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■

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OD REDAKCIE / EDITORIAL

Vážené kolegyne, kolegovia, December '94

prichádzajú k Vám posledné dve tohtoročné čísla *Medicínskej etiky a bioetiky*, ktoré znamenajú zavŕšenie prvého ročníka existencie nášho časopisu. Sme radi, že i pre toto záverečné dvojčíslo sa nám podarilo získať zaujímavé materiály, ktoré obohatia a rozšíria obzor nášho uvažovania o aktuálnych otázkach medicínskej etiky a bioetiky. Zvlášť by som Vás chcel upozorniť na úplný text "Deklarácie o právach pacientov v Európe", ktorý vychádza v našom časopise po prvýkrát v slovenskom preklade.

Do tohto dvojčísla sme zaradili dve pôvodné práce - príspevok Dr. I. Škodáčka o niektorých etických problémoch súčasnej psychiatrie a prácu Doc. R. Pullmanna a Doc. M. Sámela o etických aspektoch "molekulárnej medicíny". Aktualitou je príspevok o najdôležitejších problémoch obsiahnutých v Akčnom programe Medzinárodnej konferencie o populácii a rozvoji, ktorá sa pod záštitou Organizácie spojených národov konala v septembri tohto roku v egyptskej Káhire. V pravidelnej rubrike "Etika v ošetrovateľstve" prinášame pokračovanie pôvodného prekladu publikácie Dr. Fitzpatricka o etike v ošetrovateľskej praxi. List redakcii od Doc. R. Pullmanna sa zamýšľa nad otázkami vyučovania medicínskej etiky na úrovni pregraduálnej i postgraduálnej, a to v situácii existujúceho pluralizmu názorov a postojov v súčasnej morálnej filozofii, ako aj v konkrétnej spoločenskej praxi. Ďalej pokračujeme v uverejňovaní materiálov z medzinárodných kurzov medicínskej etiky usporiadaných naším ústavom. V tomto čísle nájdete text prednášky Dr. K. F. Gunninga o niektorých základných otázkach medicínskej etiky a príspevok Dr. U. Filibecka o problematike drogovej závislosti v Taliansku a v krajinách Európskej Únie.

Dovoľte mi, milé kolegyne a kolegovia, na sklonku starého a na začiatku nového roku zaželať Vám v mene redakcie dobré zdravie, pevné nervy, odvahu a vytrvalosť, ako aj úspech vo Vašom osobnom, rodinnom a pracovnom živote. Všetko najlepšie v novom roku 1995!

MUDr. Jozef Glasa

Dear coleagues, December '94

in a cummulated issue two last numbers of the first volume of *Medical Ethics & Biothics* are coming to your kind attention. We are pleased to publish in the issue some interesting materials, capable to broaden our mental horizons, and enhance our reasoning on the actual questions of medical ethics and bioethics. We are especially happy to reprint in this issue the full text of A Declaration on the Promotion of Patients' Rights in Europe (on the occasion of its being given here for the first time in its complete Slovak translation).

You can find two original articles in this issue - a contribution of Dr. I. Škodáček on some ethical aspects of contemporary psychiatry (in Slovak), and the work of Prof. R. Pullmann and Prof. M. Sámel on ethical impact of molecular biology on medicine (in English). Our actual contribution reviews the most important issues contained in the Program of Action of the United Nations sponsored International Conference on Population and Development (ICPD), held in Cairo (Egypt) in the beginning of September. Under our regular headings „Ethics in Nursing" we bring in this issue the continuation of our original Slovak translation of the book of Dr. Fitzpatrick on ethics in nursing practice. The letter to the editor from Prof. R. Pullmann (in English) considers different problems of undergraduate and postgraduate teaching of medical ethics in the situation of prevailing pluralism of opinion and standpoints within contemporary moral philosophy, seen also in the present „practical" life and realities of modern secularized societies. We also continue publishing the materials from the International Courses on Medical Ethics organized by our Institute. In this issue you find the text of the lecture of Prof. K. F. Gunning (Roterdam, The Netherlands) on some basic issues in medical ethics (in English), and the contribution of Dr. U. Fillibeck (Rome, Italy) on the problems of drug addiction in Italy and countries of the European Union.

Let me, dear coleagues, to use this distinguished time - quite close to the end of the Old and the beginning of the New Year 1995 - to share with you the best seasonal wishes of your ME&B redaction team, especially those for a good health, clear thoughts, strong courage and persistent brave mood, as well as for the fullest success and satisfaction in your personal, family and professional life. The best wishes for the New Year 1995!

Jozef Glasa, M.D.

Reklama

Advertisement

PLÁNOVANÉ PODUJATIA

FORTHCOMING EVENTS

INTERNATIONAL EVENTS/MEDZINÁRODNÉ PODUJATIA

EUROPE/EURÓPA

● **Biotechnology in European Society**, Nov. 21 - 22, 1994, The Hague (The Netherlands).

● **Second European Conference on Medicines Research: Perspectives in Clinical Trials**, Dec. 5 - 6, 1994, Brussels (Belgium).

● **Ethical Aspects of Brain Research**, Dec. 15 - 17, 1994, Rome (Italy).

● **Journées Annuelles d'Ethique 1994**, Dec. 16 - 17, Paris (France).

● **Randomised Controlled Trials: Ethical and Legal Issues**, Febr. 21 - 22, 1995, London (UK).

● **Psychiatry, Literature and Philosophy**, March 31 - April 8, 1995, Amsterdam (The Netherlands).

● **Volunteers in Research and Testing**, April 3 - 5, 1995, Manchester (UK).

● **First International Congress of the Hans-Jonas Society - The Conscience of Medicine**, April 19 - 22, 1995, Vienna.

● **Pluralism, Public Policy and the Hippocratic Tradition**, June 22 - 24, 1995, Budapest.

● **Fourth International Conference on Health, Law and Ethics in a Global Community**, July 16 - 20, 1995, Amsterdam (The Netherlands).

● **XXI International Congress on Law and Mental Health**, June 25 - 29, 1995, Tromso (Norway).

● **9th Annual Conference of the European Society for Philosophy of Medicine and Health Care - Medicine and Culture**, Sept. 21 - 23, 1995, Island of Cos (Greece).

OVERSEAS/ZÁMORIE

● **Limits and Latitudes - 25th Anniversary Symposium of The Hastings Center**, Oct. 29, 1994, Boston (USA).

● **Changes and Choices for IRBs**, Oct. 30 - Nov. 1, 1994, Boston (USA).

● **Ethical Issues for the Next Decade and Beyond: Genetics Research and Violence/Abuse**, Nov. 3, 1994, Colorado Springs (USA).

● **Perspectives on Medical Futility: When Patients' Faith and Culture Compel Demands for Treatment**, Nov. 3 - 4, 1994, Rosemont, Ill (USA).

● **Choices at the End of Life: A Conference Focusing on Issues Related to Death and Dying**, Nov. 4 - 5, 1994, Sarasota, Fl (USA).

OZNAMY REDAKCIE

NEWS FROM THE EDITOR

● **Z finančných a organizačných dôvodov** bude časopis ME&B **v roku 1995** vychádzať **štvrťročne**. **Pôvodná cena predplatného sa nezvyšuje**.

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PÔVODNÉ PRÁCE

ORIGINAL ARTICLES

ETIKA A PSYCHIATRIA

I. Škodáček

Klinika detskej psychiatrie DFNsP LF UK Bratislava

Abstrakt

Etické princípy sa výraznou mierou prejavujú v prístupe lekárov a spoločnosti k pacientom liečeným na psychiatrii. Neetický prístup totalitných vlád viedol v minulosti k politickému zneužívaniu psychiatrie. V bývalom Československu boli psychiatrické zariadenia skôr určitými ostrovčekmi demokracie. V súčasnosti je hlavnou mravnou úlohou reforma psychiatrickej starostlivosti, ktorá sa má prejaviť aj v novej legislatívnej úprave. Ide tiež o významnejšie zapojenie rodín pacientov a rôznych spoločenských organizácií do procesu ich úspešného zaradenia sa do života.

Kľúčové slová: *etické princípy v medicíne, politické zneužitie psychiatrie, reforma v psychiatrii, svojpomocné skupiny pacientov*

Medicína nie je len vedou, je to tiež *ars medica*, ktorá sa prejavuje v povolaní lekára. Žiaden človek snáď nedostal väčšiu zodpovednosť, ale tiež aj povinnosť voči svojmu 'blížnemu', ako ten, kto je lekárom. Svoje poslanie vykonáva na základe tzv. prirodzeného zákona, ktorého základom je rešpektovanie individuálneho práva každého človeka na život a na jeho posvätnosť. Na ochranu svojho života a zdravia. Práca lekára, o to viac psychiatra, je v dialektickom zväzku ovplyvnená štruktúrou spoločnosti. Rozpadu spoločností, zneužívaných komunistickými stranami, predchádzala rôzne vyjadrená nivelizácia vyšších citov jednotlivca. Osobnosti s najmenej narušenými vyššími citmi, so schopnosťou empatie a pochopenia pre druhých, boli často označované za zločincov, alebo za výrazne psychicky alterované osobnosti (napr. za psychopatov). Podľa vtedy užívaných "právnych" noriem totalitného režimu sa niekedy dostali - napriek pravidlám bežne uznávaných etických noriem - do väzníc alebo na psychiatriu.

Zrútením nemravného režimu, ktorý dokonca podpísal (ale nedodržiaval) záväzky v oblasti ľudských práv obsiahnuté v Záverečnom pakte Konferencie o bezpečnosti a spolupráci v Európe (Helsinky, 1975) - padla aj hranica perzistujúceho upierania dôstojnosti ľudskej bytosti. Vytvorili sa nové možnosti prístupu k človeku v zdraví a chorobe, ako po stránke telesnej, tak i duševnej. Laici so svojimi postojmi vnímajú a viac pochopia telesné poškodenie. Teologická etika pri poznaní nadprirodzeného chápe a preciťuje i duševné utrpenia človeka. Psychotraumy vie zmierniť religiózne psychoterapeutickými prístupmi. V prípade závažných psychiatrických ochorení však môže naraziť na kauzálnu bezradnosť. Vo vyspelých štátoch preto získali dôležitosť práve psychiatri. Všímajú si človeka v jeho komplexnej bio - psycho - sociálnej jednote. Pritom nehodlajú skĺznuť do psychiatrizácie občanov spoločnosti, ako sa to snažil nahovoriť verejnosti smer tzv. antipsychiatrie.

Duševná choroba môže narušiť kritickoť, úsudok, vôľu a konanie chorého, čo má svoj dopad a je niekedy predmetom i právneho riešenia. Právne normy uprednostňovali spoločenské hľadisko pred medicínskym pohľadom. V psychiatrii však vyvstáva, okrem zásadných biomedicínskych pohľadov, hlavne problém etický. Je to medziným aj otázka našich mravných povinností k chorému. Vychádzame pomerne často, aj neuvedomele, z odkazov minulosti. Európske národy vytvorili postupne tri verzie najvyššej hodnoty človečenstva: antické dobro - agathon, kresťanskú lásku -

agapé a osvietenskú slobodu - liberté. V spojení týchto hodnôt sa charakterizuje spoločenský človek, ktorý chce vytvárať solidaritu, dôveru a vzájomnosť v podobe človeka morálky [6]. Podobne od archaických dôb medicíny sa postupom času vytváral vzťah medzi liečeným a liečiteľom, ktorý v skratke vyjadril známy fyziológ Lekárskej fakulty Karlovej univerzity Prof. Mareš: „ Medzi chorým a lekárom je predovšetkým vzťah mravný" [1].

V civilizovaných krajinách možno pozorovať stálu snahu o zlepšovanie vzťahu medzi psychiatriou a spoločnosťou. Deontologické princípy v psychiatrii majú čo najjemnejšie odrážať a zhodnocovať etické normy, platné nielen v medicíne, ale aj v celej verejnosti, vrátane politického vedenia štátu. Je známe, že každá spoločnosť má do istej miery takých chorých, vrátane psychicky chorých, akých si zaslúži.

Na uplatňovanie etických zásad v lekárstve má vplyv predovšetkým mravná úroveň prostredia, v ktorom lekár vyrastal, bol vychovávaný a pôsobil. Niektorí lekári, vychovávaní ideológiou totalitnej spoločnosti, sa nevcítili do etických princípov medicíny. Sami nevhodným iatrogénnym pôsobením „vytvárali pacientov" pre psychiatriu. Devastácia okolia, prírody a mnohých ľudských vzťahov sa premietla aj do devastácie človeka pôsobiaceho dnes v takom humánnom povolaní, akým je lekárstvo. Už dávno prestal veriť v totalitný štát tak, ako tento štát neveril v človeka, občana. No viera v právo a ľudskosť sa ďalej nivelizovala. V lekárskej morálke sa porušovali špeciálne pravidlá správania určené najmä špecifickým vzťahom lekára k chorému. Veď ako sa dá hodnotiť z hľadiska morálky umiestnenie politicky nepohodlného človeka do psychiatrického zariadenia? (I keď v bývalom Československu k tomu dochádzalo v oveľa menšej miere ako v ostatných krajinách tzv. Východného bloku.)

Totalitná moc robí s osobnosťou človeka vlastne to isté, čo s celou spoločnosťou. Rozbíja dopredu dané, prirodzené a zdravé. Na troskách skutočnosti buduje čosi nové, ktoré svojimi vlastnosťami zodpovedá záujmom ľudí totality. Inkorporuje do ľudí strach, úzkosť a nezodpovednosť, spojené s paranoiditou. Potom záležalo iba od charakteru, citovej výbavy a vzdelania psychiatrov, aby v duchu Hippokratovej prísahy neškodili ľuďom, ktorí sa neetickou cestou dostali do psychiatrického zariadenia. Vo fašistickom, alebo komunistickom režime sa narušilo prirodzené chápanie morálnych noriem spoločenského odsúdenia - a čo je najhoršie - aj ich vnútorná sankcia, to jest ohlas vlastného svedomia (sebaodsúdenia, výčitky, hanba, a pod.). V tejto súvislosti si dovoľujeme tvrdiť, že psychiatria v bývalom Československu, za totalitného režimu, sa stala útočiskom prenasledovaných, nielen nástrojom intermitentného zneužívania voči politicky nepohodlným ľuďom. Vyslovený názor podporujú napríklad aplikácie komunitných systémov u pacientov, psychoterapeutické vedenia a výcviky lekárov. Tieto dynamické formy práce na psychiatrii sa neproklamovali nahlas ako demokratické, ale boli vo svojej podstate demokratickými. Takto paradoxne v psychiatrických zariadeniach vznikali tiež akési ostrovčeky demokracie v totalitnej spoločnosti.

Spoločenské zmeny, ku ktorým prišlo v krajinách bývalého východného bloku, sa neobmedzujú iba na politiku, ekonomiku, alebo štátnu správu, ale týkajú sa aj celého systému zdravotníctva, ktorý treba zreformovať. Má sa nadväzovať na všetko rozumné, vybudované v minulom období. Úroveň vývoja určitej spoločnosti sa dá merať podľa toho, ako diferencovane sa v rámci svojej zdravotníckej politiky, a tým aj v rámci psychiatrických inštitúcií, dokáže vysporiadať s individuálne vždy odlišnou problematikou svojich duševne trpiacich občanov [5]. A to je takisto otázka mravná.

Reforma psychiatrickej starostlivosti sa má začať v jadre, teda v rodine, ktorá ovplyvňuje od počiatku duševný vývin jednotlivca. Pri modernom posudzovaní ochorení sa presadzuje trend, aby sa pri všetkých ochoreniach viac zobrala do úvahy aj komponenta osobnostná, rodinná a širšie sociálna.

V praktickej pomoci človeku sa niekedy stierajú hranice medzi psychoterapeutickými prístupmi uplatňovanými v psychiatrii a v pastorálnej práci Cirkvi. Čoraz viac sa uvedomuje dôležitosť spirituálneho faktora v otázkach riešenia telesných ochorení a podpory zdravia. Tým nadobúda dôležitosť morálna zodpovednosť lekára a všetkých ostatných, ktorí sú zaangažovaní do konkrétnej liečby chorého. „Dnešná doba dúfa, že medicína a starostlivosť o zdravie sa stane humánnejšou. Láska k trpiacim je znamením a mierou kultúry a pokroku každého národa." - uvádza sa v posolstve pápeža Jána Pavla II. k sláveniu Prvého svetového dňa chorých 11. februára 1993 [7].

Prvý prezident česko-slovenského štátu T. G. Masaryk [4] dokazoval, že mravnosť je základom demokracie v politike a každej ľudskej činnosti. Aj vzťah k najposlednejšiemu pacientovi zo strany lekára, ak je mravný, je vlastne demokratický. T. G. Masaryk chápal vzťah človeka k človeku predovšetkým ako „vzťah nesmrteľnej duše k nesmrteľnej duši". Toto vyjadrenie z lekárov najintímnejšie chápu práve psychiatri.

Psychiatrická starostlivosť sa často uskutočňuje v zariadeniach psychiatrických nemocníc a liečební. Anglickí právnici ich označujú ako „totálne inštitúcie" pre určitý rozsah represívnych mechanizmov v ich činnosti. Do týchto zariadení môže byť prijatý človek nedobrovoľne iba v prípade skutočnej nutnosti: pri závažnom ohrození svojho života, zdravia, alebo ohrození svojho okolia - a to na základe dôkladného medicínskeho posúdenia (a neskoršieho súdneho rozhodnutia). Morálnym imperatívom je možnosť pacienta dožadovať sa prepustenia formou *habeas corpus* procedúry.

Prof. R. J. Bonnie [2] z Právnickej fakulty Virginskej univerzity pripomína, že každá psychicky chorá osoba má svoju dôstojnosť, ktorú označil termínom "prezumpcia slobody". V tom cítiť etickú hĺbku, tak ako aj v praktickej aplikácii nových foriem starostlivosti o psychicky chorých. V záujme pacienta sa treba aj u nás viac zapojiť do celosvetového trendu socializácie psychiatrie. Podchyteniu psychiatrických pacientov, ich liečeniu a zaradeniu do spoločnsti sa majú venovať nielen zdravotnícki pracovníci, ale aj samotní pacienti, členovia ich rodín a predstavitelia národných a nadnárodných pacientskych spoločností (napr. Word Epoch z Londýna - zaoberajúca sa otázkou týraných detí). Rodinní príslušníci majú možnosť vytvárania skupín vzájomnej pomoci, ktoré sú sprostredkovateľmi medzi anonymným štátom a bezbranným jednotlivcom. Znamenajú aj zodpovednejší prístup k životu, sú prejavom kritickejšieho a aktívnejšieho občana, uplatňujúceho humanizmus v praxi. Ako u psychicky tangovaných jedincov, tak aj u členov ich rodiny sa zmierňujú pocity izolácie a stigmatizácie spojenej s ich stavom, či životnými udalosťami. Zvyšujú sa ich zážitky kompetencie a sebaúcty.

Takto sa pred psychiatriou otvárajú možnosti uviesť do dennej praxe etické postuláty známej Schweitzerovej „úcty k životu" a brániť rôznym prejavom politickej surovosti a agresivity. Ide o to, aby sa psychiatrické zariadenia opäť nestali ostrovčekmi demokracie, ale aby slušnosť, empatia a etika, ktoré sú v základoch zavádzania integrácie postihnutých jedincov do spoločnosti, boli aj zažité v praxi politikov tejto spoločnosti. Nech sa už psychiatria - ako veda tak i ako *ars medica* - nikdy nezneužije ako *ars politica*.

Prezident bývalej ČSFR V. Havel [3] vo svojom prejave v Kongrese USA dňa 22. februára 1990 povedal: "Záchrana tohto ľudského sveta nie je nikde inde než v ľudskom srdci, ľudskej prezieravosti, ľudskej pokore a ľudskej zodpovednosti. Stále ešte nevieme postaviť morálku nad politiku, vedu a ekonomiku." Citovo rozvinutým a racionálnym ľuďom neostáva na to povedať nič iné ako - "Tak to je."

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Etika a psychiatria (Ethics and Psychiatry), I. Škodáček, ME&B, Vol. 1, 1994, No. 5 - 6, p. 3 – 5. Ethical principles are displayed considerably in the approach of physicians and the society towards the psychiatric patients. Non-ethical conduct of totalitarian governments tended to the political abuse of psychiatry. Psychiatric care institutions in the former Czechoslovakia were rather the islets of democracy. At present the reform of psychiatric care seems to be of utmost importance, to be followed by the reform of legislation. The participation of patients' families, as well as different public organizations and institutions, in the processes of a successfull integration of patients into the various aspects of ordinary life is to be encouraged and supported. Key words: ethical principles in medicine, the political abuse of psychiatry, the reform of psychiatry, the self-help groups of patients

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ETHICAL IMPACT OF MOLECULAR BIOLOGY ON MEDICINE

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Abstract

Paper gives an outline of different ethical issues rised by an enormous progress made in the field of molecular biology and genetics, that seems becoming the key area of technological and technical development in contemporary medicine and bio-medical sciences. The future of molecular medicine, as well as the real benefit of its achievments to the mankind as a whole, and to the individual patient, depends considerably on the resolution of many complicated ethical dilemmas encountered and brought about by the rapid, and continuous scientific progress.

Key words: molecular medicine, Human Genome Project, genetic diseases, ethical aspects,

Contemporary medicine is benefiting considerably from the rapidly accumulating knowledge of molecular biology and the major progress in biotechnology, as seen during the last decades of our century. The introduction of new techniques, such as DNA hybridization, polymerase chain reaction (PCR), and production of monoclonal antibodies have made possible an identification, isolation and characterization of biomedically important genes and gene products. This rapidly growing field will provide us continuously with a new information about the molecular mechanisms of many human diseases.

