Universal Human Rights and End-of-Life Care

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Abstract Universal human rights like dignity, physical integrity, health, and freedom from torture or inhuman treatment have special relevance to the end-of-life debate and form the basis on which is built the emergence of new biorights. Over the last decades, such rights as the right to informed consent, the right to die with dignity, and the right not to suffer have gained increasing importance in the international legal order. These rights have also contributed to the setting of generally accepted human rights standards that offer authoritative guidance to both domestic legislators and judges. This is particularly important in light of the fact that the regulation of legal questions surrounding the end of life is quite different in domestic jurisdictions, even in a rather homogeneous and integrated region like Europe, where the relevant legal frameworks still differ according to cultural, ideological, and religious diversities and the more or less liberal attitude adopted by individual States, as it is the case with Germany and Italy. Moving from the above considerations, this chapter will discuss some critical aspects of end-of-life decision-making and care within the international human rights framework, with a view to disclosing the relevant legal standards and obligations that may serve as general reference and starting points for a comparison between national jurisdictions. This investigation could also open up the door to a more specific debate on the consistency of domestic legislation on end-of-life issues with international (biomedical and human rights) law.

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1 The Relevance of International Human Rights Law to the Legal Regulation of Ethical Issues Surrounding the End of Life

End-of-life care and advance care planning require a range of extremely sensitive decisions that deeply affect the patients' autonomy and their personal conception of life, death, and dignity.[1] Such decisions touch upon highly debated ethical dilemmas and raise topical medico-legal questions, including the definition of the boundaries of informed consent, the ethics and efficacy of aggressive or futile medical treatments, the withholding or withdrawing of life-sustaining measures, access to palliative care, and the permissibility of euthanasia or assisted suicide.

Legal questions related to these and other key issues concerning end-of-life decision-making and care are regulated quite differently in domestic law, if not regulated at all. This is mainly due to cultural, ideological, and religious diversities and the ensuing pluralistic approach adopted by States to moral, social, and legal values. At the international level—despite a quest for universal bioethical standards

[1] Advance care planning is a voluntary process of discussion about future care between an individual and their care providers, which might include the individual's concerns and wishes, their important values or personal goals for care; their understanding about their illness and prognosis; their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

that may overcome the diversities inherent in human societies[2]—bioethically-sensitive issues related to the end of life are not specifically regulated. This is one of the evident limits of the emerging international law of bioethics, which has not so far succeeded in expressing those commonly shared values and globally accepted standards necessary for a possible harmonisation of domestic legislations in this field. In fact, although a certain degree of rapprochement between States was achieved in certain areas of biomedical practice and research, considerable differences still exist in their approach to ethico-legal questions concerning, for example, the patients' will to terminate their life, the problematic qualification and efficacy of certain life-sustaining measures (such as artificial nutrition and hydration), physician conscientious objection, and so on. Such a lack of generalised consensus resulted in a noticeable lacuna in both the Universal Declaration on Bioethics and Human Rights[3] and the Oviedo Convention on Human Rights and Biomedicine,[4] both lacking any relevant disposition in this respect.

Furthermore, it is remarkable that some legal questions concerning the end of life are regulated quite differently even in a rather homogeneous and integrated region like Europe, where the relevant legal frameworks still differ substantially according to the more or less liberal attitude adopted by States and their inclination to adopt restrictive or permissive legislations. In Germany and Italy, for example, it is evident that the relevant domestic norms testify to a very diverse approach to the legal regulation of end-of-life issues from both the civil and the criminal law perspectives, as this book will show.

Moving from these considerations, this chapter will discuss some critical issues concerning end-of-life care and decision-making within the international human rights framework, with a view to disclosing those legal standards and State obligations stemming from human rights law that may serve as general reference and starting points for a comparison between domestic legal orders. In short, it aims to assess whether in the three core domains where the comparative analysis between German and Italian law is developed in the chapters that follow (patient autonomy and advance care planning, euthanasia, and palliative care) it is possible to affirm that some relevant international human rights standards exist, whether new rights have emerged at the general level and to what extent they pose international

[2] On the issue whether "universal bioethical standards" can be translated into legal norms, see Ida (2004), pp. 376–377. According to this Author, "Although bioethics legislation exists at the national level … and at the regional level …, there are no international or universal legal rules. The diversity of values within each community is the main reason for this absence of universal legal instruments" (pp. 377–378).

[3] Unesco, Universal Declaration on Bioethics and Human Rights, 19 October 2005.

[4] Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4 April 1997, ETS No. 164, entered into force on 1 December 1999 (hereinafter 'Oviedo Convention'). The problems left unsolved by the Convention include the definition of the boundaries of patient autonomy, the refusal of treatments, and euthanasia: see Taupitz (2002b), p. 5.

obligations on States, and whether the relevant international remedies offer a better protection than the one that is available under domestic law. This investigation could also open up the door to a more specific debate on the compatibility of domestic legislation on end-of-life issues with international (biomedical and human rights) law.

The reflections that follow will build on two basic assumptions.

The first is the idea that international human rights law at the universal level can be considered quite "neutral", in the sense that it does not suffer—at least not to a considerable extent—from the influence that ideological, political, and religious factors exert on domestic legislations. Based on the recognition of universal values, generally agreed standards, and internationally acknowledged rights, it can offer a reliable and objective term of reference for domestic legislation, thus guiding legislators in the passing of statutes that do not privilege any dominant ethics (be it laic, Catholic, or others). Moreover, general principles and minimum standards set at the international level can also lend help to national judges when they interpret domestic provisions extensively and evolutively, with a view to making the law "live" and have margins of manoeuvre in its application to the new bioethical dilemmas.[5] Therefore, even if unable to achieve real harmonisation, the human rights standards affirmed and accepted at the universal level can nonetheless realise a certain degree of rapprochement between State legislations around commonly shared values and principles.

The second basic assumption refers to the asserted derivation of biomedical law from human rights law: the most influential literature on the subject insists on the concept that international instruments of biolaw are the "natural extension" of human rights instruments to life sciences and biomedicine.[6] Moreover, according to a commonly shared scholarly view, it is most opportune that biolaw be conveyed within the framework of human rights law, so that human rights and fundamental freedoms may find appropriate tools of legal protection from the challenges of medical technological progress.[7] In this respect, it is often pointed out that all major human rights treaties contain some guarantees related to the protection of fundamental rights in patient care[8] and that, despite the fact that only some of these conventions have been almost universally ratified, they all set minimum standards

[5] In this sense, see Maljean-Dubois (2000), p. 92; Tancredi (2004) pp. 408–409; Campiglio (2012), p. 112.

[6] See Byk (1999); Maljean-Dubois (2000), p. 93; Boschiero (2006), p. 13, 15; Mathieu (2006), p. 85; Andorno (2011), p. 75.

[7] Loreti Beghè and Marini (2001), p. 44; Andorno (2002), p. 960; Boschiero (2006), p. 14.

[8] See Andorno (2005b), p. 133. The Author states that the essence of some principles enunciated by the Oviedo Convention were already framed in more general terms in previous human rights treaties.

that can be considered at least morally binding also on non-Party States.[9] Moreover, the link between international human rights law and biomedical law is ever more apparent in the wording of the majority of biolaw instruments, which regularly refer to the key human rights instruments and endorse them as foundational framework for "supplements" of protection urged by the "potential implications of scientific actions" and the need to shield the individual from any threat resulting from the developments in biology and medicine.[10]

Following this line of thought, this chapter will especially focus on universal human rights—such as life, health, human dignity, physical integrity, freedom from torture—in order to attest to the relevance of international human rights law, and the prominence of universally accepted human rights standards, to the legal regulation of ethical dilemmas surrounding the end of life.

2 Advance Care Planning, Patient Autonomy, and the Right to Informed Consent

Patient autonomy encompasses the right to participate in advance care planning and to make decisions for the future. Therefore, respect for self-determination implies respect for the patients' right to express in advance their preferences as to the treatment options to be performed in case they lose temporarily or permanently their capacity to take part in medical decision-making. It falls within the purview of patient autonomy—provided that we refer to adults who understand the consequences of their choices—to refuse certain medical treatments and interventions, including those that may be administered at the end of life, and to choose that death come naturally.

Advance directives are the legal instruments designed to enable patients to retain decisional authority even in cases of incompetence; they provide a viable alternative to contemporaneous decisions and serve the scope of protecting precedent

[9] For example, the scope of the Oviedo Convention has thoroughly been debated in legal literature also with a view to assessing whether it can offer a pattern for global regulation of bioethical issues: see especially Taupitz (2002b). On the one hand, it is contended that the Convention seeks to promote the universal dimension of the biorights it enunciates and it is also remarked that the participation of Canada, the USA, Japan, Australia, the European Union, and the Holy See to its negotiation undoubtedly confers an added value to the alleged "universality" of its rules (see e.g. Millns (2007), p. 78; Gadd (2005); Boschiero (2006), p. 51). On the other hand, it is denied any "universal aspiration", both because it is substantially a regional treaty with a very low rate of ratification and because its restrictive provisions make it unlikely that it will ever be ratified by third States (on this latter point, see Riedel (2002), pp. 37–38).

