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### **Free to become martyrs? The right to refuse medical treatment on religious grounds in a comparative perspective \***

**SUMMARY:** 1. Aim of the study - 2. Defining medical treatment- 3. Treatment, consent and "religious grounds" - 4. The right to express one's religion and medical consent - 5. The legitimate limitations on the right to refuse a treatment on religious grounds - 6. Capacity to refuse a treatment - 7. The genuineness of consent - 8. Refusal and children's best interest - 9. Conclusive remarks.

#### **1 - Aim of the study**

The aim of this study is to provide a conceptual theoretical framework of the right of patients to refuse medical treatments on religious grounds and on the (supposed) right to the parents to refuse medical treatments on behalf of their children. A comparative approach has been used in order to compare and contrast the essential normative divergences and similarities between the English (and Welsh) and Italian legal systems. It is beyond the scope of this study to examine the right of conscientious refusal - claimed by doctors and paramedics (and sometimes recognised by the State) - to provide professionally accepted health care goods and services<sup>1</sup>.

This study will focus on three main issues. The first deals with the definitions of "medical treatment", "refusal" and "religious grounds"; the second issue is devoted to showing links and connections between the freedom of religion, the right to self-determination and the right to refuse medical treatment based on religious motivations; finally, the third issue will take into account legitimate limitations on the right to refuse medical treatments on religious grounds.

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<sup>1</sup> **M.R. WICCLAIR**, *Managing conscientious objection in health care institutions*, in (2014) *HEC Forum: An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues*, 2014, 26(3), 267-83.



## 2 - Defining medical treatment

While a variety of definitions of the term “Medical Treatment” have been suggested, this paper will start with the definition suggested by Dorland’s Medical Dictionary, which sees it as “the management and care of a patient for the purpose of combating disease, injury, or disorder”<sup>2</sup>.

The American Heritage Medical Dictionary suggests a similar definition: A “Medical Treatment” is every “administration or application of remedies to a patient or for a disease or an injury; a medicinal or surgical management; a therapy”<sup>3</sup>. These are medical definitions, and they are not legally binding. But they constitute the pillar on which the legal definition has been built.

In the English legal system, the main general legal definition of treatment can be found in section 64 of the 2005 Mental Capacity Act: The concept of “medical treatment” includes a diagnostic or other procedure (in a medical context), and it appears strictly linked to every medical practice directed toward combatting a disease, an injury or a disorder. In the case *A London Local Authority v JH & Anor*, District Judge Eldergill emphasised that the definition of treatment – in the context of the Mental Capacity Act - is actually very broad<sup>4</sup>: The letter of the law seems to suggest that it must be intended to be wider than the definition given by *Minister of Health v General Committee of the Royal Midland Counties Home for Incurables at Leamington Spa Chancery Division*, 9 December 1953, in which Mr. Vasey described the word “treatment” as every “process directed to the achievement of a complete (or at least a partial) cure”. Thus, the term may be intended to include both every diagnostic procedure regarding the physical or psychological disorder or condition of the patient, and the administration or application of remedies with the aim of obtaining the alleviation or relief of symptoms and complications, or the cure or elimination of the aforesaid disease, disorder or condition. The double dimension of the concept of “treatment” (a practice direct to combat both physical and psychological diseases) allows me to include in the aforesaid definition the cases of non-therapeutic sterilization and cosmetic surgery.

This wide definition includes Artificial Nutrition and Hydration (ANH). As emphasised by Mr. Bingham in *Airedale NHS Trust -v- Bland*,

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<sup>2</sup> W.A.N. DORLAND, *Dorland’s medical dictionary for health consumers*, Saunders, Philadelphia: 2007.

<sup>3</sup> *American Heritage medical dictionary*, MA: Houghton Mifflin, Boston, 2007.

<sup>4</sup> [2011] EWHC 2420 (COP), footnote 30.



“the insertion of the tube is a procedure calling for skill and knowledge, and the tube is invasive of the patient's body to an extent which feeding by spoon or cup is not. An intubated patient certainly looks as if he is undergoing treatment, and the mechanical pumping of food through the tube is a highly unnatural process”<sup>5</sup>.

As ANH is classed as medical treatment, it can be administered only by consent or according to the best interest of the patient, and it can be refused, just like any other medical treatment<sup>6</sup>.

In the Italian legal system, a binding definition of treatment has been developed by the considerations expressed in two judgments: one pronounced by the Court of Cassation, and the other made by the Council of State<sup>7</sup>. According to these decisions, a treatment is a set of procedures which are the result of a therapeutic strategy and underlying scientific knowledge, which are set up by doctors and continued by paramedical staff, consisting of the administration of chemical compounds involving technological procedures or the use of specific technological supports<sup>8</sup>.

### 3 - Treatment, consent and “religious grounds”

Every treatment requires the genuine consent of the patient or his/her representative. Herring summarizes the elements required in order to consider the consent as legally effective in this way: The consenting patient must be competent, sufficiently informed and not subject to coercion or undue influence<sup>9</sup>.

This raises questions about the effectiveness and genuineness of consent, which we will seek to answer in the next part.

According to Appelbaum and Roth<sup>10</sup>, the “refusal of (medical) treatment” can be defined as follows: The “overt rejection by the patient, or his/her representative of medication, surgery, investigative procedures, or other components of hospital care recommended or ordered by the patient’s physician”. The rejection is a patient’s choice: When the patient does not

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<sup>5</sup> [1993] 2 WLR 316.

<sup>6</sup> E. WICKS, *Human rights and healthcare*, Hart Pub., Oxford, 2007, pp. 237-9.

<sup>7</sup> Corte di Cassazione (Cassation Court), First Civil Section, 16.10.2007, n. 21478 and Consiglio di Stato (State Council), 2.9. 2014, n. 4460.

<sup>8</sup> Consiglio di Stato (State Council), 2.9. 2014, n. 4460

<sup>9</sup> J. HERRING, *Medical law and ethics*, Oxford University Press, Oxford, 2014, p. 154.

<sup>10</sup> P.S. APPELBAUM, & L.H. ROTH, *Patients who refuse treatment in medical hospitals*, in *JAMA: The Journal of the American Medical Association*, 1983, 250(10), pp. 1296-1301 (doi:10.1001/jama.1983.03340100030024, p. 1296).



have the autonomy or the liberty to make his/her own choice, the act of rejection may be performed by his/her representative. The issues linked to parents' (or legal guardians') choice to refuse - on the grounds of their religious beliefs - a treatment for a child are discussed below.

The refusal of a treatment may be considered as founded on "religious grounds" when the motives which prompt the patient (or his/her legal representative) to refuse the treatment are directly and principally linked to a religious belief. This kind of rejection seems to be considered as an external expression of the freedom of religion, because it arises from a mental process in which the choice is interconnected with the firm belief that an illness can be healed through prayer and not medical healthcare<sup>11</sup>, or depends on an explicit or implicit prohibition to receive that treatment deriving from a religious legal system to which the patient belongs.

The refusal founded on religious grounds has a strong cogency, and - according to article 9 of the ECHR - enjoys peculiar protection: These assumptions merit further consideration.

The strong cogency of religious grounds in the choice to refuse a medical treatment follows on the fact that religious traditions not only teach ethical codes, but they have a body of laws and regulations enforced through social institutions<sup>12</sup>. Usually, religious beliefs are characterised by a set of rules intended to constrain the behaviour of the faithful: These precepts can be moral (their transgression does not have juridical consequences, but carries only an ethical reproach) or juridical. In the latter case, we are in front of a set of rules that must be observed by the faithful if they do not want to suffer sanctions or other juridical consequences. The systematisation of a religious juridical set of rules, together with control functions on their observance (and on the custody of the integrity of beliefs, rites, myths and symbols linked to hierophany) are functions which are usually carried out by organised religious groups. Hence, the legal rules of religions are not solely produced by hierophany in its historical development; rather, a key role in the normative production process is linked to the group's authorities. The legal rules of religions are generally observed by believers for three reasons. First, believers consider it right and proper to comply with religious law, which becomes a means of realisation for their own personalities; there is an intimate sharing between religious precepts and existential projects. The other two cases of observance of

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<sup>11</sup> L. PLASTINE, "In God we trust": When parents refuse medical treatment for their children based upon sincere religious beliefs, in *Seton Hall Constitutional Law Journal*, 1993, p. 124.

<sup>12</sup> S. FERRARI, *Lo spirito dei diritti religiosi: Ebraismo, cristianesimo e islam a confronto*, il Mulino, Bologna, 2002.



religious laws arise from an attitude of fear that is linked to the law's infringement.<sup>13</sup> On the one hand, they are afraid of the penalty that may be imposed on them by the authorities; on the other hand - especially in religions with a strong soteriological background - the faithful decide to observe religious precepts fearing that their offences will affect the eternal salvation of their souls. Accordingly, religious precepts have the strongest level of authority in the personal lives of believers, and they may create some problems regarding the obligation to obey the laws of the states in which they reside or dwell, or in which they are citizens<sup>14</sup>.

