Jehovah's Witnesses and Bioethics, Right to Treatment and Religious Freedom

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ABSTRACT: Jehovah's Witnesses' refusal of blood transfusions has crossed legal and scientific culture for several decades, leaving an indelible mark. The analysis starts from the religious reasons for such a choice and examines the propulsive stimulus offered to the judiciary to cover the regulatory gap with its decisions, to the legislature to pass the law on informed consent, and to physicians driven to develop new techniques and to apply bloodless medicine more and more widely. The article focuses on the particular use of advance directives in a pro-life sense, the important results achieved and the difficulties that still exist in enforcing patients' rights.

KEYWORDS: Religious freedom; Jehovah's Witnesses; blood transfusions; informed consent; advanced directives

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1. Introduction

ecisions that concern ethical values involve religious denominations and their followers also in the field of healthcare. The objective of this discussion is to illustrate the position of Jehovah's Witnesses regarding the choice of medical treatments and examine it in its various bioethical aspects in relation to the new laws, the most recent case-law and new medical techniques and strategies offered by modern science to address ethical and religious dilemmas. The exam is the direct result of my professional experience. As a lawyer I have found myself several times over the years assisting Jehovah's Witnesses men and women in defending their right to selfdetermination with respect to medical care, i.e. in the practical implications of this right recognized by law: deciding in full conscience and freedom how to get treated and what health treatment to undergo. This contribution is essentially divided into four aspects. In the first one we will try to understand the religious reasons underlying the position of Jehovah's Witnesses on this issue; the second

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will analyse some of the most recent case-law on cases that directly involved Jehovah's Witnesses. The objective will be to ascertain what results have been achieved and whether there are still any unresolved issues for jurists. In the third section we will briefly examine the new regulations that regulate the matter of informed consent and the Advance Healthcare Directives (ATD), focusing on the particular use made of them by Jehovah's Witnesses, which is perhaps surprising due to its peculiar aspects, which we can define as 'pro-life', and therefore much broader than the way in which it is understood and applied in general. In the last point we will finally discover what relationship has been established over the years between the religion of Jehovah's Witnesses and medical science. That is, we will see whether there really is a conflict between the two positions, which are presumed to be driven one by faith and the other by reason, or whether there is instead a relationship of collaboration and trust.

2. Introduction. Individual responsibility in bioethical choices

No one is immune from prejudices and stereotypes and the distortions that these generate in our perception and vision of reality. Unfortunately, we often rely on cursory assessments, which are useful to overcome the lack of direct and in-depth – and perhaps more tiring – knowledge of reality. These are rigid and long-lasting mental patterns, all the stronger if they are shared by the majority. The mental images evoked by the term Jehovah's Witnesses are essentially two stereotypes: the first is that of those who go around knocking on doors and talking to others about the Bible, the second is that of the refusal of blood transfusions which probably creates a little more alarmism if not, at times, real hostility. To the average citizen, the refusal of blood transfusions seems, by logic or common sense, to be an absolutely irrational, fundamentalist choice – a sort of contempt for life and a total refusal of medical care. However, if the first mental image (i.e. the evangelization activity on the streets and door to door) corresponds to the truth, because Jehovah's Witnesses actually believe that "spreading the Word of God" is a biblical command to be respected and implemented in practice, it is not equally true that Jehovah's Witnesses do not value life and do not undergo medical treatment. It is therefore unjustified to consider the refusal of blood transfusions as a reactionary position, contrary to life or science in general, and medicine in particular. Jehovah's Witnesses believe that, just like biblical evangelism, the rejection of blood is also a biblical command that must be respected. Is it true that refusing blood transfusions is a dangerous choice and a rejection of life, and that the believers therefore prefer to let themselves die? Clichés, in this case as in every situation in life, are put before us as ready-made truths and offer clear and ready-to-use answers, but they deserve to be analysed and explored, and possibly denied, because in reality they do nothing but close the way to a true and effective knowledge of a phenomenon. Let us consider what the position of Jehovah's Witnesses is regarding medical treatment. First of all, it must be clarified that no one is born a Jehovah's Witness, unlike what generally happens for the members of the majority of other religions. Becoming a Jehovah's Witness is a personal and conscious choice, made only after having made an in-depth study of the Bible. The choice therefore does not arise from a mysterious mystical transport but from study and personal knowledge and is nothing other than the decision to align



one's life with biblical principles.1 This choice is realised and expressed through public baptism through complete immersion in water (following the practice followed by the Christians of the 1st century), with which one officially becomes a Jehovah's Witness. Baptism is not practiced on infants, since an infant could not study, understand and therefore consciously choose to conform to biblical principles. In order to be baptized and become Jehovah's Witnesses it is therefore necessary to be an adult or at least a so-called mature minor. The choices of each individual Witness to follow the doctrines and live according to the principles taught by the religion arise from a personal adherence, and not from a family imposition/tradition. It may also happen that the religion may be the family religion, shared by the entire family or by a parent, but essentially that of Jehovah's Witnesses is a religion of the individual, who with their own conscience and rationality make very personal choices. The key principle that guides these choices is that life is "sacred", 3 that is, it comes from God, as other religious denominations also declare, and it must be preserved.

The sacredness of life also has a more practical connotation. This can be understood, for example, from the respect that Jehovah's Witnesses show for life ever since it is represented only by an embryo. In the case of Jehovah's Witnesses, in fact, the problem of calculating the weeks or identifying the moment in which the foetus becomes a life so to decide whether to terminate the pregnancy or not does not arise. According to their interpretation of the Bible, from the moment the embryo is formed, life is created, which as such is considered sacred. A passage from the Bible used as a reference for this position is Psalm 139 verse 16 in which it is said: "Your eyes saw me still formless; the days were all written in your book when none yet existed!" (Ed. CEI 2008).4

⁴ Unofficial translation. Rendering of the verse in the official Catholic translation approved by the Italian Episcopal Conference extracted from the site https://www.bibbiaedu.it/CEI2008/ (accessed 23 August 2023). Compare with "Your eyes even saw me as an embryo; All its parts were written in your book. Regarding the days when they were formed, before any of them existed" according to the rendering of the New World Translation of the Holy Scriptures, available on the official website of Jehovah's Witnesses www.jw.org (last consulates on 23 August 2023). For a useful comparison with other versions widespread in the Protestant and evangelical world, below is also the translation of the same passage from La Nuova Riveduta in continuity with the version by G. Luzzi and G. Diodati: "Your eyes saw the shapeless mass of my body, and in your book all the days were written that were destined for me, when none of them had yet arisen" available on the website https://www.bibleserver.com/ (last accessed 23 August 2023).



¹R. DI MARZIO, Essere Testimone di Geova. Vivere nel mondo senza farne parte, in The Journal of CESNUR, 4 supplement, 6, 2020, 1-24. Also available on the website <u>www.cesnur.net</u>.

²Under the heading "Baptism (in the Bible)", the New Catholic Encyclopedia, 2, 59, reports: "It is evident that in the early Church baptism occurred by immersion".

³/Life' as an asset takes on a conception of 'sacredness' according to a religious and moral approach of the various confessions which, on the base of their own dogmas, attribute different contents to it. These conceptions inevitably influence the believer in his choices, including those of a healthcare nature, through which he makes use of this 'qood' in harmony with his beliefs. It therefore follows a diversity of plans and values with respect to the good-life as understood in the juridical setting referred to the values and principles of the State. In this contribution, based on long direct professional experience as a lawyer for Jehovah's Witnesses, we will limit ourselves to examining the right to refuse blood transfusions and to make use of therapies that do not use blood. These therapeutic choices which relate more closely to the 'good-health' are today fully regulated in Italy and are part of the normal medical options offered and guaranteed to the patient. However, we will not address issues relating to the use of the 'good life' to the extreme, such as euthanasia and the so called assisted-suicide, as they are extraneous and contrary to the doctrine of Jehovah's Witnesses, who exclusively advance requests that are aimed at being treated in the best possible way and in the respect for their faith.

Bible teachings give high consideration to physical, as well as spiritual health, the preservation of it and of life in general. Therefore, Jehovah's Witnesses decide to protect their health also in a preventative way by adopting a healthy lifestyle and healthy habits, not using tobacco or drugs, in order to not harmfully contaminate their bodies. Given this basis, choices regarding acceptable or unacceptable treatments depend on individual decisions and evaluations that are made following personal reflections and considerations. Knowledge of the Bible therefore also influences decisions regarding the use of blood in the medical field. Also in this case it is a conscious individual choice guided by religious beliefs. On the official website of Jehovah's Witnesses, www.jw.org, a large amount of indepth material of both a doctrinal and scientific nature is available. Among others, in a video on medical choices the Witnesses say: "We love life, and in any medical situation, we want treatments that preserve or restore our health. But more important we want to respect the Creator of life and his law on blood". These are therefore the principles that inspire the choices of Jehovah's Witnesses. Preserving health is the central theme.