New technologies provide highly sophisticated instruments that are needed to study the cell regulations and inter-cellular communications in health and disease. A cellular response following an interaction between the cell and its environment, or with other cells, or mechanisms of production of different cell products, can now be described in molecular details. The scale comprise the study of interactions between receptor molecules and their ligands via induction, transduction, degradation or blocade of signal molecules; changes in the function of the cell and the subcellular structures; the production of cascades of effector molecules, etc. The molecular basis of an increasing number of diseases can now be understood and described in terms of molecular defects of genes and their products. The description of a disease in molecular terms has been labelled **molecular medicine** [3].

The multidisciplinary nature of molecular medicine constitutes an excellent basis for research within the broad field of clinical medicine. By providing the same basic knowledge and a limited number of new technologies it has already had an enormous impact on clinical research within such as widely divergent fields as cardiology, rheumatology, oncology, and infectious medicine. Molecular medicine forms a bridge between basic sciences, such as molecular biology, biochemistry, immunology, cell biology, etc. - and clinical research. Doing so it reduces to some extent the growing gap between basic scientific developments and their practical clinical application. Molecular medicine is becoming a dominant field of clinical research during the 1990-ies.

Molecular biology originated formally in 1953 when Watson and Crick identified the structure of the DNA molecule. The last 15 years have seen the development of new methodologies able to indentify and modify DNA sequences of the human genome. A gene fragment or a complete gene may be introduced to the bacterial or phage DNA (hybrid-DNA), where it can be amplified to allow sequencing. Such gene fragments can be used as probes to identify the genes within biological material. By the introduction of altered (mutated) genes or gene fragments into cells or mouse eggs, the effect of a gene mutation on a protein function can be studied in vitro and in vivo (transgenic mouse). A major step forward was made when the Polymerase Chain Reaction (PCR) was described in 1987. This simple technique, capable of detecting a single molecule of nucleic acid, resulted in a revolution in biomedical research.

Using the techniques of **molecular genetics**, the broad field of molecular medicine may be fruitfully cultivated in studies of genetic diseases, as well as in studies of diseases caused by non-genetic dysregulation of cell functions. Molecular genetics informs us about various mutations, and other defects of the genomic DNA that may be inherited, leading to the lack of a particular protein or to the expression of abnormal proteins. About 4200 genetic diseases are known so far worldwide.

The accumulation of certain **malignant diseases** within families is a well established empirical fact. Molecular genetic studies have shown, e.g. that retinoblastoma is related to the inactivation of the recessive gene on the chromosome No. 13. Retinoblastoma served as a model for the studies of hereditary cancer. Our knowledge of genetic factors underlying human cancers is developing rapidly. Genetic factors have been identified in many adult tumours, such as mammary carcinoma, colon cancer, hypernephroma and multiple endocrine neoplasia.

Molecular biology makes possible screening for an increasing number of **genetic diseases**. For over a generation newborns in many countries were tested for phenylketonuria (PKU), congenital hypothyreoidism and other **inborn errors of metabolism,** thereby allowing early intervention-treat-

ment [13]. **Carrier detection** programs were also successfully implemented, but so far these were directed only to small high-risk populations, e.g. **Tay-Sachs** disease, or **the sickle cell** trait in ethnic minorities in various countries, the **thalassemias** in the whole population of Cyprus and Sardinia, as well as in the ethnic minorities in countries like the United Kingdom and Australia.

With successful cloning of the gene for **cystic fibrosis (CF)** [8, 9] it is now possible to detect most of the heterozygotes for this condition. Further mutations are being identified at such a rate that it can be confidently predicted that, before long, virtually all the carriers will be identifiable. In the countries of North-Western Europe and in the countries that have been peopled by emigrants from them, approximately 1 person in 2O is a carrier of one of the CF mutations, i. e. 15 milion in the USA and 3 million in the United Kingdom. Screening for these CF carriers, and the genetic screening in families have already begun. It caused also some problems because of finding of a high frequency of discrepancy between biological and legal paternity (in UK about 13%) [5]. The cloning of the CF gene belongs also to the major developments of the molecular biology.

There is a number of dominantly inherited diseases that may become manifest later in life, and because of this fact, they pose some unusual ethical questions. **Hunthington disease**, with the onset in 4th or 5th decade, is probably the best known entity of them, but other neurological disorders, such as **hereditary ataxias** and familial **Alzheimer's disease** can also exhibit late age of onset.

Hunthington disease (HD) attracted considerable attention for a number of reasons, including its prevalence in Caucasoid populations, and progressive dementia that is an invariable feature of the condition during the patient's last 10 or so years of life. The linkage of the disease to an anonymous DNA marker was demonstrated in 1983 [6], but the gene has still not been cloned. More recently the probes for HD were distributed for presymptomatic and prenatal diagnosis and it was done on the understanding that the probes would be used according to guidelines approved by the IHA (International Huntington Association) and WFN (World Federation of Neurology). **The legal, ethical and social consequences concerning the use of a predictive test for the early detection of HD cannot be ignored!**

The demand for DNA probes accelerated very rapidly during the 1980s. When some obvious commercial application was apparent, patents were applied for, and companies set up to exploit the products for financial gain. Market forces, it seems, will increasingly determine the direction in which much basic research will proceed in the First World [7].

Prenatal sexing and the termination of the male fetus because the mother is carrier of an X-linked recessive disorder (**Duchenne Muscular Dystrophy, svere hemophilia A, or X-linked mental retardation**) has been practicised for a number of years. Prenatal sexing and termination of the fetus merely because it is not of the desired sex has been carried out in many countries [4, 14].

There are other more elaborated reproductive strategies. Direct biopsy of the blastomere followed by the method of PCR enables detection of the presence of a suspected genetic disorder to be established much earlier as it is with **chorionic villus sampling (CVS)** done at about 8-9 wk gestation [12].

The success rate of the human in vitro fertilization (IVF) method in the best centers is still less than 20% (with three attempts of an embryo transfer). It is common practice in IVF programs to produce an excess of embryos for implantation. To answer the questions posed by ethical dilemmas appearing in connection to the above mentioned technical possibilities it seems necessary to ask and answer again some basic philosophical questions: What does it mean to be a human? What makes human life specifically human? When does this life begin and when does it end? Is the life of a yet non-sentient human embryo alredy a human life? (What can be defined as a "non-sentient"?) Debates, stemming from the moral pluralism of modern societies, came to the front in which philosophers, theologians, lawyers and the broader public are increasingly participating.

The assessment of the "reproductive strategies" confines the consideration of the prevention of genetic disease to prenatal diagnosis. Medicine is heading for primary prevention. Most molecular geneticists want to cure or treat disease, not to perform abortions. Primary prevention would include **gene therapy** on the zygote, and because this would entail an alteration of the **germ cell line** researchers have not yet attempted it in humans, although it is technically possible. Germ line gene therapy can be a very different and unique form of treatment that will affect future generations. The **human gene pool** is at risk in such enterprise. Because the human gene pool is the possesion of all mankind, such manipulation is ethically unacceptable [1, 2].

Somatic cell gene therapy for the treatment of severe diseases is considered ethical. It can be supported by the moral principle of beneficience, but still many ethical issues have been risen. There has been much controversy about it, and the first clinical application was approved by the National Institutes of Health and the Food and Drug Administration (USA) in January 1989 only. It was approved only after being reviewed 15-times by 7 different regulatory bodies [2].

For example, individuals wit**h familial hypercholesterolemia** have insuficient or defective receptors for LDL cholesterol on their cell membranes. As a result, they produce excessive amounts of endogenous cholesterol and are unable to clear the substance from their blood. Their cholesterol levels remain high, and increase their risk of ischaemic heart disease, which may prove fatal in young adulthood. A gene for normal LDL receptor production inserted into a patient's genome in early life might well enhance receptor production and protect him/her from myocardial infarction in the third or fourth decade of life [7].

If somatic cell gene therapy is capable of curing severe genetic disease, can it also be used **to enhance certain "normal" characteristics?** Would it be permissible, e.g. to insert the specific gene in order to "enhance" the production of growth hormone in an infant, thereby producing a person of extremely high stature - a champion basketball player, say, or to enhance memory or intelligence? Although enhancement gene therapy may not be acceptable for such frivolous purposes, it is not difficult to imagine situations in which it might be justifiable as a strategy in preventive medicine.

Yet another level of "gene therapy" can be considered. Because it would attempt to "improve" the normal genetic constitution of an individual, influencing personality, character, fertility, and intelligence, as well as physical, mental, and emotional characteristics, it is referred to as **"eugenic genetic engineering".** Constant vigilance is needed, if we are to resist drifting into a new eugenic age. When the small "improvements" process once begin, it might soon become impossible to understand where the line should be drawn ultimately. **Therefore, gene transfer should be used only for the treatment of serious diseases and not for putative improvements. The dangers of abuse of recombinant DNA technology to manipulate the genome of human beings deliberately to serve perverted sociological ends can best be guarded against by a well-informed public. Scientists have an important duty to contribute to information of the public** [7].

Nowadays, the gene therapy at the level of the somatic cells is not yet readily available, and even when it is feasible, it will probably be suitable for only a small number of individuals with relatively rare disorders. Germ line gene therapy, successfully performed on experimental animals is still considered ethically undesirable by most researchers. Some, encouraged by parents, may be tempted to strive for eugenic goals. It seems **in no field of applied molecular biology it would be more essential to ensure that all work is carried out within a well-developed framework of moral values, dis-**

cussed and debated together by scientists, theologians, lawyers and ethicists. Everything possible should be done today on a national, international, and global scale to prevent possible future disastrous developments and their consequences.

It should also be noted, that the **safety of genetic manipulations** is still questionable [10]. Lot of viral and cellular oncogenes and other genes are cloned in bacteria and eucaryots. Some of virus oncogenes can be used as vectors in human gene therapy.

The **Human Genome Project (HUGO)** promises to provide at least two interrelated benefits to clinical medicine. The first will be an improved ability to isolate, characterize, and manipulate the genes involved in **normal human biology and in human disease,** while the second will be a more powerfull means to diagnose defects at the DNA level. HUGO will accelerate the growth of molecular diagnostics in two ways. First, by facilitating the identification of disease genes, it will lead to the characterization of many mutated forms of those genes that result in clinical abnormalities. Alongside, it will bring increased opportunities for making diagnostic and prognostic assessments based on an examination of the individual's DNA. Second, many of the same methods and instruments that will be used to develop physical and genetic maps will also be immediately useful for studying DNA in clinical settings. Thus, the resulting technologies will revolutionize molecular diagnostics. A prelude of this phenomenon is already evident in an example of the Polymerase Chain Reaction (PCR) technique, which has seen a rapid introduction into the clinical laboratory. Among existing PCR-based clinical tests there are those, that detect genetic diseases, malignant changes, and infectious microorganisms. Within a few years, numerous PCR-based assays will be implemented as standard tests in various clinical laboratories.

At its core, **HUGO** is about the development of tools for the study of human biology. These tools consist of information resources, in the form of physical maps, genetic maps, and DNA sequences of the genomes of man and model organisms, and a number of powerful and sophisticated experimental techniques and technologies. Altogether these tools provide a new and powerful foundation of knowledge, that will revolutionize biology by opening the way for biomedical research that was previously unapproachable. The more direct impact of HUGO on clinical medicine will be, first, an improved ability to study a large range of genetic diseases and to reach a more sophisticated understanding of the role of genetic factors in particular diseases and, second, the development of more powerful means to test directly for abnormalities in an individual's DNA. In the long run, though, the greatest impact of the HUGO on the practice of medicine will be in providing future generations of scientists and clinicians with a powerfull resource that will allow them to study and, potentially, to treat humans in more sophisticated and, hopefully, more beneficial ways.

HUGO has raised many **ethical issues**. Presymptomatic diagnosis of serious progressive diseases for which there are yet no effective therapies (Huntington's disease is the best-known example) places in the hands of patients the **information** that they may not be capable of handling. The diagnosis of the genetic disease with late gene manifestation can bring about an unbearable psychical stress with changing attitudes to one's living style and life itself. Prenatal diagnosis is likely to become an ever-increasing service demanded, thereby increasing the rift between the pro-life groups and those of a pro-choice standing. At the family level, problems concerned with confidentiality and access to some information will become more acute (e.g. an (even side-gained) information on a paternity exclusion based on the result of molecular genetic testing, etc.). Employers and insurance companies may demand access to the confidential genetic information before employing someone, or accepting him/her for medical or life insurance. This may set up discriminatory practices, that may be difficult to prevent [7]. Information about an individual's genetic constitution could be missused by employers, insurance companies, governmental agencies, and mischievous people by an intention of blackmailing individuals with threats of exposing "sensitive" information. On the other hand, individuals at genetic risk for work-related damage to their health may opt for work in other fields.

Another level of concern raised by **HUGO** is that powerful technologies do not just change what human beings can do, they change the very way they think - especially about themselves. Potential parents might resort to complete screening of embryos and only implant those that are considered to be "high-grade". An attitude could develop that would see children as commodities, existing to satisfy demands of parents and even societies, without regard for the childrens' own rights and interests.

It was noted above, that some gene probes may reveal **determinant genes** for several conditions or diseases. The issues raised by the identification of such genes are significant. However, they are probably less complicated, than the evaluation of the seriousness of risks concerning development of a contingent condition revealed by gene probes of less determinant genes, such as those that confer "**susceptibility**" to such conditions as Alzheimer's disease, abnormal lipid concentrations and heart disease, or bi-polar (manic-depressive) illness. These later genes may cause disease in about 50 or 60 years after birth, but only if there is an interaction with yet mostly unkown genetic or environmental factors [8, 9, 13]. Do we measure the accuracy of a molecular test against the presence of identifying DNA sequences or against the eventual development of the predicted condition? What comparative standards are to be used for measuring the costs and benefits? It seems many ethical dilemmas will emerge once more with any new method of analysis, for example: definitions of "normality" and disease, controversy surrounding the elimination or treatment of genetic diseases, mandatory testing and the proper role of the state policies, arguments about non-directive counselling and the limits of beneficience, genetic discrimination, laws and safeguard measures for the control and protection of genetic information [12]. The enhanced concept of quality assurance must also become an essential part of ethical laboratory medicine.

The development of new technologies is very likely to lead to setting up **screening programmes**, run on a scale being many orders of magnitude greater than it has been the case to date. The goal of such screening will be to alert individuals to their status and to encourage them to mate with non-carriers, or to use artificial insemination or other reproductive strategies. The first - admittedly limited - attempts of screening have not been uniformely successful, being accompanied at the same time by some undesirable side effects. Imposing a genetic test on people against their will constitutes in fact an approach of new eugenics, the motives of which seem being not very different from those of the early eugenicists.

The **laboratory medicine** has not yet accepted the challenges raised by these rapid and revolutionary developments [11]. Many of the techniques mentioned are very straightforward, and with appropriate equipment and technicians' training they could be used easily even in routine laboratories. They might be used in standard service laboratories not just because the laboratory is particularly interested in the area, but because there are pressing economic reasons not to set up yet another series of laboratories, or because the limited laboratory facilities available leave no other choice. In the laboratory medicine we need to develop a sound and clear position in relation to molecular biology. This should be done not from a merely technical standpoint only, but also by considering the ethical issues surrounding the development and application of such techniques. Surely,

it is of paramount importance nowadays to find the common language among all the parties involved - on the national, international, and even global level - for defining strong and commonly accepted ethical principles for safeguarding of really beneficial and safe development of contemporary and future molecular medicine.

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Etický vplyv molekulárnej biológie na medicínu, M. Samel, R. Pullmann, ME&B, 1, 1994, č. 5 - 6, s. 5 – 8. Práca podáva prehľad rozličných etických problémov, ktoré prináša významný pokrok na poli molekulárnej biológie a genetiky. Táto oblasť sa stáva kľúčovou z hľadiska technického a technologického rozvoja súčasnej medicíny a biomedicínskych vied. Budúcnosť molekulárnej medicíny, ako aj skutočný prínos jej výsledkov pre celé ľudstvo, ako aj pre konkrétneho pacienta, bude do značnej miery závisieť od riešenia mnohých komplikovaných etických dilem, s ktorými sa stretáva a ktoré prináša rýchly a sústavný vedecký pokrok.

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"I will maintain the utmost respect for human life from the time of conception; even under threat, I will not use my medical knowledge contrary to the laws of humanity."

Declaration of Geneva (WMA, 1968, 1994)

ETIKA V OŠETROVATEĽSTVE

ETHICS IN NURSING

SESTRY, PROFESIA SESTRY A ETICKÉ PROBLÉMY (2)

F. J. Fitzpatrick

Význam zamerania starostlivosti na pacienta*

Ak prvoradou úlohou zdravotnej sestry je poskytovanie starostlivosti pacientom, potom jej prvoradá lojalita je voči nim. Toto je dôležité povedať, nakoľko veľká časť sestier pracuje v nemocniciach, a tu po väčšinu pracovného času plní príkazy ošetrujúcich lekárov. To by mohlo viesť k nežiadúcemu posunu uplatňovania jej lojality. Mohlo by sa totiž stať, že sestry budú plniť predovšetkým požiadavky lekárov alebo vedenia nemocnice a menšiu pozornosť budú venovať potrebám pacientov, ktorých majú vo svojej starostlivosti.

Možno protiklad medzi týmito dvoma pohľadmi netreba príliš zdôrazňovať. „Dobro pacientov" predstavuje dôvod existencie a činnosti tak pre vedenie nemocnice a jej lekárov, ako aj pre prácu sestier. V ideálnom prípade všetky tieto zložky harmonicky spolupracujú na dosiahnutí spoločného cieľa. Predsa však administratívne postupy v nemocnici, ako aj v iných inštitúciách, sa môžu niekedy chápať ako cieľ samé pre seba. To hrozí najmä vtedy, ak sa nemocnica chápe ako určitý druh podniku, v ktorom je efektívnosť riadenia personálnych aj hmotných zdrojov prioritou číslo jedna. Podobne lekári, najmä špecialisti, ktorých kontakt s pacientom je často obmedzený iba na najpotrebnejšie minimum, môžu mať sklon považovať pacientov skôr za "prípady" zaujímavé z odborného hľadiska, ako za celistvé osoby, pre ktoré ich zdravotné problémy môžu predstavovať situáciu hlbokého mentálneho a duševného utrpenia.

Vezmime, napríklad, nasledujúce vyjadrenie (pozn. prekl. - stalo sa v jednej anglickej nemocnici): *"Počas práce na chirurgickom oddelení som vôbec nebola spokojná s tým, ako lekári "rešpektovali" cítenie pacientov. Pri jednej vizite, napríklad, lekár podišiel k lôžku pacienta a nahlas povedal: "Hm, to je karcinóm, nie?" Náhodou ten pacient bol Španiel a hovoril len veľmi málo po anglicky - nerozumel teda pravdepodobne tomu, čo lekár povedal. Možno nerozumel aj preto, lebo ako novoprijatý pacient nevedel ešte temer nič o svojom zdravotnom stave. Ďalší pacienti na izbe však počuť i rozumieť museli... Myslím, že to bolo veľmi nerozmyslené. Nanešťastie, tento incident nebol ojedinelý, pretože tento lekár zvykol otvorene diskutovať s kolegami jednotlivé prípady priamo v dosluchu pacientov."*

Spomínaný lekár zrejme videl svojho pacienta ako zbierku orgánov, z ktorých jeden bol práve v zaujímavom patologickom stave. Tento nedostatok rešpektu voči pacientom nijako nie je charakteristický pre všetkých lekárov v nemocniciach, ani nie iba pre samotných lekárov. Sestry, fyzioterapeuti a iní zdravotnícki pracovníci sú tiež niekedy schopní chovať sa k pacientom takýmto degradujúcim spôsobom. Faktom však je, že zdravotné sestry, pre svoj neporovnateľne bližší vzťah k pacientovi, majú normálne oveľa zriedkavejšie sklon k takémuto správaniu. Akokoľvek, i tu sa však môže vykytnúť pokušenie brať pacientov nie ako osoby potrebujúce zúčastnenú starostlivosť, ale ako (povedzme) akési stroje, ktoré je potrebné udržovať v chode. Tým viac preto sestra nesmie zameriavať svoj prístup v práci výlučne len na plnenie požiadaviek lekára (alebo na prvoradé uspokojenie požiadaviek predstavených - vedenia nemocnice), ale má orientovať svoje úsilie prvomrade voči pacientovi. Sestra má vždy pristupovať k pacientovi ako k celému človeku a považovať jeho dobro (well-being) za hlavný cieľ svojho snaženia.

Súčasne s týmto zásadným postojom prvoradého záujmu o dobro svojich pacientov, existujú určité charakterové črty, ktoré sú veľmi dôležité pre každú sestru. Jej pacienti - či už ich stretáva v nemocnici, ambulancii, alebo v rámci návštevnej služby - majú zväčša skutočné zdravotné problémy, ktoré ich môžu hlboko ovplyvniť aj na emočnej, duševnej a duchovnej úrovni. Sestra by sa ukázala necitlivou až bezcitnou, ak by si neuvedomovala tieto skutočnosti, a nebola by schopná "vcítiť sa" do mysle svojich pacientov a pochopiť, čo daný zdravotný stav vlastne znamená pre nich osobne. Prístup skutočného záujmu a súcitu, citlivosti k pacientovým najhlbším osobným pocitom a reakciám by mal byť sú-

časťou vedomého profilu osobnosti zdravotnej sestry.

