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Learning to Die Analysis of the Cultural Role of Voluntary Death

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Abstract

Voluntary death is a morally and legally grey area in many countries around the world.
My speech is based on the research I conducted in Italy on the topic of euthanasia and assisted suicide for my master's thesis. Specifically, I wanted to analyze the relationship between collective law and individual morality using as a case study the phenomenon of voluntary death, which has been making people talk about itself in recent years precisely because of its as yet undefined nature. Listening to the voices of the medical class, i.e. the social group that would be most affected by the possible legalization of euthanasia, it has emerged, among other things, that Italy lacks a real education to death. The research has opened a reflection on the range of voluntary death within a Nation where it is illegal. Numerous studies have determined the enormous symbolic baggage present within the concept of death, but in the study of the legalization of *voluntary* death a new factor has emerged: a legalization is not desired until the population receives a real education on the idea of having to die. Like sex, death is still a taboo in many societies around the world. is it therefore possible, or at least necessary, to educate to death? How could it be done? This research has exalted not only a cultural deficiency but also the desire to remedy it through death education, in order to exorcise the fear of an event that sooner or later everyone has to face.

Keywords: Culture; End-of-Life; Euthanasia; Legalization; Voluntary

Social scientists have always tended to be particularly attracted to the phenomena related to death, since it is precisely in these liminal moments, between life and its cessation, that emerge many of the conceptions and beliefs that characterize a society.

The recent development of the Social Health Sciences has brought with it a new interest in the dying itself, thanks also to the innovations in the medical field that have allowed more and more people to survive for a relatively long period of time with a terminal disease.

In the last two decades, new practices have been introduced within the social-biological panorama, thanks to which an individual, under certain conditions, can voluntarily request that his life be ended through a rapid and painless injection. I'm talking about euthanasia and assisted suicide.

It is an unprecedented event that revolutionizes both the medical field and the society in which this practice is legalized. For the first time in the age of modern medicine, is allowed the possibility of dying rather than continuing with treatments.

Death becomes the ultimate cure.

The introduction of such a practice completely redefines the medical ethics and the collective morality of society: the doctor must go against the Hippocratic oath and give death instead of fighting it, society must normalize suicide, usually criminalized.

My speech is based on the research about the end-of-life in Italy that I conducted for my master thesis. My intention has been to go beyond the simple understanding of how much the practice of euthanasia and assisted suicide is accepted in Italy (a country where such actions are still illegal), the main focus has been to problematize such events in order to understand what future developments there could be. Through a qualitative research methodology and a semi-structured interview, I wanted to collect mainly the voices of the medical class as it would be the social group that would be most affected by the possible legalization of euthanasia and assisted suicide.

Creating a collective norm to regulate a phenomenon as individual as death, puts in place the mechanics that not only touch the legal-institutional sphere but also the individual and cultural one. What correlation exists between collective law and individual morality? What ideological background should be kept in mind when considering the regulation of death? What problems must

be resolved before proceeding with the creation of the norm? What situations are faced by doctors in the current condition of total illegality of voluntary death (in Italy)?

I will start by explaining the legal situation in Italy through a recent case and then I'll analyze what emerged during the research and what conclusions can be drawn.

Famous is the case of Fabiano Antoniani who was blind and quadriplegic following a car accident on June 13, 2014. Not wanting to remain in that condition, he begins to insist on asking to the Italian government the permission to end his life. This request has caused great uproar: the government did not know how to behave, and the Italian public opinion was split into two parts, those who supported the request of Antoniani and those who considered it morally unacceptable.

After years of requests he decided to take the initiative and with the help of Marco Cappato went to Switzerland where he asked and gets permission to proceed with assisted suicide. By only partially moving the fingers of his hand, he was given a button to release the lethal dose of the drug into his IV.

On 27 February 2017 Fabiano Antoniani literally died by his own hand.

