

The Patients' Rights Act 20 years on –
Achievements and Challenges
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Patients' Rights - A World View

Dr. Otmar Kloiber
Secretary General
World Medical Association

President of the Israeli Medical Association, Dr. Eidelman,
Distinguished Guests,
Shalom!

Thank you for inviting the World Medical Association to be with you at this event celebrating 20 years of a landmark law here in Israel.

On a summer's day, June 13th, a seven-year -old girl, let's call her Anna, was admitted to hospital with an ulcer on her foot.

Conservative treatment failed and a week later the surgeon recommended amputating the forefoot in order to save the girl from a potentially ascending infection. However, the father – a believer in naturopathy – did not want the surgeon to amputate. On June 23rd the surgeon decided to resect parts of the forefoot.

Unfortunately, it was too late or insufficient. On July 28th the foot had to be amputated, which finally brought the infection under control. Again, this was against the express will of Anna's father, who, despite risk, didn't want his girl to be crippled.

I will come back to Anna.

In the middle of the last century, in 1946, the World Health Organization was founded. Its Constitution¹ states that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition," marking the beginning of international law defining health as a right.

In 1948, Article 25 of the United Nations Universal Declaration of Human Rights² stated that, "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services."

The United Nations International Covenant on Economic, Social and Cultural Rights³ of 1966 states, "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." (Article 12), and lists some concrete measures to realize this right.

But as you may guess, the wording is weak and the phrase "highest attainable" in many places literally meant nothing.

The right to health, and I am not yet speaking about patients' rights, was for a long time considered as good, or as aspirational to make it sound more positive, as a right to blue eyes or sunny skies.

Not until the year 2000 did the United Nations' Committee on Economic, Social and Cultural Rights issue a statement entitled Comment No. 14⁴. The comment elevates the Human Right to health from a mere aspirational goal "to be healthy" to an entitlement, stating that, "States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services."

Now you may think at this point that we have arrived at the discussion of patient rights. Well, yes and no. Today many states, especially those with state-run health care systems, still see the entitlement to health care as a collective one, which gives rationing superiority over individual entitlements.

Parallel to this development, the World Medical Association since 1947 has been developing a system of ethical obligations or a professional deontology, which more clearly describes the physician's role versus the rights of individual patients. In the Declaration of Geneva of 1948⁵ and the first International Code of Medical Ethics of 1949⁶ patient rights do not appear as a self-standing concept. They are rather the result of a matrix of physicians' obligations to patients.

In 1964, with the Declaration of Helsinki⁷ as the first international document setting out the rules for medical experiments with humans, Informed Consent becomes **the** strong tool for protecting patient autonomy. At first this was meant to protect against unwarranted inclusion in experimentation, it later became the generally accepted standard for consent to medical treatment.

Eleven years later in 1975, the World Medical Association's Declaration of Tokyo⁸ commanded the physicians of the world to stay away from involvement in torture and degrading treatment. Unfortunately, a demand that has not lost its relevance even in our day and age. Just think of the force feeding of hunger strikers, which for more than 40 years now has clearly been deemed unethical.

In 1981, the World Medical Association started wording a first declaration on patient rights. The Declaration of Lisbon⁹ turned the paradigm of health as an aspirational aim to an individual right of each and every person. Initially a rather short document, it was made detailed and descriptive in 1995, listing various rights including:

- Right to appropriate medical care of good quality without discrimination
- freedom of choice
- dignity and self-determination
- the right to information as well as the right not to know
- the right to confidentiality
- and the right to religious assistance and
- they should restrict treatment against the free will of the patient.

At that time, a number of countries had already developed similar sets of rights – not necessarily called “patient rights”, but they de facto existed. The World Medical Association brought them together in an international declaration.

But to understand patient rights and the relation of health professionals to them it is important to be clear what patients are. Towards the end of the last century, particularly during the 1990s, the notion came into being that patients are “customers”. Now some prefer the word “clients”, which sounds much more elaborate and elegant, however it is merely the French word for “customer”.

It is undeniable that in any relationship where one pays money for a service there is an aspect or an expectation that classifies one party as a “customer” and the other as a “provider” or “vendor”. But transferring this paradigm as **the** description for the patient/physician relationship falls dangerously short of reality.

Between patients and physicians there is usually a severe imbalance of information which limits the ability of the patient to have the sovereignty necessary to be an equal partner in “making a deal”. Even worse, as the Latin word patient implies, patients are suffering from a condition, illness or injury which often limits their degree of freedom, if not even incapacitating them.

