# Self-Determination, Dignity and End-of-Life Care

## *Regulating Advance Directives in International and Comparative Perspective*

Edited by

Stefania Negri

Queen Mary Studies in International Law

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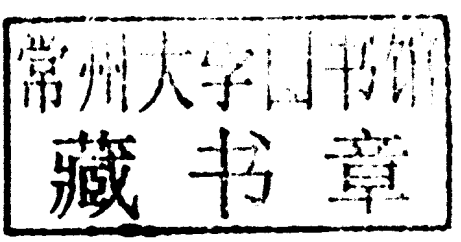


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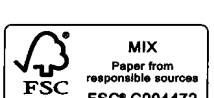


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# FOREWORD

Today, advances in medical care offer more options than ever for the treatment of diseases and the prolongation of life. Many people are now surviving with conditions that were fatal in previous generations. This represents, of course, a very significant progress. After all, the scope of medicine is the fight against disease and death. Yet there are circumstances in which patients themselves do not see advancements in clinical treatment and in life-sustaining technologies as a blessing but rather as a curse. This especially happens when patients are placed in situations of very poor prognosis and are, at the same time, confronted with aggressive medical treatments that appear to be more harmful than helpful.

In modern medical ethics and law it is widely accepted that patients have the right to refuse any kind of medical treatments. Patients' self-determination, which is the foundation of the requirement of informed consent, also includes this possibility, even if such a refusal might shorten patients' life. But what when patients have lost their decision-making capacity due to a condition that is not likely to be reversible (e.g. persistent vegetative state, coma, severe head injury, dementia, etc.)?

At present, an increasing number of people wish to make provisions for such situations by drafting a document that includes their preferences regarding the provision or the withholding of specified treatments (living will), or by empowering a trusted individual to make such decisions on their behalf (lasting power of attorney), or by combining both options. This trend is relatively recent in Europe. Only in the last few years a number of countries are realizing the value in promoting patients' self-determination and enacting specific legislation on advance directives, while others are still reluctant to regulate this issue.

Also the Council of Europe is seriously involved in the establishment of common standards relating to this matter: first, through the adoption of the Biomedicine Convention in 1997, and second, by the development of the Recommendation (2009)11 on "continuing powers of attorney and advance directives for incapacity" in December 2009.

This volume, edited by Professor Stefania Negri (University of Salerno, Italy) has succeeded in bringing together contributors from all around the world to provide a valuable comparative examination of advance directives and of the policy documents relating to them. Part I presents the

issue from the international and common European law perspectives. Part II focuses on the role and validity of advance directives in a number of specific countries. Part III addresses the current debate on advance directives and end-of-life issues that is taking place in the Italian context.

It may be hoped that this book will become a valuable resource to policy-makers and to all those seeking effective strategies for dealing with this new and challenging issue.

Roberto Andorno

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# EDITOR'S PREFACE

This book originates from the results of an international research project on *Bioethics and international law at the intersection of life, death and dignity*, which was carried out in the framework of the research activities of the *Observatory on Human Rights: Bioethics, Health, Environment*, a network of academic experts promoting international cooperation in teaching and research between the Faculty of Law of the University of Salerno and foreign academic institutions.

The volume gathers the contributions of leading academics and lawyers engaged in the fields of bioethics and biolaw, health and medical law, and human rights law. By providing an interdisciplinary reading of advance directives against the background of European and International Law and jurisprudence, this book aims to offer new insights into the most hotly debated legal issues surrounding the theme of dignity and autonomy at the end of life, including euthanasia and assisted suicide, advance refusal of life-saving and life-sustaining treatments, the rights of the terminally ill and dying patients, the right to die with dignity.

Focus on the relevant international legal framework represents the distinguishing feature of this work as compared to much of the existing literature on the subject, while cross-cultural perspectives from Europe, the Americas, Australia and China offer a comprehensive, comparative analysis of legal approaches to end-of-life decision-making and care in a considerable number of selected countries, also giving an up-to-date account of recent developments in domestic legislation and case-law. Special attention is devoted to the Italian legal system and the ongoing scholarly and political discussion on the Italian Draft Bill entitled "Dispositions in matter of therapeutic alliance, informed consent and advance treatment directives", which was first passed by the Senate of the Italian Republic on 29 March 2009, later approved with amendments by the Chamber of Deputies on 12 July 2011, and currently awaiting final adoption.