Dve charakteristiky súčasnej ošetrovateľskej praxe môžu viesť sestru k tomu, aby prestala považovať pacienta za prvoradý stred a smerovanie svojej práce, a tiež aby oslabovala spomínané kvality svojho charakteru. Prvou z nich je **vplyv moderných technológií**. Veľa dnešného času sestry zaberá obsluha rozličných prístrojov, najmä v prípade intenzívnej starostlivosti o akútne chorých. V dôsledku toho môže byť sestra celkom absorbovaná rôznymi technickými či technologickými procedúrami. Pritom však niekedy práve tá oblasť jej práce, kde sú jej vedomosti a schopnosti najprimeranejšie využité - v kontinuálnej starostlivosti o akútne chorých, alebo v temer úplnej starostlivosti o chronicky alebo terminálne chorých - sa dostáva vo svojej dôležitosti (a ocenení) až na druhé miesto.

Jeden učiteľ ošetrovateľstva to vyjadril takto: *"Pred objavením sa zázračných liekov a rýchleho technologického pokroku medicíny v tomto storočí bolo ošetrovateľstvo a ošetrovateľská starostlivosť hlavným príspevkom v oblasti zdravotníctva. V popredí bola starostlivosť o beznádejne chorého človeka a nie natoľko snaha o vyliečenie choroby. Ako sa zvyšovali možnosti medicíny v liečbe konkrétnych ochorení, znižovala sa do istej miery kvantita a kvalita ošetrovateľskej starostlivosti (care) na strane sestry, ktorá sa stala postupne akoby predĺženou rukou lekárskej technológie. Sestra, chápaná skôr ako zdravotnícky technik, smeruje potom k modelu ošetrovateľskej starostlivosti, ktorý je fragmentovaný, nehumánny a neosobný. Strata jej ošetrovateľskej identity a opustenie jej ošetrovateľských funkcií ohrozujú základnú štruktúru samotného ošetrovateľstva. Istý návrat k ošetrovateľskej starostlivosti (care) v poslednom období predstavuje určité pozitívum. Sestry samé začali si viac uvedomovať hodnotu starostlivosti, ktorú sú schopné poskytnúť aj pacientom, čo sa vymykajú z dosahu medicínskej techniky a technológií - chronicky chorým, starým a terminálne chorým ľuďom."*

Myslíte, že uvedené vyjadrenie je primeranou reakciou na technickú, či technologickú orientáciu moderného ošetrovateľstva? Zrejme nie. Táto orientácia je totiž nevyhnutným dôsledkom vedeckého pokroku a najskôr tu už ostane. Dnešné sestry musia reagovať na tieto závažné zmeny pozitívne. Snahou prispôsobiť sa novým požiadavkam - avšak bez toho, že by stratili zo zreteľa svoje primárne zameranie na starostlivosť o pacienta. Nemôžu reagovať tak (ako navrhuje autor vyššie uvedeného citátu), akoby chceli poslať modernú technológiu preč a venovať sa iba samotnej ošetrovateľskej starostlivosti. Je však pravda, že technický charakter moderného ošetrovateľstva by skutočne mohol sestru viesť k odklonu od jej vlastnej úlohy voči konkrétnym pacientom a k mylnej predstave osebe ako o akomsi zdravotníckom technológovi.

Druhý faktor, ktorý by mohol viesť sestru ku strate perspektívy jej práce orientovanej primárne na pacienta, súvisí so **spôsobom práce vedenia (riadením) zdravotníckeho zariadenia** (nemocničnej "byrokracie", či "menežmentu"). Byrokracie vo všeobecnosti sú typicky zamerané na čo najefektívnejšie dosahovanie cieľov, pre ktoré majú pracovať. Samé však obyčajne nemôžu určiť, aké tieto ciele majú byť. Tie im totiž spravidla určujú iní ľudia, či inštitúcie. Úradníci berú tieto ciele za "dané", ktoré treba splniť natoľko efektívne, ako je to len možné. V pluralistickej spoločnosti, ako je naša, kde niet jasného spoločenského konsenzu v otázke, čo je zdravie a ako súvisí s ostanými dobrami potrebnými pre človeka, vedenia nemocníc niekedy nemusia mať dostatočný prehľad o zvláštnostiach, ktoré predstavuje pojem zdravie a jeho miesto pri dosiahnutí celkového dobra obyvateľov. Preto niekedy majú sklon riadiť nemocnice ako akékoľvek iné podniky, podľa zásad maximálnej efektívnosti. Skutočný účel a cieľ zdravotníckych zariadení sa niekedy môže dostať do tieňa snáh o maximalizáciu samotnej efektívnosti, najmä v oblasti šetrenia finančných prostriedkov. Tento prístup môže významne vplývať na prácu sestier v nemocnici, alebo v rámci komunitnej (návštevnej) služby (geriatrická, detská setra, a pod.). Sestra, ktorej záujem by bol nadmerne sústredený skôr na splnenie požiadaviek "efektívnosti", než na zabezpečenie potrieb pacientov, strácala by vlastne zo zreteľa pôvodné poslanie inštitúcií, pre ktoré pracuje, a to s negatívnymi dôsledkami pre svojich pacientov i pre ňu samu.

(Pokračovanie v budúcom čísle!)

* Z anglického originálu *F. J. Fitzpatrick: Ethics in Nursing Practice. Basic Principles and their Application.* The Linacre Centre, London, 1988, 290 pp., Chapter one: Nurses, The Nursing Profession and Ethical Problems, p. 13 - 16, - preložil a redakčne upravil MUDr. J. Glasa.

DOKUMENTY A MATERIÁLY

DOCUMENTS AND MATERIALS

A DECLARATION ON THE PROMOTION OF PATIENTS' RIGHTS IN EUROPE

EUROPEAN CONSULTATION ON THE RIGHTS OF PATIENS, AMSTERDAM, MARCH 28-30, 1994

World Health Organization, Regional Office for Europe

About the Declaration

The European Consultation on the Rights of Patients, held in Amsterdam on 28-30 March 1994 under the auspices of the WHO Regional Office for Europe (WHO/EURO), and hosted by the Government of the Netherlands, was attented by some 60 persons from 36 Member States. The purpose was to define principles and strategies for promoting the rights of patients, within the context of the health care reform process underway in most countries.

The Consultation came at the end of a long preparatory process, during which WHO/EURO encouraged the emerging movement of patients rights by, *inter alia,* carrying out studies and surveys on the development of patients rights throughout Europe. These studies showed a common interest and a number of policy trends and normative initiatives in the European countries, indicating that additional support to policy development in many of those countries would be appropriate. The study results were published in the book *The Rights of Patients in Europe* (WHO 1993). With the support of the Government of the Netherlands, and in broad consultation with governments and other institutions in European countries, technical experts in the field drafted *The Principles of Patients' Rights,* a comprehensive text which could be meaningful and helpful in the development of country policies on patients' rights.

The Declaration on the Promotion of Patients Rights in Europe constitutes a common European framework for action and includes those principles, as endorsed by the Amsterdam Consultation. This declaration should be interpreted as an enhanced entitlement for citizens and patients in improving partnership in the process of care with health care providers and health services managers. The Principles of Patients' Rights endorsed at the Amsterdam Consultation will hopefully be a solid reference and a dynamic tool capable of improving new thinking in the health care process.

The complete proceedings of the consultation will be published as a separate publication during the current year.

Copenhagen, April 1994

A DECLARATION ON THE PROMOTION OF PATIENTS RIGHTS IN EUROPE

A WHO European Consultation on the Rights of Patients, meeting in Amsterdam from 28 to 30 March 1994, endorsed the annexed document (*Principles of the Rights of Patients in Europe: A Common Framework)* as a set of principles for the promotion and implementation of patients' rights in WHO's European Member States.

The meeting gave detailed consideration to a wide range of possible strategies based on the principles presented in the document and on the recent and current experiences of participants. The essence of these strategies is presented below.

STRATEGIES FOR THE PROMOTION OF PATIENTS' RIGHTS

The development of a strategy to promote patients' rights and responsibilities has to be carefully prepared, in order to ensure that the intention is translated into practical action which commands the support of all parties involved. Such action does not follow automatically, but takes time to become fully effective.

National situations vary in respect of legal frameworks, health care systems, economic conditions, and social, cultural and ethical values, but there are certain common approaches which can be appropriately adapted to the circumstances of each country. We encourage all interested parties in our countries to initiate or renew multiple strategies of implementation, which will likely need most or all of the following components:

- legislation or regulations, specifying the rights, entitlements and responsibilities of patients, health professionals and health care institutions;
- medical and other professional codes, patients' charters and similar instruments, drawn up in the light of agreed common understandings between the representatives of citizens, patients, health professionals and policy-makers, and periodically revised in response to changing circumstances;
- networking between and among patient and health care provider groups, recognizing the distinction between citizen and user participation;
- government support for the establishment and effective running of nongovernmental organizations (NGOs) in the field of patients' rights;
- national colloquia and conferences to bring the parties together to create and promote a shared sense of understanding;
- involvement of the media in informing the public, stimulating constructive debate and sustaining awareness of the rights and responsibilities of patients and users and their representative organs;
- better training in communication and advocacy skills for health professionals as well as for patients and other user groups, in order to further the development of a proper understanding of the perspective and role of all parties;
- promotion of research to evaluate and document the effectiveness of legal and other provisions and the various initiatives taken in the diverse contexts of the different countries.

INTERNATIONAL ACTION

Cooperation between WHO, the Council of Europe and the European Union in support of patients' rights would be further enhanced by action taken as a result of this Consultation. Consistency of policy position, coordinated strategies of implementation and an understanding of how their respective resources and competences can best be used are essential components of a sustained European movement to promote and protect the rights of patients and their professional providers and advisers. International NGOs also have a critical role to play in promoting the rights of patients.

The forthcoming WHO Regional Conference on Health Policy will provide an important opportunity for further promoting patients' rights in Europe. The proposed WHO Regional Conference on Health Care Systems in Transition in Europe, to be held in Vienna in 1996, will also explore issues concerning the rights, roles and responsibilities of both patients and providers. We propose to WHO that the Regional Office should establish an appropriate mechanism to monitor developments in countries and to present the findings to the Vienna Conference.

PRINCIPLES OF THE RIGHTS OF PATIENTS IN EUROPE: A COMMON FRAMEWORK

INTRODUCTION

1. BACKGROUND

Social, economic, cultural, ethical and political developments have given rise to a movement in Europe towards the fuller elaboration and fulfilment of the rights of patients. New and more positive concepts of patients' rights have been advocated. In part, this has been a reflection of the central place given both to full implementation of the concept of respect for persons and to equity in health as a policy objective in Member States. As a consequence there is now greater emphasis on the encouragement of individual choice and the opportunity to exercise it freely, and the commitment to build mechanisms for ensuring quality of care.

Developments within health care systems such as their increasing complexity, the fact that medical practice has become more hazardous and in many cases more impersonal and dehumanized, often involving bureaucracy, and no less the progress made in medical and health science and technology have all placed new emphasis on the importance of recognizing the individual's right to self-determination and often on the need to reformulate guarantees of other rights of patients.

Simultaneously, the human rights movement has gathered importance in the world since 1945 when, in the Charter of the United Nations, Member States reaffirmed their faith in fundamental human rights. This was followed, on 10 December 1948, by the adoption of the Universal Declaration of Human Rights and, on 4 November 1950, by the signature of the European Convention of Human Rights. Governments are more and more giving their active consideration to such issues. The World Health Organization's study of patients' rights in Europe shows that increasingly there are shared principles that are being adopted in a number of countries and which seem to be independent of the characteristics of a given country's health system. It seems timely to give this policy trend further momentum. The present document is an attempt to formulate a set of patients' rights which reflects the evolving concepts and is relevant to the context in which health care will be provided in future.

These Principles of the rights of patients in Europe have been drafted in full awareness of the work of others who have already been engaged in drawing up instruments specific to patients' rights. For the most part though, such earlier efforts were directed at particular groups or concerned with specific activites in health care or approached patients' rights from the perspective of the duties and responsibilities of health care providers and establishments. The present text is the result of an attempt to refocus these concerns from the patient's point of view as the user of and partner in health care in all its various forms. It has been deliberately couched in general terms, so far as possible avoiding reference to the circumstances of particular groups or illustrative examples. It is felt, however, that this exposition of general considerations embraces the basic principles and concepts to be adopted when promoting and guaranteeing patient's rights in a particular country or other situation. The text does not directly cover questions of implementation, since these are necessarily specific to a country or situation; it has nevertheless been drafted in the belief that these guidelines can be further elaborated within countries to suit their particular needs and circumstances.

GUIDING PRINCIPLES

In this text, the concept of health care is derived from the principles of the World Health Assembly resolution on health for all (HFA) (WHA30.43) and the related model of

health care set out in the Declaration of Alma-Ata. Health care thus embraces a full range of services covering health promotion and protection, disease prevention, diagnosis, treatment, care and rehabilitation. Accordingly, the patient encounters a wide variety of health care providers and fulfills a variety of roles, from sick and dependent person to client receiving advice to consumer or customer obtaining health products for self-administration. Furthermore, this variety of patient roles implies a continuum of health states from high-level wellness to permanent disability and terminal illness.

In the treatment of patients' rights, a distinction should be made between social and individual rights. Social rights in health care relate to the societal obligation undertaken or otherwise enforced by goverment and other public or private bodies to make reasonable provision of health care for the whole population. What is reasonable in terms of the volume and range of services available and the degree of sophistication of technology and specialization will be dependent on political, social, cultural and economic factors. Social rights also relate to equal access to health care for all those living in a country or other geopolitical area and the elimination of unjustified discriminatory barriers, whether financial, geographical, cultural or social and psychological.

Social rights are enjoyed collectively and are relative to the level of development of the particaular society; they are also in some measure subject to political judgment regarding priorities for development in a society.

In contrast, individual rights in patient care are more readily expressed in absolute terms and when made operational can be made enforceable on behalf of an individual patient. These rights cover such areas as the integrity of the person, privacy and religious convictions. Although this text does address social rights, the main focus is on individual rights. The conceptual foundations for this treatment of patients' rights are for the most part laid on a number of intergovernmental declarations relating to human rights and freedoms. The intention is not to create new rights but to apply them in one coherent, comprehensive statement to the field of patients and health care. For similar reasons the text does not address general rights, obligations and liabilities, which are covered by the statutes and case law of each country.

A further issue arises concerning the place of exceptional limitations to particular rights of patients. For the most part these have been kept out of the text, in order to state the proposed rights as clearly and simply as possible. It is therefore pertinent to clarify here at the outset the nature of the principal forms of limitation. Exceptions to the rights of patients are usually anticipated in law. The guiding rule in such exceptions is always that patients can be subjected only to such limitations as are compatible with human rights instruments and in accordance with a procedure prescribed by law. In practice, this means limitations which apply for reasons of public order, public health and other persons' human rights.

In some situations, the reason for restricting the rights of the patient is an overriding interest of a third party (the so-called 'conflict of duties' doctrine), i.e. the unfettered application of the patient's right would cause serious harm to a third party, there is no other means to avoid the harm and there is a reasonable expectation that the restriction would prevent the harm. In other situations a similar justification applies when the purpose is to avoid serious harm to the patient (the so-called therapeutic exception). As this document addresses general principles, these exceptional limitations to the rights of patients have mostly not been included.

PURPOSE OF THE DOCUMENT

The Principles of the Rights of Patients in Europe are offered as a contribution to support the growing interest in many Member States in the issues of patients' rights. In its scope and focus, this document seeks to reflect and express people's aspirations not only for improvements in their health care but also for fuller recognition of their rights as patients. In so doing, it keeps in mind the perspectives of health care providers as well as of patients. This implies the complementary nature of rights and responsibilities: patients have responsibilities both to themselves for their own self-care and to health care providers, and health care providers enjoy the same protection of their human rights as all other people. There is a basic assumption in the text that the articulation of patients' rights will in turn make people more conscious of their responsibilities when seeking and receiving or providing health care, and that this will ensure that patient/provider relationships are marked by mutual support and respect.

Patients should be aware of the practical contributions they can make to the optimal functioning of the health system. Their active participation in the diagnosis and treatment process is often desirable and sometimes indispensable. It is always important that they provide the relevant health professionals with all the information required for the purposes of diagnosis and treatment. The patient has an essential role, the reciprocal of the provider's, in ensuring that the dialogue between them is carried out in good faith.

Indeed, the role patients play in the appropriate delivery of health care should be underlined, especially in today's complex health systems which are largely supported by collective financial mechanisms and where the economic and equitable use of resources allocated to health care is an objective which can be shared by health professionals and patients alike. Equally, while patients' participation in clinical teaching must be subject to their informed consent, they should also be aware that the competence of future professionals in part depends on patients agreeing to be involved in their training.

IMPLEMENTATION

It is a matter for decision by countries how they might make use of a document such as this when reviewing their present policies on, practices in and legislative support to, patients' rights.

Although for the purposes of clarity of presentation some proposals are made in a clear-cut way, the text is a set of guidelines which could be used in policy discussions within countries and in the formulation or reformulation, as the case may be, of national policies, laws or official statements on any or all of the issues covered. However, it is hoped that this document will be of direct value to all parties, including patient and consumer bodies involved in health care, professional associations of physicians and of other health care providers, and associations of hospitals and other health care establishments.

2. OBJECTIVES

Against this background, the Principles of the Rights of Patients in Europe can be seen, in terms of content, as a document which seeks:

- to reaffirm fundamental human rights in health care, and in particular to protect the dignity and integrity of the person and to promote respect of the patient as a person;
- to offer for the consideration of Member States a set of common basic principles underlying the rights of patients, which might be used when framing or reviewing patient care policies;
- to help patients obtain the fullest benefit from their use of the services of the health care system, and mitigate the effects of any problems which they may experience with that system;
- to promote and sustain beneficial relationships between patients and health care providers, and in particular to

encourage a more active form of patient participation;

- to strengthen existing and afford new opportunities for dialogue between patients' organizations, health care providers, health administrations and wider societal interests;

- to focus national, regional and international attention on evolving needs in patients' rights and to foster closer international cooperation in this field;

- to ensure the protection of fundamental human rights and to promote the humanization of assistance to all patients, including the most vulnerable such as children, psychiatric patients, the elderly or the severely ill.

3. CONCEPTUAL FOUNDATIONS

In drafting these Principles of the Rights of Patients in Europe, the following intergovernmental instruments, which together offer a framework and a set of basic concepts which can be applied to the rights of patients, have been taken into account:

- *The Universal Declaration of Human Rights (1948)*,
- *The International Covenant on Civil and Political Rights (1966)*,
- *The International Covenant on Economic, Social and Cultural Rights (1966)*,
- *The European Convention on Human Rights and Fundamental Freedoms (1950)*,
- *The European Social Charter (1961)*.

THE RIGHTS OF PATIENTS

1. HUMAN RIGHTS AND VALUES IN HEALTH CARE

The instruments cited in the Introduction should be understood as applying also specifically in the health care setting, and it should therefore be noted that the human values expressed in these instruments shall be reflected in the health care system. It should also be noted that where exceptional limitations are imposed on the rights of patients, these must be in accordance with human rights instruments and have a legal base in the law of the country. It may be further observed that the rights specified below carry a matching responsibility to act with due concern for the health of others and for their same rights.

1.1 Everyone has the right to respect of his or her person as a human being.

1.2 Everyone has the right to self-determination.

1.3 Everyone has the right to physical and mental integrity and to the security of his or her person.

1.4 Everyone has the right to respect his or her privacy.

1.5 Everyone has the right to have his or her moral and cultural values and religious and philosophical convictions respected.

1.6 Everyone has the right to such protection of health as is afforded by appropriate measures for disease prevention and health care, and to the opportunity to pursue his or her own highest attainable level of health.

2. INFORMATION

2.1 Information about health services and how best to use them is to be made available to the public in order to benefit all those concerned.

2.2 Patients have the right to be fully informed about their health status, including the medical facts about their condition; about the proposed medical procedures, together with the potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis and progress of treatment.

2.3 Information may only be withheld from patients exceptionally when there is good reason to believe that this information would without any expectation of obvious positive effects cause them serious harm.

2.4 Information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimizing the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available.

2.5 Patients have the right not to be informed, at their explicit request.

2.6 Patients have the right to choose who, if any one, should be informed on their behalf.

2.7 Patients should have the possibility of obtaining a second opinion.

2.8 When admitted to a health care establishment, patients should be informed of the identity and professional status of the health care providers taking care of them and of any rules and routines which would bear on their stay and care.

2.9 Patients should be able to request and be given a written summary of their diagnosis, treatment and care on discharge from a health care establishment.

3. CONSENT

3.1 The informed consent of the patient is a prerequisite for any medical intervention.

3.2 A patient has the right to refuse or to halt a medical intervention. The implications of refusing or halting such an intervention must be carefully explained to the patient.

3.3 When a patient is unable to express his or her will and a medical intervention is urgently needed, the consent of the patient may be presumed, unless it is obvious from a previous declared expression of will that consent would be refused in the situation.

3.4 When the consent of a legal representative is required and the proposed intervention is urgently needed, that intervention may be made if it is not possible to obtain, in time, the representative's consent.

3.5 When the consent of a legal representative is required, patients (whether minor or adult) must nevertheless be involved in the decision-making process to the fullest extent which their capacity allows.

3.6 If a legal representative refuses to give consent and the physician or other provider is of the opinion that the intervention is in interest of the patient, then the decision must be referred to a court or some form of arbitration.

3.7 In all other situations where the patient is unable to give informed consent and where there is no legal representative or representative designated by the patient for this purpose, appropriate measures should be taken to provide for a substitute decision making process, taking into account what is known and, to the greatest extent possible, what may be presumed about the wishes of the patient.

3.8 The consent of the patient is required for the preservation and use of all substances of the human body. Consent may be presumed when the substances are to be used in the current course of diagnosis, treatment and care of that patient.

