

I. THE ISSUES

Drawing the Boundary Lines of Humans: In Whose Bailiwick?

AMEDEO SANTOSUOSSO
Universidad de Pavia

VALENTINA SELLAROLI
Universidad de Pavia

ILJA RICHARD PAVONE
Consejo Nacional de Investigación de Roma

1. A MATTER OF SOVEREIGNTY

In recent decades, human biological limits look like a field where battles are fought, peace treaties signed and boundary lines drawn. All this, it is well known, depends on extensive application of human genetics, new biotechnologies and medical techniques in health services, biological research and society. Human individuals as biological entities are deeply involved. Artificial ventilation, new resuscitation techniques, artificial nutrition and hydration and so on have prolonged people's lives. Assisted reproduction techniques have widened the possibilities of bearing children. Furthermore, individuals are given the possibility to radically change their physical state even when there is no disease (at least in traditional terms), such as in the case of transsexuals who want to alter their physical condition to match their psychological sexual identity. Of course the list of biotechnological opportunities grows longer every day with the addition of new items such as genetic manipulation and interaction, brain-machine and brain-web. As a result, the possibility of deciding on human biological limits and picking out what to do is further increased.

Such novelties may be regarded from many different points of view. Among them we shall adopt a legal viewpoint and focus our attention on a matter of sovereignty. In other words, once *nature* is out of play and is no longer able to tell us what to do or not to do, the question *Who has the power and is entitled to draw the boundary line of the human individual?* becomes crucial and opens many other questions, which stem from this basic

inquiry. *Is there any line not to be violated? Should the line be drawn once and for all or in relation to each specific individual? Is it a matter of scientific knowledge? Is it a matter of law or of religion and culture? Are the law-religion relationship and the secularity of public institutions involved? And assuming it is a matter of law, which kind of law should it be? Are we referring to national, supranational (i.e. the European Union) or global law? What should the content of such a law be? And so on.*

In this paper the issue is explored in relatively traditional fields such as end-of-life decisions, beginning-of-life decisions and the case of sex re-assignment through radical surgery¹. The focus will be mainly on relevant European case law and legislation. At the end some remarks and provisional replies are outlined.

2. WITH THE *IF* (ENDING OF LIFE) NOT BEING AT ISSUE, LET US TALK ABOUT THE *WHEN* AND THE *HOW*

The refusal of life-saving treatments is the extreme point of informed consent legal and ethical theory, and borders on the issues of letting die, assisted suicide, murder of consenting persons, and euthanasia cases.

At the beginning of the second Millennium the case of Ms B (UK)² takes a forefront. Ms B, born in 1958, suffered a haemorrhage in the neck portion of her spinal column on 26 August, 1999. She was admitted to hospital and a cavernoma was diagnosed, a condition caused by a malformation of blood vessels in the spinal cord. Informed by doctors of the possibility of severe disability, she executed a living will (September 1999) stating that, should the time come when she was unable to give instructions, she wished for treatment to be withdrawn if she was suffering from a life-threatening condition, permanent mental impairment or permanent unconsciousness. In 2001 she started having respiratory problems and was treated with a ventilator, upon which she has been entirely dependent ever since. She told doctors she had a Living Will on file and did not want to be ventilated. The doctors told her the Living Will was not specific enough to authorise withdrawal of ventilation. After a neurological surgical operation that did not significantly improve her condition, she asked for the ventilator to be switched off; on April 2001 she gave formal instructions to the hospital via her solicitors to this effect. Then she claimed before the High Court that the invasive treatment, which was currently being given by the respondent by way of artificial ventilation, was an unlawful trespass. The main issue was whether Ms B was competent and able to make her own decision about her medical treatment. The High Court ruled that Ms B was a competent adult patient and her doctors had unlawfully overridden her refusal of life-saving ventilation.

¹ A similar approach has been explored in A. Santosuosso, *Corpo e libertà. Una storia tra diritto e scienza*, Milano, Raffaello Cortina, 2001; A. Santosuosso, *Persone fisiche e confini biologici: chi determina chi*, in *Politica del diritto*, 2002, n. 3, pp. 525-547.

² [Ms b and an nhs hospital trust [2002] ewhc 429 (fam)].

The judgment confirms the right of competent patients to refuse medical treatments even if the result is death³. A seriously physically disabled patient who is mentally competent has the same right to personal autonomy and to make decisions as any other person with mental capacity. The view of the patient may reflect a difference in values rather than an absence of competence and the assessment of capacity should be approached with this firmly in mind. The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment in answering the primary question of whether the patient has the mental capacity to make the decision.

Two recent cases, the Italian Piergiorgio Welby's case and the Spanish Echevarria case, are very similar to Ms B from a legal point of view, even if the disease was different.

Piergiorgio Welby was a sixty-year-old man who suffered from muscular dystrophy since he was a teenager. In recent years he had several times expressed the refusal of a ventilator machine should he have respiratory distress. When, after some time, he had such a crisis, his wife, who is Catholic, violated his will and took him to the hospital where they started ventilating him. For some years after that, he accepted his condition under artificial ventilation. Meanwhile the disease worsened and, in 2006, he once again refused the ventilator continuously and publicly. He asked the Court of Rome to authorize his physician to discontinue the ventilator under sedation.

The judge rejected and took a position that many leading scholars considered inconsistent. According to the judge, Mr Welby had the constitutional right to have his life-support machine switched off but, lacking a specific Act regulating the situation, doctors would be legally obliged to resuscitate him. The Prosecutor, who is a party in this kind of proceedings (even if they are civil and not criminal), appealed against the Court's refusal on the grounds that it was against Welby's constitutional rights. The Court of Appeal not having decided yet, a physician (Dr Mario Riccio) sedated Welby and then disconnected the ventilator, thus helping him die (December 2006). The doctor denied having committed euthanasia and affirmed he had simply fulfilled the patient's legal right to refuse treatments.

On its part, the Catholic Church took a highly controversial position and denied a religious funeral "because, unlike the cases of suicide, in which it is presumed there was an absence of the conditions for full awareness and deliberate consent, Mr. Welby repeatedly and publicly affirmed his desire to end his life, something that is incompatible with Catholic doctrine". Nevertheless thousands of people participated in the non-religious funeral. A different voice within the same Church is that of the former archbishop of Milan, Carlo Maria Martini, who stated that every seriously ill person has at any moment the right to interrupt the care that keeps him alive without any hope.

³ For a commentary on the above mentioned case-law, see B. Dimond, *Healthcare Professionals and euthanasia: current law in the UK*, in *British Journal of Nursing*, 2004, p. 922-924; P. Singer, *Ms B and Diane Pretty: a commentary*, in *Journal of Medical Ethics*, 2002, p. 234 ss., A. Slowther, *The case of Ms B and the Right to Die*, in *Journal of Medical Ethics*, 2002, p. 243 ss.

After Welby's death, the Prosecutor appointed a physician as expert witness in order to establish whether the cause of death was the sedation or the lack of oxygen. The expert witness ascertained that the cause was the lack of oxygen and that sedation simply helped Welby not to suffer the symptoms of dyspnea. The Prosecutor, therefore, dismissed the prosecution, arguing that Welby had a constitutional right to refuse ventilation, as a medical treatment. The judge, who in the Italian system has the final word, disagreed and ordered the Prosecutor to charge the doctor of murder of a consenting person. The reason was that if, on the one side, the patient has a constitutional right to self-determination, on the other side, the right to life always overrides it.

In a further development of the proceedings the judge finally decided to completely discharge Mario Riccio because "his act was not a crime, as he had the duty to execute the patient's will." That is, Dr Riccio did not commit a homicide because Piergiorgio Welby had, in light of Italian law, the right to ask for his life-saving medical treatment to be withdrawn⁴.

In the same time period the government of the Spanish region of Andalusia authorized a woman suffering from muscular dystrophy (like Welby) to disconnect the respirator that was keeping her alive. The Committee on Ethics of the Council of Andalusia announced its support for the request by Inmaculada Echevarria and argued that it was a case of refusal of further treatment and not a case of active euthanasia, which is illegal in Spain. The Catholic Church, however, opposed the decision, with Cardinal Antonio Canizares describing it as a case of euthanasia and as an "attack against dignity and human life". The Church's disapproval prevented Echevarria from dying at the Catholic hospital where she had been bed-bound for a decade and where she had wanted to pass away. Inmaculada Echevarria, 51, died on 15 March, 2007 at a public hospital in the southern city of Granada, where doctors sedated her and disconnected her breathing machine.

