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Send papers to the editor in electronic form if possible. Please use reference style used in News section, do not use automatic footnotes or endnotes. Papers are peer reviewed. The papers do not represent the views of Eubios Ethics Institute, which upholds the principles of freedom of expression.

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Deadline for the May 2006 issue is **30 April, 2006**.

Editorial: Bioethics across the Region

- Darryl Macer, Ph.D.
UNESCO Bangkok, Thailand

This issue of the journal includes six papers, and a return to the News section. The News section includes papers from a range of ethics journals but omits the scientific journals and medical journals that have been useful sources of News in the past issues. Nowadays search engines for these journals provide easy access to articles on many themes. There will be mention of some noteworthy articles in these types of journals in the future, but readers' comments are invited.

In the past few months a number of UNESCO meetings on bioethics have been organized in the Asia and Pacific region, which has allowed me to meet with many readers, and also to receive feedback on how to develop bioethics in the region more effectively with network partners. There will be further meetings in more countries, and please monitor the RUSHSAP website for forthcoming events. Future issues will also include meeting reports from some of these events, including: CBEC-UNESCO Joint Conference and Workshop on Bioethics Education, 21-22 January, 2006, Karachi, Pakistan; International Bioethics Workshops, c.24-27 January, Bangalore, Vellore, Chennai, India; *Second UNESCO Bangkok Workshop on Ethics Partnerships in Asia and the Pacific*, 7-9 February, 2006, Bangkok, Thailand. There were also conferences in New Zealand and Sri Lanka (forthcoming), and teacher training in Thailand. Please see some conference announcements in the Conference section here also.

Please monitor the websites which are set to expand and develop to offer more links to regional activities, resources, teaching programs, and events. News is welcome so that we can share information and network better.

It is Time we addressed Intellectual Property Rights Issues in Genomics Research

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Intellectual Property Rights is the latest currency of the globalised world. As more and more manufacturing units and services are moving out into the third world and developing economies, the industrialised world is holding on tight to intellectual property rights. As R.A. Mashelkar puts it, 'Intellectual property will no longer be seen as a distinct or self-contained domain, but rather as an important and effective policy instrument relevant to a wide range of socio-economic, technological and political concerns.' [1] The World Trade Organisation (WTO) and its cohort organisations like the World Intellectual Property Organisation (WIPO) are now working towards harmonisation of intellectual property rights rules across the globe. They are urging nations where such systems do not exist to put in place an IP regime and where they do exist they are urging states to strengthen enforcement. For countries like India, which are presently experiencing a boom in the economy and enormous goodwill in the international community, such harmonisation of intellectual property rules are both an opportunity and a threat. On the positive side, India has a massive potential to intervene in this harmonisation and raise concerns that are relevant to its economic growth and future, which it shares with many other countries in the developing world. India has a lot to benefit from a robust and effective intellectual property regime, especially its cultural industries. India and other countries should regularly participate and contribute to the debate on intellectual property rights in the international, regional and domestic arenas, be it about genomics research or about the protection of biodiversity. The contribution of academics in this area is especially lacking and it is time academics in India launch a cross disciplinary debate on Intellectual property rights issues. It is important that all countries of the world have their say in this area of law, which has so far been the preserve of industrialised nations.

An understanding of the role of this peculiar category of property rights in society is essential in order to be able to effectively debate the pros of cons of this system. There are two main aims to an IP regime, anywhere in the world. They are 1. To encourage invention by making incentives for invention 2. Derive benefit for the society from such invention. Any IP regime should have at its heart the furthering of these two aims. Danger lies in promoting one of these aims over the other, even more so when the inventors are favoured. Historically speaking, the progress of societies through the infusion of new ideas and inventions was the first and foremost aim of an IP system. The grant of exclusive rights to inventors, which was designed to act as an incentive to get people to start thinking and inventing was only the mechanism through which society could derive benefits for itself. This has really worked in societies. Given that all conditions are equal, anybody can potentially be an inventor and utilise the IP system to his or her benefit. The United States is a case in example where its citizens have derived enormous benefits from the IP system and at the same time the society in general has benefited enormously too. Japan is another such example. However, as the IP system has grown and reached maturity in many of these countries, we are beginning to observe the dark side of the system. A good example is the Mickey Mouse case in the US. The Sonny Bono Copyright Term Extension Act passed by the US in 1998 extended copyright terms by another 20 years. This Act was nicknamed 'The Mickey Mouse Protection Act' following the hard lobbying by Disney to get the Act passed through. Mickey Mouse's copyright was about to expire in 2003 and therefore they stood to gain from an extension of term in copyrights. Copyrights on other characters like Pluto, Goofy and Donald Duck were to expire a few years later. Under this new legislation, an author's copyright would last until seventy years after his death, while copyrights for works of corporate authorship would last 75 to 95 years. Also no additional works made in 1923 or after were still copyrighted in 1998, will enter the public domain until 2019. In 1999, the CTEA was challenged on the grounds that it was unconstitutional. The case went as far as the US Supreme Court but did not succeed.

