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NA ÚVOD / INTRODUCTION

Reverence for Life

„Reverence for Life comprises the whole ethic of love in its deepest and highest sense. It is the source of constant renewal for the individual and for mankind.“

How are we to build a new humanity? Only by leading men toward a true, inalienable ethic of our own, which is capable of further development. But this goal cannot be reached unless countless individuals will transform themselves from blind men into seeing ones and begin to spell out the great commandment, which is: Reverence for Life.¹

The great fault of all ethics hitherto has been that they believed themselves to have to deal only with the relations of man to man. In reality, however, the question is what is his attitude to the world and all life that comes within his reach. A man is ethical only when life, as such, is sacred to him, that of plants and animals as that of his fellow men, and when he devotes himself helpfully to all life that is in need of help. Only the universal ethic of the feeling of responsibility in an ever-widening sphere for all that lives - only that ethic can be founded in thought. The ethic of the relation of man to man is not something apart by itself: it is only a particular relation, which results from the universal one. The ethic of Reverence for Life, therefore, comprehends within itself everything that can be described as love, devotion, and sympathy, whether in suffering, joy, or effort.²

¹ „Reverence for Life“, sermon preached on February 16, 1919. ² Out of My Life and Thought, 1931. The texts taken from the book „Reverence for Life. The Words of Albert Schweitzer“, compiled by H. E. Robles, Harper San Francisco, 1st ed., 1993, pp. 77, and 80.

Reklama

Advertisement

ETHICAL PERSPECTIVES ON LIFE SCIENCES RESEARCH AFTER MAPPING THE HUMAN GENOME

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Abstract

The essay discusses ethical perspectives of life sciences research that can help us navigate a path across the genetic landscape that opens before us with the map of the human genome that was announced recently. We can rightly anticipate many drug discoveries and genetic therapies to cure, prevent, or alleviate devastating conditions. But we must also pause with appropriate apprehension about the possible dangers and difficulties we may encounter.

Key words: human genome mapping, new therapies, risks, ethics, ethical evaluation.

Introduction

The official publication of the map of the human genome has taken our breath away. As a result, the opportunities for life sciences research at the molecular level are increasing rapidly. In mid-February two separate groups published remarkably similar analyses of the human genome. Dr. Francis Collins, the scientific leader of the Human Genome Sequencing Consortium that is funded substantially by the National Institutes of Health and the Wellcome Trust of London, published his team's results in the journal *Nature*. Dr. Craig Venter, the scientific leader and CEO of the private corporation Celera Genomics, published his team's results in the journal *Science*. These competing groups, one public and the other private, jointly announced their analysis of the human genome, just a few months after rolling-out an earlier draft in summer 2000. Although they adopted different approaches, their results are remarkably similar. Just as a world map enables us to travel to distant lands, the genome map will enable us to locate and study specific genes that cause so many diseases. Few doubt there will be effective gene therapies in the not too distant future. No wonder that transnational pharmaceutical corporations are investing trillions of dollars in genomics - they anticipate vast profits from a vast array of new gene therapies that will focus medical care upon the molecular level of disease and illness. Naturally, there will be many difficulties, not only in shifting from the map of the human genome to practical therapies in the clinic, but also in transforming health care organizations to field these fast emerging gene technologies.

The entire genome is contained in the nucleus of every bodily cell. Organized in the form of a spiraling double helix, deoxyribonucleic acid (DNA) resembles a twisting rope ladder. The rungs or steps are composed of a series of 4 bases, A, T, C, and G (Adenine, Cytosine, Gua-

nine, Thymine) that pair up in a regular manner (A & T; G & C). The long thread of DNA with corresponding base pairs folds around proteins in a set of tightly packed coils. The human genome is a single molecule, distributed over our 23 chromosomes. That is, over the length of human chromosomes there are approximately 3 billion base pairs (rungs) of chemical letters. The amazing accomplishment of the recent mapping of the human genome is to have deciphered and arranged in the correct sequence these 3 billion chemical letters of DNA across our 23 chromosomes. This assembly and analysis of the human genome - so tiny in size yet almost limitless in its potential for health - constitutes an astonishing breakthrough in modern science and technology! It certainly equals the marvel of harnessing atomic energy or landing on the moon.

There are some ethical perspectives that can help us navigate an ethical path across the genetic landscape that opens before us with the new map of the human genome. We can rightly anticipate many drug discoveries to cure, prevent, or alleviate devastating conditions. We must also pause with appropriate apprehension about the possible dangers and difficulties we may encounter.

Anticipation of New Therapies

It is almost impossible to grasp the significance of this virtual blueprint of the human condition that we can now see, read, study, and apply. Some have referred to this map as the so-called „book of life“ (a sort of „language“ used by God to created life), or the „holy grail“ of molecular medicine, that will enable us to develop treatments for a vast array of diseases at their genetic roots. Hopefully, help will be on the way for so many in the United States afflicted with gene related dysfunction, such as cardiovascular disease (50 million), diabetes (15 million), cancer (8 million), or Alzheimer's disease (8 million) - not to mention so many other costly ailments, such as psychiatric disorders, multiple sclerosis, and obesity. There is little doubt that we will have effective genetic therapies within a few years. So, it is no wonder that society applauds this remarkable accomplishment. Hopes are high and anticipation abounds!

Naturally, modesty must also prevail at such an exciting moment. After all, it is somewhat humbling to be informed that the human species possesses only 30,000 or so genes (not the 100,000 that many projected), just 11,000 more than the laboratory roundworm (19,000 genes sequenced in 1998), or just over twice as large as the fruit-fly genome (13,600 genes decoded in March 2000)! But the real cause for modesty lies in the complexity of the task ahead as we use the map of the human genome to develop reliable therapies for so many diseases and disabilities. For the sake of precision, it should be noted that future therapies are more likely to reflect the link between our estimated 30,000 genes and our estimated 300,000 proteins (genes hold the instructions for building proteins in the body) and the pathways between proteins and human diseases. The body's collection of proteins is called the „proteome“ - hence, just as „genomics“ studies how our genes function, „proteomics“ studies how our proteins function. Therefore, when discussing gene-related therapies, scientists expect future therapies to be based on this interaction between genomics and proteomics. From this perspective, the map of the human genome provides basic clues about proteins that constitute our biological building blocks as chemical messengers and mechanisms underlying diseased as well as healthy bodies. Simply, by exploring the connections between our genes and our proteins we are more likely to develop new drug therapies.

Apprehension of New Difficulties

We must temper this legitimate anticipation with a healthy dose of apprehension. Midst the euphoria of such „eureka“ moments we also need to recognize potential problems and difficulties. If we are not cautious, our genome map is capable of leading some astray on the ethical landscape of genetic manipulation. Of course, no one wants to yell „fire“ in the movie theatre without cause. But already we have encountered sufficient predicaments in genetic science to warrant hesitancy as we begin to explore this exciting landscape of the human genome. Sometimes old maps in antiquarian bookshops indicate areas of unexplored territories by writing „there be dragons“ - as we begin to explore our new map of the human genome, prudence cautions us to be wary of miniscule monsters that could assault and possibly cause devastating harm to the human condition!

So why should we have apprehension regarding what seems to be such good news about using molecular medicine for the treatment of disease at its genetic roots? Well, caution makes most sense when we can identify particular events that genuinely illustrate serious underlying ethical concerns. Here are a few such situations.

- First, we will have to monitor privacy, consent, confidentiality, and discrimination issues in the new genetic landscape of medicine. Naturally, there will be many new tests and screening opportunities to diagnose molecular predispositions and risks for gene related diseases. That scenario can be good news insofar as it will encourage a helpful shift to preventative care. But it may also be bad news if we invade privacy, compromise consent or confidentiality, or foster discrimination (even unwittingly). For example, some employers or insurers may be inclined to obtain genetic information to decline cover or claims. Just recently, on February 9, the Equal Employment Opportunity Commission (EEOC) filed a lawsuit in U.S. District Court for the Northern District of Iowa in Sioux City. The lawsuit claimed a company violated its employees' privacy rights by requiring genetic tests. The company had a nationwide policy requiring some employees who filed claims of a specific work-related injury to provide blood samples for genetic tests. Interestingly, within a matter of days after the lawsuit was filed the company discontinued its policy requiring genetic tests! Congress has yet to pass regulation in this controversial arena - but it urgently needs to pass a federal bill outlawing genetic discrimination.

- Second, we need to ensure that our scientists, hospitals, and genomics corporations do not place any patient in jeopardy in the race to file patents and develop highly profitable new genetic therapies. There are strict protocol requirements for medical research that must be followed to ensure the safety of human research subjects. Sadly, the avoidable death of the first reported gene therapy patient, Jesse Gelsinger, in 1999 illustrates the need for such caution. In September 1999 this teenager died from a severe immune reaction to an experimental virus being used as a vector (vehicle) to deliver the gene therapy for an inherited liver disease. The family filed a lawsuit, alleging fraudulence and negligence in recruiting their son as a patient, and eventually settled out of court. The director of the gene research project, Dr. James Wilson, owned stock in *Genovo*, the company funding the research! As a result of this case, the government closed all gene research protocols at the University of Pennsylvania where the death occurred. This case illustrates the urgency and importance of patient safety as a hallmark of respect for human dignity. We need to advocate for regulatory oversight at state and federal levels.

- Third, respecting the common good requires us to monitor potential social abuses by gene-related technologies. An obvious example would be gene testing or screening. Already, every newborn baby in the United States is supposed to undergo some form of gene testing. These sorts of gene-technologies are likely to increase dramatically in coming years. After all, early intervention for at-risk populations will promote health and probably diminish costs as effective treatments become available. Yet, there are very important ethical challenges that we need to engage. Perhaps the most serious ethical concern deals with genetic counseling and prenatal genetic tests that may cause the mother to consider an abortion when a serious gene disorder in the fetus is diagnosed. New gene-technologies such as genetic testing may increase the number of abortions in many nations. Faced with this prospect, health care providers will need to ensure that counselors are properly trained in the emerging science and technology of human genetics. Moreover, new gene-technologies for testing and screening are sure to reconfigure the meaning of normalcy and disease - multiplex genetic testing (that tests for more than one genetic variant) and the gene chip (akin to the computer chip, that enables the scientist to access thousands of genes simultaneously) are becoming increasingly available.

- Fourth, we need to be aware that genetic intervention may hold terrible surprises for the human species, especially from the perspective of safety. In January an Australian research team reported that an apparently harmless animal experiment had disastrous consequences. The team inserted into the mouse pox virus (a cousin of the human smallpox virus) a mouse gene to trigger the mouse immune system as a means of controlling fertility - but the virus crippled the immune system and killed the mice population. This unforeseen but disastrous result simply illustrates the difficulty of navigating our genetic terrain. That difficulty will not be removed even with a reliable map of the human genome.

- Fifth, we also need to ask whether science seeks to play God in its control of the human genome by enabling couples to have so-called „designer babies“ - not just to avoid disease related genes (such as those associated with sickle cell disease or Tay-Sachs disease), but also to select preferred traits such as skin color, complexion, and intelligence. Already, we have encountered the first known case of a genetically screened baby born to save the life of a sibling - the story of Adam and Molly Nash.

Molly was a 6-year old girl with a fatal condition (Fanconi anemia), a rare genetic disorder that prevents bone marrow being made by the body, a condition that can kill by the age of 7 years. A blood transplant from a matching sibling offers 85 percent rate of success for this disease - but Molly did not have a sibling. So, the parents opted for a process of genetic screening and assisted reproduction from the Reproductive Genetics Institute in Chicago. The parents decided to have another baby hoping, after its birth, to use the placenta and cord blood for a stem cell transplant for Molly. The parents used a technology call „pre-implantation genetic diagnosis“ to check that the new baby did not have the same disease as Molly and that there would be a good match for the transplant. On August 29, 2000 baby Adam was born. A few weeks later, and after further screening, his 6 year old sister received transfusion of stem cells from his umbilical cord and placenta. The good news is that baby Adam is flourishing and Molly is improving with a positive prognosis. It is worth noting this is the first recorded therapy that merged the technologies of genomics (via

genetic diagnosis) and stem cell research (via the transplant). There are many ethical difficulties that need urgent attention in such a case. First, we need to address the obvious problem of parents having a baby to provide a transplant for a sibling. Second, to undertake „pre-implantation genetic diagnosis“ 15 human embryos (at eight-cell stage when one cell typically is removed for genetic testing prior to implantation in the mother's womb) were created via in-vitro fertilization and some were discarded - only baby Adam was born. Simply put, we can honor technology that could provide Molly with a stem cell transplant from another baby whose blood had undergone appropriate genetic screening after birth. But creating and destroying many human embryos in the process raises fundamental concerns about respect for human dignity. The critical question here is whether we may harm or destroy a human embryo to justify therapy for another, even a sibling with a fatal disease.