[10] The Preambles to the Oviedo Convention and to the Unesco Universal Declarations both "solemnly recall [. . .] the attachment to the universal principles of human rights". See also the Explanatory Report to the Oviedo Convention, paragraphs 11–13.

autonomy.[11] Except for a specific and limited reference to the patient's "previously expressed wishes" to be found in Article 9 of the Oviedo Convention,[12] advance directives in general are not regulated in international law and the legal effects they have in domestic law vary from one jurisdiction to another.[13] In order to assess whether a generally accepted standard has emerged so far, it is necessary to focus on the principle of informed consent, which is considered the very foundation of the "new ethos of patient autonomy".[14]

2.1 The Doctrine of Informed Consent

Informed consent is both a core principle of medical ethics and a well-established fundamental rule of biomedical law. It has gained such remarkable relevance in the international legal framework that virtually all international agreements and declarations on ethical and legal standards in medicine and biomedical research endorse it as a basic rule.[15]

After the famous and most cited opinion delivered by Justice Benjamin Cardozo in the landmark Schloendorff case, according to which "every human being of adult years and sound mind has a right to determine what shall be done with his own body",[16] and the first significant enunciation in the Nuremberg Code,[17] informed

[11] Advance decision-making can take the form of either instructional directives, also known as living wills (providing specific instructions or setting out general principles to be followed for health care to be delivered when decision-making capacity has been lost), or proxy directives, also known as durable powers of attorney for health care (naming surrogate decision-makers such as proxies).

[12] Article 9 of the Oviedo Convention reads "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account". On this provision, see the legal analysis carried out in this book in the chapter authored by Di Stasi and Palladino (2013).

[13] See Negri (2011a), especially Part II: Advance directives, end-of-life decision-making, and euthanasia in comparative legal perspective.

[14] The quote is from Wear (1992), Chapter two. The body of literature on informed consent is really vast. See, ex plurimis, Faden et al. (1986); Van Oosten (1991); Switankowsky (1998); Berg et al. (2001); Manson and O'Neill (2007); Casonato (2009); Maclean (2009). For deeper insights on the status of informed consent under international law, see Negri (2011c); Negri (2012).

[15] Kollek (2009), p. 124.

[16] Opinion of Justice Benjamin Cardozo, Schloendorff v. The Society of New York Hospitals (105 N.E. 92), Court of Appeals of New York, 14 April 1914.

[17] The Nuremberg Code (1947) was printed in Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10, Washington, 1949, vol. 2, pp. 181–182. The first and best known provision of the Nuremberg Code stated: "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension

consent has enjoyed growing widespread consensus in both 'hard' and 'soft' law and has gained over time broader scope.[18]

In 1949, the World Medical Association recognised the 'right' of competent patients to accept or refuse treatment in its International Code of Medical Ethics[19] and later upheld the rule of informed consent both in the Helsinki Declaration on Ethical Principles for Medical Research (mentioning both the right to refuse to participate in research and the right to withdraw a previously expressed consent)[20] and in the Lisbon Declaration on the Rights of the Patient (where informed consent is subsumed under the right to self-determination).[21]

Turning to the legal instruments adopted by the most relevant international organisations, it is necessary to recall, first and foremost, the WHO Declaration on the Promotion of Patients' Rights in Europe of 1994,[22] the Council of Europe's Convention on Human Rights and Biomedicine of 1997 and its Additional Protocols,[23] as well as the Unesco Universal Declarations on the Human Genome and Human Rights of 1997 and on Bioethics and Human Rights of 2005.[24] To these documents it is also worth adding the WHO Guidelines for Good Clinical

of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. . . ." Among the several relevant contributions, see Weindling (2004).

[18] A collection of the relevant texts is reported in den Exter (2011).

[19] WMA, International Code of Medical Ethics, adopted by the 3rd General Assembly of the World Medical Association, London, October 1949, as amended in 1968, 1983 and 2006.

[20] WMA, Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects, adopted by the 18th World Medical Assembly, Helsinki, June 1964, as subsequently amended and revised up to October 2008.

[21] WMA, Declaration on the Rights of the Patient, adopted by the 34th World Medical Assembly, Lisbon, September/October 1981, and amended by the 47th WMA General Assembly Bali, Indonesia, September 1995.

[22] WHO/EURO, European Consultation on the Rights of Patients, Amsterdam 28–30 March 1994, A Declaration on the Promotion of Patients' Rights in Europe, ICP/HLE 121, 28 June 1994 (hereinafter Amsterdam Declaration).

[23] See Chapter II of the Oviedo Convention; see also Articles 13, 14 and 17 of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, Strasbourg, 24 January 2002, ETS No. 186, entered into force on 1 May 2006; Chapters IV and V of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, Strasbourg, 25 January 2005, ETS No. 195, entered into force on 1 September 2007; Articles 9 to 15 of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, Strasbourg, 27 November 2008, ETS No. 203, not yet in force.

[24] See Article 5 of the Universal Declaration on the Human Genome and Human Rights, 11 November 1997, and Articles 6 and 7 of the Universal Declaration on Bioethics and Human Rights, 19 October 2005. As far as the collection, use and storage of biological samples are concerned, see the Unesco International Declaration on Human Genetic Data, 16 October 2003, in particular Articles 8, 9 and 16.

Practice,[25] the International Ethical Guidelines for Biomedical Research Involving Human Subjects prepared by the WHO in collaboration with the Council for International Organizations of Medical Sciences,[26] and at regional level, the European Union Clinical Trials Directive of 2001.[27]

In light of the above-mentioned instruments, it is indisputable that the doctrine of informed consent is today widely acknowledged as the expression of one of the basic principles of international biolaw, serving as the cornerstone for the protection of the fundamental rights to physical integrity and self-determination in every field of medical intervention. In fact, according to its generally recognised scope, informed consent provides that any preventive, diagnostic, and therapeutic medical intervention, as well as any scientific research involving human subjects, may only be performed after the person concerned has given prior, free, and informed consent based on adequate information. This implies that the patient's autonomous decision to accept or refuse to undergo a medical treatment, or to take part in scientific research, has to meet some specific requirements: the person must have legal capacity to give consent and must also be conscious and fully competent; consent must result from a decision-making process devoid of any element of force, fraud, deceit, duress, threat, or any other form of constraint or coercion. Moreover, consent must be based on the appropriate disclosure to the patient, by the responsible healthcare professional, of adequate and understandable information concerning the diagnostic assessment, purpose, method, likely duration, expected benefit, and chances of success of the proposed treatment; alternative modes of treatment, including those less intrusive; possible pain or discomfort, risks and side effects of the proposed treatment; chances and risks associated with lack of treatment. In this sense, what is called "genuine consent"[28] represents the very foundation of legitimacy for any medical treatment, so much so that interventions and care provided without prior consent, even if administered in the patient's best interest, may be qualified as illegal 'bodily assaults' and may trigger both civil and criminal liability of health care providers.[29]

[25] WHO, Guidelines for Good Clinical Practice for Trials on Pharmaceutical Products (Geneva, 1995). See also the UN Special Rapporteur's recommendations as formulated in his Report containing the Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines (U.N. Doc. A/63/263, 11 August 2008, paragraphs 21–22).

[26] CIOMS-WHO, International Ethical Guidelines for Biomedical Research Involving Human Subjects (Geneva, 2002), Guideline 4, p. 32.

[27] Directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use, Official Journal of the European Communities, L 121/34, 1 May 2001.

[28] On the concepts of 'genuine consent' or 'understood consent', see Bhutta (2004), pp. 773–774.

[29] See Justice Cardozo in Schloendorff v. Society of New York Hospital, supra note 16: "a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages".

Only a few derogations to the above-mentioned rules are allowed for compelling reasons or in particular situations and in respect of vulnerable patients,[30] that is to say in case of medical emergency,[31] de facto incapacity (e.g. patients who have become incompetent in consequence of an accident or patients in a state of coma), reduced capacity of understanding (e.g. adults with mental disorders[32]), or limited legal capacity (minors and incapacitated adults). In such circumstances, informed consent is provided by a legal representative (guardian or proxy) with the association to the decision-making process of the person concerned and his active participation to the fullest extent that his capacity allows.[33] However, when a legal representative is appointed as substitute decision-maker, an intervention in case of urgent need can be performed whenever there is no possibility to obtain the representative's consent,[34] and if the legal representative refuses consent to an intervention that the physician deems appropriate and useful in the best interest of the patient, it is necessary to resort to a court or some form of arbitration of an independent body for super partes decision.[35] Moreover, according to well-established standards, whenever the patient is unable to give consent and there is no legal representative or proxy, appropriate measures should be taken to provide for a substitute decision-making process (for example, an independent body provided for by law), taking into account what is known and, to the greatest possible extent, what may be presumed about the wishes of the patient.[36]

In respect to derogations from the basic rule of informed consent, it is remarkable that according to international (hard and soft) biolaw such exceptions are admitted solely when provided by law, in accordance with ethical and legal standards adopted by States, strictly for "compelling reasons within the bounds of public international

[30] See Selinger (2009). It should be noted that, consistently with the exceptions stated in Articles 6 to 8, the Oviedo Convention does not include Article 5 among those non-derogable dispositions mentioned in Article 26, paragraph 2, while it only provides that no restrictions be placed on its protective provisions contained in Article 17, concerning persons not able to consent to research.

[31] See Article 8 of the Oviedo Convention and paragraphs 56–58 of the Explanatory report; see also Amsterdam Declaration, paragraphs 3.4, 3.6, 3.7.

[32] See Article 7 of the Oviedo Convention; Principle 11 of the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, General Assembly Resolution 46/119 of 17 December 1991; Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities, Report of the Secretary-General, U.N. Doc. A/58/181, 24 July 2003; Report of Paul Hunt, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, U.N. Doc. E/CN.4/2005/51, 11 February 2005 (hereinafter 'Report 2005').

[33] See Article 6 of the Oviedo Convention and the Amsterdam Declaration, paragraph 3.5.

[34] Amsterdam Declaration, paragraph 3.4.

[35] Amsterdam Declaration, paragraph 3.6.

