

Minors and the decision-making process at the end of life: self-determination v. paternalistic protection. A short ethical-legal restatement

Silvia Salardi*

ABSTRACT: In bioethical issues, the major role played by the self-determination principle in the decision-making process has completely redefined the hierarchy of principles inspiring medical profession. Concretely, this means that in principle the decisional power is no longer exclusively exercised by doctors according to the well-known paternalistic model. In the new scenario, where self-determination plays a key role in health care relationships, the patient has the definitive say on acceptance or refusal of medical treatments. In fact, not only has the self-determination principle gained widespread acceptance and plays a leading role in ethical theories and medical ethics, but it has been legally ruled. The self-determination principle has undergone a paradigmatic process of extension and specification also with regard to minors' participation in the decision-making process at the end-of life. The aim of the paper is to restate the ethical and legal status of minors as regards decisions at the end of life. The first step will be contextualization of this extension with regard to decisions concerning minors' health within the framework of the European continental legal tradition. Second, the analysis will focus on the main legally binding and non-binding documents that contribute to outlining minors' rights at the end of life. Finally, it will argue that whenever minors are involved in sad and painful decisions like the ones at the end of life, parents or the legal representative and physicians should always try to include them in the decision-making process, that is, to decide 'with' and not 'for' the minor.

KEYWORDS: End of life debate; children's rights; self-determination principle; incompetent patients, minors.

SUMMARY: 1. Introduction – 2. Children's rights and self-determination at the end-of life in the legal context –3. 'Instilling' self-determination – 4. The 'reasonable' attitude.

1. Introduction

The end of life has been at the center of heated discussions since the second half of the XX century. Indeed, debates concerning this relevant bioethical field emerged from, and remain embedded in, the scientific and technological development of certain nations and

* Assistant Professor, Professorship of Philosophy of Law and Bioethics, School of Law, University of Milano-Bicocca. Mail: silvia.salardi@unimib.it. Essay selected by the Steering Committee among submissions to the Call for papers on End of life issues.

End of Life Issues

certain periods, above all Western countries in the post-war era.¹ Over the same period, the European political-legal framework undergoes a radical change and begins to take on the characteristics that will shape the contemporary European Constitutional Rule of Law. In particular, processes of democratization, humanitarianism, and civilization have operated as powerful forces of reform and have contributed to progressively extending new rights and entitlements to individuals.² Not only have these processes of transformation redefined the role of women and men in society and within the family,³ but they also contributed to legally extending and imposing the self-determination principle far beyond the familial context in order to allow other vulnerable and historically discriminated groups to exercise their self-determination in social and political interrelationships.⁴ In bioethical issues, for instance, the major role played by the self-determination principle in the decision-making process regarding health care relationships has completely redefined the hierarchy of principles inspiring medical profession. This change has brought about a distinctive mode of understanding and managing the physician-patient relationship. Concretely, this means that, in principle, the decisional power is no longer exclusively exercised by doctors according to the well-known paternalistic model. Instead, in the new scenario, where self-determination plays a key role in health care relationships, the patient has the definitive say on acceptance or refusal of medical treatments. In fact, not only has the self-determination principle gained widespread acceptance and plays a leading role in ethical theories and medical ethics, but it has been also legally ruled.⁵ What is exactly the function of the self-determination principle in solving conflicts within the health care relationships?

The self-determination principle serves as a meta-principle.⁶ It is useful to solve conflicts among the substantial moral principles that have shaped the physician-patient relationship since the earliest times. Needless to say, these principles are beneficence, non-maleficence, and eventually justice.⁷ Today, the self-determination principle is arguably the principle which holds everything together and enables to adequately balance different interests and values in an ethically pluralistic society.⁸ All

¹ As is well known, the bioethical debate developed in the USA in the early 1970s. In some national systems like the Italian one, the institutional debate started with some delay in the 1980s. See P. BORSELLINO, *Bioetica tra 'moral' e diritto*, Milano, 2009, p. 5 ff.

² On the social origin of human rights and on the strict connection between social changes and birth of new rights see for all N. BOBBIO, *Diritti dell'uomo e società*, in N. BOBBIO *L'età dei diritti*, Torino, 1990, 66-85. On the theory of fundamental rights see for all L. FERRAJOLI, *Diritti fondamentali*, Roma-Napoli, 2001. On the history of fundamental rights see A. FACCHI, *Una breve storia dei diritti umani*, Bologna, 2007. See also R. PANIKKAR, *Is the Notion of Human Right a Western Concept?*, New York, 1978.