In Italy there is no law that explicitly denies any euthanasia/assisted suicide attempt, in fact those actions are never mentioned by name, but indirectly they are forbidden.

Paragraph 1 of Article 579 of the Italian criminal code states that "Whoever causes the death of a man with his consent shall be punished by imprisonment from six to fifteen years".

Being therefore illegal, once back from Switzerland Cappato decided to denounce himself in order to bring visibility to a theme too often left in the shadows. The trial lasted for years and ended only a few days before Christmas 2019 with the release of the indicted. His intent was to stir up the souls of the government in order to obtain a law, and even if this did not happen, the Italian Constitutional Court stated that under certain circumstances it is not punishable who helps another person to obtain death. The declaration has no legal value but constitutes a precedent, a first step.

This recent event highlights not only the current problems that revolve around the voluntary death but also highlights the need to study this topic at this moment in history.

As I already mentioned, my research focused on the study of voluntary death in Italy using a qualitative analysis (interviews) of the social group that would be most affected in the event of a

possible legalization of the phenomenon: doctors. For reasons of privacy it is not possible to reveal the names of those who participated or the organizations to which they were affiliated, not even the places in Italy from which they came, here I will list the results that emerged, what problems were raised by the doctors and what dynamics should be taken into account when talking about "legalizing euthanasia".

One of the first things to emerge (and one of the most important) concerns the influence that culture exerts not only on death itself (a subject already widely demonstrated by numerous studies) but also on the status/role of the social subject. In the case of the end-of-life this influence is reflected in the judgement of the doctors on the voluntary death: if at the beginning of the interview the opinion "pro euthanasia/assisted suicide" tended to emerge immediately because it was considered obvious that every human being could decide for himself, later on this position tended to be partially or totally retracted when the interviewee started to think about it "as a doctor and not as a citizen".

I deliberately structured the interview starting from a specific and well-known case (the already mentioned Fabiano Antoniani and Marco Cappato) and then gradually widening my view on the wider general legislation. In doing so, the first comments regarding the issue of the end of life concerned the need for everyone to be able to choose what to do with their own existence, however, as soon as the professional opinion took over the conversation, the initial ethical absolutism disappeared to leave the field to a greater level of problematization.

The main point that emerged during the interviews is that Death is still taboo, just as sex, and as a result the topic is taken out of the mind, ignored, with the consequent inability to deal with it the moment it comes to the door. In practice what the doctors have accused is the difficulty of creating a law on death in a society in which is ignored.

It has emerged that the discourse is not simply about the individual's desire to want a law, but rather about the actual effectiveness that the law can have in one specific context.

Law is not only an organizational tool but also a cultural product. In this regard, another particularly interesting element that emerged is the phenomenon that I called "*reverse biomedicalisation*". In Social Health Sciences the term biomedicalisation indicates a tendency to

see as biomedical phenomena those that are not necessarily biomedical, using a reductionist (everything can be explained through the biomedical lens) and exclusivist (what cannot be explained through the biomedical lens is not a health problem) perspective. By the term "*reverse biomedicalisation*" I mean the fact that in this case the phenomenon of biomedicalisation is not carried out by the medical class; on the contrary, it is the latter that fears that the population itself is doing so. In practice, I have been told many times how many patients are already asking for drugs driven by the desire to get everything immediately and thus solve a problem as quickly as possible.

In the case of the possible law on the end-of-life, the fear expressed to me concerns the fear of a possible reification of life itself, i.e. the fear that legalizing the voluntary end of life could push some people to use this possibility too lightly. Basically, it is feared that people use the biomedical lens too much to see life itself as a product to be disposed of when it is no longer convenient to preserve it.

It is interesting to note that in this case it is the medical class itself, often accused of reifying the body too much and seeing it as a machine to be adjusted, that criticizes the use of this attitude by the population. This fact adds an extra element and shows further how much talking about the end of life implies bringing complex cultural dynamics into play.