[36] Amsterdam Declaration, paragraph 3.7; see also Explanatory report to the Oviedo Convention, paragraph 57.

law" and subject to compliance with international human rights law.[37] These important caveats, included in the Oviedo Convention,[38] in the Unesco Declarations, as well as in the resolutions of the United Nations Commission on Human Rights and of the Committee of Ministers of the Council of Europe,[39] recall very closely the pattern of lawful limitations adopted within conventional human rights regimes[40] and lend support to the argument that informed consent is a rule grounded in international law, especially human rights law, just as much as it is in bioethics and medical law.

2.2 Informed Consent and Universal Human Rights

2.2.1 Informed Consent and the Right to Physical Integrity

Although it is expressly enunciated only in a few human rights conventions, the right to bodily integrity is a well-established fundamental right protecting the universal values of the dignity and inviolability of the human being. It is considered as an element of the rights to the security of the person and to privacy and, above all, of the right to be free from torture and from cruel, inhuman, and degrading treatment. In this sense, its main legal sources at the universal level are Article 5 of the Universal Declaration of Human Rights and Article 7 of the International Covenant on Civil and Political Rights (ICCPR). This latter provision, which is aimed at protecting both the dignity and the psychophysical integrity of the individual,[41] specifies that no medical

[37] See Article 9 of the Universal Declaration on the Human Genome and Article 6 of the Universal Declaration on Bioethics and Human Rights. According to Article 27 of the latter, such compelling reasons may include the need to protect public safety and public health, a situation that finds application in Article 23, paragraph 3, and Article 31, paragraph 2, of the International Health Regulations (2005), legitimising States to apply health measures to travellers, including compulsory examination and vaccination, when there is evidence of an imminent public health risk. However, it is interesting to note that the protection afforded by the International Covenant on Civil and Political Rights under Article 7 is even stricter than the one guaranteed by the norms of international biolaw, since that provision allows no derogations or limitation, not even in times of emergency (Article 4, paragraph 2).

[38] See Article 26 of the Oviedo Convention, which however does not allow restrictions on the rules governing protection of persons not able to consent to research or to organ removal. These are considered 'unconditional norms' (see Andorno (2005b), p. 136).

[39] Commission on Human Rights, Resolution 2003/69, Human rights and bioethics, adopted by consensus on 25 April 2003; Committee of Ministers, Recommendation R(99)4 to Member States on Principles Governing the Legal Protection of Incapable Adults, 23 February 1999, principle 28.

[40] Compare the proviso in Articles 8 to 11 of the European Convention on Human Rights; Articles 12, 18–19, 21–22 of the International Covenant on Civil and Political Rights; Articles 12–13, 15–16 and 22 of the American Convention on Human Rights; Articles 11–12 of the African Charter on Human and Peoples' Rights. The conditions of legitimacy of the restrictions placed on human rights are by now considered the object of a customary rule: see Fidler (2000), pp. 293–294.

[41] International Covenant on Civil and Political Rights, adopted and opened for signature, ratification and accession by General Assembly Resolution 2200A (XXI), 16 December 1966, entered into force on 23 March 1976; CCPR, General Comment No. 20: Replaces general comment 7 concerning prohibition of torture and cruel treatment or punishment (Art. 7), 10 March 1992.

and scientific experimentation is allowed without the 'free consent' of the person concerned.[42] The importance of this provision is twofold: on the one hand, it confirms the link between physical integrity and informed consent; on the other hand, it clearly shows that the right to physical integrity extends well beyond the prohibition of torture or cruel, inhuman, or degrading treatment, to which it is generally associated.[43]

The same proviso contained in Article 7 ICCPR is reproduced in Article 15 of the Convention on the Rights of Persons with Disabilities. This Convention clearly spells out the right to integrity of the person in Article 17 and makes express reference to informed consent in Article 25, para. d, in the context of the right to non-discriminatory enjoyment of the right to health.[44]

Other relevant provisions in regional human rights conventions include Article 5, para. 1, of the American Convention on Human Rights, which protects the right to physical, mental, and moral integrity,[45] as well as Article 4 of the African Charter on Human and Peoples' Rights, which affirms the inviolability of human beings and their entitlement to respect for their life and integrity of the person.[46] It is also worth mentioning the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa,[47] which states at Article 4, para. 1, that every woman is entitled to respect for life and integrity of her person, while at para. 2.h it mandates States Parties to take appropriate and effective measures to "prohibit all medical or scientific experiments on women without their informed consent".[48]

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[42] According to the Committee's interpretation, Article 7 allows no limitations or derogations and implies that the Parties to the Covenant have a legal duty to guarantee protection through legislative and other measures against the acts prohibited by this provision, "whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity". Moreover, as for the specific prohibition of non-consensual experimentations, the Committee argues that special protection is necessary with regard to persons not capable of giving valid consent, and in fact it recommends that "When there is doubt as to the ability of a person or a category of persons to give such consent, e.g. prisoners, the only experimental treatment compatible with article 7 would be treatment chosen as the most appropriate to meet the medical needs of the individual". See General Comment No. 20, paragraphs 2 and 7; Consideration of Reports Submitted by States Parties under Article 40 of the Covenant: Concluding Observations of the Human Rights Committee: United States of America, U.N. Doc. CCPR/C/USA/CO/3, 15 September 2006, paragraph 31.

[43] Unfortunately, there is no significant case law by the Human Rights Committee concerning violations of Article 7 for imposition of compulsory medication or experiments.

[44] Convention on the Rights of Persons with Disabilities, New York, 13 December 2006, entered into force on 3 May 2008.

[45] American Convention on Human Rights, San José, 22 November 1969, entered into force on 18 July 1978.

[46] African (Banjul) Charter on Human and Peoples' Rights, Nairobi, 27 June 1981, entered into force on 21 October 1986.

[47] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, Maputo, 11 July 2003, entered into force on 25 November 2005.

[48] It should be added that this protection had been earlier invoked by the Committee on the Elimination of Discrimination against Women in its General Recommendation No. 24 of 1999 concerning action by the States parties to the Convention on the Elimination of All Forms of Discrimination against Women, where the Committee stated that States Parties had to "Require all

As it will be explained in detail further in this book,[49] the most salient expression of the intertwining between the right to physical integrity and informed consent is provided at the European level by Article 3 of the Charter of Fundamental Rights of the European Union, where informed consent is listed on top of the core principles of biomedical law, including the prohibitions of selective eugenic practices, of making the human body a source of financial gain, and of reproductive cloning of the human being. Moreover, Articles 3 and 8 of the European Convention on Human Rights have been consistently interpreted by the Strasbourg Court as encompassing a right to be free from non-consensual medical treatments, testing, and experimentations.[50]

2.2.2 Informed Consent and the Right to Health

Informed consent is also considered an integral and crucial part of the right to health,[51] as protected at the universal level by Article 12 of the International Covenant on Economic Social and Cultural Rights (ICESCR).[52]

According to the UN Committee's General Comment No. 14 on Article 12, the right to health

> contains both freedoms and entitlements. The freedoms include the right to control one's health and body . . . and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.[53]

Building on the Committee's interpretation of Article 12, the former UN Special Rapporteur on the right to health, Paul Hunt, observed in his Report of 2005 that although the issue of informed consent

> is often considered in relation to the right to liberty and security of the person, as well as the prohibition against inhuman and degrading treatment, it is less frequently considered in the context of the right to health. However, consent to treatment is intimately connected with a vital element of the right to health: the freedom to control one's health and body.[54]

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health services to be consistent with the human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent and choice" (paragraph 31, al. e).

[49] See Di Stasi and Palladino (2013).

[50] On the relevant Strasbourg case-law, see Negri (2011c), pp. 46–49.

[51] Dupuy (1979); Leary (1994); Hendriks (1998); Toebes (1999); Negri (2008, 2010); Riedel (2008); Robinson and Clapham (2009); Tobin (2012).

[52] International Covenant on Economic, Social and Cultural Rights, adopted by General Assembly Resolution 2200A (XXI) of 16 December 1966, entered into force on 3 January 1976.

[53] CESCR, General Comment No. 14 (2000) on the right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), U.N. Doc. E/C.12/2000/4, 11 August 2000, paragraph 8. Another important element is access to health-related information for health decision-making (paragraphs 21–23) since information accessibility is a specific aspect of one of the four cornerstone elements of the right to health, namely availability, accessibility, acceptability, quality (paragraph 12).

[54] Report 2005, paragraph 87.

Since Professor Hunt called for an "urgent reconsideration [of this issue] with a view to better protecting, at the international and national levels, the right to informed consent" and for strict respect for "procedural safeguards protecting the right to informed consent",[55] his successor, Anand Grover, carried out an in-depth analysis of the evolution and the main components of informed consent in a report specifically dedicated to the topic, which was issued in 2009.[56] Grover's Report is particularly interesting because it represents an important systematic analysis of informed consent from an international viewpoint. The Special Rapporteur embraced the view that informed consent to treatment is a cornerstone of the right to health, stating that

> [g]uaranteeing informed consent is *fundamental to achieving the enjoyment of the right to health* through practices, policies and research that are respectful of autonomy, self-determination and human dignity. An enabling environment that prioritizes informed consent links counselling, testing and treatment, creating an effective voluntary health-care continuum. Safeguarding informed consent along the health-care continuum *is an obligation placed on States and third parties* engaged in respecting, promoting and fulfilling the right to health.[57]

It is to be noted, however, that throughout the whole Report the Special Rapporteur mainly focused on the obligatory aspects linked to informed consent, addressing the relevant duties incumbent on States in the perspective of fulfilling the obligations to respect, protect, and fulfil the right to health as interpreted and precised by the Committee.[58] This view is corroborated by the Rapporteur's conclusions recommending that national and international bodies "emphasize the importance of informed consent as a fundamental aspect of the right to health in relevant policy and practice" and "that States consider whether they are meeting their obligations to safeguard informed consent as a critical element of the right to health", since "guaranteeing informed consent is a fundamental dimension of the right to health" and "safeguarding informed consent along the health-care

[55] Report 2005, paragraph 90.