This strongest level of authority allows us to understand why religion may determinate the deepest choices in a human being's life, including the decision to perform or to refuse a treatment: in fact, such decision may be taken exclusively or predominantly in the light of rights and duties enshrined in a religious legal system, which represents – for religious people - the main landmark of the ethic.

#### **4 - The right to express one's religion and medical consent**

Article 9 ECHR states that everyone has the right to manifest his/her own religion or his/her own beliefs: This freedom can be exercised in the public sphere through worship, teaching, practice and performing rituals.

The ECtHR interpreted article 9 in the sense that the term 'practice' "does not embrace every act motivated or influenced by a religion or by a belief"<sup>15</sup>; rather, the Court used the hermeneutic approach set forth in the so-called "Arrowsmith test"<sup>16</sup> in order to distinguish actions "intimately connected" by a direct link with a religion or belief from actions which were merely inspired or motivated by them<sup>17</sup>.

However, it also emphasised that the state must retain the role of a neutral and impartial organiser of the exercise of various religions, cults and

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<sup>13</sup> C. WEISBROD, *Family, Church and State: An Essay on Constitutionalism and Religious Authority*, J. Fam. L., 1987, 26, p. 741.

<sup>14</sup> H.P. GLENN, *Legal Traditions of the World, Sustainable diversity in law*, Oxford University Press, Oxford, 2004, pp. 301 – 340.

<sup>15</sup> See *Arrowsmith v. United Kingdom*, Application 7050/75, 16 May 1977.

<sup>16</sup> Cfr. C. EVANS, *Freedom of religion under the European Convention on Human Rights*. Oxford University Press, Oxford, 2001, pp. 111-23; R.J. AHDAR, & I. LEIGH, *Religious freedom in the liberal state*, Oxford University Press, Oxford, 2013, pp. 166 -67.

<sup>17</sup> See P. CUMPER, *The public manifestation of religion or belief: Challenges for a multi-faith society in the twenty-first century*, in R. O'Dair (ed.), *Law and religion current legal issues*, IV, Oxford University Press, Oxford, 2001, p. 314.



beliefs, because only in this way can the public authorities fully ensure public order, peace and religious tolerance in a democratic society. This duty of neutrality and impartiality of the state ensures that

“but for very exceptional cases, the right to freedom of religion as guaranteed under the Convention excludes any discretion on the part of the State to determine whether religious beliefs or the means used to express such beliefs are legitimate”<sup>18</sup>

and to enforce the obligation to guarantee pluralism and genuine tolerance between groups and individuals holding different world views<sup>19</sup>.

Furthermore, the Court emphasised that pluralism, tolerance and broadmindedness are necessary elements of a "democratic society"<sup>20</sup>. Democracy cannot be reduced to the constant supremacy of the opinion of the majority: It requires a balance that ensures that minorities can enjoy fundamental rights on equal footing with the majority population, so as to avoid the abuse of a dominant position. Pluralism and democracy must also be based on dialogue and a spirit of compromise, which necessarily involves various concessions by individuals which are justified in order to safeguard and promote the ideals and values of a democratic society<sup>21</sup>.

By virtue of linking tolerance, pluralism and neutrality to religious freedom, the Court assumes that the right to freedom of conscience and religion is thus structured as a garrison to guarantee moral pluralism<sup>22</sup>: It prohibits a majority of citizens from unconditionally imposing a certain view of the world, destroying or negating the possibility of pursuing a heterodox ethic founded on imperatives with supreme cogency. It inhibits the state from supporting or blaming a confession because of its principles: However, it also involves the duty to fully protect religious minorities and to promote the exercise of moral freedom in conditions of equality.

From this perspective, the right to express one's own religion is a face of the prism of the right to express one's own personal identity. The refusal of a medical treatment is a way to witness one's own faith, and by virtue of

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<sup>18</sup> Hasan and Chaush v. Bulgaria [GC], Application 30985/96, 26 October 2000, para. 78.

<sup>19</sup> See Larissis and Others v. Greece, Application 23372/94; 26377/94; 26695/95, 10 July 1998; Serif v. Greece, Application 38178/97, 14 December 1999.

<sup>20</sup> Murphy v. Ireland, Application 44179/98, 10 July 2003, para. 72.

<sup>21</sup> This approach is strongly emphasised by C.F. STYCHIN, *Faith in the future: Sexuality, religion and the public sphere*, in *Oxford Journal of Legal Studies*, 2009, 29(4), pp. 729-55, esp. pp. 754-5.

<sup>22</sup> P. CUMPER, *The legal regulation of new religious movements*, in P. Cumper & S. Wheatley (eds.), *Minority rights in the new Europe*, Kluwer Press, Amsterdam, 1999, pp. 174-78.



the relationship between human dignity and respect for every manifestation of identity, the freedom to witness one's own faith must be guaranteed in a particular way. Such freedom is necessarily linked to ethical and religious pluralism: In fact, only a legal system in which individuals are free to become martyrs can offer real protection of the right to pursue one's life plan and to fully manifest one's own identity<sup>23</sup>.

Therefore, the freedom of individuals to martyrize themselves may legitimately be limited only if this freedom irreconcilably conflicts with the fundamental principles expressed by the Nice Treaty, the ECHR and/or the State Constitutions: Moreover, every limitation must always be reasonable and proportionate and rest on a legal basis.

From the perspective of the ECHR, the individual right to religious freedom is structured as a subjective public right intended to guarantee not only the freedom to believe or not to believe, to belong or not belong to a religious group, but also the freedom to live according to one's own conscience. In fact, a democratic, open and plural society must be able to ensure - albeit with the limitations that we will see later - the free pursuit of a life project through a series of choices and actions, even when they are not an expression of the dominant culture, but of a counterculture linked to religious precepts. Freedom of conscience and religion, as an individual right, questions the immediate relationship of individual-State and expresses the fundamental *priority*, compared to the state, of the *individual* and his/her aims in life. It guarantees every individual the opportunity of self-determination and being-in-the-world with their projects of life, and therefore, it pre-exists with respect to the rule of law, which was born and legitimated to protect the full development of such projects.

As mentioned above, there is an unambiguous relationship between the refusal of treatment and the firm belief that an illness can be healed through prayer (and not medical healthcare) or the explicit or implicit prohibition to receive that treatment deriving from the religious legal system to which the patient belongs. The table below summarises some of the cases of treatment refusal on religious grounds reported in the scientific literature.

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<sup>23</sup> S. CANESTRARI, *Rifiuto informato e rinuncia consapevole al trattamento sanitario da parte di paziente competente*, in S. Rodotà et al. (eds.), *Il governo del corpo*, Giuffrè, Milano, 2011, pp. 1901-1906.



**Table 1. Cases of treatment refusal on religious grounds reported in scientific literature**

• Firm belief that an illness can be healed through prayer and not medical healthcare.	1. Explicit or implicit prohibition to receive that treatment deriving from religious legal system to which the patient belongs.
Christian Science members <sup>24</sup>	Jehovah's Witnesses <sup>25</sup>
Followers of Christ <sup>26</sup>	Muslims <sup>27</sup>
General Assembly and Church of the First Born members <sup>28</sup>	Hindus <sup>29</sup>
	Jews <sup>30</sup>

## 5 - The legitimate limitations on the right to refuse a treatment on religious grounds

As emphasised above, the freedom of individuals to refuse a procedure on religious grounds (and so, to become martyrs of their faith) may

<sup>24</sup> **C.D. HERRERA**, *Disputes between state and religion over medical treatment for minors*, in *Journal of Church and State*, 2005, 47, pp. 823-839; **J.C. MERRICK**, *Christian Science healing of minor children: Spiritual exemption statutes, first amendment rights*, in *Issues in Law & Medicine*, 1994, 10(3), pp. 321-342; **J. HARTSELL**, *Mother may I . . . live? Parental refusal of life-sustaining medical treatment for children based on religious objections*, in *Tennessee Law Review*, 1999, 66(2), pp. 499-530 at 503- 506.

<sup>25</sup> **R. SINGELENBERG**, *The blood transfusion taboo of Jehovah's Witnesses: Origin, development and function of a controversial doctrine*, in *Social Science & Medicine*, 1990, 31(4), pp. 515-523; **O. MURAMOTO**, *Bioethics of the refusal of blood by Jehovah's Witnesses: Part 1. Should bioethical deliberation consider dissidents' views?*, in *Journal of Medical Ethics*, 1998, 24(4), pp. 223-230; **A. MCINROY**, *Blood transfusion and Jehovah's Witnesses: The legal and ethical issues*, in *British Journal of Nursing*, 2005, 14(5), pp. 270-274.

<sup>26</sup> **AAP Policy Statement**, *Conflicts between religious or spiritual beliefs and pediatric care: Informed refusal, exemptions, and public funding*, in *Pediatrics*, 2013, 132(5), pp. 962-965.

<sup>27</sup> Refusal towards porcine-derived medicaments, pigskin tissues in surgery, diagnostic procedures conducted by a male: **M.A. ALBAR**, *Seeking remedy, abstaining from therapy and resuscitation: An Islamic perspective*, in *Saudi Journal of Kidney Diseases and Transplantation*, 2007, 18(4), p. 629.