[1] Protecting Intellectual Property, R.A. Mashelkar, http://www.india-seminar.com/2005/547/547%20r.a.%20mashelkar.htm

Critics of the Supreme Court decision have called it a 'tragic mistake'[2] that the court chose to interpret the constitution in a way that it undermined the importance of the public domain for the promotion and progress of the useful arts. The behind-the-scene scene of the Mickey Mouse protection Act is not very dissimilar to what happened behind the scene in the negotiations of WIPO. Susan Sell argues that TRIPS resulted from lobbying by twelve powerful CEOs of multinational corporations who wished to mould international law to protect their markets. [3] Recounting the Chilean experience of redrafting their patent laws following pressure from the US Pharmaceutical Manufacturers Association, Sell questions – Where did this power come from? How did this come to pass? [4] The Intellectual Property Committee consisting of eleven CEOs of multinational companies[5] was formed in the 1980s. They presented a proposal, in conjunction with other corporations from around the world to the GATT secretariat; this led to the drafting of TRIPS and subsequently to the beginning of a global IP regime. The industry has demonstrated its power to make international law by 'identifying a trade problem, devising a solution and reducing it to a concrete proposal to be sold to governments' [6]. Intellectual property laws do not seem to be rooted in democracy but seem more to be the outcome of arm twisting by the corporate conglomerate that are able to hold peoples and government at ransom because of their ability to research into and provide much needed goods. James Boyle talks of the gene patenting and other appropriation of rights relating to software and the information highway as starving off the intellectual public domains. He puts forward the thesis that we are in the Second Enclosure Movement. He draws parallels between the present IP situation and the English Enclosure Movement, which he considers to have been the first Enclosure Movement. The English Enclosure was a process of fencing off of common land and turning it into private property, by those who had access to power and the law[7], thus creating the landed gentry.

One needs to consider this in conjunction with other developments such as the recent case in South Africa where the Government of South Africa was taken to court by the pharmaceutical industry association for passing a law enabling import or local manufacture of generic drugs, which they argued was infringing their IP rights. The South African government took such a step in order to address the growing incidence of HIV/AIDS in the country. The NGO Treatment Action Group intervened and made submissions in the court and argued for the right to health and dignity and stated that the law did not violate the rights of the pharmaceutical companies and that this was an essential step to address the health needs of the citizens of South Africa. A sustained campaign and international publicity to this issue ensured that the pharmaceutical companies withdrew their challenge to the law.

Closer to home is the fate of our own IP system. What have we done with our patent system? The IP system is often referred to as being imperialist. It is quite literally true in the Indian scenario. Our first IP law was enacted in 1856 and soon after independence a committee was formed to look into the functioning of the patent system. At that time, the drug prices in India were amongst the highest in the world. The new Patent Act was put in place in 1970. The impact of this new legislation was very telling. The drug prices fell to one of the lowest in the world and other countries from Africa and South America began to buy from us. The health needs of swathes of people were taken care of at affordable prices. The point I would like to stress here is that there was a long and elaborate debate on the type of IP system that would suit our country before the 1970 Patent Act and that is the need of the hour today. Since the 1st of January 2005, the new Patent regime, which substantially changes the prevailing scenario, came into existence. There are many criticisms to the new regime ranging from the Indian government having sold out to transnational corporations (TNCs) to serious concerns about its utility to the society.

Genomics is power - the power of knowledge. It is cutting edge technology and symbolises the power of humanity to get closer to the secrets of life itself. It might be that India, as a spiritual and

[2] Opposing Copyright Extension, http://homepages.law.asu.edu/~dkarjala/OpposingCopyrightExtension/

[3] Private Power, Public Law: The Globalisation of Intellectual Property Rights, Series: Cambridge Studies in International Relations (No.88), Susan K. Sell

[4] Introduction, Susan Sell

[5] Bristol-Myers, CBS, Dupont, General Electric, General Motors, Hewlett-Packard, IBM, Johnson & Johnson, Merck, Monsanto and Pfizer

[6] Introduction, Susan sell

[7] Enclosing the Genome: What the Squabbles over Genetic Patents Could Teach Us, James Boyle, creative commons.org, page 21

cultural entity very different from the West has little interest in unveiling these secrets of life, but India is not a stranger to power in the international community and we are actively courting it. We have held our own in the nuclear arena, we have played it very well in nuclear politics and it is now beginning to pay off. It is time to do the same in the intellectual property rights area. Genomics might not be a thriving industry in India but the pressing questions in genomics regulation is of great interest to the Indian economy and its people. It is important because of the direct and indirect impact Genomics research will have on the health of its people. It is important because of the power dimension to intellectual property rights that makes it so glamorous in today's economy. The IP questions in genomics are the following –

1. There are many genomics companies whose only assets are a few patents on gene sequences. They can license that out and keep making money. How does this serve the purpose of fostering innovation?
2. There are patents being granted on gene sequences, which serve no useful function except that they are research tools. One of the criteria for granting patents is that they should be useful for society. By granting patents on research tools, are we putting too many road blocks on the research path such that people are being put off from doing research which will provide valuable health benefits?
3. Since investors recoup their investment from products that they possess the rights for, they will not research into products for which there is no market. Do infectious diseases fall into that category? Should we make the IP incentives less attractive?
4. Should genes be patented? Are they naturally occurring or are they man made inventions?
5. Genomics needs capital, it is expensive. How are we going to incentivise research into genomics, if we do not guarantee IP rights to investors and researchers?

