

Basic Institutes

**WHEN CONSENT IS NOT ENOUGH: THE
CONSTRUCTION AND DEVELOPMENT OF THE
MODERN CONCEPT OF AUTONOMY**

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Abstract: This paper aims to demonstrate that there is a gap in the way patient's autonomy is being discussed. All attention is focused on informed consent, and this approach is essentially wrong. Consenting is just a part of the process of choosing, and is not enough to allow patients to exercise their right to autonomy. This can only be accomplished through the complete and understandable disclosure of all information regarding treatment, their options and possible consequences.

Keywords: Informed Consent; Informed Choice; Right to Information; Informational Negligence; Autonomy.

INTRODUCTION

When one speaks about the right to information in the healthcare context, there is an almost automatic association to the expression "informed consent." In modern society the idea that every medical intervention or experiment must be previously understood and consented to by the patient or subject of research, in order to prevent liability is virtually unanimous nowadays.

It was not always like this. For a better understanding of the present situation, it is important to look at it with an historic perspective. The first centuries of medicine were defined by a dichotomy of presumed superiority between the

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guardians of medical knowledge, and the patients. The art of medicine was seen as something divine, almost supernatural, and little or no questioning was allowed regarding the decisions and commands issued by those few men of science.

The concept that the patient – as a human being – was entitled to certain rights, began to grow after the French Revolution, and later, after the Industrial Revolution. The physicians were slowly stripped of their divine origin, being regarded as normal citizens, ordinary professionals, subject thus to failure and questioning.

At the same time, medical services lost the personal touch, surrendering to the market and the image of the doctor became something distant and unknown to the patient, raising legal issues about criminal, civil, and ethical responsibility, establishing the grounds for the informed consent doctrine in the patient-doctor relationship.

BIOETHICS AND THE DEVELOPMENT OF THE PRINCIPLE OF PATIENT'S AUTONOMY

Since the end of World War II, the bioethical concept of patient autonomy¹ has gained importance,² shifting the centuries-old balance in the paternalistic relationship between physicians and their patients.³

1 “Autonomy is a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. The autonomous person is one who not only deliberates about and chooses such plans but who is capable of acting on the basis of such deliberations, just as a truly independent government has autonomous control of its territories and policies.” Beauchamp, T. & Childress, J. *Principles of biomedical ethics*. New York: Oxford University Press, 1979, pp. 56-57.

2 “Respect for autonomy is the most frequently mentioned moral principle in the literature on informed consent, where it is conceived as a principle rooted in the liberal Western tradition of the importance of individual freedom of choice, both for political life and for personal development. ‘Autonomy’ and ‘respect for autonomy’ are terms loosely associated with several ideas, such as privacy, voluntariness, self-mastery, choosing freely, the freedom to choose, choosing one’s own moral position, and accepting responsibilities for one’s choices.” Beauchamp, T. & Faden, R. *A history and theory of informed consent*. New York: Oxford University Press, 1986, p. 7.

3 “Part of the explanation for the shift from beneficent paternalism toward autonomy lies in historical events of the twentieth century, primarily related to research, that called into question the trustworthiness of the medical profession. The atrocities revealed in the Nuremberg Trial of Nazi doctors, as well as highly publicized cases of human subjects

Of course, case law stating the importance of consent can be found in Anglo-Saxon jurisprudence since the late years of the 18th Century,⁴ but it was only after the Nuremberg trials,^{5, 6} and moreover, the Tuskegee's experiments,⁷ that

abused in the United States, sparked suspicion of the general benevolence of physicians and researchers. In this context, informed consent was seen as a protection from abuse by untrustworthy professionals. Even if the medical and research establishment could not be trusted to conduct prospective review of the likely harms and benefits and to offer individuals only research and treatment opportunities that had acceptable risk-benefit ratios, individuals could safeguard their own interests if they were adequately informed and if their autonomous authorization was required before research or treatment could proceed. Individuals were thus called upon to exercise their autonomous decisional authority to safeguard their welfare." BERG, Jessica W. [Et Al], *Informed Consent*, 2nd ed, Oxford University Press, New York, 2001, p. 20.