However, the “cultural criticism” emerged against the medical class itself as well. The unpreparedness in the field of death concerns not only the population but also the medical class. The totality of cases has in fact expressed how much the same medical preparation is currently lacking on the subject of death. There is a widespread tendency to want more attention to bioethical issues, which are too often ignored both at university and at the school of specialization. Younger doctors with more recent testimonies about the current educational process in the medical faculty have highlighted the existence of a bioethics class during university, however, often goes unnoticed and doesn’t teach what concern dealing with death. For example, H. told me:

> H: Well, beat it more, don't do the course...I'll tell you again, for example, I took the bioethics course, it was a course like that, a few credits, a few hours, who cares, easy exam…instead, beat it more on these topics, organize seminars...on

> practical cases, in short, don't do the usual little lecture like that, where you'll be told two little...nonsense shit, and then...

All this implies that each doctor must train himself or herself in the end-of-life approach, increasing the possibility that situations may arise in which both the patient and the treating doctor have personal and interpersonal difficulties.

> A: The problem, in my opinion, is that there is no medical training that would allow you to get to the suspension of treatment in a healthy, reasonable, shared way, but it could be done.

The real victim of this situation is the doctor-patient relationship, somewhat limited by the obscure presence of an issue that is difficult to manage on both sides.
Not only the preparation is insufficient, it also more focus on the behavior of the professional rather than the ethical situation in which he/she can be involved:

> C: [...] ethics was already there in my day when these things were being done... ethics was approached in a different way, ethics was just as you put yourself as a professional, not ethics referring to these choices.

The element of cultural and didactic unpreparedness on the theme of death is one of the fundamental points that emerged from this study. In essence, it means that before reflecting on the creation and implementation of a law on death, one should work on the cultural basis on which such a law would be based.
The concept of *voluntariness* applied to death brings into play new factors and different ideologies, however, it has emerged that we should before work from the educational point of view on the concept of death per se.
Many physicians have used as an example to validate this idea the Italian situation regarding D.A.T. (*Disposizioni Anticipate di Trattamento)* commonly known as *living wills.* This law allows individuals to create a document through which they can certify that they wish to renounce medical

treatment (knowing that this will lead to their death) if they find themselves in serious and irreversible health conditions. Doctors have repeatedly pointed out to me that this law was approved in December 2017 and came into force in January 2018, but although it was strongly desired by a slice of the population, in recent years less than 1% have taken advantage of the possibility of drawing up a living will:

> I: [...] you have seen the DAT, the data from the ministry tell us that the 0.01...in short, 60 thousand DAT deposited out of the 50 million people who can deposit them...after two years it means that it is not something that interests so much people...as a principle it interests many...

What is the explanation behind these numbers? For example, A is convinced that this numbers are the symptom that this type of issue is niche and is only dealt with by the most educated part of the population:

> A: for us who do this work is a continuous reflection that you do with yourself, with your colleagues always, every day in the end because ... death is here every day with us, the problem is that you never talk about it, you talk about it when it happens but people do not ... few people reflect on what is your future ... and they are still laws for a few ... they are laws that ... even the D.A.T. who makes them? They are made by the people who study...but not all of them, in my opinion, it is not something that can reach everyone, and it is wrong, because...it is a bit of a niche.

It is interesting to note how every social structure produces a system of thought related to death, outlining questions and creating answers, but in spite of this, the topic remains full of a "cultural unpreparedness".

This unpreparedness, as emerged from the research, denotes the paradox of finding oneself powerless in the face of a topic on which one should theoretically be extremely well prepared. Not only is death the only existential certainty common to every human being, it is also an event that

pushes every society to produce multiple cultural tools to conceptualize, understand and accept it. In essence, it cannot be said that it is neither a surprise nor that we do not have the ideological tools to deal with it, yet in the contemporary world it seems to be victim of a *damnatio memoriae*. During the research I noticed that an interesting topic returned several times: every different way of ending life is inserted in a different moral landscape more or less accepted. By this I mean that when we spoke more explicitly about euthanasia the moral judgement changed according to whether we were talking about active or passive euthanasia. It can be said that voluntary death is more easily placed within a shared moral scenario when it serves as a palliative of human physical suffering.