3. SOME REMARKS ON MS B, WELBY AND ECHEVARRIA CASES

The above cases raise the same question: whether a competent disabled person has the right to refuse life-saving treatments and to obtain from third parties the absolutely essential minimum cooperation in order to realize his or her will.

In the UK the patient's right of veto appears absolute: "This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent [...]"⁵. A competent person is sovereign in the territory of his own body without any possibility of interference from the doctors, the State or religion.

⁴ Tribunale di Roma, Giudice dell'udienza preliminare, 23 luglio/17 ottobre 2007.

⁵ Lord Donaldson of Lynton M.R. in *Re T. (Adult: Refusal of Treatment)* [1993] Fam. 95, 102, following *Sidaway v Guardians of Bethlem Royal Hospital and Maudsley Hospital* [1985] A.C. 871, pp. 904-905.

Since the 1980s, Italian case law has recognized the right of a competent adult to refuse medical treatment. The early occasions for Courts decisions were given by the refusal of blood transfusions on the part of adult Jehovah's Witnesses. However, the leading case regards an elderly woman who died after a surgical operation performed without her consent (1990). She had refused to be submitted to colostomy (the surgical construction of an artificial excretory opening from the colon) and consented to a less invasive operation. Waking up after anaesthesia and finding herself with an artificial excretory system, she fell into a deep depression, which, in addition to some clinical complications, led her to death. The judges sharply established that it is the exclusive power of each patient to decide whether to submit himself or herself to any kind of medical treatment and that the physician does not have autonomous power of decision against the patient's will. This basic rule has not been overturned in further cases.

The Constitutional grounds of patients' rights is the basic personal freedom⁶ and the right to health⁷. Legal scholars and the Courts have argued that the right to health, as a right to receive medical treatments, implies the right to accept or to refuse any kind of treatment, even if life-saving. This is the only possible reasoning, assuming that we want to avoid the paradox that the *right* to health automatically entails the *duty* to be healthy. Furthermore, Article 32 also confirms that nobody can be forced to receive medical treatments, unless such a possibility is explicitly foreseen by an Act of Parliament and only on a *not to harm others* basis.

This basic constitutional position has been shared since 1984 by leading jurists, included the very influential and fervent Catholic Italian professor of criminal law, Federico Stella⁸, and was further confirmed by the National Bioethics Committee (1992) under the presidency of Adriano Bompiani, who is a well-known Catholic physician as well.

Nonetheless, every time a case of the refusal of life-saving treatment occurs, the discussion goes back to basics. Something like that happened in late 2006, when the Piergiorgio Welby case arose. The Catholic Church does not recognize the right to self-determination whenever it is a matter of life and death⁹, arguing that life cannot be consi-

⁶ Article 13 "Personal liberty is inviolable." English versions of the Italian Constitution are available at the Italian Constitutional Court website http://www.cortecostituzionale.it/eng/testinormativi/costituzionedellarepubblica/costituzione_parte_i.asp or at http://www.servat.unibe.ch/law/icl/it00000_.html

⁷ Article 32 "The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent. No one may be obliged to undergo particular health treatment except under the provisions of the law. The law cannot under any circumstances violate the limits imposed by respect for the human person".

⁸ F. Stella, *Il problema giuridico dell'eutanasia: l'interruzione e l'abbandono delle cure mediche*, in *Rivista italiana di medicina legale*, 1984, p. 1007.

⁹ This is the "political" position that the Catholic Church takes in controversial cases, even though the recent Catechism (1993) seems to be more respectful of patient's decisions: "discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment" [...] "the decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected". (2278)

dered under the full control of individuals. The legal world is split into two positions; the first one is fully respectful of the individual's constitutional freedom to decide on treatments to be administered on her or his own body, whilst the second one, in line with Catholic position, considers best interest or right to life (see below) as prevalent over self-determination, even when there is no real hope of regaining health or life. In the first case the patient is sovereign (as in the UK); in the second case she or he shares sovereignty with the State and the judiciary (which can keep her or him alive against her or his will), the doctors (who have the power to say what is forbidden from a deontological point of view) and the Church, which in countries like Italy exerts an influence upon society and even (it would appear at times) upon judges. In the end, patient's sovereignty sometimes seems to disappear and after a while to re-emerge in judicial decisions, as in the final decision discharging doctor Riccio in the Welby case.

In Spanish law, not different from Italian or UK law, any medical treatment requires the patient's informed consent that may be revoked whenever she or he wants. That is what happened in the case described above. Although the final result is similar to the UK case, the Echevarria case has some peculiarities: a) the case being solved by ethical committee and administrative body, no Court was involved; b) the Catholic Church's position (similar to the Welby case) did not paralyze either the public institutions' decision or the doctors' attitude. Because of all this, the Echevarria case shows an even deeper social and cultural acceptance of the individual's sovereignty on her body and life than Ms B.

4. A CASE BEFORE THE EUROPEAN COURT OF HUMAN RIGHTS (PRETTY)

The cases presented above regard patients who in physical terms are absolutely unable to do what they want (being paralyzed, they are not able to switch off the ventilator – according to the metaphor) and need for doctors' cooperation. In this light they may be considered as bordering on assisted suicide. The European Court of Human Rights dealt with assisted suicide in the Pretty case (2002)¹⁰.

Mrs Diane Pretty was a terminally ill woman from the UK affected by motor neurone disease, a degenerative disease affecting the muscles. Being paralysed from the neck downwards, she wanted to take her own life with help from her husband so that she might die with dignity at home and at a time of her choosing. But section 2 (1) of the Suicide Act 1961 makes it a criminal offence for a person to aid, abet, counsel or procure the suicide of another. Section 2 (4) of the Act says that no proceedings for this offence shall be instituted except by or with the consent of the Director of Public Prosecutions (DPP). The DPP has been asked to undertake that he would not give his consent to Mr Pretty's prosecution if he

¹⁰ Case of *Pretty v. United Kingdom* (Application no. 2346/02). Judgment published in *Human Rights Case Digest*, Volume 13, Number 3-4, 2002, pp. 347-353. See, A. Santosuosso, *Un commento sul caso Pretty*, in *Bioetica*, 2, 2002, pp. 368-372; I.R. Pavone, *Nota alla decisione della Corte europea dei Diritti Umani del 29 aprile 2002 sul caso Pretty v. United Kingdom*, in *Affari Sociali Internazionali*, 4, 2002, pp. 37-49.

helped his wife to commit suicide, but the DPP has said he cannot do so. Mrs Pretty contended that Section 2 (1) of the 1961 Act was incompatible with the Convention Articles 2 (right to life), 3 (prohibition of inhuman or degrading treatment or punishment), 8 (right to respect for private life), 9 (freedom of conscience) and/or 14 (prohibition of discrimination) of the European Convention on Human Rights (ECHR). The Queen's Bench Divisional Court stated that a violation of the ECHR by the United Kingdom did not occur.

Hence Ms Diane Pretty presented a claim at the European Court of Human Rights. The Court, in its judgment of 29 April 2002, sustained that no violation of Articles 2, 3, 8, 9, or 14 of the Convention by United Kingdom occurred.

A couple of points are worth noting in Court's decision. The first is the passage on right to life, where the Court maintains that Article 2 of ECHR could not, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor it could create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life. The second pertains to Article 8 in conjunction with Article 14. According to Ms Pretty, "she was prevented from exercising a right enjoyed by others who could end their lives without assistance because they were not prevented by any disability from doing so". The government's blanket ban on all assisted suicide was the source of this discrimination, and it could not be justified in this case since the applicant was not one of the class of vulnerable people the law was designed to protect. The Court reiterated that discrimination under the Convention constitutes disparate treatment of people in very similar conditions or similar treatment of people in vastly different conditions. The member states, however, enjoy a margin of appreciation in drawing the line. In this case, the Court found it reasonable not to create different regimes for those able and those unable to commit suicide in this case, as the "borderline between the two categories will often be a very fine one and to seek to build into the law an exemption for those judged to be incapable of committing suicide would seriously undermine the protection of life which the 1961 Act was intended to safeguard and greatly increase the risk of abuse".