The Universal Declaration on Bioethics and Human Rights provides a very good opportunity for India to intervene and contribute to the IP debates in genomics research. The International Bioethics Committee of UNESCO, which was responsible for the drafting of this declaration is a multinational forum, with plenty of opportunity for debate and there exists an instrument, which acts as a template to base these discussions and eventually move towards a treaty on this subject. The IBC is a group of 36 experts in the field of medicine, law, ethics, sociology, politics etc appointed by the Director General of UNESCO to consider impartially various bioethical issues. Currently there is an Indian IBC member – Professor Prakash Tandon, Neurosurgeon at the All India Institute of Medical Sciences and Chairman of the Indian National Bioethics Committee. India is also currently a member of the Inter Governmental Bioethics Committee, which meets every two years to review the work of the IBC and is composed of member states of the UNESCO. The Inter-agency committee on bioethics, which was set up in 2003 has taken up the issue of IP.

Speaking at the twelfth session of the IBC in Tokyo in December 2005, Justice Michael Kirby, one of the leading figures in international bioethics and member of the IBC drew attention to what could be done to further the aims of the Declaration. He laid particular emphasis on two articles of the Declaration and submitted that these should be brought to the attention of the world's statesmen. They are Article 14 dealing with social responsibility and health and Article 17 dealing with the protection of the environment, the biosphere and biodiversity. He called for intergovernmental and industry co-operation in addressing issues of intellectual property, the risks of transgenesis, the bioethics of poverty, feminist perspectives on bioethics and other issues. I endorse this broad programme and would like to add that a grass-root level debate and a ground swell of discussions on these issues in academic institutions in India and other developing countries will provide balanced, non-prejudiced views on these issues and enhance the profile of academics too. The current series of UNESCO-Eubios Ethics Institute workshops in Bangalore, Vellore and Madras on the Universal Declaration furnishes an initial model for such debates and discussions. The next step would be document these initiatives through articles in scholarly and lay journals and to use the media to spread the message more widely to the general public, who do profess at least a passing interest in this subject. Discussions in the regional language and through alternative means such a dance, music, drama and *Katha Kalashepams* would be excellent vehicles of popular appeal which will enable us to cut through the elitist debate and include other more rustic points of view on the ethics of genomics research.

It is time Indian academics and academic institutions play a greater role in the formulation of

policy. After all education is the source of all ideas, which in turn is the basis of our society. Who else better than academics, to address these pressing issues?

Women's Issues

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Despite the fact we are entering in to the 21st century, and acclaim and proclaim various declarations and resolutions, an in-depth study on Indian women reveals their secondary position. The Indian Constitution and legislations, and UN and UNESCO Declarations guarantee fundamental Freedoms, Human Rights, Equality and Social Justice to women. In the 33rd General Conference of the UNESCO adopted by acclamation on 19th October 2005 many issues relating to Bio-Ethics and Human Rights have been discussed in the Universal Declaration on Bioethics and Human Rights. While discussing various aspects of the Declaration, I focus on women's issues, realities and solutions. Future needs to improve their condition are also emphasized.

The Declaration recognises that the ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms. Similarly the Constitution of India also guarantees freedom and equal rights to people belonging to all religion, sex, sect, caste, language etc. But in real life it is not practiced and an in depth study on the subject yields unfavourable results. The violation of these codes produce negative results and in the case of women, it is worse. It is necessary to analyse the pros and cons of the ethical issues and resolve how best they could be made to enjoy their fundamental freedom and Human Rights.

The term **bioethics** refers to the systematic, pluralistic and interdisciplinary study and resolution of ethical issues raised by medicine, life and social sciences as applied to human beings and their relationship with the biosphere, including issues related to the availability of scientific and technological developments and their applications **(Primary Draft Declaration on Universal Norms on Bioethics, Article 1).** A knowledge and application of bioethics is essential to lead a complete life and in that process students learn to safeguard their dignity and enjoy human rights and fundamental freedoms.

As I concentrate on Women's Issues, it is necessary to analyse the position of women of India from earlier times to the present day and discuss the realities. There are inequalities inherent in the traditional social structure based on caste, community, creed, religion, language and class with socially accepted rights, and there are expected roles of women which have a very significant influence on the status of women. The directions of social, economic and political changes have their impact on the status of women. Equality of women is necessary as a basic condition of socio-economic and political development of the nation. Each society owes a special responsibility to women as mothers, and house makers. Every one knows that women are victims of inequalities and disabilities which should be removed at all costs to improve the condition of women.