³ Consider, for instance, the 1975 legal reform of the Family Law in the Italian legal system.

⁴ Consider the contribution of the civil rights movement to successfully challenge the openly racist institutions of the Jim Crow South and the more covert racism characterizing USA in the 1960s.

⁵ In Italy, for instance, the Constitutional Court stated that the self-determination principle is an autonomous right constitutionally protected by Art. 32 of the Italian Constitution. See the Constitutional Court decision 2008 n. 438. For more details on the legal basis of the self-determination principle in the Italian legal system see S. RODOTÀ, *Il diritto di avere diritti*, Roma-Napoli, 2012, especially p. 261 ff.

⁶ P. BORSELLINO, cit., p. 21. On the viability of autonomy in practice see C. E. SCHNEIDER, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*, New York, 1998.

⁷ For a detailed analysis of these principles see T. L. BEAUCHAMP and J.F. CHILDRESS, *Principles of Biomedical Ethics*, Oxford, 2013.

⁸ Generally speaking, the notion of 'pluralism' is the conception that there is a variety of different phenomena which cannot be reduced to a monistic perspective, see E. LECALDANO, *Dizionario di bioetica*, Roma-Napoli, 2002, 226-227. In bioethical debates, 'pluralism' has a stricter meaning than the general one. It refers to cultural or ethical pluralism as developed in Western countries from the XX century onwards, when ethical and cultural pluralism became a key feature of Western cul-

principles involved in bioethical debates concerning the end of life as well as other bioethical issues like genetics, neuroscience, assisted procreation and the like are *prima facie*. This means that they are not rigid or absolute. In other words, these principles are not set in stone and need to be specified in order to achieve more concrete guidance as well as be balanced to reach judgments in particular cases.⁹ A testament to this is the paradigmatic process of extension and specification undergone by the principle of self-determination, which has been increasingly interpreted (specified and balanced) in order to include, whenever possible, incompetent patients in the decision-making process concerning treatments to be administered to them.

In the light of the previous brief considerations, the aim of the paper is to shortly restate the ethical and legal status of minors' exercise of self-determination as regards decisions at the end-of life.

First of all, the paper will contextualize the extension of the right to self-determination with regard to decisions concerning minors' health within the framework of the European continental legal tradition. Second, the analysis will focus on the main legally binding and non-binding documents that contribute to outlining minors' rights at the end of life. Finally, it will argue that whenever minors are involved in sad and painful decisions like the ones at the end of life (when life is just at its beginning!), parents or the legal representative and physicians should always try to include them in the decision-making process, that is, to decide *with* and not *for* the minor. This term refers here to adolescents and children who are able in principle to participate in the decision-making process. I will come back to the specification of the category of minors in the following paragraphs.

2. Children's rights and self-determination at the end of life in the legal context

In her recent book entitled *Prima i bambini*,¹⁰ Elisabetta Lamarque traces a very incisive, comparative sketch of the legal impacts of the different conceptions of children's rights in the European continental legal tradition and in the Anglo-American legal tradition. In the European continental tradition, the assumption that children are entitled to all fundamental rights as adults are is grounded in the legal uncontroversial qualification of children as persons.¹¹ Possible divergences of opinions are limited to specific topics: for instance, in health care relationships, the tension can be between the child's extension of self-determination and the parents' or legal representative's power to decide for

ture. At the beginning of the XX century, indeed, Max Weber already envisioned a 'polytheism' of value fragmentation brought about by rationalization. See M. WEBER, *Die protestantische Ethik und der Geist des Kapitalismus*, *Archiv für Sozialwissenschaften und Sozialpolitik*, Bd. XX und XXI, 1904. See on the meaning of ethical pluralism in the bioethical debates today S. GBADEGESIN, *Bioethics and Cultural Diversity*, in H. KUHSE and P. SINGER (ed.), *A Companion to Bioethics*, Oxford, 1998, 24-31; H.T. ENGELHARDT, *Bioethics and Secular Humanism. The Search for a Common Morality*, Philadelphia, 1991; J. RAWLS, *Political liberalism*, expanded edition, New York, 2005.

⁹ See for instance, H.S. RICHARDSON, *Specifying Norms as a Way to Resolve Concrete Ethical Problems*, in *Philosophy and Public Affairs*, 19, 1990, 279-310; D. DeGRAZIA, *Moving Forward in Bioethical Theory: Theories, Cases, and Specified Principlism*, in *Journal of Medicine and Philosophy*, 17, 1992, 511-539.

