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Editorial note

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Ethics Support in Clinical Practice

Status Quo and Perspectives in Europe

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WELCOME ADDRESS

Ladies and Gentlemen,

First, I would like to thank you very much for your kind invitation to attend this important conference.

You are meeting at the time when the health system has become a preferred topic of the media, of public discussions, of the daily life. The importance of the reforms, however, should not push to the background hot problems of the medical science. And this – apart from other circumstances - is why our thanks and appreciation go to those who have spent efforts to convene this conference.

The ethical dimension is of no less importance than other aspects of the care of the patient. Today's medicine is characterised by rapid progress, by perfect technologies, while at the same time forgetting that we treat the human being who not only needs recovery of his/her body but also his/her soul. Dignity, rights and needs of the patient must be primary to the doctor and should prevail over any other reasons. A kind word, empathy, support... These are the medicines that cannot be purchased anywhere or replaced by anything else.

Let me touch upon an accentuated topic such as our current reform laws. The present system of health care provision is far from operating, as it should. This is felt by not only doctors, health insurance funds, but by the patients themselves.

The reform, as approved by our parliament, means a principal change, indeed. It is something never seen before. It is my firm belief that it will help. Health insurance funds will transform into shareholding companies. State will keep the ownership of the two largest insurance funds, the General Health Insurance Company and the Common Health Insurance Company. The management and the activities of the health insurance funds will be under the control of the Health Care Supervision Authority. Priority and thus fully reimbursed diagnoses include 6000 illnesses. The government will determine the rate of the co-payments for other diagnoses. The Emergency Services Act provides for reaching any patient by the ambulance within 15 minutes of placement of the call. Although the reform has been approved, we still are at the start of our path. Laws will have to be implemented and practical problems eliminated. In my opinion, we have succeeded in laying first-class and up-to-date foundations. The outcome should be a functioning system, satisfied patients, prospering providers, and efficient insurance funds.

The crucial characteristics of laws are their political neutrality and universality. They contain an 'instrumentarium' applicable and usable by any political party or coalition in force to be able to implement its health policy.

Let me wish your event much success. No doubt, it will be a professional contribution for all of those who are present; and will help establishing new contacts, both professional and social.

Dr. Rudolf Zajac
Minister of Health of the Slovak Republic

INVITED LECTURES

ETHICS SUPPORT IN CLINICAL PRACTICE IN EUROPE - SITUATION OVERVIEW

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In order to inform the discussions at the meeting on ethics support in clinical practice held in Bratislava in November 2004, the Council of Europe's Bioethics Department sent a short questionnaire on the topics to be covered by the meeting to the representatives on the Steering Committee on Bioethics of each member state of the Council of Europe.

The central topics of the meeting were the implementation of the Council of Europe's legal instruments in bioethics in practice, and the availability of clinical ethics support services and training in ethical issues. The availability of such services and training may be relevant to the implementation of the ethical principles set out in instruments such as the Convention on Human Rights and Biomedicine in clinical practice.

It is important to remember that the implementation of an instrument does not only depend on that instrument being reflected in the law of a member state; that is only a first step. The more complex aspect of implementation concerns ensuring that the requirements set out in the law are actually implemented in daily clinical practice. For example, a law may specify, in accordance with the Convention on Human Rights and Biomedicine, that where a person has the capacity to give consent they must give free and informed consent to any medical intervention (subject to very limited exceptions, for example in the field of mental health). However, ensuring that free and informed consent is actually given by every patient to every medical intervention is a far more complex matter. Still more complex is assessing the extent to which daily practice in all parts of a country is in conformity with the law.

The purpose of the questionnaire was to gain an impressionistic picture of the situation in each country. It cannot be said to be a scientific study. As noted above, it may be difficult for anyone, particularly in a large country, to assess accurately the situation in clinical practice in all parts of the country. Therefore the responses to the questionnaire were intended to form a starting point for the discussions at the meeting, and it was anticipated that the participants would complement that information with their own perspectives on the situation in their country.

At the time the questionnaire was sent out in July 2004, the Council of Europe had 45 member states (Monaco has subsequently become a member). Twenty states responded to the questionnaire, twelve of whom were also represented at the Bratislava meeting. This paper summarises the responses received to the questionnaire.

As noted above, fully effective implementation of the Council of Europe's bioethics instruments required their principles to be put into effect in daily clinical practice. For this to happen, clinicians need to be aware of the in-

struments. However, in only one respondent country was the level of awareness of the instruments considered to be good. In most countries, awareness was considered to be variable and in six countries awareness was considered to be low.

The main reason for such low awareness was considered to be due to a lack of wide dissemination of the instruments, mentioned by 17 countries. However, in most cases this was not due to the lack of availability of translations in the local language, which was regarded as a problem in only seven countries. Seven countries also responded that the instruments were already reflected in their national law, of which clinicians were aware. Six countries suggested that clinicians did not see the instruments as relevant to their daily practice. Why this was the case was not clear, and this was one of the findings that would benefit from further exploration.

It is perhaps not surprising, given those findings, that 16 of the respondent countries indicated that there were practical difficulties in implementing the instruments in their countries. Although insufficient awareness of the instruments at local level was one of the most frequent reasons given (cited by ten countries), the same number of countries also reported that issues related to availability of resources (which would include both personnel and services) gave rise to implementation problems. Less commonly cited reasons concerned awaiting Government decisions on signature or ratification of relevant instruments (by seven countries), and unspecified public concerns by four countries. Seven countries also indicated that there were difficulties in the practical application of the instruments, and again this would be a finding that it would be useful to explore further.

A range of measures were suggested by States to help address the difficulties. The production of further written material to support implementation was suggested by 14 countries. It was suggested that different material might be needed for different audiences e.g. doctors or policy makers. Material that provided further explanation of the instruments or provided examples of successful implementation in practice was suggested. In addition, national or regional meetings to discuss and publicise the instruments were suggested by 11 countries. Other suggestions included the preparation and dissemination of training programmes in the field of bioethics.

The availability of systematic training for clinicians concerning ethical issues increases the likelihood of clinicians recognising the ethical dilemmas that may arise in their clinical practice. The training should help to provide an appropriate framework to analyse the issues underlying the dilemma, and therefore contribute to finding a reasoned approach to resolve it. The second part of the questionnaire therefore investigated the availability of such training in the Council of Europe's member states.

At this stage, we focussed purely on training for doctors. The need for training in ethical issues for all health care professionals is increasingly recognised, but historically most attention has been paid to doctors in this regard. Therefore, it seems unlikely that in any country other health care professionals would receive more training than doctors on these matters.

States were asked to give their impressions of how many doctors received training in their country at undergraduate and postgraduate level on ethical issues. **Tab. 1**

Tab. 1 Doctors receiving training on ethical issues (20 countries)

	All doctors	Most doctors	Some doctors	No doctors
Undergraduate level	5	6	6	1
Postgraduate level	0	3	15	1

shows the number of countries indicating each response.

It appears that training is more systematic at undergraduate than at postgraduate level at present, but even at that level training is not universal in most of the countries who responded.

We also asked for an impression of the extent to which doctors regarded their training as sufficient. People who perceive their training as insufficient may be more inclined to seek training to rectify this deficiency and may welcome the development of training programmes. Of course, assessing the views of every doctor in a country on this issue would be difficult, so the answers given can only be regarded as impressionistic. Nevertheless, no respondents thought that all the doctors in their country considered themselves to have had sufficient training; and indeed three countries considered that no doctor in their country would regard their training as sufficient. The remainder of the responses fell between these two extremes.

Information was also sought on the availability of training at national level which might enable doctors to overcome insufficiencies in their training. Only three countries reported that Masters degree or diploma programmes dealing with clinical ethics issues were available. Such programmes demand a very high degree of commitment from participants, and are unlikely to be appropriate for all doctors. Short programmes (for example of 2-5 days) may be a more practical approach for the majority of practitioners. A practitioner might attend a range of such short courses, or be able to supplement such a course by home study. However, only 14 of the 20 respondents thought that such short courses were available in their country. Home study materials were even less available, being reported in only seven of the 20 countries.

Over the last thirty years, the concept of clinical ethics support services has gradually developed. Such services can take a range of forms: examples include the use of a clinical ethics committee (perhaps the most common mechanism), or the use of a clinical ethicist. Clinical ethics support services can fulfil a range of functions. These include providing ethical input into the formation of guidelines or policy on ethical issues in clinical care in a hospital; contributing to staff education on ethical issues; and performing individual case consultation or case review. Therefore, the purpose of such services is to provide some form of assistance to clinicians in relation to the ethical issues raised by clinical practice.

In the questionnaire, we sought information about the availability of such services in each country. Four of the twenty respondents indicated that such services were widespread in their country; ten respondents indicated that such services existed in some areas of the country only; and four respondents indicated that such services were not available. However, in this area the responses to the questionnaire were somewhat inconsistent, in that eighteen of the twenty respondents indicated in response to a different question that clinical ethics committees did exist in their country. In conclusion it seems probable that the availability of such services is variable across Europe. The majority of the respondents to the questionnaire considered that further development of such services was desirable.

At present the use of a clinical ethics committee (CEC) appears to be the most widespread form of clinical ethics support service, eighteen countries reporting between 1-200 CECs in those countries. Six countries reported the use of theologians to provide clinical ethics support, with between "a few" and 100 theologians per country being so used. Three countries reported the use of an ethicist, with between 6-15 ethicists per country being used to provide clinical ethics support.

Sixteen of the twenty respondents considered that a Council of Europe activity to develop the use of clinical ethics support services would be helpful. All sixteen re-

commended the use of bilateral or regional meetings concerning the development of such services or which provided training for members of CECs. Fifteen respondents also considered written material would be helpful.

A range of different materials was suggested, including Recommendations of the Council of Europe, manuals for personnel, state of the art overviews on key issues, bulletins concerning recent developments and discussion of cases, and the dissemination of the experience, problems and solutions found in different countries.

The range of ethical dilemmas that arise in clinical practice is broad. We therefore sought views on which topics it would be most useful to initially focus on in any future work. Respondents were invited to give up to three priorities. As can be seen in **Tab. 2**, end of life issues were considered as a priority by the majority. A wide range of other issues were raised by one or two respondents each.

Tab. 2 Topics regarded as priorities by respondents

Issue	Number of respondents prioritising issue
End of life	12
Embryo/medically assisted procreation	9
Resource allocation	6
Autonomy/consent	4
Doctor-patient relationship	4
Psychiatry	4

In conclusion, the exploratory questionnaire indicates considerable variability in the availability of training in clinical ethics and in clinical ethics support in the responding countries. At the same time, clear difficulties in implementing the Council of Europe's legal instruments dealing with bioethical issues were identified. The aspiration to improve the situation was widespread, and the possibility of a Council of Europe action in this area was strongly supported.

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CURRENT ETHICAL DILEMMAS IN CLINICAL PRACTICE IN EUROPE

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Introduction

Clinical ethics committees and other forms of clinical ethics support have been developing in several European countries over the past ten years (Le Beer, Moulin 2000, Slowther et al 2001). While in some countries the development of clinical ethics committees has been driven by government or management directive, in other countries clinical ethics committees have been a response to the perceived need of clinicians for support in dealing with ethical dilemmas arising in their day to day work. For clinical ethics committees to be responsive to the needs

of both clinicians and patients they need to understand the types of ethical dilemmas that arise in clinical practice, and the context that frames the dilemma. Sharing experience of ethical dilemmas and ethics support between European countries may help the development of effective ethics support in a changing social and cultural environment. This paper makes some tentative suggestions as to what are the current ethical dilemmas facing clinicians in Europe as a starting point for further discussion and empirical work in this area.