- 4 Slater v. Baker and Stapleton, 2 Wils. K.B. 358 (1767). In this case, the plaintiff hired the defendants to remove the bandages from his fractured leg. Against the patient's will and in spite of his protests, both physicians decided to re-fracture the plaintiff's leg and place it in an experimental device to stretch and straighten it during re-healing. In the reasoning, the Court stated: "In answer to this, it appears from the evidence of the surgeons that it was improper to disunite the callous [bony material in healing] without consent; this is the usage and law of surgeons: then it was ignorance and lack of skill in that very particular, to do contrary to the rule of the profession, what no surgeon ought to have done; and indeed it is reasonable that a patient should be told what is about to be done to him, that he may courage and put himself in such a situation as to enable him to undergo the operation."
- 5 For more detailed information, it is recommended reading Norbert Ehrenfreund's "The Nuremberg Legacy: How the Nazi War Crimes Trials Changed the Course of History" (2007, Palgrave Macmillan); Robert E. Conot's "Justice at Nuremberg" (1993, Basic Books); and Michael R. Marrus' "The Nuremberg War Crimes Trial, 1945-46: A documentary history" (1997, Bedford/St. Martin's).
- 6 The Nuremberg Code (<http://www.cirp.org/library/ethics/nuremberg/>) states in its article first that "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs, or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity."
- 7 Again, for more information, it is recommended reading Susan M. Reverby's "Examining Tuskegee: The infamous Syphilis Study and its Legacy" (2009, The University of North Carolina Press), with an analysis of the notorious study of untreated syphilis, which took place in and around Tuskegee, Alabama, from the 1930s through the 1970s. The study

informed consent became one of the pillars of modern medicine, and almost the Holy Grail of medical ethics.

The foundations of this doctrine can be found mostly in the North-American case law jurisprudence, though. In 1905, the leading case *Mohr v. Williams*⁸ raised the issue whether the patient gives a physician specific consent to operate, does the physician have general consent to perform other surgical operations undertaken to treat other problems? In this case, the patient arranged for the physician, an ear specialist, to perform surgery on her right ear. After Williams began performing the operation he decided that Mohr's left ear rather than her right ear required surgery, although the condition was not life threatening. Williams operated successfully on the left ear without having received permission from Mohr.

Mohr sued Williams for battery and the court decided that when a doctor obtains a patient's specific consent for a particular operation he may not perform another operation on the patient without her consent. A patient's consent is implied when an emergency situation arises. However, this does not allow the doctor a free license to attempt to remedy all problems found that are not life threatening. The court held that in this case, there was no evidence that the condition of the plaintiff's left ear presented a serious or life threatening situation.

Even though there was no showing that he had a wrongful intent or that he had been negligent, Williams was still liable for battery.⁹ The court held that it was not relevant that the operation was successful.

The same understanding was reinforced in 1914 in the United States, during the leading case of *Schoendorff v. Society of New York Hospitals*,¹⁰ discussing a situation where the patient had undergone surgical intervention without his previous consent. The New York Court held accountable the hospital for violating the patient's body integrity, in spite of the positive outcome. Justice Benjamin Cardozo stated in his ruling that "every human being of adult years

involved hundreds of African American men, most of whom were told by the doctors from the U.S. Public Health Service that they were being treated, not just watched, for their late-stage syphilis; and from the same author, "Tuskegee's truths: Rethinking the Tuskegee Syphilis study" (2000, The University of North Carolina Press).

8 1905, *Mohr v. Williams*, 104 N.W. 12.

9 "The free citizen's first and great right – the right to himself this right necessarily forbids a physician to violate without permission the bodily integrity of his patient."