¹⁰ E. LAMARQUE, *Prima i bambini. Il principio di best interests of the child nella prospettiva costituzionale*, Milano, 2016.

¹¹ On the contribution of Hans Kelsen to the clarification of the concept of person in the legal sphere see H. KELSEN, *Pure Theory of Law*, New Jersey, 2005, at p. 101 ff.

In the current legal system, inspired by the culture of fundamental rights of the modern European constitutionalism, the legal qualification of person serves as a scheme in order to authorize, oblige, prohibit, or forbid behaviors. In other words, in the current legal system, who is a person is not inscribed in nature. Conversely, person is a normative scheme of qualification of behaviors, and consequently persons' equality is based on the equal legal treatment of human conducts.

or against medical treatments.¹² In cases of divergent opinions, the question is not whether the child is or not a rights-bearer as the child *is* a rights-bearer. Rather, the main point is to inquiry into the restrictions on the exercise of the specific fundamental right involved in the specific case. This legal inquiry requires a case by case consideration of the child's capacity of discernment in proportion to his or her age and degree of maturity. Hence, in the European continental legal tradition children are undoubtedly entitled to legal (fundamental) rights as adults are.¹³ This means they are entitled to exercise their right to self-determination with regard to medical treatments.

Conversely, in the Anglo-American legal tradition children are very often 'just' entitled to *moral* rights.¹⁴ This because the whole debate on children's rights takes place within a constitutional tradition that recognizes as rights-bearer those who have full capacity of self-determination. In the Anglo-American legal tradition, independence and individual autonomy are indeed main features of rights-bearers, as Lamarque notes. In this view, therefore, it is very difficult to classify doubtfully autonomous and nonautonomous subjects within the category of rights-bearers. As Martha Minow observes, «children are the paradigmatic group excluded from traditional liberal rights.»¹⁵

This very brief account of the differences between civil law and common law understanding of children's rights is instructive in both legally contextualizing our discussion and also in reminding us that in the European legal context the principle of self-determination is strictly connected with the principle of dignity, which represents, as Stefano Rodotà aptly observes, a real revolution within the post-war legal systems.¹⁶ This principle shapes indeed the legal status of person and the general constitutional framework in Europe.¹⁷ And this principle applies also to children.

So, any reflection on children's self-determination in health care relationships in Europe has to be framed within this specific legal context and tradition. In so doing, arguments for or against direct involvement of children in the decision-making process at the end of their lives can be justified against legal norms and principles in force in the legal system following a biolaw's approach.¹⁸

3. 'Instilling' self-determination

Before dealing with the legal framework ruling children's exercise of self-determination in bioethical issues, let me clarify the complexity of the category termed 'minors'. As a matter of fact, the category

¹²See for instance, P. VERCELLONE, *Il corpo del minorenne: i trattamenti sanitari*, in G. COLLURA, L. LENTI e M. MANTOVANI (ed.) *Trattato di diritto di famiglia*, Volume secondo. Filiazione, II ed., Milano, 2012, pp 1261 ff.; M. PICCINNI, *Il consenso al trattamento medico del minore*, Padova, 2007.

¹³See for instance U. KILKELLY, *The Child and the European Convention on Human Rights*, Ashgate, 1999; G. VAN BUEREN, *Protecting Children's Rights in Europe-A Test Case Strategy*, in *E.H.R.L.R.*, 1996, 171-180; E. J. EBERLE, *Dignity and Liberty. Constitutional Visions in Germany and the United States*, Prager, 2002.

¹⁴On the distinction between legal and moral rights in the European tradition see U. SCARPELLI, *Diritti positive, diritti naturali: un'analisi semiotica*, in S. CAPRIOLI e F. TREGGIARI (ed.) *Diritti umani e civiltà giuridica*, Perugia, 1992, 31-44. In the Anglo-American legal tradition, rights are «claims by autonomous, self-determining, and self-interested individuals», N. MACCORMICK, *Children's Rights: a Test-Case for Theories of Right*, in N. MACCORMICK (ed.) *Legal Right and Social Democracy: Essays in Legal and Political Philosophy*, Oxford, 1984, 154-164.

¹⁵M. MINOW, *Making All the Difference. Inclusion, Exclusion, and American Law*, U.S. and Canada, 1990, p. 283.