The understanding of a patient as a customer, being able to “make a deal” as an expression of his or her buyer autonomy is unrealistic, especially if the patient is really ill. Of course, describing this imbalanced relationship is usually disqualified with the term “paternalistic” and it may not be “politically correct” nowadays. However, it has the distinct advantage of being true.

The ability of a sick or injured person to act as a competent and freely deciding customer in health care is extremely limited, but exactly that would be necessary to have a balanced customer-vendor relationship.

Respecting the patient’s autonomy does not mean seeing him or her as a purchaser of services, but rather a partner seeking the support and guidance of a physician, ideally to reach a state where a fully autonomous decision can be taken. This state is sometimes reached in a moment, sometimes it will take months and sometimes it is unachievable, think of people suffering from

dementia or children, and sometimes it is not even desirable. I regularly have this situation with my dentist.

Some economists and politicians try to circumvent the reality by calling patients “health care consumers” – but that is even worse.

”How did it become normal, or for that matter even acceptable, to refer to medical patients as “consumers”? The relationship between patient and doctor used to be considered something special, almost sacred. Now politicians and supposed reformers talk about the act of receiving care as if it were no different from a commercial transaction, like buying a car — and their only complaint is that it isn’t commercial enough.“

The question was not raised by a medical doctor; it was raised by Paul Krugman¹⁰, an economist himself. And he concludes:

”The idea that all this can be reduced to money — that doctors are just “providers” selling services to health care “consumers” — is, well, sickening. And the prevalence of this kind of language is a sign that something has gone very wrong not just with this discussion, but with our society’s values.“

Well astonishingly enough, **patients** are **patients**. But this does not prevent any hospital or clinic extending courtesy and friendliness towards them as if they were valued customers.

The needs of patients require our care; their special situation requires our ethical behaviour. But the ethical behaviour of doctors, nurses and other health professionals would not be enough to protect this relationship. The autonomy of a patient, as I said, will often be limited. Self-determination, but even more human dignity, requires protection and assistance. In situations of helplessness, pain and despair, protecting the dignity of the person and enabling self-determination are eminent challenges for our profession. Unlike merchants or vendors, are we not allowed to “make a deal” in our favour because we are cleverer or in a favourable position. In such moments we are the guarantors of patient rights and have to put their interests before ours.

In a free market this would be ruinous. Regulation has to be in place to protect the weak against the strong, the ill against the healthy. Commercial decisions in a consumer-driven market will regularly go against patient interests. If doctors have to follow an economic dictate – and unfortunately for various reasons this is more and more the case – decisions are taken in favour of profits or savings and not in favour of health.

The strongest safeguards against such undue influence are professional autonomy and clinical independence. The protection of patients’ rights becomes a pure illusion if physicians have to take decisions dictated by profit margins.

Clinical independence and professional autonomy are not the God-given privileges of those in white coats, they are derivatives of patient rights. Their aim must be to safeguard the interests

of patients in order to guarantee appropriate treatment, access to medical resources and to avoid unfair discrimination.

Current attempts by some governments, but also by some health care organizations, to invade or reverse the professional autonomy of physicians has not been taken sufficient notice of by patient organizations. Patients have to ask the question whether they want to have a doctor who is bound by his professional ethical code or by financially motivated orders from the government or commercially driven organizations.

While on the individual level professional autonomy safeguards the patient-physician relationship, at the organizational level this is reflected in the medical ethics and the self-governing structures which make it up.

But patients' rights also have limits.

The rights of patients, like other individual rights, are limited as any other rights are. The most obvious limitation is the one of limited resources. Whether these are natural limits or artificial limits - at any point several patients or individuals may compete for the same resources.

While in the distribution of welfare we usually apply the principle of proximity, we serve those close to us in our communities first. The rationing of medical care is bound to medical need and not to affiliation of any kind. Traditionally, this model comprises a product of medical need and likelihood of benefiting from treatment, and more recently it is often combined with a measure of efficacy, considering the cost of treatment.

But patient rights can also be limited in competition with the rights of the physician. Firstly, there is **no** right of a patient to demand treatment from a specific physician – at least as long as alternatives are available. In principle, and this may be altered by contracts, a physician has the right to refuse treatment if an emergency situation does not force him to act immediately. This may happen because the physician has lost the trusting relationship with his or her patient, it may be because the physician is overworked, or simply for reasons the physician will not declare. Again, this is only feasible when there is no emergency situation and the patient can receive treatment elsewhere.

