

# Right to life, right to end of life: a critique of the Declaration of Human Rights

## The right to life and the right to end of life: a critique of the Declaration of Human Rights

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### ABSTRACT

Human rights have undergone constant evolution.. Recently, however, new generations of rights are developing: from political and civil rights to social and economic rights, so much so that this period may be defined as the age of human rights.

Many differences exist between moral rules and judicial law. While moral rights are not necessarily recorded in statutory law, some judicial laws, which are capable of being imposed and/or appealed within a true territorial government, originate from moral rules.

Common sense has reservations about whether human rights can be labelled as laws in a rudimentary way; instead, society places human rights in the category of moral rights. These moral rights, in fact, are not the fruit of compromise, but are absolute and essential to the inner self.

Throughout this article, the evolution of end of life rights is discussed, with particular regard to how those rights are directly correlated to organ transplantation.

**Key words:** end of life, ethics, human rights, living will, death, transplant

### RIASSUNTO

Negli ultimi duecento anni si è registrata un'evoluzione costante dei diritti umani. A quelli iniziali, si sono aggiunte nuove generazioni di diritti: dai diritti politici e civili, a quelli sociali ed economici, con un aumento inarrestabile, tanto da far definire l'epoca attuale come l'era dei diritti. L'accento si pone oggi e in maniera urgente, sul concetto di persona titolare di tali diritti.

Che tipo di diritti sono i diritti umani? Il sentire comune si domanda se i diritti umani possano essere chiamati diritti in senso stretto, visto che non possedendo un carattere imperativo, appartengono alla categoria dei diritti morali, comunemente considerati diritti prima facie. Le norme morali, infatti, non sono frutto di compromesso, sono assolute e obbligano solo in foro interno.

Mentre le regole morali non sono codificate, l'osservanza delle regole giuridiche è imposta, con il ricorso a sanzioni, nell'ambito di un certo territorio statale.

In campo morale chiunque può giudicare, a differenza del diritto codificato dove solo il giudice è legittimamente autorizzato ad applicare la legge e ad emettere sentenze.

La regola morale, anche in caso di dubbio, è considerata valida, mentre la regola giuridica richiede certezza e precisione per essere applicata.

Infine, la regola morale si applica al comportamento di un determinato individuo, mentre la norma giuridica si estende ad una classe di azioni che includono chiunque si trovi all'interno della fattispecie.

Inoltre, la formulazione delle norme giuridiche, nelle democrazie occidentali, deriva da un accordo politico tra le diverse parti in causa, rendendo spesso il risultato finale una soluzione di compromesso; una volta promulgate, esse hanno validità per tutti gli uomini, con carattere imperativo su tutto il territorio.

In questo articolo discuteremo dei diritti alla fine della vita umana e di come tale concetto sia mutato nel tempo.

**Key words:** fine vita, etica, diritti umani, testament di vita, trapianto

### INTRODUCTION

Human rights are rich with semantic values emerging from the seven-hundreds A.D. as an authoritative affirmation of natural born and inalienable rights in opposition to the power of the State. The analysis of the concept behind human rights during life has been assigned more importance than end of life rights.

End of life rights have remained in the shadows until now, operating more as an afterthought than the result of policy. In fact, during the creation of the Universal Declaration of Human Rights, the concept of human rights was not assigned a complete definition where scientific evolution was concerned, such as in the fields of biotechnology, genetics, and medicine. In the Universal Declaration of Human Rights, internal reasoning of both a judicial and a moral person are essential given that the terms human life, human person, and human being are all mentioned as being synonymous.

Until a few decades ago, the complex issues of artificial insemination, production and collection of stem

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cells, cloning, prenatal diagnoses, human genetic experimentation or animal and plant genetic experimentation, artificial life support, aggressive treatments, organ transplants, and the possibility of organ donation after death were unthinkable. The study of the human genome has eliminated certain barriers making it difficult to understand what particularly identifies us as belonging to the human race. This brings forth a significant question: How is it possible to identify human beings in a definite way? There must be an internal consensus to this notion of Kant's *jus cosmopolitism* which represents the right that every man can reclaim himself (Kant, 2005). Naturalistic classification seems a suitable answer, as human genetic mapping is extraordinarily similar to other living organisms. However, it is not only necessary to state these restrictions quantitatively, but also to determine the qualitative boundaries that identify the human race (Mitello,; Rufo, 2005).