Conclusion

Of course, there will be many other crucial issues that may cause us pause as we explore the impact of mapping the human genome upon life sciences research. Perhaps the most obvious question about future genetic intervention pertains to manipulated traits inherited by our progeny. How will science assess the relative risks of germline genetic manipulation that will alter the progeny of the patient and subsequent offspring? In sum, we might ponder this point: if evolution has enabled the human species to flourish in its biological diversity over a period of 500 million years, it should be with great modesty that we celebrate our astounding accomplishments in mapping the human genome and with even greater fear and trepidation that we use this map to manipulate our genetic make-up. After all, we may encounter unfriendly dragons!

(Literature by the author.)

Abstrakt

Magill, G.: Ethical perspectives on life sciences research after mapping the human genome. [Etické perspektívy výskumu v biológii a medicíne po zmapovaní ľudského genómu.] *Medicína etika & bioetika / Medical Ethics & Bioethics*, Vol. 8, 2001, No. 1 - 2, p. 3 - 5. Práca diskutuje etické perspektívy biomedicínskych vied, ktoré nám môžu pomôcť pri orientácii v novom priestore humánnej genetiky, ktorý sa pred nami otvára v súvislosti s nedávno ohlásenými úspechmi pri konštruovaní mapy ľudského genómu. Právom môžeme očakávať objavy nových liekov, ako aj nových spôsobov gébovej terapie, ktorá by mohla umožniť liečbu, prevenciu, alebo zmiernenie priebehu mnohých závažných chorôb. Súčasne však musíme venovať náležitú pozornosť aj rizikám a ťažkostiam, s ktorými sa môžeme v tejto novej oblasti stretnúť.

Kľúčové slová: mapovanie ľudského genómu, nové terapie, riziká, etika, etické hodnotenie.

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ETHICS COMMITTEES AND CONSENSUS IN THE POST-TOTALITARIAN SOCIETY

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Abstract

Ethics committees are usually expected to reach and frame their decisions by consensus. In a post-totalitarian society the conception of consensus might somewhat differ from the one present in societies with a long-term, uninterrupted tradition of democratic development. In 1990s, post totalitarian societies of Central and East Europe have been walking difficult paths from the situation, when matters of public interest had been decided almost solely within the structures of a totalitarian power (usually a 'communist' party and by the party dominated governmental or municipal structures) and the political decisions implemented by more or less coercive exercise of that power (while requiring the broadest community attainment - 'imposed consensus'); toward societies deciding their fate and matters of public interest via institutions of a modern, pluralistic, parliamentary democracy (subscribing implicitly or even explicitly to consensus, perceived mostly as 'overlapping' or 'procedural'). The paper gives an analysis of evolution of the notion of consensus in the post-totalitarian Slovakia as seen within the frame of the first decade of establishment and work of ethics committees in the institutions of biomedical research and health care. Examples of present challenges for ethics committees' consensual decision making are outlined.

Key Words: ethics committees, consensus, post-totalitarian society, democracy, plurality, health care reform.

Introduction

The fall of totalitarian regimes in the countries of Central and Eastern Europe (CEE) in 1989/1990 paved the way to an unprecedented political, social, economical and cultural transition. For Slovakia, the Czecho-Slovak 'Velvet Revolution' of November 1989, started these changes. After more than a decade of democratic development, the necessary transformation processes continue to be difficult, complex, and 'paradoxical'. The 'old problems' inherited from the past compete for attention with the new challenges, that 'young democracies' face while making their way towards more open, free, pluralistic and prosperous societies.

Bioethics, discipline born anew or 'imported' from abroad, has frequently been invited to contribute toward the public debate beyond addressing the problems of medicine, health policies and legislation. Its agenda has been broadened to include the issues of family, social justice, environmental preservation and development, as well as the pressing challenges of ongoing cultural and moral change (3). In Slovakia, medical ethics/bioethics was seen as an important ingredient of, and a mean of fostering the health care reform prepared by the Slovak Ministry of Health in the years 1990 - 1992 (4). In this perspective, establishment of ethics committees as kind of 'field workplaces' of bioethics was encouraged within the Slovak health care system. They were supposed to adopt procedures to ensure consensual approach in dealing with the problems they were entrusted to decide

about. However, little was available to their members at this point, neither as far as understanding of the very notion of consensus was concerned, nor to steer their deliberations and ensure consensus really has been sought, understood or achieved by the committee.

In this paper, an analysis of the conceptual evolution of the notion consensus in the post-totalitarian Slovakia is given, as seen within the frame of the first decade of establishment and work of ethics committees in the institutions of biomedical research and health care (11). Examples of present challenges for ethics committees' consensual decision making are outlined.

'Imposed Consensus' and Virtue of Dissensus

Societies of the CEE countries before the 'revolutions' of 1989/1990 were mostly living in the situation of quite rigid totalitarian regimes, with just a little bit of country-specific and mostly distorted 'democracy'. The matters of public interest had been decided almost solely within the structures of a totalitarian power (usually a 'communist' party and the party-dominated governmental or municipal structures). Political decisions were implemented by more or less coercive exercise of that power (sometimes with an 'assistance' of secret or regular police, and other public or hidden agents of totalitarian government). At the same time, the regime usually insisted on the mostly hypocritical, „broadest working peoples' support“ (to be shown by 'the mass' in public demonstrations, marches and other 'charades'), pretending the existence of 'consensus', that was actually imposed on people by the measures of coercion, or terror with a very little chance of 'practical' escape. A very limited exercise of personal autonomy, however, was accompanied also by a diminished sense of personal responsibility, freezing immediately all attempts of individual entrepreneurship.

In this situation of hypocrisy, the moral value and possible impact of genuine intellectual, spiritual, and - later on - also political dissensus became the most precious seed to give birth to new roots and twigs of later plants of democracy, when the deadly 'glacial age' of the 'Cold War' was over. Dissensus was sustained and nurtured in the small groups of underground intellectual and/or spiritual dissenters, in the families, and frequently paid for by a considerable personal risk of persecution and other sacrifices. Dissensus was perceived, and praised by some, as a symbol of individual autonomy and striving for freedom. However, the 'virtue' of dissensus was also acknowledged and fostered by the underground intellectual and spiritual groups. In Slovakia, the underground men and women's religious orders and other church-related underground groups played a very special role in this respect. (This sometimes was accompanied even by a 'crisis of authority' or 'obedience', endangering the integrity and safety of those religious communities in conditions of the underground existence and impending persecution.) The consensus, on the other hand, was perceived with suspicion and some 'intellectual discomfort'. This was further underlined by inner fragmentation of the totalitarian society, that eventually led to the final crash of its 'marxist-leninist' ideology, and also of its totalitarian power system (in some countries resulting in a considerable blood shed and humanitarian disaster). The overall societal dissensus and fragmentation, when confronted with 'old fashioned' cruelty of the regime (police interventions against the peaceful Christians' demonstration in Bratislava in March 1988, and the students' demonstration in Prague in November 1989), brought about an unexpected, broadly shared public consensus about the need of a profound and rapid change. In Slovakia and Czech Republic, the 1989/1990 change was surprisingly peaceful (named later as the 'Velvet Revolution').

Round Table Consensus - A School of Pluralistic Discourse

An important, perhaps one of the most characteristic features of the political, and also societal life of the first two years after the Velvet Revolution was the 'institution' of the *round table*. Interestingly, it started as an earliest strive for emancipation of the newly formed democratic forces against the power hegemony of the communist party, whose 'leading role' (i.e. absolute power predominance) in the society has been for decades inscribed directly in the Constitution (thus, the participation of proponents of previous regime in the very first 'round tables'). After removal of the communist party from the formal power within the governmental and municipal structures (informal influence and real power, however, has persisted long-long afterwards...), the striking heterogeneity of the 'velvet revolutionaries' camp led to an uphold and persistent popularity of round tables as means of managing stirred public political debate, and even as a working method in solving acutely pressing issues of the great political or societal importance (from developing a political strategy of the peoples' movement now coming into power, to outlining a particular policy for the hospital or university, or choosing a new boss for the department, into whose personality or project the co-workers were keen enough to put their confidence..., thus the 'institution' of 'proclaiming the confidence in someone' became popular in the same time as that of the 'round table').

A great amount of public enthusiasm and an unprecedented amount of 'good will' marked functioning of round tables. This way, they became a kind of schools for pluralistic public discourse, contributing to the cultivation of the new, 'dialogic' culture of public deliberation and decision-making. Thus, consensus became an important 'commodity' to strive for, to built, to negotiate, to achieve, to put one's confidence into, etc., sometimes even the 'value in itself' (12, 13, 14).

The consensual solutions sought during this 'romantic' period of political and societal development would probably best meet the Jurgen Habermas's criteria of a fair public discourse (15). However, striving to accommodate as much of differing views and ideas in optimizing the particular or more general solutions sought hampered the practical side of decision-making processes. After establishment of more regular and differentiated political parties, and an advent of the legitimate political competition within increasingly pluralistic, and fragmented political scene (more than 20 parties took part in the elections of 1992), the round tables ultimately fell into a strong disrepute, and the 'consensual mantra' was again held under the strongest suspicion.

Political and societal developments in the years 1993 - 1998, marked by elements of totalitarianism, and some political and social shortcomings of the 'young democracy', did not contributed much to any improvement of the poor 'public consensus' reputation. However, the ever increasing political culture, disrepute, and later abolition of the 'neo-totalitarian' practices of the government and municipal administrations, and introduction of a more intelligent political and public discourse (partially also due to the growing pluralism within the media space and increasing quality of 'everyday's journalism') re-introduced the public interest in, and even some appreciation of the notion of consensus.

Within this vibrantly changing political and societal scene - including the 'highs' and 'lows' of the notion of consensus - a considerable transformation of the national health care system (HCS) was prepared and eventually launched (1991 - 1992) by the Slovak Ministry of Health. (8, 10).

Ethics Committees and Health Care Reform in Slovakia

The reform turned to be a difficult and turbulent process, which has been hardly completed so far (year 2001). As yet, it consisted mainly in transition from the state-owned, centrally planned, fee-free national HCS to a more decentralised one, with a considerable proportion of the private sector. In 1992, the 'right to health care' for every citizen was re-affirmed in the Constitution (9). The extent of health care, to which a citizen is entitled, has been specified by law. Nowadays, the payment for health care services delivered by the health care providers is done through state and private health insurance companies ('plurality of health insurance' has been introduced). The hospitals and major outpatient facilities have been kept in hands of the state, a few given to the municipalities or privatised. The physician offices have been almost completely privatised, the privatisation seen as a vehicle for improvement of efficacy and quality of health care.

From the 'moral' point of view, the health care system reform was expected to enable a moral re-newal and 'humanisation' of medicine and health care in the country (3, 4). This created a unique and fruitful atmosphere in which the birth and early development of Slovak bioethics took place. The Slovak Ministry of Health (especially in the years 1990 - 1992) saw medical ethics/bioethics as an important ingredient of, even as a mean of fostering and steering the ongoing reform (9, 10).

In 1991 - 1992, ethics committees were established in research institutions and major university and regional hospitals, due to the initiative of the Central Ethics Committee (CEC), founded at the Slovak Ministry of Health already in 1990 (4). Since the very beginning, they were supposed to work along the 'gentle lines' of consensus (2). In 1992, „Guidelines for establishment and work of ethics committees...“ were formally adopted and published by the Ministry (16). They tried to embrace the language of major international documents on ethics of biomedical research available at that time, with some modifications that were due to the actual legal situation in Slovakia.

