to Lucilius*, Ep. 58.

²Genre, E. 2013. *Introduzione alla bioetica. Bioetica e teologia pastorale in dialogo*, Claudiana, Torino, 69. On this matter see also, Borsellino, P. *Stato vegetativo e decisioni sulle cure: servono le direttive anticipate?* in M. Galletti, S. Zullo (eds.), *La vita prima della fine: lo stato vegetativo tra etica, religione e diritto*, cit., 107.

³Fornero, G. 2009. “*Non esiste solo la bioetica cattolica*”. *Nota sul rapporto fra i valdesi e la bioetica*, in *Bioetica. Rivista interdisciplinare*, n.4/2009, 860.

damaged. Bluntly we could say that illness and accidents are the *bleeding* of life, an *hemorrhage*.

In conclusion we can recall the words of Niels Bohr: “The opposite of a fact is falsehood, but the opposite of one profound truth may very well be another profound truth”.

This happens because we are dealing with profound meaning of life and death that can be inquired only by an inner point of view by which comes every form of freedom. Euthanasia is for the reasons considered above, the «ultimate and extreme self-justification of man as man, and it is therefore, from purely human stand point, in a certain sense event of self-accomplished expiation for a life that has failed»¹. This is not far from the idea of Seneca according to whom “whosoever views suicide as criminal does not realize that he is closing off the path which leads to freedom”². And in another passage we can read “Should I wait for the cruelty of a disease or of a man, when I can instead escape the torments and nip adversity? That’s the only reason why we cannot complain of life: it does not hold anyone”³.

Ultimately it is an act of rebellion of man against life when the latter betrayed, in the worst possible ways, his expectations.

¹Bonhoeffer, D. 1969. *Etica*, Bompiani, Milano, 140.

²Seneca, Book VI (Letter n. 58 to Lucilius),

³Seneca, Book VIII.