<sup>28</sup> **K. HICKEY & L. LYCKHOLM**, *Child welfare vs. parental autonomy: Medical ethics, the law, and faith-based healing*, in *Theoretical Medicine and Bioethics*, 2004, 25, pp. 265-276 at 265.

<sup>29</sup> **B. QURESHI**, *Management of ethnic Asian patients in general practice*, in *Transcultural Medicine*, 1989, pp. 82-90.

<sup>30</sup> **M.A. AINA, I. AMIN, R.N. RAJA MOHD HAFIDZ, & C.M. YAAKOB**, *Identification polypeptide biomarkers of porcine skin gelatin by two-dimensional electrophoresis*, in *International Food Research Journal*, 2013, 20(3), pp. 1395-1399.



legitimately be limited only if this freedom irreconcilably conflicts with the fundamental principles expressed by the Nice Treaty, the ECHR and/or the State Constitutions: Moreover, every limitation must always be reasonable and proportionate and rest on a legal basis.

In this legal background, drawing on an extensive range of sources and jurisprudence, both in the English (and Welsh)<sup>31</sup> and in the Italian legal systems<sup>32</sup>, I shall set out some basic principles that guide the general issue of medical treatment refusal and other specific criteria devoted to determining the cases in which a refusal founded on religious grounds is lawful<sup>33</sup>. From the conjunction of these principles, four main limitations on the right to refuse a treatment on religious grounds may be identified: They can be listed as follows:

a) The patient must be capable of refusing the treatment. Issues connected to this limitation will be discussed further in section 5.

b) The refusal must be genuine and not the result of undue pressure on the patient. This will be developed in section 6.

c) Competent adults are free to pronounce a genuine refusal and to become martyrs, but they cannot martyrize their (incompetent) minor children. Thus, the parents' refusal may be overruled by a superior court judge. This will be discussed in detail in section 7.

d) The refusal of a competent minor can be overridden by the Courts when the child's welfare is threatened by a serious and imminent risk that he/she will suffer grave and irreversible mental or physical harm. Issues connected to this limitation will be discussed further <sup>34</sup>.

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<sup>31</sup> Gillick v. West Norfolk & Wisbech Area Health Authority [1985] UKHL 7; Re C (Adult, refusal of treatment) [1994] 1 All ER 819; Re B (Adult, refusal of medical treatment) [2002] 2 All ER 449; Re MB (Adult, medical treatment) [1997] 38 BMLR 175 CA; Re T (Adult) [1992] 4 All ER 649.

<sup>32</sup> Corte di Cassazione (Cassation Court), 3rd civil section, 25 July 1967, n. 1950; Corte di Cassazione (Cassation Court), 3rd civil section, 30 April 1996, n. 364; Corte di Cassazione (Cassation Court), 4th criminal section, 22 October 2005, n. 38852; Corte di Cassazione (Cassation Court), 1st Civil Section, 16 October 2007, n. 21748; Corte di Cassazione (Cassation Court), 3rd civil section, 30 July 2004, n. 14638; Consiglio di Stato (State Council), 4<sup>th</sup> section, 2 September 2014, n. 4460.

<sup>33</sup> Britain: NHS Trust v. B [2014] EWHC 3486 (Fam); Nottinghamshire Healthcare NHS Trust v. RC (2014) EWHC 1317 (COP); N (A Child) (Religion: Jehovah's Witness), Re [2011] EWHC 3737 (Fam); Re L (A Minor) [1998] 2 FLR 810; St George's Healthcare NHS Trust v. S; R v. Collins and others, ex parte S [1998] 3 All ER 673. Italy: Cagliari Assize Court, 10 March 1982; Court of Cassation, 1<sup>st</sup> Criminal Section, 13 December 1983; Rome Assize Court of Appeal, 13 June 1986 Court of Vibo Valentia, 30 November 2005; Court of Rome, 21 December 2005; Court of Treviso, 9 February 2006.

<sup>34</sup> Further readings on this topic in the literature: J. STAVERT, *Added value: Using human*



Equally, the jurisprudence and the literature indicate as the following as *not* being legitimate limitations:

a) The principle of the sanctity of life.

The principle of the sanctity of life constitutes the logical and pre-judicial antecedent of the right to life guaranteed by Article 2 of the ECHR and Article 6 of the ICCPR. The recognition of the sacredness of every human life as a common heritage of civilisation entails, from a legal point of view, the prohibition of murder - implemented either by a criminal act or by omission -, the prohibition of the death penalty, and finally, the criminal responsibility for manslaughter when the death of a person is derived from negligence, carelessness or inexperience on the part of the agent.

The debate continues about whether - by virtue of the recognition of the sanctity of life - a person who is legally capable to consent may freely dispose of the right to life, giving it up through suicide or by expressing his/her consent to an act intended to cause his/her own death (through the administration of a poisonous substance or by other means). It is a rather common heritage of European constitutionalism that the principle of self-determination, a corollary of human dignity - allows every capable patient to refuse a medical treatment, even when this choice can lead to his/her own death<sup>35</sup>. The right to life, in fact, is not identified with the obligation to care at all costs. This obligation would be an expression of a vitalist ideology which would excessively limit individual moral freedom, and, at the same time, would be contrary to the right of self-determination in health: A right which entails, as a corollary, the need for informed consent before the doctor can legally perform a medical treatment. Hence, the principle of the sanctity of human life must yield to the principle of self-determination<sup>36</sup>.

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*rights to support psychiatric advance statements*, in *Edinburgh Law Review*, 2013, 17(2), pp. 210-223 (doi:10.3366/elr.2013.0155, esp. pp. 210 -212); **S. BURNTON**, *Doctors, patients and the human rights act*, in *Medico-Legal Journal*, 2011, 79(4), pp. 115-128 (doi:10.1258/mlj.2011.011031); **E. WICKS**, *The right to refuse medical treatment under the European Convention on Human Rights*, in *Medical Law Review*, 2001, 9(1), pp. 17-40 (doi:10.1093/medlaw/9.1.17); **R. GILBAR**, *Family involvement, independence, and patient autonomy in practice*, in *Medical Law Review*, 2011, 19(2), pp. 192-234 (doi:10.1093/medlaw/fwr008); **BRITISH MEDICAL ASSOCIATION**, *Consent, rights and choices in health care for children and young people*, BMJ Publishing Group, London, 2001, esp. pp. 109- 115, pp. 145-47.

<sup>35</sup> **A. MACLEAN**, *Autonomy, consent and persuasion*, in *European Journal of Health Law*, 2006, 13(4), pp. 321-338 (doi:10.1163/157180906779160274).

<sup>36</sup> *Ms B v. An NHS Hospital Trust*, [2002] 2 All ER 449; Rome Tribunal, Giudice per l'Udienza Preliminare, 23 luglio- 17 ottobre 2007, n. 2049, Corte di Cassazione (Cassation Court), 1st Civil Section, 16 October 2007, n. 21748.



When the patient is not capable, both in the English and Italian legal systems, the decision-maker<sup>37</sup> has the duty to make decisions in the best interest of the patient<sup>38</sup>: Hence, he/she has the duty to weigh the possible benefits of the refusal against its possible disadvantages<sup>39</sup>. This assumption will be developed further in the next section. In this section, it must be emphasised that emotional, welfare and social benefits and disadvantages should be considered in determining the best interest of the patient: Hence, the balancing test may even take into account the ethical and religious views of the patient when he/she was capable of refusing. In other words, religion matters in determining the best interest of the patient, and hence, in the doctor's decision to limit or cease treatment for the disease of a non-capable patient.

Moreover, when the refusal of treatment was communicated at a prior date when the patient was capable of consent, the doctor has the duty to respect the free will of the patient, even if this can result in the latter's death.

The principle of the sanctity of life may, however, legitimate the overriding of a competent child's refusal. In subsequent sections, more references will be provided regarding these points.

b) The principle of respect for human dignity.

The principle of respect for human dignity prevents anyone from degrading a person to an object, to a mere instrument, or to a fungible entity, i.e. to treat him/her as a thing or to give him/her the same (or worse) legal status as a non-human animal. From this principle, several sub-

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<sup>37</sup> In the English legal system, the decision makers may be: a personal welfare attorney for decisions about care or treatment, the Court of Protection, the Court Appointed Deputy (neither the Court of Protection nor the Court Appointed Deputy may override a valid and applicable advance decision or a decision of an attorney in the person's best interests), the most appropriate person in relation to a specific decision. See **C. HUTCHINSON, J. FOSTER**, *Best interests at end of life: Practical guidance for best interests decision making and care planning at end of life*, Social Care Institute for Excellence (SCIE), London, UK, 2008, p. 5.

<sup>38</sup> **E. WICKS**, *Human rights and healthcare*, cit. pp. 94 -105.