The situation in United Kingdom

Ethical issues in clinical practice have received an increasingly high profile in the United Kingdom (UK) in the past few years. It is possible to find a news story related to some aspect of clinical ethics almost every week in the national press. These include reports of court cases where there is disagreement between parents and doctors over the use of life prolonging treatment in very sick children (Re Wyatt 2004), new legislation on the use of human tissue obtained at post mortem (following a inquiry into retention of organs without the consent of the next of kin) (Human Tissue Act 2004), challenges to the General medical Council's ethical guidance to doctors on withholding and withdrawing life prolonging treatment (Burke v General Medical Council 2004), and questions of using preimplantation genetic diagnosis to select 'donor siblings'. In 2000 a national survey of all health care organisations in the National Health Service (NHS) identified the development of clinical ethics committees (CECs) in a small but growing number of NHS trusts (hospitals or other health care provider organisations) (Slowther et al 2001). Since 2000 the number of CECs has increased from 20 to 70, with 25% of all acute trusts now having a CEC (Slowther et al 2004). In 2001 the UK Clinical Ethics Network was established to facilitate dissemination of information and sharing of best practice between CECs and to promote education of CEC members. The network has a website (www.ethics-network.org.uk) that is accessible to anyone, and which provides a wide range of information and links to guidance on ethical issues in clinical practice. Of particular relevance to the European context is the international section of the website which publishes information about development of clinical ethics committees in other countries.

The Network offers a unique opportunity for us to obtain regular information about the frequency and type of ethical issue that clinicians refer to CECs in the UK. Box 1 shows the type of dilemmas considered by CECs in 2000, while Box 2 shows similar information for 2004.

Dilemmas considered by CECs 2000 ^[1]

- Confidentiality/consent around HIV testing.
- Refusal of life saving treatment.
- Refusal of spouse to give permission for life saving treatment because of patient's previously stated views.
- Request from relatives not to divulge distressing information to a person with learning disability.
- Use of restraint to allow appropriate treatment.
- Relatives requesting information about patients.
- Conflict between medical team and parents over use of CPR in severely disabled children.
- Withdrawal of treatment.

^[1] Slowther et al, 2001.

Dilemmas considered by CECs 2004

- Conflict between parents and medical staff over treatment of seriously ill children.
- Patient refusal of potentially life-saving treatment.
- Patient refusing nutrition because of a wish to die following CVA.
- Request for assisted conception with a history of self harm.
- Disclosure of genetic information to an adult child when the parent is incompetent and his wife objects.
- Decisions about termination of pregnancy for foetal abnormality.
- Use of expensive novel treatment for individual patients.

The situation in other European countries

Both published and anecdotal evidence from other European countries suggest that the ethical issues facing clinicians in the UK are common to clinicians elsewhere in Europe. An interview study with general practitioners in Sweden found that the common ethical issues identified included medical futility, priority setting and cultural clashes (Bremberg et al 2001). A postal survey of medical directors in German University hospitals identified limitation of treatment, informed consent and conflict between beneficence and autonomy as the most relevant ethical issues in everyday clinical practice (Thielle 2005). A review of papers published in the *Journal of Medical Ethics* from European countries other than the UK revealed that the most common ethical issue discussed in a clinical context was end of life decision-making, with some discussion of rationing of expensive care (Krizova), and of disclosing diagnoses to patients (Pucci). A recent survey in four European countries also suggests that end of life decisions are among the most difficult ethical issues facing clinicians. (Hurst et al personal communication). Other issues that are likely to be of concern to clinicians across Europe are the relatively new areas of genetic testing and assisted conception, and the related issue of abortion.

Specific dilemmas in clinical practice

In this section I will briefly look at three areas where clinicians face ethical dilemmas, and give some examples to illustrate how these issues may translate into specific dilemmas in practice.

End of life issues: This area covers a range of issues in which clinicians may be faced with difficult decisions that involve, among other things, interpreting the law (for example on euthanasia and physician assisted suicide), dealing with family disagreements, and making judgements about quality of life. Moral questions about the sanctity of life, the right to life, respect for autonomy and fairness to other patients will underlie many of these decisions. Examples of dilemmas around end of life issues that might face a clinician include:

- Determining when, if ever, it is no longer in the patient's interests to continue life-prolonging treatment.
- Parents refusing to allow discontinuation of treatment for their child when the clinician considers the treatment is harmful or futile.
- Parents refusing treatment for their child when clinicians consider the treatment is life saving.
- Competent patients refusing life prolonging/sustaining treatment, for example a patient refusing

tube feeding after a cerebrovascular accident because they do not want to continue living in a disabled state.

- Competent patients requiring treatment that clinicians consider harmful or futile, for example a patient who is in the final stages of terminal cancer requesting that she has cardiopulmonary resuscitation in the event of a cardiac arrest.
- Trying to determine the previous wishes of an incompetent patient when different members of the family give conflicting views.

Scarcity of resources: The need to make decisions about health care in the context of resource scarcity is common to all health care systems. The specific decisions may vary depending on the overall level of available resource, for example questions about funding an innovative anti cancer treatment or diagnostic procedure may not be relevant in a country where the health care budget cannot fund basic treatment for all its citizens. However, the ethical issues involved in making these decisions are common to all countries, and raise dilemmas for both health care managers and individual clinicians. These issues include balancing the need for treatment against the benefit gained by treatment, determining the boundaries of the duty of care owed by health professionals to patients and the population as a whole, the conflict between individual patient care and population health, and addressing health inequalities. These issues translate into very real dilemmas in clinical practice. For example:

- What do you do when your intensive care unit is full and a patient is admitted to the hospital who requires intensive care?
- How do you decide which patients will receive renal dialysis when there are not enough dialysis machines for all patients who might benefit from treatment?
- Should we spend our resources on more coronary artery bypass grafts for patients who already have ischaemic heart disease, or on statins for everyone with a small increased risk of developing ischaemic heart disease?
- Should we turn patients away from our hospital or clinic because, due to staff shortages, accepting more patients would compromise the care of our existing patients?
- What weight should be given to the interests/needs of health care staff?

Conception and pregnancy: The ethical concerns facing clinicians in the area of conception and pregnancy include those commonly raised about abortion, including the sanctity of life and a woman's right to self determination. They also include questions raised by recent advances in assisted conception techniques and genetic diagnosis, including questions about the nature of disability, the use of embryos and the rights of parents to select their children's characteristics. Examples of dilemmas faced in clinical practice include:

- What degree of foetal abnormality would justify terminating a pregnancy in the third trimester?
- Should a couple with three daughters be able to select a male foetus for implantation during IVF?
- Should a woman's husband be told if genetic testing, done for other reasons, reveals that he is not the father of the child?

Cultural and religious perspectives

While the evidence would suggest that there are many similarities in the type of ethical dilemma arising in clinical practice across Europe, it is also likely that the way in which these dilemmas are identified, articulated

and resolved will differ to some extent between countries or regions. Religious and cultural norms will influence, for example, the degree to which individual choice, rather than beneficence or social justice, is seen as the dominant ethical principle governing health care. Also concepts of disease, disability and quality of life may be defined differently in different cultures. A few empirical studies in North America have identified differences between ethnic groups in values and perspectives relating to health care decisions, particularly decisions around the end of life. Many European countries are ethnically diverse, and cultural norms are being challenged with greater movement of people between countries. There is a need for comparative studies of ethical issues in different European cultures to inform the development of ethics support for clinicians and health care providers across Europe.

Conclusion

Health professionals in clinical practice throughout Europe commonly experience ethical dilemmas. There are many similarities in the type of ethical issue facing clinicians but there are also likely to be some differences in both the type of issue encountered and the way in which the dilemma is perceived in different social, cultural and economic settings. There is much to be gained by sharing experience of both ethical dilemmas and ethics support for clinicians between European countries, and by collaborative research to develop a better understanding of the key ethical issues in the context of a culturally diverse European community.

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Clinical Ethics Committees and Ethics Consultation in German Hospitals. In Slowther A, Johnston C, Goodall J, Hope T. A practical guide to clinical ethics support. Oxford. The Ethox Foundation, 2005.

Note

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Abstract

The need for clinical ethics support is increasingly recognised by clinicians and health services across Europe, and many countries already have clinical ethics committees. The range of ethical issues for which clinicians may require support is likely to show some similarity across countries, but differences in the frequency and type of ethical issue will also be seen, related to cultural, economic, and systematic differences between countries. In this paper I consider some of the common ethical issues faced by clinicians, drawing on my knowledge and experience of the UK situation, and informed by discussions with other European colleagues. I consider some specific examples to illustrate general issues, and suggest some possible areas of difference that will be important in addressing clinical ethics support in a European wide context.

Key words: ethics, clinical practice, Europe, end of life, resource scarcity

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CLINICAL ETHICS SUPPORT SERVICES IN EUROPE ^[1]

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Introduction

This paper is primarily based on the final report of the BIOMED II project *Ethical Function in Hospital Ethics Committees* (1999-2002), an European Commission's concerted action [1].

It presents a very brief summary comparing the various situations of clinical ethics committees in our European reference area (nine European countries: Belgium, Denmark, France, Greece, Italy, Norway, Spain, Sweden and the United Kingdom) and more especially the main debates this comparison elicited in this small circle of experts [2]. All the questions under discussion in this field will not be reported. Nevertheless the differences that

sparked lively discussions in our group of experts highly reflect current issues in the institutionalisation of ethics in medicine. Indeed, all the questions whether they concern, for instance, the composition of ethics committees or training for their members revolve around the more fundamental issue of the role, attributions and responsibilities of ethics committees and thus their present and future capacity to effect deep-seated transformations in medical practice.

The European clinical ethics committees: a great variety of formula

Denmark is the only partner country that does not have clinical ethics committees (CECs). The eight others do have CECs although only two have accorded them legal status: Belgium and Greece. In these two countries, in fact, the hospital ethics committees are "mixed", with a dual mission to supervise research and address questions raised by clinical activities.

The other countries vary in the extent these structures have been institutionalised. In Spain, a Commission of INSALUD (the Spanish National Institute of Health, a network of 80 public hospitals) had approved some 20 hospital committees by the end of the concerted action period. In Norway, the creation of regional ethics committees in 1985 resulted in the disappearance of the hospital committees. A gap in the system, however, became apparent and the Ministry of Welfare and Health decided to conduct a study based on a triple experience with clinical ethics committees. This study, lasting from 1993-1998, led to recommendations to establish a CEC in each major hospital.

In France, Italy, Sweden and the United Kingdom the CECs seem to have been established spontaneously. They may be "specialty" committees, like some in France and Italy. Our Italian partners, for instance, were members of the ethics committee in the paediatrics department of the University of Padova hospital. Similarly, some British assisted conception centres have their own ethics committee. Nevertheless, the "spontaneous" committees are usually "trans-specialty" dealing with the range of healthcare practices and hospital policy.