The Declaration of Geneva and the International Code of Medical Ethics demand the physician to exercise his or her profession with conscience. That, of course, is meaningless if a conscientious objection is impossible. No physician must be forced to carry out activities that are either deemed to be unethical altogether, like participation in capital or corporal punishment, the force feeding of prisoners or to perform services he morally cannot subscribe to.

In essence, physicians do not surrender their human rights when becoming a physician. Not be coerced to provide certain treatments is a matter of dignity and integrity for the physician as well. And likewise, a physician does not lose the right to build coalitions for his interests i.e. his

or her salary or working conditions. Where the right to strike exists, there is no justifiable reason to deny this right to physicians in particular.

Achieving a balance between the rights of patients to be treated and the right of physicians to industrial action appears for many physicians to be an insurmountable task. Many of us see going on strike as a violation of the ethical imperative to do no harm. However, physician strikes of the past decades have shown that patients who understand the physicians' perspective and who feel reassured that they will receive urgent treatment show understanding, respect and sometimes even support for their physicians. Such successful strikes have either concentrated on administrative tasks in hospitals or clinics, thereby making billing extremely difficult, or they have strictly ensured that while truly elective treatments were postponed, emergency and pressing treatments were carried out properly and on time.

And while most of my colleagues would agree with me that physician strikes are a method of last resort, they are not principally excluded for ethical reasons, as long as this does not cause harm to the patients.

Let me summarize:

Patient rights should they be meaningful and must include an individual right to effective and timely treatment that is medically necessary and desired by the patient. These rights should also include or enable the

- freedom of choice
- dignity and self-determination
- the right to information as well as the right not to know
- the right to confidentiality
- and the right to religious assistance

Secondly, patient rights are not to be confused with "consumer rights". Patient rights extend far beyond that concept. Patients are not simply "customers" and doctors are not simply "service providers".

Thirdly, protecting patient rights requires doctors to have necessary professional autonomy allowing them to put their patients first and not the financial interest of any other party, including themselves. This doesn't rule out the obligation to save and share resources, but it does not allow financial interests to be put first.

Fourthly, a solid self-governing structure is necessary to provide the ethical and professional framework to guide the behaviour of physicians. Ideally, leading a patient by shared decision-making through an ultimately self-determined process - if the patient wishes to do so.

Fifth, patient rights have limits. They may be limited by the competing rights of other patients or society, but also by the rights of their physicians. Patients' rights to an effective medically indicated treatment do not automatically force obligations on other individuals, unless serious danger or suffering is imminent.

Let us go back to Anna, the little girl in the hospital. Anna had bone tuberculosis. The surgery to amputate her foot most likely saved her life. Nevertheless, her father sued the physician because the amputation was carried out against his will.

A year later the national court stated:

“The fact that somebody, according to his conviction or the judgment of his peers, has the ability to understand the real interest of his nearest better than him or herself, [...] does not give that person the legal right [...] to exercise force and to use the other person’s body for well-meant treatment attempts.” This was the imperial court of Germany on May 31st, 1894¹¹.

More than 120 years later, we are still learning.

Thank you very much for your attention.

¹ Constitution of the World Health Organization, 1946

http://www.who.int/governance/eb/who_constitution_en.pdf

² United Nations Universal Declaration of Human Rights, 1948

<http://www.un.org/en/universal-declaration-human-rights/>

³ United Nations International Covenant on Economic, Social and Cultural Rights

<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx> 1966, 1976 (entry into force)

⁴ United Nations' Committee on Economic, Social and Cultural Rights issue a statement entitled Comment No. 14 E/C.12/2000/4 , 11 August 2000

<http://www.nesri.org/resources/general-comment-no-14-the-right-to-the-highest-attainable-standard-of-health-un-committee-on-economic-social-and>

⁵ WMA Declaration of Geneva 1948, 2006 (last version)

<http://www.wma.net/en/30publications/10policies/g1/>

⁶ WMA International Code of Medical Ethics, 1949, 2006 (last version)

<http://www.wma.net/en/30publications/10policies/c8/>

⁷ WMA Declaration of Helsinki 1964, 2013 (last version)

<http://www.wma.net/en/20activities/10ethics/10helsinki/>

⁸ WMA Declaration of Tokyo 1975, 2005 (last version)

<http://www.wma.net/en/20activities/10ethics/20tokyo/>

⁹ WMA Declaration of Lisbon 1981, 2015 (last version)

<http://www.wma.net/en/30publications/10policies/l4/>

¹⁰ Paul Krugman. Patients Are Not Consumers, New York Times 21.04.2011

¹¹ Reichsgericht RGSt 25, 375 Entscheidungen des Reichsgerichts in Strafsachen, 1894