<sup>39</sup> In Italy, the Cassation Court emphasised that the guardian must, above all, act in the exclusive interest of the incapacitated person, reconstructing the presumed will of the unconscious patient and taking into account the wishes expressed by him before the loss of consciousness, or inferring that will from his personality, his lifestyle, his inclinations, his basic values and his ethical, religious, cultural and philosophical convictions. The principle of self-determination implies, alongside the right to choose between different therapies, the opportunity to reject them and interrupt them in a terminal phase of life. This right 'can' be freely exercised even when it leads to the sacrifice of life. See **G. FERRANDO**, *Fine vita e rifiuto di cure. Profili civilistic*, in In S. Rodota et al. (eds.), *Il governo del corpo*, cit., pp. 1873- 1893.



principles seem to descend as corollaries according to the State Members of the Council of Europe: the equality between men and women, the unity of marriage, the illegitimacy of all forms of violence in the education of children, the respect for the physical dimension, the prohibition of inhuman or degrading treatment, the freedom of entry or exit from a community, and the right to self-determination.

This principle may, however, legitimate limitations on self-determination, banning conducts which can prejudice the physical or psychological integrity of the person, even when he/she agrees. These limitations are an exception, not the rule. They are justified by a general ethical rejection of specific behaviours (the commercialisation of parts of the body, FGM) or by the will to guarantee the “core content” of the right to life, banning active euthanasia and assisted suicide.

The refusal of a treatment may move the patient towards death (passive euthanasia) but, in such a case, the decision is not against the “core content” of the right to life, which must yield to the principle of self-determination.

A wide debate may be opened on the legitimation of the refusal in a case in which it could involve cruel or degrading consequences, but it is beyond the scope of this essay.

## **6 - Capacity to refuse a treatment**

As pointed out in the previous section, only patients with capacity are entitled to refuse a treatment on religious grounds. This principle is clearly expressed – in the English (and Welsh) legal system – in the 2005 Mental Capacity Act (MCA), together with the presumption of capacity (a person must be assumed to have the capacity to make decisions, unless it can be established that he lacks capacity, section 1.2), the principle of helping in decision making (people must take all practicable steps to help persons to make their own decisions, section 1.3) and the right to make unwise decisions (a person who makes a decision that others think is unwise should not automatically be labelled as lacking the capacity to make a decision, section 1.4). In the Italian legal system, this principle is linked to the capacity to exercise rights as ruled by Article 2 of the Civil Code<sup>40</sup>, according to

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<sup>40</sup> Part of the Italian literature assumes that the capacity to refuse a treatment is not linked to article 2 of the Civil code, but rather, to the concept of “natural capacity” (the ability of the individual to understand the meaning of his/her own actions and the power to determine his/her own wishes and to develop a strategy in order to realise them). See



which the capacity to acquire and to exercise subjective rights and to take on obligations is acquired generally at 18 years old.

According to Coggon and Miola<sup>41</sup>, “capacity” derives from the sum of “autonomy” and “liberty”. Autonomy relates to free will, so an “autonomous agent” is someone with free will, and liberty relates to the freedom to act without the interference of a third party. Liberty is a juridical dimension, which may not necessarily proceed from autonomy: It rather necessitates the presence of predetermined, general and abstract requirements which are set by parliament.

As a first step, I will try to define the correct juridical dimension of the concept of “autonomy”.

Autonomy is a personal dimension linked with awareness and self-determination<sup>42</sup>: It requires the functioning of the mind and brain of the patient at such a level as to understand the implications of the medical information and of the refusal for his or her life<sup>43</sup>, to reason about these implications (also) in the future, to deliberate the refusal in accordance with the rules and principles of his/her own choosing and to communicate it to the medical staff<sup>44</sup>.

Autonomy implies that the patient “has the rational acumen (‘mental capacity’) to reach a decision”, but it does not require the patient to make a wise (according to the common sense) decision: A patient may be autonomous but irrational in his/her decision to refuse. The debate continues regarding this assumption.

For example, Grisso and Appelbaum (1998) point out that autonomy ought to be evaluated through an appreciation test. The patient’s system of belief, which support the decision:

- Should not be irrational, unrealistic, or a considerable distortion of reality
- Should not be the consequence of impaired cognition or affect
- Should not be relevant for the decision<sup>45</sup>.

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**M. DOGLIOTTI**, *Le persone fisiche*, in P. Rescigno (dir.), *Trattato di diritto privato*, 2, Utet, Torino, 1982, p. 81.

<sup>41</sup> **J. COGGON, & J. MIOLA**, *Autonomy, liberty, and medical decision-making*, in *The Cambridge Law Journal*, 2011, 70(3), pp. 523-547 (doi:10.1017/S0008197311000845).

<sup>42</sup> **E. WICKS**, *Human rights and healthcare*, cit., pp. 61-64.

<sup>43</sup> See **J.F. DRANE**, *The many faces of competency*, in *The Hastings Center Report*, 1985, 15(2), pp. 17-21.

<sup>44</sup> *Nottinghamshire Healthcare NHS Trust v. RC (COP) [2014] EW COP 1317*.

<sup>45</sup> **T. GRISSO, & P.S. APPELBAUM**, *Assessing competence to consent to treatment: A guide for physicians and other health professionals*, Oxford University Press, New York, 1998, pp. 45-49.



This study fails to fully acknowledge that the right to make an autonomous but irrational choice about a treatment is a corollary of the right to manifest one's religion: this right is protected by international law and may be limited so long as the limitation is prescribed by law, is necessary and proportionate, and pursues the interests of public safety, the protection of public order, health or morals, or the protection of the rights and freedoms of others. Moreover, the article does not explain why the moral choices of a person should be considered valid only if they are caused by a rational thought process, when, in fact, many everyday actions are governed by feelings or ideas of metaphysical nature.

A different perspective has been adopted by other scholars, who argue that the decision is the result of life history: it reveals personal identity and, at the same time, it contributes to the development of it<sup>46</sup>, opening "the way for compassion to those who rely on care from others"<sup>47</sup>, without renouncing the provision of "room for persuasion when a caregiver feels that his patient is at risk of relapse"<sup>48</sup>. This study acknowledges that religious duties are sometimes not directly linked to reasonableness, and that they may depend on the forcefulness of a taboo<sup>49</sup>.

England and Wales have followed the path traced by this latter perspective: In fact, Section 1(4) of the MCA 2005 states: "A person is not to be treated as unable to make a decision merely because he makes an unwise decision"<sup>50</sup>.

This choice, which was made by Parliament in the MCA, has deep roots in two Court decisions.

In *Re C (Adult: Refusal of Treatment)*<sup>51</sup>, Mr Justice Thorpe stated that a paranoid schizophrenic patient at Broadmoor had the right to refuse the amputation of a gangrenous injured leg on the basis of his religious beliefs. Although the general capacity of the patient was impaired by

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<sup>46</sup> G. WIDDERSHOVEN, & R. BERGHMANS, *Advance directives in psychiatric care: A narrative approach*, in *Journal of Medical Ethics*, 2001, 27(2), pp. 92-97 (retrieved on January 05, 2015, from <http://www.jstor.org/stable/10.2307/27718653?ref=no-x-route:4ff8028e81dd80b2ec02f6854fbd4b9a>).

<sup>47</sup> M.J. JANSSENS, *Pressure and coercion in the care for the addicted: Ethical perspective*, in *Journal of Medical Ethics*, 2004, 30(5), pp. 453-458 (doi:10.1136/jme.2002.002212, p. 455).

<sup>48</sup> M.J. JANSSENS, *Pressure and coercion*, cit. (2004), *ibidem*.

<sup>49</sup> R. SINGELENBERG, *The blood transfusion taboo of Jehovah's Witnesses: Origin, development and function of a controversial doctrine*, in *Social Science & Medicine*, 1990, 31(4), 515-523 (doi:10.1016/0277-9536(90)90048-W).

<sup>50</sup> J. SAMANTA, & A. SAMANTA, *Medical law*, Palgrave Macmillan, Basingstoke, 2011, pp. 160-161.

<sup>51</sup> [1994] 1 WLR 290 (FD).



schizophrenia, he was judged to be able to understand the nature, purpose and effects of the proposed medical treatment: As a consequence, he had the right to self-determination and to refuse the treatment on religious grounds, even if that would lead to his death. In *Re B (Adult: Refusal of Medical Treatment)*<sup>52</sup>, the High Court of Justice Family Division, Principal Registry, pointed out that a competent adult patient has the right to refuse to consent to any medical treatment, whether the reasons appear irrational, unknown or non-existent to a healthcare professional, if they make sense in light of the patient's religious and personal beliefs.

In Italy – taking into account that the Oviedo Convention on Human Rights and Biomedicine is not legally binding because the Italian authorities have failed to deposit the instrument of ratification, but that it must be used in the interpretation of internal rules<sup>53</sup> - there are mainly four sources from which the full legal validity of an apparently unwise refusal may be deducted.

First, it must be pointed out that the Italian Constitution states:

a) There are no restrictions on personal freedom except by a warrant which states the reasons from a judicial authority and only in cases and in a manner provided for by law (art. 13);

b) All have the right to profess freely their own religious faith in whatever form, individual or associate, to propagate it and to exercise it in private or in public cults, provided that the rites are not contrary to morals (art. 19);

c) No one may be obliged to undergo a 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 (art. 32, 2).

Second, it must be emphasised that, in 2008, the National Bioethics Committee, in its opinion on "Conscious refusal and renunciation of healthcare in the patient-doctor relationship"<sup>54</sup>, stated that religious grounds may legitimate a refusal of treatment.

