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BIOETHICS

H. Baumgartner and F. Gerstenbrand (Innsbruck - Vienna):

PATIENTS UNABLE TO GIVE LEGAL CONSENT

The patient's „informed" (or better: „valid") consent is a basic legal prerequisite for every medical intervention (and pivotal for any good patient-doctor relationship). However, many patients in neurology and psychiatry are incapable of consenting legally. Such „vulnerable" persons receive special protection by specific laws, rules and regulations.

Reduced capacity or inability to consent is encountered in routine medical practice. In cases of children (parents and guardians as proxy, depending on maturity of minors); in patients with cognitive impairments; in apallic patients; in patients with severe progressive or terminal disease; in patients in intensive care: consent has to be obtained from the person, authorized to make decisions on his/her behalf. In emergency situations „presumed consent" is the basis for medical action. However, „advance directives" („living will") play an ever increasing role. All these measures are attempts to ensure that the rights, integrity and dignity of a person not able to consent are not violated by medical interventions. As surrogates for an autonomous decision, these instruments suffer from intrinsic shortcomings.

In clinical practice it is often the responsible, treating physician, who becomes the protector of the incapacitated patient. Health policy decisions resulting in insufficient funding and lack of facilities and services (e.g. insufficiency of hospital beds or of qualified personnel) can make it impossible to provide adequate medical care, including palliative care. For some patients, especially those with long-term needs, there might only be minimal basic support resulting at worst in slow „euthanasia" by neglect. The discrepancy between what should be possible and what is actually available (due to scarcity and/or allocation of resources), can be extremely frustrating. Demographic developments and changes in family structure compound these problems. Some patients are even abandoned by their next of kin. Under such circumstances decisions at the end of life and decisions about ending life by withdrawing or withholding treatment, euthanasia or medically assisted suicide become particularly contentious [1]. The medical profession has a particular responsibility in a pluralistic democratic society to strive for the best possible protection and care of incapacitated patients by influencing political decisions, e.g. relating to resource allocation. Neurologists and psychiatrists have to voice their concerns in public, if necessary, and become advocates of their patients, who are no longer able to claim for their own interests and rights.

Research in persons unable to consent presents special ethical, legal and social challenges: the conflicting demands of advancing medical knowledge and protecting research subjects can be particularly difficult. Emergency treatment was hampered in the US by very restrictive regulations until recently. However, recognizing the need for emergency research, a waiver of informed consent for participation in certain specific research activities has been possible in the US since 1996 [2]. This can be seen as an encouraging example demonstrating that medical experience and needs may positively influence the conditions for research.

Article 17 (Protection of persons not able to consent to research) of the Council of Europe's „Convention on Human Rights and Biomedicine" addresses the complex issue of research on patients not able to consent. It has become one of the most hotly contested elements of this legal document (which attempts to harmonize a European position) [3].

In *article 20* the above Convention deals also with the possibility of „the removal of regenerative tissue from a person who does not have the capacity to consent" (the recipient has to be a brother or a sister of the donor) [3].

Genetic testing - particularly if done on those not able to consent or dissent - is another area with challenging issues not only for the medical profession but for all members of society (*chapter IV*, human genome [3]).

The dramatic progress in medicine and biology and the financial restraints in the health sector call for a common effort to deal with the ethical, legal and social impacts of these developments [4]. It is up to the medical profession to make sure that

Underprivileged groups, like some neurological or psychiatric patients, do not become the victims of health care „reforms",

Ethically sound research [5] does not exclude patients unable to consent.

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Dr. H. Baumgartner, Inst.f.Biochem.Pharmakologie, Peter Mayer Str. 1, A-6020 Innsbruck, Prof. Dr.med. Franz Gerstenbrand, Past-President, European Federation of Neurological Societies, Vienna