[56] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, U.N. Doc. A/64/272, 10 August 2009 (hereinafter 'Report 2009'), paragraph 9.

[57] Report 2009, summary, p. 2 (emphasis added).

[58] Report 2009, paragraphs 5, 18. This approach is consistent with the existence of indirect references to the rule of informed consent in the definition of State obligations stemming from Article 12 of the Covenant according to the traditional tripartite typology (to respect, protect, fulfil) employed in the language of the Committee, as well as in the relevant scholarship. In this respect see the indirect references to informed consent in General Comment No. 14, at paragraphs 34, 35, and 37: "obligations to respect include a State's obligation to refrain … from applying coercive medical treatments, unless on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases. Such exceptional cases should be subject to specific and restrictive conditions, respecting best practices and applicable international standards … In addition, States should refrain from … censoring, withholding or intentionally misrepresenting health-related information … as well as from preventing people's participation in health-related matters. … The obligation to fulfil (promote) the right to health requires States to undertake actions that create, maintain and restore the health of the population. Such obligations include: … (iv) supporting people in making informed choices about their health."

continuum is an obligation placed on States and third parties engaged in respecting, promoting and fulfilling the right to health".[59] The Rapporteur's conclusions were further upheld by the Human Rights Council in a resolution of 2010, where all States were for the first time invited to "safeguard informed consent . . . as a critical element of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".[60]

2.3 *The Emergence of the "Right to Informed Consent" as an International Human Right and its Relevance to Advance Directives Regulation*

Just as much as it is well-established in both domestic law and jurisprudence, the "right to informed consent" has gained prominence also at the international level and it can be argued that it has emerged as an international human right.[61]

Such an argument is not very common in the legal literature devoted to international biolaw and biorights.[62] In fact, scholars tend to use more vaguely worded expressions, stating that informed consent is a 'requirement' that protects the patients' fundamental rights to integrity and self-determination—of which it is also defined as a 'corollary'[63]—and that such 'requirement' is based on the principles of 'respect for persons' and 'respect for human dignity'.[64] Informed consent is also very often defined as a general and basic principle of biomedical law,[65] while sometimes it is referred to as a principle and a right at a time.[66] But it

[59] Report 2009, paragraphs 7, 93–94.

[60] Human Rights Council, Resolution 15/22, 30 September 2010, paragraph 4 (o) (adopted by consensus).

[61] See Negri (2011c).

[62] See, however, Boschiero (2006), p. 53, who states that the 'right to express an informed consent' is codified in the Universal Declaration on Bioethics and Human Rights.

[63] Boschiero (2006), p. 14.

[64] Kollek (2009), p. 126. Similarly, see Millns (2007), p. 79, who argues that "fundamental bio-rights and freedoms are to be respected *through the provisions governing the requirement to obtain an individual's free and informed consent* to medical interventions", and again she speaks of "the general consent requirements imposed by articles 5 and 6" (pp. 79–80); however, when dealing with the Charter of Fundamental Rights of the European Union, she recognises free and informed consent as one of the four basic principles provided by Article 3, adding that the "remit of these is striking in its overlap with that of the principles enshrined in the Biomedicine Convention" (pp. 80–81).

[65] See, for instance, Maljean-Dubois (2000), pp. 94–95; Boschiero (2006), p. 51. Andorno stresses the fact that in the Oviedo Convention, informed consent is "required for the first time as *a general principle* for any biomedical intervention", Andorno (2005b), p. 136, 138.

[66] Compare Tancredi (2004), p. 397, who observes that the 'principle' is considered the basis of the doctor–patient relationship, while, illustrating the relevant European case law, he refers to it as the 'right in question'.

also happens that only its negative element, that is to say refusal of treatment, is qualified as a right.[67]

This lack of unequivocal consensus as to the legal qualification of informed consent mirrors the lack of consistency that also characterises the international instruments of biomedical law. The Oviedo Convention, the first binding instrument to address the issue of consent in a detailed fashion, does not provide any specific legal qualification of informed consent within its text, while its Explanatory Report refers to it as a 'general principle' or a 'general rule' and qualifies as individual rights 'the patient's right to information' and 'the right to withdraw consent'.[68] The Unesco Declarations on Bioethics regulate consent under the rubric of both 'rights of the persons concerned' and 'principles'.[69] Moving to other relevant soft law acts, it is worthy of note that the WMA Lisbon Declaration on the Rights of the Patient articulates, within the right to self-determination, "the right to give or withhold consent to any diagnostic procedure or therapy",[70] while the WMA Declaration of Helsinki on Medical Research Involving Human Subjects, though expanding on consent in medical research, only provides that "the potential subject must be informed of the right to refuse to participate in the study or to withdraw consent to participate".[71] On the contrary, the European Charter on Patients' Rights, inspired by the EU Charter of Fundamental Rights, proclaims a 'right to consent'.[72]

Although not perfectly coincidental, the views of the UN Special Rapporteurs on the right to health add some further useful hints. In fact, while in his report of 2005 Paul Hunt explicitly referred to a 'right to informed consent' and called for measures aimed at a better protection of that right,[73] Anand Grover's Report seemed to embrace a less clear-cut position, setting as its objective the analysis of "the fundamental role that informed consent plays in respecting, protecting and fulfilling the right to health".[74] Nonetheless, the Rapporteur explicitly mentioned a "right to consent" when referring to legal capacity, which confers on adults "the right to consent to, refuse or choose an alternative medical intervention"; in respect

[67] See e.g. Bompiani, Loreti Beghé, Marini, who define informed consent (as well as dissent), as the "expression" of the principles of autonomy and self-determination, while refusal of futile therapies is instead construed as a "right" (2001, p. 13).

[68] See the Explanatory Report to the Oviedo Convention, especially paragraphs 34, 40, 48, 101, and 136.

[69] See, respectively, Article 5 of the Declaration on the Human Genome and Human Rights and Article 6 of the Declaration on Bioethics and Human Rights. However, Article 9 of the former defined consent as a principle.

[70] WMA, Declaration on the Rights of the Patient, paragraph 3b.

[71] WMA, Declaration of Helsinki, paragraph 24.

[72] Active Citizenship Network, Europe Charter on Patients' Rights, Rome, November 2002, Article 4.

[73] Report 2005, paragraph 90.

[74] Report 2009, paragraph 5.

to "the need for special protections guaranteeing a woman's right to informed consent", especially in the field of sexual and reproductive health; concerning the fact that "the right to consent to treatment also includes the right to refuse treatment"; and with reference to those regional instruments that he considers to be the legal sources of such a right (i.e. the Oviedo Convention and its Additional Protocol on Biomedical Research, the EU Charter, and the EU Directive on Clinical Trials).[75]

In the light of the considerations above, it is possible to posit that an internationally protected human right to informed consent has emerged from the convergence of international human rights law and international biolaw over the same key objective: the protection of the integrity and inviolability of the human being. Moreover, despite its robust rooting in other basic human rights, the right to informed consent has come to live its own life and can be considered sufficiently independent of them. In fact, the scope of informed consent is broader and is not exclusively linked either to the right to health (not only is there a right to assent to or refuse medical treatment but also a right to consent to organs and tissue removal and donation or to participation in non-therapeutic experimentations, both being independent of any healing activity of direct benefit to the person concerned) nor to the right to bodily integrity (since not all interventions impinge on mental and physical integrity).

It could also be added that the non-derogable nature of the international human right to informed consent in respect of adult competent patients should be given paramount consideration in determining the legal value of advance directives.

From the standpoint of international law, advance directives lack any specific regulation and even in international instruments of soft biolaw express reference to them is really scant.[76] Notwithstanding its ambiguities and shortcomings, the pattern provided by Article 9 of the Oviedo Convention, as integrated by the Council of Europe's relevant resolutions,[77] is considered an important reference point to enhance the status of advance directive both at the global[78] and regional level. In fact, although the Convention has not yet been ratified by many of the European Union Member States, it is noteworthy that in a recent resolution on the situation of

[75] Report 2009, paragraphs 10, 20, 28, and 57.

[76] For example, the Amsterdam Declaration took into account "a previous declared expression of will" to the effect of preventing, even in situations of urgent need, the performance of a medical intervention based on a presumed informed consent when, according to such previous will, it is clear that the patient would have refused consent (paragraph 3.3).

[77] Committee of Ministers, Recommendation (2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity, 9 December 2009; Parliamentary Assembly, Resolution 1859 (2012) on protecting human rights and dignity by taking into account previously expressed wishes of patients, 25 January 2012. See Andorno (2010), pp. 119–124, (2011); Di Stasi and Palladino (2013).

[78] See, for example, Beširević (2010), p. 107: "the standards concerning the role of precedent autonomy in treating incompetent patients, guaranteed in Article 9 of the Oviedo Convention could, at least potentially, be implemented on a territory much wider than the territory of the Council of Europe Member States".

fundamental rights in the Union, the European Parliament invited all Member States lacking a specific legislation on living wills to adopt such laws as necessary

> to ensure that, according to Article 9 of the Oviedo Convention on Human Rights and Biomedicine, 'the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account' and *to ensure the right to dignity at the end of life*.[79]

Such a recommendation is remarkable because it associates respect for advance directives to a 'right to dignity at the end of life'. This element is particularly telling since it lends support to the argument that advance directives favour death with dignity inasmuch as they translate into medical instructions the patient's personal views, values, and beliefs as to their idea of a dignified death. This also means that through advance directives the patient has the opportunity to exercise two fundamental and non-derogable rights: the right to dignity and the right to informed consent.[80]

Therefore, since international law as it stands today posits that compulsory treatments or interventions, even if life-saving, are inconsistent and irreconcilable with the right to informed consent, the relevance of this right deserves adequate consideration as apt starting point for determining the legal value of advance directives from an international law perspective, as well as for assessing the consistency of relevant domestic regulation with international standards.