Of course, this endeavour would not have been possible without the important contribution of all the Authors who have kindly agreed to put their expertise at the disposal of this initiative. I owe a debt of gratitude to all of them.

I am particularly indebted to Professor Roberto Andorno for his invaluable and continued support and advice and to my colleague Professor

Vitulia Ivone for her friendly and unconditional support offered throughout the whole implementation of this project. I also wish to appreciatively acknowledge the kind supervision of Professor Penney Lewis over the English translation of the Italian Draft Bill which is reproduced as an Annex to the book.

Last but not least, I would like to thank very warmly Professor Malgosia Fitzmaurice and Brill for the inclusion of this volume in the prestigious series *Queen Mary Studies in International Law*.

Finally, I personally dedicate this book to the memory of my beloved father and to all the victims of incurable diseases.

Stefania Negri

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# HUMAN DIGNITY: FROM CORNERSTONE IN INTERNATIONAL HUMAN RIGHTS LAW TO CORNERSTONE IN INTERNATIONAL BIOLAW?

*Angela Di Stasi**

## I. The "End-of-Life" Choices and Human Dignity

It is indubitable that the new frontiers of (Bioethics and) Biolaw are characterized by a strong need for normativization[1] implying a difficult definition of the limits to be imposed on the so-called sovereignty of the individual over his body.[2] The scientific and technological process, showing the extraordinary potentials that the new sciences have provided to man, has caused a sort of "eagerness of lawfulness" in relation to several needs of the human beings, which are halfway between life and death[3] and may influence the process of enlargement of the international "catalogues" of human rights.[4]

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[1] At least according to the prevailing approach of the European doctrine which includes those rights pertaining to Bioethics and Life Sciences among the so called "rights of third generation".

[2] In the Italian legal literature see, among others, Andrea Bompiani, Adriana Loreti Beghé and Luca Marini, *Bioetica e diritti dell'uomo nella prospettiva del diritto intemazionale e comunitario* (Torino, 2001); Nerina Boschiero (ed.), *Bioetica e biotecnologie nel diritto internazionale e comunitario* (Torino, 2006); Francesco Francioni (ed.), *Biotechnologies and International Human Rights* (Oxford, 2007). See, particularly Maria Rita Saulle, *Bioetica (diritto internazionale)*, in *Enciclopedia del diritto (Aggiornamento)* (Milano, 1997), pp. 252–264. For an interdisciplinary approach, see the huge treatise directed by Stefano Rodotà and Paolo Zatti, *Trattato di biodiritto*, and with regard to the subject of this chapter see especially volume V, edited by Rosario Ferrara, *Salute e Sanità* (Milano, 2010).

[3] It is our translation of that "insistent eagerness of lawfulness" referred to by Salvatore Amato, "Diritto e corpo: il soggetto incarnato", 29 *Democrazia e diritto* (1988), pp. 63–92, at 69. It is then one of the aspects of the wider problem about "what is the role of law in the age of technique". See on this point a well known passage taken from the interview to M. Heidegger published in *Spiegel* on September 23rd, 1966 which is referred to by Caterina Resta, *Stato mondiale e nomos della terra* (Roma, 1999). For an investigation of this subject from the constitutional point of view, see, with special reference to euthanasia, Chiara Tripodina, *Il diritto nell'età della tecnica. Il caso dell'eutanasia* (Napoli, 2004), especially the Introduction. With specific reference to the living will and the proxy consent see the same text at p. 103 ff.

[4] As it is well known, the borders of the category of human rights have undergone significant reconsiderations in the context of a marked relativization in a space-time sense.

