

ETHICAL ISSUES IN NEUROLOGICAL RESEARCH AND PRACTICE

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Progress in biology and medicine, scarcity of resources, demographic developments, the political changes on our continent and the process of "globalisation" precipitate important ethical, legal and social issues.

Ethical issues in neurological research concern:

- new therapies: drug research, research on medicinal products and devices, somatic gene therapy, especially in persons not able to consent; research on the human embryo and fetus (including pre-implantation diagnosis and in vitro fertilisation); transplantation research including xenotransplantation and implantation of human tissues in the central nervous system (eg. embryonic and fetal tissue)
- new diagnostics: development and testing of new diagnostic tools, predictive genetic testing (pre-implantation diagnosis; ante- and postnatal genetic diagnosis, genetic counselling); obtaining and using material for tissue and organ banks;
- research into the mechanisms of disease: risk/benefit issues, participation of patients unable to consent; (potential) consequences like: prediction, prevention, eugenics

General ethical issues in research include: Upholding the principle of justice challenged currently e.g. by conducting research in poor countries for the benefit of wealthy countries or populations ("exportation of risk"); assuring adequate quality and safety standards (risk/benefit assessment – East vs West), confidentiality and data protection; conducting genetic testing (non-discrimination; appropriate counselling) and doing research on vulnerable groups (e.g. patients not able to consent; emergency research) and on vulnerable populations.

The current dramatic disparity between east and west makes it an ethical imperative for the research community to respond adequately by building and maintaining "bridges" between the affluent and the transition countries by e.g. establishing research, training, exchange and travelling grants and scholarships.

Current ethical issues in neurological practice include:

- resource allocation and adequate medical care: Unbalanced health policy decisions in rich countries supporting glamorous high-tech/high visibility interventions at the expense of long-term care services (resulting at worst in slow "euthanasia" by neglect); in poor countries even acute care might not be available for many neurological patients and equitable access might not be possible;
- Withholding of therapy and/or withdrawing life preserving measures and/or discontinuation of life support systems; medically assisted suicide and euthanasia;
- Advance directives (living will)
- Palliative treatment in terminal neurological disease, care for the moribund patient;
- Organ transplantation (brain death, selection of donor and recipient; "organ traffic"; commercial aspects), tissue transplantation (safety issues; procurement)
- Implantation of stimulating systems
- Genetic testing, its consequences and adequate counselling.

The Council of Europe's recent Biomedicine Convention defines the basic principles of a European concept "for the protection of human rights and dignity of the human being with regard to the application of biology and medicine". However human rights and human dignity have currently a quite different meaning in different part of this continent. Ten years after the disappearance of the political division of Europe the profound inequality in the availability of health care has created a new and much less visible division of this continent. The health care systems serving about 350 million citizens of the former "socialist" countries are in some of these countries under sever stress depriving many of basic medical support. This situation calls for international cooperation. In neurology this could perhaps be done through international partnership programs between neurological societies, institutions and/or individuals.

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