3 The Euthanasia Debate and the Right to Die with Dignity

3.1 Advance Refusal of Treatments and Requests for Euthanasia and Physician-Assisted Death

Advance care planning involves communicating one's directives on end-of-life issues, including withholding or withdrawing life-sustaining measures, refusing certain kinds of treatment, abandoning life-shortening pain and symptom management and sedation at the end of life. Such directives may also include requests for euthanasia and physician-assisted death, thus raising both legal and ethical dilemmas.

Actually, advance directives originated as a way to avoid the excesses of life-prolonging measures as provided by advanced medical technology and thus as a means of protecting patients from unnecessary prolonging of the dying process under conditions hard to endure or contrary to their own concept of dignity. This is the reason why instructional directives very often consist in the advance refusal of futile, disproportionate, or aggressive treatments and life-sustaining measures (such

[79] European Parliament, Resolution of 14 January 2009 on the situation of fundamental rights in the European Union 2004–2008, Official Journal of the European Union, C 46E/08, 24 February 2010, pp. 48–69, paragraph 167 (emphasis added).

[80] At least for adult competent patients, and where derogations due to emergency situations and public health interests do not apply, the non-derogable nature of informed consent is no longer controversial: see Wear (1992), p. 1.

as mechanical ventilation or artificial nutrition and hydration) or in DNR orders (i.e. 'do not resuscitate' orders amounting to a refusal of life-saving measures, such as cardiopulmonary resuscitation). Their rationale resides in the patient's will to escape the risk of being subject either to prolonged unbearable suffering or to a condition of mere physical survival devoid of any cognitive functions.

It must be stressed, in this respect, that while it is generally acknowledged that patient autonomy implies that no authority is entitled to deprive the individual of their right to choose what they deem best for themselves, including the right to refuse or halt medical treatments,[81] it is often questioned whether respect for this right should be disregarded when it leads to the patient's death. In this connection, a lively discussion has developed on the legal limits of patient autonomy in the practice of end-of-life care, that is to say whether autonomy encompasses the individual right to choose freely and knowingly to refuse treatment when this choice will have fatal consequences. The debate has focused on two major issues: whether there is a recognised right to die, or to die with dignity, and whether respect for individual autonomy may legitimise passive euthanasia and assistance to suicide at the request of a competent terminally ill or dying patient.

Domestic legislation and practice show that also in this respect the legal regulation of end-of-life issues offers a vast array of solutions differing from one jurisdiction to another[82] and that there seems to be no universal standard, except for the generally agreed view that non-voluntary and involuntary active euthanasia is outright prohibited as amounting to the offence of murder or manslaughter. Also international law, as it stands today, cannot yet provide any exhaustive and clear-cut answer to such challenging issues. It was in fact observed that euthanasia is one of the fields that have "largely eluded efforts of international regulation".[83] Therefore, since there are no existing international biolaw instruments that explicitly address euthanasia nor any human rights convention providing for a right to die, the euthanasia debate has essentially developed within the framework of the universal rights to life and to human dignity.

3.2 Euthanasia and Universal Human Rights

3.2.1 Euthanasia and the Right to Life

As a preliminary observation, it has to be noted that a clear distinction is made between the refusal or withdrawal of life-sustaining, life-prolonging, disproportionate, or futile treatments upon request or by will of the interested person

[81] See Europe Charter on Patients' Rights, Article 4; Amsterdam Declaration, paragraph 3.2; Report 2009, paragraph 28; UN Mental Illness Principles, paragraph 4.

[82] See Byk (2007).

[83] Schabas (2009), p. 445; see also Negri (2011b).

(including passive euthanasia or 'letting die') and the taking of action lacking medical, therapeutic, or palliative justification and the intending solely to terminate life (i.e. active euthanasia that is considered as amounting to an arbitrary taking of life contrary to international human rights law). Although generally agreed upon, such a distinction does not fall short of criticism on grounds that it may build on misleading arguments intended to separate morally justified deaths from morally unjustified deaths.[84]

The scope of self-determination in end-of-life care is deeply intertwined with the universal recognition of the value and protection of human life. Around this theme, two approaches based on different moral and philosophical rationale contrast each other in medical ethics: the 'sanctity of life' approach, according to which life is 'sacred' and valuable per se and is worth protecting independently of any physical disability or psychological deficiency; the 'quality of life' approach, which posits that life can be renounced when physical existence is not supported by mental and social qualities that make living meaningful for the interested person.

International human rights conventions protect the right to life as the "supreme right",[85] which is fundamental, indisposable, and inviolable even in times of public emergency or armed conflict,[86] that is to say a right that enjoys the status of jus cogens. Human rights treaties are couched in terms that clearly recognise that every human being has the inherent right to life, which is protected by law, and that "no one shall be arbitrarily deprived of his life"; they thus envisage only very limited circumstances where a person can be deprived of life (i.e. capital punishment), and no reference is ever made to assisted suicide or euthanasia.[87]

That said, the question was put whether the legalisation of euthanasia in some jurisdictions constitutes a dangerous violation of the most basic rules of human rights, in contrast with the international obligations assumed by those States. This problem was raised at the beginning of the twenty-first century in relation to the first two euthanasia laws adopted in Europe (The Netherlands and Belgium), since it was questioned whether they were compatible with the obligations arising from Article 6 ICCPR and Article 2 of the European Convention on Human Rights (ECHR).

As far as the Dutch law on euthanasia and assisted suicide of 2001 is concerned, its alleged incompatibility with Article 6 ICCPR was discussed at the UN Human Rights Committee on the occasion of its consideration of the periodic reports sent

[84] See Orentlicher (1998).

[85] The Human Rights Committee interpreted the right to life as "the supreme right from which no derogation is permitted": Human Rights Committee, CCPR General Comment No. 6: The right to life (art. 6), 30 April 1982, paragraph 1.

[86] See, in this respect, Article 15 of the European Convention on Human Rights, Article 4 of the International Covenant on Civil and Political Rights, and Article 27 of the American Convention on Human Rights.

[87] See, for example, Article 6 of the International Covenant on Civil and Political Rights, Article 2 of the European Convention on Human Rights, Article 4 of the American Convention on Human Rights, and Article 4 of the African Charter on Human and Peoples' Rights.

by the Dutch government. The Committee considered the ways the law was applied in light of the principle that

> where a State party seeks to relax legal protection with respect to an act deliberately intended to put an end to human life, the Committee believes that the Covenant obliges it to apply the most rigorous scrutiny to determine whether the State party's obligations to ensure the right to life are being complied with (articles 2 and 6 of the Covenant).

In its concluding observations, the Committee expressed its concern in respect of certain critical aspects of the application of the Dutch law (in particular, its applicability to children, the effectiveness of controls, the application of criteria for determining non-punishability), recommending that it be revised in the light of Article 6 ICCPR.[88] In this respect, the approach of the Committee was indeed 'soft', since it chose to avoid addressing the core question at stake and to pronounce itself on the outright incompatibility of the euthanasia law with the Covenant, merely criticising certain aspects of its implementation and the effectiveness of the relevant safeguards.

Also in considering the Swiss legislation on assisted suicide, the Committee limited itself to recommending that Switzerland

> consider amending its legislation in order to ensure independent or judicial oversight to determine that a person who is seeking assistance for suicide is acting with full free and informed consent.[89]

Along with the Committee's mild position, it should be remarked that also other UN human rights bodies (especially the General Assembly and the Human Rights Council) have remained completely silent on this topic, so that the debate on euthanasia and assisted suicide has mainly developed within the Council of Europe, whose organs have instead taken a clear stance against both active euthanasia, physician-assisted death, and the partial decriminalisation of mercy killing.[90] In fact, in the relevant documents approved on the subject, the Parliamentary Assembly clearly stated as early as 1976 that the physician "has no right, even in cases which appear to him to be desperate, intentionally to hasten the natural course of death".[91] It later recommended that States adopt all necessary measures to protect the fundamental rights of the terminally ill and dying patients, especially

[88] Human Rights Committee, Concluding Observations of the Human Rights Committee: Netherlands, CCPR/CO/72/NET, 27 August 2001 and Concluding Observations of the Human Rights Committee, CCPR/C/NLD/CO/4, 11 August 2009, paragraph 7.

[89] Human Rights Committee, Consideration of Reports Submitted by States Parties under Article 40 of the Covenant: Concluding Observations of the Human Rights Committee: Switzerland, CCPR/C/CHE/CO/3, 3 November 2009.

[90] Parliamentary Assembly, Verbatim Records: 2005 Ordinary Session (Second Part), 12th Sitting, Wednesday, 27 April 2005, e Doc.10455 on Assistance to Patients at End of Life, 9 February 2005.

[91] Council of Europe, Parliamentary Assembly, Recommendation 779 (1976) on the rights of the sick and dying, 29 January 1976, paragraph 7; Resolution 613 (1976) on the rights of the sick and dying, 29 January 1976.

> upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while: i. recognising that the right to life, especially with regard to a terminally ill or dying person, is guaranteed by the member states, in accordance with Article 2 of the European Convention on Human Rights which states that 'no one shall be deprived of his life intentionally'; ii. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person; iii. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.[92]

Even recently, it reaffirmed that "Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited".[93]

Unfortunately, the active role played by the organs of the Council of Europe was not coupled with an unequivocal and authoritatively guiding case law of the European Court of Human Rights,[94] which has never declared euthanasia as being absolutely contrary to Article 2 ECHR, rather invoking the "margin of appreciation" doctrine to avoid taking a clear position on such a controversial matter.[95]

In conclusion, international practice, as expressed by the UN human rights bodies and by the Strasbourg Court, suggests that under present international law euthanasia is not to be considered absolutely contrary to the right to life,[96] which means that no universal prohibitive rule has emerged so far.