A first consideration arising from the cases examined above is that, while Ms B asked the Court for her doctors to be authorised to switch off the ventilator that was keeping her alive, in the Pretty case the question at issue was the violation of the right to life and other rights (as protected in the European Convention on Human Rights) consequent to the lack of a right to be helped to die in UK legislation. Precisely this conceptual horizon led European judges to reject such a request, assuming that protecting the right to life can never turn into its contrary (that is, obligating the member States to provide a right-to-die protection law) and that States enjoy a margin of appreciation in the field.

The main point in the case is who has the sovereignty over Diane Pretty's life: the patient (who is deprived of her free right to life, see below), the European Convention and the Court (which define how life and conscience are to be interpreted), the State (which have the power to draw the line between people who are physically capable of committing suicide and people who are not).

5. ENGLARO, CRUZAN AND BLAND: WHOSE WILL?

Irreversible incompetence of people in Permanent Vegetative State (PVS) marks a further border of human life, the border between competence and irreversible loss of cognitive abilities.

With regard to people in PVS, the main problem is whether hydration and nutrition are legally due medical acts. Though recognition of the importance of avoiding medical over-treatment or ‘*over-zealous*’ medical treatment may be universally shared, the ethical divide is centered on the substantive nature of hydration and nutrition, medical treatment or act of ordinary care.

Ethical and religious positions often affect the legal reasoning. Should hydration and nutrition be considered a form of *overtreatment*, they may be discontinued, regarded as treatments the doctor is not obliged to administer; otherwise they must per force be continued. Furthermore, should hydration and nutrition be considered *ordinary care*, they could not be legitimately interrupted. Should withdrawal be considered an *omission that causes death*, it would also be a form of euthanasia.

In any case, it must be said that from a strictly legal constitutional point of view, the patient has the right to refuse treatment, for even an act of treatment is an intrusion into the patient’s personal sphere and must therefore be justified in legal terms, on the grounds of informed consent, of best interest or dignity, and not of the patient’s mere survival.

The two international leading cases (Cruzan, USA, and Bland, UK), although the first is based on previously expressed will and the second on best interest¹¹, shared the basic evaluation of hydration and nutrition as medical treatments.

An Italian case started eight years ago and has not yet reached conclusion, after seven decisions of different Courts of all levels. It is the Eluana Englaro case, a young woman who has been in PVS for fifteen years, since 1992, when she had a car accident. Until 2006 all the Courts have rejected the application of Eluana’s father, who acts also as her guardian, to withdraw hydration and nutrition from her.¹² What is remarkable is that five out of seven decisions did not effectively decide the merit of the case, focusing instead on procedural points. In other words, according to the judges, procedural reasons made the decision impossible. In the latest round (December 2006) several witnesses were heard and they confirmed that Eluana, in discussion with them on similar cases (one involving a common friend), expressed the will not to be kept alive in similar conditions. Nevertheless the Court of Appeal of Milan denied the authorization, clearly stating that Eluana’s previous wishes

¹¹ The withdrawal of artificial nutrition and hydration (ANH) from a patient in a permanent vegetative state (PVS) cannot be considered murder even though the doctor knows that his decision not to act will result in the death of the patient, as continuation of ANH will not be in his “best interests”: see *Airedale NHS Trust v Bland* [1993] 1 All ER 821 (HL).

¹² A. Santosuosso – G.C.Turri, *La trincea dell’inammissibilità, dopo tredici anni di stato vegetativo permanente di Eluana Englaro*, *La Nuova Giurisprudenza Civile Commentata*, maggio 2006, parte I, pp. 477-485.

were not able to solve the case because they had been expressed while she was young and healthy and thus cannot be considered as a serious, conscious and strong-minded informed refusal. On the other hand, judges stated that, whatever the nature of hydration and nutrition (medical treatment or personal care), their withdrawal would be an omission causing Eluana's death and thus would constitute a form of "indirect" euthanasia and a crime. Eluana's father and guardian appealed to the Supreme Court and the case is still pending.

In the Englaro case there is no doubt as to what the patient expressly and repeatedly wanted when she was alive and healthy. Different from the Cruzan case, judges here deemed all this not to be sufficient to recognize her right to self-determination, even if they did not affirm how an acceptable quality of life should be defined, once and for all, by public institutions, law, religion, philosophy or anyone else other than the individual himself. In any case, the Italian Court missed the further point: recognizing the individual's power to define her or his personal idea of acceptable quality of life should imply the patient's power to decide in advance to withdraw useless or painful medical treatments when she or he thinks her or his life is no longer worth living. If it is true that the refusal expressed in prior directives/wishes does not match the legal standard of full-informed consent/refusal in competent people, it is also true that previously expressed wishes are the only ones we have that are related to the specific patient.

In other words, the Court's decision would appear to be a blind alley from which there is no escape. Because of its lack of specificity, the patient's will is dismissed, as is a societal evaluation of quality of life because of its related abuses. The result is that some people are kept alive through medical devices and are, in fact, deprived of their basic constitutional right not to be invaded bodily.

Thus, while in the Cruzan case judges recognized the value of previous wishes in order to avoid a decision based on non-individualistic criteria, and in Bland, lacking previous wishes, they decided according to a medical evaluation in accordance with family opinion, Italian judges made neither the first nor the second choice, simply stating instead that between the right to life and the right to self-determination and human dignity, the right to life (or more correctly, "survival") must prevail. Only recently the Supreme Court, on appeal from Eluana's father and guardian, reversed the Court of Appeal decision and remanded the case to a different chamber of the same Court, giving the following instructions:

"In the case of a patient who has been in a Permanent Vegetative State for many years (15 years in this case) and is fed by a nasogastric tube, on request of the Guardian, the judge may authorize the withdrawal of enteral nutrition and hydration once that two kind of circumstances are ascertained:

- a. the PVS condition is irreversible according to the internationally recognized medical standards;
- b. the Guardian's request is in accordance with previously expressed wishes, ideas and life style of the patient and the proof of them is brought before the Court."

Finally, the Italian Supreme Court judges seem to follow in the footsteps of *Cruzan*, rather than *Bland* (UK)

6. DIFFERENT KINDS OF EUTHANASIA AND LEGAL APPROACHES

In Europe active, voluntary euthanasia is not legally accepted, except in the Netherlands and in Belgium. Euthanasia is the most controversial issue, especially because its boundaries are not clear.

The very concept of euthanasia is broad, elusive and has changed according to the evolution of social values. In our opinion it is preferable to use it in the precise and narrow sense. Euthanasia is the behaviour deliberately aimed to cause death (not necessarily by a physician) which is a strict condition of the occurrence of death, whether the person be competent and willing or incompetent or unaware. According to this definition all cases of letting die or refusal of medical treatments are not encompassed in the concept of euthanasia, in the first case (letting die) because the physician's omission is not aimed at causing death and in the second (refusal of medical treatments) because the physician has a duty to respect the patient's integrity and self-determination. Of course this is a questionable matter. For instance, a broader definition of euthanasia might include, in accordance with its etymology, all the situations where a "good death" is the result of a patient's or doctor's decision. But, such a broad idea of euthanasia would encompass all refusals of life-saving medical treatment and would end up labeling as case law on euthanasia all the transnational case laws on patients' right to self-determination, producing an exaggerated (if not paradoxical) result. Indeed, we should say that even Pope Wojtyła's death was a case of euthanasia, as he stated, at the end of his life, when it was still possible to go to the hospital for special treatments, "Please, let me go to the Father's home".

In the United Kingdom, courts and legislators have refused to remove the fundamental criminal law objection to the practice of euthanasia, and active euthanasia is prohibited. A physician that practices "compassionate killing" violates the criminal law and commits the crime of murder. It may carry a mandatory life-sentence, but, analyzing relevant case-laws, few doctors who have actually been prosecuted for assisting their patients to die have been condemned. At the same time, section 2 (1) of the Suicide Act 1961 makes it a criminal offence for a person to aid, abet, counsel or procure the suicide of another. Section 2 (4) of the Act says that no proceedings for this offence shall be instituted except by or with the consent of the Director of Public Prosecutions. Helping another person to commit suicide is a crime punishable by a maximum term of imprisonment of 14 years. That either of these is done with the consent of the individual is irrelevant, as are the good motives of the homicide, that the individual is terminally ill and close to death anyway. There is no special exemption from the law for doctors¹³.