3. First aspect: the religious reasons for refusing blood transfusions

How does the refusal of blood transfusions arise and what does it involve? The principle according to which blood is life and therefore sacred is already expressed in the books of Genesis and Leviticus. For example, Leviticus chapter 17 verses from 10 to 12 – Ed. CEI 2008 – states "Every man, Israelite or foreigner living among them, who eats any kind of blood, against him, who has eaten the blood, I will turn my face and cut him off from his people. For the life of the flesh is in the blood. Therefore, I have allowed you to place it on the altar as atonement for your lives; because blood atones, as it is life. Therefore, I said to the Israelites: No one among you will eat blood, not even the stranger who lives among you will eat blood". The same concept is finally addressed in the book of Acts of the Apostles in chapter 15, verses 28 and 29, which states: "In fact, it seemed good to the Holy Spirit and to us not to impose any other obligation on you other than these necessary things: abstaining from

⁵Video *How to make Health-Care Decisions Regarding Blood*, available at <u>www.jw.org/library/videos/TheBible/ApplyBibleprinciples</u> (last consulted on 23 August 2023).

⁶ Unofficial Translation. Rendering of the verse in the official Catholic translation approved by the Italian Episcopal Conference extracted from the site https://www.bibbiaedu.it/CEI2008/ (last accessed 23 August 2023). Compare this with "If any man of the house of Israel or any foreigner who is residing in your midst eats any sort of blood, I will certainly set my face against the one who is eating the blood, and I will cut him off from among his people. For the life of the flesh is in the blood, and I myself have given it on the altar for you to make atonement for yourselves, because it is the blood that makes atonement by means of the life in it. 12 That is why I have said to the Israelites: 'None of you should eat blood, and no foreigner who is residing in your midst should eat blood'." from the New World Translation of the Holy Scriptures, available on the official website of Jehovah's Witnesses, http://www.jw.org/, used as a reference translation by Jehovah's Witnesses (last accessed 23 August 2023). For a useful comparison with other versions widespread in the Protestant and evangelical world, below is also the translation of the same passage from La Nuova Riveduta in continuity with the version by G. Luzzi and G. Diodati: "If a man of the house of Israel, or one of the foreigners who live among them, eats any kind of blood, I will set my face against the person who eats blood and will cut him off from among his people. For the life of the flesh is in the blood. This is why I ordered you to place it on the altar to make atonement for your people; because the blood is what makes the atonement, through life. Therefore, I said to the children of Israel: 'No one among you will eat blood; not even the stranger who lives among you will eat blood", available on the website https://www.bibleserver.com/ (accessed 23 August 2023).

meat offered to idols, from blood, from strangled animals and from unlawful unions. You will do well by staying away from these things. Good health to you!" (Ed. CEI 2008). This statement of principle was the fruit of the first apostolic council in 49 AD, when 'the pillars' of Christianity met in Jerusalem to decide what were the doctrines to follow to define themselves as 'Christians0: among these they included that of abstaining from meat offered to idols and blood. Jehovah's Witnesses trace their roots back to 1st century Christianity, when the first believers did not accept blood in any way. We learn this from various historical sources.

For example, at the end of the 3rd century AD Eusebius of Caesarea reports in the Ecclesiastical History that in Lyon in 177 AD, more than a hundred years after the Council of Jerusalem, a woman named Biblide said to religious enemies who accused Christians of eating children: "'How could these people who are forbidden even to feed on the blood of animals without reason eat children?' Then she confessed herself Christian and was counted among the martyrs". At the end of the 2nd century Tertullian, (Christian apologist and writer, ca.160-230 AD), writes in the Apologeticum: "You are in error towards the Christians and should blush for it. We do not even have the blood of animals among our foods and for this reason we also abstain from the meat of animals that have suffocated or died , so as not to be contaminated in any way by the blood even buried inside the entrails, so much so that to torture Christians you also give them some black pudding, because you are very sure that it is a food forbidden to them and through it you want to lead them astray". 9 Minucius Felice, a Roman lawyer whose life is variously placed between 160 and 300 AD, highlighted the same fact by writing: "We are not allowed to witness or learn about a murder, and such is our horror of human blood, that we wouldn't even want to taste blood in edible animal foods".10

It is a documented historical fact that at the dawn of Christianity the current practice to 'unmask' Christians or to induce them to renounce their faith was to ask them to carry out one of these two actions as a condition for saving their lives: 1) offer incense to the emperor; 2) drink blood. Christians did not agree to carry out either of the two actions: 'incense' represented the adoration that had to be directed solely and exclusively to God, and offering incense to the emperor was therefore understood as an act of idolatry; the blood, representing the sacred life of a person, had to be treated according to precise rules and could not be eaten or taken even for medical reasons. It is interesting, in

¹⁰M. MINUCIO FELICE, Ottavio, XXX, 6, trans. by L. RUSCA, 64, Milan, 1957, unofficial translation.



⁷ Unofficial Translation. Rendering of the verse in the official Catholic translation approved by the Italian Episcopal Conference extracted from the site https://www.bibbiaedu.it/CEI2008/ (accessed 23 August 2023). Compare with "For the holy spirit and we ourselves have favored adding no further burden to you except these necessary things: to keep abstaining from things sacrificed to idols, from blood, from what is strangled, and from sexual immorality. If you carefully keep yourselves from these things, you will prosper. Good health to you!" from the New World Translation of the Holy Scriptures, available on the official website of Jehovah's Witnesses, www.jw.org, used as a reference translation by Jehovah's Witnesses (accessed 23 August 2023). For a useful comparison with other versions widespread in the Protestant and evangelical world, below is also the translation of the same passage from La Nuova Riveduta in continuity with the version by G. Luzzi and G. Dio-DATI: "In fact it seemed good to the Holy Spirit and to us not to impose any other burden on you other than these necessary things: that you abstain from things sacrificed to idols, from blood, from things strangled and from fornication, you will do well to guard yourselves from these things. You are well.", available on the website https://www.bibleserver.com/ (accessed 23 August 2023).

⁸E. DI CESAREA, Storia ecclesiastica, V, I, 26, unofficial translation.

⁹TERTULLIAN, Apologetico, IX, 10, 13, 14, trans. by I. GIORDANI, Rome, 1967, unofficial translation.

fact, that the Romans already made medical use of blood. Tertullian himself informs us of this and again in the Apologeticus reports: "Where do you put all those who, during a gladiatorial show, rush to drink greedily, to cure their illness (epilepsy) with the still warm blood gushing from the throats of criminals slaughtered in the arena?". ¹¹ Therefore, Christians were deceptively presented with this choice, since their position was known in advance, and then they were brutally executed using this refusal as a 'justification'. We have traces of it in the story of the lives of those who are still remembered today as Christian martyrs ¹².

3.1. What exactly do Jehovah's Witnesses reject?

Jehovah's Witnesses declare that they want to totally follow to primitive Christian doctrine. Thus, in imitation of the Christians of the first century, they 'abstain' from blood. The term 'abstain' indicated in Acts 15:29 is interpreted as the need not to ingest¹³ or take blood in any way, either orally or intravenously.

So, what do Jehovah's Witnesses reject today? Their refusal refers to blood in its four main components: plasma, white blood cells, platelets and red blood cells. These four parts are considered unacceptable, just as heterologous whole blood, i.e. coming from another person, is considered unacceptable, as is autologous blood if it is collected and stored in bags to be re-infused later. Although this choice is mainly based on religious reasons that refer to the verses of the Bible already cited, later we will discover that there is also a scientific reason to support the refusal, sustained even by those who are not Jehovah's Witnesses. The refusal refers to the four main components of blood, but what about the other fractions of the it? From a scientific point of view, we can affirm that today it is technically possible to do what was unthinkable in the past, such as separating small fractions of blood, such as fractions of plasma, white blood cells, platelets and red blood cells, i.e. such infinitesimal parts of blood which in themselves may no longer be considered as such. In these cases we talk about blood products,14 which include: albumin, gamma globulins and coagulation factors. The religion does not provide any specific indication regarding the acceptability of blood products. Each Witness, based on their own conscience, evaluates and decides whether these fractions are still to be considered 'blood' or not and whether they thus fall within the object of the biblical prohibition or not.

Therefore, if transfusions of whole blood and the four main components are generally refused by all Jehovah's Witnesses, since smaller fractions of blood, or blood products, do not expressly fall within the biblical command to 'abstain from blood', they may or may not be accepted: it is a decision that can vary from person to person.