3.2.2 Euthanasia and the Right to Human Dignity

The role of human dignity in the context of end-of-life choices is crucial.[97] It is considered the unique universal value that inspires the major common bioethical principles, and it is therefore considered the noyau dur of both international biolaw

[92] Parliamentary Assembly, Recommendation 1418 (1999) Protection of the human rights and dignity of the terminally ill and the dying, 25 June 1999, paragraph 9.c.

[93] Parliamentary Assembly, Resolution 1859 (2012), supra note 77, paragraph 5.

[94] This aspect was highlighted also by the Committee of Ministers: see Parliamentary Assembly, Doc. 9404, 8 April 2002, Protection of the human rights and dignity of the terminally ill and the dying, Recommendation 1418 (1999), Reply from the Committee of Ministers, adopted at the 790th meeting of the Ministers' Deputies (26 March 2002), paragraph 11.

[95] See Schabas (2009), p. 445. In principle, the Strasbourg Court excluded the admissibility of derogations from Article 2 different from those expressly provided therein (McCann and others v. the United Kingdom, no. 18984/91, judgment of 27 September 1995, paragraph 147); however, the Commission had previously found that the failure of the Swiss legislator to criminalise passive euthanasia was not incompatible with Articles 2 and 8 of the Convention (European Commission on Human Rights, Widmer v. Switzerland, no. 20527/92, decision of 10 February 1993). The relevant cases decided by the Court are Pretty v. the United Kingdom, no. 2346/02, judgment of 29 April 2002; Haas v. Switzerland, no. 31322/07, judgment of 20 January 2011; Koch v. Germany, no. 497/09, judgment of 19 July 2012, Gross v. Switzerland, no. 67810/10, judgment of 14 May 2013.

[96] Focarelli (2009), paragraphs 30–31.

[97] See Andorno (2005a, 2009); Di Stasi (2011).

and international human rights law. Nevertheless, human dignity is a difficult concept to be defined, since it is often used in a rather vague and under-conceptualised sense.[98] Also in this context, dignity is invoked in support of contradictory arguments and rights claims, since both supporters and detractors of euthanasia appeal to the notion of human dignity arguing from completely different assumptions and pursuing opposite purposes. Following their arguments, dignity could justify both respect for life in the name of the principle of the sanctity of life and the right to euthanasia in the name of the principle of quality of life (which is translated into the right to live and die with dignity).

The vagueness of human dignity becomes problematic when it is put forward as a standard to evaluate individual conduct or public policies; it is deemed a potentially useful concept, but it calls for elaboration of more specific criteria that make it more meaningful for evaluative purposes.[99] Dignity as such does not provide any objectively assessable standard; to the contrary, it is a subjective, relative, relational, and holistic concept that provides an evaluation criterion that builds on the "lived experience" of the right holders and how they feel that their dignity is being affected. Therefore, since the interpretation and application of the right to human dignity in the context of euthanasia do not fall short of ambiguities,[100] it is claimed that the notion of dignity should be given a more concrete and less equivocal meaning in relation to end of life choices, especially in light of the fact that most of the legal considerations are developed around the question of whether or not there is freedom to give up one's life in the name of a right to a dignified death. In conclusion, the effective relevance of human dignity to the emergence of a "right to die with dignity" is highly debated and often considered overstated.[101]

3.3 The Controversial Emergence of a "Right to Die with Dignity" as Part of the Right to Personal Autonomy and Privacy

The recognition of the "right to die with dignity" is advocated with strength by those who claim that restrictive legislation is undemocratic, violates an individual's basic rights, discriminates unfairly against people who do not share certain religious beliefs, is inappropriate in a multicultural society, causes unnecessary pain and suffering, and is inhumane.

[98] According to Chapman (2011), pp. 3–4: "[w]hile human dignity is a powerfully evocative and widely accepted concept, it is elusive as to its precise meaning and requirements... there is the distinct possibility that not only the term human dignity may convey a multiplicity of understandings, it may even be referring to different things. ... A lack of clarity about the meaning of human dignity can relegate the concept to be used as little more than rhetorical dressing."

[99] Chapman (2011), p. 5, 10, and 12.

[100] Mathieu (2005), p. 72.

[101] See, in this sense, Amarasekara and Bagaric (2002).

Advocates of the right to a dignified death also try to add further strength to their arguments by referring to personal autonomy and private life. This approach was substantially supported by the Strasbourg Court in the case of Pretty v. UK when it found that "a person may claim to exercise a choice to die by declining to consent to treatment which might have the effect of prolonging his life",[102] conceding that personal autonomy may lead to choices that are not necessarily respectful of the concept of the inviolability of life:

> Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.[103]

These considerations led the Court to conclude that it was "not prepared to exclude" that the existence of a law preventing individuals from exercising their personal choice to avoid what they consider as an undignified and distressing end to their life would constitute an interference with their right to respect for private life.[104] The Court further developed this case law in Haas v. Germany and expanded on the relevance of the right to private life by acknowledging that an individual's right to decide in which way and at which time their life should end, provided that they he is in a position to form freely their own will and to act accordingly, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention.[105] This consideration was however 'mitigated' by the Court's placing special emphasis on two elements: the need to interpret Article 8 in light of Article 2 (right to life) and the absence of a general consensus among the Members of the Council of Europe as to the existence of a right to choose how and when to put an end to one's life. However, the Court concluded that, even assuming that States may be under an obligation to adopt measures facilitating a dignified suicide (and therefore to guarantee a "right to die with dignity"), this obligation had not been violated in the circumstances of that specific case (shifting again the attention to the States' margin of appreciation).[106]

The latest decision delivered in the case of Gross v. Switzerland was the object of fierce criticism because it was interpreted as opening up the door to the official recognition of a right to assisted suicide. In this case, the Court stated that the Swiss law does not provide sufficient guidelines ensuring clarity as to the extent of the right to obtain on medical prescription a lethal dose of a suicide drug. It accordingly found that there had been a violation of Article 8 of the Convention since this lack of clarity had caused the applicant a considerable degree of anguish in a situation

[102] Pretty v. the United Kingdom, supra note 95, paragraph 63.

[103] Pretty v. the United Kingdom, supra note 95, paragraph 65.

[104] Pretty v. the United Kingdom, supra note 95, paragraph 67.

[105] Haas v. Switzerland, supra note 95, paragraph 51.

[106] Haas v. Switzerland, supra note 95, paragraph 61.

concerning a particularly important aspect of her life. In this respect, the Court considered that the applicant's wish to be provided with a lethal dose of medication allowing her to end her life fell within the scope of her right to private life, though it did not take a stance on the merits of the question of whether she should have been granted the possibility to acquire that drug in consideration of her personal situation and health conditions.[107]

It follows from this case law that while a strict domestic criminal prohibition of euthanasia and assisted suicide is in accordance with the Convention, the question of whether the legalisation or decriminalisation of assisted suicide amounts to a human rights violation depends on a careful balancing of the State's positive obligation to protect the right to life and its obligation to respect the right to die with dignity, which can be derived from the right to respect for private life. It must be stressed, however, that this position only reflects the European perspective as expressed by the Strasbourg Court, and it cannot be considered as reflecting any general consensus on this issue, given that the variety of domestic legislations still testifies that there are no universally accepted norms to justify euthanasia or assisted suicide.

4 Palliative Care and the Right Not to Suffer

4.1 Objectives of Palliative Care

Palliative care is a specialised form of health care that aims to enhance the quality of life of patients who are faced with serious illness. In recent decades, the issue of pain treatment has reached worldwide recognition, especially in the framework of end-of-life care.

In the early 1980s, the Cancer Unit of the World Health Organization (WHO) began to develop a global initiative aimed to promote pain relief and opioid availability worldwide.[108] Some important achievements were reached, such as the progressive expansion of a worldwide network of national and international organisations designed to respond to the urgent need to develop and implement comprehensive programs of palliative care. Since then, enhanced cooperation between such organisations, health professionals, and the civil society has played a key role in promoting the development of these programs.[109]

[107] Gross v. Switzerland, supra note 95, paragraphs 63–69.

[108] Sepúlveda et al (2002).

[109] In fact, dissemination of palliative care and pain management has been conducted for several years through the work of both governmental organisations and NGOs, such as the WHO, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the International Association for the Study of Pain (IASP), the International Association for Hospice and Palliative Care (IAHPC), the Global Alliance for Palliative Care (WPCA), the European (EAPC), Latin-American (ALCP) and African (APCA) Palliative Care Associations, and many other national associations operating in this sector. See Astudillo et al (2009).

In 1990, the WHO adopted a definition of palliative care according to which "palliative care is the active total care of patients whose disease is not responsive to curative treatment", also stressing that "control of pain and other symptoms, and of psychological, social and spiritual problems is paramount".[110] In 2002, the official definition was expanded pursuant to the idea that palliative care should not be relegated only to the later stages of care:

> palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[111]

According to the WHO, palliative care's objectives are to improve the quality of life of the patient, to reaffirm the importance of life, to consider dying as a normal process without lengthening or shortening life, to provide relief from pain and other symptoms integrating the psychological and spiritual aspects of patient care, to offer a support system to help patients live as actively as possible until death, to support the family during the illness and bereavement.