Third, it can be deducted (*a contrario*) from art. 4-1, point 3, of the Ministerial Decree of 1 September, 1995, that an express refusal of a blood transfusion cannot be overridden, even if it is grounded on "unwise" reasons.

Fourth, it must be pointed out that law number 18 of 3 March 2009, ratifying the UN Convention on the Rights of Persons with Disabilities,

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<sup>52</sup> EWHC 429, [2002] 1 FLR 1090.

<sup>53</sup> Corte di Cassazione (Cassation Court), First Civil Section, 16 October 2007 n. 21748.

<sup>54</sup> [http://www.governo.it/bioetica/eng/pdf/refusal\\_3.pdf](http://www.governo.it/bioetica/eng/pdf/refusal_3.pdf)



recognises the importance for the disabled of their individual autonomy and independence, including the freedom to make their own choices.

According to these sources, the jurisprudence stated that doctors are not allowed to treat against the will of a patient. The consent of the patient must exist in order to consider a treatment to be lawful<sup>55</sup>, and if the refusal of a treatment is informed, real and current, it cannot be disregarded, even if it is unwise<sup>56</sup>: The patient's right not to be treated is guaranteed, even if the refusal places his or her life at risk<sup>57</sup>.

Therefore, in both England (and Wales) and in Italy, autonomy does not require reasonableness, but rather, an act of free will performed by a patient who:

- a) is able to understand, communicate, reason and deliberate,
- b) is sufficiently informed, and
- c) has fully understood all of the consequences, implications and operating methods of the treatment.

This general concept of autonomy, characterized by the three aforesaid elements, must be now discussed as regard as the issue of the adult patients lacking capacity.

Regarding the issue of the adult religious patient lacking capacity, the English and Welsh legal systems are based on the following principles expressed by the 2005 MCA:

- a) If the adult religious patient has created an effective advance decision which refuses the treatment, the advance decision must be respected (as said, even if it seems "unwise");
- b) If the adult patient has effectively created a lasting power of attorney, the donee of the LPA may be able to make the decision, but only in the best interest of the patient;
- c) If the court has appointed a deputy, he/she can make the decision in the adult patient's best interest;
- d) If there is no effective advance decision and no LPA, and no deputy who can make the decision, then the question is whether the treatment is in the best interest of the adult patient<sup>58</sup>.

Therefore, the first main issue is to define the "best interests of a religious patient", mainly if he/she belongs to a religious group which explicitly or implicitly bans some medical treatments, or holds the firm belief that an illness can be healed through prayer and not medical

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<sup>55</sup> Corte di Cassazione (Cassation Court), 4th Criminal Section, 14 March 2008, n. 11335.

<sup>56</sup> Corte di Cassazione (Cassation Court), First Civil Section, 16 October 2007, n. 21748.

<sup>57</sup> Corte di Cassazione (Cassation Court), 3<sup>rd</sup> Civil Section, 15 September 2008, n. 23676.

<sup>58</sup> Sections 24 – 26 of the 2005 MCA



healthcare. The 2005 MCA provides a statutory checklist in order to decide what is in the patient's best interest: It requires the decision to emerge from a balancing test between the advantages and disadvantages linked to the treatment from a clinical, emotional and welfare point of view. This test must take into account "the beliefs and values that would be likely to influence" the patient's decision if he/she had capacity, but these beliefs and values cannot be the only factor which defines the patient's best interest. Hence, when a patient lacks capacity and did not create an advance decision, a weakening of the central importance of the religious belief in the decision-making process has to be noted, taking account of the fact that a competent patient may refuse a treatment exclusively for religious reasons.

This weakening may be questionable in light of the right to personal identity and the right of self-determination. According to Jill Marshall<sup>59</sup>, it must be pointed out that religious freedom is fully guaranteed only if everyone can pursue his/her own freely chosen lifestyle: The freedom to be and become the person one chooses can be limited only with regards to activities that are harmful/dangerous to others or to acts conflicting with the principle of the respect for human dignity. It does not seem so simple to find reasons to exclude religious patients who lack capacity from the chance to pursue their own lifestyles in situations which may involve treatments not complying with their religion, especially in cases in which - despite not having left an advance directive - they have always shown, by their actions, a strong link to the precepts of a religious belief.

In Italy, the law is silent on the point of advance decisions. The Cassation Court tried to find a way to give patients the chance to have their will respected by enhancing the status of the Guardian (*Amministratore di sostegno*), introduced by Law n. 6 of 9 January 2004<sup>60</sup>: Every person in a physical or mental disablement, who cannot, even partially or temporarily, take care of his/her own interests, can, in effect, be assisted by a Guardian, appointed by the tutelary judge.

According to Article 408 of the Civil Code, every person can prepare a *pro futuro* act for the appointment of a Guardian. This act

a) will bind the Guardian to respect the patient's will, and allow him to consent or to refuse a medical treatment;

b) will guide the intervention of the doctor, who has the duty to verify the actuality of the patient's will (until the time of loss of consciousness, the patient always has the power to revoke or modify the choice made);

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<sup>59</sup> J. MARSHALL, *Human rights law and personal identity*, Routledge, Abingdon, 2014, pp. 176-180, 216- 218.

<sup>60</sup> Corte di Cassazione (Cassation Court), First Civil Section, 20 December 2012, n. 23707.



c) will force the exequatur by the competent court, which has the task of establishing the powers to be given to the guardian, or may authorise a treatment on the person.

The second main issue concerns people who suffer from Alzheimer's disease or other forms of dementia, in which the cognitive status is unclear or fluctuates.

People suffering from these diseases do not necessarily lack the capacity to make all decisions: As a corollary to the right of self-determination and the right to make unwise decisions, they ought to be considered autonomous and capable of refusing a treatment until the moment when they cannot understand the implications of the medical information and of the refusal for his or her life, even if they can only retain the information for a short period<sup>61</sup>.

Moreover, the patient's right to religious freedom seems to require the medical staff to repeat the assessment every time he/she appears best able to understand and retain the information, and to use different communication methods which may be acceptable to him/her.

So far this section has focussed on the concept of autonomy.

According to Coggon and Miola<sup>62</sup>, liberty demands a focus on establishing whether the patient is in a rightful position to reach a legally binding decision ('legal capacity').

Legal capacity is not necessarily linked to autonomy: for example, in the case of children (they can be autonomous, but not fully legally free to make their own decisions) and adults who want to perform or to refuse an act, but are not legally free to do so.

Both in Italy and in England (and Wales), an autonomous adult always has the liberty to refuse a treatment on religious grounds.

On the subject of the liberty of an autonomous adolescent, it must be emphasised that – in the English and Welsh legal system - the Family Law Reform Act 1969, section 8, states that a child aged 16 or 17 can consent to 'treatment' and that such consent is to be managed in the same way as an adult's consent. However, an autonomous teenager aged 16 or over actually has "limited freedom" to refuse a treatment for religious grounds, because his/her decision may be overridden by the Court in the child's best interest<sup>63</sup>. Even a patient under 16 may have the liberty to reject a treatment on religious grounds, but this liberty is strictly linked to the patient's

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<sup>61</sup> S. BINGHAM, *Refusal of treatment and decision-making capacity*, in *Nursing Ethics*, 2012, 19(1), pp. 167-172 (doi:10.1177/0969733011431925, p. 169).

<sup>62</sup> J. COGGON, & J. MIOLA, *Autonomy, liberty, and medical decision-making*, cit., (2011).

<sup>63</sup> *Re W (a minor) (medical treatment)* [1992] 4 All ER 627.



autonomy: The adolescent (or child) must be assessed as “Gillick competent” to be free to refuse, and this means that he/she must be considered mature and capable of fully understanding the nature of the treatment, the options, the risks involved and the benefits<sup>64</sup>. Moreover, it must be pointed out that, even in such a case, firstly (and this relates to all minors up to 18 years of age) even a competent child’s refusal can be overridden if just one of the parents consent to the treatment on the child’s behalf; secondly, the Court may override a minor patient’s decision (even if he/she is aged 16 or 17<sup>65</sup>) in order to ensure his/her physical welfare<sup>66</sup>, and that – when the minor patient needs urgent medical treatment to avoid death or serious harm - the doctor may perform that treatment even without the protection of a court order<sup>67</sup>. This solution raises some issues about the real liberty of minor patients and their best interests<sup>68</sup>: The necessary, indisputable connection between best interest and the execution of the treatment is questionable, especially when the need to safeguard the patient’s physical well-being compresses, absolutely, the freedom of choice and the ethical grounds that support the patient’s will.

In the *Simms Case*, Butler-Stoss LJ pointed out that – in view of the 1989 Children Act, which defined a child’s welfare as the court’s paramount consideration - the concept of best interest has to be assessed

“in the widest possible way to include the medical and non-medical benefits and disadvantages, the broader welfare issue of the two patients, their abilities, their future with or without the treatment, the view of the family and the impact of refusal of the applications”<sup>69</sup>;

hence, it is a multifaceted dimension of the concept of “best interest”, which is not exclusively and uniquely linked with the physical dimension of the patient, but has to be assessed, even taking into account the cultural and religious values of the child or the parents.