10 *Schoendorff v. Society of New York Hospital*, 106 N.E. 93 (N.Y. 1914).

and sound mind has a right to determine what shall be done with his own body,” words that became paramount for the informed consent doctrine with the passing of the years.

The expression “informed consent” appeared for the first time in 1957, in the leading case *Salgo v. Leland Stanford Junior University Board of Trustees*,¹¹ dealing with a malpractice case where the patient found himself paralyzed in his lower members after a surgical procedure, without being informed of such possibility as a risk. The case decided that proper consent required provision of information. In the ruling, the judges decided that the physician has the duty to **disclose** “*any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.*”

In the French doctrine, one of the first trials regarding patient’s rights happened in 1942, and not by chance deals with consent issues.¹² The concept of *consentement éclairé* is widely spread in France, present in several laws, such as the Law from December 20th 1978 (regulating biomedical experiences), the Law 94.653 from July 29th 1994 (inserting article 16, section 3 in the French Civil Code¹³), and the 1995’s French Medical Ethics Code, reinforcing the evidence and necessity of respecting the informed consent doctrine.

In 1973, The American Hospitals Association were the first to implement the Patient’s Bill of Rights, which specified the right of any patient to receive complete and comprehensive medical information that he can evaluate and understand. The patient was given the right to accept or to refuse the recommended treatment after being advised of the consequences of his decision: “The patient has the right to obtain from the physician **complete current information** concerning his diagnosis, treatment and prognosis in

11 *Salgo v. Leland Stanford Jr. University Board of Trustees*, 317 P.2d. 170 (Cal. App. 1957).

12 Cf. André Pereira, in *O consentimento informado na relação médico-paciente*, Ed. Coimbra, Coimbra, 2004, p. 61: *Cour Cassation*, 28-1-1942 (*arrêt* Teyssier): “... attendu que, comme tout chirurgien, le chirurgien d’un service hospitalier est tenu, sauf cas de force majeure, d’obtenir le consentement du malade avant de pratiquer une opération dont il apprécie, en pleine indépendance, sous la responsabilité, l’utilité, la nature et les risques; qu’en violant cette obligation, imposée par le respect de la personne humaine, il commet une atteinte grave aux droits du malade, un manquement à ses devoirs proprement médicaux et qui constitue une faute personnelle se détachant de l’exercice de ses fonctions...”

13 Code Civil, art. 16, n. 3: “Il ne peut être porté atteinte à l’intégrité du corps humain qu’en cas de nécessité médicale pour la personne. Le consentement de l’intéressé doit être recueilli préalablement dans le cas où son état rend nécessaire une intervention thérapeutique à laquelle il n’est pas à même de consentir”.

terms the patient can reasonably be expected to **understand**. The patient has the right to receive from his physician information necessary to give **informed consent** prior to start of any procedure and/or treatment.¹⁴ The patient has the right to **refuse** treatment to the extent permitted by law, and to be informed of the medical consequences of his action.”

INFORMED CONSENT, THE DUTY TO INFORM AND INFORMED CHOICE

There are several legal issues regarding consent, and litigation is increasing in relation to consent issues. Too many aspects need to be taken into consideration for consent to be considered valid, such as when consent was obtained and whether the risks have been explained. Moreover, whether they were understood by the patient (sometimes, cultural issues or language barriers can be a complication); whether the patient is a minor (if so, mature or not to decide by him/herself); whether an adult patient has legal capacity to decide (and also, if having legal capacity to decide, clinical capacity is absent); and whether an oral consent constitutes enough evidence that information has been given and understood. But above all – and that is precisely the object of this study – whether the patients have been given sufficient, adequate, complete information, so that they can actually decide, and not just consent to a physician’s suggestion.