As it can be inferred from the WHO definition and the basic principles that complete it, palliative care endeavours to provide a professional, scientific, and human response to the needs of all patients in advanced and terminal stages of illness. Its scope has extended from the treatment of patients affected by cancer to all medical contexts where there is a need to provide services to persons suffering from irreversible diseases, such as AIDS, neurological diseases, specific organic failures (kidney, heart, liver, etc.) in their final stages.[112] It follows that the primary purpose of palliative care is to provide comfort and improve or maintain the quality of life for patients not amenable to cure, that is to say terminally ill and dying patients. Its aim is to prevent or treat as early as possible the symptoms and side effects of serious illness, as well as all relevant psychological, social, and spiritual problems related to it. Moreover, although it is generally acknowledged that palliative care may have as side effect the acceleration of death (indirect euthanasia), it is not intended to hasten death and excludes active or passive euthanasia, nor is it to be equated to physician-assisted suicide. Rather to the contrary, it is argued that improvements in palliative care in fact render assisted suicide unnecessary and lessen requests for euthanasia.

4.2 A Human Rights Approach to Palliative Care: The Relevance of Universal Rights

As illustrated before, the concept of palliative care includes comprehensive, individualised, and continuous treatment of people with a limited life expectancy

[110] WHO (1990).

[111] WHO (2002).

[112] Fernández (2007), p. 145. See also Stjernswärd and Clark (2005).

through a holistic approach respectful of the dignity of patients and their right to self-determination.[113] A key point of this approach is the belief that every human being has the right to be treated with dignity and to die with dignity (although, as discussed before, this latter right is still considered controversial) and that the relief of pain—physical, psychological, spiritual, and social—is a crucial element in this process. A human rights approach to palliative care is therefore advocated to better understand which obligations are incumbent on States under international human rights law and which international standards are by now consolidated.

4.2.1 Palliative Care and the Right to Health (Including the Right to Access to Essential Medicines)

In order to examine palliative care in the human rights perspective, the first relevant norm is Article 12 ICESCR, notwithstanding this provision does not include any expressly mentioned 'right to palliative care'. According to the interpretation provided by the UN Committee in General Comment No. 14, "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services" and has also noted, with respect to the elderly, the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity".[114] In this regard, the UN Special Rapporteur on the right to health—who considered palliative care to be an issue requiring "urgent attention"[115]—asserted that palliative care "is absolutely crucial in order to prolong the lives of older persons affected by life-threatening diseases and to ensure their death in dignity".[116]

Furthermore, in accordance with General Comment No. 3,[117] the parties to the Covenant on Economic, Social and Cultural Rights have a core obligation to ensure the satisfaction of minimum essential levels of each of the rights enunciated therein, including essential primary care health. In light of this clear guidance, the

[113] The holistic approach that characterises palliative care is consistent with the definition of health provided in the WHO Constitution: "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". See Preamble of the Constitution of the World Health Organization, adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States in force from April 7, 1948, and amended by resolutions WHA26.37, WHA29.38, WHA51.23 WHA39.6 and the World Health Assembly

[114] General Comment No. 14, paragraphs 34 and 25, respectively.

[115] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/63/263, 11 August 2008, paragraph 50.

[116] Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, A/HRC/18/37, 4 July 2011, paragraph 60.

[117] CESCR, General Comment No. 3, The nature of States parties obligations (Art. 2, paragraph 1 of the Covenant), 14 December 1990, paragraph 9.

Committee considered that the non-derogable core obligations stemming from Article 12—for which a State party cannot, under any circumstances, justify its non-compliance—include, inter alia:

> (a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; … (d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs; (e) To ensure equitable distribution of all health facilities, goods and services; (f) To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population ….[118]

With specific reference to palliative care, this means that States should ensure universal access to palliative care services, provide basic medications for pain relief, and implement specific policies of palliative care as a public health problem.[119] Therefore, governments should adopt and implement a strategy and action plan aimed to extend the treatment of pain and palliative care services, which, according to the WHO, should have priority status within public health programs of disease control. Furthermore, States are required to ensure an appropriate policy and regulatory system, develop plans for the implementation of these services, and take all necessary and reasonable measures, within the available resource, to carry out the plan.

As part of these basic obligations, States have to guarantee access to palliative medicines and provide opioid analgesics—which are included in the WHO List of Essential Medicines and are completely under governmental control—ensuring not only that these drugs be available in sufficient quantities but that they be also physically and financially available to those who need them. To achieve this goal, States should implement an effective system of supply and distribution and create a regulatory framework that allows public health systems, both in the public and private sectors, to obtain, prescribe, and dispense these drugs.[120]

The availability of opioid analgesics, such as morphine and codeine—which WHO has included in its Model List of Essential Medicines[121]—also depends on

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[118] General Comment No. 14, paragraph 43.

[119] See also Brennan (2007), p. 495.

[120] Lohman et al (2010). Since access to medicines is an integral and fundamental element of the right to health, governments and the international community as a whole have a responsibility to provide such access to everyone. The primary responsibility for expanding access to medicines rests, in any case, on the States. See Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health—Expert consultation on access to medicines as a fundamental component of the right to health, A/HRC/17/43, 16 March 2011; Human Rights Council, Resolution 15/22, The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/RES/15/22, 6 October 2010. See also Brennan et al (2007), pp. 207–209; Gwyther et al (2009), pp. 770–771. For a comprehensive analysis of the obstacles to the provision of pain treatment and palliative care, see Human Rights Watch, "Please, do not make us suffer any more…" Access to Pain Treatment as a Human Right, 3 March 2009, pp. 19–43, 47–50, available at http://www.hrw.org/reports/2009/03/02/please-do-not-make-us-suffer-any-more.

[121] De Lima et al (2007).

the regime of international narcotics control, regulated by the UN Conventions.[122] The Single Convention on Narcotic Drugs of 1961[123] recognises in its preamble

> that the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.

Article 4 provides that

> The parties shall take such legislative and administrative measures as may be necessary. . . to limit exclusively to medical and scientific purposes the production, manufacture, export, import, distribution of, trade in, use and possession of drugs.

The Convention on Psychotropic Substances of 1971[124] used more or less the same terms in Article 5. But while the UN treaties on narcotics assert that the medical use of these drugs is legal and 'indispensable' to alleviate pain, in practice, many governments have implemented strict laws and policies that focus on drug abuse and ignored their obligation to ensure legitimate access to pain-relieving drugs. This problem has been addressed at different levels. The International Narcotics Control Board, the body charged with overseeing the implementation of the UN convention, stated in 1995 that the 1961 Convention

> establishes a dual drug control obligation for Governments: to ensure adequate availability of narcotic drugs, including opiates, for medical and scientific purposes, while at the same time preventing the illicit production of, trafficking in and use of such drugs.[125]

In 1999, it recognised that

> outdated restrictive regulations and, more frequently, uninformed interpretations of otherwise correct regulations, misguided fears, and ingrained prejudices about using opioids for medical purposes continue to prevail in many countries.[126]

In the same direction, the Board stated in 2007 that it

> remain[ed] concerned about seriously low levels of consumption of opioid analgesics for the treatment of pain in many countries, particularly in developing countries. The Board again urge[d] all Governments concerned to identify the impediments that may exist in their respective countries with regard to the usage of appropriate opioid analgesics for the treatment of pain and to take measures to increase the availability of these drugs for medical purposes, in accordance with the recommendations of the WHO.

In the same year, in consultation with the INCB, the WHO established the Access to Controlled Medications, aimed to address all the identified obstacles to

[122] Heilmann (2010, 2011).

[123] Single Convention on Narcotic Drugs, signed in New York on March 30, 1961, in force since December 13, 1964.

[124] Convention on Psychotropic Substances, signed in Vienna on 21 February 1971.

[125] INCB, Report of the International Narcotics Control Board for 1995: Availability of Opiates for Medical Needs, available at http://www.incb.org/pdf/e/ar/1995/suppl1en.pdf.

[126] INCB, Report of the International Narcotics Control Board for 1999: Freedom from Pain and Suffering, available at http://www.incb.org.

the accessibility of controlled medicines, with emphasis on regulatory, attitudinal, and knowledge barriers.[127]

Other international bodies such as the Economic and Social Council of the United Nations and the World Health Assembly also called on countries to ensure an adequate supply of opioid analgesics. In its resolution 2005/25, the Economic and Social Council recognised the importance of improving the treatment of pain, including through the use of opioid analgesics, especially in developing countries, and called on Member States to remove barriers to the use of such analgesics taking fully into account the need to prevent their diversion for illicit use.[128] In May 2005, the World Health Assembly adopted Resolution 58.22 on the prevention and control of cancer, urging Member States to ensure the medical availability of opioid analgesics and requesting the WHO Director General to explore funding mechanisms for cancer prevention, control, and palliative care and to examine, together with INCB, how adequate pain treatment with opioid analgesics can be facilitated.[129] In addition, the special session of the Commission on Narcotic Drugs of the United Nations Office on Drugs and Crime, which took place on March 11, 2009, addressed the lack of access to medicines for pain relief in many countries, firmly stating the commitment of States to ensure an adequate supply of drugs for palliative care while preventing their diversion into illicit channels, in accordance with the treaties of international drug control.[130]

Also the Special Rapporteur on the right to health, in his 2010 report on international drug control, noted that

> Restricted access to opioids has an obvious impact on the availability of OST [Opioid Substitution Treatment] . . . However, there are three other primary areas in which access to controlled medicines is essential: (a) management of moderate to severe pain, including as part of palliative care for people with life-limiting illnesses.[131]

The Rapporteur therefore recommended to Member States to amend laws, regulations, and policies to increase access to controlled essential medicines and to the United Nations drug control bodies to "integrate human rights into the response to drug control in laws, policies and programmes" and to "formulate guidelines that provide direction to relevant actors on taking a human rights-based

[127] Joint report by WHO and INCB, Assistance Mechanism to Facilitate Adequate Treatment of Pain with Opioid Analgesics, 2 March 2007.