The document defined 3 types of ethics committees:

a) *Central Ethics Committee* of the Ministry of Health. Its main task should have been the review of legislation proposals, as well as the conceptual and methodological work in the field of medical ethics/bioethics, international collaboration and networking.

b) *Research Ethics Committees (REC)* reviewing projects or protocols of biomedical research (therapeutic and non-therapeutic).

c) *Health Care Ethics Committees (HCEC)* dealing with ethical problems arising within the health care provision in particular health care facility. The committees in major teaching/university hospitals were assumed to perform both functions sub b) and c) - *mixed type ethics committees*.

The research ethics committees were supposed to review also the experimental research projects to be conducted in animals. Though a new regulation on ECs is expected to follow recently adopted legislation on drug clinical trials (Law No. 288/1999 on drugs), and the International Conference on Harmonisation (ICH) principles of Good Clinical Practice are already broadly acknowledged and voluntarily implemented in practice, ECs still perform their work basically according to the original Guidelines of 1992 (5, 6).

'Consensual Decision Making' - Guidelines versus Reality

Besides specifying various procedural and organisational issues (such as establishment, reporting, member-

ship, chairmanship, seat, documentation, etc.) the guidelines paid a particular attention to deliberations and 'decision making' of ethics committees. It stated explicitly, that EC should preferably reach its decisions by 'means of consensus'. If consensus was not achieved, EC should resort to a formal vote. However, special provision was included to accommodate 'irreconcilable dissenters': they were entitled to have their opinion explicitly mentioned, as a 'minority view', in the statement of the committee. This provision was made because of serious concerns, that certain views and people (such as people with strong christian, or vice versa - 'liberal' beliefs; sometimes the people with an outstanding theological or philosophical insight and education) could get *a priori* excluded from the deliberations and work of ECs, thus jeopardising considerably the quality of EC's work; and also because of respecting the principle of fair representation of particular community's views on the committee (more than 60% of the population in Slovakia are Roman Catholics, almost 30% subscribe to other Christian denominations, only about 9 - 10% consider themselves 'atheists').

During the first period of their work, the 'practice' of EC's deliberations and decision-making hardly met the standards given by the Guidelines. The major pitfalls were due to the lack of education and training of the ECs members, insufficient support from the health care administrators, misconceptions concerning their mission, procedures, scope of responsibility, reporting, but also because of the underdeveloped 'dialogic' culture of impartial discussion and democratic discourse (12, 20, 21).

Plurality of 'Traditions'

Situation left behind the 'passed-away' marxism-leninism, was one of a considerable intellectual and cultural vacuum. This was especially true for all scientific disciplines listed in the group of humanities. People coming into the field of bioethics in Slovakia were members of different societal groups (8, 10).

Firstly, former dissenters against the totalitarian ethics and ideology, mostly adherent to the Judaeo-Christian tradition, or to the various schools of 'secular humanism'.

Secondly, former university teachers of 'scientific disciplines' of the marxism-leninism, quickly becoming proponents of different schools of secular (or even 'religious') philosophical thought.

Thirdly, fresh 'domestic' pupils or 'imported' proponents of different interest groups, 'schools', ideologies, and value systems present within the contemporary bioethics world. Some of those, because of a substantial financial support from abroad, were able to exercise a considerable presence in media.

Thus, irreconcilable 'ideological' clashes in the work of ethics committees seemed inevitable. The reality, however, was not that hot (11). Why this 'plurality of traditions' lived quite peacefully on ethics committees might possibly be explained by the following reasons (17, 18, 19, 20):

1. Despite the pluralism outlined above, during the first years of its development, and even nowadays, a modified 'Hippocratic' tradition has been (consciously or subconsciously) the most prominent within the professional ethical 'make up' of the majority of health care professionals. This was also reflected in the 'moral' expectations of patients and general public from the medical professionals and medicine/health care system as a whole.

2. Nomination process for the membership of an ethics committee was (consciously or subconsciously) done by directors of research institutions or hospitals (usually upon the recommendation of the pre-nominated chairperson of the committee) in a way to ensure 'wor-

king ability' of the committee in terms of the possibility to reach consensus on important moral issues. Proponents of 'extreme views' were usually not nominated for the committee.

3. In a particular institution (research institute, hospital) people already knew each other for years, and a kind of 'informal' consensus on moral issues encountered within the institution was already developed and shared. People interested most in ethical problems within particular institution tended to be close with their views, thanks to the shared medical/health care experience, culture and education background.

4. Ethical issues posed before the ethics committees at the beginning of their work were relatively simple from the theoretical and practical point of view. Some problems were 'procedural' in nature, others were concerning application of the national legislation or national and international ethical documents and standards in the case in question.

5. Special group consisted of the projects of un-ethical clinical trials submitted to various health/medical research institutions by the international pharmaceutical companies. In these cases the ethics committee took role of a 'protector' of the people (patients or volunteers) against an unacceptable risk or exploitation. Usually, this was a strong impetus for reaching the consensus.

Conflicts and Distortions

If the un-ethical trials mentioned above were backed by a strong financial incentives for the investigator or institution's administration (such as the gift of a costly instrument, or money, or invitation to take part in an international scientific meeting at an attractive location abroad, etc.), this (usually hidden) 'conflict of interest' could lead to a strong conflict of the committee with principal investigator or institution's administration, or even within the committee itself. Sometimes the 'incentive' was just a strong interest of the investigator himself/herself in proceeding with his/her research. In Slovakia, such example might be seen in efforts of a group of neurosurgeons to foster the ethically questionable research on stereotactic surgical treatment in some psychiatric disorders (without, at that time, sufficient safeguards of the protocol concerning the respect of the patient's personal integrity and dignity).

The other sources of conflicts were the irreconcilable opposite moral views of the committee members. In the situation of yet under-developed ability and 'culture' of dialogical exchange and fair discourse the 'pat' situation (as in the chess play) usually ensued, blocking the work and decision making capacity of the committee. Problem was then usually solved by a decision of the responsible administrator (director) of the institution. These cases were extremely rare, however.

The misunderstanding of the status and role of the ethics committee by its member(s) and/or chairperson led sometimes to the attempts to gain decision making power within the institution or to solve other, usually interpersonal agendas by means of 'political' decisions of the committee (via blocking or rejecting a research project, administration decision or institution's policy).

On the other hand, especially at the beginning of their work, ethics committees were seen as 'prolonged hands' of institution's administration to exert a kind of totalitarian control over the researchers or other personnel. Their independence status has been challenged and suspected, which was matched by a lack of confidence, various rumours 'behind the scene', and some reluctance in submitting the project proposals for review to them.

Toward New Plurality

- Consensus Challenges and Limitations

At present, developments both in the health care sector, medicine and related disciplines, and in the Slovakian society as a whole, are being increasingly influenced by the integration efforts of the country into the European economical, political and cultural structures, especially those of the European Union and NATO. The overall progress in this direction is conditioned (and helped, on the other hand) also, among other issues, by the rise and development of democratic structures and 'democratic culture' within the social and political life of the country. These processes, however, are neither straightforward, nor easy.

Growing pluralism of contemporary society, at the same time, makes the communication and dialogue between the proponents of an increasing number of different moral (ethical) views still more complicated and complex (1, 22). An increasing number of seemingly irreconcilable positions are entering the public arena, sometimes without any genuine interest in a dialogic discourse, and/or in building/finding consensus, or an acceptable compromise. The basis for reaching an „overlapping“ consensus, with broader society participation, seems being shrinking progressively. This picture is especially troubling and pessimistic in a fashionable 'post-modern' perspective, paying tribute to nearly „absolute“ individualism, subjectivism and relativism. The „good old“ notions, such as the truth, reality, virtue, common understanding, respect, common good, history and the future, together with many others, are just scratched away from the path of „the progress“, heading rapidly and vigorously nowhere... The only consensus seemingly widespread and held by everyone is that on the impossibility, impracticability, and „no need“ of any consensus that might be contemplated, built, striven for, agreed upon, or implemented...

These developments are simultaneously counteracted, however, by many examples of positive and responsible cultural developments, fostering the dialogue, mutual understanding, and good interpersonal, intrasocietal, inter-ethnic, and international relationships. In this respect, the activities of many non-governmental organisations, the churches (recent major ecumenical developments might be recalled here), the personalities of science, arts and other fields of culture, as well as the growing success of political ('dialogic') approaches in solving international conflicts in Europe and elsewhere, are bringing more optimism into the globalising existence of contemporary mankind. Thus, bringing the case of consensus again „on the wheels“.

We cannot predict the future developments in this field, as the changes are rather quick and sometimes unexpectedly profound. We do believe, however, that consensus itself will continue to be one of the most important themes for reflection, analysis and implementation in the pluralistic and democratic times/societies to come.

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Abstrakt

Glasa J., Glasová M.: Ethics Committees and Consensus in the Post-Totalitarian Society. [Ětické komisie a konsenzus v post-totalitnej spoločnosti.] *Medicínska etika & bioetika / Medical Ethics & Bioethics*, Vol. 8, 2001, No. 1 - 2, p. 5 - 9. Od etických komisií sa zvyčajne očakáva, že dospejú k svojim rozhodnutiam na základe a prostredníctvom konsenzu. V post-totalitnej spoločnosti sa môže byť pojem konsenzu v niektorých ohľadoch odlišovať od toho, ako je bežne vnímaný v spoločnostiach s dlhodobými, nepretrženými tradíciami demokratického vývoja. Od 90-tych rokov 20. storočia prechádzajú post-totalitné krajiny strednej a východnej Európy náročným vývojovým obdobím. Zo situácie, kedy o veciach verejného záujmu rozhodovali temer výlučne štruktúry totalitnej moci (zvyčajne vrcholné orgány 'komunistickej' strany alebo stranou ovládané štátne a zastupiteľské orgány) a rozhodnutia sa uvádzali do praxe viac alebo menej zjavnými donucovacími opatreniami tejto moci (pričom sa vyžadoval i formálny súhlas čo najširších vrstiev spoločnosti ('pracujúcich mäs') - vnútený konsenzus); k žiadúcemu stavu, kedy sa o ďalšom vývoji spoločnosti a veciach verejného záujmu rozhoduje prostredníctvom inštitúcií modernej, pluralitnej, parlamentnej demokracie (pričom sa cieľavedome usiluje o čo najširšie založený konsenzus, vnímaný ako 'vzájomný', prípadne ako 'procedurálny'). Príspevok analyzuje vývoj chápania a uplatnenia pojmu konsenzus v podmienkach post-totalitného Slovenska, a to zvlášť z hľadiska hodnotenia prvej dekády existencie a činnosti etických komisií v oblasti biomedicínskeho výskumu a zdravotnej starostlivosti. Uvažuje aj nad súčasnými problémami, ktoré kladie pred etické komisie rozhodovanie formou konsenzu.

Kľúčové slová: etické komisie, konsenzus, post-totalitná spoločnosť, demokracia, pluralita, reforma zdravotníctva.

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Council of Europe

Recommendation 1512 (2001)[1]

PROTECTION OF THE HUMAN GENOME BY THE COUNCIL OF EUROPE

1. The Council of Europe's Parliamentary Assembly notes that the human genome international research project, in view of the numerous and unimaginable consequences that it might have for medicine and for the animal and plant world, conjures up scenarios for all humanity that raise numerous ethical questions, while holding out the promise of enormous improvements in the quality of life.

2. The protection of human dignity should be the guiding principle for the handling of the Human Genome Project.

3. The genetic age will dawn with the completion of the project: diagnosis will become objective, and it will be possible to identify the presence of genetic disorders or a genetic predisposition to illnesses at an early stage. In many cases, gene therapy will become possible, and this will basically give rise to a form of genetic engineering designed, for instance, to avoid the development of a tumour in an individual found to be at risk. It might also be applied to other illnesses, such as hypertension, diabetes, Alzheimer's disease, osteoporosis, certain psychiatric disorders, etc.

4. At the same time, the Assembly is aware of the enormous ethical implications of further research on the human genome, including some of a negative nature. These include questions regarding the cloning of cells, the conditions ruling genetic testing and the divulgence and use of obtained information.