3.9 The informed consent of the patient is needed for participation in clinical teaching.

3.10 The informed consent of the patient is a prerequisite for participation in scientific research. All protocols must be submitted to proper ethical review procedures. Such research should not be carried out on those who are unble to express their will, unless the consent of a legal representative has been obtained and the research would likely be in the interest of the patient.

As an exception to the requirement of involvement being in the interest of the patient, an incapacitated person may be involved in observational research which is not of direct benefit to his or her health provided that that person offers no

objection, that the risk and/or burden is minimal, that the research is of significant value and that no alternative methods and other research subjects are available.

4. CONFIDENTIALITY AND PRIVACY

4.1 All information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death.

4.2 Confidential information can only be disclosed if the patient gives explicit consent or if the law expressly provides for this. Consent may be presumed where disclosure is to other health care providers involved in that patient's treatment.

4.3 All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of their storage. Human substances from which identifiable data can be derived must be likewise protected.

4.4 Patients have the right of access to their medical files and technical records and to any other files and records pertaining to their diagnosis, treatment and care and to receive a copy of their own files and records or parts thereof. Such access excludes data concerning third parties.

4.5 Patients have the right to require the correction, completion, deletion, clarification and/or updating of personal and medical data concerning them which are inaccurate, incomplete, ambiguous or outdated, or which are not relevant to the purposes of diagnosis, treatment and care.

4.6 There can be no intrusion into a patient's private and family life unless and only if, in addition to the patient consenting to it, it can be justified as necessary to the patient's diagnosis, treatment and care.

4.7 Medical interventions may only be carried out when there is proper respect shown for the privacy of the individual. This means that a given intervention may be carried out only in the presence of those persons who are necessary for the intervention unless the patient consents or requests otherwise.

4.8 Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy, particularly when health care providers are offering them personal care or carrying out examinations and treatment.

5. CARE AND TREATMENT

5.1 Everyone has the right to receive such health care as is appropriate to his or her health needs, including preventive care activities aimed at health promotion. Services should be continuously available and accessible to all equitably, without discrimination and according to the financial, human and material resources which can be made available in a given society.

5.2 Patients have a collective right to some form of representation at each level of the health care system in matters pertaining to the planning and evaluation of services, including the range, quality and functioning of the care provided.

5.3 Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care providers.

5.4 Patients have the right to continuity of care, including cooperation between all health care providers and/or establishments which may be involved in their diagnosis, treatment and care.

5.5 In circumstances where a choice must be made by providers between potential patients for a particular treatment which is in limited supply, all patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.

5.6 Patients have the right to choose and change their own physician or other health care provider and health care establishment, provided that it is compatible with the functioning of the health care system.

5.7 Patients for whom there are no longer medical grounds for continued stay in a health care establishment are entitled to a full explanation before they can be transferred to another establishment or sent home. Transfer can only take place after another health care establishment has agreed to accept the patient. Where the patient is discharged to home and when his or her condition so requires, community and domiciliary services should be available.

5.8 Patients have the right to be treated with dignity in relation to their diagnosis, treatment and care, which should be rendered with respect for their culture and values.

5.9 Patients have the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times.

5.10 Patients have the right to relief of their suffering according to the current state of knowledge.

5.11 Patients have the right to humane terminal care and to die in dignity.

6. APPLICATION

6.1 The exercise of the rights set forth in this document implies that appropriate means are established for this purpose.

6.2 The enjoyment of these rights shall be secured without discrimination.

6.3 In the exercise of these rights, patients shall be subjected only to such limitations as are compatible with human rights instruments and in accordance with a procedure prescribed by law.

6.4 If patients cannot avail themselves of the rights set forth in this document, these rights should be exercised by their legal representative or by a person designated by the patient for that purpose; where neither a legal representative nor a personal surrogate has been appointed, other measures for representation of those patients should be taken.

6.5 Patients must have access to such information and advice as will enable them to exercise the rights set forth in this document. Where patients feel that their rights have not been respected they should be enabled to lodge a complaint. In addition to recourse to the courts, there should be independent mechanisms at institutional and other levels to facilitate the processes of lodging, mediating and adjudicating complaints. These mechanisms would, inter alia, ensure that information relating to complaints procedures was available to patients and that an independent person was available and accessible to them for consultation regarding the most appropriate course of action to take. These mechanisms should further ensure that, where necessary, assistance and advocacy on behalf of the patient would be made available. Patients have the right to have their complaints examined and dealt with in a thorough, just, effective and prompt way and to be informed about their outcome.

7. DEFINITIONS

In these Principles of the Rights of Patients in Europe, the following terms have been used with the meaning given:

PATIENT(S): User(s) of health care services, whether healthy or sick.

DISCRIMINATION: Distinction between persons in similar cases on the basis of race, sex, religion, political opinions, national or social origin, associations with a national minority, or personal antipathy.

HEATH CARE: Medical, nursing or allied services dispensed by health care providers and health care establishments.

HEALTH CARE PROVIDERS: Physicians, nurses, dentists or other health professionals.

MEDICAL INTERVENTION: Any examination, treatment or other act having preventive, diagnostic, therapeutic or rehabilitative aims and which is carried out by a physician or other health care provider.

HEALTH CARE ESTABLISHMENT: Any health care facility such as a hospital, nursing home or establishment for disabled persons.

TERMINAL CARE: Care given to a patient when it is no longer possible to improve the fatal prognosis of his or her illness/condition with available treatment methods; as well as the care at the approach of death.

Reklama

Advertisement

DEKLARÁCIA O PRÁVACH PACIENTOV V EURÓPE

EURÓPSKA KONZULTÁCIA O PRÁVACH PACIENTOV, AMSTERDAM, 28. - 30. MARCA 1994

Svetová zdravotnícka organizácia,
Regionálna úradovňa pre Európu

O Deklarácii

Na Európskej konzultácií o právach pacientov, ktorá sa konala v Amsterdame v dňoch 28. - 30. marca 1994 pod záštitou Regionálnej úradovne Svetovej zdravotníckej organizácie pre Európu (WHO/EURO) a s pohostinnou podporou holandskej vlády, sa zúčastnilo 60 osôb z 36 členských štátov. Cieľom konzultácie bolo definovať princípy a stratégie podpory práv pacientov v kontexte reformného procesu zdravotníckej starostlivosti, ktorý prebieha vo väčšine krajín.

Konzultácia sa uskutočnila ako vyvrcholenie dlhého prípravného procesu. V tomto období WHO/EURO podporovalo rozvíjajúce sa hnutie v prospech práv pacientov, medzi iným aj uskutočňovaním štúdií a prieskumov o vývoji práv pacientov v rámci Európy. Tieto štúdie ukázali spoločný záujem, i viacero trendov prístupu k tomuto problému a tiež prítomnosť normatívnych iniciatív v európskych krajinách. Poukázali aj na vhodnosť ďalšej podpory rozvíjania podobných smerníc v mnohých z týchto krajín. Výsledky štúdie boli publikované v knihe *Práva pacientov v Európe (WHO 1993).* S podporou holandskej vlády a na základe širokej konzultácie s vládami a inými inštitúciami v európskych krajinách pripravili technickí experti návrh *Princípov práv pacientov.* Predstavujú súhrnný text, ktorý môže mať význam a byť užitočným pri vypracovaní smerníc o právach pacientov v tej-ktorej krajine.

Deklarácia o právach pacientov v Európe konštituuje spoločný európsky rámec pre aktivity v tejto oblasti a obsahuje princípy, ktoré sa prijali na Amsterdamskej konzultácií. Deklarácia sa má interpretovať ako zvýraznenie oprávnenia občanov a pacientov na zlepšovanie partnerstva s poskytovateľmi zdravotníckej starostlivosti a manažérmi zdravotníckych služieb v procese zdravotníckej starostlivosti. Dúfame, že princípy práv pacientov prijaté Amsterdamskou konzultáciou budú solídnym základom a dynamickým prostriedkom, schopným zlepšiť nové myslenie v procese zdravotníckej starostlivosti.

Kompletný záznam konzultácie bude uverejnený ako zvláštna publikácia v priebehu tohto roka.

Kodaň, apríl l994

DEKLARÁCIA O PRÁVACH PACIENTOV V EURÓPE

Európska konzultácia Svetovej zdravotníckej organizácie (SZO) o právach pacientov, ktorá sa konala v Amsterdame od 28. - 30. marca 1994, prijala pripojený dokument *(Princípy práv pacientov v Európe: Spoločný rámec)* ako súbor princípov na podporu a uplatnenie práv pacientov v európskych členských štátoch SZO.

Stretnutie venovalo detailnú pozornosť zváženiu širokej palety možných stratégií založených na princípoch prezentovaných v dokumente a na súčasných skúsenostiach účastníkov. Podstata týchto stratégií je uvedená nižšie.

STRATÉGIE NA PODPORU PRÁV PACIENTOV

Vypracovanie stratégie na podporu práv a zodpovednosti pacientov treba dôkladne pripraviť. Ide o to, aby sa pôvodný úmysel skutočne pretlmočil do praktickej aktivity, ktorá získa podporu všetkých zúčastnených stránok. Takáto aktivita neprichádza automaticky, ale vyžaduje si určitý čas, kým dosiahne plný účinok.

Situácia v jednotlivých štátoch je odlišná čo do legislatívneho rámca, zdravotníckych systémov, ekonomických podmienok, sociálnych, kultúrnych a etických hodnôt. Existujú však isté spoločné prístupy, ktoré možno vhodne prispôsobiť podmienkam každej krajiny. Povzbudzujeme všetkých zainteresovaných v našich krajinách, aby začali alebo obnovili mnohoraké stratégie uplatnenia práv pacientov, ktoré si budú vyžadovať väčšinu alebo všetky nasledujúce komponenty:

- zákony alebo iné predpisy, upresňujúce práva, nároky a zodpovednosť pacientov, zdravotníckych pracovníkov a inštitúcií zdravotníckej starostlivosti;
- lekárske a iné profesijné kódexy, charty pacientov a podobné dokumenty, vypracované vo svetle prijatého spoločného stanoviska zástupcov občanov, pacientov, zdravotníckych a riadiacich pracovníkov, ktoré sa pravidelne reviduje podľa zmeny aktuálnych podmienok;
- vytváranie spojení medzi a vo vnútri skupín pacientov a poskytovateľov zdravotníckej starostlivosti, pričom sa rešpektuje rozdiel medzi účasťou občanov a používateľov (zdravotníckych služieb);
- vládna podpora založenia a efektívnej činnosti mimovládnych organizácií pracujúcich na poli práv pacientov;
- národné kolokviá a konferencie umožňujúce spoločné stretnutie zainteresovaných stránok, zamerané na vytvorenie a podporu vzájomného porozumenia;
- zapojenie masových médií pri informovaní verejnosti, stimulovaní konštruktívnej debaty, a venovaní trvalej pozornosti právam a zodpovednosti pacientov a používateľov zdravotníckej starostlivosti, ako aj orgánom, ktoré ich reprezentujú;
- zlepšenie výcviku v komunikácií a schopnosti argumentácie pre zdravotníckych pracovníkov, ako aj pre pacientov a iné skupiny používateľov zdravotníckych služieb, aby sa dosiahol pokrok v náležitom porozumení perspektív a rolí všetkých zainteresovaných;
- podpora výskumu zameranému na hodnotenie a dokumentáciu efektívnosti legislatívnych a iných opatrení a rozličných iniciatív, ktoré sa uskutočňujú v rozdielnych kontextoch rôznych krajín.

MEDZINÁRODNÉ AKTIVITY

Spolupráca medzi SZO, Radou Európy a Európskou úniou zameraná na podporu práv pacientov sa ďalej posilní aktivitou začatou v dôsledku tejto konzultácie. Konzistentnosť konkrétnych stanovísk, koordinácia stratégií uplatnenia a pochopenie toho, ako čo najlepšie využiť vlastné zdroje a kompetencie sú základnými zložkami trvalého európskeho hnutia na rozvíjanie a ochranu práv pacientov a ich profesionálnych poskytovateľov a poradcov. Medzinárodné mimovládne organizácie majú tiež zohrať dôležitú úlohu pri podpore práv pacientov.

Nadchádzajúca Regionálna konferencia SZO o zdravotnej politike poskytne významnú príležitosť na ďalšie presadzovanie práv pacientov v Európe. Navrhovaná Regionálna konferencia SZO o systémoch zdravotníctva v Európe v období zmeny, ktorá sa uskutoční vo Viedni v roku 1996, bude skúmať aj otázky týkajúce sa práv, rolí a zodpovednosti pacientov a poskytovateľov zdravotníckej starostlivosti. Navrhujeme SZO, aby Regionálna úradovňa založila vhodný mechanizmus monitorovania vývoja v jednotlivých krajinách a predložila zistenia Viedenskej konferencii.

PRINCÍPY PRÁV PACIENTOV V EURÓPE: SPOLOČNÝ RÁMEC

ÚVOD

1. VÝCHODISKÁ

Sociálny, ekonomický, kultúrny, etický a politický vývoj v Európe dali vzniknúť hnutiu zameranému na úplnejšie vypracovanie a naplnenie práv pacientov. Podporu získali nové a pozitívnejšie koncepcie týchto práv. Bolo to zčasti odrazom ústrednej polohy, ktorá sa dala plnému uplatneniu koncepcie rešpektovania (ľudskej) osoby a tiež požiadavky rovnosti v zdraví, ako cieľov politiky členských štátov. V dôsledku toho sa v súčasnosti prejavuje zvýšený dôraz na podporu individuálnej voľby a možnosti slobodne ju uplatniť, a tiež odhodlanie budovať mechanizmy na zabezpečenie kvality starostlivosti.

Zmeny v rámci systémov zdravotníctva, akými sú ich vzrastajúca zložitosť, ďalej skutočnosť, že medicínska prax sa stala nebezpečnejšou a v mnohých prípadoch ešte neosobnejšou a odľudštenejšou, pričom často zahŕňa byrokraciu; nemenej aj pokrok dosiahnutý v lekárskej a zdravotníckej vede a technológií, toto všetko položilo nový dôraz na význam uznania práva jednotlivca na sebaurčenie a na potrebu znovu formulovať záruky i ďalších práv pacientov.

Zároveň od roku 1945, kedy v Charte Spojených národov členské štáty znovu potvrdili svoje presvedčenie o základných ľudských právach, vo svete narastal význam hnutia ľudských práv. Nasledovalo prijatie Všeobecnej deklarácie ľudských práv (10. decembra 1948) a 4. novembra 1950 podpis Európskej konvencie o ľudských právach. Vlády stále viac a aktívnejšie venujú pozornosť týmto otázkam. Štúdia Svetovej zdravotníckej organizácie o právach pacientov v Európe ukazuje, že sa zvyšuje miera spoločne uznávaných princípov, ktoré sa prijímajú v mnohých krajinách a javia sa ako nezávislé od charakteristík zdravotníckeho systému tej-ktorej krajiny. Zdá sa, že je vhodné takýto trend ďalej posilniť. Tento dokument je pokusom formulovať súbor práv pacientov, ktorý odráža vyvíjajúce sa koncepcie a je dôležitý vzhľadom na kontext, v ktorom sa zdravotnícka starostlivosť bude poskytovať v budúcnosti.

Princípy práv pacientov v Európe boli navrhnuté pri plnom uvedomení si práce tých, ktorí sa v minulosti podujali vypracovať špecifické dokumenty o právach pacientov. Predošlé snahy boli však väčšinou smerované na určité skupiny, alebo sa zaoberali istými špecifickými aktivitami zdravotníckej starostlivosti, alebo pristupovali k právam pacientov z perspektívy povinností a zodpovednosti poskytovateľov zdravotníckej starostlivosti alebo zdravotníckych zariadení. Prítomný text je výsledkom pokusu nanovo koncentrovať tieto záujmy z pohľadu pacienta ako používateľa a partnera zdravotníckej starostlivosti v jej rozličných formách. Úmyselne bol formulovaný všeobecne, a pokiaľ možno, vyhýba sa odvolávkam na podmienky určitej skupiny alebo ilustratívne príklady. Myslíme však, že toto vysvetlenie všeobecných dôvodov zahŕňa základné princípy a koncepcie, ktoré treba prijať pri presadzovaní a zaistení práv pacientov v určitej krajine alebo situácií. Text nezahŕňa priamo otázky jeho uplatnenia, nakoľko tieto sú nevyhnutne špecifické pre pre danú krajinu alebo situáciu. Bol však navrhnutý v presvedčení, že uvedené smernice možno ďalej rozpracovať v rámci jednotlivých krajín, aby vyhovovali ich zvláštnym potrebám a okolnostiam.

VEDÚCE PRINCÍPY

V tomto texte je pojem zdravotníckej starostlivosti odvodený z princípov rezolúcie Svetového zdravotníckeho zhromaždenia o zdraví pre všetkých (WHA30.43) a súvisiaceho modelu zdravotníckej starostlivosti načrtnutého v Deklarácii z Alma-Aty. Zdravotnícka starostlivosť zahŕňa plné spektrum služieb pokrývajúcich podporu a ochranu zdravia, prevenciu ochorení, diagnózu, liečbu, ošetrovateľskú starostlivosť a rehabilitáciu. Pacient sa preto stretáva s celým radom poskytovateľov zdravotníckej starostlivosti a vypĺňa rozličné roly, od chorej a závislej osoby po klienta dostávajúceho odporúčanie pre konzumenta, alebo konzumenta získavajúceho zdravotné produkty pre vlastné použitie. Naviac, spomínané spektrum rolí pacienta prepokladá kontinuum zdravotných stavov od vysokej úrovne dobrého stavu zdravia po trvalé postihnutie a terminálne ochorenie.

Pri narábaní s právami pacientov je potrebné rozlišovať medzi sociálnymi a individuálnymi právami. Sociálne práva sa v zdravotníckej starostlivosti vzťahujú na záväzky spoločnosti, ktoré preberá alebo presadzuje vláda a iné verejné alebo súkromné inštitúcie, zabezpečiť obyvateľstvu poskytovanie primeranej zdravotníckej starostlivosti. Čo sa považuje za primerané v zmysle objemu a rozsahu dostupných služieb a stupňa komplikovanosti technológie a špecializácie, to bude závisieť od politických, sociálnych, kultúrnych a ekonomických faktorov. Sociálne práva súvisia aj s rovným prístupom k zdravotníckej starostlivosti pre všetkých, čo bývajú v danej krajine alebo geopolitickej oblasti, a elimináciou neoprávnených diskriminačných bariér, či už finančných, zemepisných, kultúrnych, alebo sociálnych a psychologických.

Sociálne práva sa užívajú kolektívne a majú vzťah k úrovni vývoja danej spoločnosti; sú do istej miery aj predmetom politického rozhodnutia o prioritách vývoja spoločnosti.

Individuálne práva v starostlivosti o pacienta sa naproti tomu vyjadrujú skôr v absolútnych pojmoch. Keď sa uplatňujú, možno ich vynucovať v záujme individuálneho pacienta. Tieto práva pokrývajú také oblasti, ako sú integrita osoby, súkromie, náboženské presvedčenie. Hoci tento text sa zaoberá aj sociálnymi právami, hlavný dôraz sa kladie na individuálne práva. Koncepčným základom pre takýto prístup k právam pacientov sú najmä viaceré medzivládne deklarácie, ktoré sa vzťahujú na ľudské práva a slobody. Úmyslom nie je vytvárať nové práva, ale aplikovať ich v jedinom súvislom, súhrnnom vyjadrení v oblasti pacientov a zdravotníckej starostlivosti. Pre podobné dôvody sa text nezaoberá všeobecnými právami, povinnosťami a zodpovednosťou, ktoré pokrývajú zákony a súdna prax každej krajiny.

Ďalší problém predstavuje možnosť výnimočného obmedzenia určitých práv pacientov. Tieto prípady sa väčšinou z textu vynechali, aby bolo vyjadrenie navrhovaných práv čo najjasnejšie a najjednoduchšie. Preto je vhodné hneď na začiatku objasniť povahu hlavných foriem obmedzenia. Výnimky z práv pacientov sú zvyčajne predvídané zákonom. Hlavný princíp, ktorý sa uplatňuje v týchto prípadoch, hovorí, že pacientov možno podrobiť iba takým obmedzeniam, ktoré sú zlučiteľné s dokumentmi ľudských práv a sú v súlade s postupom predpísaným zákonom. V praxi ide o obmedzenia, ktoré sa uplatňujú kvôli verejnému poriadku, verejnému zdraviu a ochrane ľudských práv iných osôb.

V niektorých situáciách je dôvodom obmedzenia práv pacienta prevažujúci záujem tretej strany (tzv. princíp "konfliktných povinností"). Prichádza do úvahy, ak by neobmedzené uplatnenie práva pacienta spôsobilo závažné poškodenie tretej strane, nie je iná možnosť ako odvrátiť poškodenie a možno primerane predpokladať, že dané obmedzenie predíde vzniku poškodenia. Podobné zdôvodnenie platí aj v tých prípadoch, keď je účelom odvrátiť závažné poškodenie pacienta (tzv. terapeutická výnimka). Kedže tento dokument sa zaoberá všeobecnými princípmi, spomínané výnimočné obmedzenia práv pacientov zväčša do textu neboli zahrnuté.