¹⁶S. RODOTÀ, cit., p. 183 ff.

¹⁷On the strict connection between the concept of person and fundamental rights see R. ESPOSITO, *Terza persona*, Torino, 2007.

¹⁸P. BORSELLINO, cit.

of minors includes a variety of subjects with different features. It ranges from newborn babies¹⁹ to adolescents, including disabled children.

The difference between these subjects is not just a matter of age, of course. Nonetheless, age impacts greatly on the response to administration of drugs and other treatments influencing the ethical debate. It also impacts on the degree of maturity and the capacity of discernment. This variety of situations would require separate investigation. However, as many institutional reports at the European and national level discuss in detail problems regarding end of life decisions concerning different categories of minors, in particular administration of palliative care in terminal children,²⁰ it is not my intention here to discuss the peculiarities of each category. Instead, I will focus on children and adolescents, that is, on minors who are able in principle to participate in the decision-making process. In so doing, the inquiry into the role of self-determination within the minor-physician relationship and the minor-family relationship can hopefully produce fruitful results.

A second brief, albeit important, remark concerns the typology of medical treatments that are highly ethically and legally controversial. To talk about consent or refusal of medical treatments at the end of life means indeed to primarily focus on the possibility of withdrawing or withholding life preserving medical treatments.²¹ Indeed, consent to life sustaining medical interventions is usually not perceived as ethically and legally so problematic as their refusal is, irrespective of the age of the patient involved in the decision-making process. I do not delve into this aspect here as this point would broaden the horizons of my discussion far beyond what is of interest. The point I want to make with this specification is that also in case of minors the main ethical controversies and divergences of opinion regard refusal of life sustaining treatments when they appear to be futile or of no utility at all. In this regard, there are many problems to deal with: for instance, the case of divergent positions between the child and the parents or legal representative as far as decisions of withholding or withdrawing life sustaining treatments is concerned; in particular, do minors have the right to refuse such treatments? How and to what extent should minors be informed?

In order to answer these challenging questions, the inquiry into legally binding and non-binding documents will be very useful. I will select some relevant documents explicitly ruling the position of minors, in order to avoid the analysis being unnecessarily too extensive.

Consider, first of all, the legally relevant, albeit not binding, 2014 'Guide on the decision-making process regarding medical treatment in end-of life situations' drawn up by the Committee on Bioethics (DH-BIO) of the Council of Europe in the course of its work on patients' rights and with the explicitly

¹⁹ With regard to preterm babies many ethical questions arise when it ought to be decided about utility or futility of intensive care. See, especially with regard to the robust studies of decisions about neonatal end of life in the Netherlands, E. VERHAGEN, *Neonatal Euthanasia: Lessons from the Groningen Protocol*, in *Seminars in Fetal & Neonatal Medicine*, Elsevier, XXX, 2014, 1-4. In Italy, after promotion of the Groningen Protocol a heated debate started, see M.S. PIGNOTTI, *Il convegno di Firenze ed il dibattito sui grandi premature*, in *Bioetica*, 1-2, 2009, 27-36, della stessa autrice *La Carta di Firenze ha il sostegno dei documenti internazionali: un primo bilancio scientifico*, in *Bioetica*, 17:3, 553-562. See also NUFFIELD COUNCIL ON BIOETHICS, *Critical Care Decisions in Fetal and Neonatal Medicine: ethical issues*, London, 2006.

²⁰ See Comitato Nazionale per la Bioetica, *Sedazione palliativa profonda continua nell'imminenza della morte*, 2016; EAPC European Association for Palliative Care, *IMPACT: standard per le cure palliative pediatriche in Europa*, 2007; Ministero della Salute, *Documento tecnico sulle cure palliative pediatriche*, 2008; Ministero della Salute, *Cure palliative rivolte al neonato, bambino e adolescente*, 2006; ASSM, *Cure palliative*, Basilea, 2013.

²¹ On the distinction between withholding (not starting) and withdrawing (stopping) and their ethical meaning see T. L. BEAUCHAMP and J.F. CHILDRESS, cit., p. 158 ff.

declared intention of facilitating the implementation of the principles enshrined in the Convention on Human Rights and Biomedicine (Oviedo Convention, ETS n. 164, 1997).