5. In this connection, the Assembly is fully aware of the now well-known fact that laboratories, with their associated data banks, which conduct experiments specifically on DNA separation are already actively at work in certain European countries and enjoy, among other things, the financial support of prominent pharmaceutical companies.

6. It is also aware that substantial economic interests are at stake in the Genome Project, by virtue of the very fact that it might hold out incalculable opportunities for preventing illness and improving treatment, as it involves many public and private research centres to which considerable financial resources will be allocated.

7. The Assembly is of the opinion that the results of this grandiose research effort - in which the United States has the lead over Europe - must be made available to all, genetic information being a common human heritage, as set out in Article 1 of the Universal Declaration on the Human Genome and Human Rights, adopted at Unesco in Paris on 11 November 1997. The Assembly in particular refers in this context to the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine - Convention on Human Rights and Biomedicine (European Treaty, Series No. 164) as well as its own Recommendations 1425 (1999) on biotechnology and intellectual property and 1468 (2000) on biotechnologies.

8. In particular, the Assembly is aware that the prospects opened up by the discoveries associated with the Genome Project pose a whole series of ethical problems, essentially concerning such fundamental issues as the use of genetic information for preventive purposes and

possibly a presumed right, at a later stage, to take preventive action when certain genetic information is obtained. However, a crucial question will be the assessment of *who will have which rights to use the information*: the case of insurance companies, employers, parents, schools, etc.

9. The Assembly calls, inter alia through the establishment of a Euroforum on Human Genetics, for the widest possible participation by citizens in the discussion of the human genome through the involvement of the European media and suitable and accurate information by the Council of Europe.

10. The Assembly expresses the wish that the scope of action of the above-mentioned authority should not be confined to Europe, but that it may become part of a world authority under the aegis of the UN. To this end, the Assembly advocates that the necessary contacts be established with the appropriate bodies within the UN and UNESCO as soon as possible.

11. In view of the above, the Assembly recommends that the Committee of Ministers:

i. invite every Council of Europe member state concerned to set up, under its own domestic legislation, a national authority having the express task of monitoring, informing and advising on the compliance of research on the human genome with universally recognised ethical and moral principles of respect for life and human dignity;

ii. set up, at European level as well, and more specifically in the context of the Council of Europe, a body or authority to fulfil on a permanent basis the task of monitoring the development of the Genome Project research process, ensuring respect for ethical principles in the context of research on the human genome, assessing the effects of such research also regarding health risks, and giving thorough consideration to all the ethical aspects of the project and consider in this context the role of the Steering Committee on Bioethics (CDBI);

iii. ensure that these bodies for monitoring research on the human genome will familiarise the European public with new possibilities for progress in genetics in terms of information and technology and also serve to promote campaigns to inform and educate the public, in particular the health professions;

iv. make sure that consultation of the European authority be mandatory, and that it formulate an opinion when conventions are drafted on this subject in the context of the Council of Europe and codes of ethics produced; such a body should also have free access to important information on genetics and be able to carry out its own inspections of public and private European research institutes;

v. ask member states to sign, ratify and implement the Convention on Human Rights and Biomedicine;

vi. ask all Council of Europe member states to strive to change the basis of patent law in international fora, as far as the ownership of human being tissue and genes is concerned, into law pertaining to the common heritage of mankind.

The Pontifical Academy for Life

RESPECT FOR THE DIGNITY OF THE DYING PERSON ETHICAL OBSERVATIONS ON EUTHANASIA

1. From the 1970s onwards, beginning in the most developed countries of the world, an insistent campaign has spread in favour of euthanasia understood as an action or omission to act which by its nature and intentions brings about the ending of the life of the gravely ill per-

son or even of the malformed newly born child. The motive which is usually advanced in support of such a policy is that of wanting, thereby, to save the patient himself or herself from suffering - a suffering which is defined as being useless.

Promoted with the support of pro-euthanasia associations operating at an international level, campaigns and strategies of this character have been developed marked by public *manifestos* signed by intellectuals and men of science; by publications favourable to this policy - some of which have even been provided with instructions designed to teach sick people and others the various ways of ending life when this is believed to be unbearable; by inquiries which assemble the opinions of medical doctors and figures known to public opinion who are in favour of the practice of euthanasia; and lastly, by legislative measures laid before parliaments, in addition to attempts to bring about sentences by courts of law which could lead on to the *de facto* practice of euthanasia or at least to a status of not being punishable.

2. The recent case of Holland, where for some years there had already existed a sort of regulation which made the medical doctor not punishable when he or she practised euthanasia in response to the request of the patient, presents a case of the real and authentic legalisation of *euthanasia on demand*, albeit limited to cases of serious and irreversible illness accompanied by suffering and on the condition that such a situation is subjected to a medical inquiry which is strict and scrupulous in character.

The core of the justification which people seek to put forward and assert in relation to public opinion is essentially made up of two fundamental ideas. Firstly, the *principle of the autonomy* of the individual who is said to have the right to decide in relation to his or her own life in an absolute way. Secondly, the conviction, which is more or less made explicit, that the pain which can at times accompany death is *unbearable* and *useless*.

3. The Church has followed this evolution in thought with apprehension and has seen it as one of the manifestations of a spiritual and moral weakening in relation to the dignity of the dying person, as well as a 'utilitarian' route towards an approach of disengagement in relation to the real needs of the patient.

In her reflections on the subject the Church has maintained constant contact with specialists and workers in the field of medicine. She has striven to be loyal to the principles and values of humanity shared by the large majority of men, in the light of reason enlightened by faith, and has produced documents which have met with the appreciation of professionals and a large section of public opinion. We would like here to refer to the Declaration on *Euthanasia* (1980) published some twenty years ago by the Congregation for the Doctrine of the Faith; the document of the Pontifical Council 'Cor Unum', *Ethical Questions Connected with the Seriously Ill and the Dying* (1981); the encyclical *Evangelium Vitae* (1995) by His Holiness John Paul II (and in particular sections 64-67); and the *Charter for Health Care Workers* (1995) drawn up by the Pontifical Council for Pastoral Assistance to Health Care Workers.

These documents of the Magisterium have not limited themselves to defining euthanasia as morally unacceptable, *since it is the deliberate killing of an innocent human person* (cf. *EV*, section 65; the argument of this encyclical is dealt with in detail in section 57, thus allowing a correct interpretation of the passage from section 65 which has just been quoted), or as a 'shameful' action (cf. Vatican Council II, *GS*, 27). They have also suggested a course of action for the care of the gravely ill person or the dying person, both from the point of view of medical ethics and from a spiritual and pastoral perspective, based upon the dignity of the person, respect for life,

and respect for the values of brotherhood and solidarity, and have called on people and institutions to respond with practical witness to the contemporary challenges of a widespread and rampant culture of death.

This Pontifical Academy for Life recently dedicated one of its general assemblies (after preparatory work which lasted several months) to the same subject, and then published the final acts of this assembly in a volume entitled 'The Dignity of the Dying Person' (2000).

4. It should be remembered at this point - always, however, bearing in mind the documents which have just been referred to - that the pain of patients which is spoken about and upon which a kind of justification of, or almost obligatory need for, euthanasia and/or assisted suicide is based, is today, more than ever before, pain which is 'treatable' through the use of suitable instruments of analgesia and palliative treatment proportionate to the pain itself. Such pain, when accompanied by suitable human and spiritual care, can be alleviated and be the object of comfort within a climate of psychological and affective support.

Possible *requests for death* from people undergoing major suffering - as is demonstrated by surveys based on patients and the testimony of clinics close to the situations of dying people - are almost always the *extreme expression* of an anguished request by the patient for more human attention and nearness, in addition to appropriate forms of treatment, both of which are elements which are at times lacking in today's hospitals. The observation already made by the *Charter for Health Care Workers* is here of great accuracy: 'The sick person who feels surrounded by a loving human and Christian presence does not give way to depression and anguish as would be the case if one were left to suffer and die alone and wanting to be done with life. This is why *euthanasia is a defeat* for the one who proposes it, decides it, and carries it out'(section 149)

In this regard one is led to ask oneself if it is not the case that behind the justification which is based upon the idea that the pain of the patient is *unbearable* we find hidden the inability of 'the healthy' to accompany the dying person in his or her difficult trial of suffering, to give meaning to human pain - which anyway can never be completely eliminated from the experience of human life here on earth - and a kind of rejection of the idea itself of suffering, a rejection which is increasingly widespread in our societies of prosperity and hedonism.

And it is not to be excluded that behind some 'pro-euthanasia' campaigns are to be found hidden questions of public expenditure, which is held to be unsustainable and senseless in the context of the extension over time of certain kinds of illness.

5. It is in declaring that pain is treatable (in a medical sense) and in proposing that care for people who suffer is an undertaking required by solidarity that one comes to uphold and promote real humanism. Human pain calls for love and solidarity-inspired sharing, and not for the hurried violence of a premature death.

Furthermore, the so-called *principle of autonomy*, which at times acts to carry to extremes the concept of individual freedom, pushing it beyond its rational confines, can certainly not justify the elimination of one's own life or that of another person. Personal autonomy, in fact, has as its first premise *being alive* and requires the responsibility of the individual, who is *free in order to do good* according to truth. He or she will come to affirm himself or herself, without contradictions, only in recognising (even from a purely rational perspective) that he or she has received *the gift* of his or her life, of which, therefore, he or she cannot be the 'absolute master'. To end life means, in definitive terms, to destroy the very roots of the freedom and the autonomy of the person.

When society then comes to legitimise the elimination of the individual - irrespective of the stage of life in which he or she is to be found or the extent to which his or her health is compromised - it denies its purpose and the very foundations of its existence, opening up the road thereby to increasingly grave inequities.

The legitimisation of euthanasia, lastly, encourages a perverse complicity of the medical doctor who, because of his or her professional identity, and as a result of the mandatory deontological requirements connected with that identity, is always called upon to support life and treat pain, and never to give death, 'not even when moved by the concerned persistence of anybody at all' (the Hippocratic Oath). This ethical and deontological belief has come down the centuries substantially intact, as is confirmed, for example, by the 'Declaration on Euthanasia' of the World Medical Association (thirty-ninth assembly, Madrid, 1987): 'euthanasia, that is to say the act of deliberately ending the life of a patient, both following the request of the patient himself or the request of his family relatives, is immoral. This does not prevent the medical doctor from respecting the wish of the patient to allow the natural process of death to follow its course during the final stage of the illness'.

The condemnation of euthanasia expressed by the encyclical *Evangelium Vitae* because such a practice is a 'grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person' (section 65), contains the weight of universal ethical reason (it is based upon natural law) and the elementary requirement of faith in God, the Creator and the custodian of every human person.

6. The approach towards the gravely ill person and the dying person must, therefore, be based on respect for the life and the dignity of the person. It must perform the task of making proportionate forms of treatment available, without indulging in any form of 'aggressive treatment'. It must ascertain the will of the patient in the case of unusual or risky forms of treatment - which there is no moral obligation to engage in. It must always ensure the provision of usual forms of treatment (including the supply of sustenance and liquids, even if administered artificially) and involve palliative forms of treatment, above all in the suitable treatment of pain, always fostering dialogue and the exchange of information with the patient.

When a death which by that point appears inevitable and imminent is drawing near 'it is legitimate at the level of conscience to take a decision to refuse forms of treatment which would only produce a precarious and distressing extension of life' (cf. *Declaration on Euthanasia*, part IV) because there is a great ethical difference between 'procuring death' and 'allowing death'. The first approach rejects and denies life; the second accepts its natural conclusion.

7. The forms of home support and assistance - which today are increasingly developed, above all in relation to patients who have tumours - and the psychological and spiritual support of family relatives, professionals, and voluntary workers, can and must transmit the conviction that every moment of life and every form of suffering are rendered liveable by love and are valuable in the eyes of men and in the eyes of God. An atmosphere of fraternal solidarity dispels and defeats an atmosphere of loneliness and the temptation of despair. In particular, religious assistance - which is the right of, and constitutes valuable help for, every patient (and not only during the final stage of his or her life) - if it listens, transfigures pain itself into an act of redemptive love, and death into openness towards life in God.