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With specific reference to the "End-of-life" choices and with specific regard to the debate on Advance Directives Regulations, such call for normativization could not but have to do with a search for a more ore less "shared" social consensus. Lack of such consensus delays or hinders the legislator's activity,[5] as it is shown—just like it happens in other legal systems—by the difficult course followed by the Italian Draft Bill concerning "Disposizioni in materia di alleanza terapeutica, di consenso informato e di dichiarazioni anticipate di trattamento", which has been approved by the Senate and recently amended by the Chamber of Deputies.[6]

As it is well known, European States share a substantially uniform position as to the exact definition of the notion of death, which is considered as brain death.[7] However, the aspiration of individuals (and of their relatives) to orient "End-of-life" choices by extending the decision-making autonomy even to a such really delicate moment of a man's existence, does not find any unified solution either in national or in international and European legal systems.[8] This lack of unicity is the consequence of the

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Once the rights of the individualistic tradition of the so called first generation (i.e. civil and political rights) have been recognized, those of the "socialist" tradition of the so called second generation (i.e. economic, social and cultural rights) have been added, as well as further sub-categories, among which there is first of all the one concerning the rights of the so called third (and fourth) generation. See, in particular, Norberto Bobbio, *L'età dei diritti* (Bologna, 1992), p. 27 ff., and Paolo Barile, "Nuovi diritti e libertà fondamentali", in AA.VV., *Nuovi diritti dell'età tecnologica* (*Atti del Convegno di Roma 5–6 maggio 1991*) (Milano, 1991), p. 36. On "human rights between universalism, regionalisms and multiplicity of constitutions" we refer to Angela Di Stasi, *Diritti umani e sicurezza regionale. Il «sistema» europeo* (Napoli, 2011), particularly at p. 125 and the following, as well as by the same author, *Il sistema americano dei diritti umani. Circolazione e mutamento di una international legal tradition* (Torino, 2004), particularly the introduction.

[5] On shared or "by intersection" consent see Raffaele Prodromo, "Etica di fine vita: é possibile un consenso condiviso sulle direttive anticipate?", in Francesco Lucrezi and Francesco Mancuso (eds.), *Diritto e vita* (Catanzaro, 2010), pp. 179–195 referring to Rawls (at 180). On the necessity that the questions raised by the developments of biology and medicine can be the subject of a public debate, see Article 28 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine (see *below*). It provides that: "Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light, in particular, of relevant medical, social, economic, ethical and legal implications, and that their possible application is made the subject of appropriate consultation".

[6] The Bill, which has been approved by the Chamber of Deputies on 13 July 2011, outlines a discipline which is more restrictive than the one adopted by other European countries, leaving vital treatments out of the range of those wishes that the individual concerned may express in the so called leaving will.

[7] See art. 1 of the law No. 578 dated 29 December 1993, concerning "Norme per l'accertamento e la certificazione di morte".

[8] It is shown by some debated judgements. See, recently, the judgement dated 25 June 2010 issued by the German Supreme Court (Bundesgerichtshof), and the comments by

necessary collocation of such question within the wider context of the respect of the "sacred nature" of life, both in the light of the moral Hebrew-Christian tradition and of the laic idea of the "sacred character" of biological life.

It is undoubted that Advance Directives at the "End of life" affect those fundamental rights and values of the individual which can potentially be even opposed to each other. Among others there are: the prohibition of degrading treatment, the right to life, the right to privacy and the right to make individual choices (self-determination). In particular they state a suitable consideration of free and informed consent, a fundamental principle concerning health protection whose sources have by now overcome the borders of the national legal system as also witnessed by the Italian Constitutional Court.[9]

How is it possible to strike a fair balance within the context of a right which is defined as "hard"?[10]

The purpose of this work is to examine the role that human dignity, in its bio-ethical and bio-juridical implications, can play between