For this purpose, right at its beginning the Guide presents «[...] the principles that can be applied to the decision-making process regarding medical treatment in specific end-of life situations».²² And the first principle taken into account is the principle of self-determination or autonomy. It is highlighted that *free and informed consent* represents the means by which autonomy can be implemented. The Guide explicitly refers to minors in just one point, when the focus is on the role of legal representatives. After highlighting the differences that may concern the role and power of legal representatives in different national systems, the Guide clearly states that «the legal representative can act only in the interests of the protected person. Whatever the legal system, in accordance with the principle of respect for the person's dignity, the fact that there is a legal representative should not exempt the doctor from involving the patient in the decision-making process, if the latter, despite lacking legal capacity, is able to participate him or herself. It is widely accepted that the objection of persons who lack the legal capacity to give their free and informed consent to a medical intervention should always be taken into account. *In the case of minors, their opinion shall be viewed as an increasingly decisive factor, in proportion to their age and their capacity for discernment.*»

The position of the Council of Europe with regard to minors' possible participation in the decision-making process is consistent with the general legal recognition that minors should always take part in the information process and be truthfully and completely informed about administration of medical treatments. This represents indeed an important and unavoidable step in the progressive development of minors' decisional autonomy.²³ If we now turn to consider a legally binding document like the Oviedo Convention (Convention on Biomedicine and Human Rights), Art. 6 clearly states that «where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorization of his or her representative or an authority or a person or body provided for by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.»

In the Italian context, despite the lack of an *ad hoc* regulation concerning the end-of life, in particular there is currently no explicit legislation concerning advance directives and informed consent, there is no legal vacuum. The abovementioned documents shape the case by case legal interpretation on the part of the courts along with specific Italian rules. These rules are mainly constitutional provisions: Art. 32 concerning the right to health and voluntariness of treatments, Art. 13 concerning personal freedom, and Art. 2 concerning protection and promotion of inviolable rights on the part of the institutions. In particular, in Art. 2, the Italian Constitution reinforces, more than others do, the paramount protection of the person. Besides the relevance attributed to the dignity of the person, it pays

²² At p. 7 of the 2014 *Guide on the decision-making process regarding medical treatment in end-of life situations*.

²³ See for instance, the position of the Italian Comitato Nazionale per la Bioetica in its Report entitled *Orientamenti genetici per i test genetici*, 1999. See also the trend in clinical trials, Art. 29 of the new clinical trials Regulation 536/2014 clearly states that «this Regulation is without prejudice to national law requiring that, in addition to the informed consent given by the legally designated representative, a minor who is capable of forming an opinion and assessing the information given to him or her, shall also assent in order to participate in clinical trial.» See also the Italian Law on abortion n. 194/1978.

specific attention to the developing process of the person, including the child, and provides protection of the person, within the “social groups where human personality is expressed.”²⁴

In addition to these general legally binding rules, the 2014 Code of medical ethics commits the doctor to informing the minor in order to allow him or her to understand his or her health condition (Art. 33). Moreover, according to the Code the physician ought to take into account the minor’s opinion in the decision-making process (Art. 35).²⁵

The legal trend emerging from the rules as referred to above is precisely directed towards implementation and fulfillment of the self-determination principle also with regard to minors. Justification of this legal trend is grounded in a specific interpretation of the respect for self-determination at the ethical level. As regards this point, Beauchamp and Childress clearly note that «respect for autonomy in health care relationships requires much more than avoiding deception and coercion. It requires an attempt to *instill*²⁶ relevant understanding, to avoid forms of manipulation, and to respect persons’ rights.»²⁷

With regard to minors the operation of ‘instilling’ awareness and understanding becomes much more important, especially when the child is faced with his or her end of life. Not only, in this painful case, is truthful information to the child an ethical and legal duty, but it is useful to implement the best interests of the child, including to know his or her clinical situation. This knowledge is a precondition that can allow to elaborate the complex emotional and psychological situation in which he or she finds himself or herself. In this way, he or she will not run the risk of feeling guilty, excluded, and not supported. As a matter of fact, if it is true that (perhaps) truth hurts, lies hurt even more. In fact, the risk is to fall, albeit sometimes unwittingly, into the trap of ‘the conspiracy of silence’. This has historically played a major role in the attitudes of physicians and family members towards the patient, including children, with the well-known negative impacts on the quality of his or her life.²⁸

²⁴ See for instance V. ONIDA, *Le Costituzioni. I principi fondamentali della Costituzione italiana*, in G. AMATO and A. BARBERA (ed.), *Manuale di diritto pubblico*, Bologna, 1997, 103-104; M. AINIS, *I soggetti deboli nella giurisprudenza costituzionale*, in *Pol.dir.*, 1999, 25-52. Protection ‘within’ the social groups comprises also protection ‘against’ groups in which a person is included irrespective of his or her will, as is the case of a child within his or her family.