The brief observations offered here take their place at the side of the constant teaching of the Church, which,

in striving to be faithful to her mandate to 'actualise' in history the gaze of God's love for man, above all when he is weak and suffering, continues to proclaim with force the *Gospel of life*, certain as she is that in the heart of every person of good will this Gospel can ring out and be heard - all people, in fact, are called to be a part of the 'people of and for life' (cf. *Evangelium Vitae*, section 101).

The Vice-President
+ Mons. Elio Sgreccia

The President
Juan de Dios Vial Correa

Vatican City, 9 December 2000

The original Italian text, published in „L'OSSERVATORE ROMANO“, 11-12 December 2000, p. 6.

BEIJING DECLARATION ON THE RIGHTS OF PEOPLE WITH DISABILITIES IN THE NEW CENTURY

1. We, the leaders of Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, and the World Federation of the Deaf, as well as national non-governmental organizations (NGOs) of and for people with disabilities from all continents, have convened in Beijing from 10 - 12 March 2000 to develop a new century strategy for the full participation and equality of people with disabilities,

2. We recognize, with appreciation, that the last two decades of the twentieth century witnessed and increased awareness of issues faced by over 600 million people with disabilities, assisted in part by various United Nations instruments,

3. We expressed deep concern, that such instruments and mandates have yet to create a significant impact on improving the lives of people with disabilities, especially women and girls with disabilities, who remain the most invisible and marginalized of all disadvantaged social groups,

4. We emphasize, that the continued exclusion of people with disabilities from the mainstream development process is a violation of fundamental rights and an indictment of humankind at the inception of the new century,

5. We share the conviction, that the full inclusion of people with disabilities in society requires our solidarity in working towards an international convention that legally binds nations, to reinforce the moral authority of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities,

6. We believe, that the inception of the new century is an opportune time for people with diverse disabilities and their organizations, and other civic organizations, local and national governments, members of the United Nations system and other inter-governmental bodies, as well as the private sector, to collaborate closely in an inclusive and wide consultative process aimed at the development and adoption of an international convention to promote and protect the rights of people with disabilities, and enhance equal opportunities for participation in mainstream society,

7. We therefore urge, all heads of state and government, public administrators, local authorities, members of the United Nations system, people with disabilities, civic organizations that participate in the development process, and socially responsible private sector organizations, to immediately initiate the process for an international convention, including by raising it in all forthcoming international forums, especially the Special Session of the United Nations General Assembly on Social Develop-

ment, the NGO Millennium Forum, the United Nations Millennium General Assembly and Summit and related preparatory meetings,

8. We further urge, all participants in this process to actively facilitate the adoption of such convention, which should address, inter alia, the following areas of priority concerns:

(a) Improvement of the overall quality of life of people with disabilities, and their upliftment from deprivation, hardship and poverty.

(b) Education, training, remunerative work, and participation in decision-making process levels.

(c) Elimination of discriminatory attitudes and practices, as well as information, legal and infrastructure barriers.

(d) Increased allocations of resources to ensure the equal participation of people with disabilities.

9. We hereby, send out a call to action, to all concerned with equality and human dignity, to join together in widespread efforts embracing capitals, towns and cities, remote villages, and the United Nations forums, to ensure the adoption of an international convention on the rights of all people with disabilities, and

10. We commit our respective organizations to strive for a legally binding international convention on the rights of all people with disabilities to full participation and equality in society.

Adopted on March, 12, 2000, at the World NGO Summit on Disability, Beijing, People's Republic of China.

ADDRESS OF JOHN PAUL II TO THE 18th INTERNATIONAL CONGRESS OF THE TRANSPLANTATION SOCIETY

Distinguished Ladies and Gentlemen,

1. I am happy to greet all of you at this International Congress, which has brought you together for a reflection on the complex and delicate theme of transplants. I thank Professor Raffaello Cortesini and Professor Oscar Salvatierra for their kind words, and I extend a special greeting to the Italian Authorities present.

To all of you I express my gratitude for your kind invitation to take part in this meeting and I very much appreciate the serious consideration you are giving to the moral teaching of the Church. With respect for science and being attentive above all to the law of God, the Church has no other aim but the integral good of the human person.

Transplants are a great step forward in science's service of man, and not a few people today owe their lives to an organ transplant. Increasingly, the technique of transplants has proven to be a valid means of attaining the primary goal of all medicine - the service of human life. That is why in the Encyclical Letter *Evangelium Vitae* I suggested that one way of nurturing a genuine culture of life „is the donation of organs, performed in an ethically acceptable manner, with a view to offering a chance of health and even of life itself to the sick who sometimes have no other hope“ (No. 86).

2. As with all human advancement, this particular field of medical science, for all the hope of health and life it offers to many, also presents *certain critical issues* that need to be examined in the light of a discerning anthropological and ethical reflection.

In this area of medical science too the fundamental criterion must be *the defence and promotion of the integral good of the human person*, in keeping with that unique dignity which is ours by virtue of our humanity.

Consequently, it is evident that every medical procedure performed on the human person is subject to limits: not just the limits of what it is technically possible, but also limits determined by respect for human nature itself, understood in its fullness: „what is technically possible is not for that reason alone morally admissible“ (Congregation for the Doctrine of the Faith, *Donum Vitae*, 4).

3. It must first be emphasized, as I observed on another occasion, that every organ transplant has its source in a decision of great ethical value: „the decision to offer without reward a part of one’s own body for the health and well-being of another person“ (*Address to the Participants in a Congress on Organ Transplants*, 20 June 1991, No. 3). Here precisely lies the nobility of the gesture, a gesture which is a genuine act of love. It is not just a matter of giving away something that belongs to us but of giving something of ourselves, for „by virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions . . . rather it is a constitutive part of the person who manifests and expresses himself through it“ (Congregation for the Doctrine of the Faith, *Donum Vitae*, 3).

Accordingly, any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable, because to use the body as an „object“ is to violate the dignity of the human person.

This first point has an immediate consequence of great ethical import: *the need for informed consent*. The human „authenticity“ of such a decisive gesture requires that individuals be properly informed about the processes involved, in order to be in a position to consent or decline in a free and conscientious manner. The consent of relatives has its own ethical validity in the absence of a decision on the part of the donor. Naturally, an analogous consent should be given by the recipients of donated organs.

4. Acknowledgement of the unique dignity of the human person has a further underlying consequence: *vital organs which occur singly in the body can be removed only after death*, that is from the body of someone who is certainly dead. This requirement is self-evident, since to act otherwise would mean intentionally to cause the death of the donor in disposing of his organs. This gives rise to one of the most debated issues in contemporary bioethics, as well as to serious concerns in the minds of ordinary people. I refer to the problem of *ascertaining the fact of death*. When can a person be considered dead with complete certainty?

In this regard, it is helpful to recall that *the death of the person* is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person. The death of the person, understood in this primary sense, is an event which *no scientific technique or empirical method can identify directly*.

Yet human experience shows that once death occurs *certain biological signs inevitably follow*, which medicine has learnt to recognize with increasing precision. In this sense, the „criteria“ for ascertaining death used by medicine today should not be understood as the technical-scientific determination of the *exact moment* of a person’s death, but as a scientifically secure means of identifying *the biological signs that a person has indeed died*.

5. It is a well-known fact that for some time certain scientific approaches to ascertaining death have shifted the emphasis from the traditional cardio-respiratory signs to the so-called „neurological“ criterion. Specifically, this consists in establishing, according to clearly deter-

mined parameters commonly held by the international scientific community, the complete and irreversible cessation of all brain activity (in the cerebrum, cerebellum and brain stem). This is then considered the sign that the individual organism has lost its integrative capacity.

With regard to the parameters used today for ascertaining death - whether the „encephalic“ signs or the more traditional cardio-respiratory signs - the Church does not make technical decisions. She limits herself to the Gospel duty of comparing the data offered by medical science with the Christian understanding of the unity of the person, bringing out the similarities and the possible conflicts capable of endangering respect for human dignity.

Here it can be said that the criterion adopted in more recent times for ascertaining the fact of death, namely the *complete* and *irreversible* cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology. Therefore a health-worker professionally responsible for ascertaining death can use these criteria in each individual case as the basis for arriving at that degree of assurance in ethical judgement which moral teaching describes as „moral certainty“. This moral certainty is considered the necessary and sufficient basis for an ethically correct course of action. Only where such certainty exists, and where informed consent has already been given by the donor or the donor’s legitimate representatives, is it morally right to initiate the technical procedures required for the removal of organs for transplant.

6. Another question of great ethical significance is that of *the allocation of donated organs* through waiting-lists and the assignment of priorities. Despite efforts to promote the practice of organ-donation, the resources available in many countries are currently insufficient to meet medical needs. Hence there is a need to compile waiting-lists for transplants on the basis of clear and properly reasoned criteria.

From the moral standpoint, an obvious principle of justice requires that the criteria for assigning donated organs should in no way be „discriminatory“ (i.e. based on age, sex, race, religion, social standing, etc.) or „utilitarian“ (i.e. based on work capacity, social usefulness, etc.). Instead, in determining who should have precedence in receiving an organ, *judgements should be made on the basis of immunological and clinical factors*. Any other criterion would prove wholly arbitrary and subjective, and would fail to recognize the intrinsic value of each human person as such, a value that is independent of any external circumstances.

7. A final issue concerns a possible alternative solution to the problem of finding human organs for transplantation, something still very much in the experimental stage, namely *xenotransplants*, that is, organ transplants from other animal species.

It is not my intention to explore in detail the problems connected with this form of intervention. I would merely recall that already in 1956 Pope Pius XII raised the question of their legitimacy. He did so when commenting on the scientific possibility, then being pre-saged, of transplanting animal corneas to humans. His response is still enlightening for us today: in principle, he stated, for a *xenotransplant* to be licit, the transplanted organ must not impair the integrity of the psychological or genetic identity of the person receiving it; and there must also be a proven biological possibility that the transplant will be successful and will not expose the recipient to inordinate risk (cf. *Address to the Italian Association of Cornea Donors and to Clinical Oculists and Legal Medical Practitioners*, 14 May 1956).

8. In concluding, I express the hope that, thanks to the work of so many generous and highly-trained people,

scientific and technological research in the field of transplants will continue to progress, and extend to *experimentation with new therapies which can replace organ transplants*, as some recent developments in prosthetics seem to promise. In any event, methods that fail to respect the dignity and value of the person must always be avoided. I am thinking in particular of attempts at human cloning with a view to obtaining organs for transplants: these techniques, insofar as they involve the manipulation and destruction of human embryos, are not morally acceptable, even when their proposed goal is good in itself. Science itself points to other forms of *therapeutic intervention* which would not involve cloning or the use of embryonic cells, but rather would make use of stem cells taken from adults. This is the direction that research must follow if it wishes to respect the dignity of each and every human being, even at the embryonic stage.

In addressing these varied issues, *the contribution of philosophers and theologians* is important. Their careful and competent reflection on the ethical problems associated with transplant therapy can help to clarify the criteria for assessing what kinds of transplants are morally acceptable and under what conditions, especially with regard to the protection of each individual's personal identity.

I am confident that social, political and educational leaders will renew their commitment to fostering a genuine culture of generosity and solidarity. There is a need to instil in people's hearts, especially in the hearts of the young, a genuine and deep appreciation of the need for brotherly love, a love that can find expression in the decision to become an organ donor.

May the Lord sustain each one of you in your work, and guide you in the service of authentic human progress. I accompany this wish with my Blessing.

Tuesday, August 29, 2000.

KONFERENCIE / CONFERENCES

WORKSHOP „ETIKA A VEDECKÉ TEÓRIE MEDICÍNY“

Frankfurt nad Odrou, 10. - 12. 5. 2001

V poradí druhý výročný workshop na tému „Etika a vedecké teórie medicíny“ sa uskutočnil v dňoch 10. - 12. 5. 2001 vo Frankfurte nad Odrou (Nemecko). Zorganizovala ho Európska univerzita VIADRINA, presnejšie jej Interdisciplinárne centrum pre etiku, spolu s Univerzitou Martina Luthera v Halle-Wittenbergu (Inštitútom pre dejiny a etiku medicíny). Na konferencii sa zúčastnili filozofi, právnici, lekári, teológovia a etici. Témy konferencie boli vhodne vybrané so zreteľom na ich aktuálnosť pre dnešnú medicínu i pre súčasnú spoločnosť moderného sveta.