The literature shows that this multifaceted evaluation of a child’s best interest in healthcare has never been taken into account. Freeman, for example, critically pointed out that – both in the English and in the Welsh

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<sup>64</sup> *Gillick v. West Norfolk and Wisbech AHA* [1985] 3 All ER 402.

<sup>65</sup> *Re W (a Minor) (Medical Treatment)* [1992] 4 All ER 627.

<sup>66</sup> **M. FREEMAN**, *Rethinking Gillick*, in M. Freeman (ed.), *Children’s health and children’s rights*, Martinus Nijhoff Publishers, Leiden/Boston: 2006, pp. 201-217 (205-213).

<sup>67</sup> Department of Health. (2009). Reference guide to consent for examination or treatment (2nd ed.). DH, London, p.35, para 18; p. 38, para.27.

<sup>68</sup> **J. FORTIN**, *Children’s rights and the developing law* (3rd ed.). New York: Cambridge University Press, 2009, pp. 155-163.

<sup>69</sup> *Simms v. Simms and Another* [2003] 1 All ER 669.



legal systems – “a child can say yes to medical treatment but cannot say no. This is the simple, indeed trite, conclusion to which one comes after an examination of the cases”<sup>70</sup>. Taylor emphasised an asymmetry between the broad guarantees provided with regard to a child’s right to consent and the uncertain protection of the child’s right to refuse<sup>71</sup>. The problem is that it is not easy to let a competent patient who is under 16 years of age become a martyr because of his/her own faith, although the literature has reported that – by virtue of article 14 of the UNCRC - autonomous children have the right to (religious) self-determination and to choose their (religious) lifestyles<sup>72</sup>: Concerning patients who are under 16 years old, the right to refuse a treatment is strictly connected, not only with the full awareness, but also with the necessity of balancing the right to self-determination with the duty of the State to protect vulnerable children’s lives and health from the results of their own actions<sup>73</sup> and with the necessity of guaranteeing the genuineness of children’s refusals against forms of coercion or undue pressure.

The outlined issues have been questioned extensively in the Italian legal system, in which the full liberty to exercise an act of refusal is acquired upon attaining majority<sup>74</sup>. However, according to article 6 of the Oviedo Convention on Human Rights and Biomedicine (which, as mentioned, is not a legally binding instrument, but a document which must be taken into account to correctly interpret and apply the current legislation) and article 33 of the Code of Medical Ethics, the opinion of the minor must be taken into account when treatment is prescribed, as an increasingly determining factor of the function of the patient’s age and degree of maturity<sup>75</sup>.

Improving and enhancing the dialogue between the medical staff, the child patient and his/her family is supposed to be a key issue in the management of this sensitive case of treatment refusal motivated by

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<sup>70</sup> M. FREEMAN, *Rethinking Gillick*, cit., p. 211.

<sup>71</sup> R. TAYLOR, *Reversing the retreat from Gillick? R (Axon) v Secretary of State for Health*, in *Child and Family Law Quarterly*, 2007, 19(1), pp. 81-97.

<sup>72</sup> E. VERHELLEN, *Changes in the image of the child*, in M. Freeman & P. Veerman (eds.), *The ideologies of children’s rights*, MartinusNijhoff, The Hague, 1992, pp. 79 -94.

<sup>73</sup> T. SCHAPIRO, *Childhood and personhood*, in *Arizona Law Review*, 2003, 45, pp. 575-594.

<sup>74</sup> C. VIGNALI, *La tutela della salute del minore*, in *Diritto di famiglia e delle persone*, 2005, 34(4), 1421-1445.

<sup>75</sup> L. PASCUCCI, *Autodeterminazione terapeutica ed esigibilità delle cure*, in M. Sesta (ed.), *L'erogazione della prestazione medica tra diritto alla salute, principio di autodeterminazione e gestione ottimale delle risorse sanitarie*, Maggioli Editore, Santarcangelo di Romagna, 2014, pp. 259-260.



religious beliefs and values<sup>76</sup>. The correct balance between a competent child's will and the protective duty of society<sup>77</sup> may be more easily created by an intercultural approach managed by the care providers; those care providers ought to understand if a tradition-based insecurity regarding certain interventions exists in the mind of the patient, recognise the kind of religious concerns that may disturb his/her reflection, develop the exchange of views between the patient and his/her family, avoid coercion or undue pressure on the patient, and finally, manage the process of an open and respectful exchange or interaction with the child, in order to help him/her to freely express what he/she really desires.

In this section, it has been explained that the capacity to refuse a treatment on religious grounds is strictly linked to the autonomy and liberty of the patient.

The section that follows moves on to consider when an act of refusal, given by a patient with full capacity, may be considered genuine and free, or rather elicited in response to an undue pressure.

## 7 - The genuineness of consent

The key question linked to the genuineness of consent is whether an act of refusal might be considered free if it has been given under the influence of the (lay, clerical, prominent) members of the religious group to which the patient belongs. Can this influence on the patient's free will be considered undue?

As a preliminary remark, it must be stressed that the refusal is a personal act, which must be performed with sufficient knowledge of its consequences and with the full internal freedom to choose it: It requires a will that must be absolutely free and not elicited in response to pressure from another.

On this topic, the issue of the capacity to refuse medical treatment in light of the influence of a third party on the patient's decision must be discussed. With regard to the English legal system, in *Re T (Adult: Refusal of Treatment)* [1993]<sup>78</sup>, Judge Donaldson stressed that the real question – in

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<sup>76</sup> L. HAGGER, *The child as vulnerable patient: Protection and empowerment*, Ashgate, Farnham, 2009, p. 53.

<sup>77</sup> A. GRUBB, *Refusal of treatment (child): competence -- Re L (Medical Treatment: Gillick Competency)*, in *Medical Law Review*, 1999, 7(1), pp. 58-61.

<sup>78</sup> [1993] Fam 95, 113.



understanding whether or not the refusal depends on a genuine decision - is

“Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself?”

In other words: “Is it a decision expressed in form only, not in reality?”

It has been emphasised that a tired, in pain or depressed patient may be very weak and vulnerable to external influences, which are capable of substantially diminishing the patient’s freedom of will, and that the deference towards those to whom the patient is bound by a strong bond founded on piety, respect and (or) honour may force him to express a decision that is contrary to his/her own real will. Therefore, in these circumstances, the medical staff should be very careful in considering whether the refusal is genuine.

In *Re T (Adult: Refusal of Treatment)* [1992]<sup>79</sup>, the Court decided that a 20-year-old pregnant woman who had been injured in a wreck and had rejected the required blood transfusions lacked free will, because her treatment refusal had been given under her mother’s (a practising Jehovah’s Witness) pressure (and under the influence of drugs). Therefore, the Court stated that the patient’s decision had to be overridden.

The general rule on this topic is that a patient’s refusal of a particular treatment is not valid if it is expressed under undue influence, i.e. psychological pressure exerted by another person for which the patient feels reverence or who is linked to the patient by trust or confidence, which compelled the latter to refuse the treatment against his or her own will.

Turning to the Italian legal system, it can be seen that there is no explicit solution for this problem. However, it must be emphasised that the National Bioethics Committee has stated that the refusal or renunciation of the therapies by an autonomous and competent patient is legally legitimate when the patient is exercising his/her own free will, is self-conscious and aware of his/her own condition, as well as thoroughly informed about the illness and the consequences deriving from the acceptance or refusal/renunciation of the therapies<sup>80</sup>. *A contrario*, it may be stressed that a lack of free will caused by undue pressure may invalidate the patient’s refusal.

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<sup>79</sup> [1992] 4 All ER 64.

<sup>80</sup> [http://www.governo.it/bioetica/eng/pdf/refusal\\_3.pdf](http://www.governo.it/bioetica/eng/pdf/refusal_3.pdf)



This assumption seems to be broadly confirmed by taking into account that the refusal ought to be considered as a unilateral legal act of private autonomy, a manifestation of free will that is directed to the production of legal effects, by which patients express their will to exercise, in a specific way, the self-determination granted to them by the law<sup>81</sup>. As a legal act of private autonomy, the refusal is valid if it is free from error, duress and fraud, although the concept of duress, in Italian private law, must “amount to a serious and unjustified threat, that is, one sufficient (...) to provoke fear in a reasonable person in order to be grounds for violability”<sup>82</sup>, and, as such, it excludes reverential fear.

The Italian approach to the issue of the influence of the members of the religious group to which the patient belongs on his/her decision to refuse the treatment seems very different from that of the English (and the Welsh). The latter seems to give preference to the effective genuineness of refusal against every kind of pressure, implicit or explicit; the first seems to consider only a kind of pressure exercised through an overt threat as legally relevant.

It is questionable whether the Italian approach is appropriate: It does not seem adequate to guarantee the right of self-determination in healthcare for patients who belong to religious “encompassing groups” which heavily restrict the personal lives of their members.

According to Margalit, an encompassing group can be defined as “a competing group, in the sense that anyone belonging to it cannot in principle belong to another encompassing group [at] the same time”<sup>83</sup>.