This inadequate description of a human being, to which scientific advancement has provided some insight, brings to light the complexity of completing the description for moral and judicial protection not yet specified by the Declaration; for example, the body after the death or abortion issues with reference to the embryo and the fetus (Mori, 2002). Controversy has risen over new scientific discoveries, calling upon moral and judicial decisions to clear the air, or else there is a risk of over-extending definitive boundaries into oblivion, jeopardizing a definitive, operative, and practical view of them.

## HUMAN RIGHTS IN THE CONTEMPORARY WORLD

Emerging after WWII, the Universal Declaration of Human Rights represented a historical compromise among opposing views, thus developing a tool of propaganda used for the advancement of the cold war coalition and international politics based on self-interest. After the Nuremberg trials of 1948, legislators of human rights acted as representative delegates of governmental state members of the United Nations. These delegates of the UN also acted as indirect representatives of the general welfare of their respective countries (Gambino, 2001). Consequently, various cultural traditions and politics have resulted in creating the Universal Declaration of Human Rights, a negotiation to establish the criteria of inclusive and exclusive principles based on their universality.

Universality poses the diffusion of values which aim to achieve domination over the rest of the world including the expansion of human rights in the form of the cultural colonization of Western ideas (Glendon, 1988). Difficulties arise because the cultural colonization of

Western ideas does not allow for the resolution of opposing viewpoints if two laws conflict with one another in the same Declaration. For example, American jurors are individualized elements of the incomplete categories of human rights. First, they heed and are influenced by various lobbies that determine the pretence of sanctions as law. Through the influence of North-American jurisprudence, the Declaration of Independence is an unwavering document; it lists multiple assertions for the individual, each one important in its own right. This Declaration affirms an individualist conception of life with liberty and autonomy, preparing the individual for independence rather than unity and collectivity. This movement can be seen in action within the contemporary family unit which has been redefined progressively to reject any kind of consensual cohabitation.<sup>5</sup> The United States should not assume its worldly position based on a particular moral ethic, but instead create the conditions of cohabitation to guarantee to all the pursuit of the *proprio bene* (Engelhardt, 1999).

Therefore, defining human rights in a declaration is not necessarily a successful method for creating an essential common foundation. In fact, the United States currently presents a political character resulting from compromise, and a moral character that is obliging to the government; its usual position is to live only in the *foro interno* (Bobbio, 1996). The United States, as a member of the United Nations, should conform to UN regulations and welcome and codify these regulations, adopting them as national legislation.

Since the development of the Declaration of Human Rights which Renè Cassin and Eleanor Roosevelt were the principal promoters, human rights has developed and expanded progressively, extending to every part of the globe as an inspiring principal for various national constitutions. Consequently, the continuous assimilation of new subjects under the law waters down the basic underlying principle (Henkin, 1993). Certainly when defined as absolute, eternal, or self-evident, human rights have acted as a contributing determinant to some problems when relatively applied with its historical power of assuring efficiency and efficacy, thus continuously modernizing the list of fundamental rights.

Despite limitations in respect to the foundation of the epistemology, human rights becomes ineffective from a historical and political point of view. Human Rights expresses ambiguity in respect to the same sources of human rights and remains obstinate within a set of rules that would avoid the return to the threatening past immediately after WWII and the horrors of Nuremberg. The Declaration of Independence, founded upon empirical self-evidence of the fundamental rights of a human being, represents to the civil world a belief that is held as unacceptable (Ignatieff, 2003).