Manu, the ancient lawgiver, specifies the subordinate nature of woman all through her life. 'In childhood, a girl should be subject to her father; in youth to her husband; and when her husband died, to her son. A woman must be never independent.' Birth of the son is greatly rejoiced by the family members. In the Vedic society, woman was much needed for performing the religious rites and her place was inside the house. Pollution was attached to menstruation and child birth. Hindu women suffered due to child marriage, polygamy, widowhood, dowry, bride price, illiteracy, unemployment, underemployment, inequality in wages, Sati, prostitution, divorce etc. In the case of Muslim women, though the Holy Quran regards both men and women as equals , in real life, women are treated inferior to men. The practice of divorce, purdha, polygamy etc are not favourable to women. In the Christian society, women enjoy considerably a good status.

"**The 2005 conference is aware that human beings are an integral part of the biosphere, with an important role in protecting one another and other forms of life, in particular animals."** The word **'**Human beings' includes both men and women. But the plight of women in the male dominated world is pitiable.Woman, though needing protection, is the great protector. She bears and rears children; she protects elders at home; she is the light of the house. However strong she is in mind, she needs the protection of her counterpart.

But in most of the families, she is exploited. It is interesting to note that the Conference recommends protection of all living beings and equal importance is to be given **to the protection of animals**. But what is the condition of women in the 21st century? In fact pet animals are treated better than the womenfolk in many places. Men may protect their women with selfish attitude but in the case of women, selflessness and sacrifice are part of their life and in that process they may be the losers too. The society also expects them to be like that and attaches no special importance to them. There is no doubt that the literacy and employment level of women has increased, but their economic and social freedom are at stake. Politically too, the percentage of women involved in active politics is very less.

The Conference has recognized that based on the freedom of science and research, scientific and technological developments have been, and can be, of great benefit to humankind in increasing, *inter alia*, life expectancy and improving the quality of life, and emphasized that such developments should always seek to promote the welfare of individuals, families, groups or communities and humankind as a whole in the recognition of the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms. In spite of the advancement in science and technology, and the improvement in women's education and financial status, women at large are denied of their fundamental rights and dignity due to the chauvinistic attitude of men-folk. The rural women do not enjoy the fruits of scientific and technological developments because of ignorance and poverty. The quality of their life remains at very low ebbs. If individual freedom and rights are respected, the society as a whole will improve. The quality of life of the society depends on the quality of life of women in that society. Ignoring women, no society could progress.

Women play different roles in a changing society. But the traditional practice of decision making left to men continues in many families. Male domination could be seen not only in families but also in village panchayats, municipalities, corporation, legislative assemblies and parliament. Child bearing and rearing, cooking and stitching are identified with feminity. Whether women work in offices, fields, factories, construction sites, mines etc, they are expected to be home makers like unemployed women. They are not treated on par with men. The agricultural and masonry women and factory workers face more ordeals due to lack of financial independence though they also earn. The well-to-do women are spared from the drudgery of house work because they could afford domestic help but they are expected to run the home and bring up the children. Working women have to balance between official and home work. There is problem of adjustment for them.

The Conference recognizes that health does not depend solely on scientific and technological research developments but also on psychosocial and cultural factors. First of all, the development in medical research does not reach the poor and they do not seek any remedy for their ailments due to poverty and ignorance. Rich can afford even costly treatment for their sickness. But it is sad to note that many women of India- rich or poor, urban or rural- are psychologically put out and feel socially backward because the way in which they are treated in the family and in the work spot is not satisfactory. Their mental health is affected because of various social and cultural factors. Their secondary position affects them psychologically. Most of them have no right over their earnings and have no say in decision making too. This social disability makes them weaker still. Hence it is necessary to recognize them for what they are and keep them in good humour so that their productivity will improve and they can participate more actively.

The Declaration specifies that a person's identity includes biological, psychological, social, cultural and spiritual dimensions. Though the word 'person' means woman too, she is not viewed in different dimensions. Though biologically she is treated as a woman, her psychological aspect, social status, spiritual identity are not given any prime attention in the male dominated world. She is identified as someone's daughter, wife or mother. Even if a woman is well employed and settled, if she is married to a man employed in different place, either she has to resign, or go on leave or get her transfer to her husband's place. Similarly, she may be a good singer or dancer, but the decision of her husband whether she could continue her music or dance is final. Most of the women lose their identity or get new identity because of marital status. The negative elements in it are to be avoided. In many families, though she is the breadwinner, she is not given due recognition. Her likes and dislikes are no matter for people at home. She is psychologically affected due to various reasons. In many families women lose their identities. This situation should

change, and woman should be allowed to have her identity based on her biological, psychological, social, cultural and spiritual dimensions.

The UNESCO conference has recognized that an important way to evaluate social realities and achieve equity is to pay attention to the position of women. The progress of any country or society could be evaluated on the progress made by women. But an analysis of existing social realities reveals the pathetic position of women in the society and it is not possible for women to have equal ranking with men in many spheres. The social evils continue to exist, though regulations have been passed to abolish the same. There is no need for sympathy for women, but they must be given equality, freedom and rights. They should be given education and employment and financial independence. They should be treated as human beings.