France holds a special place in the clinical ethics landscape. The network of Parisian public hospitals (Assistance Publique – Hôpitaux de Paris or AP-HP) in 1995 set up an innovative and trans-hospital structure: the *Espace Ethique* (Ethics Forum). It is an original place of study, analysis and comparison that focuses on thought about the ethics of care and hospital practices, with all the economic and social issues involved. In particular it fosters the creation of thematic reflection groups ("Groupes Miramion") composed of healthcare professionals and outside experts to think about the hospital. These groups exist for the period of the reflection process, then they disband, start up again or are replaced by other groups. The *Espace Ethique* also fulfils an educational mission, and in this area are similar to many other European clinical ethics committees.

Multiplicity of functions

While the scopes of the research ethics committees do not seem burdened by ambiguity and are relatively homogenous throughout Europe, the same cannot be said for the clinical ethics committees. But what are CECs exactly? The European CEC is first and foremost a body for reflection. It can also fulfil other functions, essentially drawing up guidelines in hospital policy and, more rarely, direct assistance in decisions.

In Belgium where, we recall, the CECs are inseparable from RECs, recent statistics show that over four out of five questions handled by the Belgian hospital committees concern the examination of protocols, and that only a small portion of the questions deal with assistance to decisions [3]. In the "mixed" Belgian - and Greek - committees, clinical ethics has drastically receded, literally overwhelmed by tasks related to research ethics. To counteract this effect, some hospitals doubled up the function by creating a sub-committee dealing more specifically with matters of clinical ethics. This "demotion" of clinical ethics or the fear of this happening is not felt solely in Belgium and it leads many observers to recommend a clear distinction between the two structures. This separation would thus not be founded on principles - there is no fundamental difference in the ethical goals pursued by research and clinical ethics committees - but rather on the practical experience of the "mixed" committees.

The European CEC is primarily available for the hospital's practitioners, occasionally families (for example the CEC in a paediatrics department), and sometimes - but this is rare - for patients. This last case was cited in Spain. In some Spanish hospitals the patients can apply to an ethics committee, but most often only after a filtering-body has sorted the patients' requests into those admissible for an ethics reflection and others assimilated to complaints which are heard by a completely different body. The CEC audience rarely goes beyond the hospital grounds - only when it has itself been established on an external basis, such as the French *Espace Ethique*.

CECs frequently work to draw up guidelines. This is particularly true for the CECs created at the initiative of hospital management. In some countries, such as Belgium, management is a *persona non grata* in the CECs. Neither the administrative management, nor the medical or nursing directors can belong, so as to not inhibit the expression of the committee members. In Norway, management participation was under discussion. In Italy, however, particularly in the ethics committee of the Padova University paediatrics department, management is closely associated with the work of the committee. This involvement is justified by the idea that you can never truly expect to modify hospital practices without the practical and symbolic support of management, on the one hand in terms of realism and organisational competence and on the other for political legitimacy. This management involvement does not necessarily have to be as full-fledged committee member, which experience shows can also adversely affect the freedom of discussion. Other schemes exist, the most usual being to invite management at strategic points of the discussion and thus to preserve the committee's autonomy in the opinions it hands down.

Ethics consultation

The mission of *a priori* assistance in medical decisions is fairly rare in the European CECs. This does not mean, however, that it cannot be ensured in another form such as an individual "ethics consultant". This institution is well-known in the United States but also found in some European countries, Sweden in particular. The "ethics consultant" institution has its proponents and detractors. The proponents see the ethics consultant as a lightweight, mobile structure that can be mobilised at any time, especially in an emergency. It is thus favoured by those who conceive a hospital's "ethics" function as directly associated with medical decision-making. This formula usually has a major implication: the ethics consultant is a specialist in medical ethics. This is why the partisans also favour professional specialist training. This

view, dominant in the United States, is far from unanimous in Europe.

The detractors of "ethics consultation" - whether entrusted to one person or a committee - hold up several reasons. Some feel that proclaiming a specific competence in ethics runs the risk of encouraging clinicians to consult the expert(s) on any occasion, especially in the present context of increasing pressure by society regarding the responsibility of the medical corps. This itself entails the risk of divorcing medical practice from its essential ethics component, calling into question the time-honoured relationship between the doctor and patient founded on the therapeutic pact. Others also state that the doctor's power of decision, as a power, is thus considerably undermined. Refusing the "ethics consultation" function and the notion of ethics expertise that it implies is thus justified by the concern to recognise the doctor's ethical competence or even moral authority. Another category of detractors prone the same type of arguments but this time - and the difference is essential - not from the doctor's perspective but from the ordinary citizen's. For these critics, ethics is not the domain of specialists but is a matter for us all since ethics deals with the wish to say something about the final meaning of life, as Wittgenstein stated [4]. Consequently the designers of the Norwegian project considered it crucial to recognise a "non-expert grounding" for ethics: the ethical review is primarily based on a non-expert foundation in regard to experience and virtue. In their eyes, training in ethics is nevertheless important but cannot be a *sine qua non*. This perspective is clearly more consistent with a notion of the ethics committee as a reflection body (possibly on an individual medical decision but in this case *a posteriori*) and/or as the producer of general guidelines rather than a partner in medical decisions *in vivo*.

Diverging views on the committees' composition and training

The antagonism between the positions for or against a concept of the ethics committee assisting medical decisions and ethics as a specialised competence has repercussions at two levels: training for committee members and the role they accord themselves in this area, and the composition of the committees, in particular the participation of lay people.

We can thus describe initially the divergence between two types of stances: one favourable to specialised ethics competence at the service of a medicine in quest, the other favouring a collective non-specialised competence built on discussion and addressing the equally collective issues of a medicine questioned first from the outside. In the first stance the committee members are doctors, nurses and paramedical staff providing support to an ethicist who must be present. A legal expert may participate as well but this is not obligatory. In the second stance the committee is open to multiple points of view - philosophers, sociologists, legal experts, psychoanalysts,... along with lay people or "public representatives". This last category is nevertheless problematical, even for those in favour. For who exactly can "represent the public"? Members of political parties, as in Denmark and Sweden? But in this case the notion of personal membership as a representative of humanity is replaced by a collective membership representing special interests. The "man in the street"? But how to choose such a person? Haphazardly or on the basis of criteria, and then which criteria? These questions are still open.

We could then schematically group the following positions under one category: first, the view that an im-

portant function of an ethics committee is to offer assistance in medical decisions that remain to be taken, the recognition of a specialised ethics competence, the need for *ad hoc* qualifying training, the ethics committee's contribution to the training process, the presence of a duly trained ethicist and discounting the need for a lay point of view, in other words outside scientific, clinical, philosophical or even legal references. This schematic type can then be opposed to a second set of positions: that an ethics committee is first a body for reflection on the generalities of medical practice, especially in relation to its social, political and economic context, the position of principle whereby ethics cannot be the territory of a particular social group, an interest in training but not as a condition for ethical reflection, an ethics committee not seen as a forum for ethical expertise and which can thus not claim to be one of specialised training - in this case the term would rather be "awareness function" -, the concern for the broadest diversity in viewpoints, with the presence of lay members symbolising the points of view of other members of society on the whole.

This schematic description certainly offers a pertinent grid to interpret the reality of the European CECs. But it is merely schematic and only reflects broad types of positions. The divergence it illustrates only quite partially covers the variations actually found among the partner countries of our project. In some countries the divergence can be pertinent, not to describe and compare in block one national system with another, but to illustrate the internal tensions within a single country. In Belgium, in fact, the two opposite positions can be found: although regulated by law the ethics committees can actually serve two contradicting purposes. The "spontaneous" nature of the way clinical ethics committees were created in some countries obviously means that their goals and activities can reflect highly diverse concepts - this is highly probable in France and also likely in the UK as well.

A hypothetical relationship could be seen between strong medical authority and resistance towards forming an ethical expertise that proposes - or even claims the right - to intervene in medical decisions, and inversely between contested medical authority and affirming an ethics specialty, as in the United States. In Europe the situation is more complex. The Spanish committees set up by the INSALUD Commission are quite comfortable with a medical context that is still extremely dominant. As it happens, however, when these committees were set up one condition was that the creators follow a clearly specialising training. And this is still a prerequisite for any new ethics committee. In this system, ethics expertise is thus clearly affirmed and assumed. In other countries, however, the medical establishment is extremely reticent to forms of institutionalised ethics that would undermine its dominance. Denmark has no clinical ethics committees. France has local committees that are not recognised by law where doctors are largely in the majority. Belgian law recognises hospital ethics committees, but almost all of them merely deal with the bureaucratic aspects of protocols. As such, some may say that the European ethics committee structures are either barred to the outside or at best co-managed by a homey alliance between a strong medical authority and a new group called: the ethicists.

Paths to ethical inventiveness

This analysis, however pertinent it may seem to some people, nevertheless does not fairly reflect two concomitant processes. In the first place, in the interstices of the various institutionalised ethics systems we can find extremely innovative initiatives under development, spaw-

ned more by premises of a political nature than drawn from the specialised corps of medical ethics. Furthermore, at the heart of the medical profession, practitioners are increasingly open to a critical reconsideration of their practice, a reconsideration which both draws from and leads to an ethical reflection. In some countries, like Belgium, hospitals over recent years have set up new bodies for ethics reflection, in parallel with the official committees. The professionals behind these new bodies are disappointed in the official committees and many hold what sociologists term "dominated" positions in the hospital structure: nurses, psychiatrists, geriatrists, palliative care staff, etc. In France, the doctors participating in the *Espace Ethique* accept, in a context other than that of their workplace, to place themselves on equal footing with other hospital professionals and with actual or potential patients - something they are hardly used to in their daily practice. The subjects raised in these groups frequently touch on macro-social dimensions extending beyond hospital walls. And we should not forget that the *Espace Ethique* was created by the Parisian public hospital system. A recent work by the *Espace Ethique* director is entitled "The hospital revolution. Democracy in healthcare"...[5].. a programme and manifesto. Training for hospital staff is at the heart of the *Espace Ethique's* mission. This training consists in a series of conferences primarily cultural in scope; the aim is not strictly qualification in terms of acquiring operational skills. The UK is experiencing an exponential rise in the number of CECs, a phenomenon that interpolates us. For our British partners it may well be that the Clinical Ethics Committees in the UK can gradually grow into bodies for emulation and monitoring, and someday possibly even mandated to guarantee the respect of people's basic rights.

Patients' rights

We have here a new notion of the clinical ethics committee. No longer a body at the service of the patients through the auspices of a medical profession wishing to become more ethical, or via a public debate forum on the aims of hospital practice, but rather a place for observation and incitement at the service of the patients in the respect of their basic rights. This vision obviously calls into question the consultative nature of the clinical ethics committees, a task on which the countries of Europe have pragmatically agreed until now. Indeed, it is somewhat hard to imagine how a committee observing major infringements on basic rights would not have the possibility, in other words the authority, to impose respect of these rights. If the committee is to have this authority, however, it must receive a public mandate along these lines which ensures at least the necessary independence from the hospital structure. And Europe is far from taking this step. As we have seen, few countries have granted a legal status to the CECs. Many observers feel that this mission, if granted to CECs one day, is in total contradiction with a mission of reflection. Few practitioners would be ready to submit an ethical problem for discussion by a committee that would then have a direct or indirect legal authority to sanction, in other words to what could well be called a potential "medical practices court".