Very often, tough physicians and health care providers misunderstand the concept of the so-called *informed consent*.¹⁵

Informed consent is the authorization given by the patient to undergo treatment, based on the knowledge of the nature of a medical procedure, and be submitted to risks, side effects, possible complications, benefits and

14 A physician should convey the risks of an operation when a reasonable person would be likely to attach significance to the risk in deciding whether or not to forgo the proposed therapy. The standard measuring performance of the duty to disclose is conduct which is reasonable under the circumstances. There are two exceptions to this general rule: (1) where the patient is unconscious and harm from a failure to treat is greater than any harm threatened by the proposed treatment; and (2) where disclosing the risk to the patient poses a threat to the patient’s well being.

15 “It is always an open question whether an autonomous person with the capacity to give an informed consent actually has, in any specific instance, given an informed consent, in the sense of making an autonomous choice to authorize or refuse an intervention”. Faden, R, Beauchamp, T L, *A History and theory of informed consent*, Oxford University Press, 1986, p. 237.

alternatives to the proposed treatment. In other words, it is the acceptance of the services to be delivered by a healthcare professional, after understanding what is being consented to.

It is necessary to understand that the process of consenting constitutes, at the same time, a patient's right and a physician's duty.¹⁶ The patient must be informed in a clear and comprehensible way, according to his cognitive capabilities, about his diagnostic, risks, prognosis, and existing treatment alternatives, even those the doctor does not think fit for the specific case.

It is also important to point out that the mere act of reading and signing a paper, a consent form, is not enough to release the physician from his duties, from his obligation to inform accordingly (even if this written form is an important piece of evidence of due diligence).

The right to be informed has nothing, or very little, to do with the true exercise of patient's autonomy. The act of consenting *to* some treatment, research, experiment or surgical procedure is just part of a bigger process, where the patient can exercise its autonomy. Someone can consent, based on the trust put in the doctor, based on indifference, fear, or even *because* he/she did not receive all necessary information to really *choose* among different possible options.

Informed consent is often mistaken for informed choice – this last one being essential to achieve the fulfillment of the right to be informed (and the physician's duty to inform). The patient needs not only to receive, but also to understand the information that has been handed over, and not just simply receive it without processing it properly. Information without comprehension is legally void, because it could be proven that the patient consented (or signed a consent form), but did not exercise his right to free and informed choice. His autonomy would be jeopardized.

Article 5 of the Oviedo Convention (European Convention of Human Rights and Biomedicine, 1997), clearly provides that “An intervention in the health field may only be carried out after the person concerned has given free and informed consent. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its

¹⁶ Regarding this, see for example articles 22, 24, 26, 31 and 34 of the Brazilian Medical Ethics Code, issued by the Federal Council of Medicine as Resolution 1931/2009.

consequence and risks. The person concerned may freely withdraw at any time.”

And what can be considered appropriate information? That is a difficult question, since the answer may differ, given the specific situation. But mostly, the communication between the physician and his patient must include the existing treatment options (not only the main options) with their purposes and details, their benefits and risks (commonly occurring risks and those unlikely to occur), possible side-effects, success rates, the reasons why a specific option is being recommended, the prognosis, and the risks of not having treatment.

That being said, the act of obtaining consent without allowing proper choice does not represent an automatic release from professional duties regarding information, if this was withheld, distorted, tampered with, or incomplete. The physician would still be held liable for informational negligence.¹⁷

Another North-American leading case followed in the same direction, *Canterbury v. Spence*,¹⁸ from 1972. Its historical relevance lies on the demonstration of the imperative necessity of the patient’s understanding of the information transmitted by the doctor before a surgical intervention. In this case, the patient, who developed a paralysis after a laminectomy had not been informed of a 1% risk possibility of occurring such side effect. The Court ruled that:

“A physician is under a duty to treat his patient skillfully but proficiency in diagnosis and therapy is not the full measure of his responsibility. The cases demonstrate that the physician is under an obligation to communicate specific information to the patient when the exigencies of

17 Regarding informational negligence, France had a particularly prolific year in 2010, with important decisions issued by the Cour de Cassation recognizing civil responsibility and negligence for the breach of duty to inform the patient properly. For an overview of the French jurisprudence, it is recommended reading the decisions from January 28th, June 3rd and October 14th.