One of the aims of the Declaration is to promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law (Declaration, Article 2,c). The framers of Indian Constitution have worked out with good intentions to promote the cause of women and if the provisions are followed with real spirit, women folk would definitely benefit. It is necessary to respect the Fundamental Rights stated in the Constitution of India as they suit the Indian conditions. But in reality, various pressure groups work against the provisions ensuring equality, and damage the dignity of womenfolk in India. The Human Rights which are to be protected and enjoyed are at cross roads. The portrayal of women in advertisements, cinema and television is not of good taste. When women are unable to enjoy their rights and their dignity is not safeguarded, there is no chance to ensure them respect, freedom and dignity

The Declaration aims at safeguarding and promoting the interests of the present and future generations (ibid .g) Though it sounds well and there is some improvement in the status of women due to education and employment, a thorough study reveals that it is not easy to safeguard and promote the interests of women. Women face opposition, discouragement and non-cooperation from family members if it is home and from colleagues and superiors, if office. Women are offended and affected in various ways. Though there are chances of getting help from the State, it cannot do any possible help if the atrocities are not reported to it on time. If women of future generation realize the predicaments in women's issues, and improve their standard of life with education and employment and gather strength and courage to face opposition, their future will be bright.

Human dignity, human rights and fundamental freedoms are to be fully respected and the interests and welfare of the individual should have priority over the sole interest of science or society (Article 3). But it is sad to note that the interest of the people who have money and muscle power has become primary than the average ones. In the case of women, it is still worse. The relationship between earning capacity and status and autonomy within the family for the women depends to a great extent on the status of her earning activity. Since manual labour has a low status in our society, women labourers, unskilled and menial workers do not enjoy good status . They struggle for existence as they work for the whole day in various capacities with no honour and dignity. They are exploited by their superiors, especially men at the workspot. They do not even know the meaning of human rights and dignity. Their welfare and interests do not find any place in the male dominated world. She suffers with the drudgery of daily cores, drunkard husband, weak and unhealthy children and malnutrition. Her ailments are not properly treated and she has no time to think about the same. In the case of elderly poor women, the treatment is worse. She is an unwanted burden and in many families, they are thrown out and they are picked up by organizations like Vishranthi (a home for the Aged). In such situations, how could they think of welfare, interests, dignity and fundamental freedom? Perhaps in the long run, if the interests, dignity, freedom and welfare of the individuals, especially women are respected , the society as a whole will benefit.

The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected (Article 5). From earlier times, the decision making, not only in the family but in state too, is the privilege of men. Education and employment are denied to many women so that they totally depend on menfolk. The practice of dowry and bride price lowered their status. Till recently, women had no right over the property of their parents or husbands which belittled their position. Though some are educated and employed, many do not have any say over their own earnings.

Hence with few exceptions, women are deprived of their rights in decision making. Though after their marriage they are expected to respect the in-laws in their new environment, there is no hard and fast rules to stress their importance in the family. It is one- way traffic in many families.

The Declaration states that any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information (Article 6). In spite of this article and the Indian Constitution guaranteeing fundamental rights, many women feel that they have no right over their own body, child or property. She becomes a victim of not only circumstances but also of the whims and fancies of her husband and in-laws. Though the law sanctions her the right over her own body and her right to deny sex to her husband if she is unwilling, most of the husbands feel that it is the duty of the wife to yield to their call. As far as abortion and infanticide are concerned, the mother's instinct in her never allows her to abort the girl child even if she already has girl babies. In the Indian society where female infanticide is illegally practiced by the family members themselves, women especially of the poorer section, are at a loss to execute their will. Preventive measures are not taught to them and they are the ultimate sufferers. Their consent is never asked at any stage. Of course in modern times, there is great awareness of family planning and the educated couples discuss things well in advance before they take any decision, but it is of low percentage. Even in their cases, women have to bow down to the interests of men folk. Otherwise, their life will be miserable. Even though for the time being, women give consent willingly or unwillingly for preventive actions like abortion, they should have the right to change their opinion next time. They cannot be forced to by any one in this aspect.

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law (Article 9). This is relevant not only in medical research and treatment but in regular day-to –day life. Though the medical reports are to be kept confidentially, various factors hinder the process and we hear some medical personnel falling a prey to some forces knowingly or unknowingly. It affects the patient not only physically but to a greater extent psychologically too.

In offices and home too women face ordeals and are exploited by their opponents who take the delicate and secret issues connected with women. In this connection, though some may feel it is out of context, I would like to highlight the role of women in Mega serials in almost all channels. The exposition of women in many serials is nauseating and damages the image and dignity of women. They enter into the privacy of women and exploit them with revengeful attitude. This is to be condemned. Whether it is medical report or a personal report, it should not be disclosed to anyone without the consent of the person concerned.