A biomedical citizenship?

Europe presents a mosaic of situations. This variety in the extent to which clinical ethics has been institutionalised cannot be explained simply. It is a combination of several causes: power of the medical corps, weight of religion, legal system, cultural representations about medi-

cine, the political and economic organisation of the health care system... This analysis is still largely to come.

The disparities between the various models of clinical ethics committees have arisen from different concepts regarding the institutionalisation of ethics in medicine: assistance to medicine, reflection beyond the strict medical field, protecting the rights of patients. Neither do the partner countries of our European project clearly line up along either side of the issue. The disparities tend rather to illustrate internal tensions, as if all the partner countries experienced this conflict in the different notions, albeit to various extents and in variable configurations. The clinical ethics committees, at the onset seemed full of inventive promise, opening the health care system to external and multiple points of view, thus renewing with the with age-old concern to recompose a humanist project for medicine. Some people have seen ethics committees as opportunities to render reflections more democratic, to establish public fora for thinking on medical ethics. If we continue to accept more and more the idea that "what affect the body, health, well-being and happiness, suffering and death is a political matter" [6]., then there is perhaps a chance to see the setting up of a real "biomedical citizenship" [7]. Will clinical ethics committees play some role in this process?

Notes and References

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Abstract

The paper presents the main debates that have taken place on clinical ethics committees within the European project entitled *Ethical Function in Hospital Ethics Committees*. It depicts the great variety of formula existing in Europe in terms of legal status, functions, accessibility, composition and training requirements and at the onset of clinical ethics concept itself. Moreover, in the interstices of the various institutionalised ethics systems we can find extremely innovative initiatives under development, spawned more by premises of a political nature than drawn from the specialised corps of medical ethics. Could clinical ethics committees play some role in the overall democratisation process in medicine?

Key words: ethics committees, clinical ethics, health care policy, medical power, professional and organisational ethics.

THE CHALLENGES FOR CLINICAL ETHICS EDUCATION IN EUROPE

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1. General overview

The development of clinical ethics education in an European perspective represents an interesting and relevant challenge in this historical moment. There is an increasing role of bioethics in health care institutions and in society, with many initiatives of debates, publications, guidelines and bio-legislation.

And one urgent thing is the education of people involved not only in the theoretical cultural debates but in practical-clinical decisions, particular in the hospital context. Therefore, there is the problem of: how can clinical ethics education be organized? Which goals and target? What is the meaning of an European dimension of it?

The goals of clinical bioethics education are seen as threefold. Firstly there is a cognitive goal; to provide the theoretical knowledge and analytical abilities needed to recognize and manage ethical issues. The second goal is a practical goal; to develop professional skills and close the gap between ethical theory and principles and ethical reasoning in practice. The third is an attitudinal goal; to promote tolerance, acceptance of diversity and to create an awareness of the special circumstances of the sick.

The experiences of bioethics education tend to be provided at three levels. At undergraduate level a more general approach to bioethics is offered that may include both medical and non-medical students. Post graduate education may be formal, usually at advanced degree or doctorate level, or part of continuing professional development, either in the form of a course in clinical bioethics or through experience gained by sitting on a clinical ethics committee. Two of these postgraduate approaches - a Masters programme in bioethics and the experience gained in developing a Hospital based bioethics programme - are considered in more detail in this presentation.

2. The European Master in Bioethics ^[1]

This Master has been designed to offer an intensive introduction into health care ethics, specifically giving attention to European philosophical and theological traditions in this area. The focus is on the practical health care settings, paying emphasis on multidisciplinary comparison and exchange of ideas and experiences between participants and teaching staff. The two years Master programme is shared in four residential months, close by the European Universities of Nijmegen, Basel, Leuven and Padova. The main topics covered include: human and clinical genetics, palliative care, public health and prevention, treatment decisions, ethics and reproductive technologies, ethics of care, religion and bioethics, research ethics, clinical ethics.

Up to now, the Master programme has successfully completed two full intakes. In **Fig. 1** and **2** the team student compositions are given. We can see that not only the number of students has been increased in the second edition but also participants came from different cultural and professional backgrounds.

The diversity can be considered a value especially in order to achieve the main goal of the programme, that is practical experience. In fact, at the end of the Master programme, participants are required to write a publishable paper on a particular bioethical subjects, under the supervision of one professor of the programme. Besides participants should undertake some concrete experience in order to provide an exposure to some of the daily realities of clinical and research ethics. In this way the theoretical knowledge, which have been acquired during the Master, can be integrate with specific attitudes, with the aim to find a useful application in a clinical context. So there is a permanent contact with the clinical practice and the effort to improve the European dimension visiting four European Centres, knowing literature and legislation in Europe, discussions...

3. The European Hospital (- based) Bioethics Programme ^[2]

Hospitals bring together a variety of professional and non-professional groups in the place where clinical dilemmas are daily events, and would seem ideal places to conduct an ongoing bioethics dialogue yet evidence that is being achieved is sparse.

The European Hospital (-Based) Bioethics Program (EHBP) brings together eleven partners of ten countries of the EU in a project that aims to access the current situation as regards bioethics education in hospitals, identify any short falls and address these.

This initiative is an ongoing project financed by European Commission under the Fifth Framework Programme, and involves 10 European Hospitals (in France, Germany, Italy, Lithuania, the Netherlands, Poland, Portugal,

the Slovak Republic, and United Kingdom).

The goals of the EHBP are in summary:

► to survey the participant countries regarding current hospital-based educational programs in clinical bioethics
► to elaborate a model of a basic bioethics course
► to test the model in the hospitals of countries participating in this project involving all hospital professional workers
► to collect, analyse and interpret data from the test model concerning the contents and the methodology that has been applied
► to produce a didactic textbook detailing the basic course.

It has been laid stress on the importance of hospitals as places for bioethics education. Besides, a common framework on clinical bioethics has been planned to encourage the exchange of ideas and experiences, supporting also the development of clinical bioethics in the new State members of EU.

This project has allowed to know the situation of Western and Central-Eastern European countries concerning the Educational Programs on Clinical Bioethics in Hospitals with particular reference to contents and methodology of existing seminars and courses (**Tab. 1**).

Curricula for post-qualification training has until recently not contained any substantial ethics component. The provision of bioethics education in hospital varies from country to country and from institute to institute. The most initiatives are lectures or seminars and very few hospital have well structured comprehensive programs. In fact, courses tended to be more advanced or specialised nature. Most interested professions are nurses and doctors, other health workers did feature but less so. With regard to methodologies, case analysis, lectures/discussion, literature review, role-play and self directed study are most frequent. The main topics are principles of professional ethics, physician/nurse-patient relationship, patient rights, organ transplantation, genetics, consent, research ethics, palliative care.

Unfortunately initiatives are often patchy and sporadic. Besides, there is less interdisciplinary approach and a lack of uniformity in education: in fact some professional have very little knowledge and a few have a lot. Training in ethics differs widely between groups in content and orientation. There is not any clear body responsible for the investigation of teaching in bioethics. However there is evidence of the wish to improve the present situation and provide ethics training for staff.

Work is ongoing on the next stage of the project, to analyse the results of the model course tested and develop it further with the production of a supporting textbook/sourcebook.

The final version of the course will include the following subjects:

► introduction to bioethics
► principles and methodologies in clinical bioethics
► bioethics, deontology and law
► relationship between health care professionals and patient
► allocation of resources
► clinical ethics at the beginning of life
► clinical ethics at the end of life
► hospital ethics committees and research ethics committees.

Fig. 1 EUROPEAN MASTER IN BIOETHICS - FIRST EDITION (2000-2001)

Number of participants: 15

Countries:

- Europe (11: Italy, Belgium, Germany, Portugal, The Netherlands, Spain)
- Israel (1)
- Egypt (1)
- USA (1)
- Peru (1)

Professions: physician (9), lawyer (3), priest (2), health care administrator (1).

Fig. 2 EUROPEAN MASTER IN BIOETHICS - SECOND EDITION (2002-2003)

Number of participants: 21

Countries:

- Europe (17: Italy, Bulgaria, Germany, Croatia, Belgium, Switzerland, The Netherlands, Sweden)
- Canada (2)
- Colombia (1)
- China (1)

Professions: physician (14), nurse (1), lawyer (2), priest (2), philosopher (2).

	Response rate (%)	Symposia	Seminars	Introductory courses	Advanced courses	Specialised courses
Italy	28%	9	10	1	7	3
Netherlands	32%	4	3	3	0	0
France	69%	25	17	25	21	18
Portugal	40%	Sporadic	Sporadic	0	0	0
United Kingdom	69%	63	12	11	0	13
Germany	43%	12	21	15	4	8
Slovenia	44%	Sporadic	0	0	0	0
Slovak Republic	23%	Sporadic	0	0	0	0
Poland	65%	21	7	3	3	7
Lithuania	71%	15	8	0	3	5

The textbook/resource book will contain chapters designed to support teachers in providing the basic course, and will include annexes with some of the more important texts from the bioethics literature, particularly European, as a basis for discussion.

Ethics is on the political health agenda in many countries and is increasingly being formalised as part of the decision-making processes in health care. For this reason it seems timely to try to formulate a common base for the provision of bioethics education to European healthcare workers. In light of the gap in the provision of bioethics training in hospitals revealed by the survey, the EHBP group plans to identify the fundamental requirements of bio-ethics education to create a common basic educational program covering essential ethical concepts and some common issues, with a supporting textbook. Training projects that will fit the practical constraints on hospital workers will be proposed, helping ethics to be seen not only as an important subject in itself, but also a useful instrument to make daily choices about health care. Bioethics education may be oriented to the clinical experience of all health workers (not only students), opening minds to critical comparison and sharing experiences among people from different cultural and professional backgrounds. Increased mobility of health care professionals within Europe requires these professionals to discuss and debate health care and bioethical issues within a common framework. In fact, there are already some successful attempts at 'European harmonisation' in ethics; although these trends are strongest in research, they are beginning to occur in clinical care as well.

4. Projects for the future

The sorts of questions that still need to be considered are: who should attend bioethics training, what structures should be involved, what is the best model and methodologies to use?

The challenges for the future are:

- to address these questions in order to improve education in bioethics throughout the multidisciplinary team and to encourage dialogue between the diverse countries within (and beyond) Europe;
- to develop experiences of continuing professional education (e.g. EHBP: common contents, methodologies, bibliography);
- to improve the interdisciplinary approach among all the workers in the medical field;
- to develop trainings on clinical cases (discussion/resolution).
- workshop or seminars on specific topics in each hospital units (intensive therapy, oncology...);
- to improve activity of Ethics Committees, Services of Clinical Bioethics and Bioethics consultation;
- to create a common base of contents, skills in bioethics and methodologies, working together for a "European Harmonisation".

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Notes

- [1.] Further details can be seen at: www.masterbioethics.org
- [2.] Project coordinators secretariat: cinzia.montagna@sanita.padova.it

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Abstract

The experiences of bioethics education tend to be provided at three levels. At undergraduate level a more general approach to bioethics is offered that may include both medical and non-medical students. Post graduate education may be formal, usually at advanced degree of doctorate level, or part of continuing professional development, either in the form of a course in clinical bioethics or through experience gained by sitting on a clinical ethics committee. Two of these postgraduate approaches - a Masters programme in bioethics and the experience gained in developing a Hospital based bioethics programme - are considered in more detail in this presentation.