In Brazil, the Superior Court of Justice (STJ) also decided in favor of the plaintiff, holding a blood bank liable for lack of proper communication of test results (REsp nº 1.071.969/PE). In 2007, another case, involving plastic surgery (AgRg in Ag 818.144/SP) had a similar result, with the court ruling that “the physician who does not inform his patient about the risks of surgery is negligent, being liable for all damages resulting from the intervention”. In the opposite direction, a case judged in 2009 (REsp 1.051.674/RS) exempted the doctor from being considered responsible for an unexpected result, because he proved the fulfillment of the duty to inform. All three rulings available at www.stj.jus.br.

18 *Canterbury v. Spence*, 464 F.2d 772 (DC Cir 1972).

reasonable care call for it. Due care may require a physician perceiving symptoms of bodily abnormality to alert the patient to the condition. It may call upon the physician confronting an ailment, which does not respond to his ministrations to inform the patient thereof. It may command the physician to instruct the patient as to any limitations to be presently observed for his own welfare, and as to any precautionary therapy he should seek in the future. It may oblige the physician to advise the patient of the need for or desirability of any alternative treatment promising greater benefit than that being pursued. Just as plainly, due care normally demands that the physician warn the patient of any risks to his well-being which contemplated therapy may involve.

(...)

In our view, the patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked. And to safeguard the patient's interest in achieving his own determination on treatment, the law must itself set the standard for adequate disclosure.

(...)

The topics importantly demanding a communication of information are the inherent and potential hazards of the proposed treatment, the alternatives to that treatment, if any, and the results likely if the patient remains untreated. The factors contributing significance to the dangerousness of a medical technique are, of course, the incidence of injury and the degree of the harm threatened. A very small chance of death or serious disablement may well be significant; a potential disability which dramatically outweighs the potential benefit of the therapy or the detriments of the existing malady may summons discussion with the patient."

We have been stressing the importance of consent – and consent forms – over the past years, forgetting that there are more important situations to be dealt

with, arising from the relationship in question. Let's take as an example, article 5 of the European Convention on Human Rights and Biomedicine (the Oviedo Convention), as previously stated here. All attention is drawn to the first part of the text, which says that "*an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.*" However, the key to understand the true spirit of the law lies in the second part of the article, which states that "*this person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.*"

In the same direction, Sheila McLean¹⁹ highlights the importance of information in the process of consenting and choosing:

"One way, it seems obvious, that we can facilitate the making of a valid choice, is by ensuring that the patient is provided with the wherewithal to make a decision in the first place. In other words, the patient needs information on which to base his or her choice. The "informed", or more accurately informational, aspect of consent is the element that focuses on the patient's right to receive relevant and sufficient information in order to enable him or her to make a decision. It is generally assumed, then, that – in the absence of a competent refusal to receive any information that might be offered – a valid consent (or refusal) depends on the sharing of information with the patient. The doctor is, therefore, under an obligation to share information with his or her patient."

Appropriate information seems to be the main element about patient's autonomy rights. The information, to be "appropriate," does NOT need to meet the doctor's assessment of the situation, but the patient's. All relevant data, alternatives (even those the physician thinks are not recommended to the case, based on its experience) and risks must be disclosed to the patient, in an understandable way, in order to provide sufficient elements for a decision – a choice – to be made. This – and not consenting – is the real exercise of autonomy. These exact same ideas are exposed in article 5 of the Inter American Convention of Human Rights (1969).²⁰

In the U.S., the *Patient Self-determination Act* (1991) regulates the idea of

19 McLean, Sheila A. M., *Autonomy, Consent and the Law*, Routledge-Cavendish, 2010, p. 42.

20 Article 5. Right to Humane Treatment - 1. Every person has the right to have his physical, mental, and moral integrity respected.

the right to information as a basic requirement, being the right to informed consent being just a part of the process, not its final goal. A consent form signed by the patient is not a safeguard from lawsuits. Of course, it is an important document, but cannot be seen as the only thing that matters in defensive medicine.