ÚČEL DOKUMENTU

Princípy práv pacientov v Európe sa ponúkajú ako príspevok na podporu vzrastajúceho záujmu mnohých členských štátov o otázky práv pacientov. Vo svojom zábere a zameraní sa tento dokument snaží odrážať a vyjadriť nielen úsilie ľudí o zlepšenie vlastnej zdravotníckej starostlivosti, ale aj o plnšie rešpektovanie svojich práv ako pacientov. V tejto snahe má na zreteli rovnako hľadisko poskytovateľov zdravotníckej starostlivosti ako hľadisko pacientov. To zahŕňa komplementárnu povahu práv a povinností: pacienti majú zodpovednosť rovnako za seba samých, za svoju vlastnú sta-

rostlivosť, ako aj voči poskytovateľom zdravotníckej starostlivosti, a poskytovatelia zdravotníckej starostlivosti majú právo na rovnakú ochranu svojich ľudských práv ako ostatní ľudia. Základný predpoklad textu je v tom, že formulovanie práv pacientov pomôže na druhej strane si lepšie uvedomiť vlastnú zodpovednosť, keď človek vyhľadáva, prijíma alebo poskytuje zdravotnícku starostlivosť, čo zaistí, aby sa vzťahy medzi pacientom a poskytovateľom zdravotníckej starostlivosti vyznačovali vzájomnou podporou a úctou.

Pacienti si majú uvedomovať praktický príspevok, ktorý môžu poskytnúť pre optimálne fungovanie zdravotníckeho systému. Ich aktívna účasť v diagnostickom a liečebnom procese je žiadúca a niekedy nepostrádateľná. Vždy je dôležité, aby poskytli príslušným zdravotníckym pracovníkom všetky informácie, ktoré sú potrebné pre účely diagnostiky a liečby. Pacient má podstatnú úlohu, recipročnú s úlohou poskytovateľa zdravotníckej starostlivosti, aby ich vzájomný dialóg bol skutočne vedený s potrebnou dôverou.

Úlohu, ktorú zohrávajú pacienti pri náležitom poskytovaní zdravotníckej starostlivosti, je potrebné osobitne zdôrazniť. Zvlášť prichádza do úvahy v súčasných komplexných zdravotníckych systémoch, udržovaných prevažne kolektívnymi finančnými mechanizmami, kde efektívne a spravodlivé použitie prostriedkov pridelených do zdravotníctva môže byť spoločným cieľom tak zdravotníckych pracovníkov ako aj pacientov. Podobne, hoci účasť pacientov pri klinickej výuke musí byť vecou ich informovaného súhlasu, majú si tiež uvedomovať, že kompetencia budúcich odborníkov do istej miery závisí aj od ochoty pacientov zúčastňovať sa na ich výcviku.

UPLATNENIE DOKUMENTU

Je vecou rozhodnutia jednotlivých krajín ako použijú tento dokument pri revízii svojej súčasnej politiky, praxe a legislatívnej podpory vo vzťahu k právam pacientov.

Hoci pre jasnosť prezentácie textu sú niektoré návrhy formulované jednoznačným spôsobom, text predstavuje súbor smerníc, ktoré sa môžu použiť pri diskusiách o prístupe k právam pacientov v rámci jednotlivých krajín. Podobne aj pri formulácii alebo prepracúvaní štátnej politiky, zákonov alebo oficiálnych vyhlásení vo veci niektorých alebo všetkých spomínaných problémov. Predpokladá sa, že tento dokument bude mať priamu hodnotu pre všetky zúčastnené strany, vrátane organizácií pacientov a konzumentov zainteresovaných do zdravotníckej starostlivosti, profesijných organizácií lekárov a iných poskytovateľov zdravotníckej starostlivosti, ako aj asociácií nemocníc a iných zariadení zdravotníckej starostlivosti.

2. CIELE

Na uvedenom základe možno čo do obsahu Princípy práv pacientov v Európe vidieť ako dokument, ktorého cieľom je:

- zdôrazniť základné ľudské práva v zdravotníckej starostlivosti, zvlášť ochraňovať dôstojnosť a integritu (ľudskej) osoby a presadzovať rešpektovanie pacienta ako osoby;
- ponúknuť na zváženie členským štátom súbor spoločných základných princípov tvoriacich základ práv pacientov, ktoré možno použiť pri vytváraní alebo prehodnocovaní smerníc starostlivosti o pacienta;
- pomôcť pacientom dosiahnuť čo najplnší úžitok pri používaní služieb zdravotníckeho systému a zmenšiť dôsledky problémov, s ktorými sa môžu zo strany týchto systémov stretnúť;
- podporovať a udržiavať užitočné vzťahy medzi pacientami a poskytovateľmi zdravotníckej starostlivosti, a zvlášť povzbudiť aktívnejšiu formu účasti zo strany pacientov;
- posilniť existujúce a poskytnúť nové príležitosti dialógu medzi organizáciami pacientov, poskytovateľmi zdravotníckej starostlivosti, riadením zdravotníctva a širšími záujmami spoločnosti;
- sústreďovať štátnu, regionálnu a medzinárodnú pozornosť na vyvíjajúce sa potreby v oblasti práv pacientov a podporovať užšiu medzinárodnú spoluprácu v tejto oblasti;
- zabezpečiť ochranu základných ľudských práv a podporovať humanizáciu pomoci všetkým pacientom, vrátane tých najzraniteľnejších, ktorými sú deti, psychiatrickí pacienti, starí alebo ťažko chorí ľudia.

3. KONCEPČNÉ ZÁKLADY

Pri vypracovaní týchto Princípov práv pacientov v Európe sa vzali do úvahy nasledovné medzivládne dokumenty, ktoré poskytujú spoločný rámec a súbor základných pojmov, ktoré možno aplikovať na práva pacientov:

- *Všeobecná deklarácia ľudských práv (1948),*
- *Medzinárodná konvencia o občianskych a politických právach (1966),*
- *Medzinárodná konvencia o ekonomických, sociálnych a kultúrnych právach (1966),*
- *Európska konvencia o ľudských právach a základných slobodách (1950),*
- *Európska sociálna charta (1961).*

PRÁVA PACIENTOV

1. ĽUDSKÉ PRÁVA A HODNOTY V ZDRAVOTNÍCKEJ STAROSTLIVOSTI

Dokumenty citované v úvode sa majú považovať za špecificky platné aj pre oblasť zdravotníckej starostlivosti. Preto ľudské hodnoty, vyjadrené v týchto dokumentoch, sa majú odrážať v zdravotníckom systéme. Rovnako treba pripomenúť, že ak sa výnimočne uplatňujú obmedzenia práv pacientov, musia byť v súlade s dokumentmi ľudských práv a mať právny základ v zákonodarstve danej krajiny. Ďalej možno konštatovať, že nižšie špecifikované práva nesú súvzťažnú zodpovednosť konať s náležitým záujmom o zdravie iných, ako aj v záujme ich rovnakých práv.

1.1 Každý človek má právo na rešpektovanie svojej osoby.

1.2 Každý má právo na sebaurčenie.

1.3 Každý má právo na telesnú a duševnú celistvosť (integritu) a bezpečnosť svojej osoby.

1.4 Každý má právo na rešpektovanie svojho súkromia.

1.5 Každý má právo na rešpektovanie svojich morálnych a kultúrnych hodnôt, ako aj náboženského a filozofického presvedčenia.

1.6 Každý má právo na takú ochranu zdravia, akú poskytujú primerané opatrenia prevencie ochorení a zdravotnícka starostlivosť, a na možnosť usilovať sa o získanie najvyššej dosiahnuteľnej úrovne svojho zdravia.

2. INFORMÁCIA

2.1 Informácia o zdravotníckych službách a o tom, ako ich čo najlepšie používať, sa má poskytnúť širokej verejnosti, aby prospievala všetkým zainteresovaným.

2.2 Pacienti majú právo byť plne informovaní o svojom zdravotnom stave, vrátane medicínskych skutočností; o navrhovaných lekárskych výkonoch, vrátane potenciálnych rizík a prínosu každého výkonu; o alternatívach k navrhovaným výkonom, vrátane dôsledkov neuskutočnenia liečby; ako aj o diagnóze, prognóze a postupe liečby.

2.3 Pacientovi možno výnimočne informáciu zadržať vtedy, ak je závažný dôvod predpokladať, že táto informácia by bez akéhokoľvek priaznivého účinku spôsobila jeho závažné poškodenie.

2.4 Informácia sa pacientovi musí oznámiť primeraným spôsobom a s ohľadom na jeho schopnosť jej porozumieť. Použitie neznámej technickej terminológie musí byť minimálne. Ak pacient nekomunikuje v danom jazyku, je potrebné zabezpečiť tlmočenie.

2.5 Pacienti majú právo nebyť informovaní, ak o to výslovne požiadajú.

2.6 Pacienti si majú právo vybrať, kto (ak vôbec niekto) má byť informovaný v ich mene.

2.7 Pacienti majú mať možnosť získať si ďalší [odborný]

názor [na svoj zdravotný stav].

2.8 Pri prijatí do zdravotníckeho zariadenia majú byť pacienti informovaní o mene a profesionálnom postavení zdravotníckych pracovníkov, ktorí sa o nich starajú, ako aj o všetkých pravidlách a bežných postupoch, ktoré sa týkajú ich pobytu a starostlivosti.

2.9 Pri prepustení zo zdravotníckeho zariadenia majú mať pacienti možnosť žiadať a obdržať písomný súhrn svojej diagnózy, liečby a ošetrovania.

3. SÚHLAS

3.1 Informovaný súhlas pacienta je podmienkou každého medicínskeho zásahu.

3.2 Pacient má právo odmietnuť alebo zadržať medicínsky zásah. Dôsledky odmietnutia alebo zadržania takéhoto zásahu sa musia pacientovi starostlivo vysvetliť.

3.3 Keď pacient nie je schopný vyjadriť svoju vôľu a medicínsky zásah je urgentne potrebný, možno jeho súhlas predpokladať, pokiaľ z predošlého výslovného vyjadrenia vôle pacienta nie je zrejmé, že v danej situácií by súhlas odmietol.

3.4 Ak sa vyžaduje súhlas zákonného zástupcu a navrhovaný zásah je urgentne potrebný, možno tento zásah vykonať aj vtedy, ak nie je možné včas súhlas zákonného zástupcu zabezpečiť.

3.5 Ak sa vyžaduje súhlas zákonného zástupcu, pacienti (či už maloletí alebo dospelí) sa musia podieľať na rozhodovacích procesoch do maximálnej miery, ktorú dovoľujú ich schopnosti.

3.6 Ak zákonný zástupca odmieta dať súhlas a lekár alebo iný poskytovateľ starostlivosti je názoru, že daný zásah je v záujme pacienta, musí sa rozhodnutie odovzdať súdu alebo inej forme arbitrážneho rozhodovania.

3.7 Vo všetkých ostatných situáciách, kedy pacient nie je schopný dať informovaný súhlas a kde niet zákonného zástupcu alebo zástupcu určeného pacientom pre takýto účel, majú sa prijať primerané opatrenia na zabezpečenie náhradného rozhodovacieho procesu, berúc do úvahy to, čo je známe a čo s najväčšou možnou istotou možno predpokladať o prianiach pacienta.

3.8 Súhlas pacienta sa vyžaduje pre skladovanie a použitie všetkých zložiek ľudského tela. Súhlas možno predpokladať, ak sa majú použiť v aktuálnom priebehu diagnostiky, liečby a starostlivosti o daného pacienta.

3.9 Informovaný súhlas pacienta je potrebný na jeho účasť v klinickej výuke.

3.10 Informovaný súhlas pacienta je podmienkou jeho účasti vo vedeckom výskume. Všetky výskumné protokoly sa musia predložiť na náležité etické posúdenie. Výskum nemožno vykonať na tých osobách, ktoré nie sú schopné vyjadriť svoju vôľu, pokiaľ sa nezískal súhlas právneho zástupcu a výskum nie je hodnoverne v záujme pacienta.

Ako výnimka z požiadavky, aby účasť vo výskume bola v záujme pacienta, môže sa nesvojprávna osoba zúčastniť observačného výskumu, ktorý neprináša priamy prospech pre jej zdravie, za podmienky, že táto osoba nevyjadruje (voči tomu) žiadne námietky, že riziko a/alebo záťaž sú minimálne, že výskum má významnú hodnotu a že nie sú k dispozícií žiadne alternatívne metódy alebo výskumné subjekty.

4. DÔVERNOSŤ A SÚKROMIE

4.1 Všetky informácie o zdravotnom stave pacienta, jeho ochorení, diagnóze, prognóze a liečbe, ako aj každá ďalšia informácia osobného charakteru sa musia považovať za dôverné, a to aj po jeho smrti.

4.2 Dôverná informácia sa môže oznámiť len vtedy, ak pacient k tomu udelí svoj výslovný súhlas, alebo ak je to umožnené zákonom. Súhlas možno predpokladať, pokiaľ ide o oznámenie informácie iným poskytovateľom zdravotníckej starostlivosti [zdravotníckym pracovníkom] zúčastneným na jeho liečbe.

4.3 Všetky osobne identifikovateľné údaje o pacientovi musia byť náležite chránené. Ochrana údajov musí byť primeraná spôsobu ich uchovávania. Rovnako chránený musí byť aj každý ľudský materiál, z ktorého možno identifikovateľné údaje získať.

4.4 Pacienti majú právo prístupu k svojej zdravotnej dokumentácií, k technickým záznamom a ku všetkej ďalšej dokumentácií a záznamom týkajúcim sa ich diagnózy, liečby a ošetrovania. Majú tiež právo obdržať kópiu svojej dokumentácie a záznamov, alebo ich častí. Z tohto prístupu sa vylučujú údaje týkajúce sa iných osôb.

4.5 Pacienti majú právo požadovať opravu, kompletizáciu, vypustenie, objasnenie alebo aktualizáciu osobných a medicínskych údajov, ktoré sa ich týkajú a sú nepresné, neúplné, nejednoznačné alebo zastaralé, alebo ktoré nie sú významné pre účely ich diagnózy, liečby alebo ošetrovania.

4.6 Zásah do súkromia alebo rodinného života pacienta nie je prípustný. Takýto zásah možno vykonať vtedy a len vtedy, ak pacient nielen udelí k nemu svoj výslovný súhlas, ale ak ho súčasne možno považovať za potrebný pre pacientovu diagnózu, liečbu a ošetrovanie.

4.7 Medicínske zásahy možno vykonať iba vtedy, ak sa náležite rešpektuje súkromie jednotlivca. To znamená, že daný výkon možno uskutočniť iba v prítomnosti tých osôb, ktoré sú potrebné pre jeho vykonanie, pokiaľ pacient nesúhlasí alebo nepožaduje inak.

4.8 Pacienti prijímaní do zdravotníckeho zariadenia majú právo očakávať také vecné vybavenie zariadenia, ktoré zaistí ich súkromie, a to zvlášť vtedy, keď im zdravotnícki pracovníci poskytujú osobnú starostlivosť, vykonávajú vyšetrenia alebo liečbu.

5. STAROSTLIVOSŤ A LIEČBA

5.1 Každý má právo na poskytnutie zdravotníckej starostlivosti, ktorá je primeraná jeho zdravotným potrebám, vrátane preventívnej starostlivosti a činností zameraných na podporu zdravia. Zdravotnícke služby majú byť k dispozícií priebežne. Majú byť dostupné pre všetkých spravodlivo, bez diskriminácie a podľa finančných, ľudských a materiálnych zdrojov, ktoré možno v danej spoločnosti dať k dispozícií.

5.2 Pacienti majú kolektívne právo na určitú formu svojej reprezentácie na každom stupni zdravotníckeho systému vo veciach súvisiacich s plánovaním a vyhodnocovaním [zdravotníckych] služieb, vrátane rozsahu, kvality a fungovania poskytovanej starostlivosti.

5.3 Pacienti majú právo na takú kvalitu starostlivosti, ktorá sa vyznačuje súčasne vysokou technickou úrovňou a humánnym vzťahom medzi pacientom a jej poskytovateľmi [zdravotníckymi pracovníkmi].

5.4 Pacienti majú právo na kontinuitu starostlivosti, vrátane spolupráce medzi všetkými poskytovateľmi zdravotníckej starostlivosti a zdravotníckymi zariadeniami, ktorí/é sa môžu podieľať na ich diagnostike, liečbe a starostlivosti.

5.5 V okolnostiach, keď sa zo strany poskytovateľov [zdravotníckej starostlivosti] musí robiť výber medzi potenciálnymi pacientami na určitý druh liečby, ktorý je dostupný iba v obmedzenej miere, všetci pacienti majú právo zúčastniť sa v spravodlivom výberovom postupe týkajúcom sa tejto liečby. Výber musí byť založený na medicínskych kritériách a vykonávaný bez akejkoľvek diskriminácie.

5.6 Pacienti majú právo si vybrať a zmeniť svojho lekára, alebo iného poskytovateľa zdravotníckej starostlivosti [zdravotníckeho pracovníka], ako aj zdravotnícke zariadenie, za predpokladu, že je to zlučiteľné s fungovaním daného zdravotníckeho systému.

5.7 Pacienti, u ktorých už nie sú medicínske dôvody pre ďalší pobyt v zdravotníckom zariadení, majú právo na dôkladné poučenie pred ich prekladom do iného zdravotníckeho zariadenia alebo pred prepustením domov. Preklad sa môže uskutočniť iba vtedy, ak dané zdravotnícke zariadenie súhlasilo s príjmom pacienta. Ak je pacient prepúšťaný domov a jeho zdravotný stav to vyžaduje, musia byť k dispozícií potrebné komunitné a domáce služby.

5.8 Pacienti majú právo na dôstojné zaobchádzanie v súvislosti so svojou diagnózou, liečbou a ošetrovaním, ktoré sa majú poskytovať s rešpektovaním ich kultúry a hodnôt.

5.9 Pacienti majú počas trvania [zdravotníckej] starostli-

vosti a liečby právo na podporu zo strany svojej rodiny, príbuzných a priateľov, ako aj právo na duchovnú podporu a vedenie v každom čase.

5.10 Pacienti majú právo na úľavu vo svojom utrpení v súlade so súčasným stavom [medicínskeho] poznania.

5.11 Pacienti majú právo na humánnu terminálnu starostlivosť a právo umrieť dôstojne.

6. UPLATNENIE

6.1 Uplatnenie práv predložených v tomto dokumente predpokladá, že sa vytvoria na tento účel primerané prostriedky.

6.2 Uplatnenie týchto práv musí byť zaistené bez diskriminácie.

6.3 Pri uplatnení týchto práv možno pacientov podrobiť iba takým obmedzeniam, ktoré sú v súlade s dokumentami ľudských práv a s postupom určeným podľa zákona.

6.4 Ak pacienti nemôžu uplatňovať práva predložené v tomto dokumente sami, majú sa [tieto] uplatniť prostredníctvom ich právneho zástupcu, alebo osoby, ktorú pacient na tento účel určil; pokiaľ právny ani osobný zástupca nebol určený, je potrebné uplatniť iné spôsoby zastupovania [týchto pacientov].

6.5 Pacienti musia mať prístup k takým informáciám a poradenstvu, ktoré im umožní uplatniť práva predložené v tomto dokumente. Ak sú pacienti názoru, že ich práva neboli rešpektované, musí sa im umožniť podanie sťažnosti. Okrem prístupu k súdom, musia existovať nezávislé mechanizmy na úrovni zdravotníckych zariadení a na iných úrovniach, na uľahčenie procesov podávania, sprostredkovania a posudzovania sťažností. Tieto mechanizmy musia okrem iného zabezpečiť, aby informácie, ktoré sa týkajú sťažností, boli pre pacientov dostupné, a aby bola pre pacientov k dispozícii nezávislá osoba na konzultácie o voľbe najvhodnejšieho postupu v danom prípade. Tieto mechanizmy majú ďalej zaistiť, kde je to potrebné, pomoc a právne zastupovanie v záujme pacienta. Pacienti majú právo na dôkladné, spravodlivé, efektívne a promptné vyšetrenie a posúdenie svojich sťažností, ako aj na informáciu o ich výsledku.

7. DEFINÍCIE

V týchto Princípoch práv pacientov v Európe sa použili nasledovné termíny s týmto významom:

PACIENT(I): používateľ(lia) zdravotníckych služieb, zdravý/í alebo chorý/í.

DISKRIMINÁCIA: rozlišovanie medzi osobami v podobných prípadoch na základe rasy, pohlavia, náboženstva, politického názoru, národného alebo sociálneho pôvodu, v súvislosti s národnou menšinou alebo osobnou antipatiou.

ZDRAVOTNÍCKA STAROSTLIVOSŤ: lekárske, ošetrovateľské alebo súvisiace služby vykonávané poskytovateľmi zdravotníckej starostlivosti a zdravotníckymi zariadeniami.

POSKYTOVATELIA ZDRAVOTNÍCKEJ STAROSTLIVOSTI: lekári, sestry, dentisti alebo iní zdravotnícki pracovníci.

MEDICÍNSKY VÝKON: každé vyšetrenie, liečba alebo iný úkon majúci preventívny, diagnostický, liečebný alebo rehabilitačný zámer, ktorý vykonáva lekár alebo iný poskytovateľ zdravotníckej starostlivosti.

ZDRAVOTNÍCKE ZARIADENIE: každé zdravotnícke zariadenie, ako nemocnica, dom opatrovateľskej služby alebo zariadenie pre [zdravotne] postihnuté osoby.

TERMINÁLNA STAROSTLIVOSŤ: starostlivosť poskytovaná pacientovi, keď už nie je možné zlepšiť fatálnu [veľmi zlú] prognózu jeho ochorenia/stavu dostupnými liečebnými metódami; ako aj starostlivosť pri priblížení sa smrti.

Z anglického originálu preložil MUDr. Jozef Glasa.

(Pozn. prekladateľa: Slová v [ ] zátvorkách boli vložené do textu prekladu kvôli lepšiemu porozumeniu. Preklad neprešiel jazykovou úpravou.)