The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably (Article 10). Similar to this the Indian Constitution stress equality and social justice. But what is happening in real life is different. The caste, creed, religious, class, sex and language differences play havoc in promoting equality and justice. The ' Sons of the soil' theory put an end to the slogan that 'Kashmir to Kanyakumari, we are one'. The Tamil proverb that 'poor cannot get justice' proves to be correct as the money power clubbed with muscle power could purchase justice. In this process women are also involved and victimized. Subramania Bharati, the National poet of India dreams about the liberation of women and equality in Indian society. He feels that men and women are like two eyes and if one eye is blinded we will not get complete vision. By this he means that a society which harms women will not prosper. Women should be given good education like men so that they could progress.

No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms (Article 11). It is very easy to say that no one shall be subjected to discrimination based on any ground intended to infringe or having the effect of infringing the human dignity,human rights or fundamental freedoms of an individual,nor shall such grounds be used to stigmatize on an individual, a family,a group or a community. . But in actual practice we find that there is discrimination. Even at home,at all levels, there is difference in treatment between the male and female children. The parents give priority to male children . If they could afford education to

one child, the preference is to the son as they feel that he would take care of them at old age and the daughter would go to different family. But in reality we see that most of the parents are taken better care by their daughters than sons. In the poorer sections, it is shocking to note that son is fed and educated better than the daughter. In most of the families in the below poverty line, the daughter has to take care of the younger siblings as both the parents go to work.

Similarly, at the below poverty line, the problems faced by tribal and Schedule caste women are horrible. Though there are Non-Governmental Organisations to take up their cause, solution or justice is not got easily. The gender discrimination is deep rooted in India and it is necessary to find ways of eradicating it completely.

It is sickening to note the condition of a raped girl in a society. There is lot of discrimination in treating the raped girl, though a man or men are the real culprits. Stigma is attached mainly to the girl. Though the society is not happy with the incident, men escape from serious punishment and stigma. The attitude of the society should change. In the villages, the village assembly tries to solve the problem by marrying the raped girl to the rapist as they feel they have given a future to the girl. But there are girls who feel instead of marrying the accused, it is better to penalize him and they take the matter to the court of law. To decide that way, they should be strong willed, as they have to face nasty questions in the court and the insults from the society. Till last the society attaches some stigma to her. All these happen because she is a woman. Man escapes from these realities. Many women's organizations take up the issues of affected women and encourage them to lead a courageous life.

In the case of divorcees also, more stigma is attached to women. A man becomes an eligible bachelor for the second marriage after the divorce but women face many ordeals. The stigma is attached to her for ever. Similarly, the single women and single mothers face lot of problems and their dignity is affected by the gossipers or negative people. The children of the divorcees and single mothers are looked upon with coloured glasses by the society. There should be an end to it.

The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope (Article 12). While making any decision or following any practice, it is necessary to keep in mind the cultural backgrounds, school of thought, value systems, traditions, religious and spiritual beliefs and other relevant features of society. But these considerations should not affect human dignity, human rights and fundamental freedom. In course of time, there are changes in the society due to various factors. Education and financial independence have improved the status of some women. The western culture has made great impact on the youth. But in that process, they should not lose their identity or dignity. Co-education and employment have brought men and women closer. Inter caste marriages and inter dining have become common. But at the same time, there are people who attach stigma to all these things and the most affected are women. . There should be proper and better understanding between two genders. Any relationship or friendship should not cause damage to human dignity, human rights and fundamental freedom.

Article 14 speaks of Social Responsibility and Health. Every citizen has the fundamental right which guarantees access to quality health care and essential medicines, including for reproductive health and child health.. It is the duty of the government to look into the needs of the people. Health of the girl child and women are highly neglected areas. It is necessary to create awareness among people about the need for health and hygiene. Due to ignorance and carelessness many girl children have been affected by polio in our country and their future is bleak. Similarly many women are affected by AIDS due to no fault of their own but face humiliation and insults. Post-maternity care is totally absent in the poorer society and nutritious food is unknown to the pregnant women.

Women and children should have adequate nutrition and water. Water has become a scarce commodity and it is to be purchased both by the rich and poor. In many places, getting water is the toughest task for women folk. Drinking water poses a great problem and water pollution causes diseases. It is duty of the government to provide good and adequate water facilities to the people.

To lead a healthy life, there should be clean environment. People who live in places where there is pollution of different kinds face health problems. This is to be rectified not only by the government but by the people themselves. Reduction of poverty and illiteracy may contribute to better health

conditions of the people especially women who are the more responsible people of the society.

Application of these ethical principles is not difficult. It needs proper understanding of the theme and correct application. The Declaration recommends different **Ethics Committees** (**Article 19**) which will be independent, multidisciplinary and pluralist in character to assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings; to provide advice on ethical problems in clinical settings and to foster debate, education and public awareness of, and engagement in, bioethics. At this juncture I would like to stress the importance of Moral Instruction classes to the students from the elementary school level. In this class the concerned teacher teaches to the students many morals through stories and the children are impressed with the positive aspects of life and are warned against negative aspects. It is the age in which they could be well shaped for dos and don'ts. Whatever be the religion, the students should be taught to understand the moral stories which would enable them to know the realities of life. The children should be taught to know the significance of health and hygiene in day-to-day life.