The examples of legal documents could go on and on, in Brazil,²¹ Portugal,²² Spain,²³ France²⁴ and Israel,²⁵ and all over the world, showing that there is a new way of dealing with old dilemmas, and that health care providers have to adapt their concepts to the new ideas. The world has evolved, and that requires adaptation.

A patient does not need to consent to a proposed treatment. This may come as a shock to many doctors, as they are trained to “fight” diseases, and save lives, no matter what. What they are not taught in medical schools is the fact that their main obligation – apart from acting with the best of their techniques and skills – is that they must provide information to the patient. The patient will decide, based on his/her personal life, values, morals and beliefs, which is the best option. Only then can autonomy be respected and enforced. These ideas are well explained in the words of Irene Switankowsky²⁶:

“The ultimate purpose of informed consent is to ensure that the patient makes an autonomous, rational, reflective, well-understood decision about a medical procedure or treatment alternative that s(he) believes will be most beneficial. In short, the ultimate purpose of properly informed consent is to protect a patient’s autonomy under all medical circumstances.”

It is a mistake to think that obtaining informed consent – as it happens today in most of the cases – is enough to exempt the physician from liability, excluding

21 In Brazil, Federal laws, such as Law 8.080/1990 (Consumer’s Defense Code) article 7, section V, reinforces to the patient the right to information about his/her health conditions; Law 10.741/2003 (Elderly’s Protection Act) ensures the right to choose the most favourable health treatment; Law 9.434/1997 (Organ and Tissues Transplantation) requires consent for every procedure. State Law also regulates patient’s rights, such as Law 10.204/1999 (São Paulo); Law 14.254/2003 (Paraná); and Law 16.279/2006 (Minas Gerais).

22 Deontological Code from the Portuguese Order of Physicians (Regulamento 14/2009), specially articles 44 to 51.

23 Ley 41/2002.

24 Law of March 4th, 2002. And also, for example, article 1111-2 of the Public Health Code.

25 The Patient’s Rights Law, 1996.

26 Switankowsky, Irene S., *A new paradigm for informed consent*, University Press of America, 1998, p. 2.

legal responsibilities in the event of an undesired outcome occurring during the treatment or procedure.

A treatment or procedure can be considered successful from a clinical point of view, but later seen as inappropriate when confronted with other possible outcomes that could be expected if a different therapeutic method had been related to – and chosen by – the patient.

This lack of information does not necessarily mean negligence. It may represent the expression of the physicians beliefs, based on his own experience or in the medical literature, that the proposed solution was the most adequate to the situation faced at a given moment. The problem is that this behavior goes against ethical principles and legal commands that consider mandatory the disclosure of all information available. Withholding information about alternatives may be considered – in a lawsuit or in a disciplinary investigation – an undue interference in treatment, thus breaching confidence and contrary to the principles of good-faith and autonomy.

This notion is not different in several jurisdictions. In fact, it represents a tendency towards autonomy, as can be seen in the words of André Pereira,²⁷ when stating that “recently, some authors have been proposing a more comprehensive concept. The expression *informed consent* has been criticized in Anglo-Saxon doctrine, since information is but an aspect of proper consent (‘comprehensive or enlightened consent’). Thus, the use of the expression *informed choice* is being suggested. This concept could comprise, among other aspects, information about the consequences of refusal or withdrawing consent, therapeutic alternatives, choice of medicinal products (implicating changes in the regulatory frame of advertisement, choice of medical facilities, etc.). In Portuguese law, the well established right to “information on the existing health services” and the “right to free choice of physician,” and also the right to a “second opinion.” All these aspects considered they go beyond simple informed consent; they are advanced expressions of the right to an informed consent, in the modern version of *informed choice*: self-determination in health care implies not only the patient’s consent or refusal to a proposed intervention, but in possessing all elements to analyze treatment possibilities in medical, chirurgial and pharmaceutical field.”²⁸