Key words: clinical ethics, education, Europe, bioethics, hospital, clinical practice

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COUNTRY INFORMATION

ALBANIA

Jona Mati

◆ Ethics support in clinical practice

The principles of bioethics in Albania are contained in the Deontology Code, and implemented in the provisions of certain laws, such as the law on transplantations, etc. The National Committee of Medical Ethics and Bioethics, and the Medical Doctors Association are the only organizations in Albania dealing with bioethical issues. These institutions started to function during the last ten years only. So far, they play a limited role, and are not able to deal with the ethics violations in medical environment. Lack of promotion of the ethical norms among medical doctors is evident. Normally, this would be a duty of the the Medical Doctors Order.

At present, there are no specific structures in the hospitals that can supervise or promote medical ethics. Among the main ethical dilemmas in Albania, there are the lack of respect for the rights of the patient, and also for the basic ethical principles. In this context, there is an obvious need for awareness-building among medical doctors, and for a greater promotion of respect concerning the duties derived from the Deontological Code. To help doctors to become more conscious about the importance, and practical consequences of the respect for ethical norms, a support of the NGO engagement in these type of activities, and the implementation of the National Ethical Network are necessary.

◆ Professionals' education and training in clinical ethics

Training of medical professionals in clinical ethics represents an important problem. It does not need to be emphasized that the overall lack of ethical training during the university education is evident in Albania.

The ethical and deontological principles are studied at the faculty of medicine in the context of legal medicine or medical history courses.

At the faculty of law, there is no department that would teach medical ethical issues, or medical and health law.

The students' awareness on the importance of bioethics education, and of medical ethics education are both a goal, and a challenge in Albania. It lacks systematic training of the medical and paramedical professions on ethical issues.

◆ Suggested Council of Europe activities

The National Committee of Medical Ethics and Bioethics would welcome the support of the Council of Europe, in order to face the above mentioned problems. Following activities would be especially welcome:

- Organizing of workshops to debate clinical ethics issues, in particular by analysing of concrete cases, in order to continuously train the medical and paramedical professionals, and to inform a multidisciplinary professional public (lawyers, journalists, sociologists, etc.).
- Development of the undergraduate and postgraduate bioethics programs at the university.

- Organizing of promotion activities for awareness building concerning ethical and bioethical norms for the students and medical staff.

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ARMENIA

Igor Madoyan

◆ Ethics support in clinical practice

Unfortunately, there is no experience concerning ethics support in clinical practice in Armenia.

◆ Professionals' education and training in clinical ethics

National Center on Bioethics of Armenia elaborates the plan of actions on education in bioethics of specialists in jurisprudence, sociology, philosophy, medicine, biology, international affairs. With help of our Russian colleagues (e.g. Prof. B. Yudin) we would like to prepare short courses (20 hours) for correspondence faculties of some Universities in Yerevan.

◆ Suggested Council of Europe activities

We would need an assistance from the concrete European country with a rich experience in this field to establish ethics committees in Yerevan's hospitals. We are also in a great need in the textbooks on bioethics in the national or, at least for the beginning, in Russian language.

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CROATIA

Božidar Vrhovac

◆ Ethics support in clinical practice

According to the *Law on health protection* (issued in 1997), every health care institution (without giving details) should have an ethics body composed of 5 members. The more recent amendment of the law (2003) says "at least 5 members".

A survey on ethics committees was done in 2003. A questionnaire was sent to 241 health care and other institutions (including faculties of medicine, veterinary medicine, dental medicine, and pharmacy, as well as various professional chambers - medical, dental, pharmaceutical). Altogether, 75 institutions answered. In 11 of those an ethics committee exists. Members of these committees are mostly health professionals, but there are also 'medical laymen', such as a lawyer, priest, economist, etc. The members are often university professors. The activity and regularity of committee's meetings are variable.

The clinical (hospital) ethics committees usually have

their meetings once a month (on average). They mainly discuss the clinical trial protocols that have been before that discussed and accepted by the hospital drug committees. Ethical questions concerned with a lot of existing problems (e.g. impolite behaviour of health professionals towards patients, colleagues, corruption, etc.) are much less or never discussed. Ethics committees in the scientific institutes, and university faculties discuss mostly the ethical aspects of research projects.

From the description given above, it could be inferred, what **activities of the Council of Europe** may be especially helpful in improving the existing situation. I believe, a document describing the aims, duties, and functioning of such (clinical ethics) committees could help the interested persons in the country (not very numerous) as an argument in their efforts to persuade those responsible about what should be changed, and how. A survey, sponsored by the Council of Europe, could also be useful, but in many member states the local situation is already well known – Croatia could serve as a typical example of this – but the willingness to change, or improve it, is mostly lacking.

◆ **Professionals' education**

Education in the field of (bio)ethics is insufficient in Croatia.

The National Bioethics Committee (members of which have just been changed by the government of Croatia) started last year the annual meetings of clinical ethical committees. It was planned to organise such a meeting every year. The first one was successful indicating interest for ethical questions and problems existing everywhere.

It is obvious that education of members of local ethics bodies in the first place, and than the education of health professionals in general, is very necessary, if not mandatory. The undergraduate students have a number of lectures concerning ethics during the whole curriculum. Some postgraduate studies have a few hours devoted to ethics (e.g. postdoctoral study, course of clinical pharmacology and toxicology at the Medical School in Zagreb). More discussions and problem solving of actual or simulated cases should be included into these activities.

Council of Europe could help here by writing a recommendation on how should, optimally, education of the mentioned parties be organised. Of course, some printed educational materials, drafted in the European perspective, would also help teachers in performing their educational roles better.

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CYPRUS

Maria Demetriou

◆ **Ethics support in clinical practice**

Cyprus is actually in the beginning in dealing with formal issues concerning bioethics. Having in mind that the Cyprus National Bioethics Committee is only 2 years old, this is understandable.

What the National Bioethics Committee aims is to promote research ethics committees. But regarding ethics support in clinical practice as such, there is nothing on the air at the moment. This role is undertaken partly by the National Bioethics Committee, which foresees in the

development of such services. The hospital authorities in co-ordination with the relevant professional bodies could set these up.

It is therefore clear, that clinical ethics support services need to be developed in the nearer future. Such services could be established with the **assistance of the Council of Europe** in means of meetings, aiming in the training of their members. Another useful activity could be the dissemination of other countries' experiences, problems and suggestions in that direction.

◆ **Professionals' education and training in clinical ethics**

Doctors' education depends on where medical professionals have studied. Since the University of Cyprus has no Medical School for the moment, there is no uniformity in the knowledge of clinical ethics among them. Still the medical faculties at the universities abroad offer such knowledge at undergraduate and postgraduate level.

Therefore, professional knowledge in clinical ethics depends on the professionals' background and their own initiative. What is available for increasing such knowledge is just suitable information from the local libraries and Internet access to information.

It would be helpful if some key persons in clinical practice could study at a degree level of diploma in clinical ethics, in order to anticipate any challenges, and act as support reference for other professionals. At the same time it would be wise if short courses could be held for a wider participation to increase awareness among professionals in clinical ethics. It would be also helpful if conferences were held at local level with the **assistance of the Council of Europe** to promote clinical ethics in Cyprus.

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ESTONIA

Tiina Talvik

◆ **Ethics support in clinical practice: present state and current needs**

In Estonia, the problems of ethics support in clinical practice are not sufficiently solved, in spite positive development of the understanding of the needs of knowledge in medical ethics in everyday clinical practice.

During the last three years, medical ethics is included in the undergraduate curriculum of medical students. Teaching is planned during the first grade (confidentiality, informed consent etc., altogether 40 teaching hours: 24 hrs lectures, and 16 hrs practical work; teaching is supervised by the Department of Public Health) and students should sign the confidentiality agreement after the course and before the beginning of clinical studies. We believe, however, that additional teaching concerning medical ethical problems related to clinical practice is necessary in the 5th or 6th grade. This is because the involvement of students and their understanding of clinical ethical problems are certainly better after some clinical experience.

Medical ethics in clinical practice is a small part of the bioethics course contained in the curriculum of PhD. students (80 teaching hrs), and this subject is one of the

compulsory examinations (also supervised by the Department of Public Health).

Due to the recent changes, we hope that young doctors are even better informed on ethical problems than some more experienced senior colleagues already in clinical practice.

The first ethics committee in Estonia was established at Tartu University already in 1990, and this was the very first one in the Baltic region (the first chairman was professor A. Tikk, at present the Committee is chaired by professor L. Allikmets). A general agreement exists in Estonia from 1991 that biomedical research committees (in accordance with the Act on Medicinal Products) should approve all biomedical research, including drug clinical trials.

For ethical decisions in clinical practice, we have clinical ethics committees in two big hospitals only – at the Tartu University Hospital (chaired by Prof. A. Tikk) and at the Tallinn Children's Hospital (chaired by Prof. A. Levin).

Estonian Council on Bioethics, as the national ethics committee, was founded at the Ministry of Social Affairs in 1998 to co-ordinate the bioethics activity in general.

To control and evaluate the ethical problems in the framework of the Estonian Genome Project, the Council of the Estonian Genome Project Foundation established a special ethics committee in 2001.

During the last 4 years, Professor A. Tikk has been very active (together with other specialists from our country) in organising advanced courses on bioethical issues for our doctors. The courses have been very popular, which also could be seen as a sign of need in education in bioethics.

What we need:

1. Implementation of additional teaching at the undergraduate level.
2. Implementation of regular advanced courses for members of existing research and clinical ethics committees and creation of the rules/regulations for these committees and committee members.
3. More frequent seminars and conferences in clinical ethics for clinicians of different specialties.
4. International workshops on special topics with specialists from other countries are needed (with possible help of the Council of Europe). For instance, DEBRA Project of the Council of Europe to develop the research ethics in Eastern and Central Europe has been very effective. Our suggestion is to create similar project for clinical ethics.
5. To organise regular advanced courses with special presentation of complicated cases by the participants for discussion and decision-making for special groups of doctors:
 - doctors/nurses from intensive care units,
 - neonatal units,
 - neurologists (progressive neurodegenerative disorders),
 - psychiatrists.

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Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

Convention on Human Rights and Biomedicine, Article 1

ETHICS COMMITTEES IN GREECE

Tina Garanis-Papadatos

In Greece, many attempts have been made regarding the establishment of ethics committees. The first attempt took place in 1965, at the Institute of Child Health. This Committee suspended its function in 1981, due to the political instability, and started its work again in 1990.

Other attempts followed in 1973 with Legislative Decree 97/1973 (section 2, paragraph 6), which concerned mainly the approval of clinical drug research, and in 1978 with a Ministerial Circular (A2/oik3061/5.6.1978), which imposed the establishment of ethics committees at a local level.

In the early nineties, the **National Council of Medical Ethics and Deontology** was established (Law 2071/1992 on the "modernization and organization of the National Health Service", which was initially established in Greece with law No. 1397/1983). The Council's main objectives included participation in forming the general policy of the Ministry of Health and Welfare on issues of medical ethics and deontology, handing down opinions on all such issues, consultation to settle disagreements in local ethics committees, and the establishment of the Centre of Medical Ethics.