²⁵ In 2014 the Charter of the rights of the dying child (Carta dei diritti del bambino morente, Carta di Trieste) was published. The Charter provides 10 rights and highlights the relevance for the child of participating in and being an active actor of the decision-making process. Before this Charter specifically dedicated to the children, in 1997 the C.E.F.F. released the Charter of the rights of the dying (Carta dei diritti dei morenti).

²⁶ Italics inserted by the author.

²⁷ T. L. BEAUCHAMP and J.F. CHILDRESS, cit., p. 121.

²⁸ See on the problem of initiating discussion about end of life for instance R.B. BALABAN, *A physician’s guide to talk about the end of life care*, in *J Gen Intern Med*, 15:3, 2000, 195-200. See also N. BERLINGER, B. JENNINGS, S. M. WOLF, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, Oxford, 2013. See on the positive effects of disclosure M. LIPSON, *What Do You Say to a Child with AIDS?*, in *Hastings Cent Rep*, 32:2, 1993, 6-12; M. BLUEBOND-LANGER, *The Private Worlds of Dying Children*, Princeton, NJ, 1978; S. DUNLOP, *The Dying Child: Should We Tell the Truth?*, in *Pediatric Nurs.*, 20:6, 2008, 28-31; L. A. SLAVIN, J.E. O’MALLEY, G. P. KOOSHER, D. J. FOSTER, *Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-Term Adjustment*, in *Am J Psych.*, 139:2, 1982, 179-183. See also the Report of the Council on Ethical and Judicial Affairs, CEJA Report1-I-10, *Pediatric Decision-Making*, 2010 released by AMA (American Medical Association).

4. The ‘reasonable’ attitude

When decisions at the end-of life concern children, to act in a ‘reasonable’²⁹ way may not only seem utopic, but it is also to some extent neither expected nor demanded. As it has been observed, historically, children with terminal illness were given limited information about their diagnosis and prognosis, due mainly to a desire to protect them from emotional burdens associated with illness and a belief, albeit unfounded, that children would not understand their situation.³⁰ Reasons for excusing behaviors and decisions that would not be excused in other circumstances are of a different kind, but in the most of the cases they play at the psychological and emotional level. Let me explain this with the following example.

When the ‘Stamina case’ made headlines in the Italian and international newspapers some years ago,³¹ Italian institutions made decisions concerning enrollment of minors (very young children in that case with degenerative diseases) in the ‘trial’ process mainly on the basis of emotional pressure that media contributed to heating up. So, court decisions justified their arguments in favor of prolonging administration of stem cells elaborated with the ‘Stamina method’, in cases in which the administration had already started, on the basis of an allegedly constitutionally provided ‘right to hope’. This is however not a fundamental right constitutionally protected as some judges pretended in their arguments.³² In the ‘Stamina case’, institutions preferred undoubtedly to follow the ‘emotional’ way,

²⁹ The arguments I propose in this paragraph with regard to the ‘reasonable’ attitude are inspired by J. RAWLS, *Justice as fairness*, in *A Theory of Justice*, Cambridge, 1971.

³⁰ See L. S. WIENER, M. A. MELLINS, S. MARHEFKA, H. B. BATTLES, *Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions*, in *J Dev Behav. Pediatr.*, 28:2, 2007, 155-166; P. S. HINDS, D. DREW, L. L. OAKES, M. FOULADI, S. L. SPUNT, C. CHURCH, W. L. FURMAN (2005), *End-of-life Care Preferences of Pediatric Patients With Cancer*, in *Journal of Clinical Oncology*, 23:36, 9146-9154.