¹⁴ For further information on *blood products*, please refer to the AIFA (Italian Medicine Agency) website https://www.aifa.gov.it/emoderivati (accessed 23 August 2023).



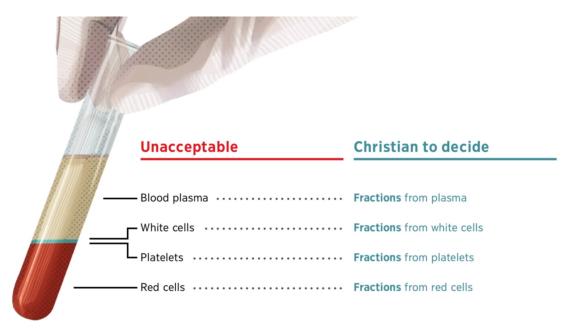
¹¹Tertullian, *Op.cit*.

¹² martyr /'martyr/ noun m. and f. [from lat. eccles. *martyr-ȳris* , Gr. *mártys* – *yros* "witness"]. – **1.** (*relig*.) [in primitive Christianity, those who were willing to suffer and even face death in order not to give up their faith]. In Treccani dictionary http://156.54.191.164/vocabolario/martire "28Sinonimi-e-Contrari%29/ (accessed 21 August 2023).

For further information: *Is a transfusion really the same as eating blood?*, in https://www.jw.org/en/library/books/Reasoning-From-the-Scriptures/Blood/ (accessed 23 August 2023).

In summary, the main issues to understand are essentially three:

- 1. A Jehovah's Witness patient values life, adopts a healthy lifestyle to prevent, as far as possible, damage to their body and in case of illness, seeks the best care available;
- 2. The refusal of blood transfusions is a choice based on the Bible:
- 3. Accepting blood fractions is a strictly personal choice based on knowledge of the Holy Scriptures and on the conscience of the individual.



(Image taken from the website www.jw.org – Accessed 23 August 2023)

Can the refusal of blood transfusions be considered medically reasonable? Or, as some hastily conclude, is it a sinister and reckless position against life and therefore in direct contrast with the declared respect for its sacredness?

Although the refusal of blood transfusions is known as a prerogative of Jehovah's Witnesses for religious reasons, today it also concerns the scientific world in a much broader way for reasons of a strictly medical nature. Let's start with what is commonly called PBM, Patient Blood Management. It is a "multidisciplinary and multimodal strategy that puts patient health and safety at the centre and improves clinical results based on the patients' blood resources. This approach significantly reduces the use of blood products, addressing all modifiable transfusion risk factors even before it is necessary to consider the use of transfusion treatment itself". 15 The PBM program is promoted by the National Blood Centre in Italy, in line with the World Health Organization Resolution¹⁶ aimed at preparing "innovative and more effective methods and tools to guarantee the appropriateness of the organizational and clinical management of the blood resource". These are the main objectives of PBM:

¹⁶Resolution WHA63.12 of 21 May 2010, of the World Health Organization.



¹⁵See the National Blood Center website: pbm.centronazionalesangue.it (accessed 23 August 2023).

1) improve the clinical *outcome* of patients;¹⁷ 2) prevent avoidable transfusions; 3) reduce management costs.

In Italy, and even more so in the world, the number of healthcare facilities that apply and develop PBM is growing. In the United States, the Houston Methodist Hospital in Texas has long been an internationally cutting-edge hospital in *bloodless surgery*, the use of techniques and methods that avoid the use of blood even in the case of very invasive surgical interventions. It is interesting to note that in Houston, within the NSBRI (National Space Biomedical Research Institute), a consortium of all the universities and medical centres in the USA founded by NASA to carry out research on human exploration in space, there is a team that specifically deals with the study and experimentation of operating techniques that exclude the use of blood.¹⁸

A dangerous misunderstanding often promoted in the media, and unfortunately also in the medical field, is that refusal to blood transfusions is a form of passive euthanasia, given that very often the equation 'transfusion refusal = death' is taken for absolutely certain, although it is incorrect in the abstract from a medical-scientific point of view. As we will see later, the data reported by doctors on the front line in *bloodless surgery* confirm that adopting clinical strategies aimed at avoiding the use of blood actually improves, and does not worsen, *the outcome* in patients, i.e. the postoperative course and recovery times.¹⁹ We thus understand that the cliché that there is an inevitable correspondence between the refusal of a blood transfusion expressed by Jehovah's Witnesses and their certain death can be resolved thanks to the dissemination of greater and better knowledge in the medical field.

4. Second aspect: the legal aspects involved in the refusal of blood transfusions

Each religion has its own system of beliefs that guide the believers' choices in their daily lives, including those in the medical field. Regardless of what the belief is, the rules of law recognize, protect and make the right to choose effective. In the medical field, informed consent is the prerequisite for eve-

that patients who avoid [blood transfusions] achieve the same, if not better, outcomes than those who accept [blood transfusions]" and this "approach could reduce risks, improve outcomes and reduce costs for all patients". A recent European study demonstrates that the implementation of strategies aimed at reducing blood losses, in all surgical disciplines, carried out in four German university clinics, was safe, minimized the risks deriving from blood transfusions and generated savings in costs of approximately 3,000,000 euros per year (Meybohm P. and others; PBM-study Collaborators. Patient blood management is associated with a substantial reduction of red blood cell utilization and safe for patient's outcome: a prospective, multicenter cohort study with a noninferiority design Ann Surg 2016;264(2):203-11). The Italian medical journal Minerva Anestesiologica states: "it is evident that a large number of seriously ill patients undergoing a blood transfusion today may not have tangible results resulting from the transfusion". The leading experts in the field illustrate the reasons in the video of the Australian National Blood Authority entitled: Blood Transfusions – What is the evidence telling us? available on the website https://www.blood.gov.au/health-professionals (accessed 23 August 2023). Unofficial translations.

¹⁸Science, Space Biomedicine, An RX for Astronauts, 295, 18 January 2022, 435.

¹⁹M.F. LEAHY AND OTHERS, Improved outcomes and reduced costs associated with a health-system-wide patient blood management program: a retrospective observational study in four major adult tertiary-care hospitals, in National Library of Medicine, National Center for Biotechnology Information (nih.gov) (accessed 23 August 2023).

ry healthcare treatment and finds its rationale in constitutional principles that protect and guarantee freedom of treatment and the right to health. We refer first of all to articles 2, 13 and 32 of the Italian Constitution and the values that inspired them. To this end, it may be useful to remember that article 32, in which the right of choice in the medical field and informed consent find their foundation, was wanted and promoted by the 'founding fathers' 20 as a reaction to what had happened during Nazism and Fascism. The freedom of the individual to choose without being forced to forcibly undergo unwanted health treatments became a founding value of our system, aimed at preventing a recurrence of the wicked experience of totalitarianism which had subjected people to experimental treatments against their will, to inhuman medical experiments that had damaged not only the physical integrity of the individual but his dignity and freedom. This historical connotation reinforces the need to impose a limit also on the legislator, who is required to respect the human person and their right to decide which treatments to accept and which to refuse. It follows that, since the Constitution itself limits the legislative power by requiring it to respect this right, the latter cannot be violated in any way either by a doctor or by a judge, as there is in fact no 'superior' reason or interest.

Although this freedom does not always find adequate protection, it must nevertheless be recognized that there has been a notable evolution in case-law in recent years in the name of full recognition of the religious connotation of the exercise of freedom of choice in the medical field by Jehovah's Witnesses. A milestone is the famous 'Giulini' ruling no. 2437/2008, issued by the joint criminal division of the Supreme Court of Cassation, which represented a starting point by stating that "the unshakeable requirement that justifies a health treatment must be found in the free and conscious choice [...] of the person undergoing that treatment" and paragraphs 6 and 7, recognized the "certain wrongfulness, even in criminal terms, of the conduct of the doctor who has operated in corpore vili 'against' the patient's will, directly or indirectly expressed, regardless of the outcome—whether favourable or unfortunate—of the health treatment practiced, since it is a conduct that at the very least illegitimately coerces another's will". And also:

"The concept of coercion [as per article 610 of the Criminal Code – ed.], implies in fact the refusal of the victim, who suffers the conduct of the agent and, as a consequence, is induced to do, tolerate or omit something in contrast with their own will [...] requirement of conflict of will between the active and passive subject which constitutes an unshakeable requirement, inherent in the very concept of compulsion of the human being, 'towards' (and, therefore, to consciously carry out) a specific active, passive or omissive conduct" (unofficial translation).