[128] Economic and Social Council of the United Nations, Resolution 2005/25, Treatment of pain using opioid analgesics, 22 July 2005.

[129] World Health Assembly, Resolution WHA 58.22, Cancer Prevention and Control, 25 May 2005.

[130] UNODC, Political Declaration and Plan of Action on International Cooperation towards an Integrated and Balanced Strategy to Counter the World Drug Problem, 12 March 2009.

[131] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/65/255, 6 August 2010, paragraph 42.

approach to drug control, and devise and promulgate rights-based indicators concerning drug control and the right to health".[132]

4.2.2 Palliative Care and the Right to Freedom from Torture and Cruel, Inhuman, or Degrading Treatment

The concern of UN bodies and their insistence to adopt a human rights approach to international drug control are grounded on the consideration that non-compliance with the basic obligation to ensure access to palliative medicines constitutes both a violation of Article 12 ICESCR and a breach of the fundamental right to be free from torture and inhuman or degrading treatment as provided by Article 7 ICCPR.[133]

In this respect, the UN Special Rapporteur on torture explicitly stated that "the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment".[134] In the same wake, together with the Special Rapporteur on the right to health, he issued a joint statement addressed to the Commission on Narcotic Drugs affirming that

> The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment. International human rights law requires that governments must provide essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health. Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation. Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully.[135]

The relevance of this approach is testified by the subsequent steps taken by the Special Rapporteur on torture. In particular, it is noteworthy that he issued a specific

[132] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/65/255, 6 August 2010, paragraphs 76–77.

[133] The right to freedom from torture and inhuman or degrading treatment is also recognised by regional conventions: see Article 3 of the European Convention for the Protection of Human Rights and Fundamental Freedoms of 1950; Article 5 paragraph 2 of the American Convention on Human Rights of 1969; Article 5, paragraph 2 of the African Charter on Human and Peoples' Rights of 1981; Article 4 of the Charter of Fundamental Rights of the European Union of 2000. According to Somerville, failure to treat pain is also a violation of patients' autonomy and their right to self-determination: Somerville (1994); Amon and Lohman (2011).

[134] Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, 14 January 2009, paragraphs 72, 74 e).

[135] Joint Statement of the Special Rapporteur on the question of torture and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health to the Chairperson of the of the 52nd Session of the Commission on Narcotic Drugs, 12 December 2008, paragraph 3, p. 4.

Report on Torture in Health Care Settings that focuses on certain forms of abuses that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman, or degrading treatment or punishment. In this report, the Special Rapporteur applied the torture and ill-treatment framework to the issue of denial of pain treatment and concluded that

> not every case where a person suffers from severe pain but has no access to appropriate treatment will constitute cruel, inhuman, or degrading treatment or punishment. This will only be the case when the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment; when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps to protect individuals' physical and mental integrity.[136]

Such an approach also finds support in some important statements of principle by the European Commission and Court on Human Rights, according to which lack of medical care in cases where someone is suffering from a serious illness or is exposed to 'severe or prolonged pain' could in certain circumstances amount to inhuman treatment contrary to Article 3 ECHR.[137]

4.3 The "Right Not to Suffer" as an Emerging International Human Right

In the last decade, there has been a widespread and growing support for recognition of palliative care status as a human right and States have been urged to fulfil their relevant obligations under international human rights law.

International organisations and the civil society advocate that palliative care be not considered a privilege for a few people but a right guaranteed at universal level. This view is based on the conviction that there is a basic right of the terminally ill and dying that guarantees respect for the fundamental and non-derogable right to human dignity. In this sense, although palliative care is generally described as an "inalienable element of the right of citizens to health care",[138] it is called for a

[136] Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53, 1 February 2013, p. 13, paragraph 54.

[137] European Commission on Human Rights, Tanko v. Finland, no. 23634/94, decision of 13 May 1994; European Court of Human Rights, McGlinchey and Others v. the United Kingdom, no. 50390/99, judgment of 29 April **2003**; see also N. v. the United Kingdom, no. 26565/05, judgment of 27 May 2008, where the Grand Chamber stated that "a lack of medical and palliative care . . . might be equally relevant to the finding of a separate potential violation of Article 3 of the Convention" (paragraph 21).

[138] Council of Europe, Recommendation Rec(2003) 24 on the organization of palliative care, adopted by the Committee of Ministers on November 12, 2003; see also Recommendation 1418 (1999), supra note 92.

consideration of palliative care in medical ethics not only as good medical practice but also as an imperative based on patients' rights,[139] including the right to a dignified death.[140]

It should also be noted that, following the seminal work of Margaret Somerville, a broad consensus has grown on the idea that the alleviation of suffering of the terminally ill is a human right[141] and that "the unreasonable failure to treat pain is poor medicine, unethical practice, and is an abrogation of a fundamental human right".[142] In the medical and legal literature an intense debate has developed to demonstrate effectively that this statement has a sound legal basis beyond rhetoric[143] and soft law.[144]

Still, it seems that the debate has focused in most cases on the assertion of a right to palliative care as a derivation of the right to health—and thus primarily based on Article 12 ICESCR, supported by the existence of the corresponding binding obligations clarified by the UN Committee in its interpretation of the normative content of the provision—while it seems clear that a broader right has emerged, that is to say the "right not to suffer", which is based on the inviolable principles of dignity, universality, and non-discrimination. According to a holistic approach, this right represents the synthesis of some fundamental rights applicable in the field of health care—human dignity, psychophysical integrity, health, freedom from torture or inhuman or degrading treatment—and is associated with the other basic patients' rights as recognised and protected by international human rights law.

[139] Brennan et al (2007), pp. 210–211: "Frustrated by the slow pace of medical, cultural, legal, and political change, many within the community of pain clinicians have begun to promote the status of pain management beyond that of appropriate clinical practice or even an ethic of good medicine. They advocate nothing less than a paradigm shift in the medical professions' perspective on pain management from simply good practice to an imperative founded on patient rights."

[140] Veronesi (2011), pp. 18–19. According to Brennan et al (2007), p. 210: "If there is a clear ethical duty to relieve suffering or to act virtuously by doing so, then one may argue that from that duty springs a right. The moral right to pain management emerges from, and is directly founded upon, the duty of the doctor to act ethically".

[141] Somerville (1992); "to leave a person in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights" (Somerville 1995); "the relief of severe, unrelenting pain would come at the top of a list of basic human rights" (Cousins 1999).

[142] Brennan et al (2007), p. 205.

[143] Brennan (2007), p. 494.

[144] See, for example, The Declaration on the promotion of patients' rights in Europe of 1994; the European Charter of Patients' Rights of 2002; the Cape Town Declaration of 2002; the Declaration of Korea of 2005; the Montreal Statement on the Human Right to Essential Medicines of 2005; the Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights of 2008.

5 Concluding Remarks

Universal human rights like dignity, health, physical integrity, and freedom from torture or inhuman treatment have special relevance to the end-of-life debate. Indeed, exploring biomedical, ethical, and legal issues surrounding the end of life through a human rights approach is pivotal to assessing the emergence or affirmation of new international biorights.

In the domains of patient autonomy and end-of-life decision-making and care, such rights as the right to informed consent, the right to die with dignity, and the right not to suffer have emerged over the last decades and gained increasing importance in the international legal order, also imposing specific obligations on States in respect of any and all individuals under their jurisdiction. These rights have also contributed to the setting of generally accepted human rights standards that offer authoritative guidance to both domestic legislators (in their difficult attempt to provide a satisfactory normative regulation to bioethical questions) and judges (in interpreting national law in harmony with international biomedical and human rights law).

However, it is to be questioned whether they are merely aspirational or legally enforceable rights. Several scholars have criticised the lack of appropriate jurisdictional guarantees associated to the so-called rights of fourth generation, and many share the view that it is the national judge who is best entitled to satisfy the need for justiciability of bioethical rights.[145]

Despite the absence of specific protective machineries devised by the relevant instruments of international biolaw, international biorights are not completely devoid of protection. At the regional level, for example, it has to be stressed that while the Oviedo Convention does not confer any contentious competence on the Strasbourg Court, the jurisdiction of this Court can nonetheless be exercised every time the violation of the rights protected by the Oviedo Convention also amounts to the breach of one of the rights guaranteed under the European Convention on Human Rights (as the several cases concerning informed consent and assisted suicide show).[146]

The same paradigm may apply at the universal level, although it is to be noticed that the contribution offered by the UN treaty-based bodies so far is almost non-existent, given the paucity of relevant case law developed by the Human Rights Committee with regard to Article 7 ICCPR and the complete absence of case law on

[145] Chapter VIII of the Oviedo Convention articulates the obligations incumbent on States Parties to guarantee a right to justice through the provision of an appropriate judicial protection for unlawful infringements and threats of infringement of the rights and principles set therein (Article 23), the adoption of sanctioning measures (Article 25), and the effective guarantee of redress (Article 24). Article 29 only confers on the European Court the competence to deliver advisory opinions on general legal questions concerning the interpretation of the Convention independently of any judicial proceedings pending before national courts (see also the Explanatory Report, paragraphs 164–165).

[146] See, for example, Negri (2013).

Article 12 ICESCR due to the fact that the Optional Protocol to the Covenant only entered into force on 5 May 2013. In the alternative, relevant violations of international biorights could be denounced through recourse to the "special procedures" of the Human Rights Council and of the Special Rapporteurs on the right to health and on torture. Although unable to reach a binding decision, these mechanisms may contribute significantly to the promotion and protection of these rights, which mirror not only the ethical and legal imperatives shared by the entire human community but also the values accepted by the international community as a whole, as embodied in universal human rights instruments.

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