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Cristina Campiglio, "Decisioni di fine vita: la sentenza del *Bundesgerichtshof* nel contesto della prassi europea", 4 *Diritti umani e Diritto internazionale* (2010), pp. 543–553 and Giorgio Resta, "Dignità e autodeterminazione nelle scelte di fine vita: il *Bundesgerichtshof* espande la tutela dei diritti fondamentali", 4 *Diritti umani e Diritto internazionale* (2010), pp. 566–574. See, as regards the normative solutions experimented in other Countries, the dossier no. 104/2009 drawn up by the Servizio studi del Senato della Repubblica (available online at http://www.senato.it) and entitled "La disciplina sul testamento biologico in alcuni Paesi (Francia, Germania, Regno Unito, Spagna e Stati Uniti)". See Roberto Andorno, Nikola Biller-Andorno, and Susanne Brauer, "Advance Health Care Directives: Towards a Coordinated European Policy", 16 *European Journal of Human Rights* (2009), pp. 207–227. As it is well known, among the European countries, The Netherlands were the first country to legalize assisted suicide and euthanasia (law dated April 12th 2001, in force from April 1st 2002).

[9] See Constitutional Court, Judgement No. 438 of 15 December 2008, available online at http://www.cortecostituzionale.it. In this judgement (drawn up by Judge Saulle) the need for the patient's informed consent to medical treatments is traced not only by referring to domestic sources, but also according to Article 24 of the Convention on the Rights of the Child, of Article 5 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, of Article 3 of the Charter of Fundamental Rights of the European Union. On free and informed consent see a wide account in the chapter by Stefania Negri, "The Right to Informed Consent at the Convergence of International Biolaw and International Human Rights Law", in this book.

[10] This unusual term is used by Stefano Rodotà, "Dal soggetto alla persona. Trasformazioni di una categoria giuridica", *Filosofia politica* (2007), pp. 365–378, where (at 375) the term "hard" right stands for a right which "does not send life off from itself, but tries to penetrate it, a right which does not fix an unchangeable rule but outlines a procedure for the continuous and joint involvement of different individuals" (our translation from the original into English).

self-determination and end-of-life care.[11] The Human Rights approach—which is here adopted—is based on the conviction of the necessary interface between Bioethics and Human Rights, considering that bio-medical issues, when they deal with fundamental values and rights, not only concern the bio-medical field but also require the conceptual support of International Biolaw. It states the overcoming of oppositions between the progress of science and knowledge and the protection of human rights; it also identifies, in the existing and coming instruments of International Biolaw, the attitude to generate a dynamic process giving an increasing role to individuals in the international society.[12]

In the by now recurring debate on Advance Directives—which starting from the Natural Death Act[13] has found in international instruments a variety of reference sources, even if sometimes only indirectly—does the defence of human dignity represent a starting point or a point of arrival?

From being an ethical and pre-juridical value, a principle informing catalogues and deontological codes,[14] it aims more and more at assuming,

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[11] Any attempts for a historical-philosophical reconstruction of the concept of human dignity clearly lie beyond the purpose of this chapter. On the relationship between dignity and freedom we limit ourselves to mention the perspectives outlined by Immanuel Kant (see in *Fondazione della metafisica dei costumi*, Italian translation by Vittorio Mathieu, Milano, 1944, pp. 144–145), according to whom human dignity resides in personal autonomy and in its promotion and respect for the individual's dignity is respect for the individual's autonomy.

[12] We refer to an international society as universal society where "a continuous relationship of material and spiritual exchanges exists, through which the whole mankind shows itself to be a society that civil development tends to make more intense" or a society that identifies itself "in order to find its own *raison d'être* or to portrait its *way of being* according to the existence of independent or sovereign entities" and therefore international society or community *in its own sense* (our translation from the original into English). Then the classical realistic approach of Rolando Quadri, *Diritto Internazionale Pubblico* (Napoli, 1968), V ed., p. 19. See the enlightened reflections by Piero Ziccardi, (heading) *Diritto internazionale*, in *Enciclopedia del Diritto* (Milano, 1964), vol. XII, p. 1004 where, with reference to a pluralistic conception, the distinguished Author defines a legal system as "any environment of social coexistence, both among individuals, and groups of already associated individuals, admitting their unlimited multiplicity", and also by the same author, in *Diritto internazionale* (Milano, 1962), p. 79 where the existence of "a universal, naturally juridical community, the norms of which are meant both for single individuals and States" (our translation from the original into English) is emphasized. About the mixed international community, as society of States and individuals, see particularly Umberto Leanza and Ida Caracciolo, *Il diritto internazionale: diritto per gli Stati e diritto per gli individui*, Parte generale (Torino, 2008), II ed., with specific reference to chapter 4: "Oltre la soggettività internazionale: i beneficiari delle norme internazionali".