The patient's wishes are, therefore, an immovable pillar in the field of medical activity.²¹ The subsequent rulings of the Supreme Court have reconstructed at a case-law level the legal basis and the le-

In the Nuremberg trial was addressed the question of limiting the power of the doctor who, if uncontrolled, can trample on the dignity of people. It was established that the patient's consent constitutes the source of legitimation of medical action and that the duty to act for the patient's good does not in itself have its own justification. Compare R.J. LIFTON, I medici nazisti. Storia degli scienziati che divennero i torturatori di Hitler, Milan, 2002. ²¹ Lambert and Others v. France [Grand Chamber], no. 46043/14, §§ 89-95, ECHR 2015 §147: the Grand Chamber confirmed that among the member states of the Council of Europe there is "consensus as to the para-



²⁰In this regard, see the documented preparatory works of the founding fathers of the Italian Constitution published in www.nascitacostituzione.it and www.camera.it, documenti.camera.it/ dati/Costituente/Lavori/Assemblea/sed103/sed103.pdf (accessed 21 August2023).

gitimation of medical-surgical activity, as well as the institution of informed consent, and the foundations of the specific crime of 'battery' provided for by art. 610 of the Criminal Code, committed by the doctor who carries out a health treatment in corpore vili, in the presence of refusal on the part of the patient (manifested expressly, indirectly or even simply reconstructed, as in the well-known case of Eluana Englaro) and also the hypotheses of applicability of article 54 of the Criminal Code which excludes the punishment of the person who committed the crime "for having been forced to do so by the need to save themselves or others from the current danger of serious damage to the person". The non-applicability of the justification of necessity, referred to in article 54 of the Criminal Code, as regards the action of the doctor who does not take into account the patient's refusal, imposing forced treatment to 'save their life', is undisputed. The law that would exclude the doctor's liability must in fact be applied only following a constitutionally-oriented interpretation, i.e. in harmony with articles 2, 13, 19 and 32 of the Italian Constitution to which the ordinary law is subordinated. Therefore, the application criteria of article 54 of the Criminal Code must be inspired by the value and dignity of the individual and their freedom of choice, rather than by medical and judicial paternalism. The rule - immediately preceptive - referred to in article 32 of the Constitution, which first and foremost establishes the fundamental right to health and also constitutes a source of legitimacy of medical activity and healthcare treatment conditioned by the patient's consent, also establishes the patient's absolute right to the freedom to refuse treatment and, therefore, identifies the limits of the medical activity itself. This means that if the patient refuses medical treatment, the legitimacy of the medical activity ceases. For no reason, therefore, article 54 of the Criminal Code could justify a behaviour that is detrimental to constitutionally-guaranteed freedoms.

The particularity of the refusal of blood transfusions expressed by Jehovah's Witnesses lies in the fact that it is not only the exercise of the rights provided for and guaranteed by the articles cited so far, but it is also an expression of religious freedom, and therefore the exercise of the right recognized in Article 19 of the Italian Constitution. We then understand that in the specific case of Jehovah's Witnesses it is necessary to carry out a connection between the cited articles and article 19 of the Constitution due to an inseparable connection between the exercise of religious freedom and the exercise of the right to choose treatment in the medical field. In particular, Jehovah's Witnesses' refusal of blood transfusions is an expression of their religious faith and is the consequence of a decision-making process based precisely on the principles contained in the Bible.

The case-law of the Supreme Court now recognizes with extreme clarity that the freedom of choice in the case of the Jehovah's Witness who refuses a blood transfusion has a guarantee, so to say, strengthened by article 19 of the Constitution. In its decision no. 1451/2017 the Supreme Court stated: "The issue is made even more relevant and deserving of protection and guarantee by the fact that the choice or refusal of medical treatment is connected and included in the expression of a religious faith, the free exercise of which it is enshrined in Article 19 of the Italian Constitution. It is

mount importance of the patient's wishes in the decision-making process, however those wishes are expressed"; §178: "[...] it is the patient who is the principal party in the decision-making process and whose consent must remain at its heart", in https://hudoc.echr.coe.int (accessed 25 August 2023). For a comment, see C. Casonato, Un diritto difficile. Il caso Lambert fra necessità e rischi, in La Nuova Giurisprudenza Civile Commentata, 9/2015, 489 ff. and L. Poli, L'ultimo diritto. Esitazioni, contraddizioni, ma anche aperture nella giurisprudenza della Corte EDU in materia di fine vita, in Giurisprudenza Criminale Web, 2019, 1-bis "Questioni di fine vita".



known, in fact, that the refusal of blood transfusions by Jehovah's Witnesses, even in life-threatening situations, is based on religious and ideological reasons" (unofficial translation).

Of the same tenor, in an even more significant way, is decision no. 12998/2019 in which the Supreme Court recognizes that

"our Constitution [...] sees in the human person an ethical value in itself and looks at the limit of "respect for the human person" in reference to the single individual, at any moment of their life and the entirety of their person, in consideration of the bundle of ethical, religious convictions [...] and the new dimension that health has taken on [...] also to possibly refuse treatment and to consciously decide to interrupt it, in all phases of life, even in the terminal phase (Supreme Court, decision issued on 16 October 2007, no. 21748). This takes on even stronger connotations, worthy of protection and guarantee, where the refusal of healthcare treatment falls within, and is connected to, the expression of a religious faith whose free exercise is provided by article 19 of the Constitution" (unofficial translation).

Even more recently, with the ruling no. 515/2020, the Supreme Court stated: "It is sufficient to reiterate that the nature of the right that has been exercised, i.e. the refusal of blood transfusion, has acquired such relevance also in the social conscience that it does not allow any limitations to its exercise; and there is no one who does not see that intervening on the containment of the compensation consequences for the offender would mean indirectly intervening on the intensity and quality of its recognition" (unofficial translation).

For the Supreme Court, the practice of refusing blood transfusions by Jehovah's Witnesses takes on the value of a true form of conscientious objection. Such a reconstruction, which underlines how the value of personal beliefs must prevail over other instances, is also found in the Supreme Court ruling no. 29469/2020²² where it is stated that for a Jehovah's Witness, the refusal to blood transfusions "does not constitute a mere health self-determination, but a true form of conscientious objection, rooted in religious reasons", 23 given that "if a Jehovah's Witness voluntarily accepted a blood transfusion, this would be equivalent to an act of renunciation of their faith" and that, "it is not, therefore,

²³Since these are healthcare choices made by a believer, the meaning attributed to the concepts of 'health', 'life' and 'preservation of life' pertains to a religious paradigm which cannot be ignored in order to first understand and then respect the patient's wishes. Therefore, these terms can take on a different content and value compared to those that are purely medical-scientific or in connection with a non-believer. Courts began to deal with these positions as far back as 1980 with the well-known 'Oneda Case'. Since then, there has been enormous progress within case-law by progressively guaranteeing to an ever-greater extent respect for human rights of freedom, including religious freedom, which finds affirmation in the health self-determination of the patient whether they are the bearer of secular or religious values. For some notes on how these concepts have been interpreted by courts over the last 40 years, starting from the Oneda Case up to the most recent rulings, see. P. Consorti, "Libertà di scelta della terapia e violenza medica. Brevi considerazioni sul rifiuto delle trasfusioni di sangue dei Testimoni di Geova", published in the online magazine Stato, Chiese e pluralismo confessionale, 10, 2021. It reads: "with reference to health self-determination – and the more general social appreciation for conscientious objection - Italian society would perhaps not have developed its current legal sensitivity if Jehovah's Witnesses had not remained firm their position. In short, we must admit that these believers have played a coherent and militant, albeit often silent, role, paying the price for their diversity in favor of everyone" unofficial translation.



²² For an in-depth comment on the ruling F. PAPINI, L. MARSELLA, Laicità dello Stato e rifiuto di trattamenti sanitari per motivi religiosi: un nuovo riconoscimento della Cassazione per "medici liberi" di "uomini liberi" in Rivista Italiana di Medicina Legale, 4/2021.

a question of respecting only the person's body in its physicality, but of respecting the human person in their entirety, that is, in their moral, ethical and religious values". In other words, there is "no principle to contrast with that of self-determination and religious freedom" guaranteed with "full and direct implementation" by Article 19 of the Constitution. Furthermore, it is the same ruling that definitively excludes the possibility of invoking 'necessity' as a cause of justification for the doctor's conduct that does not respect the patient's wishes, where it states: "The patient always has the right to refuse medical treatments that are administered to them, even when such refusal could cause their death" (unofficial translation).