Z KONGRESOV A KONFERENCIÍ

CONGRESSES & CONFERENCES

AKČNÝ PROGRAM MEDZINÁRODNEJ KONFERENCIE O POPULÁCII A ROZVOJI V KÁHIRE

Program of Action of the International Conference on Population and Development (ICPD), Cairo (Egypt), 5 - 13 September 1994

J. Glasa

Ústav medicínskej etiky a bioetiky, Bratislava

Akokoľvek rozpornou a nezrozumiteľnou sa mohla javiť káhirská konferencia menej zasvätenému pozorovateľovi, predsa všetci účastníci i všetky viac alebo menej ohraničené a proti sebe stojace "tábory" sa úplne zhodli v jednom: bola konferenciou vskutku historickou. Hlavným dokumentom, okolo ktorého sa točili všetky rokovania v Hlavnom výbore, v mnohých dohadovacích výboroch, ba ešte viac v neprehľadnom zákulisí konferencie, bol 105-stránkový podrobný materiál s názvom *"Akčný program Medzinárodnej konferencie o populácii a rozvoji" (Program of Action of the International Conference on Population and Development (ICPD) (ďalej PA-ICPD))*. V tomto príspevku sa pokúsime poukázať na niektoré problémy obsiahnuté v tomto dôležitom medzinárodnom dokumente i na to, ako boli reflektované a (niektoré z nich) riešené počas rokovaní Hlavného výboru ICPD. Pokúsime sa byť čo najstručnejší, mnohé tu môžeme len spomenúť, či naznačiť. Je zrejmé, že podrobnejšia analýza jednotlivých problémov a s nimi spojenej rôznorodej argumentácie ďaleko presahuje priestor vymedzený tomuto príspevku.

Návrh PA-ICPD bol pripravený na predchádzajúcich zasadnutiach Prípravného výboru ICPD a schválený na jeho poslednom zasadnutí v New Yorku v apríli 1994 ako konečný podklad pre rokovanie konferencie. Text návrhu PA-ICPD predstavoval materiál, ktorého obsah na cca 90% odsúhlasili delegácie všetkých členských štátov OSN. Ostatný text - uvedený v zátvorkách - mal byť predmetom posúdenia a rokovaní v priebehu konferencie. V dôsledku závažných rozporov, ktoré sa prejavili počas prípravy PA-ICPD, neboli práve východiskové časti dokumentu, t.j. *Preambula* a najmä *Princípy* vôbec diskutované počas zasadnutí prípravného výboru a ponechali sa na diskusiu a posúdenie priamo ICPD. PA-ICPD pozostáva zo **16-tich kapitol**. V krátkosti k ich obsahu a niektorým problémom, ako sa objavili počas rokovaní.

Prvá kapitola - *Preambula* - predstavuje úvod k dokumentu. Spolu s nasledujúcou kapitolou (Princípy) popisuje v krátkosti základné východiská a medzinárodné aktivity na úrovni OSN, ktoré ICPD predchádzali. Počas rokovaní bola Preambula podstatne skrátená a mnohé formulácie vecne i štylisticky prepracované. Výrazy v hranatých zátvorkách boli upravené v súlade s výsledkami rokovania ICPD.

Počas rokovaní delegáti kritizovali prílišný optimizmus preambuly a zvolili skôr vecnejší a triezvejší tón prijatých formulácií. Viaceré delegácie poukázali na to, že sa z textu prakticky vytratil aspekt rozvoja a všetka pozornosť sa venovala otázkam kontroly populácie. Čínska delegácia upozornila na posun (zníženie) odhadu vzrastu svetovej populácie v priebehu jedného roka podľa predložených projekcií OSN (z 93 mil. pokles na 86 mil. prírastku obyvateľov sveta ročne).

Druhá kapitola - *Princípy* - obsahuje formuláciu princípov, z ktorých delegáti ICPD mali vychádzať počas svojich rokovaní na konferencii a dopracovaní PA-ICPD. Podstatná časť - dohromady 15 formulovaných princípov - predstavuje citácie predchádzajúcich dokumentov OSN. Na viacerých miestach však návrh predstavoval pokus o podstatnú ino-

váciu prístupu - až po formuláciu a definíciu nových odborných pojmov ("reproductive health, sexual health, fertility regulation") a zásah do problematiky ľudských práv ("reproductive rights", "right to the highest attainable standard of the sexual and reproductive health").

V diskusii sa i druhá kapitola podstatne skrátila. ICPD zdôraznila, že nie je konferenciou, ktorá by mala definovať nové ľudské práva. Sporný termín "sexual and reproductive health (care)" bol nahradený termínom "reproductive health (care), including family planning and sexual health". Delegáti zdôraznili princíp suverenity jednotlivých štátov pri implementácii PA-ICPD, ktorá má byť v súlade s legislatívou tej-ktorej krajiny a medzinárodne uznanými štandardmi ľudských práv. Má rešpektovať sociálne a kultúrne, ako aj náboženské tradície danej krajiny. V prípade výchovy mládeže sa opäť zdôraznili a potvrdili práva a povinnosti rodičov, ktoré v pôvodnom návrhu chýbali. Zapracovali sa aj formulácie zdôrazňujúce význam a poslanie rodiny.

Tretia kapitola - *Vzájomné vzťahy medzi populáciou, udržateľným ekonomickým rastom a udržateľným rozvojom* - obsahovala hodnotenie vzťahov medzi súčasným a projikovaným populačným vývojom v rôznych oblastiach sveta (vyspelé krajiny, rozvojové krajiny, krajiny "with economies in transition" - medzi ktoré bola zaradená spolu s inými stredo a východoeurópskymi štátmi i Slovenská republika) a ekonomickým rastom, chudobou a znehodnocovaním životného prostredia.

Delegáti kritizovali pesimistický a príliš jednoznačný tón návrhu a poukázali na to, že najväčším bohatstvom a zdrojmi každého národa je jeho populácia. Pripomenuli aj neudržateľnosť súčasných foriem a rozsahu spotreby obyvateľstva v rozvinutých krajinách, ktorá mnohonásobne prekračuje spotrebu na obyvateľa v krajinách rozvojových.

Štvrtá kapitola - *"Rovnosť pohlaví, rovnosť a "empowerment" žien* - je venovaná problematike súčasného stavu a žiaduceho pokroku v otázke postavenia a práv žien, problému diskriminácie detí ženského pohlavia (už prenatálne - selektívny abort, i postnatálne - nápadne vysoká postnatálna úmrtnosť dievčat v niektorých krajinách), ako aj zodpovednosti mužov a ich väčšej participácii na riešení otázok plánovania rodičovstva.

Piata kapitola - *Rodina, jej roly, zloženie a štruktúra* - bola venovaná otázkam rôznych foriem rodiny existujúcim v súčasnosti ako aj možnostiam sociálnej a ekonomickej pomoci rodinám. V diskusii sa zdôraznil význam manželstva ako základu rodiny. Viaceré, najmä moslimské štáty presadzovali vynechanie termínu "other unions - iné zväzky" (i pre poukaz na homosexuálne zväzky a ich legislatívne presadzovanie v posledných rokoch).

Šiesta kapitola - *Rast a štruktúra populácie* - obsahuje rozbor globálnych demografických údajov. Obsahuje zvláštne podkapitoly venované deťom a mládeži, starým ľuďom a postihnutým osobám.

Siedma kapitola - *Reprodukčné práva,* [*sexuálne*] *a reprodukčné zdravie* [*a plánovanie rodičovstva*]. Obsahuje veľa protirečivých pojmov a výrazov. Časť z nich súvisí s problematikou umelého potratu, najmä s jeho zahrnutím do služieb „starostlivosti o reprodukčné a sexuálne zdravie", ako aj so snahou definovať nový - viac individualistický prístup k týmto súčastiam ľudského zdravia, až po oblasť dotýkajúcu sa problematiky ľudských práv. V tejto časti sa nachádzajú aj podkapitoly o prevencii sexuálne prenosných ochorení, vrátane HIV/AIDS, ďalej o ľudskej sexualite a vzťahoch pohlaví, o adolescentoch. V poslednej menovanej narazila na odpor snaha zabezpečiť úplnú anonymitu a voľný prístup k službám "reprodukčného a sexuálneho zdravia" (najmä 'poradenstvo' a antikoncepcia, vrátane umelého potratu), s vylúčením vplyvu rodičov. Delegáti v súhlase s predchádzajúcimi dokumentami OSN (napr. Chartou práv dieťaťa) zdôraznili práva i povinnosti rodičov pri výchove detí podľa svojho presvedčenia, a to i v oblasti výchovy k manželstvu a rodičovstvu, resp. výchovy 'sexuálnej'.

Ôsma kapitola - *Zdravie, morbidita a mortalita.* Popri analýze uvedených javov v celosvetovom meradle (vrátane niektorých nových negatívnych tendencií v "krajinách s ekonomikou v prechode", medzi ktoré spolu s inými bývalými "socialistickými" krajinami patrí aj Slovenská republika) obsahuje táto časť i paragraf 8.25 venovaný priamo problematike umelého potratu. Tento paragraf, pripravený v dvoch odlišných verziách - jednej 'relatívne' extrémnej, požadujúcej priamo zakotvenie "práva na potrat" ako základného ľudského práva s následnou revíziou legislatívy členských krajín OSN a v druhej "kompromisnej" - pripravenej najmä Európskou úniou, sa stal jedným z mnohých "jabĺk sváru" servírovaných na konferencii. 'Extrémna' verzia sa na ICPD vôbec nediskutovala. Kompromisná verzia 8.25 obsahovala viaceré vyjadrenia a termíny (napr. "safe/unsafe abortion" - "bezpečný/rizikový potrat", výraz "need for abortion" - "potreba potratu", "fertility regulation" (metódy zahŕňajúce aj umelý potrat) v kontraste s "family planning" (terminologicky priamo nezahŕňajúce umelý potrat), atď.), ktoré sa v komplikovanej debate problematizovali i vyjasňovali. Dôležité bolo vystúpenie zástupcu Svetovej zdravotníckej organizácie (SZO), ktorý potvrdil, že termín "fertility regulation" podľa pracovnej definície SZO skutočne zahŕňa umelý potrat. Konečná verzia tohto kontroverzného paragrafu zdôrazňuje, že "umelý potrat v žiadnom prípade nemožno uplatňovať ako metódu plánovania rodičovstva", ďalej potrebu "citlivého poradenstva ženám" a starostlivosti o ženu v prípade komplikácií a následkov umelého potratu, ako aj nutnosť predchádzania neželaným ťarchavostiam, aby sa výskyt umelého potratu znížil na minimum.

Deviata kapitola - *Distribúcia populácie, urbanizácia a vnútorná migrácia.* Popri hodnotení javov uvedených v názve kapitoly, ktoré nevyvolalo väčšie diskusie, obsahuje kapitola i odsek o osobách nútene premiestnených v rámci danej krajiny ("internally displaced persons"). Pri riešení tohto problému sa hľadalo stanovisko zaručujúce rešpektovanie suverenity danej krajiny pri požiadavke efektívnej pomoci a zvládnutia neraz ťaživej a komplikovanej situácie týchto osôb.

Desiata kapitola - *Medzinárodná migrácia.* Obsahuje problematiku dokumentovanej (legálnej) a nelegálnej medzinárodnej migrácie, ktorá - najmä vzhľadom na prebiehajúce vojenské konflikty v rôznych oblastiach sveta - predstavuje jeden z najzávažnejších humanitárnych medzinárodných problémov. Temer neprekonateľným kameňom úrazu sa stala požiadavka umožňovať a napomáhať zjednotenie migráciou rozdelených rodín, ktorá už predstavuje - ako "právo dieťaťa vyrastať v úplnej rodine" - ľudské právo uznané v predchádzajúcich dokumentoch OSN. Rozpor medzi zainteresovanými krajinami sa podarilo vyriešiť kompromisom až po dlhotrvajúcej debate s rekordnou účasťou rečníkov a práci zvláštnej dohadovacej komisie. Podľa predsedajúceho Hlavného výboru ICPD išlo o situáciu, ktorá mohla závažným spôsobom ohroziť celý priebeh i samotný úspech konferencie.

Jedenásta kapitola - *Populácia, rozvoj a vzdelanie.* Zdôrazňuje význam vzdelania, vrátane neinštitucionálneho vzdelávania a vhodného využitia masovokomunikačných prostriedkov.

Dvanásta kapitola - *Technológia, výskum a rozvoj.* Obsahuje problematiku výskumu v oblasti demografie, sociológie, ekonómie, medicíny a biotechnológií, ktorý má dopad na oblasť populácie a udržateľného rozvoja.

Trinásta kapitola - *Aktivity na národnej (štátnej) úrovni* a **Štrnásta kapitola** - *Medzinárodná spolupráca.* Obe kapitoly riešia predovšetkým finančné zabezpečenie populačných programov v rozvojových krajinách a v 'krajinách s ekonomikou v prechode' (t.j. programov populačnej 'kontroly') na národnej i medzinárodnej úrovni. Ide o pomerne veľké sumy financií, z ktorých však 2/3 musia dať samotné cieľové krajiny týchto programov. Chýbajúcu 1/3 by mali rôznou formou doplniť rozvinuté krajiny, resp. medzinárodné organizácie a inštitúcie. Odhad potrebných nákladov na progra-

my v oblasti "reprodukčného zdravia", vrátane "plánovania rodičovstva", "zdravia matky" a prevencie sexuálne prenosných chorôb, ako aj základné aktivity potrebné na zber a analýzu populačných údajov je nasledovný: v roku 2000 pôjde o 17.1 miliardy USD, v roku 2005 o 18.5 miliardy USD, v roku 2010 o 20.5 miliardy USD a v roku 2015 o 21.7 miliardy USD.

Pätnásta kapitola - *Partnerstvo s mimovládnym sektorom.* Zdôrazňuje význam, postavenie a úlohy mimovládnych organizácii, ktoré svojimi aktivitami majú napomáhať realizáciu a presadzovanie populačných programov v jednotlivých krajinách. Dokument sa pokúsil zvýšiť prestíž a vplyv týchto organizácií v medzinárodnom meradle.

Šestnásta kapitola - *Aktivity po skončení ICPD (follow-up).* Stanovuje rozličné aktivity na regionálnej, národnej a medzinárodnej úrovni, ktoré majú zabezpečiť realizáciu Akčného programu ICPD a jej kontrolu.

Záverom je potrebné poznamenať, že tento veľmi stručný výpočet niektorých problémov obsiahnutých v Akčnom programe ICPD zďaleka nie je úplný. Priestor tohto príspevku nedovolil dobre rozvinúť niekedy protikladnú argumentáciu týkajúcu sa spomenutých problémov, ba ani celkom dobre dešifrovať problematičnosť niektorých termínov, či vyjadrení. Káhirská konferencia, podľa nedávneho výroku českého premiéra Václava Klausa - "po dlhých a ostrých debatách prijala nakoniec menej hrozivé formulácie", čo zaiste treba hodnotiť pozitívne. Avšak tzv. "káhirský proces" sa zatvorením brán konferencie v Káhire zďaleka neskončil - dostal sa len do jednej zo svojich ďalších vývojových fáz. Čo v ďalšom prinesie pre riešenie populačných problémov a pre vývoj ľudskej civilizácie na našej planéte - to ukáže už najbližšia budúcnosť.

(Literatúra u autora.)

Program of Action of the International Conference on Population and Development (ICPD), Cairo (Egypt), 5 - 13 September 1994, J. Glasa, ME&B, Vol. 1, 1994, No. 5 - 6, p. 19 – 21. Author, the member of the Slovak governmental delegation to the International Conference on Population and Development (ICPD), held in Cairo (Egypt) on September 5 - 13, 1994, gives an overview of the broad scope of different problems contained in the key document of ICPD - *The Program of Action of ICPD*, together with some remarks on how some of them were discussed and solved in debates of the Main Committee and its working groups during the conference.

Pozn. Dr. J. Glasa bol členom delegácie Vlády Slovenskej republiky na Medzinárodnej konferencii o populácii a rozvoji (ICPD) v Káhire.

● Svoj život zasvätím službe ľudskosti.

● Svoje povolanie budem vykonávať svedomito a dôstojne.

● Zdravie pacienta bude mojím prvoradým záujmom.

● Zachovám všetkými dostupnými prostriedkami vážnosť a vznešené tradície lekárskeho povolania.

● Nedopustím, aby záujmy náboženstva, národnosti, rasy, politickej strany alebo spoločenského postavenia sa postavili medzi moju povinnosť a môjho pacienta.

● Zachovám úplný rešpekt voči ľudskému životu od okamihu počatia; ani pod nátlakom nepoužijem svoje lekárske vedomosti v rozpore so zákonmi ľudskosti.

Ženevská deklarácia (WMA (SAL), 1968, 1994)

LISTY REDAKCII

LETTERS TO THE EDITOR

SOME REFLECTIONS ON THE INSTRUCTION IN MEDICAL ETHICS

R. Pullmann

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Sir,

The instruction in medical ethics and bioethics has undergone a dramatic development over the last two decades. Biomedical ethics came of age in 1970s. The growth of knowledge on one hand has been an outcome of marked development of philosophical disciplines, that have formed a great deal of the new background of bioethics. On the other hand, the rapid and intensive development of biological and medical sciences as well as new biomedical technologies have posed previously unthought-of problems and ethical dilemmas infront of the medical personell. The biomedical technology of the 1980s has progressed so rapidly, that wherever we turn, we are faced with novel and highly complex ethical quandaries.

The development of philosophical disciplines has been accompanied by developments underwent by religious communities and their teachings as a reflection of the changing world. Hand-in-hand with these developments we are experiencing a growth in legal and civil consciousness. Ethics has ceased to be exclusively the matter of a doctor, and since the methods of modern analytical philosophy are applied, ethics in the classical sense grows into the bioethics, acquiring a pluralistic and interdisciplinary character. In addition to the problems considered by the "old" traditional ethics, bioethics deals with completely new questions, such as ecological ethics, etc., and it prefers the use of methods of the modern philosophical enquiry.

Contemporary medical ethics represents an application of bioethics to the modern medicine and health care. In contrast to the traditional medical ethics (characterized partially by the Hippocratic Oath) which has been formed and formulated almost exclusively by doctors - present moral philosophy, theology, and jurisprudence participate in the formulation of bioethical theories, and, which seems to be a marked novelty, also an opinion of patients begins to play an important role.

Some older ethical codices, declarations and memoranda need some completition and replenishment to represent a sound reflection of contemporary ethical problems. This makes their validity and practical use limited to certain degree. One of the major reasons seems to be that contemporary medical practice (or health care) - in some contradiction to the past - is becoming increasingly a matter of teamwork, which is also reflected by the professional heterogeneity of the medical personnel (doctors, psychologists, natural scientists, engineers, etc.) and various levels of its education. It is quite natural, that these groups are in numerous mutual interactions and they wish to participate, directly or indirectly, in the formulation of the moral standards. These interactions are joined by patients themselves, who project various civic rights into the relationship patient - medical staff. Patient's feelings and expectations are reflecting his or her preferrences, which on one hand are shattering the traditional doctor's paternalism, on the other they make a contribution to the plurality of opinions and have a feedback effect on medical staff. The secularization of the society and

ongoing change of the hierarchy of values have brought about several new phenomena, such as the efforts to legalize an active euthanasia.

Contemporary upsurge of **modern biomedical technologies** and molecular medicine (which brings with e. g. revolutionary changes in intensive care, transplantation, gene engineering and therapy, diagnostic tools and therapeutic interventions - including new drugs) contributes to further differentiation of opinion within the medical community as well as the patients› public. Physicians are being increasingly forced into the roles of "economic gatekeepers" - deciding which patient should receive an expensive diagnostic procedure or therapy. Besides the moral challenges of the newest biomedical technologies, doctors still remain faced by older and equally deep ethical problems connected with medicine as a profession and health care as a specific human activity.

At the same time it could be seen that the **fundamental philosophical questions**, such as those about the nature of man and his dignity, his origins and his destination, about what makes man›s life specifically human, about the beginning and end of life, about the flow of time and the biological clock (frozen human embryos), question on whether a human embryo or an irreversibly unperceiving human with arteficially maintained vital functions are still to be considered living human beings, is an anencephalus a human being, what is to be considered quality of human life and its dignity, is there an inferior and a superior quality of human life, can inferior quality, if it exists, be sacrificed to achieve temporarily superior quality (transplantation of embryonal tissues or cells produced by genetic engineering to the patients with various defects, e. g. Parkinson's disease), the problem of obtaining of some somatic genes or pluripotent cells, the question of "animals' rights", and many others, occupy today the minds of a considerable part of the medical community.

The medical personnel will not be able to avoid these, and similar questions and shift the responsibility to someone else. What would be the outcome (what decision would be taken) of different attitudes of individual members of the medical team? The answers to many of the above-mentioned questions are decisive for further attitudes.

What then are the targets of bioethical instruction and what should be its purpose ?

a) First of all, to **define and designate ethical aspects of everyday's practice**, and where possible, to define clearly what is to be considered an ethical, and what a specifically medical problem. In other words - to cultivate a sense for differentiating values. This aspect is of paramount importance, as there exists traditionally a tendency to camouflage ethical problems and present them as medical ones, and vice versa. It is, however, true that the borderlines between medicine and ethics are sometimes very difficult to define, which is caused by the very essence of medicine.

b) **Work out a logical philosophical conception** and format instructions for solutions.

c) Acquaint the medical personnel with the **rights of patients**, also with the rights of patients (probands) as research subjects of clinical research.

d) Increase the sensibility of **ethical perception** and apprehension of the hierarchy of values and fundamental preferences and **formation** of a moral "mirror of the soul".

One could summarize by saying that bioethical teaching is a form of education of medical personnel towards a more moral approach. Bioethicists are trying to teach people the methods of making ethical decisions.

In a **pluralistic democratic societies** bioethics cannot give consistent and universally valid instructions for solutions of every problem, acceptable for all strata of patients and health care personnel. On the other hand not even perfect knowledge of bioethics is a guarantee of moral behaviour. This contradiction is likely to grow in the near future, as can be seen, e.g. in the transplantation practice, whether in obtaining cells, tissues and organs, or in their application. Because bioethics is a relatively new discipline, the vast majority of physicians, nurses (also scientists) have not been educated in it, in particular in our country (Slovakia).