The same law 2071/1992 also provided for the establishment of **local ethics committees** in public as well as in private hospitals and clinics. The tasks of these committees, which by law have five members, include consultation on issues of medical ethics to governing boards of the hospitals or the clinics, as well as monitoring the respect of related rules and principles. It is only very recently that this Council has been actually activated. Until now, however, it has not dealt with ethics committees, as in the meantime other pieces of legislation have addressed this issue, though partially.

A recent law (No. 2889/2001 on the "improvement and modernization of the National Health Service") has been enacted in order to decentralize the management of the health care system and to ensure the public character of the National Health Service. Under this law, the country is split into healthcare regions corresponding to the administrative regions. The new law provides for ethics committees. As far as the *regional level* is concerned, section 2 paragraph 6 states that a Scientific Council, which is established in each Regional Health Service, is responsible, among other things, also for the establishment of the **ethics and deontology committee**. As far as the *hospital level* is concerned, section 5 paragraph 11 states that in each hospital the Scientific Council, which is established, also has the responsibilities of the ethics and deontology committee.

On the national level, some new bioethics committees have emerged, stimulating the general interest in this field.

The **National Bioethics Commission**, whose mission is to explore the ethical and legal impact of the possible applications of biological sciences. This Committee does not examine research protocols but a part of its role consists of outlining, in collaboration with the respective ministries, proposals of general policy and of providing specific recommendations on related issues.

The **Bioethics Committee of the General Secretariat of Research and Technology**. This Committee also has a general role regarding opinions towards the Ministry of Development, public debate on biomedical issues and funding of research.

Greece has also signed and ratified the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and*

Medicine (Council of Europe) which has been incorporated into domestic law (Law 2619/98).

Moreover, *Directive 2001/20/EC regarding laws and regulations relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use* has become domestic law in Greece, with a Ministerial Decision issued by both the Ministries of Health and Finance (Ministerial Decision DYC3/89292, State Journal B' 1973/31.12.2003) regarding the harmonization of the Directive with national law. This decision applies to clinical trials including multicentre studies on human subjects. Its scope does not include non-interventional studies.

According to this decision, the ethics committees of the Regional Health Councils, will provide expert opinion regarding every proposal towards the newly established "National Committee on Deontology of Clinical Trials", which will finally decide on the approval of the project.

Editorial note: This contribution was provided in writing, as the personal attendance of the author had not been feasible on the dates scheduled for the conference.

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LITHUANIA

Eugenijus Gefenas

- ◆ **What is my country's situation concerning ethics support in clinical practice?
What are my country's needs in this respect?**

Evaluation of Lithuanian HECs

Anonymous questionnaire was distributed to Lithuanian HECs in the beginning of the year 2000. We will provide a summary of the results relevant to the ethics support in clinical practice. [1]

The number of HECs. There were 117 questionnaires distributed - 62 of them (53%) were returned. It appeared that 56 HECs were established, 6 institutions still did not have established HECs. The majority of HECs (47) were established from 1996 to 1998. Only four HECs were established in 1998.

Frequency of HEC meetings. 67 % HECs reported meetings on ad hoc basis. We could just extrapolate the average number of meetings from other answers: once a year 4% of HECs, twice a year 11%, four times a year 16%, every month 2%.

The most frequent cases. It is important to analyze the most frequent cases referred to HECs. It appeared that most often HECs were asked to resolve difficult situations related to hcp - patient relationship as well as the conflicts between hcp themselves (e.g., refusal to participate in the round with the chief of the department, being crude to the patient and the like). What could be called as an "inadequate behaviour" of the health care staff was also a rather typical example of the cases referred to the HECs (e.g., bribery, providing information about the deceased to the funeral company).

It seems therefore, that health care ethics is still conceptualized in Lithuania, and probably in many other European transition societies, differently as compared to the Western societies. It is easy to see that the cases most often reported and dealt with by hospital ethics committees have usually not been difficult end-of-life decisions, refusals to accept life-saving interventions, or controversial cases of allocating scarce biomedical resources (the

cases usually referred to the hospital ethics committees in Western Europe or USA), but rather intra-professional disputes among health care providers, conflicts between health care practitioners and patients in cases of negligent behavior, malpractice, or bribery. If we conceptualize health care ethics as a critical reflection on moral values and norms directing the development of life sciences and, in particular, influencing the delivery of health care, we might end up with a skeptical conclusion that bioethics is still at the crossroad to find its place in the European transition societies. To facilitate its development, training programs at both graduate and post-graduate level should be significantly strengthened.

- ◆ **What is my country's situation concerning professionals' education and training in clinical ethics?
What are my country's needs in this respect? [2]**

Based on the European Commission Project "European Hospital (-Based) Bioethics Program", a survey of educational activities at health care institutions was conducted in Lithuania in 2003. The survey revealed a few tendencies, such as:

- in the hospitals the most common educational activities are lectures and seminars;
- the methodological means used are most often lectures/discussions, case analysis and role play;
- usually these activities are organized by the management unit of the hospital, hospital ethics committee or the Faculties of Medicine (or Medical schools);
- most often these educational activities take place 4-5 times per year.

It should be noted that there is a strong need to strengthen and introduce a systematic postgraduate training on health care ethics.

Even though there are several books translated into Lithuanian (e.g., Rogers A., Bousingen D. D. *Bioethics in Europe*; Wulff H, S. A. Pedersen, R. Rosenberg. *Philosophy of Medicine*; H. A. M. J. ten Have, R. H. J. Meulen, E. van Leewen, *Medical Ethics*), which provide a basis for training, there is a need to publish a special textbook on clinical ethics relevant to health care professionals.

Notes

[1] (For a detailed interpretation of the results see E.Gefenas: Is "Failure to Thrive" Syndrome Relevant to Lithuanian Healthcare Ethics Committees, HEC Forum, No. 4, 2001, pp. 381 - 392.) [2] It should be noted that the following comments do not cover undergraduate teaching of medical ethics /bioethics for students studying at the Medical and Nursing Faculties of the universities.

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ROMANIA

Octavian Doaga

- ◆ **What is my country's situation concerning ethics support in clinical practice?
What are my country's needs in this respect?
What could the CoE do to help?**

Dealing with ethical problems in medical practice in Romania is usually considered to be part of everyday duties of medical doctors. That's why in every hospital there is an Institutional Ethical Committee (IEC). It is supposed to deal with cases considered to exceed the limits

of regular procedures. Reporting of such cases, or decisions adopted is not compulsory. Therefore, it is rather difficult, or almost impossible to monitor such activities at the national level.

Even though the ethics reviewing system in medical research is already regulated in Romania (since 1997) according to the European standards, there is still no legislation on IEC activities.

The bioethics principles are introduced into the Medical Deontology Code. Every practising physician has to (or is supposed to) know them, and he or she has to be prepared to act accordingly. The 'upgrading' of the Code is the task of the Romanian College of Physicians and its regional chapters. To help in this endeavour, there exists the Bioethics Committee with an advisory role.

The Ministry of Health and Family is working at present on a new law project concerning ethical support of IECs in medical practice.

Accordingly to the international recommendations, in Romania, there were already adopted laws on patient rights, personal data protection, organ transplantations, and very recently, the law on human embryos and genetic materials.

Frequently, the 'ethical dilemmas' in Romania are related to the fact that a medical doctor, who is supposed to work with minimal or rather insufficient medical supplies, has a responsibility that is too much challenged. This is made even worse by another big issue: the underpayment of health professionals in general. These problems are more economical and social in nature, and need to be dealt with by an increased Government's attention and involvement in the future.

For the moment, the level of interest among patients regarding their rights or major ethical principles is still very low. We believe, however, this will quickly improve in the near future. The number of malpractice trials is increasing in Romania. This is not related to the fact that medical doctors become more incompetent, but to the fact that people are more interested in protection of their rights.

We believe that increasing doctors' awareness about possible consequences of their misjudgement in making ethical decisions may be very important in the near future. Such debate among medical doctors at local, and also at the international level should be encouraged and helped. There are some activities that to our opinion may help in this respect:

- stimulation of the involvement of NGOs in this area,
- development of concrete projects focused on improvement of IEC activities,
- support in developing of a national ethical network,
- encouraging a stronger interest and responsibility of authorities in surveillance and dealing with bioethical problems within drafting and legislation procedure of IEC law that is actually in its project phase.

◆ **What is my country's situation concerning professional's education and training in clinical ethics?
What are my country's needs in this respect?
What could the CoE do to help?**

Biomedical ethics departments were recently introduced in almost every Medical University in Romania, but the attendance of education activities is not always compulsory. Faculty of Law, University of Bucharest has also a Medical Ethics Department.

At the university level, there is a lot to be done for increasing the impact of bioethics education among medical students. We may need support in:

- developing undergraduate and postgraduate training programs in bioethics,
- increasing the international mobility of students and teaching staff involved,

- encouraging the organisation of national and international meetings, conferences on bioethics with a multidisciplinary attendance: physicians, philosophers, jurists, biological scientists, etc.

◆ **Possible activities of the Council of Europe**

1. Encouraging the establishment of a surveillance system for IECs at the national level by a concrete help in developing and introducing the appropriate regulations.

2. Support in dissemination of the information on bioethical principles among caregivers by help in production of printed materials, or 'advertising' video clips.

3. Support in dissemination of the information on ethical principles and patients' rights among the citizens by help in producing various awareness-building programs using different mass media channels.

4. Encouraging of NGOs' involvement in the activities mentioned sub 2 and 3.

5. Encouraging of funding and other help provision for the projects focused on the development of medical ethics networks at the national level.

6. Organisation of more international bioethics meetings and providing financial support for participants from eastern European countries on a selective basis (level of impact and interest in medical ethics).

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RUSSIAN FEDERATION

Pavel Tischenko

◆ **Ethics support in clinical practice**

Ethical support in clinical practice is at the very beginning stage of its' development. We have Russian National Committee on Bioethics in Russian Academy of Sciences, Ethical Committee of Russian Ministry of Health Care, and several other committees related to regional academic or health care authorities. They work on ad hoc basis, have no official status. Meetings are very rare; decisions have no sound influence in clinical practice. To some extent a good exclusion from this rule is Ethical Department of the Volgograd Center of Academy of Medical Sciences organised by Prof. Natalia Sedova. This department has trained personal. Its' status is established by administrative policies of the Center. It works at regular basis, and in spite of usual difficulties, has some influence (still not sufficient) in clinical setting.

Medical centers and hospitals that have programs in clinical trials had organised their research ethics committees (unfortunately most of them in a paper form). There is no evidence of their activities.

I think that in existing situation development of clinical ethics committees has questionable perspectives. The basic obstacle is unresolved conflict between official self-description of the Russian health care as universal in access and free of charge, and real commercialisation in a lot of areas (particularly in surgery). There are no laws that regulate commercial medical services, and because of this, no good legal basis for physician - patients relations. And, what is also important, in most cases money for development of commercial services come in from unjust redistribution of scarce public resources into private sector. Understandably - medical authorities are not rea-

dy to be open to public observations of procedures of distribution of resources in hospitals, as well as at the regional and national levels of health care system.

We have some perspectives in development of research ethics committees. But without new legislation on experimentation on human subjects that will match basic principles of European Union Convention on Bioethics this could be very difficult.