¹³ For a general overview of British law on euthanasia, see, A. Grubb, *Euthanasia in England – A Law*

According to Italian criminal code there is no legal definition of euthanasia and an act of euthanasia may be judged as a case of murder (Article 575) or of murder of a consenting person (Article 579) or of help in committing suicide (Article 580). Similarly in France euthanasia is not a specific crime and is currently sanctioned by the provisions of the criminal code relating to voluntary homicide. Article 221-3 of the criminal code states, "A murder perpetuated with premeditation constitutes an assassination. It is punished by life imprisonment".

In France, after an important public debate, the law of 22 April 2005 on the rights of the patient and on the end of life was enacted¹⁴. According to its provisions all the decisions on the limitation or withdrawal of treatment must be justified with a good reason and must be registered in the medical file. Far from legalising euthanasia, the text merely clarifies the position on withholding treatment, which is disproportionate and can only lead to the artificial prolongation of life. The procedure for withdrawing treatment varies according to whether or not the patient has lost consciousness. A patient who is conscious may refuse to undergo treatment for a life threatening and terminal condition provided that he or she is made fully aware of the consequences of his or her decision (art. L. 1111-10 of the Code of Public Health). If the patient is not able to express his or her wishes, medical staff must make a collegiate decision as to whether to withdraw treatment in consultation with relatives or the patient's designated representative. Under the new article L. 1111-6 of the Code of Public Health, a patient may designate in writing a "trustworthy person," for example a relative, doctor or close friend, who should be consulted in the event that he or she becomes unable to express his or her wishes. A general provision (incorporated under art. L. 1110-5 of the Code of Public Health) also purports to help avoid disproportionate and unnecessary treatment. The clause provides that the primary obligation of doctors is to relieve patients of pain, even at the expense of life expectancy, so long as either the patient, the person designated as trustworthy, or a close relative is informed.

This law emphasizes patient autonomy, advocating that the patient be fully informed before treatment, and creates specific procedures to be followed according to whether the patient is conscious or unconscious. In the latter situation, the law reinforces the role of both the patient's surrogate and the patient's advance directives in establishing consent. In these extreme situations, doctors have the option to request a second medical opinion. This joint decision-making procedure is laid down by law and becomes obligatory in the interests of transparency.

Lacking Compassion?, in *European Journal of Health Law*, 2001, p. 89-93; M. Otlowski, *Voluntary Euthanasia and the Common Law*, Oxford University Press, Oxford, 2000.

¹⁴ *Loi n. 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de la vie.*

7. RIGHT TO LIFE *V.* SELF-DETERMINATION?

Generally speaking, respect for patients' consent implies the possibility that they may refuse medical care, creating an ethical and legal dilemma of administering medical care or respecting patients' wishes. The fundamental question is as follows: Who has the power to balance right to life, in its absolute value, and right to self-determination, including the right to choose one's own acceptable quality of life and the right to decide under what conditions life is not worthy living anymore? And what are the general rules and parameters of such a balance, if they exist?

In the Welby case the judge ordered the prosecutor to charge the doctor of murder of a consenting person because, even though Welby refused the ventilator on the basis of his constitutional right to self-determination, the right to life is the right upon which all other rights are based; it thus always overrides other constitutional rights. Similarly in the latest opinion of the Court of Appeal in the Englaro case, the judges firstly rejected the evidence regarding Eluana's previous wishes (even though the standard of such a proof was not lower than that in Cruzan, USA), and, secondly, stated that, whatever the nature of hydration and nutrition (medical treatment or personal care), their withdrawal would be an omission causing Eluana's death and, thus, the (not clearly specified) crime of "indirect" euthanasia. They reached such a conclusion arguing that many legal provisions in the Italian criminal law protect life and, thus, that right to life prevails over other rights.

Even though not explicitly named in the Italian Constitution, the right to life is usually considered among the basic constitutional principles because of its intrinsic nature and because of the provision of the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)¹⁵. Recently the Charter of Fundamental Rights of the EU (2000) recalls the ECHR right to life at Article 2 (1. Everyone has the right to life. 2. No one shall be condemned to the death penalty, or executed).

At this point it seems clear that the issue of right to life has indeed found new life. Though first introduced as an argument against the death penalty, it now serves as a wild card applied to address decisions involving end of life and beginning of life as well (see below). We might well question the wisdom of this reasoning. For instance, if it is true that the right to life prevails over all other rights, why is it that so many jurists (even Catholic jurists) have ignored such a clear concept and upheld the incoercible freedom of a person to refuse life-saving medical treatments? Were those jurists ill-informed or inattentive?

In our opinion, there is something flawed in this right to life new wave. In several cases, the legal reasoning seems to confuse life as a *biological phenomenon* with life as the content of a *right* and, thus, the "right to life". The point is very clear in the Pretty case before

¹⁵ Article 2: Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

the European Court of Human Rights (29 April 2002). The Court sustained that Article 2 of ECHR could not, without a distortion of language, be interpreted as conferring the diametrically opposed right, namely a right to die; nor it could create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.

However, Ms Pretty's claim was very different and more precise. She submitted that article 2 of ECHR protects not life itself but the right to life. The purpose of the article is to protect individuals from third parties (the State and public authorities). But the article recognises that it is for the individual to choose whether or not to live, and so protects the individual's right to self-determination in issues of life and death. Thus a person may refuse life-saving or life-prolonging medical treatment, and may lawfully choose to commit suicide. The article acknowledges that right of the individual. While most people want to live, some want to die, and the article protects both rights. The right to die is not the antithesis of the right to life but is its corollary, and the State has a positive obligation to protect both.

Although all this is a questionable matter and it is possible to disagree with such a thesis, the Court's decision did not express a different opinion but simply missed the point. To say that Ms Pretty was claiming a right *diametrically opposed* to right to life implies the confusion of *biological life* with life as *right to life*. Death is the opposite of life in biological terms, whilst the opposite of the *right* to life is the *duty* to life. As any legal dictionary clarifies, a right is an entitlement to something, whether to concepts like justice and due process, or to ownership of property or some interest in property, real or personal. Right is that quality in a person by which he can perform certain actions, or possess certain things, which belong to him by virtue of some title. In this sense, we use it when we say that a man has a right to his estate or a right to defend himself. Right is the correlative of duty, for whenever a person has a right due to him, some other must owe him a duty.

Hence the right to life is, firstly, a right to obtain full protection against intentional or unintentional assaults to our life from third parties, even public authorities, as the case of the death penalty (which is the historical root of the right to life) clearly shows. The question may arise of whether a person endowed with the right to life can dismiss that right, but it cannot be denied that a person may act by virtue of the right or, also, not act by virtue of the same right.

Reasoning as Italian and ECHR judges seem to do leads us to the same paradox we saw above regarding the right to health, the paradox of a *right* that changes into a *duty*.

The present revival of right to life seems to be the signal of things turned full circle. When some decades ago the patient's self-determination in life and death decisions was affirmed in case law and legislation, some people, mostly though not exclusively from the Catholic side, disagreed and considered it inadmissible and unwise to leave people to choose about their own lives. More recently, this opposition weakened because of the general acceptance of the self-determination standard and was restricted to critical areas, such as incompetent patients, euthanasia or assisted suicide. Many times we have heard people say they agree with the theory of informed consent and self-determination, but this

ethical and legal rule cannot work if the patient is incompetent or if his decision is an act of disposition of his body or life.

Nowadays this shift (between critical situations and ordinary situations) has disappeared and even ordinary cases of self-determination are controversial, while triumphant (right to) life seems to ride in the desert of Constitutional rights. We wonder whether Italy, and intermittently Europe, can afford Court refusals, at all levels, to give replies on fundamental rights.

8. BEGINNING OF LIFE

After the birth of the first human being conceived *in vitro* (Louise Brown, 1978), the beginning of life, too, became a battlefield, and the questions we have laid out in this paper (see par.1) took on new shape and strength after the historical, controversial issue of abortion.

Questions like when human life begins and at what point human beings become entitled to personal rights have many implications from both the philosophical and practical point of view: if human beings acquire full legal personhood only from their birth, no right to be born in itself may be acknowledged to them, and human embryos may be considered a matter of scientific research like any other human biological tissue; if, on the contrary, a fertilized egg has to be afforded the same rights as other subjects of procreation, each fertilized egg has the same dowry of rights as do all people, starting with the right to life. Of course many intermediate degrees are present between these two extreme positions.