## BIOETHICS AND BIOLOGICAL RIGHTS

The birth of biological rights is an attempt to resolve with judicial instruments the problems posed by bioethics (Tallacchini, 2000). The principles of the Universal Declaration of Human Rights and subsequent conventions that have taken place served the purpose of inspiring various governmental legislations; and, have therefore been necessary as a practical tool for binding judicial norms in relation to human rights. On the issue of fundamental rights, Reichlin states that the fundamental problem involving the relationship between rights and bioethics revolves around the question of bioethics being recognized as the inclusion of some fundamental rights relating to bioethics, reflecting only a part of the complete list of human rights (Reichlin, 2002). How is it possible then to understand the inspiring principles of human rights? To this proposition there are two distinct problems: the concept according to the situations that can be brought to justice in the bioethical laws of the State, or to leave deontology to only those professionals involved in these pragmatics. The deontological codes introduce a large problem. For example, Italian nurses' code, (assembled in 2008), is too generic and it does not collect all instances of all professional group. The hypothesis, therefore, to address in Europe and the rest of the world, about the deontological codes and the regulation of the radical situation set by bioethics, poses three objectives: first, the opinion of ethical committees, worth no more than you or I; second, ethical committees are only a fraction of society and may monopolize delicate decisions that concern all citizens; finally, the deontological codes show some signs of use, but they have not been shared with other aspects of human rights, such as abortion.

In another matter, the complex premise in different countries to regulate by law the phenomenon of bioethical interest is seen as the problem of choosing what type of regulation is most effective: that of a centralized system, in which the judges, making decisions based on precedence, provide a judgment based on critical analysis, or, in the countries that have used the common law system, the decision of the judge in the *vacatio legis*, ratified by the Supreme Court and becoming precedence for further cases.

Also, there are those who believe that the problems of bioethics must not be absolutely regulated, but this is not a sufficient solution considering how socially influential bioethics has become (Lecaldano, 2002). Rodotà suggests a "mild" law with appeal to both ethical and social differences in efforts to find an approach to negotiation (Rodotà, 1997; Ignatieff, 2005).

The motivations leading to the regulation of matters of bioethical origin depend on three principal factors:

first, the novelty of the problems and the rapidity of change; second, statutory law promulgated by a legislative branch that is more rigid and less able to adapt and assimilate to new situations when the common law is enforced; and, finally, the difficulty of society to find an ethical precedent.

Modern legislation functions to regulate science as well as validate scientific knowledge; yet, it is complicated by the fact that scientific concepts can not be translated using only common sense. Every time the law adopts a scientific concept, this concept becomes legitimate, debunking alternative concepts, thus breaking free of the problem of criteria validating the quality of science.

In regards to law, a legacy of problems remains concerning efficacy and efficiency in the event that the United States is prepared to reciprocate and observe the directives established by the United Nations. For the determination of human or material things, these problems are still in the theoretical phases and remain a wide open field for philosophical speculation.

We now arrive at the point of investigating our assignment, where we attempt to analyze the nature of human rights, in an attempt to answer the questions: "What do we intend for human beings?" "When do individuals stop having a right over their own body?" Considering the discourse on human rights as a central factory for human nature, the idea of what is truly natural for humans becomes unclear since the life of a contemporary person is intrinsically bound to scientific technology, thus creating an alternate nature (Veca, 2005).

Objective evidence exists that there is no natural approach to resolve the difficulties surrounding the complexities of human nature. This difficulty becomes insurmountable when bioethical matters open up a "new frontier", as in end of life issues where some ethical ideas are acceptable in sustaining life for patients with terminal illness by conventional or basic means, without resorting to extreme unconventional or aggressive methods (Veca, 2005). Artificial methods of sustaining life, the conventional/unconventional or basic/aggressive treatment, are matters of life that modern man must evaluate. For this to be achieved, we must go against time.

## THE END OF THE HUMAN LIFE

The legislation of human rights clung to the traditional concepts of a timeline of a human being, where human life begins with the first cry and ends with a last breath. With the progress of medicine, genetics, and biotechnology, the doors of knowledge are pioneering new technological superhighways to

arrive at DNA manipulation as a form of intervention.

## THE DECLARATION OF DEATH USING ANALYTICAL CRITERIA: A PARADIGM CHANGE

Under the scope of human rights and determining what is human, we will analyze the declaration of death by critical analysis and ownership of the body after death. For modern man, biotechnological advances allow for interventions at the beginning of life, as well as for situations at the other end of life's spectrum, where life is artificially supported by hydration, feeding, respiration, and circulation. These biotechnological advancements have caused a distortion of the lines previously set between a person's "natural" life and death; therefore, it is fundamental to define what constitutes death for a human being (Scanlon, 2003). Scientific discoveries have not modified the definition of death, as evidenced by a sustained definition of total and irreversible loss of one's bodily functions (Ellis, Hartley, 2001).