The line had already been drawn by the case-law of the European Court of Human Rights, first with the ruling *Jehovah's Witnesses of Moscow v. Russia* of 10 June 2010, which recognized the unlawfulness of any medical treatment imposed without the patient's consent:

"§135. The very essence of the Convention is respect for human dignity and human freedom and the notions of self-determination and personal autonomy are important principles underlying the interpretation of its guarantees [...]. In the sphere of medical assistance, even where the refusal to accept a particular treatment might lead to a fatal outcome, the imposition of medical treatment without the consent of a mentally competent adult patient would interfere with his or her right to physical integrity and impinge on the rights protected under Article 8 of the Convention (see *Pretty*, cited above, §§ 62 and 63, and *Acmanne and Others v. Belgium*, no. 10435/83, Commission decision of 10 December 1984)".²⁴

The same ruling recognizes that the freedom to accept or refuse particular medical treatments or to choose alternative treatments is essential for the principles of self-determination and autonomy of the individual, and specifies that this freedom takes on a tangible meaning only if patients are put in a position to make choices even when this makes them appear 'irrational, unwise or imprudent'. The interference of the State in the freedom of choice in the field of health, even when motivated by the intent to protect the health of the individual themselves, inevitably decreases and does not increase the value of life, a value which is strictly related to the degree of freedom of choice and self-determination that one enjoys.

Although they may seem irrational to some, the choices of Jehovah's Witnesses are never deliberately against life or in contempt of it. Their refusal is not a renunciation of medical care but a search for better, more effective medical treatments with fewer side effects in the long term. The aforementioned ECHR ruling is also crystal clear on this point: "§132 [...] the situation of a patient seeking a hastening of death through discontinuation of treatment is different from that of patients who – like Jehovah's Witnesses – just make a choice of medical procedures but still wish to get well and do not exclude treatment altogether".

The ECHR has expressed the same opinion also in the ruling *Taganrog and Others v. Russia no.* 32401/10 of 7 June 2022. The decision takes up and reiterates the key points of the previous rulings which can be summarized as follows: 1) the freedom to accept or refuse healthcare treatment is fundamental to the principles of self-determination and personal autonomy; 2) for freedom to have real value, patients must have the right to make choices that may appear irrational, unwise or imprudent

²⁴ European Court of Human Rights, Application no. 302/02, *Jehovah's Witnesses of Moscow c. Russia*, ruling of 10 June 2010, unofficial Italian translation available on the website <u>www.cesnur.org</u> (accessed 23 August 2023).



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to others; 3) the State must refrain from interfering with individual freedom of choice, since such interference can only decrease and not increase the value of life.

4.1. Rejection expressed by minors and for minors: respect and limits of parental authority

What if the person who refuses the transfusion is a minor or the parents refuse the transfusion for their minor child? Public opinion is very attentive to this issue. There is a fear that minors are not sufficiently safeguarded and protected from choices that parents might make 'against their interests'. It is certainly a legitimate concern. However, in the name of this fear and in the absence of precise regulatory provisions unquestionably irregular measures – also excessively drastic ones – have been adopted to achieve the aim of overcoming the parents' refusal and transfusing the minor with the opening of procedures to suspend parental responsibility and put the minor up for adoption.²⁵

Law no. 219/2017 filled this specific regulatory gap, giving rise to greater protection of minors and their wishes and allowing for greater uniformity of decisions at a national level and therefore greater equality. Article 3 of the law provides that, in terms of refusal/informed consent, the wishes of the minor are expressed by their legal representative, therefore generally by the parents. By transposing international regulations such as the Oviedo Convention, the New York Convention on the Rights of the Child, the Strasbourg European Convention on the exercise of the rights of minors, Law no. 219/2017 affirmed that minors have the right to the "enhancement of their own understanding and decision-making abilities" also requiring their legal representatives to take their wishes into account when expressing refusal or consent to a healthcare treatment. The minor's wishes should be all the more binding the more maturity the minor shows. For example, think of a minor of 14 years of age who by law can decide, independently of their parents' consent and even without their knowledge, whether to have sexual intercourse, take oral contraceptives, have an abortion, join a political party, choose their own beliefs. It is clear that their wishes, even in the medical field, will have a different weight than that of a child.

Article3, paragraph 5, of the law provides that "in the event that the legal representative of the minor refuses the proposed treatments and the doctor instead deems them appropriate and necessary, the decision is left to the Guardianship Judge". This means that, when accepting or refusing treatment in the minor's interest, the parents must also take the minor's wishes into account and very often the refusal of Jehovah's Witness parents reflects the clear and firm will already expressed by the minor. Unfortunately, no rulings have yet been recorded in which the wishes of a minor, in particular of a mature minor, have been duly valued as required by the law and implemented by the judge. However, it can be acknowledged that many doctors, even when authorized by the judge to transfuse, have worked to respect the wishes of mature minors by treating young patients as best as possible without resorting to blood transfusions.

In any case, the innovative scope of Law no. 219/2017 has had practical and positive repercussions on the procedure that must be adopted in the event of parental refusal in relation to health care

²⁶ F. Papini, Minori di età o minori diritti?, in Rivista Italiana di Medicina Legale, 2, 2017.



²⁵ P. Borsellino, Brevi note su rifiuto di trasfusioni ematiche e responsabilità genitoriale. Quando il provvedimento restrittivo del Tribunale non trova giustificazione, in Quaderni di diritto e politica ecclesiastica, 3 December 2020

deemed necessary by doctors. The competence to intervene no longer lies with the Family Court but with the Guardianship Judge.²⁷ The shift in jurisdiction made it possible to abandon the procedure before the Family Court which was not limited to giving rise to a provision authorizing blood transfusions, but often resulted in much more invasive and irregular measures of suspension/revocation of parental authority beyond the scope of medical choices. Often the Family Court instructed, and still instructs, Social Services to fully evaluate parental capacity.

Unfortunately, today there is still a certain difficulty in abandoning the old procedure, which is often due to an unjustified, and still widespread, ignorance of the new Law no. 219/2017. Faced with the reluctance of some Family Courts and some health facilities to abandon the old procedure, it was necessary to challenge and appeal many contra legem provisions so that they could be revoked. There are many decisions from various Courts of Appeal²⁸ which have all reaffirmed the exclusive competence of the Guardianship Judge, as is clear from the law. In reference to the legitimacy of expressing consent, or refusal, to a health treatment for the minor, the Courts have also highlighted that refusal to blood transfusions expressed by Jehovah's Witness parents, as an exercise of their right recognized by article 3 paragraph 5 of Law no. 219/2017, can never lead to the hypothesis of parental incapacity, nor can it be sanctioned with the suspension of parental responsibility itself. It is worth remembering the ruling of the Court of Appeal of Milan which stated: "The mere refusal of parents to blood transfusions in adherence to religious beliefs cannot be used as the basis for an assessment of unsuitability for the exercise of parental authority" and that of the Court of Appeal of Rome, where it is stated that "the sole refusal expressed by the parent to the blood transfusion in adherence to their religious belief can no longer lead to the hypothesis of their unsuitability for the exercise of parenthood" and that the challenged order adopted by the Family Court was issued "by a body no longer competent to decide the dispute and also there were insufficient grounds [for the decision was] where, in addition to authorizing the transfusion treatment, the suspension of parental responsibility was ordered and a temporary guardian was appointed" (unofficial translations).²⁹

The Guardianship Judge today is therefore not called upon to express evaluations on the choices of the parents,³⁰ but only to authorize or deny the health treatment, always taking into account the wishes expressed both by the latter and by the minor themselves, in the event that the minor has

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²⁷F. PAPINI, M. BOLCATO, Il rifiuto degli esercenti la responsabilità genitoriale ai trattamenti emotrasfusioni per il minore – Quale procedura adottare ai sensi della legge 219/2017 e del programma ministeriale di PBM (Patient Blood Management), in Rivista società italiana di neonatologia, 112, 2023.

²⁸Among the many: Court of Appeal of Rome (dd. 17/12/2019, RG no. 52315/2019), Court of Appeal of Milan (dd. 10/09/2020, RG no. 785/2019), Court of Appeal of Catania (dd. 13/10/2020, RG no. 332/2020) and, lastly, Court of Appeal of Perugia (dd. 14/12/2020, RG no. 763/2020). The decisions have overcome the conflicts between doctors and legal representatives of minors regarding the medical care to be administered to minors, and have clarified that mere refusal on the part of parents to a health treatment proposed by a doctor in the interest of the minor (such as a blood transfusion, surgery, etc.) cannot per se legitimize the opening of proceedings before the Juvenile Court nor, a fortiori, a ruling limiting parental responsibility pursuant to articles. 330 - 333 of the Civil Code.

²⁹Pronouncements already cited in note 28.

³⁰ LIV HÖPPNER, (former guardianship judge at the Court of Bolzano), Trattamenti sanitari sui minori: consenso informato e disposizioni anticipate di trattamento, article published on www.diritto.it (accessed 17 August 2023).

adequate capacity of discernment to be evaluated on a case-by-case basis, and not merely with reference to their age.