Teaching of bioethics in a post-totalitarian society is marked by some specific features. These concern all four spheres, i.e. teaching staff, students and subject-matter, as well as methodology. The pluralist approach makes it evident, that the instruction of medical ethics cannot be left, in an undergraduate teaching, to the "re-trained" former marxist philosophy teachers. It seems practical, at present, to invite practicising doctors, researchers, theologians, and lawyers (after some self-education and formation period) to participate in teaching activities. (In perspective, naturally, also a new generation of philosophers, after it is grown up enough for the task...) We find it also appropriate, as seen at many universities in the world, that the common introductory courses are organized for the students of various humanities groups (medicine, law, philosophy), however, this approach faces difficulties in establishing a good cooperation among faculties or universities.

Doctors participating in the instruction of biomedical ethics are supposed to posses also a highly professional, up to date standard of knowledge in medicine, or their particular discipline, not only a good understanding of ethics. The traditional image of a lecturer, as a highly honourable, wise, retired university teacher (professor) passing his lifetime experience and summarizing his carreer - now as a specialist in ethics, is irretrievably lost. Postgradual instruction in medical ethics emphasizes even more understanding of the professional aspect, and requires even a certain specialization.

From the point of view of the instructors it seems necessary to realize an important aspect: the resulting **reality** from the previous orientation **of the society**, characterized by unitarianism and standardization, brought about by application of a unitary philosophical system. Its projection into the everyday's activities of a medical personnel has been manifested in strong paternalism (characteristic of classical medical ethics). Strong, totalitarian paternalism, almost annihilating the autonomy of a patient in all circumstances, was characteristic for the ethics of a totalitarian society.

Although discussions are held about justification of some degree of **paternalism**, this approach does contain a danger, namely, that many ethical problems are not identified as such, but rather as medical ones. Doctors then tend to claim for themselves an exclusive right to offer a solution on the strength of their experience from the practice. The doctors find it difficult to accept that also other members of medical personnel, and even a broad lay community, have a say in questions of medical ethics. The impact of such an approach can be seen in various allegations about the end of medical ethics.

Discussions about strong or weak paternalism and its justification are in fact discussions about the basis of bioethics or medical ethics and to what extent the importance of philosophical sciences and of analytical philosophical tradition can be accepted. In evaluating the sources of today's bioethics we encounter the question of the **position of the law** and its practical application. An emerging new legal system does not necessarily mean that the legal norm become automatically and completely part of legal practice in the society under transformation. Relicts of previous legal conceptions persist. Lack of confidence to the mainstays of bioethics, to the modern philosophy and reluctant restructuring of the legal system of the society are projected into the present-day status of public opinion and legal awareness. The aforementioned facts are augmented by the equally important factor, namely, that many bioethical aspects from medical practice are automatically transferred to the emerging society as cut-and-dried instructions. It is often forgotten, that the birth of bioethics, of its principles, took place within

a broad **public discussion** in medical as well as lay circles, and thus became a matter of public and civic interest. This exchange of opinions enriched both the medical circles as well as the current and potential patients. This exchange of opinion was enabled by an upsurge of medicine and technology on the one hand, and the development of civic rights and freedoms on the other. Deletion of such discussions when adopting some a priori given, ready bioethical position for medical practice can weaken the civic sense and interest in bioethics with possible negative effects on the further development of bioethics in our country.

Of no lesser importance is the **formal aspect of teaching** of biomedical ethics. The development and availability of a new teaching equipment brings up several untraditional, effective teaching methods. **Undergraduate** instruction, ideally, is graded into several years of study (and, if possible, taught in basics for various humanities together). Further progress is more differentiated, but various models have in common the tutorial discussions, teaching in small groups with a patient-oriented approach. In some countries the ethical aspects of a given discipline are taught within that discipline. This is true mainly for gynaecology, pediatry, medical genetics and neurology.

In **postgraduate** teaching an emphasis is given to the organization of postgraduate courses for small groups, more general in content as well as a higly specific ones; and also tutorial discussion classes in the form of clinical - ethical conferences (involving case studies of concrete patients). Well functioning ethics committees in the health care institutions, with an optimal structure and well-defined spheres of activity, are evidence and simultaneously a pre-requisite of lively interest in bioethical issues. People (general public), and health care workers as well, need to be given an understanding, that bioethics is a living, progressive discipline, going on every minute, every day, together with a rapid progress of contemporary medicine and biomedical sciences.

(Literature by the author.)

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● A DOCTOR MUST always bear in mind the obligation of preserving human life.

● A DOCTOR OWES to his patient complete loyalty and all the resources of his science. Whenever an examination or treatment is beyond his capacity he should summon another doctor who has the necessary ability.

● A DOCTOR SHALL preserve absolute secrecy on all he knows about his patients because of the confidence entrusted in him.

International Code of Medical Ethics (WMA)

MATERIÁLY Z KURZOV ÚMEB

MATERIALS FROM COURSES OF IMEB

International Course on Medical Ethics, Bratislava, IMEB - PMI, June 24 - 27, 1992 (2)

BASIC ISSUES IN MEDICAL ETHICS

K. F. Gunning

World Federation of Doctors who Respect Human Life, Rotterdam, Holland

A. BASIC TERMS AND PRINCIPLES

I think that ethics can be defined as the study of right or wrong behaviour, behaviour that is good or evil for the individual man and for humanity. An ethics or ethical system is a specific set of rules indicating what is good. There are professional ethical systems, such as Medical Ethics, which are valid only for the members of a profession. An ethics for society as a whole is called general.

As there are different opinions about what is right or wrong behaviour, I think we must distinguish between different types of ethics, according to what will be achieved by a specific behaviour; according to what is the aim or the result of this behaviour. In some cases a specific type of behaviour is consciously choosen in order to reach a specific aim (winning the Olympics). In other cases a specific behaviour leads to certain results which are not intended (contracting a disease). In some cases a specific behaviour is the result of a certain (religious) conviction, giving results that are not intended either.

The aim of this study is to investigate whether there is a basic ethics, whether there are some basic principles on which a universal and objectively good but restricted ethics can be based, an ethics that is valid (universal) and acceptable (objective) for each society all over the world, and which ought to be included in every more specific ethics, such as e. g. Christianity offers. Such a religious ethics may be far more elaborate and go deeper, but as not all people are Christians, this ethics can not be called objective and universal, as non-christians will not regard it as valid and acceptable.

Medical ethics is a professional type of ethics, showing the doctor which type of behaviour is good, or at least is agreed upon by the whole profession. Such a type of professional ethics is usually part of a general type of ethics. Thus we can speak of a Christian medical ethics, and so on. If we must conclude that there is a basic ethics which is universal and objectively good, then this medical ethics is only acceptable if it includes this basic ethics.

B. HISTORY AND PRESENT SITUATION OF MEDICAL ETHICS WORLDWIDE

B.1. Hippocrates

As far as I know, medical ethics has first been described by the Greek physician, Hippocrates, who summed up the doctor's duties (towards God, his teachers and colleagues, and his patients) in the so-called Hippocratic Oath. The last duty is described as follows (Encyclopaedia Britanica, 1961):

"The regimen I adopt shall be for the benefit of my patients according to my ability and judgment, and not for their burt or for any wrong."

"I will give no deadly drug to any it be asked of me, not will I counsel such, and especially I will not aid a women to procure abortion."

" Whatsoever house I enter, there will I go for the benefit of the sick, refraining iron all wrongoing or corruption, and espacially from any act of education of male or female, of bond or free."

" Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not to be noised abroad I will keep silence thereon, counting such things to be as sacred secrets".

In this oath the benefit of the patient and his houshold, without discrimination is the central theme. The patient's life and dignity are to be respected and the treatment given must be aimed at his well-being. Killing, either before or after birth, with or without the patient's request, is strictly rejected. We must add, that Hippocrates also warned against treating a disease which is "overpowering". The so-called "acharnement therapeutique" (inexorable treatment), which may cause people to ask for legalized authanasia, is not regarded as good medical practice.

Hippocrates realised that a doctor has the power to kill or to cure. The patient receiving a drug can not know for which purpose the doctor really intends to cure him is : to make the doctor swear

that he will use his knowledge only for the benefit of the patient. That is the reason why the oath was conceived. As the individual patient's well-being and respect for his life are the central theme or aim of the type of behaviour the Hippocratic Oath prescribes, this oath is an expression of a kind of ethics which I like to call Humanitarian Ethics.

B.2. "Life unworthy to be lived"

In the early 1920's in Germany a lawyer Karl Binding and a psychiatrist Alfred Hoche published a book entitled "Legalizing the Destruction of Life Unworthy to be Lived". They said that idiots and demented people should be killed, as "their lives are absolutely senseless" and "for their families and for society they are a terrible burden...". The authors describe another kind of ethics, which allows killing a patient, dependent on his usefulness for society, and the sense or value or quality of his life (the highest quality, apparently, has the person who is healthy, handsone and strong). I therefore like to call this ethics the Utilitarian Ethics.

This kind of thinking became reality in 1939, when Hitler ordered his personal physician "to extend the authority of certain doctors, to be designated by name, in such a way that patients, who, humanly speaking and upon post critical judgment of their condition, are incurably ill, can be granted a merciful death". On the basis of this order over 100.000 German psychiatric patients were killed in the gas-chambers, that were specially designed for this purpose on the instructions of 12 professors in psychiatry designated for this task.

When after the Second World War physicians were put on trial because they had cooperated with this euthanasia-program, they appealed against their conviction citing this order signed by Hitler on September 1, 1939. This appeal was rejected on the ground that there is a Law superseeding all laws and to which all laws must conform: the Natural Law. "One of these deeply and inextricably rooted rules of law is the sanctity of human life and the individual's right to life ". (Bandgericht Frankfurt an Main, March 21, 1947, 4Kls 7/41)

This "natural law" is based on the same basic principles as humanitarian ethics, but the former term may cause confusion which is avoided by using the later term. It is clear that humanitarian and utilitarian ethics are incompatible.

B.3. The Geneva Declaration

Because doctors had cooperated, not only in Germany, and not only with these pass-killings but also with mutilating and lethal experiments on human beings, in 1948, the World Medical Association, in order to prevent recurrence, decided to rephrase the Hippocratic Oath in modern language, adopting the so-called Geneva Declaration, that read as follows:

"At the time of being admitted as a member of the Medical Profession:

I solemnly pledge myself to consecrate my life to the service of humanity;

I will give my teachers the respect and gratitude which is their due;

I will practice my profession with conscience and dignity;

The health of my patient will be my first consideration;

I will respect the secrets which are confined to me;

I will maintain by all means in my power the honour and the noble traditions of the medical profession;

My colleagues will be my brothers;

I will not permit considerations of religion, nationality, race, party politics or social standing to intervene between mu duty and my patient;

I will maintain the utmost respect for human life from the time of conception;

Even under threat, I will not use my medical knowledge contrary to the laws of humanity;

I make these promises solemnly, freely and upon mu honour."

It is clear that this declaration is also an expression of humanitarian ethics.

B.4. The Universal Declaration and the European Convention on Human Rights

In the same year, December 10, 1948, the General Assembly of the United Nations, for similar reasons as the doctors had, proclaimed the Universal Declaration on Human Rights. The first right mentioned in this document is: "Everyone has the right to life, liberty and security of person." (Art.3)

On November 4, 1950, this right to life was guaranteed by the member-nations of the Council of Europe, when they decided to enforce these rights collectively in the European Convention for the Protection of Human Rights and Fundamental Freedoms. In Art. 2 we read: "Everyone's right to life shall be protected by law."

B.5 Humanitarian ethics

The preamble to the Universal Declaration starts: "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the fundation of freedom, justice and peace in the world....". Inherent dignity means that this dignity is inextricably connected with being human, and inalienable rights are rights which cannot be taken away by anyone, not even by the person himself. So the preamble explains that it is impossible to reach a free, just and peaceful world, unless we recognize that dignity is inseparable from being human (which includes the unborn child) and that certain human rights cannot be taken away and not even given away by the person himself.

As the individual's wellbeing, regardless of the quality of the life or his usefulness to the society, is the aim of the type of behaviour both the Universal Declaration and the Geneva Declaration (the rephrasing of the Hippocratic Oath) prescribe, both can be seen as an expression of an ethics which I have called Humanitarian Ethics. Only the preamble of the Universal Declaration describes the aim this kind of behaviour will achieve: a just, free and peaceful world.

B.6. Utilitarian ethics

What will be the result of the kind of ethics that is based on notions such as usefulness to society and quality of life, which I have called Utilitarian Ethics? As a matter of fact, contrary to what the World Medical Association and the United Nations had hoped in 1948, this ethics was not abandoned. After an incubation period of several decades, it has manifested itself again as a tough opponent to humanitarian ethics, and during the last 20 years in Western Europe, it has gradually been eroding and even replacing humanitarian ethics.

Utilitarian ethics was already described in September 1970 in an editorial in *California Medicine*, the official organ of the California Medical Association. According to this editorial everyone's quality of life will eventually be judged by doctors, and those who do not meet certain medical standards will be removed. The editorial predicts that besides birth control we will also have death control.

Already today unborn children with a handicap are aborted because their life's quality is too low and their usefulness is not equal to their costs to society. Today experiments are allowed with babies produced by IVF (in vitro fertilization). In Holland we now have euthanasia with and without request of the patient, and even one case has been reported where treatment was stopped against the patient's will.

B.7. The Dutch example

This prediction in *California Medicine* looked absurd in 1970. Is it still absurd? In September last year, in my country, Holland, a government-sponsored committee produced a report on the practice of euthanasia. A summary of this report was published in the medical journal *The Lancet*. Reading the report for the first time one comes to the conclusion that euthanasia is applied 'only' 2,300 times a year.

But on October 29, 1991, *The Lancet* published an article from my hand (*The Lancet*, Vol. 338; Oct. 29, 1991, page 1010) explaining that on careful reading the report leads to the conclusion that on a total mortality of 130.000 persons per year in Holland, the doctor had intended to end the patient's life in almost 20.000 cases. The astonishing difference is explained by a three-fold restriction the committee puts on the term euthanasia: only if death is the result of (1) a lethal drug, (2) applied by a doctor (3) at the explicit request of the patient, it is called euthanasia. Thus, a 400 cases of assisted suicide, where the lethal drug is prescribed by the doctor but taken by the patient himself, and 1000 cases where the drug was administered without the patient's explicit request, were not called euthanasia. And the almost 16,000 cases (80% of the total number). Where no lethal drug was given but a therapeutic drug was either overdosed or withdrawn with the explicit or implied intention to end the patient's life, were called "normal medical practice". And in almost 12.000 cases, that is almost 60% of the total number, there was no explicit request by the patient to have his life ended.

I want to make clear from the outset, that I am sure almost all these doctors were convinced they were doing something good for their patients. That is why we simply must stick to the rule that a doctor is never alloved to kill a patient. Once you accept killing as a means to solve problems, you will always find new situations where killing sens to be the solution. Today you allow killing at the request of the patient who is suffering unbearably, tomorrow you kill one without a request, then you kill not because the patient is suffering but because be looks so awfull or because you think his life no longer has meaning, etc. And even if you yourself are strictly addhering to the rule that killing on request is not allowed, you find that your colleagues have already gone much further. The Hippocratic ethics which says "never kill" is a strong support for the doctor. Once you allow a doctor to kill, ethics becomes elastic, always allowing what you want to be allowed. The Dutch example shows what will happen in any country where killing is accepted.

As a motive for applying euthanasia is given in most cases:

unbearable suffering. This means that the doctor is at his wits' end and does not know how to deal with the patient's problems. Can you believe that in a modern country like Holland this situation occurs 20.000 times a year? If that were true, Dutch medicine would be the very worst in the world.

In November last year our government introduced a bill, which enables a doctor to commit euthanasia without being persecuted. The bill changes the law in such a way that the doctor who commits euthanasia or assists a suicide should notify the coroner and give him a report. The coroner inspects the body externally and gives the report to the public prosecutor. If the report seems acceptable the prosecuter. If the report seems acceptable the prosecuter may decide not to prosecute the doctor. This means that we can predict already today what will happen. For, as the chief witness, the patient himself, is no longer alive, the report is the only document the prosecutor can base his judgment on, and so nobody can be expected to witness against himself, the report will always be acceptable and no doctor will ever be punished. Morever, the cases of overdosing or withholding treatment, even with the intention to kill the patient, will not be reported at all, as the government considers these cases to be "normal medical practice".

Of course, killing is not part of medicine, but its opposite. And if patient asks to be killed, the doctor should kill his pain, not end his or her life. So Holland has indeed become a very dangerous country, as patients may have their lives ended without their request and without knowledge of the authorities. The doctor thus has become a powerful man, able to decide on life or death.

B.8. The European Parlament

But is the rest of Europe safe? In all our countries voices are raised to allow doctors to kill without fear of prosecution. In the European Parliament in Strasbourgh a resolution is presented which demands that under certain circumstances an explicit request of a patient to have his life ended "should be satisfied without thereby involving any breach to respect for human life." Yet our countries have signed the European Convention on Human Rights, of which Art. 1 says: "Everyone's right to life shall be protected by law." Is it possible to protect someone's life and at the same time allow it to be destroyed?

I do hope we will soon have one United Europe, of which all our countries will be participants. But what kind of Europe will it be? Will Europe follow the Dutch example, or will we stick to the European Convention on Human Rights?

The big question is: should each man's life be protected? And that value depends on the type of ethics we choose, humanitarian or utilitarian. Can science help in this choice?

C. ETHICS AND SCIENCE

How can it be explained that utilitarian ethics has made its reentry as a real threat to humanitarian ethics? Utilitarian ethics is supported by the materialistic assumption that only matter exists, which means that there is no fundamental difference between man, animal and thing. If we can dispose of a cow or a car when they are no longer useful, why not of a useless person? Then indeed the value of human life is decided by a market mechanism. In many universities we are told that this materialistic concept of man, which leads to the acceptance of utilitarian ethics, is supported by science. My next question is: Is this conclusion really justified?

Scientific research asks for objective proof. Objective means: perceptable to our physical senses. And because these senses are only sensitive to physical stimuli, we will never discover anything alse but matter with this method. So there are two possibilities: 1. Matter alone exists; that is the assumption of materialism; 2. Next to matter there is another reality, usually called spiritual; this concept may be called realism. Neither assumption can be proven scientifically, as neither the existence nor the non-existence of spiritual reality can be demonstrated objectively. Both assumptions are equally scientific or equally speculative.

C.1. Materalism and realism

According to the materialistic concept man is a purely physical being, consisting only of a body, which means that mental events such as consciousness, thinking and the experience of pain and joy must be regarded as mere physical phenomena which are a product of the brain.

According to the realistic concept a person is a spiritual-physical unity, of which the spiritual aspect as long as the physical aspect is alive, from conception until death. Consciousness and communication are faculties of the spirit, which can be expressed by means of the brain, because the human brain is sensitive to spiritual influence. The presence of these faculties can only be ascertained, however, when the brain is sufficiently developed to allow communication. But nobody can prove that these faculties are absent before that moment.On the contary, we must assumme that the embryo is a person from conception, as its whole development is aimed at building a communication apparatus, which would be senseless if there were not a person to use it. Recently is has been demostrated that certain areas of the cerebral cortex can be activated by a willed intention (J. C. Eccles: "Evolution of the Brain, Creation of the Self", Routledge, London, 1989, p. 187). This founding cannot be explained by materialistic theories but it supports the realistic assumption that the human mind can use the brain to express thoughts.

Our conclusion must be that science cannot decide whether the materialistic or the realistic concept is true, which would mean that either utilitarian or humanitarian ethics is supported by the science. The most one can say is that modern brain research does not support the materalistic idea that thoughts are products of the brain, but that it gives more credit to the realistic assumption that the brain can be activated by spiritual influence. The choice between the two types of ethics depends on what kind of future we want. Do we want to see our own lives and those of our children protected by the law, or protected only when we are useful to others or wanted by them?

C.2. An universal and objective basic ethics

If science cannot decide which ethics is objectively good, that does not mean that it is impossible to find such ethics. Summarizing what has been said above, I believe we can say that there is an objectively good basic ethics, the ethics I have called humanitarian. It is an ethics which is good for every individual and which helps to build a society that is good for all people, a just, free and peaceful society, where everyone can grow and develop his own specific capacities.

Utilitarian ethics, on the contrary, is not good for everyone; it is only useful to a restricted group of people; the healthy and strong. For the weak and sick it is not good but lethal. So it can not called objectively good. According to my opinion "Respecting human life and dignity" is one of the basic principles for an ethics, which can be called universal and objectively good, as it is valid universally and acceptable (objective) for each society all over the world. This basic ethics should be an integral part of every more specific ethical system, such as medical ethics or Christianity. Christian ethics is an outstanding example of humanitarian ethics, which is objectively good, but not objective in the sense that it is also valid and acceptable to non-christians. Let us see how these basic principles can be applied in practice.

D. RESPECT FOR THE UNBORN

When we talk about the duty to respect the unborn, the first question to be asked is, whether the unborn is a human being from the moment of conception. Is the human zygote a human being? We have just seen that we must approach this questions from two points of view - materialism and realism.

Regarding the physical aspect of the zygote there is complete agreement: biology shows that each living being belongs to one species, according to the genetic material it contains, and that it can never change from one species to another, as all its life the genetic material remains the same. The zygote is a living being with the genetic material of man. So realism and materialism agree that the zygote is a human being and remains the same living being until the moment of his death. If human life must be respected it must be respected from conception.