Growing influence of patients groups, increasing number of suits in courts against physicians, development of research and education in the area of bioethics and medical law gives some moderate hope of progress.

The basic need of Russia is to come to understanding – what kind of health care system it would like to have not only as desirable, but also affordable for existing level of economic and political development of the country.

We also need more cooperation with European colleagues, some resources for participation in international services, and resources to buy literature and to pay for subscriptions for bioethical journals for individual scholars and libraries.

◆ **Clinical bioethics education of health care professionals**

Bioethics is an obligatory discipline for medical students. We have official program of teaching adopted by The Ministry of Health Care. Students study bioethics during the second year of their stay in medical schools (32 hours of lectures and seminars). Nurses and other medical professionals have no obligatory courses. There is teaching of bioethics in some schools for nurses. There is no postgraduate teaching of bioethics.

We need more textbooks in bioethics, and special programs for teaching of teachers in bioethics. Any cooperation with European scholars will be helpful.

There is an unresolved conflict: Who should teach bioethics – philosophers or medical doctors? To some extent, it is a conflict of different ideas of bioethics, to another – a matter of distribution of scarce resources of teaching hours between medical and philosophical chairs in medical schools.

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SERBIA AND MONTENEGRO

Adzivic Omer

◆ **What is my country's situation concerning professionals education and training in clinical ethics? What are my country's needs in this respect? What could CoE do to help?**

Medical ethics as a science is studied in the second year of medical school and deals with medical ethical and legal problems of applying acquired modern medical knowledge in medical practice. In my opinion, as a doctor with long clinical career, medical ethics should be studied in final years of medical school studies, when students are already familiar with clinical medicine. Most of the ethical principles are applicable during the direct contact with the patient.

After graduation, there is a graduation ceremony, when young doctors have to swear to Hippocratic Oath, which contains the resume of basic principles of humanity and

ethics. And after finishing one-year internship following graduation, doctors must take so-called "State exam", which also entails the legal issues concerning the health care system.

◆ **What is my country's situations concerning ethics support in clinical practice? What are my country's needs in this respect? What could CoE do to help?**

Ethics committees or commissions are established at the level of professional organisations like doctors' chambers, doctors' societies, bigger health care institutions and medical schools. According to our health care laws, every bigger health care institution is obliged to found the ethics committee or commission. Ethics committees or commissions are composed of doctors and other caregivers from the same institution and other "non-medical" members. Duties of ethical committees are to analyse the routine practical work of doctors and other caregivers, as well as practice of health care institutions regarding all ethical aspects.

The proof that medical ethics is very important in our community is the fact that many medical books are published and used by students, doctors and other medical workers, doctors' societies, doctors' chambers and health care institutions. I believe that during the socialistic political regime, doctors and other medical workers were more ethically educated and therefore more applying humane moral-ethical principles in practice.

Following the break of the socialistic regime, and due to the well-known events (civil wars, political crises, long-term process of transition and constitution), a bad economic situation and falling of living standards effected negatively the development of health care system. I know that in our country we have important capacities regarding overall development of medical science, and therefore also medical ethics. But, because of the matters that I have mentioned previously, many practical ethical dilemmas are occurring that can only be solved by improving the economy and democracy.

The help that European Union is offering to our country is important and heterogeneous. The most important is a gradual integration with the institutions of European Union in order to attain a full membership. Simultaneously with this process, there is a co-operation with the Council of Europe going on in all domains, also in the domain of bioethics and medical ethics, through the possibilities of implementation of recommendations that are carefully and in details prepared by CDBI.

In order to reach that goal, there should be more consultative meetings, seminars and symposia organised under the sponsorship of the Council of Europe in countries that are yet not the full members of European Union, including the meetings of CDBI, as it is planned for the next year in Dubrovnik.

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An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

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.

The person concerned may freely withdraw consent at any time.

Convention on Human Rights and Biomedicine, Article 5

SLOVENIA

Dusica Pleterski-Riegler

◆ **What is my country's situation concerning ethics support in clinical practice. What are my country's needs in this respect? What could CoE do to help?**

The experience of the National Medical Ethics Committee of Slovenia (NMEC) will be briefly referred to. The NMEC is often approached with questions and dilemmas, to which it responds individually, but often also with a more general published opinion.

The requests for opinion are submitted by clinicians, Slovene Medical Association, Medical Chamber, National Health Council, Minister of Health, Director of National Health Insurance Agency, occasionally by other ministers and MPs, media, NGOs, members of religious communities, general public, individuals.

The following **opinions** have been, *inter alia*, published in the last 6 years:

1. Diagnosing brain death: the third generation of criteria (1998).
2. Ethics of biomedical research on human beings – guideline to proposers of projects for ethical review (1998).
3. On euthanasia and other end of life decisions (1998).
4. The position of the national Medical Ethics Committee on alternative healing practices (1998).
5. Consent and authorisation to treatment and research in paediatrics: the principles of the Oviedo Convention (1998).
6. Patient's consent: ethical questions related to the refusal of necessary treatment, to the choice, withholding or withdrawal of treatment (1999).
7. Ethics in rehabilitation: the gap between the possible and the affordable (1999).
8. On the ethical price of human cloning (2000).
9. Biomedically assisted procreation: where should medicine be told to stop? (2000).
10. Ethical aspects of the 'new' biotechnology (2000).
11. Patient's rights in their terminal illness (2000).
12. Compulsory immunisation of children (2000).
13. Control groups on placebo in psychiatric clinical trials (2001).
14. The embryo in medicine and law: ethical aspects of genetic testing (2001).
15. Ethical questions of costly treatment with new drugs (2001).
16. Ethical boundaries of research in psychiatry (2002).
17. When our patient becomes a dangerous driver (2002).
18. The ethical price of 'therapeutic' human cloning (2002).
19. On refusing non-emergency surgical interventions to Jehovah's witnesses (2002).
20. Ethical problems in organ transplantation (2003).
21. Patient's rights in the last days of life (2003).
22. On medical interventions on the corpse that are not part of routine autopsy, and on treatment of the biological materials of human origin (2003).
23. Ethical review of post-registration clinical drug trials (2003).
24. National regulations on ethics and research in Slovenia (2003).
25. Ethics and scarcity of public health funds (2003).
26. Non-academic medical practitioners intrude into the public health care system (2004).
27. On ethical background and goals of the Slovene

health care reform as described in the White Paper (2004).

28. Ethics of health care in old age (2004).

29. Respect for human dignity in biomedicine: European standards and the Slovenian legal practice (2004).

Other opinions include:

1. Legitimate ways to recruit egg cell donors.
 2. Legitimate sources of human stem cells.
 3. Respecting the right to posthumous confidentiality of sensitive medical data.
 4. MAR with donated egg cells: is it justified in a perimenopausal woman?
 5. Recording personal medical data on the social security electronic card.
 6. Maintaining confidentiality in consultation between doctors of different institutions.
 7. Treatment decisions in severely ill or very premature neonates.
 8. Living will – shape, content, validity.
 9. Treatment decisions in permanent vegetative state.
 10. MAR with donated egg cell to prevent transmission of familial polyposis of the colon.
- In general, the opinions of the NMEC have been well-taken and respected.

◆ **What is my country's situation concerning professionals' education and training in clinical ethics? What are my country's needs in this respect? What could the CoE do to help?**

In Slovenia, such education is part of the undergraduate curriculum in medical studies (1st year – lectures, seminars; and the 5th year), and also of the curricula for nurses and other health professionals.

The **Council of Europe** could organize activities promoting education of teachers concerned with clinical ethics. This could take shape of regional seminars, recommending literature and other educational material for the use by educators, and opening a dedicated web site.

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SLOVAK REPUBLIC

Jozef Glasa

◆ **Ethics support in clinical practice**

Clinical ethics support services at local or regional level are still scarce in Slovak Republic. At present, there are ethics committees in major hospitals and medical research institutes (approximate number of the committees for the whole country: 40-50, more accurate data are so far missing). They occasionally (so far quite rarely) take on the consultation of ethically difficult cases.

The new health legislation (the Law No. 576/2004 Coll. on health care; which enters into force on January 1, 2005) does ask all inpatient health care facilities to have ethics committees to deal with the ethical problems connected with health care provision. Ministry's of Health regulation on ethics committees is under preparation (to be issued under the new law). It is supposed that it will require the registration of ethics committees, and thereby also their fulfilling of certain criteria, newly reset by it (e.g. specific requirements concerning statutes, membership, education and training of ethics committees members, etc.).

The Central Ethics Committee, located at the Ministry of Health, has been much involved in the preparation work on the regulation, and the accompanying guidelines. It also was very active in drafting of the new health legislation mentioned above (especially the chapters on informed consent, ethics committees, biomedical research, transplantation, etc.). It has also been very supportive in developing, or reactivation of ethics committees' system throughout the country (e.g. by organising annual meetings of ethics committees (since 2002), contributing to the journal "Medical Ethics & Bioethics", providing consultations and guidance on difficult cases (either in writing, or as telephone consultations), starting a web page for ethics committees within its own web page hosted by the server of the Ministry, etc.).

Ethics support in clinical practice is felt being a necessary pre-requisite, and of growing importance, for the development and reform of the Slovakia's health care system, which is nowadays undergoing a profound organizational transformation.

◆ Professionals' education and training in clinical ethics

Undergraduate level: Medical ethics is taught as a compulsory discipline at all 3 faculties of medicine in Slovakia (only in one of them, however, a specialized department has been established (Bratislava)). Ethics is also a compulsory discipline within the education and training of nurses, in advanced studies in nursing (M.A., PhD.), and in public health (MPH, PhD.). Teaching activities usually comprise lectures, discussions, small groups activities, and essay writing. Some education materials (texts, textbooks) were produced in Slovak language. The students from abroad, enrolled into the international programmes, are usually taught in English.

Postgraduate level: The availability of training in clinical ethics for health professionals already in practice is still insufficient. There are no specific training programs at the hospital level for doctors, nurses, or other health care workers (1). Seldom lectures, seminars, or small conferences are held in university teaching hospitals settings, or within the activities of the Institute of Medical Ethics and Bioethics in Bratislava (in 1991, postgraduate courses in medical ethics started at the Postgraduate Medical Institute, where the first country's Chair of Medical Ethics was established; these very well attended, popular events, attracting health professionals from all around the country).

In recent years a steady progress is being made in the continuous medical education field, where lectures on bioethics are frequently included into the programs of specialized courses of various medical disciplines, and courses for nurses. The courses on Good Clinical Practice are held regularly at the Slovak Medical University (since 1996). Specific education for members of ethics committees is being prepared and should be offered soon (2005). It will be required by new, pending ministerial regulation on ethics committees.

◆ Possible activities to be supported by the Council of Europe

I believe, the Council of Europe could continue its active role in the field of bioethics, bioethics education, and also the legal collaboration in this important area (see various thematic conferences within DEBRA Program held during the previous decade, program sessions at the recent COMETH meetings, publications supported, etc.).

The activities possibly to be considered for support and encouragement could be listed as follows:

- international meetings (consultations, workshops, conferences), information exchange and networking concerning the development of clinical ethics support services and training of members of such services (e.g. within DEBRA or similar program activities),
- production of a written material, such as information paper on ethics support in clinical practice, and on education of health professionals in bioethics;
- later on, subsequently, production of a recommendation on these topics.