Some religious groups can surely be defined as “encompassing”: They do not usually permit double or multiple membership, and their competing vision of society causes their members to be unable to understand and accept the inclusive nature of a liberal society. Moreover, some of them heavily restrict the lives of their own members: These groups are structured as legal systems and impose a large set of rules upon their members, which can cause them to be unable to fully express and foster

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<sup>81</sup> C. CASTRONOVO, *Il negozio giuridico dal patrimonio alla persona*, in *Europa e diritto privato*, 2009, 87, pp. 100-103.

<sup>82</sup> G. ALPA, & V. ZENO-ZENCOVICH, *Italian private law*, Routledge-Cavendish, Abingdon, 2007, p. 165.

<sup>83</sup> A. MARGALIT, *The decent society*, Harvard University Press, Cambridge, Mass., 1996, p. 177.



their own personal individual identities<sup>84</sup>. In this case, a clash between individual identity and group identity could be found<sup>85</sup>.

It must be observed, in this regard, that the right to freedom of choice in healthcare must be ensured, even (and especially) when it is denied by the social group to which the patient belongs, because - according to the approach of the Court of Strasbourg-ethical pluralism must be guaranteed to all individuals, and therefore, also to the faithful of various denominations, who are considered both *uti singuli* and as members of social groups having a religious purpose.

According to these premises, the evidences of this study suggest that a democratic pluralistic legal system, based on the respect of human rights, must prevent situations in which patients manifest a will to refuse a treatment only because of the pressure of group members and/or because of the fear of being banned from the group to which they belong and losing every kind of support offered by it.

Therefore, in my opinion, in order to assure that an act of will by an adult, competent patient who refuses a treatment for religious reasons is really free and has not been subjected to undue influence, a test ought to be passed. Table 2 describes a test proposal and its assessments.

**Table 2. Test proposal to evaluate the genuineness of treatment refusal in competent religious adult patients.**

<b>Is the patient religious?</b>	No=0 Believer=1 Practising believer =2	<b>Comment:</b> The disclosure of religious association and/or of religious beliefs constitutes sensitive data, which may be used only when necessary for medical purposes and the processing is done by a health professional or a person with an equivalent duty of confidentiality. In case of refusal of treatment, a patient's religious convictions may be a key issue in the choice of medical strategy, and it may be the first step in order to understand the genuineness of the patient's choice.
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<sup>84</sup> J. SPINNER-HALEV, *Surviving diversity: Religion and democratic citizenship*, Johns Hopkins University Press, Baltimore, 2000, pp. 2-6.

<sup>85</sup> E. VITALI, *Legislatio libertatis e prospettazioni sociologiche nella recente dottrina ecclesiastica*, in *Il Diritto Ecclesiastico*, 1980, 91(1), pp. 58- 64.



**Is the patient tired, in pain or depressed?** Rating scale from 0 to 3 based on empirical observations and health data. **Comment:** The more the patient is in pain, tired or depressed, the more he/she may be subjected to undue pressure with the view of forcing him/her to refuse the treatment against his or her own will.

**Can the group to which the patient belongs be considered encompassing and as restricting the lives of its own members?** Rating scale from 0 to 3 based on scientific contributions regarding the attitude of the group. **Comment:** A considerable amount of literature has been published on the history, practices and legal systems of the religious groups present in Europe. These studies may clarify the position of every single group towards the inclusive nature of liberal society and towards the relationship between individual self-determination and the rules on which the group operates. The more the group denies the inclusive nature of liberal society and compels individual autonomy, the more the patient may be subjected to undue pressure.

**Did the aforesaid group offer its moral or material support to the patient?** Rating scale from 0 to 3 based on patient history. **Comment:** The physician may investigate facts about the patient's personal life which are relevant to the medical assistance provided, for example, concerning moral or material support offered to the patient by the group to which he/she belongs. The more the group is/was supportive to the patient, the more the patient may be subjected to undue pressure.

**Is the treatment against the religious law which governs the group?** No=0  
It is not recommended, but it is lawful =2  
Yes=3 **Comment:** In this test, it is "against the religious law which governs the group" if both every treatment is banned or not recommended, both treatments are considered as disallowed on the ground of the doctrinal idea that illness can be healed through prayer (and not medical healthcare).

**Has someone in the group cooperated with the patient in order to understand** Rating scale from 0 to 3 based on empirical observations and patient history. **Comment:** Investigations are required in order to clarify whether the informed decision-making process has been



**the treatment and to make a decision regarding it?**

developed in cooperation with a third party which is member of the group to which the patient belongs. This cooperation is not *per se* unlawful, but the medical staff must investigate the real and concrete influence of the patient's advisor(s).

**What is the relationship between the decision co-operator and the patient?**

Rating scale from 0 to 3 based on patient history.

**Comment:** The more the relationship between the patient and his/her advisor is characterised by trust or confidence, the more the patient feels reverence for the advisor, the more he/she may be subjected to undue pressure.

In case of a positive answer to question n. 1 and if the value of the answer n. 5 is  $> 0$ , a total final score  $\geq 15$  could show undue influence.

Furthermore, in addition to the aforesaid test, in the Italian legal system, the concept of "reverential fear" may be taken into account in order to enable a real evaluation of possible undue influence.

Both the proposed test and a serious inquiry on the presence of an undue influence/reverential fear in the mind of the patient could be critiqued as unlawful: It could be argued that both of these survey issues require a treatment of sensitive data (concerning the patient's religious opinions and beliefs) that is not permitted by the law. However, this criticism does not take into account that EU Directive 95/46/EC - the Data Protection Directive - states that 'sensitive personal data' can be processed

"without specific consent if it is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health care services, and where those data are processed by a health professional subject to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy".

This principle has been confirmed in the legal system of the UK by schedule 3.8 of the Data Protection Act 1998 (the treatment of the data linked to Medical Confidentiality).

In Italy, Article 20 of Legislative Decree 196/2003 provides that public bodies may process sensitive and judicial data if the treatment is authorised by an express provision of the State law that emphasises the categories of operation that may be performed, as well as the substantial public interest pursued.



Moreover, article 85 of the aforesaid decree emphasises that the activities falling within the scope of the tasks committed to the National Health Service and other public health care bodies shall be considered to be in the substantial public interest when the process is performed in order to reach certain specific purposes.

Therefore, in the healthcare sector, sensitive data concerning religious beliefs can be processed for administrative activities related to the prevention, diagnosis, care and rehabilitation of the persons assisted by the National Health Service (including foreigners and Italian citizens abroad) and as regards the planning, management, control and assessment of medical treatments. The specific regulation for which the data are actually required in each case is explicitly regulated by schedules which should be adopted by every Region in accordance with the opinion of the Privacy Ombudsman.

## **8 - Refusal and children's best interest**

As described on the previous pages England, Wales and Italy, the legal responsibility to make decisions regarding the healthcare of younger children who lack sufficient understanding and intellectual capacity is generally upon their parents or guardians. This responsibility includes the right to make everyday choices regarding the children's health and to participate – in agreement with healthcare professionals or with the intervention of the court – in decisions regarding medical treatments for their children<sup>86</sup>. Hence, an absolute right of the parents to refuse treatments for their children on religious motivations is groundless: The refusal may be overridden by the Court in order to promote the child's best interest<sup>87</sup>.

As discussed above, a child's best interest in healthcare has a multifaceted dimension which transcends the physical dimension of integrity to embrace the principles and values that underpin the personality of the patient and the ideological background of his/her parents.

Hence, it may be pointed out that the best interest of an incompetent child is strictly related to his/her own welfare: But what constitutes a child's welfare?

From a theoretical point of view, it is a child's welfare in a mosaic-concept, i.e. a combination of various elements like his/her ascertainable

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<sup>86</sup> J. BRIDGEMAN, *Because we care? The medical treatment of children*, in S. Sheldon & M. Thomson (eds.), *Feminist perspectives on healthcare law*, Cavendish, London, 1998, p. 100.

<sup>87</sup> J. SAMANTA, & A. SAMANTA, *Medical law*, cit. (2011), pp. 253-256.



wishes and feelings, his/her physical, emotional and educational needs, and his/her religious background. Hence, according to Sheldon, “what truly constitutes the ‘welfare’ of the child is a matter of perspective”: it has been emphasised that “the notion of “best interest” is inherently a question of values and most parents believe they are making a decision in the best interest of their child. Parents who are Jehovah’s Witnesses, for example, may truly believe that they are making a decision in the best interest of their child when they refuse to consent to a blood transfusion. Loss of salvation is not, after all, a trivial consequence of acting on the physician’s recommendation”<sup>88</sup>.

In the end, however, there is a kernel in this mosaic-concept: the medical staff and the state powers have “to ensure that children ultimately become adults, able to decide, independently, what is in their own best interest”, thus legitimising the overriding of a refusal that could expose the child to the danger of death.