In the past, traditional cultures believed the body of a dead person was unusable and was revered as an object of worship. Ancient cultural heritages and traditions are still seen in some judicial cases, where a dead body is deserving of being treated with respect. Actually, our common law of today suggests that the death of a body is defined as when the heart stops beating. Death, according to law, can be classified according to various criteria: biological, clinical, anatomical, cardiac, neurological, or brain death. Yet, brain death does not necessarily mean that a person has died since artificial life-support can take the place of specific non responding neurological functions.

Additionally, death can not be considered an instant phenomenon, because all the cells of the body do not stop activity simultaneously; instead, it is a continual process of cell expiration dependent upon increasing lack of oxygen (Porter, Johnson et al 2005). It is possible then, to allow for the complete and irrevocable process of necrosis to ultimately define the moment of cessation of an individual's life. From the moment in which techniques of artificial resuscitation allow for principal biological functions (heart, circulation, breath), society has chosen to identify death as the time when organs can no longer be harvested for donation. Brain death is not a revolutionary definition of death, but a separate way to identify death; therefore, many nations have come to an agreement on a definition of death by virtue of new scientific discoveries thus redefining the concept of human life. The definition of death can be frustratingly ambi-

guous given that brain death is defined as the death of an organ inside of a live person; whereas, the death of a person's body is considered the death of any single major organ.

Italian CNB (National Bioethics Committee) has sustained that the concept of death is the total and irreversible loss of independent ability to maintain control over one's functions (Mori, 2002). Lack of artificial support allows for cardiac pulsation, respiration, and nutrition to reach complete necrosis spontaneously (Rachels, 1989).

Brain death was described in 1959 by Mollaret and Goulon as the autolysis and antiseptic necrosis of the cerebral hemispheres and trunk or the complete and irreversible destruction of the whole content of the cranial hollow up to the first cervical segment. The actual declaration of brain death had its debut in the USA in 1968 from the "Committee ad hoc in Harvard", founded for the purpose of regulating organ transplants.

Society's view of brain death is a cause for concern because it is filled with significant misconceptions that a person will experience suffering during organ harvesting while the body is still alive, even though the EEG appears as a flat-line. Thus, bioethics and scientific advancements prove that society's view is incorrect, demonstrating that one cannot resort to primal feelings to arrive at scientific conclusions.

Taking into account the fact that the declaration of brain death has not modified the concept of death, the common moral perception of this condition is that it only limits a still living body. Furthermore, if it is true that entrusted representatives exist for patients, as in the case of incompetent people protected by the judiciary, is it then possible to also artificially sustain the life of a patient using opposing moral views? This is a controversial subject set on a slippery slope (Singer, 2001).

The characteristics of death in the contemporary world reflect the general movement towards the hospitalization of terminally ill patients, illustrated by the idea of Mirko Grmek: "alta mortalità ad una ad alta morbilità" (Botti, Rufo et al 2002). Consequently, care of terminally ill patients frequently takes place in the hospital, prolonging indefinitely an irreversible condition by resorting to the techniques of resuscitating the patient by feeding, hydrating, and breathing through a machine (Zucker & Zucker 1994). Such efforts increase the period of suffering of the terminally ill. Once terminally ill patients become completely dependent upon the care of healthcare professionals, they lose their self-determination, and nothing can be done to escape useless suffering (Weir, 1986). Physicians and nurses can either distance a patient from imminent death or allow a dignified death that



respects the desires of the ill person when he or she chooses to discontinue care (Kung, Jens, 1995).

The refusal of care is possible in certain countries with laws on "direttive anticipate di trattamento" or a living will (Sansoni, Ingui, Mitello, 2009). A living will, also called an advanced directive, is an explicit directive stating a patient's desire to control his or her end of life care. At any moment in a person's life, a living will can be drafted.

The person records his wishes to receive or refuse care and clinical treatment in the event he or she becomes incompetent, such as in a state of coma. Advanced directives can also delegate a person(s) of trust (family, friend, family physician, and family nurse) as a representative in the event of unexpected personal incompetence (Dimond, 2004). The designated trustee appointed by the patient will receive medical information and participate along with healthcare professionals in the process of planning and making decisions in relation to therapeutic treatment.