Basically, it has emerged that the end of life needs to be regulated so as to give a scheme to something which, however, as someone told me, is already being done in the shadows, but when it comes to this regulation, multiple factors of both cultural and moral nature come into play. In this regard, from a theoretical point of view, I have defined *moral schismogenesis* the process of ethical conflict within the experts of the medical world, using a term more than known among social scientists. The word schismogenesis was created by Gregory Bateson almost a century ago but it is a term full of theoretical potential. If for Bateson the conflict is obviously external, I wanted to incorporate it within the individuals, an incorporation that inevitably brings with it a part of the external social structure. To put it simply, by moral schismogenesis I mean the process that leads to the emergence of an ethical difference within the individual based on status and external roles. My idea is based on the assumption that some statuses and roles are more morally imbued than others on the basis of the actual task they have to perform within society. This causes some roles to develop a kind of autonomous morality independent of the individual who then fits into them, as if the role of "doctor" alone possesses an ethics of its own based on what society expects of those who embody this category. All this means that when a person who already has his or her ideological, cultural and moral background finds himself or herself playing a role that has its own ethics, the moral of the role and that of the individual can come into conflict, thus generating even opposing opinions on the most sensitive issues.

The whole analysis highlights how many problems come into play when we start talking about voluntary death: it is not enough to be for or against this phenomenon to understand its infinite nuances, we must first of all give it the right political and personal, practical and moral weight, so as to understand how much more complex the situation is than we might think.

Often, when we talk about a topic that is so ideologically and ethically connoted, we tend to lose sight of the overall picture, we crystallize on our own positions and criticize those against. Before getting stuck inside one's own idea one should analyze the whole phenomenon so as to understand its various implications in order to take a real position. As far as voluntary death is concerned, this research should make it clear that the same personal opinion can be split, that's why is still complicated to create a law. The main point is that before the law we need a specific cultural preparation, a sort of death education, otherwise the law alone will not have efficacy.

In conclusion, why should we study this topic? While at a scientific level it allows us to highlight certain aspects of the structure of a society and its relationship with the various individual agencies, at a human level it allows us to improve a situation that still today has no resolution. The controversial status that voluntary death has in many countries of the world is a symptom of a situation that must be changed and, as social scientists, we must study and understand in order to change and improve. The euthanasia issue is part of the research-action strand, and since the discipline in question is medical anthropology, it is necessary to focus here on improving the human health condition in its broadest sense.

While Fassin spoke of *Ethics of Life*, the study of euthanasia allows us to reflect on the Ethics of Death as a study of the ways in which various social subjects give moral meaning to death through their practices. The end-of-life, being such a symbolically dense topic, tends to present itself as an event imbued with a single moral (or similar morals), and therefore it is thought that it is possible to create a homologated and homologating norm. The difficulty in creating a single law is instead the proof that there are different ethics that are not easy to reconcile, just think of the fact that capital punishment is the institutionalization of a death that is however accepted, this means that the same event (death) is connoted differently. The contrast between death penalty and euthanasia,

from a legal and social point of view, allows us to reflect, to use Fassin's words again, not so much on which economies of life are implemented but which economies of death are preferred.

During the first Italian medical anthropology conference (2013) Fassin argued that this discipline should have three characteristics: theory, criticism and politics. As social scientists we have to study theories with a critical approach with the ultimate aim of having a political impact on reality in order to improve people's lives.

Studying the end-of-life is therefore important because it allows us to lean towards understanding and change. There is still a lot that needs to be done in order to achieve a regularization of euthanasia; studying it will one day allow us to reach a situation that will make everyone satisfied

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