This kernel is deeply rooted in article 6 of the UNCRC, which does not simply guarantee “the inherent right to life” of every child, but also states that “States Parties shall ensure to the maximum extent possible the survival and development of the child”, thus legitimising the ban of every behaviour that is linked to activities endangering the child’s health, which is considered to be an objective and supreme value. Article 6 of the UNCRC goes beyond the provision of article 2 of the ECHR, because it generates a legal duty on the State parties to provide all of the positive measures directed at prolonging children’s lives to the maximum extent and to assure the full development of their personality “both from a material and spiritual point of view”. This hermeneutical approach creates many questions regarding the laws allowing terminally ill children to die, but that is not the topic of this essay: It surely makes parents’ (or guardians’) decisions which may damage the health and safety of their children unlawful, regardless of the reasons on which they are grounded. Even a refusal grounded on cultural and religious reasons may be overridden, because Protocol 1, Article 2 of the ECHR enshrines a right to religious education that must be constrained in order to assure the absolute and unequivocal implementation of Article 6 of the UNCRC.

Hence, it could be argued that the general principle governing parents’ (or guardians’) right to refuse – on religious grounds - treatments

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<sup>88</sup> **D.S. DIEKEMA**, *Parental refusals of medical treatment: The harm principle as threshold for state intervention*, in *Theoretical Medicine*, 2004, 25(4), p. 246.



for their children is the same as that expressed by the U.S. Supreme Court in the case *Prince v. Massachusetts* (although it addressed a different subject):

“[P]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves”<sup>89</sup>.

In other words, no one can become a witness of his/her religious faith by seriously endangering the mental or physical welfare of his/her own child: Hence, a refusal of medical treatment to a child, given by parents or guardians on religious grounds, must be overridden when it may expose the child’s health to an unnecessary and imminent risk.

In Italy, this approach has been confirmed by the Supreme Court in the *Oneda case*: In order to avoid the ban of the Jehovah's Witness faith, Mr and Mrs Oneda refused to allow their daughter to undergo periodic blood transfusions which were necessary for her survival. When the girl died, the Court clearly affirmed the unlawfulness of the parents’ or guardians’ refusal of treatment – even grounded on religious motivations - when it was necessary for the protection of the child’s life. Hence, Mr and Mrs Oneda were judged responsible for the crime of manslaughter<sup>90</sup>.

From this perspective, it seems very difficult to find legislative solutions which may generate a “religious accommodation” in order to allow parents to choose their favourite healthcare plan: Medical staff (if it is possible) ought, however, to try to create a dialogue with the patients and the parents, with the aim of avoiding a court’s intervention and determining all of the possible ways to receive the parents’ consent or – at least – to perform the treatment in a way that tries to avoid emotionally scarring the family.

However, it is questionable whether the principle of the “non-martyrization of children patients” can legitimate the parents’ refusal of a treatment which may, in the future, prevent the child from incurring serious injuries when the refusal does not expose the child to an unnecessary and imminent risk: A good example of this topic is represented by the refusal of a vaccine by a parent.

On this issue, it must be emphasised that childhood vaccination is not compulsory in the UK, while, in Italy, some vaccinations (against Diphtheria, Hepatitis B, Polio and Tetanus, to be precise) are –in general -

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<sup>89</sup> U.S. Supreme Court. *Prince v. Massachusetts*, 321 U.S. 158 (1944).

<sup>90</sup> S. CANESTRARI, *Rifiuto informato e rinuncia consapevole al trattamento sanitario da parte di paziente competente*, in S. Rodotà et al. (eds.), *Il governo del corpo*, cit., pp. 1908-09.



part of the national immunisation plan and mandatory for every newborn<sup>91</sup>. In the latter case, the parents' responsibility to immunise their children responds to an interest of the community: Hence, even if the refusal of mandatory vaccinations does not expose the child to an unnecessary and imminent risk, the general interest in public health prevails over parents' and guardians' beliefs.

On the other hand, a recommended (but not compulsory) vaccination, which is not linked to a superior and general interest, may be freely refused by the parents: However, it must be emphasised that immunisation should not be included in that "small group of important decisions"<sup>92</sup> which should only be made if there has been an agreement between everyone who has parental responsibility for the child<sup>93</sup> because of the connection – underlined by the courts – between it and the welfare of the child. Hence, in light of the aforesaid connection, in case of disputes between parents, the best interest of the children is to receive the vaccine, even overriding (if they are under 16) the parents' different opinions<sup>94</sup>.

In such cases, however, a religious accommodation for religious parents may be found. For example, pharmaceutical companies may be obliged to use gelatines or other added ingredients which minimise religious issues or concerns<sup>95</sup>.

## 9 - Conclusive remarks

Religion matters, even in medical law. The "tragic choices" made by patients to sacrifice their lives on the altar of the obedience to a set of religious rules are only one of the faces of a prism which medical and paramedical staffs are – very often– compelled to confront.

The "disenchantment" of Europe and its increasing secularisation are very far from destroying the persistence of religion in a certain part of the population, which adopts lifestyles and behaviours strongly linked to a

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<sup>91</sup> M. HAVERKATE, F. D'ANCONA, C. GIAMBI, K. JOHANSEN, P.L. LOPALCO, V. COZZA, et al., *Mandatory and recommended vaccination in the EU, Iceland and Norway: Results of the VENICE 2010 survey on the ways of implementing national vaccination programmes*, in *Eurosurveillance*, 2012, 17, pp. 1-6.

<sup>92</sup> J (A Minor) (Prohibited Steps Order: Circumcision), Re [1999] 2 FLR 678.

<sup>93</sup> F v. F [2013] EWHC 2683.

<sup>94</sup> F v. F [2013] EWHC 2683.

<sup>95</sup> For the UK, see the 2013 vaccines and gelatine: PHE response (<https://www.gov.uk/government/news/vaccines-and-gelatine-phe-response>)



confessional set of rules<sup>96</sup> and wants to perform them, even ahead of a medical treatment<sup>97</sup>. Moreover, taking religious freedom seriously means – among other things – that the genuine refusal of medical treatments on religious grounds, expressed by a competent adult, must be guaranteed without any doubt. This freedom is necessarily linked to ethical and religious pluralism: In fact, only a legal system in which the individual can freely choose between science and religion can offer real protection for the right to pursue one's life plan and to fully develop one's personality.

At the same time, a secular State which really wants to take religious freedom seriously has the duty to protect children against every abuse of their parents' (or guardians') right to religious freedom and to religious education, the duty to verify the genuineness of the refusal, and the duty to avoid – if possible and to the maximum extent – a clash between a patient's religious conscience and the treatment which is necessary in a specific case.

This – as emphasised above – requires the provision of concrete obligations on the pharmaceutical industry: However, a medical and paramedical staff that is expert in religious issues and competent in an intercultural dialogue with the patient (and with his/her parents or guardians) may also be very important in avoiding the aforesaid clash.

Concerning the latter issue, it has been emphasized above that, both in England (and Wales) and in Italy, every person has the right to receive appropriate information on the nature and possible development of a treatment in which he/she is involved, as well as any alternative therapies.

This information should be as comprehensive as possible in order to ensure a free and conscious choice on the part of the patient and, therefore, to guarantee his/her own self-determination: It ought to be substantiated by detailed explanations, and it should be appropriate for the cultural level of the patient, expressed in a language that takes into account the particular subjective state of the patient and the degree of knowledge at his disposal. Most of all, it ought to be dialogic, expressed through communication codes that are not only appropriate for the patient's intellectual capacity, but also for the specificities of the ethnocultural group to which the patient belongs.

To sum up, in a case of a refusal of treatment motivated on religious grounds, it is to be hoped that the medical and paramedical staff is able to initiate and manage an intercultural process that promotes exchange and

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<sup>96</sup> J. DE HART, P. DEKKER, & L.C.J.M. HALMAN, (eds.), *Religion and civil society in Europe*, Springer, Dordrecht, Heidelberg, New York, London, 2013.

<sup>97</sup> L. LINNARD-PALMER, *Parents' refusal of medical treatment for cultural or religious beliefs: An ethnographic study of health care professionals' experiences*, in *Journal of Pediatric Oncology Nursing*, 2005, 22(1), pp. 48-57 (doi:10.1177/1043454204270263).



interaction, through a cross-cultural dialogue. The aim of this dialogue ought to be the translation of medical language into a language which can be fully understood by the patient, and the creation of a reciprocal comprehension between the (mainstream) ethnocultural communication codes and instances of the staff and the (nondominant) ethnocultural (and religious) communication codes and instances of the patient (and of his/her parents and legal guardians).

**ABSTRACT:** This study focuses on the right of patients to refuse medical treatments on religious grounds and on the (supposed) right to the parents to refuse medical treatments on behalf of their children, emphasizing the links and connections between the freedom of religion, the right to self-determination and the right to refuse medical treatment based on religious motivations. After a comparison between the norms devoted to rule the exercise of these rights in the English (and Welsh) and Italian legal systems, the article suggests that the approach of medical staff towards a Refusal of Medical Treatment on Religious Grounds ought to start an intercultural process. This process ought to be a cross-cultural dialogue devoted not only to translate medical language in a language which can be fully understood by the patient, but also to create a reciprocal comprehension between the (mainstream) ethnocultural communication codes and instances of the staff and the (nondominant) ethnocultural (and religious) communication codes and instances of the patient (or of his/her parents).

**Keywords:** Law; Medicine; Religion; Treatment; Refuse; Religious Freedom