I believe, in a foreseeable future, the problem of ethical dilemmas in clinical practice may become even more prominent agenda on the international stage. Also because of an increasing moral pluralism of the European societies, on the top of the speedy development of medicine itself.

Note

(1) Results of the study undertaken under the "European Hospital-based Bioethics Education Program" (EHBP) - the Project of 5th Framework Program of the European Commission, in 2003.

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MACEDONIA

Zudi Biljali

◆ Ethics support and clinical practice

In the Republic of Macedonia the hospitals have several types of ethics committees:

1. The first one is the Ethics Committee of the Medical Faculty dealing with ethical aspects of clinical research in the domain of publications, projects, drugs, etc.

2. On the other hand a central hospital ethical committee is also in function. This one deals more with ethical problems of everyday work with patients, and possible infringements of their rights. It is of note that the ethical committee also is in charge of reviewing cases of professional conduct (misconduct) of the health care staff. Malpractice is also becoming a very important issue.

3. In addition, some hospitals have their own ethics committees. They deal with following issues:

- ethical questions concerning patients (terminally ill, abortions and the indications for pregnancy termination, especially in the late stages of pregnancy),
- professional aspects of the physician's practice.

The basis for work of these committees is formed by the documents on medical ethics in research, and in clinical practice (e.g. Declaration of Helsinki, Declaration of Geneva, Directive 91/507/EEC, ICH Guidelines on Good Clinical Practice, etc.), as well as the existing legislation in the field of biomedical ethics and health care.

◆ Professionals' training in clinical ethics

The Medical Faculty curriculum contains subjects of medical ethics, and dianoethics.

◆ What should be improved in the future

It is our belief that further improvements should be made in the following fields:

1. Expanding the educational process in medical ethics. Namely, the ethical problems of the clinical work are more known by younger members of medical profession.
2. Seminars, workshops should be held in medical ethics.
3. Several improvements in the existing legal system should be made. It seems that some legal provisions are outdated, especially in the field of patients' rights.
4. All those changes should be based on the models of competency within the existing provisions of the EU educational and legal system.

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TURKEY

Sener Dalyan

◆ What is my Country's situation concerning ethics support in clinical practice? What are my Country's needs in this respect?

Although institutional structure of clinical ethics committees is very good, the problems of ethics support in clinical practice are not sufficiently solved. We have some problems in ethics practice.

There are two kinds of clinical ethics authorities in Turkey:

- a) Local Clinical Ethics Committees,
- b) Central Clinical Ethics Committees.

Local clinical ethics committees have been founded in Medical Faculties and also in State Hospitals. The Patients' Rights Units, which are working as subordinate units of Human Rights Units, have been founded in many governorships. Ethics committees of Medical Faculties are dealing with ethical aspects of clinical research in the domain of publications, projects, drugs. In many State hospitals, there are clinical ethics committees, but they are generally referred to as 'Patients Rights Committees'. Both Patients Rights Committees and Patients' Rights Units deal with dilemmas of patient rights, problems between clinicians and nurses, and problems between patients, health professionals, and administrators of hospitals. For example, if the Patients' Rights Unit of a governorship determines the violation of the patient's rights, it approaches the person, who is responsible for the violation (a clinician, nurse, or another personnel).

Central ethics committees are founded in the Ministry of Health of the Republic of Turkey. There are many central ethics committees. According to their working areas, their names are different. Some of them are dealing with ethical aspects of clinical research in the domain of publication, projects, and some of them are dealing with patients rights and ethical problems of every day work with patients and possible infringements of their rights.

The central ethics committees have not any supervision power upon the local ethics committees, and there is not any network among local ethics committees. Also there is not any networking among the local and central ethics committees. But in some cases, the central ethics

committees can work together. It will be very useful and can increase the quality of work of ethics committees. The number of local ethics committees is inadequate and the distribution of local ethics committees is not at an optimum level. For example, in some cities, there is not any ethics committee.

The Ministry of Health is working on a law project concerning the regulation of the clinical ethics committees' activities.

◆ What is my country's situation concerning professionals' education and training in clinical ethics? What are my country's needs in this respect?

Clinical ethics is the subject of study for undergraduate, graduate and doctorate medical students. At the university level, it is compulsory. A journal named Clinical Ethics Journal is being published. Many national and international symposiums, congresses, conferences and seminars about clinical ethics have been organised in many cities of our country since 1996.

We may need support in encouraging the organisation of national or international meetings, conferences on bioethics with multidisciplinary attendance: physicians, philosophers, jurists, biological scientists etc. We may need also support in training all physicians and nurses by two or three day's regional seminars.

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UKRAINE

Zoreslava Shkiryak-Nyzhnyk

Regarding the issue of coming ratification by Ukraine of the *Convention on Human Rights and Biomedicine*, we can observe that much has been done during the period Ukraine became a member of the Council of Europe. All this, in spite of complicated political and economical problems the country is facing. But nevertheless, the interest of Ukrainian society continues to grow during the last years in different areas of medical sciences, health care, and particularly - modern biotechnology.

Thanks to the fruitful activities of the National Bioethics Committee of the Academy of Sciences, which lead and instruct the local ethics committees, these have been established in early 2001 in each Research Institute affiliated to the Medical Science Academy of Ukraine. A National Commission on Bioethics was organised by the Cabinet of Ministers of Ukraine. We achieved a good understanding and relationship between these bodies, as well as with responsible people from the Ministry of Health and Ministry of Foreign Affairs. A good partnership and collaboration has been achieved in not an easy process of the ratification of the 'Oviedo Convention', and implementation of bioethics principles in social life, research, and health care. With the above mentioned institutions, and ethics bodies existing in Ukraine, with official members from the Ministries, we work in a good, close contact and understanding. An important progress has been achieved, and a good ground for future work on ratification of the Convention has been established.

I have also to mention here, with gratitude, that many important activities in the field of bioethics in Ukraine are supported by the US National Institute's of Health "Fogarty International Centre for International Training

and Research in Environmental and Occupational Health”, and by the University of Illinois at Chicago Great Lakes Centers. Fruitful is also our work with experts from the Council of Europe.

Thus, Ukraine developed a structured net of bioethics bodies, which can help in the implementation of ethical principles from the governmental and society level to the community and even individual one. But all of us know that it is not enough. We have a lot of problems and gaps in the bioethics field, which can not be solved simply.

For example, we have objective difficulties in realising the fundamental Article 3 of the Convention, demanding equitable access to the health care of an appropriate quality. Ukraine has a multi-billion population, which lives in rural areas. Among them, many live in quite a remote villages, in Carpathian mountains, forests, steppes and mine areas. During the years of the so-called “perestroika”, the well-oiled system of primary medical care, which was highly valued and recognised all over the world, has been totally ruined. The system of medical rehabilitation, with large net of sanatoriums, resorts, mother and child rehabilitation health centres, summer camps for children etc., which had been functioning well in previous years, is in a very poor condition nowadays because of lack of money. Many health care units, which previously had provided medical care free of charge, were closed because of the same financial reasons.

Ukraine, more than any other from NIS countries, is confronted by such social disasters as unemployment, corruption, criminality, drug abuse, alcoholism, refugees. High percentage of population has a very low income and lives in poverty. As a consequence of these social negatives, there is a striking reduction of birthrate, increasing morbidity and mortality, and with every year's decrease of the population of between 300.000 – 400.000 people.

How can we guarantee, in such conditions, the fundamental right mentioned above – i.e. „the equal accessibility to health care of appropriate quality“? I do not know, even at this meeting, if somebody from the experts could give us a good, effective advice. Well, it is not at all easy. We hope that growing of the health insurance system and the implementation of the improved standards of health care (the obligatory minimum of guaranteed care), and, of course, the improved economy will lead in Ukraine also to a better „access to good health care of an appropriate quality“.

The next barrier on the way of a successful implementation of bioethics in Ukraine relates to the problem of a documented **informed consent**. For Ukraine, it is more than an actual issue. From the ‘deep past’, we have had a paternalistic model of physician – patient relationship. Patients in our culture trust their doctors that they would do just the best for them. Many of them would become suspicious (especially in the rural areas), if doctors began to explain a lot of details and asking their permission. And, of course, patients’ suspicions would be further deepened, if they were required to sign a paper. In our traditional culture, communication normally occurs between the doctors and patients’ families, not only with the patients alone. Thus, we have to foresee that seeking an informed consent from a patient would more or less violate the long-standing tradition, custom, and could place a strain on the physician – patient relationship. In many rural areas, particularly in the Western Ukraine, husbands have control over their wives, and women do not decide to act independently in any of the main life's events, which require to make a decision. We have also to take into account the patients’ lack of the educational background to understand, what they are told about the nature of the disease, treatment choices, and other issues in the process of obtaining consent. Already now, when we speak more about it, the doctors are heard to lament. “How is a documented informed consent possible? Pa-

tients haven't been to medical school, have they?” Physician are unaccustomed to explaining issues to their patients. They doubt ever being able to make clear to the low literate persons, or to those with a very little formal education, the information that would be necessary for their full comprehension.

It is known that standard account of informed consent identifies some key elements: the provision of adequate information enabling the patient to make an informed choice, the capacity of the patient to understand, what she or he is told, and making a reasoned choice based on that information. At least the third element is the voluntariness, with which the choice is made. So, there is thus an information component, and a consent component. The first refers to adequate disclosure of information from the doctor's side, and adequate comprehension by the patient. It is clear that both depend on the patient's educational background. The next element refers to a voluntary decision, or agreement on the part of a competent person.

What problems regarding the informed consent are we facing nowadays? In Ukraine, according to an old tradition, the physician, as a rule, gives only a minimum information to the patient about the illness. In particular, in the cases with oncological pathology. Most of people in our country believe that such illnesses are incurable. The great progress of modern oncology in successful treatment of many malignant diseases still practically unknown to the general population. Poor information of the population about real situation in oncology makes it necessary to use a “holy lie” to avoid psychological trauma of patients. So, once more, we came to a very important issue – education. How to inform the patients? How much information to give? What kind of information are doctors obliged to give to the patients? Whatever recommendation the physician makes, it must be patient – centred. It can be patient – centred in one of the two ways: in accordance with what is best for the patient from a medical point of view, and in conforming with the patient's informed refusal of the recommended method. It is a recognition of patients as full-fledged decision-makers, moral agents with the capacity for reasoned choice and as members of the moral community, whose autonomy must be respected.

We understand that our country is not yet implementing fully the informed consent in everyday's clinical practice. In biomedical research, the problem will be solved sooner. But in the health care practice, it will need a joint effort of different professionals in promoting the patient's consent. Societies should equip their members for technical, scientific and ethical proficiency, but also for sensitivity to understand and respect patient's circumstances that explain their choices.

There is a necessity to develop a well – structured system for modern education in bioethics in medical schools at the under graduate and postgraduate levels, and within the continuing medical education. We also need to educate on different bioethics topics the mass-media professionals, the whole population, the Government and Parliament members, and the President as well. Their understanding of bioethics principles, their acceptance of importance of human rights and dignity protection in all aspects of biomedicine, is a guarantee of sustainable, stable democracy in our country.

We are sure, that through the discussions with international experts, using their experience, recommendations, and advice, Ukraine will sooner achieve these goals.

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