5. Third Aspect: the new rules on informed consent and the protection of refusal

The promulgation of Law no. 219 in 2017³¹ (or Living Will Law as it is often called) filled a regulatory gap by establishing in detail the ways in which patients can exercise their right to choose in relation to medical care. In particular, the object of Law no. 219/2017 is the protection of the right to life, health, dignity and self-determination of the person, and it places informed consent as a central element for their realization, by including within the right to accept any diagnostic test or health treatment, in whole or in part, also the right to refuse it. To make the exercise of informed consent/refusal effective, Law no. 219/2017 introduced the document for 'Advance treatment directive' in which each person can declare their wishes in anticipation of a future inability to self-determine regarding health treatments, with the possibility of making very detailed and timely choices on both treatments and diagnostic procedures. Although the name by which the law is best known, i.e. Living Will Law, suggests that it only deals with last wishes relating to end-of-life treatments, in reality this is not the case. The wishes, in fact, can include consent or refusal in relation to diagnostic tests, treatment choices and individual health treatments. By virtue of this, the use made of it by Jehovah's Witnesses is, so to speak, a use for life, that is, a much broader use than one might commonly think. The inspiring principles of the law are those of informed consent and the law establishes the right to refuse treatment by creating an ad hoc rule with respect to what could already be derived from the articles of the Constitution cited so far. However, the facts demonstrate that since the promulgation of this law onwards, fewer forced blood transfusions have been recorded³² and this demonstrates a greater affirmation of freedom of choice for Jehovah's Witnesses and beyond.

On the other hand, it was already clear in the medical code of ethics that no patient can be subjected to a health treatment against their will, but the transposition of this principle into law is making it



³¹ S. CACACE, La nuova legge in materia di consenso informato e D.A.T.: a proposito di volontà e di cura, di fiducia e di comunicazione, in Rivista Italiana di Medicina legale, 3/2018, 941, observes that with the new law "the legislator confirms and strengthens the jurisprudential approaches, placing a seal on them that will now be very difficult to undo in Court. And, above all, it will no longer be necessary to go to Court". See also L. BALESTRA, II testamento biologico nell'evoluzione del rapporto medico-paziente, in Famiglia, persone e successioni, 2/2006, 104, which defines "the ATD...as the logical outcome of the process of placing value on informed consent". Regarding the scope of Law no. 219/2017, it is worth mentioning the order no. 242/2019 of the Constitutional Court in the Cappato Case, which states: "This, pursuant to Law 22 December 2017, no. 219 (Regulations regarding informed consent and advance processing instructions), whose regulations essentially incorporate and develop the conclusions which ordinary case-law had already reached at the time – in particular following the sentences on the W. case (Judge of the preliminary hearing of the ordinary Court of Rome, sentence 23 July-17 October 2007, no. 2049) and E. case (Court of Cassation, first civil section, sentence 16 October 2007, no. 21748) – as well as the indications of this Court regarding the constitutional value of the principle of the patient's informed consent to the healthcare treatment proposed by the doctor (order no. 207 of 2018): a principle that can be qualified as a true human right, which is based on the principles expressed in the articles 2, 13 and 32 of the Constitution (sentences no. 253 of 2009 and no. 438 of 2008)" unofficial translation.

³²Data provided by the Christian Congregation of Jehovah's Witnesses, collected based on reports received.

more effective over time. We recall here below what was stated in two rulings by the Supreme Court which declared doctors responsible for the crime of battery for having ignored the patient's wishes. In the historic 'Volterrani' ruling no. 3122/2002, the First Criminal Section of the Court of Cassation, already stated that: "In the presence of authentic and genuine expressed wishes of the person entitled in the sense of refusal of treatment, the doctor cannot help but stop [...] if the doctor still carries out the refused treatment, they may be charged with the crime of battery" (unofficial translation). A few years later the Joint Criminal Divisions of the Supreme Court declared in ruling no. 2437/2009 the "certain wrongfulness, even in criminal terms, of the conduct of the doctor who has operated in corpore vili against the patient's will [...] the unshakeable requirement that 'justifies' the health treatment must be found in the free and conscious choice [...] of the person" (unofficial translation). A more recent ruling that deserves to be cited, although it concerns a case prior to the promulgation of law no. 219/2017, is the ruling no. 1179 issued on 9 December 2020 by the Criminal Section of the Court of Tivoli, with which a doctor was convicted of having transfused an unconscious patient. Before finding herself in this state, the patient had drawn up advance treatment directives in which she had expressed her refusal to the blood transfusions and at the same time had indicated a health care agent, who was later appointed by the Guardianship Judge pursuant to articles 404 and following ones of the Civil Code. The ruling is interesting from many points of view. In particular, emphasis is placed on placing value on the wishes of the Jehovah's Witness patients through the use of the health care agent arrangement which allowed the designation of a trusted person chosen by the patient in order to act as the bearer of their wishes in all cases in which the patient was unconscious. This is worthy of note as a useful initiative aimed at filling the regulatory gap which was finally filled by Law no. 219/2017 with the provision of the appointment of a 'fiduciary'.

5.1. ATD: Advance Healthcare Directive and its particular pro-life use

Law no. 219/2017, at article 4 paragraph 1 establishes that:

"Any adult in full possession of his/her faculties, in readiness for any future incapacity to self-determine and after having acquired appropriate medical information regarding the consequences of his/her choices, may, by means of the ATD,³³ express his/her wishes on the subject of healthcare treatments as well as his/her consent or refusal regarding diagnostic tests or treatment choices and individual healthcare treatments. The adult will nominate a trusted person, hereinafter named 'fiduciary',³⁴ that

³³It is possible to register ATD following Ministerial Decree no. 168 of 10 December 2019 "Regulations and technical specifications of the national database of advance treatment directives (ATD)".

³⁴ In the approximately ten years preceding the entry into force of law no. 219/2017, Jehovah's Witnesses tried to fill the regulatory void of the of the 'trustee' figure, through the designation of a 'support administrator', provided for in the articles 469 and following of the Civil Code and introduced into the legal system with law no. 6/2004. The institution allows anyone to designate a trusted person as a support administrator so that in the event of partial or total loss of autonomy (for example disabled people, elderly people who are no longer self-sufficient, people affected by a stroke or Alzheimer's) they can act and make decisions in favour and in the interest of the party concerned, taking into account their wishes. However, the support administrator is authorized to act only after having been appointed by decree by the Guardianship Judge who can be appealed to. In the ten years prior to the law, the offices of Guardianship Judges throughout Italy issued dozens of decrees appointing support administrators who were authorized to express the refusal to receive blood transfusions in the name and on behalf of the party concerned who had expressed their wishes before falling into a state of

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will act on his/her behalf and represent him/her in dealings with the doctor and healthcare facility. It is provided that this appointment is done by public deed or private authenticated deed, or delivered to the Civil Registrar of the town council of residence of the instructing party" (unofficial translation).

Jehovah's Witnesses have prepared a form in which the declarant, in addition to expressing their refusal to blood transfusions, and if they deem it appropriate also their wishes regarding the end of life, can also indicate which other treatments and diagnostic tests they consider personally acceptable and which ones they does not. Usually in the free space provided in point 4 of the document, Jehovah's Witnesses specify whether or not they accept blood fractions, or blood products, and possibly which ones they accept. In the same form, for example, they can include arrangements relating to organ transplantation, the use of the heart-lung machine, haemodialysis, to name a few. The use of a standard form which still leaves the individual the possibility of filling it out according to his own wishes, constitutes a valid aid in filling out one's provisions in a clear and intelligible way. This form is now known to healthcare workers throughout the country and has the advantage that, once inserted in the medical record, is easily recognizable by medical staff and allows every healthcare worker who comes into contact with the patient to know their wishes and motivations.