Európska univerzita VIADRINA vo Frankfurte/nad Odrou nadväzuje na tradície Alma mater Viadrina (z lat. „univerzita na Odre“), ktorá existovala ako prvá Brandenburská univerzita v rokoch 1506 - 1811. Vtedajší univerzitní profesori práva, slúžiaci ako diplomati pruského štátu, či profesori teológie, filozofie alebo medicíny sa významne podieľali na rozkvetení vedy a výuky v približne dvadsiatich piatich vedných disciplínach. Už v tých časoch univerzita symbolizovala stretávanie pedagógov a študentov Západu i Východu - z oboch strán rieky Odry. Univerzita vo svojich archívoch uchováva dokumenty o štúdiu vzácných osobností vtedajšej doby, akými boli hudobný skladateľ Carl Philipp Emanuel Bach, bratia Alexander a Wilhelm von Humboldt a ďalší. Terajšia

Európska univerzita VIADRINA bola znovuzaložená v roku 1991. Pozostáva z týchto fakúlt a inštitútov: Fakulta práva, Fakulta ekonómie a obchodnej administratívy, Fakulta sociálnych a kultúrnych vied, Interdisciplinárne centrum pre etiku, Collegium Polonicum a Jazykové centrum.

Odborný program workshopu bol zaujímavý a veľmi podnetný. Hlavným motívom všetkých prezentácií bola úcta k človeku, ku každej ľudskej bytosti, v akomkoľvek štádiu jej ontogenetického vývoja alebo v akomkoľvek stave jej prípadnej fyzickej či psychickej degradácie. Prednášky, nasledované bohatou diskusiou, odznali v nasledovnom poradí (uvádzame vždy iba prvého autora prezentácie):

- Nie klonovaniu človeka, staré a nové aspekty, J. Bodo (Katolícka Univerzita Petra Pázmanya, Budapešť, Maďarsko),
- Konflikt záujmov a jeho význam v medicíne, A. Górski (Inštitút Ludwika Hirszfelda, Wroclaw, Poľsko),
- Povinnosti medicíny v prípade potreby súhlasu pacienta s liečbou, najmä v prípade terminálne chorého pacienta, H. Zielinska (Varšavská univerzita, Varšava, Poľsko),
- Výzvy etiky prostredníctvom vedy o živote a nových pokrokov medicíny, H. Lohman (Univerzita Otto von Guericke, Magdeburg, Nemecko),
- Limity beneficencie, L. Holowka (Varšavská univerzita, Varšava, Poľsko),
- Ľudská genetika a medzinárodná spravodlivosť, H. Ranft (Univerzita M. Luthera, Halle-Wittenberg, Nemecko),
- Potreby vo všeobecnosti a v partikularite, A. Parve (Univerzita Tartu, Tartu, Estónsko),
- Dvojitý účinok liečby z pohľadu teológa, V. Chojnacki (Európska univerzita VIADRINA, Frankfurt nad Odrou, Nemecko),
- Má pacient právo na smrť? M. Szeroczynska (Varšavská univerzita, Varšava, Poľsko),
- Skupinové práva v medicínskej etike, H. Joerden (Európska univerzita VIADRINA, Frankfurt nad Odrou, Nemecko).

Slovenský príspevok pod názvom „Vývoj bioetiky na Slovensku - výučba, inštitúcie a verejná debata“, autori M. Mojžešová, M. Černáková, A. Štefko, J. Porubský, J. R. Klepanec, sa stretol s pozitívnym ohlasom. Účastníci workshopu sa v diskusii zaujímali nielen o podrobnosti vývoja bioetiky (medicínskej etiky) na Slovensku od „Nežnej revolúcie“ do súčasnosti, ale aj o to, ktoré témy v oblasti bioetiky sú teraz aktuálne v slovenskej spoločnosti a aké postoje k nim zaujíma verejnosť a médiá (napr. novelizácia Ústavy SR a téma ochrany ľudského života, problematika eutanázie, klonovania, biomedicínskeho výskumu ai.).

MUDr. Mária Mojžešová, PhD.*

* Ústav medicínskej etiky a bioetiky LFUK a SPAM, Bratislava

I am confident that social, political and educational leaders will renew their commitment to fostering a genuine culture of generosity and solidarity. There is a need to instil in people's hearts, especially in the hearts of the young, a genuine and deep appreciation of the need for brotherly love, a love that can find expression in the decision to become an organ donor.

John Paul II, 2000

10 ROKOV ŠKOLY VEREJNÉHO ZDRAVOTNÍCTVA V BRATISLAVE

Ladislav Badalík, Vít Šajter, Ladislav Hegyi, Daniela Farkašová

Škola verejného zdravotníctva (ŠVZ) v Bratislave bola zriadená pred 10-timi rokmi ako organizačná jednotka Slovenskej postgraduálnej akadémie medicíny, priamo riadenej Ministerstvom zdravotníctva Slovenskej republiky. ŠVZ zabezpečuje postgraduálne, ako aj kontinuálne vzdelávanie vo verejnom zdravotníctve.

ŠVZ je súčasťou siete Európskych škôl verejného zdravotníctva, združených v Asociácii škôl verejného zdravotníctva v Európskom regióne (ASPHER). Bola založená v rámci programu EUROHEALTH ako výsledok dohody o spolupráci medzi Regionálnou úradovňou Svetovej zdravotníckej organizácie v Kodani a Ministerstvom zdravotníctva SR v Bratislave. Budúci pracovníci ŠVZ stážovali na renomovaných zahraničných školách, ako na Londýnskej škole hygieny a tropickej medicíny, školách verejného zdravotníctva v Göteborgu, Düsseldorfe, Renách, Granade, Bielefelde, Valencii, Krakove a Barcelone. Významnou udalosťou v histórii ŠVZ bolo vydanie koncepcie odboru verejného zdravotníctva Ministerstvom zdravotníctva SR v roku 1997.

V priebehu 10 rokov existencie sa štruktúra ŠVZ postupne menila. V súčasnosti má maticový typ organizačnej štruktúry. Programový manažment je vo vzájomnom vzťahu s manažmentom jednotlivých oddelení. Súčasná ŠVZ má 5 kateder, a to Katedru sociálneho lekárstva a organizácie zdravotníctva, Katedru medicínskej informatiky, Katedru zdravotníckeho práva, Katedru manažmentu a Katedru medicínskej pedagogiky. V niektorých katedrách boli zriadené subkatedry, napríklad Katedra sociálneho lekárstva a organizácie zdravotníctva má Subkatedru zdravotnej výchovy a Subkatedru sociológie zdravia.

V programovom manažmente dominuje štúdium Master of Public Health (MPH), ktoré v súčasnosti existuje ako trojročné prerušované štúdium. Každý rok absolvujú poslucháči štyri dvojtyždňové sústreďenia. Na konci prvého a druhého školského roku sa uskutoční obhajoba seminárnej práce a kolokviálna skúška. Na konci tretieho roku štúdiá potom študenti obhajujú záverečnú prácu a skladajú záverečnú skúšku formou písomného testu.

Počas akademického roku ŠVZ organizuje okolo 80 školiacich podujatí (kurzy krátkodobé, semináre, školiace miesta, špecializačné kurzy, atď.). Počas posledného školského roku (1999/2000) absolvovalo kurzy poriadané ŠVZ 1946 postgraduálnych študentov, z toho 22 absolventov ukončilo trojročné štúdium MPH (Masters of Public Health).

ŠVZ sa stala úzko spolupracujúcou inštitúciou Ústavu medicínskej etiky a bioetiky (ÚMEB) v Bratislave (a vice versa) a podieľala sa na príprave niektorých špecializovaných medzinárodných konferencií a seminárov ÚMEB (1, 2, 3, 4, 5). Možno pozorovať, že verejno-zdravotnícka etika, ako súčasť bioetiky s rastúcim významom v celom kultúrnom svete, už prešla svojimi prvými vývojovými krokmi aj na Slovensku (6, 7).

Výskumné aktivity ŠVZ sa uskutočňujú v rámci 7 výskumných projektov. Počas posledného akademického roku pracovníci ŠVZ uverejnili 4 odborné knižné publikácie a 88 článkov vo vedeckých časopisoch doma i v zahraničí.

Počas 10-ročnej histórie ŠVZ boli jej pracovníci ocenení viacerými významnými cenami: Jeseniova cena (1993), Reimanova cena (1994), Cena Slovenského literárneho fondu (1999), Dieškova medaila (2000), Dérerova cena (2000), Zlatá medaila Slovenskej lekárskej spoločnosti (2000).

Záujem o štúdium na ŠVZ sústavne narastá.

The School of Public Health (SPH) in Bratislava was established 10 years ago at the Slovak Postgraduate Academy of Medicine, which is directly governed by the Ministry of Health of the Slovak Republic. The SPH offers both postgraduate, and continuing education in public health. The SPH is engaged in the network of European schools of public health - Association of Schools of Public Health in the European Region (ASPHER).

The school was established within the framework of the EUROHEALTH Programme as a result of the Collaborative Agreement between the World Health Organization's (WHO) Regional Office for Europe in Copenhagen and the Ministry of Health of the Slovak Republic. The future SPH staff visited several well-renowned similar institutions in Europe, such as London School of Public Health and Tropical Medicine, Schools of Public Health in Göteborg, Düsseldorf, Rennes, Granada, Bielefeld, Valencia, Kraków and Barcelona. An important event in the history of SPH was adopting and publishing of the conception of the discipline of public health by the Ministry of Health of the Slovak Republic in 1997.

In the course of its ten-year existence, the organisational structure of SPH has gradually evolved. Currently, SPH has a matrix-type structure. Programme management of SPH is interrelated with the management of the departments. Present SPH has 5 departments: Department of Social Medicine and Organization of Health Care, Department of Medical Informatics, Department of Management, Department of Medical Law, and Department of Medical Education. Some SPH departments are divided into subdepartments (e.g. Department of Social Medicine and Organization of Health is divided into the Subdepartment of Health education and Subdepartment of Sociology of Health).

In the programme management, an important place belongs to the study of Master of Public Health (MPH), which at present exists as a 3-year part-time study. Each year, MPH students attend four two-week courses. At the end of the first and second school year, they have to defend a concrete project work submitted in writing, and pass a colloquy. At the end of the third school year the students defend dissertation, and pass the final examination in the form of a written test.

SPH organizes about 80 educational activities per academic year (short-term courses, seminars, individual tutorships, special training courses, etc.). During the last school year (1999/2000), 1946 postgraduate students passed through different teaching activities and courses organised by SPH; 22 students completed successfully the three-year MPH study.

SPH became a close collaborating institution to the Institute of Medical Ethics and Bioethics (IMEB) in Bratislava. The faculty members of SPH took part in various educational activities of IMEB (and vice versa) and also in the specialised international conferences and seminars of IMEB (1, 2, 3, 4, 5). It might be observed, that public health ethics - being an increasingly important part of the contemporary bioethics enterprise worldwide - has already passed its first steps of development in Slovakia (6, 7).

Research activities of SPH are accomplished within the framework of 7 research projects. During the last academic year the SPH staff published 88 articles and 4 books.

During the ten-year history of SPH the following prizes have been awarded to its employees: Jesenius Prize (1993), Reiman's Prize (1994), Slovak Literary Fund Prize (1999), Dieška's Medal (2000), Dérer's Prize (2000), Golden Medal of the Slovak Medical Association (2000).

The interest in the study at SPH has been constantly growing.

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EVALUATION OF THE MASTER OF PUBLIC HEALTH STUDY BY THE PARTICIPANTS

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Abstract

Authors report the results of an evaluation study of the Master of Public Health (MPH) programme at the School of Public Health (SPH) in Bratislava. The group of 21 MPH programme participants (the class 1998 - 2001) took part in the study. A standardized questionnaire was administered. The results of evaluation were positive. Possibilities of further improvement of the programme were also revealed.