³¹ Davide Vannoni, founder of the Stamina Foundation, pretended to cure patients suffering from neurodegenerative diseases by converting mesenchymal stem cells into neurons. The real content of the ‘cocktail’ of what has been administered to the patients was kept secret and could not be scientifically validated. After intense pressure from the media the Italian government decided in 2013 to start testing the Stamina ‘therapy’. Many institutional actors were involved in this case, national and European. See at the EU level, for instance, the case *Durissimo v. Italy* decided by the European Court of Human Rights, 6 May 2014 (decision on the admissibility). As reported in the Factsheet-Health, May 2016, of the European Court of Human Rights, this case concerned the refusal by the Italian courts to authorize the applicant’s daughter to undergo compassionate therapy (experimental treatment known as the “Stamina” method) to treat her degenerative cerebral illness. The therapy was undergoing clinical trials and, under a legislative decree, was subjected to restrictive access criteria. The applicant alleged in particular that the legislative decree in question had introduced discrimination in access to care between persons who had already begun treatment prior to the entry into force of the decree and those who – like his daughter – were not in that situation. The Court declared the application inadmissible (manifestly ill-founded) under Article 8 (right to respect for private and family life) and under Article 14 (prohibition of discrimination) taken in conjunction with Article 8 of the Convention. On the one hand, noting in particular that a scientific committee set up by the Italian Ministry of Health had issued a negative opinion on the therapeutic method in issue and that the scientific value of the therapy had not therefore been established, it found that the interference in the right to respect for the applicant’s daughter’s private life, represented by the refusal to grant the request for medical therapy, could be considered as necessary in a democratic society. On the other hand, even supposing that the applicant’s daughter was in a comparable situation to that of the persons who had received exceptional judicial permission to undergo treatment, the Court could not conclude that the justice system’s refusal to grant her permission had been discriminatory. Thus, in particular, the prohibition on access to the therapy in question pursued the legitimate aim of protecting health and was proportionate to that aim. Moreover, sufficient reasons had been given for the Italian court’s decision, and it had not been arbitrary. Lastly, the therapeutic value of the “Stamina” method had, to date, not yet been proven scientifically. reasons had been given for the Italian court’s decision, and it had not been arbitrary. Lastly, the therapeutic value of the “Stamina” method had, to date, not yet been proven scientifically.

³² See for all the ordinance of the Court of Gorizia May 9th, 2013. For a complete overview of the Stamina case see <http://www.biodiritto.org/novita/news/item/330-dossier-staminali>, last accessed August 30th, 2016.

instead of respecting the rules concerning clinical trials. Hence, they did not act in a 'reasonable' way. Why is this case relevant for the current discussion?

Because it has been a paradigmatic example of how misunderstandings and lack of clear information about scientific advances, medical treatments, compassionate use of drugs and the like result in an overall confusion that impacts greatly on the exercise of the right to self-determination of those involved in health care relationships. Not only were physicians obliged to administer a treatment scientifically neither valid nor under validation in violation of their professional autonomy, but the obstinate refusal on the part of the founder of the Stamina foundation of disclosing the content of the 'cocktail' of drugs administered to the patients/children hindered the free and autonomous choice of the parents. In that case, they lacked truthful and complete information useful to develop the necessary awareness in order to decide whether or not to continue administration of the 'therapy' to their children. In addition, the institutional attitude contributed to confusion as institutional actors behaved as though there was no legal framework to decide otherwise, that is, to decide 'reasonably'.

But what does it mean to act in a 'reasonable' way when it comes to decisions at the end of life? And especially when a minor is involved?

First of all, at the institutional level, to act 'reasonably' means to act accordingly to the legal framework provided by the legal order, if present. And in the above mentioned case, there were legal rules concerning both clinical trials and compassionate use of drugs.³³ These rules were intended to protect patients enrolled in clinical trials: first of all, by guaranteeing transparency of methods and protocols as well as truthful information about side effects, risks, and possible sponsors with economic interests in the method; second, by respecting the scientific method based on the intersubjective control; and eventually by protecting against arbitrary administration of drugs. Hence, the values underpinning these rules were compliant with the framework of fundamental rights ruling the health care relationships today. To respect them, despite the emotional pressure, would have meant to act reasonably as well as respectfully towards all the actors involved, especially towards children. Indeed, respect for this legal framework would have protected and promoted the best interests of the children by providing truthful information to the parents about the real impacts of the proposed therapies.