Durable Power of Attorney for Health Care 1. 1,		
cells, white cells, platelets, or plasma be given me under any circumstances, even if health-care providers believe that such are necessary to preserve my life. (Acts 15:28, 29) I refuse to predonate and store my blood for later infusion. 3. Regarding end-of-life matters: [initial cane of the two choices] (a) I do not want my life to be prolonged if, to a reasonable degree of medical certainty, my situation is hopeless. (b) I want my life to be prolonged as long as possible within the limits of generally accepted medical standards, even if this means that I might be kept alive on machines for years. 4. Regarding other health-care instructions (such as current medications, allergies, medical problems, or any other comments about my health care wishes), I direct that: Commended Commen		to ensure that my wishes are honored. If my first appointed agent is unavailable, unable, or unwilling to serve, I appoint an alternate agent herein to serve with the same power and authority.
Segurating desired matters (intimal rule of the two choices]	cells, white cells, platelets, or plasma be given me under any circumstances, even if health-care providers believe that such are necessary to preserve my life. (Acts 15:28, 29) I refuse to	(Address)
Page 1 of 2 dpa-E 1/16 Page 2 of 2	(a) I do not want my life to be prolonged if, to a reasonable degree of medical certainty, my situation is hopeless. (b) I want my life to be prolonged as long as possible within the limits of generally accepted medical standards, even if this means that I might be kept alive on machines for years. 4. Regarding other health-care instructions (such as current medications, allergies, medical problems, or any other comments about my licalth care wishes), I direct that: 5. I give no one (including my agent) any authority to disregard or override my instructions set forth herein. Family members, relatives, or friends may disagree with me, but any such disagreement does not diminish the strength or substance of my refusal of blood or other instructions. 6. Apart from the matters covered above, I appoint the person named herein as my agent to make health care decisions for me. I give my agent full power and authority to consent to or to refuse treatment (including artificial nutrition and hydration) on my behalf, to	my presence. He or she appears to be of sound mind and free from duress, fraud, or undue influence. I am 18 years of age or older. I am not the health-care agent or alternate agent appointed in this document. Superior of witness Chapter of witness Chapter of witness

ATD form used by Jehovah's Witnesses

(source: Congregazione Cristiana dei Testimoni di Geova)

unconsciousness. This judicial practice, widespread among Jehovah's Witnesses, has certainly raised the awareness of legal practitioners throughout Italy to ensure increased respect for the patient's wishes. On the use of the support administrator figure and related case-law prior to Law no. 219/2017, see F. Papini, Rispetto della persona umana o divieto di rifiutare le emotrasfusioni per motivi religiosi? in Rivista Italiana di Medicina Legale, 1/2017.



5.2. The difficult affirmation of ATD: The case of the Town Council of Naples³⁵

A further possible cause of the poor use of ATD at a general level can also be found in the delays with which many town councils have implemented the legislation, and the delay in organizing an adequate structure to receive ATDs in advance. An emblematic case of the concrete difficulties that citizens are faced with on a daily basis in attempting to assert their wishes in the healthcare field is that of the town council of Naples. After futile attempts to obtain the registration of their ATD by the council office in charge, a Neapolitan married couple of Jehovah's Witnesses turned to Court asking to order the Civil Registrar of the town to receive their advance directives and proceed with the relevant annotation in the 'Register of Living Wills'. This as a mere application of the provision of article 4, paragraph 6 of Law no. 219/2017 according to which ATD can also be drawn up by private deed delivered personally to the Civil Registry Office of their town of residence, which registers the ATD in a specific register, if established. The town employee had long justified the failure to register for safety measures due to Covid-19, effectively denying the service for many months. The applicants, as Jehovah's Witnesses, considered it necessary to protect their determination in the healthcare field in accordance with their religious beliefs, given that only by completing the formalities required by article 4, paragraph 6, of Law no. 219/2017 to give legal value to their ATD, doctors are required to respect them. Therefore, if the possibility of recording one's ATD today becomes an essential element for every adult citizen for the effective exercise of the right to health and self-determination, to protect one's values and one's personal conceptions of life and health (meaning the entire psychophysical-existential dimension that goes beyond mere physical well-being), in the case of Jehovah's Witnesses this additionally implies a complex combination of principles that call into question the

³⁵G. ALESSI, Court of Naples – Order 907/2022: The Civil Office Registrar Refuses to Register Advance Treatment Directives (ATD), in <u>www.biodiritto.it</u>; M. PARADISI, Disposizioni anticipate di trattamento (D.A.T.): il Tribunale ordina all'Ufficio dello Stato civile la registrazione, nota di commento allegata all'articolo di G. Alessi, op.cit., (accessed 17 August 2023).



exercise of freedom of religion and worship.³⁶ Starting from these assumptions, the couple from Naples decided to appeal to the judicial authorities with the instrument provided for by art. 95 of Presidential Decree no. 396 of 2000, in order to obtain the application of the national legislation which, without many formalities, places the burden of collecting the ATD on the town councils. In fact, it provides that the Civil Registrar, once the conditions established by the law have been verified, has the obligation to receive the ATD and issue a formal receipt (Circular no. 1/2018 of 8/2/2018 of the Ministry of the Interior which provided operational indications to the town councils). Thus, the Court of Naples with the decree issued on 6 May 2022, in accepting the appeal, ordered the Civil Registrar to receive the ATD and register it in the Register of Living Wills and other legal obligations. This very recent case offered by the Jehovah's Witnesses of Naples gives us the opportunity to revive the debate on the issues of Law no. 219/2017 and, in particular, on the actual state of implementation of the Advance Treatment Directives (ATD).

6. Fourth Aspect: The relationship of collaboration and stimulus provided to medical science

The relationship between science and religion is often seen as antithetical, as two visions of human reality that are inextricably opposed. However, in the case of Jehovah's Witnesses the question takes on a particular character. Many doctors say that the refusal of blood transfusions by Jehovah's Witnesses was a request that has been not an obstacle to science, but rather a driving force. In fact, the request made by Jehovah's Witnesses to doctors is not to abstain from treating them, but to use all the knowledge they have, the most advanced techniques and all the ingenuity available to find new solutions that allow them to be treated without use of blood. This instance has meant that modern bloodless surgery strategies could be developed on behalf of all patients, not just Jehovah's Witness patients, to be treated while avoiding the consequences and side effects that a transfusion can entail, as it is a treatment that is not risk-free. The new techniques of bloodless surgery today make it possible to carry out bloodless operations even among the most complex, and at risk of bleeding, such as liver transplant, kidney transplant, pancreas surgery and aortic dissection.



³⁶The Supreme Court of Cassation, Civil Section, has expressed its consolidated position in this regard several times. Consider the last recent decision issued by the Court of Cassation, Civil section. I, no. 21748 on 16 October 2007 ('Englaro case') which refers to the "new dimension that health has taken on (no longer understood as the simple absence of illness, but as a state of complete physical and mental well-being, and therefore engaging, in relation to the perception that each person has of himself, the internal aspects of life as perceived and lived by the individual in their experience)". The Court of Cassation, in ruling no. 29469 issued on 23 December 2020, stated the following principle of law: "Jehovah's Witnesses, who assert the right of selfdetermination in matters of healthcare treatment to protect the freedom to profess their religious faith, have the right to refuse blood transfusion despite having given consent to the different treatment that subsequently required the transfusion, even with a declaration expressed before the treatment itself, provided that the will to prevent the transfusion unequivocally emerges from the same declaration even in the event of lifethreatening situations". Furthermore, the same Supreme Court with ruling no. 515 issued on 15 January 2020, stated with regard to the Jehovah's Witness patient: "It is sufficient to reiterate that the nature of the right exercised, i.e. the refusal of blood transfusion, has acquired such relevance also in the social conscience that its exercise cannot be limited". Unofficial translations.

6.1. The Hospital Liaison Committees (HLC)³⁷

An international network of around 1,700 Hospital Liaison Committees (CAS) of Jehovah's Witnesses operates in over 110 countries around the world.³⁸ It includes religious ministers from local communities who interact knowledgeably with doctors, hospital staff and social workers. The CAS have the task of acting as a point of contact between doctors and Jehovah's Witness patients and assisting doctors who treat Witness patients, providing articles taken from authoritative medical journals and scientifically reliable information on clinical strategies that allow them to manage the patient without resorting to allogeneic blood transfusions. They help Witness patients and health care providers clarify any ethical issues associated with medical care. In particular, they help Jehovah's Witnesses to contact structures and specialists who are adequately trained and have the technical equipment necessary for surgery without transfusions. In Italy there are currently 80 committees and they play a liaison role with 5,000 doctors working in over 600 healthcare facilities.³⁹

Over time, this collaboration has promoted greater attention in the medical profession towards the needs of the patients, which has led to the recognition of greater dignity and value to their wishes, as well as having favoured excellent results in the field of bloodless medicine and surgery, which deserve to be reported. In fact, bloodless techniques were often used for the first time on Jehovah's Witness patients who requested them. However, in light of the benefits found, today they are generally used by anyone. As we mentioned at the beginning of our consideration, this is also in line with the recommendations of the Italian Ministry of Health (*Patient Blood Management Italia | Patient Blood Management in Italy (centronazionalesangue.it)*)⁴⁰ and of the OMS/WHO (*The urgent need to implement patient blood management: policy brief (who.int)*).⁴¹

Furthermore, the presence of CAS within healthcare facilities guarantees the patient a certain degree of serenity. In fact, they carry out the function of directing patients towards the structures that are willing to operate without resorting to blood and this gives the patient the peace of mind that his wishes will be respected. Prof. Massimo Franchi, full professor of gynaecology and obstetrics and Director of the Maternal and Child Department of the Integrated University Hospital of Verona, spoke about these benefits in an interview where he stated: "I must say that in the CAS I have always found extremely reasonable people. I can say from experience that collaboration with CAS has produced enormous benefits in relationships with Jehovah's Witness patients. The same happened in foreign



³⁷Some general information on the Hospital Liaison Committees for Jehovah's Witnesses is available on the official website https://www.jw.org/en/medical-library/medical-information/hospital-liaison-committees-jehovahs-witnesses/ (accessed 17 August 2023).

