CLINICAL ETHICS

Informed consent in neurosurgery—translating ethical theory into action

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Objective: Although a main principle of medical ethics and law since the 1970s, standards of informed consent are regarded with great scepticism by many clinicians.

Methods: By reviewing the reactions to and adoption of this principle of medical ethics in neurosurgery, the characteristic conflicts that emerge between theory and everyday clinical experience are emphasised and a modified conception of informed consent is proposed.

Results: The adoption and debate of informed consent in neurosurgery took place in two steps. Firstly, respect for patient autonomy was included into the ethical codes of the professional organisations. Secondly, the legal demands of the principle were questioned by clinicians. Informed consent is mainly interpreted in terms of freedom from interference and absolute autonomy. It lacks a constructive notion of physician–patient interaction in its effort to promote the best interest of the patient, which, however, potentially emerges from a reconsideration of the principle of beneficence.

Conclusion: To avoid insufficient legal interpretations, informed consent should be understood in terms of autonomy and beneficence. A continuous interaction between the patient and the given physician is considered as an essential prerequisite for the realisation of the standards of informed consent.

The moral commitment to respecting the right of self-determination of patients began in the 1970s in the US. The basic power structures in healthcare were intended to be altered by creating the well-informed patient. But how has this shift in paradigm been translated into clinical practice? Why do the proposals of bioethical theory and law still seem unrealisable or even mythical¹ to many clinicians? How did the concept of informed consent affect the physician–patient relationship? In neurosurgery, many patients find themselves incapable of understanding their situations enough to be able to make the proper decisions, let alone provide proper consent. In addition, neurosurgical procedures often assume high risks to the physical as well as mental health of the patients. These risks often imply not only difficult preconditions for obtaining valid consent for the physician, but also substantial value choices and an extraordinary level of compliance on the part of the patients and their family. By reviewing the reactions to and adoption of this principle of medical ethics in neurosurgery, we wish to emphasise the characteristic conflicts that emerge between theory and everyday clinical experience and propose a modified conception of informed consent.

THE APPROACH OF PROFESSIONAL ORGANISATIONS

In 1986 the American Association of Neurological Surgeons summarised the new debate on the rights of patients in a new Code of Ethics created for the association. The need to revise the existing code (the first revision in 50 years) was justified by the inappropriateness of the Hippocratic oath and of other older codes regarding the wishes of the patients and those of the society. "Early codes of professional ethics emphasised proper relationships between physicians more than the interaction between physicians and patients."² The new Code of Ethics is based on four moral principles to which both "physicians and society at large might agree".² These fundamental moral principles—beneficence, nonmaleficence, autonomy of the individual, and justice—are designated in accordance with the *Principles of biomedical ethics* written by

Tom L Beauchamp and James F Childress, which first appeared in 1979.³ In the presidential address 1986 American Association of Neurological Surgeons, the principle of autonomy was introduced as speaking "of individual freedom of choice", which "responds to the charge of paternalism" and has to be respected, "even if the physician believes that something else might be more beneficial".² Furthermore, the concept of informed consent in surgery is mentioned as an example for the inherent conflict in the principle of autonomy in medicine, although a solution for this conflict is not offered. The four principles approach of Beauchamp and Childress (principlism) is often criticised as limited in its usefulness for the physician.⁴ Similarly, the new Code of Ethics is expressed too much in the abstract and does not specify or balance the moral principles to meet the individual demands in neurosurgery.

Another, more practical approach to the contemporary issue of informed consent has been adopted by the European Association of Neurosurgical Societies.⁵ In the report of their Ethico-Legal Committee, several recommendations on the purpose and content of disclosure are given, which mainly refer to legal demands on valid consent. It is also claimed, however, that the duty to inform is "primarily an essential step in the management of patients, and not primarily for the protection of surgeons against litigation".⁵ The committee's report discusses neither the underlying moral rule nor its realisation in the standards of informed consent.

THE CLINICIAN'S APPROACH

Subsequently, a number of publications on neurosurgery have focused on informed consent and the right of self-determination. Most of them presented pessimistic conclusions. The "increasing demand of patients to direct their own care" is experienced as an "intrusion in the traditional patient–physician relationship", that might "increase health care costs".⁶ The "fulfillment of the doctrine of informed consent under the intent of the law" is considered to "be mythical".¹ Further research is called for "to establish what really is 'appropriately informed consent'".⁷

These assertions were often based on evaluations of the effectiveness of patient education before consent. The tests, without exception, yielded unsatisfying results in recall and comprehension of the provided information, leading to the conclusions quoted above. The reviewed literature serves as an example of the growing influence of the legal implications in providing health care. For the most part, neurosurgeons have only been questioning the legal demands placed on informed consent. Only a few authors considered the moral aspects, repeating the abstract principles of bioethical theory.

INFORMED CONSENT—IS IT A MYTH?

In terms of the legal doctrine of informed consent, much of the criticism seems to be justified. The law's focus on self-determination and damage control "has little positive to say, and ... tends to motivate clinicians to hyper-inform patients 'just to be safe'".⁸ Given the frequent difficulties in obtaining valid consent, this motivation to over-inform must seem inappropriate, particularly to the neurosurgeon. Neither the legal doctrine of informed consent nor the idealistic understanding of patient autonomy has appeared to be helpful in such a situation, as has been illustrated in the reviewed literature.

Traditionally and according to its historical roots, the idea of informed consent has been understood in terms of freedom (from interference) and patient autonomy. This concept serves well when securing the rights of patients against paternalistic infringement and in cases of malpractice. It, however, lacks a constructive notion of physician–patient interaction in its effort to promote the patient's best interest "against a background relationship of trust",⁹ which, potentially emerges from a consideration of the principle of beneficence. Although this is a major principle of medical ethics, it is usually not applied to the context of informed consent.

AUTONOMY AND BENEFICENCE?

Owing to the principle of beneficence, the physician is first and foremost obliged to establish a relationship with the patients to understand their best interest. This knowledge seems to be a necessary precondition of any application of the principle of beneficence. In discussing which risks and benefits of the procedure in question could be especially relevant for each patient, the standards of informed consent offer the chance to better get to know the patients, their moral beliefs and social structures. Only then is the physician able to support the patient in weighing possible benefits and harms and in making a decision of substantial autonomy. Keeping beneficence as well as respect for autonomy in mind when obtaining informed consent implies also that the physician abstains from persuading the patients or determining their best interest. In this scenario both principles do not conflict, but complement each other in producing a more meaningful informed consent.

In cases where the patient is not sufficiently capable of decision making, both the principle of beneficence as well as the principle of respect for autonomy require that the physician makes every effort to find out what the patient could wish and what could be the best interest of the patient. In this situation, again the standards of informed consent offer the chance to better accomplish this obligation through establishing a meaningful and trusting relationship with the patients and their surrogate decision makers.

Obviously, these standards are left weakened when a patient moves from one physician to the other, never allowing a trustful relationship to develop nor to understand the best interest of the patients. At such a point, the proposals for strengthening informed consent may very well turn out to be mythical. If the rights of patients are discussed, it is essential to talk about ways of establishing physician–patient relationships. Informed consent is a needed and potentially helpful tool of clinical practice. It should, however, be understood in terms of autonomy and beneficence to avoid paternalistic actions as well as one-sided legal interpretations, suited only for cases of malpractice.

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