Key words: public health, School of Public Health (Bratislava), programme evaluation.

Introduction

In the year 2001, we not only enter the new millenium, but at the same time the School of Public Health (SPH) in Bratislava celebrates its 10th anniversary. During the whole period of the SPH's existence, its programmes were continuously evaluated by the participants concerning their quality and correspondence to the participants' needs. The results of evaluations were published (1, 2, 3, 4) and used to foster improvements and further development of the programmes.

Comparisons of the previous expectations and evaluation of the Master of Public Health (MPH) programme by the students at the programme completion (5, 6), as well as reports on the first experiences with application of the knowledge and skills obtained within the programme by its frequentants were also published previously (7, 8).

In this study, we aimed at evaluation of the 1998 - 2001 run of the MPH programme at SPH in Bratislava from the point of view of the programme participants.

Methods

The group of respondents consisted of 21 participants of the 3-year part-time course of the MPH programme at SPH in Bratislava. They entered the programme in September 1998 and successfully completed it in June 2001. The survey evaluated and reported here was conducted at the MPH study completion. The standardised, anonymous questionnaire was administered to all MPH programme participants.

The participants were asked to evaluate the MPH study according to the following dimensions:

1. General enrichment of knowledge.
2. Proportion between theoretical and practical education.
3. Didactic sequence of individual themes in the programme.
4. Appropriateness of space and time given to individual modules and themes.

The participants were asked to rate their answers on the scale ranging from 1 (most appropriate) to 5 (not appropriate). The questionnaire contained also two open-answer questions about the positives and negatives of the completed MPH study programme.

Results

The most positive reactions (**Table 1**) were expressed regarding the question about the general enrichment of knowledge. All 21 participants considered it as appropriate, 10 of them even most appropriate.

Table 1

Evaluation of the Master of Public Health Programme at the School of Public Health in Bratislava by the Programme Participants

Item Evaluated	Evaluation*					Total
	1	2	3	4	5	
General enrichment of knowledge	10	11	-	-	-	21
Proportion between theoretical and practical knowledge	4	14	3	-	-	21
Didactic sequence of individual themes	10	9	2	-	-	21
Space of time given to individual modules and themes	8	11	2	-	-	21

* Range: 1 - most appropriate, 5 - inappropriate.

When answering the second question concerning the proportion between theoretical and practical education, 18 out of 21 participants considered it as appropriate, and 4 of them as the most appropriate. Three participants found the extension of the practical part of the educational process as especially useful.

As to the third question about didactic sequence of individual themes within the MPH study, the majority of answers (19) considered it as appropriate, 10 of them as the most appropriate. Two participants considered it as partly appropriate.

The last question about appropriateness of the space and time given to individual modules and themes was answered by the majority of participants (19) as appropriate, 8 of them as the most appropriate. Two participants considered it as partly appropriate.

The questionnaire contained also two open-answer questions about the positive and negative aspects of the

MPH programme. Each respondent could list three items in each category. As to the positive aspects, the participants most often considered the following ones: modern educational methods used, very competent teachers involved, content and presentation of the programme modules, team work, the amount of new knowledge comprised and delivered by the programme. Among the negative aspects most often listed by the participants were the following items: lack of practical application within some topics, relatively late distribution of the written materials for some modules, missing of the summarizing „ex post“ seminars. All participants shared the opinion that educational objectives of the programme had been achieved.

Table 2

Teachers of the SPH* Master of Public Health Programme (1998 - 2001)

Teachers	A*	B**	C***	Total
University professors	6	7	4	17
Associated professors	9	13	-	22
Other experts	12	42	5	59
Total	27	62	9	98

* Employees of the School of Public Health (SPH), Bratislava.

** Slovak citizens not employed by SPH.

*** Visiting teachers, non-citizens of the Slovak Republic.

The teachers involved in the SPH's MPH programme play a decisive role in securing the programme's quality and proper delivery. The information concerning the teachers' degree of education and their relationship to SPH is given in the **Table 2**. Total number of teachers involved in the MPH programme was 98. This number included also the specialists teaching at the specialised seminars organised by SPH during the MPH study period. In general, the MPH programme teachers were highly educated specialists possessing a considerable pedagogical experience.

Conclusion

The evaluation of the SPH's MPH study programme by the participants of the 1998 - 2001 MPH course highlighted the positive results of the programme. Some possibilities for the programme's improvement and future development were also revealed. Periodical evaluation of the MPH programme performed by the students at its completion is an indispensable mean of fostering the programme's quality and practical applicability.

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Abstrakt

L. Badalík, J. Matulník, V. Šajter, L. Hegyi, D. Brukkerová: Evaluation of the Master of Public Health Study by the Participants. [Hodnotenie štúdia 'Master of Public Health' účastníkmi.] Medicínska etika & bioetika / Medical Ethics & Bioethics, Vol. 8, 2001, No. 1 - 2, p. 16 - 17. Autori referujú o výsledkoch hodnotiacej štúdie programu Master of Public Health (MPH) Školy verejného zdravotníctva v Bratislave. Na štúdiu sa zúčastnila skupina 21 frekventantov programu (beh 1998 - 2001). Výskum sa uskutočnil pomocou štandardizovaného dotazníka. Výsledky hodnotenia programu zo strany účastníkov boli veľmi pozitívne, pričom poukázali i na možnosti jeho ďalšieho zlepšenia.

Kľúčové slová: verejné zdravotníctvo, škola verejného zdravotníctva (Bratislava), hodnotenie študijného programu.

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GERIATRICKÉ SOCIÁLNE SYNDRÓMY

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Abstrakt

Za sociálne kritériá, ktorými sa skupina starých ľudí odlišuje od ostatnej populácie, považujeme najmä vek, sociálna príslušnosť k vrstve poberateľov starobného dôchodku, nižší ekonomický štandard, postihnutie dôsledkami zníženia v somatickej i mentálnej oblasti, chronické choroby, vedúce k častejšiemu výskytu zlého zdravotného stavu a skutočnosť, že 80 % populácie umiera vo veku nad 65 rokov. Ako geriatrické sociálne syndrómy označujeme klinicky významné situácie, ktoré postihujú osoby vyššieho alebo vysokého veku a vznikajú pri narušení ich rovnováhy pri priamom pôsobení nepriaznivých sociálnych činiteľov alebo pri neprimeranej reakcii starého človeka na ne. Medzi geriatrické sociálne syndrómy počítame dysfunkciu rodiny, sociálnu izoláciu, násilie na starom človeku a sociálnoekonomický stres.

Kľúčové slová: geriatRIA, geriatrické sociálne syndrómy, starý pacient.

Starý pacient sa od chorých z mladších vekových skupín odlišuje kritériami biologickými, psychologickými i sociálnymi, pričom za najväčšie riziká staroby možno

považovať vysoký vek s jeho sociálnymi dôsledkami, zlý zdravotný stav, ohrozenie stratou sebestačnosti a vznikom odkázanosti na pomoc a blízkosť smrti (1).

Pokiaľ ide o **sociálne kritériá**, skupinu starších ľudí odlišuje od ostatnej populácie najmä:

- vek,
- sociálna príslušnosť k vrstve poberateľov starobného dôchodku,
- nižší ekonomický štandard,
- postihnutie dôsledkami starnutia v somatickej i mentálnej oblasti,
- chronické choroby, vedúce k častejšiemu výskytu zlého zdravotného stavu,
- skutočnosť, že 80% populácie umiera vo veku nad 65 rokov (2).

Ako **geriatrické sociálne syndrómy** označujeme klinicky významné situácie, ktoré postihujú osoby vyššieho alebo vysokého veku. Vznikajú pri narušení ich rovnováhy pri priamom pôsobení nepriaznivých sociálnych činiteľov alebo pri neprimeranej reakcii starého človeka na ne. Ku geriatrickým sociálnym syndrómom rátame najmä dysfunkciu rodiny, sociálnu izoláciu, násilie na starom človeku a sociálnoekonomický stres (2).

1. Dysfunkcia rodiny vzniká, ak rodina nechce, nemôže alebo nevie plniť svoju podpornú funkciu voči svojmu starému členovi. Ten na to môže reagovať celým radom psychosomatických ťažkostí, alebo adaptačným zlyhaním. Dysfunkcia rodiny patrí k najčastejším sociálnym syndrómom v geriatrickej praxi.

2. Sociálna izolácia znamená vyradenie jedinca zo spoločnosti. Toto vyradenie môže byť dobrovoľné alebo nútené. Sociálna izolácia vzniká:

a. z faktorov psychosociálnych, ako je strata spoločenskej úlohy a prestíže odchodom do dôchodku, pocit nepotrebnosti, nepripravenosť na starnutie a iné;

b. z prítomnosti obmedzenia, ktoré spočíva v poruche zdravia, ako je napr. inkontinencia, strata zraku alebo sluchu, alebo zo sociálneho obmedzenia, ako je extrémna chudoba;

c. z osamelosti po strate partnera, alebo v dôsledku vysokého veku po úmrtí rovesníkov a neprítomnosti rodiny;

d. z antisociálneho správania, ako je porucha chovania, sociálna deprivácia a iné.

Sociálna izolácia sa podľa Pacovského (3) prejavuje viacerými spôsobmi:

● *psychosociálnou depriváciou* pri pasívnom spôsobe života a odmietaní komunikácie alebo pomoci,

● *syndrómom osamelosti*, so snahou o samostatnosť bez ohľadu na reálnu situáciu,

● *syndrómom závislosti*, s nízkym sebahodnotením a snahou prijímať pomoc i v situáciách, keď to nie je nutné,

● *stratou pocitu bezpečia*, strach zo sociálnej budúcnosti, strata životných istôt,

● *syndrómom štyroch stien*, spôsobeným stratou programu,

● *ponorkovou chorobou*, ktorá je prejavom izolácie vnútri malej skupiny, snažiacej sa zachovať nemennosť situácie,

● *syndrómom opusteného hniezda* po odchode detí, keď partneri nezvládnu novú situáciu vo vzťahoch,

● *zanedbávaním seba i domácnosti (Diogénov syndróm)*,

● *vynucovaním pozornosti sťažnosťami* na často nepatrné problémy, ktoré je signalizáciou potreby pomoci.

Rizikovými faktormi sociálnej izolácie sú:

- psychosociálne faktory, ako viazanosť na zamestnanie,
- prítomnosť handicapov, ako inkontinencie, hluchoty, slepoty,
- objektívna osamotenosť - vdovy, gerontické rodiny,
- sociálne rizikové osoby, t.j. osoby s antisociálnym chovaním.

3. Násilie na starom človeku je pomerne časté a má svoje typické prejavy:

● o *zneužívanie* ide, ak sa od starého človeka vyžaduje viac fyzickej a psychickej pomoci a ekonomickej podpory než je schopný zdravotne a ekonomicky poskytnúť,

● o *zanedbávanie* ide, ak vznikne deficit v citových vzťahoch, nedostatok podpory, starostlivosti a prejavov rodinnej súdržnosti,

● *týranie* môže byť fyzické alebo psychické.

Fyzické násilie je častejšie, než sa predpokladá, a jeho obeťou sú najčastejšie ženy. Stále sa zvyšujúca kriminalita v posledných rokoch zaznamenala zvýšený počet násilných trestných činov práve proti starým ľuďom.

Psychické týranie sa prejavuje hrozbami, príkormi, nátlakom, snahou o inštitucionalizáciu alebo zbavenie svojravnosti.

4. Sociálnoekonomický stres. Stres, podmienený sociálnymi faktormi, sa môže manifestovať v sociálnom správaní a jeho zvládnutie môže byť sociálnym dŕhaním. O sociálnom strese by sa malo hovoriť vtedy, ak nedochádza len k narušeniu osobnej identity, ale k ohrozeniu sociálnej existencie jedinca alebo skupiny, k ohrozeniu, obmedzeniu alebo spochybneniu jeho sociálnej kompetencie. Sociálny stres môže spôsobiť adaptačné zlyhanie, ktoré sa vo vyššom veku prejavuje pod obrazom geriatrického maladaptívneho syndrómu (4).