So, assuming that human embryos may be afforded different status according to the point of view (gender, legal, religious, scientific and so on) and the beliefs of the specific observer, the question is again who has the power to decide, and what are the criteria according to which the line demarcating the beginning of human life may be drawn. In this paper we consider the issue from the legal point of view and limit our exploration only to some case law and legislation; a comprehensive description of the last thirty years of legal debate would become too lengthy¹⁶.

Among the different legislations, the UK takes a *gradualist* position on the moral status of the embryo. According to the “Warnock Report”¹⁷, a moral distinction between pre-embryo (from 0 to 14 days) and human embryo exists. Protection is guaranteed in proportion to the embryo’s degree of development, and scientific research on a human embryo *in vitro* is only permitted under licence during the first two weeks of its existence¹⁸.

¹⁶ A. Gentilomo, A. Piga, S.Nigrotti, *La procreazione medicalmente assistita nell’Europa dei quindici*, Giuffrè Editore, Milano, 2005.

¹⁷ *Report of the Committee of Enquiry into Human Fertilisation and Embryology*, 1982. The Warnock Report became the basis of a general social consensus about the moral issues associated with IVF, and the starting point for the 1990 Human Fertilization and Embryology Act.

¹⁸ Article 1 of the Human Fertilization and Embryology Act (*Human Fertilization and Embryology Act, of 1 November 1990*, in *IDHL* 1991, nr. 42, p. 350 ss.) provides: “(1) In this Act, except where otherwise

The use of embryos and embryonic stem cells in research on birth defects and infertility has given rise to vigorous discussion of the ethical, moral and legal status of the embryo. On 22 January 2001, the UK became the first country to approve embryonic stem cell research by passing the Human Fertilisation (Research Purposes) Regulations 2001, which legislated new research purposes for which early embryos can be used, in addition to those approved by the Human Fertilisation and Embryology Act 1990. In France, the first relevant judicial case concerning medically assisted reproduction and human embryos arose in 1993. A French Court faced the issue of whether a sperm bank had the duty to return frozen embryos to a widow after the death of her husband, with the aim of attempting post-mortem pregnancy¹⁹. The Court maintained that *in vitro* embryos are living creatures (“*un être vivant*”) but not persons and thus ordered them to be destroyed²⁰. In addition, the French *Conseil Constitutionnel* ruled on the status of human embryos *in vitro*²¹ and established that the disposition of the French law on Bioethics (“*Chaque être humain mérite respect dès le début de sa vie*”) does not apply to human embryos *in vitro*. But the recently revised law on Bioethics²² simply says that the human being has to be respected from the beginning of his life and does not say anything on when life begins²³.

This legal and judicial approach reflects a societal ambiguous position on scientific research involving human embryos. In order to find moral permissibility to such research, the United Kingdom coined the term “pre-embryo” (see Warnock Report), indicating an embryo less than 14 days old, adopting in 1990 a legislation which, under certain conditions, allows scientific research on human embryos. French laws on bioethics of 1994, on the contrary, permitted only research that does not definitely harm the “embryo”, thus

stated— (a) embryo means a live human embryo where fertilisation is complete, and (b) references to an embryo include an egg in the process of fertilisation, and, for this purpose, fertilisation is not complete until the appearance of a two cell zygote. (2) This Act, so far as it governs bringing about the creation of an embryo, applies only to bringing about the creation of an embryo outside the human body; and in this Act: (a) references to embryos the creation of which was brought about *in vitro* (in their application to those where fertilisation is complete) are to those where fertilisation began outside the human body whether or not it was completed there, and (b) references to embryos taken from a woman do not include embryos whose creation was brought about *in vitro*”. See A.J. Klotz J.D., *The Regulation of Embryo Research under the Human Fertilisation and Embryology Act of 1990*, in D. Evans (a cura di) *Conceiving the Embryo*, Kluwer Law International, Oxford, pp. 303-314; A. Plomer, *Beyond the HFE Act 1990: The Regulation of Stem Cell Research in the UK*, in *Medical Law Review*, 10, 2002, pp. 132-164.

¹⁹ *Tribunal de Grande Instance Rennes*, 1re Ch.Civ., 30 Juin 1993: Mme O...c./ *Centre d'Etude et de Conservation des Oeufs et du Sperme Humain (CECOS) de l'Ouest La Semaine Juridique, JCP*, 1994, 22250, p. 169 ss.

²⁰ The case highlighted the conflict surrounding the fate of thousands of supernumerary embryos kept frozen in French hospitals and fertility clinics. Cfr. A. Dorozynsky, *French Court orders destruction of frozen embryos*, in *British Medical Journal*, 1994, 308: 1319-20.

²¹ *Décision n° 94-344 DC Loi relative au respect du corps humain et loi relative au don et à l'utilisation des éléments et produits du corps humain, à l'assistance médicale à la procréation et au diagnostic prénatal*, in *Journal officiel du 29 juillet 1994*, p. 11024.

²² Law n.2004-800. 6 August, 2004, on Bioethics.

²³ The law provides in Chapter II (“Respect for the Human Body”), art. 2: “La loi assure la primauté de la personne, interdit toute atteinte à la dignité de celle-ci et garantit le respect de l'être humain dès le commencement de sa vie”.

banning any embryo research, as it was practically impossible to carry on research on embryos without destroying them. However, a shift occurred in 2004, when the *Code de la santé publique* (as modified by art. 25 of Law 800/2004: *Revised Laws on Bioethics*) allowed scientific research on human embryos under strict circumstances²⁴, even though it did not give any new definition of the embryo's legal status. The Italian Parliament, one of the last in Europe to introduce a law in the matter, solved doubts and uncertainties of other legislations, and established in Article 1 of Law n.40/2004²⁵ that each fertilized egg has the same rights of the woman and the man from whom the gametes come, and, in doing so, banned both any kind of research involving embryos and also any kind of pre-implantation test (in order to detect their genetic make-up, when parents may pass on genetic diseases to offspring).

In this heterogeneous and fragmented European legislative environment, some relevant cases challenged the European Court of Human Rights.

In the case *Vo v. France* the question concerned an application brought by a refugee, Mrs Thi-Nho Vo. On 27 November 1991 she attended the Lyons General Hospital for a medical examination scheduled during the sixth month of pregnancy. On the same day another woman, Mrs Thi Thanh Van Vo, was due to have a coil removed at the same hospital. Owing to a mix-up caused by the fact that both women shared the same surname, the doctor who examined the applicant pierced her amniotic sac, making a therapeutic abortion necessary.²⁶ Following a criminal complaint lodged by the applicant and her husband in

²⁴ In the following paragraph the article specifies that: "A titre exceptionnel, lorsque l'homme et la femme qui forment le couple y consentent, des études ne portant pas atteinte à l'embryon peuvent être autorisées sous réserve du respect des conditions posées aux quatrième, cinquième, sixième et septième alinéas. «Par dérogation au premier alinéa, et pour une période limitée à cinq ans à compter de la publication du décret en Conseil d'Etat prévu à l'article L. 2151-8, les recherches peuvent être autorisées sur l'embryon et les cellules embryonnaires lorsqu'elles sont susceptibles de permettre des progrès thérapeutiques majeurs et à la condition de ne pouvoir être poursuivies par une méthode alternative d'efficacité comparable, en l'état des connaissances scientifiques. Les recherches dont les protocoles ont été autorisés dans ce délai de cinq ans et qui n'ont pu être menées à leur terme dans le cadre dudit protocole peuvent néanmoins être poursuivies dans le respect des conditions du présent article, notamment en ce qui concerne leur régime d'autorisation. «Une recherche ne peut être conduite que sur les embryons conçus in vitro dans le cadre d'une assistance médicale à la procréation qui ne font plus l'objet d'un projet parental. Elle ne peut être effectuée qu'avec le consentement écrit préalable du couple dont ils sont issus, ou du membre survivant de ce couple, par ailleurs dûment informés des possibilités d'accueil des embryons par un autre couple ou d'arrêt de leur conservation. A l'exception des situations mentionnées au dernier alinéa de l'article L. 2131-4 et au troisième alinéa de l'article L. 2141-3, le consentement doit être confirmé à l'issue d'un délai de réflexion de trois mois. Dans tous les cas, le consentement des deux membres du couple est révocable à tout moment et sans motif. «Une recherche ne peut être entreprise que si son protocole a fait l'objet d'une autorisation par l'Agence de la biomédecine. La décision d'autorisation est prise en fonction de la pertinence scientifique du projet de recherche, de ses conditions de mise en oeuvre au regard des principes éthiques et de son intérêt pour la santé publique. La décision de l'agence, assortie de l'avis du conseil d'orientation, est communiquée aux ministres chargés de la santé et de la recherche qui peuvent, lorsque la décision autorise un protocole, interdire ou suspendre la réalisation de ce protocole lorsque sa pertinence scientifique n'est pas établie ou lorsque le respect des principes éthiques n'est pas assuré.