³⁸S. Attollino, Fede, cura, sanità – Contributo allo studio degli ospedali religiosi nel sistema nazionale, Bari, 2020, 31-34.

³⁹ Data provided by the Christian Congregation of Jehovah's Witnesses.

⁴⁰ https://pbm.centronazionalesangue.it/pagine/patient-blood-management-italia.html (accessed 23 August 2023).

⁴¹ https://iris.who.int/handle/10665/346655 (accessed 23 August 2023).

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patients who had communication difficulties because they could not count on the help of cultural mediators". 42

6.2. Medical progress and the relationship of trust between doctor and patient

Regarding bloodless surgery, Prof. Franchi states:

"There is no surgery that cannot be performed without resorting to the use of blood. The problem is the doctor's ability and the possibility of adopting the appropriate measures. I have repeated moments of consultation with the patient regarding his wishes, so that I am certain, from an ethical point of view, that they are ready to defend their faith even at the possible cost of his life. This, in my opinion, is the most important aspect, as a doctor and a person I believe that it is never possible to go against a patient's wishes, once that their wishes are well established. I am totally convinced of this fact".⁴³

Let us now consider the statement we often hear that Jehovah's Witnesses refuse transfusions and would thus cause their children to die. This too is a prejudice that needs to be overcome. Prof. Alessandro Frigiola, Director of Cardiac Surgery for Congenital Pathologies at the San Donato Polyclinic in Milan, and President of the Association of Children with Heart Disease in the World says: "In Third World countries it is difficult to find blood. If there had been no alternative strategies to blood transfusions, thousands of children would not have been able to undergo surgery and would probably have died. Certainly, the stimulus to look for solutions outside of transfusion came precisely from working with Jehovah's Witnesses". 44

Prof. Alessio Pace, pioneer of bloodless medicine in Italy, former head of the Abdominal Clinic of Rome, of the Emergency surgery at the Aurelia Hospital and teacher at the specialization schools of the University of Tor Vergata in Rome, explains one aspect of considerable interest: "Every transfusion blocks the marrow in the production of white blood cells, red blood cells and platelets and this applies both to the transfusion and to the pre-deposited [blood] because when the blood leaves the circulation it behaves like that of another individual" Many doctors believe that re-infusing a person's body with his own previously-taken blood is equivalent to an organ transplant and still creates incompatibility problems and therefore risks for the patient. This is not why Jehovah's Witnesses also reject autologous blood; they do it for religious reasons and they did it before it was discovered that the blood coming out of the body behaves like that of another individual. However, it must be said that their choices in some way preceded scientific discoveries. Prof. Pace adds: "In the 80s it was impossible to think of not transfusing below certain blood values. Today it is a practice also suggested by the WHO". Prof. Pace has carried out at least 40,000 surgeries in his life, the majority of which



⁴²Interview with Prof. Massimo Franchi, published by the DIRE news agency and available on the website https://www.dire.it/05-09-2022/783642-franchi-trasformazione-atto-abbastanza-intutti-tranquillizza-piu-il-medico-che-the-patient/ (accessed 22 August 2023), unofficial translation.

⁴³Cit. note 41.

⁴⁴Interview with Prof. Alessandro Frigiola, published by the DIRE news agency and available on the website https://www.dire.it/19-09-2022/791599-la-storia-del-piccolo-andrea-testimone-di-geova-operato-a-open-heart-without-blood/ (accessed 22 August 2023), unofficial translation.

⁴⁵Interview with Prof. Alessio Pace, published by the DIRE news agency and available on the website https://www.dire.it/28-06-2022/754708-professor-alessio-pace-pioniere-medicina-senza-sanque-storia/ (accessed 22 August 2023), unofficial translation.

without the need for transfusions, of which approximately 13,000 on Jehovah's Witness patients. In his interview he recalls how bloodless medicine is good for everyone's health, and it is at the basis of the Patient Blood Management strategies promoted with the WHO resolution to preserve haemoglobin levels in patients and minimize blood loss in all patients. The professor recalls that in the 1980s no one operated with haemoglobin values lower than 7; in such cases it was in fact inconceivable and impractical for the medical science of the time not to transfuse. The professor thus began as a pioneer to operate without transfusing, tracing a path in which thousands of doctors continue to-day.

Regarding the prejudice that many doctors had towards Jehovah's Witnesses, Professor Pia Di Benedetto, Professor of Anaesthesia, Director of the Operating Unit Coordination of the Sant'Andrea Hospital in Rome, also recalls: "Thirty years ago there was an obvious prejudice towards those who refused blood, since the request came from a religious group. At the time, doctors did not yet have the scientific literature that is now evident to support the request. We must say thanks to Jehovah's Witnesses, who with their input underwent operations with severe anaemia, improving transfusion triggers more than we thought". 46

There was no scientific literature because there was no one who agreed to act as a 'guinea pig'. The comfortable and safe old road is always preferred. Seneca once said that it is not because things are difficult that we don't dare to do them, but it is because we don't dare to do them that they seem difficult ⁴⁷. Jehovah's Witnesses, taking the risk themselves, dared and asked doctors to dare. The result was surprising! The advancement of *bloodless techniques* has been rapid and significant, bringing benefits to all patients around the world. This is why, as previously mentioned, there is a particular relationship between the religion of Jehovah's Witnesses and science: it was not religion, as often happens, that adapted to scientific progress, but it was medical science that made a leap forward by accepting the challenge of welcoming the requests of Jehovah's Witnesses.

7. Brief conclusions

The brief analysis conducted so far leads us to conclude that, although there are some issues still to be resolved, many results have been achieved. What we can hope for is that we continue to pay ever greater attention to the needs and wishes of patients, whoever they are and regardless of the ethical and/or religious reasons that move them to self-determine in a certain way. Thus, once the legal and medical bases in which to move have been laid, even if they are constantly evolving, the point is no longer whether the doctor or jurist shares the patient's choices: they must limit themselves to respecting them. The request made by Jehovah's Witnesses to see the right to refuse non-mandatory healthcare treatments, such as blood transfusions, even when life itself is at risk, has been present in the legal, medical and social culture of our country for over forty years. In recent years we have gone from the total rejection of the patient's wishes (with the prevalence of a paternalistic attitude of doc-

⁴⁷"Non quia difficile sunt non audemus, sed quia non audemus difficilea sunt" in L.A. Seneca, Lettere a Lucilio, lett. 104, 26 798, R. MARINO (translator), Trebaseleghe (PD), 2016.



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⁴⁶Interview with Prof.ssa Pia Di Benedetto, written and video published by the DIRE news agency and available in https://www.dire.it/18-07-2022/763274-di-benedetto-sangue-trasfuso-da-immunodepressione-e-recrudescenza-nei-oncology-patients (accessed 22 August 2023), unofficial translation.

tors who demanded an almost total abdication of the individual's wishes in favour of the protection of life at all costs), to the reversal of positions and the affirmation of favor patientis with recognition of their wishes as the fulcrum of the treatment process. The experience of Jehovah's Witnesses and their relationship with bioethics therefore presents itself as a positive case of propulsion. This has happened in both the legal and medical fields. In the first, the affirmation of the right to selfdetermination was the result of a growing case-law which, often requested by Jehovah's Witnesses, in the face of the regulatory void, indicated the route to the legislator until the approval of the Law no. 219/2017. In the second, the requests of Jehovah's Witnesses have directed research towards new bloodless strategies which are today a common heritage for the benefit of every patient, allowing the request not to undergo forced blood transfusions to be accepted, even in the most extreme cases.

The experience offered by Jehovah's Witnesses has provided a contribution in the scientific and legal fields to the affirmation of ethical and religious values in reference to medical choices, contributing to the progress of medicine and the evolution of case-law in the sense of increasingly recognizing and placing value on religious freedom in its many applications. A step forward in the protection of the rights of Jehovah's Witnesses, which turned into a step forward in the protection of the freedom of every individual. As Roland H. Bainton stated: "Where religious freedom is not guaranteed, no civil freedom can flourish. The problems of religious freedom, in fact, expand to the point of touching the problem of every freedom and every right".48

⁴⁸R.H. BAINTON, La lotta per la libertà religiosa, F. Medioli Cavara (translator), Bologna, 1963, unofficial translation.