Sociálna kompetencia je obmedzená, ak sa znížila doterajšia miera možností ovplyvňovať konanie druhých.

Sociálna identita je postihnutá, ak príde k obmedzeniu sociálnych úloh, s ktorými bol ich nositeľ identifikovateľný.

Stresová reakcia jednej osoby môže výrazne ovplyvniť sociálny postoj a správanie inej osoby. Čím silnejšia je stresová reakcia, tým nižšia je schopnosť nadviazať pozitívny emocionálny kontakt k iným, tým väčšie je riziko vyvolania negatívnej odozvy, čo opätovne zosilňuje stres.

V domácnosti opatrovaný starý človek je stresovaný stratou sociálnej kompetencie a sociálnej identity, reaguje mrzutosťou na snahy svojich rodinných príslušníkov, spôsobuje napätia, ktoré napokon vedú k tomu, že sa ho rodina vzdáva a usiluje sa o jeho inštitucionalizáciu, čo zvýrazní pôvodný sociálny stresor.

Úroveň sociálnych vzťahov významne ovplyvňuje telesné i duševné zdravie. Hospodárska chudoba ako stresový faktor ovplyvňuje strednú dĺžku života nielen vysokou doženskou úmrtnosťou, kvalitatívnou alebo kvantitatívnou podvýživou, infekčnými chorobami, napr. opakovaným vzostupom incidencie tuberkulózy alebo hnačkovými ochoreniami detí, ale i stresom z neslobody, existenčnej neistoty, strachom z budúcnosti. Tieto faktory nie sú prítomné len v krajinách tretieho sveta a v totalitných krajinách, ale i v transformujúcich sa krajinách, trpiacich následkami totalitného režimu. Sú prítomné i vo vyspelých krajinách, kde postihujú väčšinou menej vzdelanú a menej kvalifikovanú časť obyvateľstva. Stres zo sociálnych vzťahov postihuje takisto ekonomicky dobre zabezpečené vrstvy vysokým pracovným vypätím, konkurenčným prostredím a z toho plynúcim stálym existenčným ohrozením.

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Abstract

Hegyí, L. Badalík, L.: Geriatric Social Syndromes. [Geriatrické sociálne syndrómy.] Medicínska etika & bioetika / Medical Ethics & Bioethics, Vol. 8, 2001, No. 1 - 2, p. 17 - 19. Social criteria differing a group of elderly people from the rest of population involve, in particular: the age, belonging to a social group on social scheme benefits, lower economical standard, being affected by consequences of ageing both physically and mentally, chronic diseases leading to a frequent incidence of worsened health status, and finally the fact that 80% of population dies at the age over 65 years. Geriatric social syndrome includes clinically significant situations affecting the balance of individuals of high or very high age as a direct effect of unfavourable social factors or an inadequate reaction of the elderly to them. **1.** Family dysfunction arises, when the family does not wish, cannot, or is unable to fulfill its supportive role to its old family member. The elderly may react by a variety of psychosomatic complaints or maladjustment failure. Family dysfunction ranks among the most common social syndromes in geriatrics. **2.** Social isolation means exclusion of the elderly from the society. This exclusion may be either voluntary or forced. **3.** Violence against the elderly has its typical manifestations, such as abuse, neglect, or maltreatment, which may be both physical and psychic. **4.** Socio-economic stress is induced by social factors. Social stress occurs, when not only the personal identity of the elderly is affected, but also the social existence of an individual or a whole group is endangered, restricted, or the person's social competence is equivocal. Social stress may cause maladjustment failure, which manifests itself as the geriatric maladjustment syndrome.

Key words: geriatric medicine, geriatric social syndromes, elderly patient.

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O KNIHÁCH / BOOK REVIEWS

JOURNAL OF MEDICAL ETHICS - CLINICAL ETHICS COMMITTEES SUPPLEMENT

An outstanding 1/2001 Supplement to one of the most prestigious medical ethical journals in the world - the *Journal of Medical Ethics* (London) - has been entirely devoted to the problem of clinical ethics committees (CECs). As editors (*A. Slowther, T. Hope and R. Ashcroft*) note in the editorial introduction, CECs are already well established in North America, where they are known as hospital or health care ethics committees, but similar groups and kinds of clinical ethics support are now developing in Europe as well. The timely supplement provides an overview of the issues arising from the provision of clinical ethics support services, and clinical ethics committees in particular. Its primary focus is on UK but contributors from North America and continental Europe provide an international perspective.

Following contributions were included in the Supplement: * Editorial: Clinical ethics committees: a worldwide development (*A. Slowther, T. Hope and R. Ashcroft*) * Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health care professionals in the UK (*A. Slowther, Ch. Bunch, B. Woolnough, T. Hope*) * Snapshots of five clinical ethics committees in the UK (*M. Szeremeta et al.*) * Support for ethical dilemmas in individual cases: experience from the Neu-Mariahilf hospital in Goettingen (*A. Simon*) * The Freiburg approach to ethics consultation: process, outcome and competencies (*S. Reiter-Theil*) * What triggers requests for ethics consultation? (*G. DuVal et al.*) *

Electronic communication in ethics committees: experience and challenges (*A. R. Eiser et al.*) * What is the role of clinical ethics support in the era of e-medicine? (*M. Parker, J. A. Muir Gray*) * Developing standards for institutional ethics committees: lessons from the Netherlands (*H. H. van der Kloot Meijburg, R. H. J. ter Meulen*) * Teaching old dogs new tricks - a personal perspective on a decade of efforts by a clinical ethics committee to promote awareness of medical ethics (*M. G. Tweeddale*) * Clinical ethics committees and the formulation of health care policy (*L. Doyal*) * Legal aspects of clinical ethics committees (*J. Hendrick*) * Clinical governance - watchword or buzzword? (*A. V. Campbell*).

I agree with the editors that the supplement provides a good reference point for considering the future development of clinical ethics support services in UK. I do believe, however, it may be useful in countries beyond UK as well, especially in those of Central and Eastern Europe struggling with profound and difficult reforms of their health care systems. The editors are optimistic for the future of CECs, or other ethics support services, especially concerning their potential of improving and promotion of the quality of health care. It remains to be seen, however, whether CECs can make good this early promise in UK and beyond.

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HEALTH CARE REFORMS IN CENTRAL AND EASTERN EUROPE

E. Křížová, J. Šimek, 3rd Faculty of Medicine, Charles University - Institute of Postgraduate Medical Education - School of Public Health, Prague, 2000, pb, 134 p.

An interesting collection of papers from the international conference held in Prague in 1999. The conference aimed at „dealing with ethical, sociological and philosophical aspects of health care systems in the Central and Eastern Europe with respect to the Western-European development and admission to the European Community, and to promote international discussion on problems of health care reforms in this part of the world, perceived in the broader context of interdisciplinary approaches with special regards to reflection through the prism of humanities. These are usually neglected in the current discussion, dominated by economy and law.“

In an introductory chapter *J. Šimek* and *V. Špalek* (Prague) review most important ethical, sociological and philosophical aspects of health care systems providing an interesting and important framework. *D. Callahan* (The Hastings Center, Garrison (NY), USA) analyses the relationships between medicine and the market. *J. Payne* (Prague) puts forward some refreshing thoughts on justice, and its somewhat paradoxical ties with lottery. *A. DenExter* (Rotterdam) analyses health legal reforms in the Czech Republic and Hungary. *L. Hoffman* and *H. Janěčková* devote their papers to the problems of Czech physicians within the health care reform. *E. Křížová* gives an overview of the Czech health care system transformation, which she sees as placed at the important crossroads of the past and future. *M. Mastilica* reports on health care system reforms in Croatia. *R. Rychlik* in Germany, *I. Forgács* in Hungary, *C. Włodarczyk* in Poland, and *L. Šoltés* in the Slovak Republic.

As *M. Bojar* puts it in the preface, the „book should

not be read by the health care transformation connoisseurs and "fans," only, but also by students of medicine and students of social and political science. The health care and health care market represent a serious, very broad, and challenging theme, which should be a target for the study and research of the new generation of health care and social science researchers. (...) This book is aimed at the motivated and interested readers and let us hope it will find them." Congratulating the editors for an outstanding achievement, I recommend the book to the attention of both the professionals mentioned, and of their students.

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MEDICINE IN CONDITIONS OF DEFICIT OF RESOURCES **(Medicina v uslovijach deficita resursov)**

V. V. Vlasov, Triumph, Moscow, 1999, pb, 192 pp.

Very interesting, well documented and thoughtful study on the problem of medicine, which is to function in the situation of a serious deficit of necessary resources. It brings to the reader a unique information about the health care system in Russian Federation (RF), and about the problems it encounters within its profound transformation. The focus of the monograph is placed on the problem of rationing, which author understands as the only possible approach in dealing with the problem of scarcity of resources in health care in a rational and just way.

The material of the book is organised into 8 main chapters (besides the preface, introduction, conclusions, and references). The first chapter gives the reader an overview of the legal, legislative, and economical basis of functioning of the health care system in RF. Next chapter deals with the technological aspects of the problem of choosing a particular health intervention in the situation of scarcity. The chapter on the principles of rationing of the scarce resources analyses the decision-maker, and other elements of the rationing procedure itself. The following chapter analyses some negative factors that prevent the rational utilisation of scarce health care resources from taking place in practice. Then, some examples of rationing approaches and methods from the countries outside RF (such as USA, United Kingdom, Scandinavian countries, Israel, New Zealand) are described. The ratio-

ning possibilities at the level of a single health care facility are discussed in the next chapter. The experience of rationing in medicine and health care during the war, or when dealing with serious catastrophies of nature (such as earthquakes) are also recalled. The last three chapters form probably the most interesting part of the book. They are devoted to the problem of health care rationing in relationship to the concrete patient, to the ethical analysis of rationing, and to the role society can/should play in the process.

The book is dedicated „to the physicians, health policy makers, sociologists and social workers, and to all, interested in the development in RF of a just and effective health care system.“ Besides the readers in RF and other independent countries of the former Soviet Union, I believe, the book may be of particular interest and use also to health care professionals, managers, and health policy makers in Central and East European countries that undergo similar transformation processes of their formerly „socialist health care systems“, albeit their situation of scarcity may not match the one encountered by the RF health reformers. The book might be of help also to those readers, who want to understand better the RF health care system conditions, prevailing theoretical and practical approaches to the problem of rationing in RF, and also the „way of thinking“ of their Russian colleagues. The monograph would be worth of a good English translation.

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If mankind is not to perish after all the dreadful things it has done and gone through, then a new spirit must emerge. And this new spirit is coming not with a roar but with a quiet birth, not with grand measures and words but with an imperceptible change in the atmosphere - a change in which each of us is participating and which each of us regards as a quiet boon.

Albert Schweitzer, 1959

In this area of medical science [organ transplantation] too the fundamental criterion must be *the defence and promotion of the integral good of the human person*, in keeping with that unique dignity which is ours by virtue of our humanity.

John Paul II, 2000

Medicínska etika & bioetika - Medical Ethics & Bioethics, založený ako časopis Ústavu medicínskej etiky a bioetiky v Bratislave, spoločného pracoviska Lekárskej fakulty Univerzity Komenského a Inštitútu pre ďalšie vzdelávanie zdravotníckych pracovníkov v Bratislave. Je určený pracovníkom etických komisií v Slovenskej republike, ako aj najširšej medicínskej a zdravotníckej verejnosti. Má tiež za cieľ napomáhať medzinárodnú výmenu informácií na poli medicínskej etiky a bioetiky. Prináša informácie o aktuálnych podujatiach a udalostiach v oblasti medicínskej etiky a bioetiky, pôvodné práce, prehľady, reprints legislatívnych materiálov a smerníc pre oblasť bioetiky, listy redakcii a recenzie. Príspevky a materiály uverejňuje v slovenskom alebo anglickom jazyku. Vybrané materiály vychádzajú dvojazyčne. Vedecké práce publikované v časopise musia zodpovedať obvyklým medzinárodným kritériám (pozri Pokyny prispievateľom - ME&B 2/94, s. 10).

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