The role of the healthcare professionals involved, both physicians and nurses, is to inform the trustee about the patient's health status, to provide education about the state of the patient and the illness, and discuss treatments available in the final stages of his life.

Some controversial subjects to consider for the terminally ill are those of assisted suicide, euthanasia and aggressive treatment.

Assisted suicide may occur when a patient willingly and independently decides to end his life by self-administering a lethal substance prescribed by a physician (Manning, 1998). The restrictions upon physicians when prescribing lethal substances for the purpose of euthanasia brings to attention the topic of the trusting relationship that society has with medical professionals, and their traditional position of sustaining human life (Smith, 1997). Contrastingly, euthanasia is used as an intervention when a physician or medical team decides to administer a lethal substance to end the life of a patient who has expressed a wish to die due to extreme suffering in the terminal phase of illness (Lamb, 1998).

In Italy, the law n.91 of 1/4/99 of the declaration of death and transplant of organs, introduces a conception of silent-assent, in which the citizen can write under conditions of competence his opposition to the collection of his own organs. Despite being both a dynamic and an effective law, it is sometimes not executed.

This matter can be faced, therefore, by way of analyzing two points: first, defining the exact moment in which a person is legally declared dead; and second, once declared dead, if organ donation is possible in the event that there is no documented wish against doing so.

## RIGHTS OF A HUMAN BODY AFTER DEATH

Lecaldano ('07) finds it improper to speak of organ donation for the purpose of transplant after death. In fact, to ask in advance for a person's consent characterizes permission for transplant as a donation, highlighting the discretionary nature of making a choice of moral obligation, because in doing so, the person may save human lives (Lecaldano, 2007).

Jonas also understands the good intentions of a practice that allows saving many human lives, putting into perspective certain aspects of respecting the ownership of one's own body after death. On the principle of declaration of brain death, Jonas agrees substantially on the question of cellular sensibility and wonders if it is equal to that of neuro-physiological perceptions from the patient. The principal and fundamental question Jonas poses is not if the patient is really dead, but, "what to do with him?"

Jonas believes ('97), in fact, that if a person is declared dead, he or she is no longer a patient (Jonas, 1997). Rather, he or she is a cadaver which the law can take possession of. In this case, Jonas is promoting the possibility of organ transplantation after death, pushing the limits of the body as an object among other things, where he would be able to use the body as a reserve for blood, seen through artificial feeding in which the body would be able to continue producing blood, serum, and bone marrow. This philosophy takes him a step further, to the idea that experimentations can be performed on the body in order to verify the toxicity of certain substances on the human organism, thus avoiding submitting living individuals to the dangers of experimentation. The body can also be used to allow aspiring surgeons to perform operations without risks to a patient. In effect, there are no logical motivations to base upon Jonas's theory. Jonas refers to those declared dead yet kept alive as "simulated life", and asks whether or not this body has rights in this condition. What becomes of the dead man after the official declaration of death? If he has the right to his body, what is the answer to the question, "Can society take possession of his organs?" Once again, the question becomes that of an ontological nature. Legislation regards the subject of titular rights as a concept traditionally attributed to human beings. However, it is still not understood if the dead body still has rights (Van Niekerk, 2002).

Therefore, in the contemporary world it is not sufficient to invoke a right to die because this matter is contingent upon imminent death or severe pain that can be defined as "condizione infernale" (Mori, 2002). In this condition, it is possible for a person to invoke a right to his or her own body after death. Jonas firmly believes that a person can be responsible

for his live body as well as his corpse.

From the viewpoint of political philosophy, Jonas speculates whether society can come to some public interest or scientific agreement about the internal organs of a human being after death. In fact, the legitimate social contract has some deceptions on our public actions, even hidden to ourselves. Collectively, morality influences us by directing us to behave a certain way within society towards each other and towards our material possessions. However, between the barriers of the external world and the internal body, all public rights stop existing.

Jonas leaves unresolved a practical matter in theory: the shortage of organs to be transplanted for the many sick waiting for organ donation and the principle of unity that is essential for the survival of society. This reasoning is built upon the issue of individual rights, dismissing the idea that everyone has responsibilities toward society. As a working union, society is represented as a shapeless collection of parts that occasionally find each other, eliminating spontaneity and altruism as seen in the association of free and active agreement (Jonas, 1997).