[13] Adopted in the State of California by Law 3060 of 1976.

[14] See, inter alia, art. 39 of the Deontological Code of Medical Profession of 2006, that consecrates the absolute respect for the person's "dignity, freedom and autonomy".

in International and European Law,[15] a juridical value, as basis and source of the respect of all (or almost all) human rights.

Within the international community, the emergence of new values linked to the respect of human dignity and their submission to States' compliance, in terms not only of *facere* but also of *non facere* obligations, has helped the more general evolution of the principle of non-intervention and the progressive erosion of the State's reserved domain[16] in the field of human rights protection.[17] Moreover, if it is indubitable that the categories of human rights, both of internal and international source, represent an *evolving list*[18] continuously subject to modifications according to

[15] There is an extensive legal literature on this subject. See the publications existing since the '80s, by Oscar Schachter, "Human Dignity as Normative Concept", 77 *The American Journal of International Law* (1983), pp.103–110 and David Feldman, "Human Dignity as a Legal Value", *Public Law* (1999), pp. 682–702. See the wide references included, among others, in Deryck Beyleveld and Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford, 2001); David Kretzmer and Eckart Klein (eds.), *The Concept of Human Dignity in Human Rights Discourse* (The Hague, 2002); Matthias Kettner (ed.), *Biomedizin und Menschenwürde* (Frankfurt am Main, 2004); Mariana Blengio Valdés, *El derecho al reconocimiento de la dignidad umana* (Montevideo, 2007). This process concerns, of course, several sectors of the legal system. See above all, Luigi Manconi and Roberta Dameno (eds.), *Dignità nel morire* (Milano, 2003) as well as Pier Paolo Portinaro, "La dignità dell'uomo messa a dura prova", in A. Argiroffi, P. Becchi and D. Anselmo (eds.), *Colloqui sulla dignità umana. Atti del Convegno internazionale*, Palermo, ottobre 2007 (Roma, 2008), p. 221 when, by drawing on Häberle, he affirms that "human dignity is the anthropological-cultural basis for a constitutional State" (our translation from the original into English). The idea of the equal dignity of all human beings can be found, among others, in the French Constitution dating back to 1789. In the Italian Constitution the reference to human dignity appears in the first paragraph of art. 3 as "equal social dignity" of citizens and in the second paragraph of art. 41 as limit to the freedom of private economic enterprise which "cannot be carried out ... in a way that may cause damage ... to human dignity". But the reference to human dignity as the fundamental value of the whole legal system appears in several other Constitutions (see e.g. the Canadian, Danish, Portuguese, Swedish, Swiss, and the American Constitutions). Remember the provision of the German Constitution which in art. 1 states: "Human dignity is inviolable. To respect and protect it is a duty of each power of the State".

[16] See art. 2, para. 7, of the United Nations Charter.

[17] Fallen within the province of International Law, human rights have "overcome national borders and have become a problem of the international community". See in this sense Claudio Zanghì, *Diritti dell'uomo (protezione internazionale dei)*, in *Enciclopedia giuridica Treccani*, vol. XI, pp. 1–9, particularly p. 1, followed by Jacques Mourgeon (in *Les droits de l'Homme*, Paris, 1996, p. 75) who affirms: "l'affirmation internationale des droits a cessé d'être balbutiante pour être abondante et nette".

[18] It does not close the "catalogue" of human rights, as the very new rights consecrated in a variety of international instruments issued over the last year (from the right to inhabiting, to the right of protection of the young as regards compulsory education in the social Charter revised by the Council of Europe, from the prohibition of eugenic practices to the right to the protection of personal data in the Charter of Fundamental Rights of the European Union, joining the rights already codified some decennia before). It is not

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