If, however, only a human person is to be respected, then the two points of view differ. If materialism is right, then there is no thought, no consciousness, no personhood if there is no well-functioning brain, such as in the human zygote. If, however, Eccles theory is true, then we must assume, as we have seen above, that the zygote is already a person. As neither of the two theories can be proven, we must give the embryo the benefit of the doubt and respect his life and dignity. Abortion, producing dispensable embryos by IVF and experiments with embryos should strictly be icebidden.

E. THE PATIENT IN PROLONGED COMA

E.1. An utilitarian document

In 1985 the Royal Dutch Medical Association (KNEG) has nominated the „Committee on Accepptability of Life-Ending Treatment", which was charged the task to investigate: „Life-ending Treatment of Incompetent Patients's." The term „life-ending treatment" is chosen in order to distinguish between deliberate killing of patients who are not able to ask for death themselves, and euthanasia, which in Holland is defined as „a deliberate killing of a patient at his/her own request". This Committee recently produced its second report on „Treatment of Patients in Prolonged Coma". It is important to know about this report, as it advocates life-ending instead of life-saving measures in cases of prolonged coma, and suggests, that doctors who refuse to cooperate should be urged to hand over the treatment of comatose patients to others who are more willing to do so.

E.2. What is coma?

Coma is decribed as "a state of complete loss of consciousness from which the patient cannot be aroused by the most powerful stimulation". Of course we must keep in mind that the patient is completely unable to communicate, because no voluntary movements are possible. The problem with what we call unconsciousness is, that the bystanders cannot detect any sign of consciousness, but this does not mean that the patient is not aware of what is going on. Sometimes the patient who recovers from coma can tell exactly what was done during his 'unconsciousness'. But as long as the patient is still in coma, the examining doctor usually is unable to say whether he is or is not aware of himself or his surroundings.

Oddly, the committee on the one hand denies the existence of conscious perception during the comatose state, but on the other hand it does not want to exclude the possiblity that the patient suffers, possibly even severely. But suffering implies the existence of conscious perception, whereas consciousness does not necessarily mean that the patient suffers. If all causes of pain (bedsores, absces) are carefully treated, there is no reason to assume the existence of somatic pain. On the contrary, the patient may appreciate any loving care he receives, especially when he is treated as if he were understanding everything.

E.3. The Persistent Vegetative State

In English literature we find the term "Persistent Vegetative State" being defined as a syndrome, usually beginning two to four weeks after the initial coma, when the patient regains a wake-sleep rhytm and is arousable in the sense of eye-opening on stimulation or spontaneously, without any sign of cognition. The word vegetative is used to indicate the fact that the vegetative functions of the brainstem are still functioning after the damage to the cerebral cortex. Unfortunately the committee translates this term as "vegetating state", suggesting that the patient is no longer a human being but just a plant, so that there is no sense in trying to save his life. In fact, as the condition is characterized by the unability to respond to external stimuli, a better name would be Prolonged Non-responsive State.

E.4. The prognosis of coma

The main reason, however, why the committee considers life-saving treatment to be unwarranted after a certain period, is the fact that the patient may be severely handicapped for the rest of his life, when he recovers from coma, especially nontraumatic coma. This is often a great burden for the family. The committee complains that too many doctors refuse to let the patient die, and urges these collegaues to hand over their patient to a doctor who is willing to end his life.

Yet the report mentions that handicapped patients recovering from coma only seldom ask for euthanasia, and that some of these patients, who have signed a written will that they would want to be killed in the case of coma, were very grateful afterwards, that their doctor had ignored their will. If the committee wants to compel doctors to these patients, this would actually not only be done without any request of the patient, but even against his/her will!

E.5. The incidence of coma in Holland

The report estimates the number of people who stay in coma more than 6 hours at 500 per year (population 15 million). Of these, 10% are still in coma after 1 month, and after 1 year 1,5% are still in coma when the cause was traumatic and 0,4% when non-traumatic, whereas 45% and 85% respectively then have died.

E.6. What about the law?

The report mentions a number of possible life-ending treatments: abstaining from treatment, stopping a treatment, stopping the administration of food and fluids, direct killing. Only the last possibility is considered to cause unnatural death, which means that the doctor can not issue a death certificate and therefore has to notify the coroner. All the other possiblities are not regarded as causing death, if the doctor does not have intention to kill but to stop a treatment which is medically senseless. So the doctor can issue a certificate of natural death, which means that he avoids any interference from legal procedures. And as this line of action is applicable in any case of an incompetent patient, we may expect a steady increase of incompetent patients being starved to death.

It is unthinkable that the committee has not realized these consequences. Probably few of those, who lately have accepted a utilitarian line of thought, have asked what would be the results. But it is a horrifying picture of the future. And if we take account of the editorial in *California Medicine*, which predicts that eventually the doctors will decide who is allowed to live, then we in Holland have indeed almost reached the final stage of death-control next to birth-control. Human society then will be put on a paar with a cattle-breeding farm.

The hour is late, but if we all realize that we have to choose between humanitarian and utilitarian ethics, there is hope that the present development may be stopped and that freedom, justice and peace may still once become a reality all over the world.

F. FINAL CONCLUSIONS

These are examples to show the importance of distinguishing between humanitarian ethics, which respects human life and dignity from conception until death regardless of development, age or condition, and utilitarian ethics, which judges the patient's quality of life and usefulness to society as criteria to decide whether to save or end his or her life.

In my opinion it can be said that humanitarian ethics is the basic ethics we are looking for, as it is universal and objectively good. Only ethics which include this basic humanitarian ethics is universally acceptable. Utilitarian ethics, on the contrary, is objectively wrong, as it excludes those who do not meet certain standards and denies the possiblitity of a patient's growth in certain conditions.

"Respecting human life and dignity" should be the basic of both general ethics (see Universal Declaration on Human Rights) and medical ethics (Hippocratic Oath and Geneva Declaration of the World Medical Association). Starting from this basic principle, we should be able to elaborate an ethics for each field of human activity and concern: medicine, environment, international relations, media, etc. This is too much for one person to achieve, as no one can be familiar with every profession, and no one can speak for each culture and religion. Yet it must be regarded as our aim, an aim for which we need the teamwork of many professionals from all parts of the world.

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THE SYSTEM AND ORGANIZATION OF PREVENTION AND MANAGEMENT OF DRUG ABUSE IN ITALY AND E.C. COUNTRIES

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ITALY

1. SITUATION OF DRUG ABUSE IN THE YEAR 1991

1.1. Drug abuse

We do not have accurate figures on the total number of drug users in Italy, especially if we wish to have a global estimate including soft-drugs users (cannabis). Heroin users in Italy are approximately 130,000-170,000. Drug addicts treated at public health centres during 1991 were approx. 90,000; 35% of these were first-treated. The majority of drug addicts is being treated at public health centres. Out of 5 drug addicts, 4 are treated at public health centres and 1 is treated at private specialized centres.

1.2. Description of drug users and type of use

The most popular substance among drug addicts treated at health centres is heroin (91%), injected intravenously followed by cannabis (4%). Only 1,5% of them use cocaine as chief substance. The largest age class of drug addicts is that ranging from 26 to 29 years. The average age of the drug addicts who died of overdose or AIDS is higher than that of addicts undergoing treatment at health centres.

1.3. Drug addiction and HIV/AIDS

The estimated average prevalence of HIV seropositives among Italian drug addicts treated at public health centres is around 40%.

Among the 11.609 AIDS cases reported in Italy by December 31, 1991, drug-abuse related cases were 7637 equal to 67% to which we should add paediatric cases of heterosexual infection.

2. NATIONAL COMMITTEE FOR THE COORDINATION OF THE ANTI-DRUG POLICY

Law No. 162 of June 26, 1990, provides for the setting up of the National Committee for the Coordination of the Anti-drug Policy, chaired by the Minister for Social Affairs appointed by delegation of powers of the President of the Cabinet of Ministers. The Committee is composed by 11 Ministers and by the Deputy of State to the Cabinet of Ministers. The Communittee also formulates organizational rules concerning the responsibilities of the Ministers and the cooperation of Italy with inter-

national bodies, as well as the formulation of policies to assists developing countries producing base substances for drugs.

In order to better harmonize the decisions of the different Ministries, the Committee of Ministers - whose responsibilities are guiding and promoting a general policy for prevention and action against the illicit production and distribution of narcotic drugs and psychotropic substances at national and international level - coordinates actions and decides criteria for allocating resources from the National Fund for the anti-drug action, for the prevention and rehabilitation of drug addicts.

3. THE NATIONAL LAWS

3.1. Basic approach of the national legislation

The new law has made the anti-drug set of laws more comprehensive through integrated actions aiming at the prevention of both illicit trafficking and consumption, as well as the rehabilitation of drug users and suppression of illicit conducts. As for the latter aspect, this law is based on three fundamental criteria:

1) drug use is considered illicit;
2) detailed description of illicit drug trafficking offences;
3) types of sanctions and punishments.

3.2. Legislation. Punishments and sanctions for drug use, possession and selling

The Italian law punish the possession of illicit drugs for personal use. Only administrative punishments are allowed if the dose is lower than the "daily average dose" (1) determined by the Ministry of Health. The anti-drug law aims at avoiding the exclusion of drug users and drug addicts from social life for the sake of their rehabilitation. Therefore, measures have been adopted to create a wide-scope programme to rehabilitate drug users and addicts starting with counselling interwiews to dissuade them for the bad doing; followed by the offer to enter a therapeutic programme and, only when there is no positive response, the application of sanctions.

The system of sanctions for drug users is based on innovatory concepts; one of the penalties is the temporary disqualification of the driving licence, of the gun licence, of the passport or equivalent travel documents and of the stay permit in the case of foreigners; the prohibition to obtain such dokuments; the seizing of their vehicles; the obligation to work free for the community; various types of prohibitions to frequent certain places; the obligation to report to the police office on a regular basis. When the drug user or addict does not comply with the sanctions imposed on him, he can be imprisoned for a period up to three months or must pay a fine up to 5 million Italian lire (approx. 4,000 dollars).

[(1) "The daily average dose" has been determined on pragmatic and pharmacotoxicological basis by taking into account the maximum dose over 24 hours according to the Italian Pharmacopeia and the composition of the street drug illicitly supplied. The new anti-drug law has taken this concept into consideration in order to distinguish illicit conduct of trafficking from the personal use of drugs.]

3.3. Practical application of the legislation

In the first period of enforcement, the anti-drug legislation has had positive results although some difficulties in the interpretation of the law were encountared.

4. INFORMATION, EDUCATION, PREVENTION

4.1. General principles

The new anti-drug body of legislation envisages a first aspect concerning prevention and the need to remove the accuses of the youth's discomfort. Therefore, priority should be given to a series of actions both in the schools and colleges, where the personality of young people is formed; as well as in the central and local offices of the Education Department. Important tasks are given to the Military Department and to its Health Service. Other actions and programmes are envisaged at the level of regions and local authorities.

A commission of experts has been set up to analyze projects, aiming at preventing and rehabilitating drug addiction habit, submitted by the public administration, the Regional administration and the municipalities; and it must also decide on the funding of such programmes. Priority is given to projects concerning persons at risk as well as educational environments (family, school, youth associations), and dissemination campaigns for the public opinion formation are envisaged.

4.2. Organization and policy of the services responsible for the information on drug abuse

The Ministry of Health decides the approach to be given to drug abuse prevention activities. The Public Services for drug addicts carry out information and dissemination activities especially designed for young people. To this end, an ordinance of the Ministers of Health and Social Affairs established an increase in the staff of the above mentioned services directly proportional to the number of young people living in a given area. The Ministry of Defence organizes at military academies and schools, as well as at military health schools, information courses on the damages caused by the use of narcotic drugs and psychotropic substances, alcohol and tabacco. These courses are part of the health education programme for conscript soldiers to whom additional information is given on the crime phenomenon connected to drug trafficking.

4.3. Organization and policy of services responsible for education in schools

Provincial Education Authorities, together with the Public Services for drug addicts are setting up information and counselling centres for high-school students where the same students participate directly and actively.

The above-mentioned information activities, together with other forms of education which have already proved being succesful, help the young people to develop self-esteem and the capacity to take decisions consciously by using specific educational instruments.

4.4. Organization and policy of services responsible for other prevention activities (with the audience, the groups at risk, the use of mass-media, etc.).

10 billion Italian lire (about 8 million dollars) per year have been allocated to develop information campaigns on the negative effects on health deriving from the use of narcotic and psychotropic substances, on the significance and seriousness of the criminal phenomenon of trafficking such substances, to be realized through public and private radio and TV networks and also through newspapers, magazines and posters.

4.5. Prevention of HIV infection among drug users

Prevention of HIV infection among drug users is carried out:

a) at the **local level**: by the Public Services for drug addicts on the subjects being treated at the said Services and Therapeutic Communities, by means of HIV test, health information, counselling, periodic check-ups, addressing to specialist centres for early pharmacological treatments (AZT) and immunological check on seropositives.

b) at the **national level**: by the Ministry of Health, by means of campaigns addressing drug addicts and "pionneering" training courses for staff at the Services for Drug Addicts;

c) by marketing self-occluding syringes with the aim to replace those being presently used.

4.6. Evolution of current programmes and possible new proposals

The Ministry of Health is developing training programmes for "outreach workers", i. e. people who can perform a general preventive action and addicts who do not reach specialized centres.

5. TREATMENT AND REHABILITATION

5.1. General principles for treatment and rehabilitation policy

Any user of narcotic and psychotropic substances:

a) may request to the Public Services for Drug Addicts to joint free therapeutical and socio-rehabilitative programmes;

b) he/she will be granted anonymity, upon request;

c) the Public Services staff is obliged to keep confidentiality;

d) workers who need treatment have the right to retain their jobs during the rehabilitation treatment for a period no longer than 3 years;

e) drug-addicted prisoners are granted treatment to be provided by the Public Services within the prison.

The rehabilitation policy is based on the Therapeutic Communities for socio-rehabilitation and reintegration; and specific yearly contributions.

5.2. General organization of services

Over 500 public services (for drug users and addicts) operate on the national territory. The new anti-drug legislation envisages a further increase in the number of the Public Health Centers. The number of operators working within each of these public services is established on the basis of the number of drug addicts being treated at the same time over the same period. A medical doctor, a psychologist, a social worker, a nurse and vocational teacher schould be part of the staff.

Public Services for drug addicts will be kept open for at least 12 hours a day every week day and 6 hours on holidays. Futhermore, they should coordinate their activities with family advisory bureaus, with centers for the treatment of AIDS and other infectious diseases, with forensic services, with test laboratories and other types of health centres.

Private residential and semi-residential centres for drug addicts treatment and rehabilitation work together with Public Services.

5.3. Types of treatment

Each Public Services Center is a reference point for drug addicts and their families since it plays a supporting and counselling role. Moreover it shall provide psychological treatments, and pharmacological treatments (within its framework, also treatment with methadone should be provided at Public Health Centres to people addicted to opiates where other treatments have proved unsuccessful.

5.4. Assessment of the current programmes and possible proposals

It is also envisaged to make assessment of the effectiveness of the actions carried out. The methods to be used are still being studied.

E.C.COUNTRIES

1. INTRODUCTION

The definition of drug policies and the setting up of appropriate actions reflect the socio-cultural and political context at various levels. In this respect in each Member State, national, regional and local levels have their own competence in the field of drug demand reduction. Most of the Member States involve each level with specific responsibilities. In most Member States policies and general guidelines for drug demand reduction are established at national level, while the implementation of actions in prevention, treatment and rehabilitation is the responsibility of regional or local bodies. There is a trend towards decentralization even in Member States where such responsibilities are not clearly distributed.

National support and coordination are often considered essential for the establishment of general policies. There is a willigness to keep a balance between local innovative acitivities and the necessity to have a minimum coordination of policies. The sources of funding and their allocation reflect the distribution of responsibilities between the national, regional and local levels. In some Members State the levels of government funding are enhanced by the substantial countributions made by the non-governmental sectors. In several of them the levels of funding have shown a substantial increase in recent years, in a number of cases due to the additional threat of AIDS.

The level and trends of drug use, when looked at in comparison, must be considered with caution, since each Member State use different methodologies and definitions for data collection. In some cases trends cannot be ascertained within some Member States, since non consistent data collection has been performed over a period of time. Member States stressed the difficulty of estimating the total number of drug users since many do not seek help, nor do they come into contact with the authorities. According to the limited data available on the number of drug users registered, many of Member States have experienced an increase in the numbers in recent years. In some Member States there are reports of stabilization in the overall number of users, in particular for heroin. This probably reflects the overall changing pattern of supply and demand, and the type of drug use. Health-based indicators on drug users applying for a treatment and drug related deaths show an increasing trend of drug-related problems in most Member States. In a number of Member States, there is a clear indication that the average age of the drug-using population is increasing, heroin and polydrug use remain the main problems; there is evidence in some Member States that the use of cocaine and new drugs is increasing; however this is not substantiated at present by health data.

2. LEGAL ASPECTS

Regarding the legal framework of drug demand reduction in Member States, four aspects are to be pointed out: legal provisions regarding drug possession or use, and the consequences for drug users; regulations and practices concerning compulsory detoxification and treatment; volunatry detoxification and treatment, and substitution treatments; special provisions related to the prevention of HIV transmission and AIDS. There is a constant adaption process of legislation and regulations in response to a complex and changing situation. In most Member States the legal privisions favour the therapeutic approach for drug users. This may be voluntary or compulsory, and it is, when compulsory, an alternative to prison. There is, however, in certain Member States a tendency to increase the penalties for drug possession for a personal use. More recently, the awareness of the role of intravenous drug use as a risk behaviour for HIV infection has been emphasized in the legislation of many Member States, the public health aspects of drug misuse. Two examples can be mentioned in this respect: the substitution treatments on one hand, in particular onvolving methadone, which are increasingly approved in some Member States for pilot experiments where methadone was not avaiable for normal medical treatments; and on the other hand, the liberalization of the sales of syringes to take into account the new risk of HIV transmission and AIDS. Needle exchange programmes still remain limited.

3. PREVENTION

Member States have made numerous efforts to deal with the drug abuse problem. As a common factor for most Member States the increasing recognition of the need to develop coordinated, continuous and structured preventive actions can be highlighted responding to a rapidly evolving situation.

Guidelines for prevention activities include:

- the importance of a broader framework of prevention measures in which various culture, health and social problems are addressed;
- the need for a comprehensive approach to the drug abuse problem, covering a range of different environments simultaneously, taking into account the risk factors and including illicit and licit drugs;
- the importance of adapting interventions to local needs and circumstances;
- the integration of drug education into general health education school programmes;
- the emphasis on the promotion of a healthy life style and avoiding risk behaviours;
- the need for factual, objective, non-dramatized and non-fear raising information;
- the importance of the responsibility of parents and leading figures as positive role models;
- the training of educators, youth workers, and health professionals.

There are two approaches concerning the use of mass media in information campaigns. Some countries consider them as being not very effective in carrying out prevention interventions, while others have recently launched such campaigns.

4. TREATMENT AND REHABILITATION

Most Member States have treatment structures with services ranging from hospital and community based medical facilities, outpatient centres, and therapeutic communities to self help groups. The average, diversification and decentralization of services varies considerably between the countries; both formally structured institutions with professional staff, and loosely organized voluntary assistance provide these services.

Member States report the need to continue striving for better, more diversified and increased number of the treatment possibilities. An important factor conditioning treatment policies is the role of intravenous drug use as a risk factor for HIV transmission. This fact has prompted many Members States to have flexible approaches to substitution treatments and syringe availability, as well as to try reaching drug users in their environments, and to make a help available to them without the requirement of a drug-free lifestyle as the first goal.

The balance between health and social services in the approaches to the care of drug users is different between the Member States; while in some of them the emphasis is on the social approaches with the collaboration of the health care when needed, in the others the trend is to include the treatment of substance abuse into the general health care system with the collaboration of social services. Finally, in some Member States the Menthal Health Care system also plays an important role.

Most Member States report a need for better adapted services aimed at individuals with specific problems: prisoners, AIDS patients and HIV positive persons, drug using pregnant women, children of drug users, etc..

5. MANPOWER TRAINING

Most Member States report a recent increase in awareness of the urgent need for adequately trained personnel for the prevention and treatment of drug abuse. Up to the moment, the most common approach to the manpower training has been sporadic and/or of short duration and sometimes outside normal structures. Interdisciplinary courses for professionals and, a few cases, continuous trainig has been provided. Some Member States have produced resource information/training materials for physicians, pharmacists, teachers and parents. Several member States have structured, regular university and post-graduate studies for trainig and specialization in substance abuse. The need to develop permanent programmes is recognized by a number of Member States, and in some instances, the planning is well underway. Examples of such plans are: the integration of substance abuse training into the university curricula of teachers, health professionals and psychologists, university and postgraduate trainig on substance abuse; and continuing education systems for professionals involved in prevention and treatment.

6. CONCLUSIONS

Member States are deeply aware of the importance of drug demand reduction programmes and the need to develop them as an essential element in an overall drug policy. The approaches to drug demand reduction are continually and often rapidly evolving in E.C. States; furthermore a large variety of approaches is being explored. Member States consider it important to introduce and improve evaluation programmes. They emphasize the importance of a broader framework of prevention measures in which various cultural, health and social problems are adressed, and for a comprehensive approach to drug abuse problems, covering a range of environments simultaneously, and taking into account risk factors and including illicit and licit drugs. Member States stress the need to have a variety of different treatment methods for drug users available. They consider a clear need for developing of comparable data collection systems on drug demand reduction. They recognize the need for increased support and coordination of research efforts. Adequate funding and manpower resources allocation are fundamental to ensuring that drug demand reduction (prevention, treatment and rehabilitation) is carried out effectively.

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