²⁵ Law 19 February 2004, n. 40 "Norme in materia di procreazione medicalmente assistita", in *Gazzetta Ufficiale* n. 45, 24 February 2004.

²⁶ See T. Goldman, *Vo v. France and Fetal Rights: The Decision not to decide*, in *Harvard Human Rights Journal*, vol. 18, Spring 2005; C. Pitea, *Vo v. Francia, sentenza 8 luglio 2004*, in L. Pineschi, *La Tutela inter-*

1991, the doctor was charged with causing unintentional injury, the charge subsequently being increased to one of unintentional homicide. On 3 June 1996, the Lyons Criminal Court acquitted the doctor. The applicant appealed and on 13 March 1997 the Lyons Court of Appeal overturned the Criminal Court's judgment, convicting the doctor of unintentional homicide and imposing a six-month suspended sentence and a fine of 10,000 French francs. On 30 June 1999, the Court of Cassation reversed the Court of Appeal's judgment, holding that the facts of the case did not constitute the offence of involuntary homicide; it thus refused to consider the foetus as a human being entitled to the protection of the criminal law.

Relying on Article 2 of the Convention (right to life), the applicant complained of the authorities' refusal to classify the unintentional killing of her unborn child as involuntary homicide. She maintained that France had an obligation to pass legislation making such acts a criminal offence. In *Vo v. France*, the Grand Chamber of seventeen judges of the European Court of Human Rights evaded the controversial issue of whether a foetus is a person for the purposes of Article 2 of the European Convention on Human Rights. The judges stated, "Firstly, that the issue of such protection has not been resolved within the majority of the contracting States themselves [...] and, secondly, that there is no European consensus on the scientific and legal definition of the beginning of life". Although recognizing the right of the foetus to special protection, the Court considered it "neither desirable, nor even possible to answer in the abstract the question of whether a foetus constitutes a person in this case"²⁷.

More recently the European Court had to face again the question of legal status of embryos. Natallie Evans, who was diagnosed with a pre-cancerous condition in late 2001, brought the case *Evans v. UK*. She and her then fiancé, Cheltenham man Howard Johnston, underwent IVF treatment. Six embryos were created by the couple and placed in storage. Miss Evans was left infertile after subsequent surgery to remove her ovaries. When the couple's relationship broke down some six months later (May 2002), Mr Johnston withdrew his consent for the future use and continued storage of the embryos.

The current Human Fertilisation and Embryology Act – which governs IVF treatment – emphasises the importance and significance of the effective consent of both donors to IVF treatment. Natallie Evans began legal proceedings in 2002 in an attempt to overturn this law. She unsuccessfully took the case through the High Court, the Court of Appeal and the House of Lords. Then she applied to the European Court of Human Rights (ECHR) in February 2005²⁸, the basis of her complaint being that requiring the father's consent for the continued storage and implantation of the fertilised eggs was in breach of her rights (under Articles 8 and 14 of the Convention) and the embryo's right to life (under Article 2). The ECHR found against Natallie in their judgment (released on 7 March

nazionale dei diritti umani. Norme, garanzie, prassi, Giuffrè, Milano, 2006, p. 340 ss.

²⁷ *Vo*, No. 53924/00, 85 (Eur. Ct. H.R. July 8, 2004), available at <http://www.echr.coe.int>.

²⁸ Chamber Hearings, *Evans v. the United Kingdom*, 11 February 2005.

2006).²⁹ Evans then asked for the case to be referred to the Grand Chamber. The Grand Chamber of the European Court of Human Rights ruled against Natallie Evans on 10 April 2007³⁰. The Court held unanimously that there had been no violation of Article 2 (right to life) of the European Convention on Human Rights, by thirteen votes to four that there had been no violation of Article 8 (right to respect for private and family life) of the Convention, and by thirteen votes to four that there had been no violation of Article 14 (prohibition of discrimination) taken in conjunction with Article 8.

The Court observed that there is no international consensus with regard to the regulation of IVF treatment or to the use of embryos created by such treatment. Again, there is no consensus on the moment when it becomes no longer allowed to withdraw the consent to the use of genetic material provided as part of IVF treatment by one of the parties; in certain States, it appears that consent may be withdrawn only up to the point of fertilization, whereas in other States such withdrawal may occur at any time prior to the implantation of the embryo in the woman; in still other States the point at which consent may be withdrawn is left to the courts to determine on the basis of contract or according to the balance of interests of the two parties. The Court recalls, however, that in *Vo v. France* it held that, in the absence of any European consensus on the scientific and legal definition of the beginning of life, the issue of when the right to life begins comes within the margin of appreciation which the Court generally considers that States should enjoy in this sphere. Under English law, as was made clear by the domestic courts in the present applicant's case (see paragraphs 16 and 21 above), an embryo does not have independent rights or interests and cannot claim—or have claimed on its behalf—a right to life under Article 2.

9. EUROPEAN LAW AND CASE LAW ON DEFINITION OF LIFE

Laws generally avoid defining life and its beginning. On the one hand, European national legislation is mostly oriented in the sense of not recognizing a legal *status* to the embryo/foetus. On the other hand, no international treaty or declaration on human rights (with the only exception of the Inter-American Convention on Human Rights) recognizes the legal status of person to the human embryo/foetus³¹.

The European Convention on Human Rights, as stated by the European Court of Human Rights in the above-mentioned judgments, protects the right to life from the moment

²⁹ ECHR, Fourth Section, Case of *Evans v. The United Kingdom*, Application no. 6339/05, Judgment, Strasbourg, 7 March 2006. This case was referred to the Grand Chamber which delivered judgment in the case on.

³⁰ *Evans v. United Kingdom*, application no.6339/05, Grand Chamber, Judgement of 10-04-2007.

³¹ American Convention on Human Rights, O.A.S.Treaty Series No. 36, 1144 U.N.T.S. 123, entered into force July 18, 1978. Article 4. Right to Life: "Every person has the right to have his life respected. This right shall be protected by law and, in general, from the moment of *conception*".

of birth. The same position can be found in the Convention on Human Rights and Biomedicine (Oviedo Convention). According to articles 18 and 19 of the Explanatory Report the Convention does not define the term "everyone" (in French "toute personne")³².

In terms of the absence of European consensus regarding clear definitions of the beginning of life and the right to life, the case law of the ECHR is very interesting. When judges say in *VO* that it is "neither desirable, nor even possible to answer in the abstract the question of whether a foetus constitutes a person in this case," they take a position that, on the one hand, may be considered a way to sidestep their judicial role to interpret the Convention (according to the intent of the drafters, foetal life is not encompassed within the meaning of article 2) or, on the other hand, a way to avoid a clash with the majority of the Council of Europe's member States, which recognize the right of abortion. However, they are certainly right when they avoid the pitfall of defining "life in abstract," for law may define who the players are in social interaction but not "life," which is a biological continuum, from a scientific point of view. As Francis Galton says, "*Nature teems with latent life, which man has large powers of evoking under the forms and to the extent which he desires. We must not permit ourselves to consider each human or other personality as something super-naturally added to the stock of nature, but rather as a segregation of what already existed, under a new shape, and as a regular consequence of previous conditions*"³³.

The *Vo* and *Evans* cases are different in their object. The case *Vo v. France* regards the legal status of human embryo *in utero* and has major implications concerning women's reproductive rights. The *Evans* case, on the contrary, regards the legal status of *frozen* embryos that are still outside the woman's womb and its major implications concern the possibility of carrying on scientific research on "abandoned" or frozen embryos that are no longer useful for future implantation because of the excessive time elapsed since the freezing. Such a useful destination of those embryos is, at the moment, prohibited by some national legislations, like the Italian one, that make no difference between human embryo *in vitro* and human embryo *in utero*, affording them the same "rights". It is, however, worth noting the position of the Additional Protocol to the Convention on Human Rights and Biomedicine (Oviedo Convention). The Protocol deals with research activities involving intervention on *human beings* and states that it does not apply to research on embryos *in vitro*, on the assumption that no equal protection is possible between human beings and embryos *in vivo*, on one side, and embryos *in vitro*, on the other³⁴.