The state has to play an important role in solving women's issues. It should insist and extend free education for girl children promoting nutritious food, free medical checkup and advice to them. Training programmes could be arranged for women to create awareness on ethical issues. Bioethics education should be a compulsory part of the curriculum. It is necessary to foster multidisciplinary and pluralistic dialogue about bioethical issues between scientists, health professionals, lawyers, philosophers, ethicists, theologians and all other intellectual, religious and professional groups concerned, policy makers non-governmental organizations representatives of civil society, the persons concerned and society as a whole. Definitely women, though a minority, will be members of these groups or organizations. Though regulations have been enacted to end the atrocities (sati, widowhood, illiteracy, unemployment, prostitution, eve teasing, rape etc) against women, they exist in one form or other in the society. Government should be strict in dealing with people who harm women and the severity of the punishment should be an eye opener to the culprits. The ultimate point is that men should respect and honour women and there should be mutual understanding and caring which would help to solve women's issues and promote their welfare, safeguarding their dignity, human rights and fundamental freedoms.

References

Primary Sources:

Constitution of India

Final Report on the UNESCO RUSHSAP Regional Meeting for the Ethics of Science and Technology in the Asia Pacific, 5-7 Nov. 2003, Bangkok

International Declaration on Human Genetic Data, 16 October,2003, UNESCO.

Preliminary Draft Declaration on Universal Norms on Bioethics, 28 January, 2005, Paris.

Status of Women in India, ICSSR, New Delhi, REPRINT, 1998

The First Bangkok Workshop on Ethics Partnerships for Asia- Pacific Region, Bangkok, (Background Material prepared by RUSHSAP, UNESCO Bangkok)

Universal Declaration on Bioethics and Human Rights, UNESCO, 19, October, 2005.

Published works

Altekar, A.S. *The position of women in Hindu Civilization from Prehistoric Times to the* Present *Day*, Second Edition, Delhi, 1978.

Balambal, V. *Studies in the History of the Sangam Age,* Delhi, 1998.

Basham, A.L., *The Wonder That Was India*, London, 1954.

Desai, P.B. *Jainism in South India*, Sholapur, 1957

Billington, Fraces: *Women in India,* Second Edition, Delhi, 1987.

Datta, V.N: *Sati, A Historical, Social and Philosophical Enquiry into the Hindu Rite of Widow Burning*, New Delni, 1988.

Gupta, A.R. *Women in Hindu Society*, Second Edition, New Delhi, 1982.

Kamala Mankokar, *Women in India*, New Delhi, 1975.

Kane, P.V. *History of Dharma Sastras*, Vols, I-V, Bombay, 1940.

Krishnaswamy. S. *Glimpses of Women in India*, New Delhi,1983.

Majumdar, R.C. (Ed) *History and life of the Indian People*, Vols. I-V, Bombay, 1951-60.

Mukerji Kumar Santosh, *Prostitution in India*, Delhi, 1986.

Pillay, K.K. *A Social History of the Tamils,* Second Edition, Madras,1975

Radhakrishnan, S. *Religion and Society*, London, 1947.

Ram Ahuja, *Rights of Women, A Feminist Perspective*, New Delhi,1992.

Subbamma, Malladi, *Women - Tradition and Culture*, New Delhi, 1985.

Tara Ali Baig(Ed) *Women of India*, Reprint, and New Delhi, 1990.

Vijayalakshmi, R. *Women of Tamilnadu* (Tamil), Chennai, 1997.

The Participation of Cognitively Impaired Elderly in Mental Health Research

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Abstract

Cognitive impairment threatens every elderly person as well as society in view of the world's aging population. Unfortunately, the very nature of these mental illnesses also hinders promising research due to the subjects' inability to consent. It is the intent of this paper to argue the empirical need and ethical acceptability of involving cognitively impaired elderly in mental health research as long as proper regulatory safeguards are in place. The need for advance directives in research, recognition of the importance of surrogate decision-makers as well as the need to seek participants' assent will be re-examined in light of the special situation of the cognitively impaired elderly.

Introduction

The abilities to comprehend, to articulate choices, and to logically elaborate one's decisions are cognitive capacities that enable persons to decide autonomously. Losing the capacity to decide can be an unfortunate consequence of a medical, neurologic or psychiatric condition. These conditions more often than not occur in old age. Stroke, major depression, Alzheimer's disease, dementia and other neurodegenerative disorders may bring about this process of cognitive impairment. Unfortunately, current treatment options for most of these conditions are still far from being effective. Hence, such situation calls for further research. However, the very condition that makes these neuropsychiatric problems devastating also hampers research. The loss of proper cognition may hinder the elderly's capacity to decide and to express informed consent for research participation.

In the U.S. alone, the elderly (persons aged 65 and above) presently comprise 13% of the total population. It is estimated that they will continually increase up to 20% by the year 2030 (US Admin. on Aging, 2005). Parallel with the growth of the aged population, the number of elderly with cognitive impairment is also expected to increase. The prevalence of Alzheimer's disease is estimated at 1.5% among persons age 65 years old. This prevalence increases every four years, reaching 30% by the time the elderly reach the age of 80 (Gorelick, 2004). In 2000, there were 49,600 deaths attributed to Alzheimer's disease, making it the 7th leading cause of death among the U.S. elderly (CDC, 2005). In addition to these high morbidity and mortality rates, the estimated health care cost of cognitive impairment for the U.S. will be around US$58 Billion annually (Max, 1993).