Second, to act 'reasonably' within the physician-patient relationship and within the family-patient relationship has a precise meaning. It means that the decision-making process should be grounded in the idea of deciding 'with' and not 'for' the patient. Of course, this is not so simple to do, especially when the patient is a minor, as adults tend to think they have to protect him or her. This is both true for physicians and parents. In the former case, the authoritative position of the physician allows him or her (he or she assumes!) to determine the patient's best interests without including the patient in the decision-making process, and this attitude is likely to be stronger towards minors. In the latter case, parents act according to the traditional paternalistic view, that is, they assume they know what the best interests of their children are and act accordingly to protect their welfare, so they do not let

³³ At that time in Italy the regulation concerning clinical trials was the Legislative Decree n. 211/2003, and compassionate use of drugs was regulated by a Ministerial Decree dated May 8th, 2003.

the children participate in and make decisions.³⁴ However, in the current social system, to 'instill' self-determination in children, being ill or not, is part of the parental (and in general of adult's) contribution to the child's process of personal development. The fact that a child is nearing the end of his or her life does not mean he or she is no longer entitled to the same rights as healthy children are. Indeed, no legal or moral rule provides such an exception today. Both parents and physicians should therefore try to put aside their personal emotions, interests, and fears and listen to the child's own ones. It is a big effort required, of course. However, this is the adequate way to guide the child through development of self-determination and to not impose *tout court* decisions and values from an external source, especially in such critical situations. To try to act in this way requires a great sense of responsibility as well as a particular capability to discern within the personal hierarchy of values and manage one's emotions. The capability of acting 'reasonably' is a 'virtue' that one should try to develop in order to prevent and minimize the moral tension that characterizes end of life decisions.

In general, a person acts in a reasonable way insofar he or she is aware of his or her own intellectual, emotional, and moral prejudices and is able to assess and balance interests of another person as he or she evaluates his or her own ones. In case of minors, this is more difficult as the emotional and psychological pressure is increased by the fact that a young or very young human being is involved. However, minors deserve to be treated respectfully till the end of their lives, even when this occurs earlier than expected and hoped. So, considerations of the degree of maturity and capacity of discernment should always be the criteria against which to measure to what extent and how a child should be involved in the information process and consequently in decision-making. Respect for the child as a person at the end of life means to recognize his or her dignity. This implies the inevitably duty of adults, being physicians or parents, to avoid unjustified intentional overriding of the child's opinions and preferences, and consequently of his or her informed, voluntary, and free choice. In all those cases in which a minor is likely to reach adequately reasoned decisions, the self-determination principle should be specified and balanced against other principles like the principle of beneficence in order to warrant the child's active participation in the decision-making process. This ethical duty has been legally ruled as referred to earlier. Hence, the next major step will be to concretely and widely transpose it into medical practice. In order to rapidly move forward and achieve this goal, cultural and educational intervention programs are unavoidable.

As regards physicians, a possible strategy is the progressive and increasing diffusion of continuing professional education specifically focused on ethics and psychological aspects of communication. An important, albeit still insufficient, stage further in this process is currently represented by the regional implementation of the 2014 State-Regional Authority Conference Agreement concerning basic mandatory education for professionals in palliative care. This Agreement specifies indeed the need for a basic knowledge of the ethical aspects concerning health care relationships and foster better education in this direction. Consider, for instance, that on the basis of the abovementioned Agree-

³⁴ For interpretations of (hard) paternalism as insult, disrespect, and treatment of individuals as unequals see R. DWORKIN, *Taking Rights Seriously*, Cambridge, 1999. See also J. F. CHILDRESS, *Who Should Decide? Paternalism in Health Care*, New York, 1982. See also D. VANDEVEER, *Paternalistic Intervention: The Moral Bounds on Benevolence*, Princeton, 1986; J. KLEINIG, *Paternalism*, Totowa, 1983; E. H. LOEWY, *In Defence of Paternalism*, in *Theoretical Medicine and Bioethics*, 26, 2005, 445-468.

ment, Regione Lombardia is elaborating a basic three-year course of education concerning different questions in palliative care to be started in fall this year. What is of interest here is the attention paid by this regional initiative to ethical aspects, for instance, to the question of ethical conflicts and possible tools for their solution.

As regards the public, specifically family members, only given programs for advancement of cultural standards concerning the problematic field of the end of life along with transparency of medical practices could be useful to help parents or legal representatives to overcome or at least control the moral tension with their children, and in general moral tensions between family members and patients. Again, a first step could be a widespread diffusion (more than what has been done till present days in our national context) of public events in which experts like bioethicists, philosophers, jurists, and enlightened physicians explain the state of the art of end of life decisions in our national and European system with the real (not ideologically³⁵ influenced) aim of removing the 'veil of ignorance' in which individuals seem to (still often) unwittingly find themselves.

³⁵ 'Ideological' has here a precise meaning: «Ideology [...] veils reality either by glorifying it with the intent to conserve and to defend it or by misrepresenting it with the intent to attack, to destroy, and to replace it by another.» See H. Kelsen, *op. cit.*, p. 106.