Other authors believe that the authorization of transplanting organs from a dead body neither depends on the consensus of *de cuius*, nor of the family; rather, from a decision of social character. The understanding of individual will is not taken into consideration, because the spirit of a man remains after death, while the body and organs decay. "Every person becomes *ope legis* and a potential donor" (Hoeftler, 1994).

Also, in respect to autopsy, no one can oppose the necessity of avoiding danger or verifying the cause of death. Another issue to consider is an individual's right to receive organs in the case of serious illness even though he openly opposes donating his organs after death.

From an ethical standpoint, how should one behave in this case? To deny assistance to the seriously sick would seem inhumane, but to encourage these behaviors could promote "free riding", which is harmful for society as a whole.

## CONCLUSION

Human rights and bioethics are western ideas. The typical product of the contemporary west implies: a particular conception of science, a methodological individualism, a model of liberal society, all based on the market economy, as well as constitutional and democratic political structures (Rossi, 2002). These characteristics represent a theoretical breakdown of the relationship between bioethics and human rights.

Furthermore, if these characteristics of western society are considered as the propulsion for development and progress, they fail to remember conditions that influenced the original foundations negatively: the individual's return to privacy; mistrust in science; European immigrants fleeing from oppressive governments; increasing necessity to control economic inequality; and pushing science towards programs and objectives not shared by public opinion (Filene, 1998). To those agonistic and antagonistic factors, there are overlapping situations that could swathe argument in either direction, economic globalization and the need to transfer information to people around the world in real time.

The legal issues of bioethics are characterized by a great universal uncertainty and conflict concerning their influence in every part of the world in relation to all living things, exposing people to new dilemmas (Botti, Rufo, et al 2002). Finally, in a time where individuals are more aware of the consequences on their beliefs, bioethical issues have begun to affect individuals more intimately. Assisted by the contemporary Western world, it is possible to come to certain agreements on great topics of social importance such as the control of what is right and wrong along with the variety of preferences. Therefore, it becomes clear that every person has a fixed moral center that is formed from the person's affiliated and assimilated culture.

Bioethical issues will always provoke endless controversy because they affect the fundamental values that give persons their identity; and since these issues cannot be completely resolved, they instead leave societies with ambiguous answers (Berlinguer, 2000).

With generic rights – the right to a job, education, and a clean environment – conflicts are rare because these rights are positive and desirable values for all, even when these rights are regularly taken for granted and even when tolerance is observed when people are deprived of these rights. However, for human rights linked with bioethics, the situation is more complicated. The exercise or hindrance of any bio-rights provokes reactions even from people who are not involved personally. In a field such as this where so little is actually known, many anxieties and fears are amplified due to the irresponsible management of some of those involved in this technological science.

Contemporary bioethics on the new frontier (Lecaldano, 2002) is a gray area where clear evidence can be found for both opposing positions. This is seen with scientific knowledge as well where issues often step over the boundaries set by written law. Bioethics relies on dialogues where the final solution must be a negotiation through rational discussion and compromise where all sides are understood and taken into consideration.

Consent on a minimal foundation of human rights on which to eventually build an overlapping consensus implies that disagreements among moral systems stem from religious, philosophical, and cultural traditions. To overcome these disagreements means to come to a political compromise. For human rights, consent is achieved democratically, through agreement among States instead of opposing moral systems (Donatelli, 2012).

A part of the problem is the demand to give some laws bioethical positions of profound duality, represented by management of the scientific investigations that, through technology, become an instant part of daily life. We have spoken about the complex relationship between rights and science, the separation of scientific knowledge and common sense, and physiological hindrance of potentialities by conventionalism. The link between the issues and scientific knowledge becomes a matter of bioethical reasoning. Traditionally, when human rights were vindicated, distinguishing good from evil using practical knowledge was not necessary; however, the contemporary world requires the kind of knowledge necessary to understand the various disciplines. Also, excess information is not appropriate when discussing issues of bioethics although it is characteristic of modern society.

Finally, control of scientific research yields to market demand, and society is hesitant and resistant to change or new impositions posed by political authority. We conclude by questioning the politics that control the development of scientific advances to market demand without suffering the consequences of a changed image of man.

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