³² These two terms are equivalent and found in the English and French versions of the European Convention on Human Rights, which however does not define them. In the absence of a unanimous agreement on the definition of these terms among member States of the Council of Europe, it was decided to allow domestic law to define them for the purposes of the application of the present Convention. 19. The Convention also uses the expression "human being" to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began".

³³ Francis Galton, *Hereditary Genius* (1869), Chapter *General Considerations*.

³⁴ "Article 2: 1. This Protocol covers the full range of research activities in the health field involving intervention on human beings. 2. This Protocol does not apply to research on embryos *in vitro*. It does apply to

10. RADICAL SURGERY AND SEX RE-ASSIGNMENT

Radical (and physical) choices about one's own sexual predisposition are a further battlefield in the definition of human-being boundaries. The question is whether individuals are free to choose their sex and what limitations they meet in such a choice and, if so, who has the power or the duty to establish these limitations. On one side, the question may appear easier than more critical end-of-life decisions. With no individual's death at stake, the basic rule "not to harm third parties" might steer our legal attitude. On the other side, we must take into account the widespread idea that radical and definitive surgical procedures affecting the individual's personal integrity have to be justified by therapeutic reasons³⁵ and the Catholic principle that human life and also the human body in itself are gifts from God, thereby excluding from the individual any power of disposition on physical integrity. National and supranational Courts have faced several conflicts stemming from sexual radical surgery.

In the case *Van Kuck v. Germany* (n. 35968/97) the applicant, Bernhard Friedrich, born in 1948 and registered as a male, changed his name in 1990 to Carola Brenda and was recognized as a male-to-female transsexual, even though not typical. In 1992 she filed a lawsuit at the Regional Court in Berlin against the health insurance company for reimbursement of all expenses sustained to carry on hormonal medical treatments. The Court appointed an expert in order to ascertain whether the applicant was a male-to-female transsexual, whether the gender re-assignment surgery was the proper treatment for her case, and whether the medical and scientific community commonly accepted this kind of medical treatment. Although the expert positively replied to all of these questions, the Court finally ruled that the applicant had no right to have the expenses reimbursed as the doctors recommended the gender re-assignment surgery solely for psychiatric and psychotherapeutic purposes: since it would have not solved all his physical problems, it could not be defined as "necessary medical treatment".

The European Court of Human Rights highlights that, considering the distress and the physical and psychological pain caused by the several steps of the gender re-assignment surgery, it cannot be qualified as unnecessary or superfluous. So the Court stated that the national Courts' decisions were a breach of European Convention, Art. 6 ("everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law"). The Court also deemed it disproportionate and in violation of Art. 8 of the Convention to put the burden of proof of the real necessity for

research on foetuses and embryos *in vivo*," from the Additional Protocol to the Convention on Human Rights and Biomedicine concerning biomedical research, adopted by the Council of Europe in Strasbourg on 25th of January 2005 (available at <http://conventions.coe.int/treaty/en/treaties/html/195.htm>).

³⁵ An exception to such principle may be considered the possibility of organ donation justified for altruistic purposes.

medical treatment (the surgery, in this case) on the applicant in one of the most private matters of her personal life³⁶.

In a previous case, *Christine Goodwin v. United Kingdom* (application n. 28957/95) the applicant, Christine Goodwin, was a United Kingdom citizen born in 1937 and a post-operative male-to-female transsexual. The applicant had a tendency to dress as a woman from early childhood and underwent aversion therapy in 1963-64. In the mid-1960s, she was diagnosed as a transsexual. Though she married a woman and had four children, her conviction was that her “brain sex” did not fit her body. From that time until 1984 she dressed as a man for work but as a woman in her free time. In January 1985, the applicant began treatment in earnest, attending appointments once every three months at the Gender Identity Clinic at the Charing Cross Hospital, which included regular consultations with a psychiatrist and a psychologist. She was prescribed hormone therapy, began attending grooming classes and voice training. Since that time, she has lived fully as a woman. In October 1986, she underwent surgery to shorten her vocal chords. In August 1987, she was accepted on the waiting list for gender re-assignment surgery. In 1990, she underwent gender re-assignment surgery at a National Health Service hospital. Her treatment and surgery were provided for and paid for by the National Health Service. The applicant divorced her former wife but continued to enjoy the love and support of her children. The applicant claimed that between 1990 and 1992 colleagues at work sexually harassed her. She attempted to pursue a case of sexual harassment in the Industrial Tribunal but she was unsuccessful because she was considered in law to be a man. She did not challenge this decision by appealing to the Employment Appeal Tribunal. The applicant was subsequently dismissed from her employment for reasons connected with her health, but alleges that the real reason was that she was a transsexual. In 1996, the applicant started work with a new employer and was required to provide her National Insurance (“NI”) number. She was concerned that the new employer would be in a position to trace her details, since once in the possession of the number it would have been possible to find out about her previous employers and obtain information from them. Although she requested the allocation of a new NI number from the Department of Social Security (“DSS”), this request was rejected and she eventually gave the new employer her NI number. The applicant claimed that the new employer had traced her identity, for she began experiencing problems at work. Colleagues stopped speaking to her and she was told that everyone was talking about her behind her back. The DSS Contributions Agency informed the applicant that she would be ineligible for a State pension at the age of 60, the age of entitlement for women in the United Kingdom. In April 1997, the DSS informed the applicant that her

³⁶ “Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.”

pension contributions would have to be continued until the date at which she reached the age of 65, the age of entitlement for men, namely April 2002. On 23 April 1997, she therefore entered into an undertaking with the DSS to directly pay the NI contributions, which would otherwise be deducted by her employer as they are for all male employees. In light of this undertaking, on 2 May 1997, the DSS Contributions Agency issued the applicant with a Form CF 384 Age Exemption Certificate. The applicant's files at the DSS were marked “sensitive” to ensure that only an employee of a particular grade had access to her files. This meant in practice that the applicant had to make special appointments for even the most trivial matters and could not deal directly with the local office or pose queries over the telephone.

The Court recalled that the notion of “respect” as understood in Article 8 is not clear cut, especially as far as the positive obligations inherent in that concept are concerned: with regard to the diversity of practices followed and the situations obtaining in the Contracting States, the notion's requirements will vary considerably from case to case and the margin of appreciation to be accorded to the authorities may be wider than that applied in other areas under the Convention. The Court found that “the respondent Government can no longer claim that the matter falls within their margin of appreciation, save as regards the appropriate means of achieving recognition of the right protected under the Convention. Since there are no significant factors of public interest to weigh against the interest of this individual applicant in obtaining legal recognition of her gender re-assignment, it reaches the conclusion that the fair balance that is inherent in the Convention now tilts decisively in favour of the applicant. There has, accordingly, been a failure to respect her right to private life in breach of Article 8 of the Convention”.

The Court concluded that there was a breach also of Article 12 of the Convention (right to marry)³⁷ because, even though the right to marry is subject to the national laws of the Contracting States, the limitations thereby introduced must not restrict or reduce the right in such a way or to such an extent that the very essence of the right is impaired.

A quite different and, in certain respects, more interesting perspective arises from the Italian Constitutional Court's decision no. 161/85.

In 1979 the Court of Appeal of Naples rejected a transsexual's claim to obtain his sex and name re-assignment after he underwent gender re-assignment surgery. Deciding on the issue, the Italian Supreme Court noticed that in 1982 a law governing the possible questions concerning sex re-assignment entered into force, and further questioned the constitutionality of several articles of this law. The Constitutional Court upheld the 1982 Law and considered transsexuals' will to undergo radical surgery in the light of finding the correspondence between physical and psychological gender. In many cases, surgery and sex re-assignment succeed in improving the patients' quality of life, giving them a

³⁷ “Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right”.

healthier physical and psychical condition. The Court argued that “law 164/1982 is the product of an evolving society with a bigger awareness of fundamental values such liberty and dignity of human beings even in minority or abnormal situations”.