27 Pereira, André, *O consentimento informado na relação médico-paciente*, Ed. Coimbra, Coimbra, 2004, p. 74.

28 Translated from the original “Mais recentemente, alguns autores vêm propondo um conceito

The right to consent, as an attribute of personal autonomy, is fundamental to ethical medicine. Its components are: information disclosure, voluntariness, and competency. Breach of informed consent may be actionable as battery or as malpractice.

In other words, obtaining a so-called valid and regular informed consent may be considered void, if it is not a result of an informed choice, leaving the doctor vulnerable to the legal risks and to the unpredictability of the medical activity.

CLOSING REMARKS

“To violate a person’s autonomy is to treat that person merely as a means, that is, in accordance with others’ goals without regard to that person’s own goals. Such treatment is a fundamental moral violation because autonomous persons are ends in themselves capable of determining their destinies.”

(Beauchamp and Childress, *Principles of Biomedical Ethics*, 1994, 4th ed., p. 125.)

Health care providers tend to think that the sanctity of life is the most important guarantee, and the most important fundamental right in modern constitutions in the western world. It is *not*. Legislators – and philosophers – all over the world begin to understand *Human Dignity* as a fundamental principle. And that dying with dignity – choosing not to undergo painful treatments to prolong life beyond cure; choosing to withdraw useless treatment, leave the hospital and die at home, surrounded by family and friends instead of doctors,

mais abrangente. Assim, na doutrina anglo-saxônica critica-se a expressão *informed consent*, visto que a informação é apenas um aspecto do consentimento esclarecido (“*comprehensive or enlightened consent*”). Assim, vem sendo proposta a utilização da expressão *informed choice*. Este conceito teria a virtude de abranger, entre outros aspectos, a informação sobre as conseqüências da recusa ou revogação do consentimento, as alternativas terapêuticas, a escolha dos medicamentos (o que implica alterações à regulamentação da publicidade dos medicamentos, a escolha do estabelecimento de saúde, etc.). No direito português encontramos consagrado o direito à “*informação sobre os serviços de saúde existentes*” e o “*direito à livre escolha do médico*”, e ainda o direito à “*segunda opinião*.” Tudo aspectos que vão para além do simples consentimento livre e esclarecido. São expressões avançadas do direito ao consentimento informado, na sua vertente mais moderna de *informed choice*: a autodeterminação nos cuidados de saúde implica, não só que o paciente consinta ou recuse uma (heteronomamente) determinada intervenção, mas que tenha todos elementos de análise sobre as possibilidades de tratamento possíveis, no domínio médico, cirúrgico e farmacêutico.”

nurses and beeping machines; and even refusing treatments that would oppose deeply a patient's religious beliefs – is part of living with dignity. This is the fundamental right that must be enforced.

The physician's obligation, then, is to help the patient in choosing what is best for him/her, providing complete and adequate information. Is the doctor more prepared to understand the technical consequences of each choice? Undoubtedly, yes. But the patient has the final word that cannot be compromised by the physician's personal opinions. Or else, we are back to Tuskegee and Nuremberg.

These words may sound to some as praise for suicide. They are not. They are a vivid defense of autonomy, of the right of choice. A defense of the idea that responsibility for one's own acts has to walk side by side with rights. Therefore, we need to stop discussing so much about informed *consent*, and start focusing on informed *choice*. We are accustomed to talking and reading about patients' rights and medical liability, but it's time to start thinking about shared responsibilities, to start thinking about patients' duties, since they are granted the power of actually choosing how their life and treatment must be conducted. And with great power, comes great responsibility.

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