The Constitutional Court’s opinion has to be appreciated when it upholds the Constitutional legitimacy of the Act with respect to Articles 2 and 32 of the Italian Constitution³⁸ and rejects the argument that this kind of surgery breaches the legal limitation to the disposition of one’s own body. In fact, disposing of one’s own body is allowed when it aims to protect one’s physical and psychical health. It cannot be said, ruled the Court, that the transsexual’s sex re-assignment could harm any fundamental right on the part of the people who have some relationship with him. The Constitutional Court considered also the alleged violation of Art. 29 of the Constitution (sex re-assignment of the transsexual, being apparent, would end in destroying the “natural rules of the family”)³⁹ and stated that such fundamental and natural rules are broken by the transsexual syndrome in itself and not by the sex re-assignment, which simply reaches the result of creating a new harmony between the physical and the psychological aspects of the transsexual’s sexuality and helps in giving certainty to his/her social relationships.

One initial uncontroversial conclusion we may draw from the above-examined cases is that radical choices about one’s personal physical and psychological well-being are clearly a matter of self-determination and require the individual’s consent. The right question, in light of defining the sovereignty over such decisions, is whether any limitation may be placed on the individual’s power of choice, and, if so, who may pose such limitations.

One first point must be highlighted: it is surely true that these are fundamental choices regarding one’s personal identity and they imply radical changes of what, in the eyes of law and society, an individual is or has been until then. But, as life and death decisions are not involved in, even though radical physical consequences are caused, it should not be a matter falling under the domain of religious and moral institutions. Thus the question remains why limitations to such radical intervention are usually justified when no health purposes are present. It should mean that the individual’s psychological well-being is not considered a sufficient reason for such changes, while we have to admit that no third parties’ other right or interest is involved. It appears clear, in fact, that quoting society’s right to trust in someone’s physical aspect or a third person’s right to know is not enough to justify any limitation to the individual’s right to self-determination. That is the fundamen-

³⁸ Art. 2, “The Republic recognizes and guarantees the inviolable rights of man, as an individual, and in the social groups where he expresses his personality, and demands the fulfilment of the intransgressible duties of political, economic, and social solidarity”; Art.32, “The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent. No one may be obliged to undergo particular health treatment except under the provisions of the law. The law cannot under any circumstances violate the limits imposed by respect for the human person”.

³⁹ Art. 29, “The Republic recognizes the rights of the family as a natural society founded on matrimony. Matrimony is based on the moral and legal equality of the spouses within the limits laid down by law to guarantee the unity of the family”.

tal principle that is really at stake. Neither can we talk about a sort of public interest in order to pose limitations on the individual's physical self-determination when no harm to society or third persons can derive from the individual's choices on his/her body.

11. CLOSING COMMENTS

The above-reported case law and legislation and the picture they give of the legal boundaries of human beings are not and do not have any pretence to be exhaustive. The aim of this paper is rather to start framing, in legal terms and in terms of sovereignty, a question which is often overlooked: the boundary litigation on shaping human individuals.

The issue is extremely broad and encompasses the more traditional challenges we have considered in this paper as well as the greater and more complex challenges arising from biotechnologies, informatics, cognitive sciences, nanotechnologies and their convergence. Human enhancement is the most controversial result, as the case of the athlete *Pistorious* has recently shown (July 2007).

In any case, both old and new technological applications on the human body challenge old naturalistic assumptions of bodily boundaries. If this is true, the following are only a few of the partial and provisional remarks we might formulate on the limited number of reported cases and materials⁴⁰:

- The European Court (ECHR) and national courts have been entrusted several times in the last few years with issues ranging from assisted suicide, informed consent and assisted procreation to the legal status of embryos and fetuses. In the near future, judgements in these fields are likely to increase at the same pace as the advancement of science and biotechnology. The ECHR often referred to the Oviedo Convention as essential instrument for a correct and updated interpretation of the articles of the European Convention on Human Rights, with a view to the progressive development of law⁴¹.
- The main feature in all the matter is the equal dignity given to the consent as well as to the refusal of any medical treatment, even when they are life-saving or they cannot be technically defined as disease treatment. In the first respect, any individual seems to be entitled to choose (as far as possible) when and how to die (discontinuing painful and degrading medical treatment when no real hope of regaining health exists).

⁴⁰ A further and wider research project is in progress by Amedeo Santosuosso.

⁴¹ For instance, in the case *Evans v. United Kingdom*, the ECHR quoted article 5 of the Oviedo Convention (informed consent). In the case *Glass v. United Kingdom* (2004), the Court remarked that "it does not consider the regulatory framework in place in the United Kingdom is in any way inconsistent with the standards laid down in the bioethics and Human Rights Convention in the area of consent. It is an important step as it is now probable that in relevant cases those standards will be applied to member states that have not ratified the Convention".

This basic rule is internationally confirmed by legislation on organ transplant as far as people are allowed to choose if their death has to be ascertained according to the brain-death criterion or the traditional (heart-death) criterion in contrast with the general legal criterion⁴². On the other hand, critical decisions for the individual's life and quality of life are at stake even though death is not directly questioned, but fundamental choices about personal integrity or procreation are under discussion. It seems that, under the legal European perspective, no basic limitations may be posed upon the role of the individual's consent when any invasion to personal integrity is at issue. But European judges seem to consider national legislators completely free in defining when a human being, with his/her fundamental rights, really comes into existence.

- On the real crucial point of *who has the power to define the biological boundaries of an individual's life*, we may say that it is more and more a matter for the individual's decision, even though this does not always happen in every case and in every country. Alleged universal levels (such as old naturalistic limits or religious, political and philosophical beliefs) often challenge the individual's sovereignty.
- Europe is a complex reality. The European Court (ECHR) seem to be neither able nor willing to take any position in relation to the moment of the beginning of life as well as to the legitimacy of active euthanasia/assisted suicide, generally referring to the national legislations. The basic assumption is "the judges cannot create a framework or scheme to regulate the practice of euthanasia and such supervision and control of the practice would be essential if the law was to change. It must be the national legislator, who could do this". It is obvious that an international tribunal cannot force national States to modify their national legislation⁴³. On the other hand, the Council of Europe took a very clear position excluding *in vitro* embryos from the umbrella of the protection provided by the Additional Protocol to the Oviedo Convention on biomedical research.
- National legislations, although quite different from one another, perhaps show a more open approach to research on abandoned or non-implantable *in vitro* embryos in recent years, with the sole exception of Italy. It should not be forgotten that the reproductive issue is a very personal one and involves mainly women. In this light the State's intervention should be as light as possible and geared toward self-restraint. It is worth noting that when post-mortem implantation is forbidden (as in Italian legislation), the clash between women's reproductive rights and the State's power looks very harsh and paradoxically aimed at the protection of an "idea" of family more than the same alleged embryo's right to life.

⁴² For the mirror experience of New Jersey and Japan legislation on death criteria see A. Santosuosso, *Giudici senza leggi: rimedio o nuova prospettiva?*, in A.Santosuosso- G.Gennari (eds.), *Bioethical Matters and the Courts: do Judges Make Law?*, numero monografico di *Notizie di Politeia*, n. 65, 2002.

⁴³ The question of what court will be the EU Constitutional Court is still open.

- Finally a judicial paradox has to be stressed. The European Court’s decision not to take a position on the beginning of human life, as all the Courts’ rulings demonstrate, is anyway a decision and has a legal meaning. Saying that the right to life provision of the Convention (Article 2) does not bind in any way the possibility of State members to legislate even in opposite way, as UK and Italy have done, is a way of reasoning that makes right to life radically meaningless, at least in this field. If it is true that UK legislation does not infringe the right to life provision, it is also true that the Italian *Legge n.40/2004* can no longer be considered as grounded on the Convention.
- Many of the cases in which life boundaries and physical integrity are at stake turn into judicial decisions. So we cannot avoid posing the question of what are the judicial and legal principles ruling such issues. The courts have played a very important role in recognizing individuals’ right to self-determination in decisions involving physical integrity and their bodies. Informed consent is now considered the single justification of the invasion of anyone’s personal integrity. But, in recent years, mainly in Italy and sometimes at ECHR, judges seem to be reluctant in continuing this attitude. We wonder whether Italy and Europe, can afford Courts intermittently refusing to give replies on fundamental rights. Even if the story and situation are different under many respects, Judith Resnik’s commentary on the latest year of the US Supreme Court seems to be very interesting: “the year they closed the courts”⁴⁴.

⁴⁴ Reported in *Steps Big and Small, Supreme Court Moved Right* by Linda Greenhouse, New York Times, July 1, 2007.