The development of cognitive impairment in the elderly does not automatically render an individual to be incompetent to consent. However, many of the elderly with advanced mental illnesses such as Alzheimer's disease, vascular dementia, schizophrenia and major depression may not be able to give competent consent either for medical care or research participation (Grisso & Appelbaum, 1995). This places our society on the quandary of whether to include the vulnerable and cognitively impaired elderly in research activities in light of their growing number, cost of care and poorly treated mental health problems. Corollary to this, how do we protect the autonomy of the cognitively impaired elderly? Should we allow their appointed surrogate decision-makers to automatically carry over their substituted judgment for research activities? Will assent from the elderly be necessary at all times?

Development of Research Ethics for the Cognitively Impaired

The Nuremberg code was the first international document that galvanized the need for informed consent among human participants. It is however silent about the conduct of research among those who can not consent because of cognitive impairment. To interpret literally, the Nuremberg code forbids research without the consent of subjects. Even more, it does not open any possibility for surrogate consent in research (Bonnie, 1997).

The Helsinki Declaration was the first international guideline to give way to the possibility of including incompetent subjects in research by

assuring favorable risk-benefit considerations (World Medical Association, 1964). Following the Nuremberg Code and the Helsinki Declaration, several initiatives have come up with their own research ethics guidelines concerning subjects who can not give informed consent. Currently, there are several international institutions that place safeguards in clinical research concerning the cognitively impaired. In the U.S., the National Bioethics Advisory Commission came up with a 1998 report, *Research Involving Persons with Mental Disorders that may affect Decision-making Capacity*. Other guidelines include the Canadian Tri-Council, the Council of Europe's recommendations, and several branches of the U.S. National Institutes of Health with their own recommendations (Wendler & Prasad, 2001).

The issue of informed consent is central to the debate regarding the participation of cognitively impaired elderly. Rhodes (2005) argues that the centrality of informed consent has hindered the conduct of research and has set the current U.S. research policies in the wrong direction. Levine (2005) in a commentary about the Rhodes' article, *Rethinking Research Ethics*, also concedes that the informed consent process consumes more than its appropriate allocation in reviews conducted by U.S. institutional review boards. According to Rhodes (2005), this overemphasis on informed consent has brought a culture of over-protection among the vulnerable subjects. Fins (2003) echoes the same contention that the current protectionist attitude has had the unintended consequence of imperiling advances in the neurosciences that could benefit the very population that research ethics has sought to protect.

Quandary for the Cognitively Impaired Elderly

There are contradicting reports as to the current status of research among the cognitively impaired elderly. On the contrary, some clinicians and investigators perceive the lack of clear regulatory protection in the U.S. (Kim, *et al.* 2004). Some fear that conservative institutional review boards may inappropriately censor research with cognitively impaired elderly as reflected by the views of Rhodes (2005) and Hougham (2005).

The U.S. Code of Federal Regulations approves the process of informed consent by a legally authorized representative (Appelbaum, 2002). Similar institutions also suggest the same solution of utilizing legally authorized representatives. These include the National Bioethics Advisory Commission, the state of Maryland's Attorney General's office, the New York State Office of Mental Health, the Canadian Tri-Council and the Council of Europe (Wendler & Prasad, 2001). Another notable declaration would be the position paper of the American College of Physicians (1989) which states that:

Consent to research may be taken in advance from the subject and designate a proxy to supervise the subject's participation. In cases where there is no advance or proxy designated, a legally authorized surrogate should act as the decision-maker…surrogates may consent to research if participation is in the incompetent person's best interest (pp. 844-845)

However, these guidelines stand as mere recommendations if not given legislative support. In addition, many of the guidelines have conflicting suggestions on the process of seeking informed consent for the enrollment and continued participation of cognitively impaired participants. Kim *et al*. (2004), believe that many U.S. researchers are still confused and in need of clearer regulatory guidelines. They cited the example of appointing legally authorized representatives which rest mostly on individual U.S. state laws, which more often than not insufficiently address the issue. As a result, many researchers and stakeholders may not be aware of the applicable laws in their own state.

Even family members who have been customarily considered as surrogate roles in treatment have been questioned by U.S. courts in their attempt to act as surrogate decision-makers in research. In New York, an intermediate appellate court declared that, "No incompetent adult or minor could be entered into a research protocol that contained any element that has no therapeutic benefit…and presented more than minimal risk, such as a lumbar puncture or a PET scan" (Appelbaum, 2002, p.122). Similarly, Maryland's Supreme Court held the same ruling, "a parent, appropriate relative, or other applicable surrogate cannot consent to the participation of a child or other person under legal disability…in which there is any risk of injury or damage to the health of the subject" (Appelbaum, 2002, p.122). These two court decisions, if interpreted conservatively, may potentially block the enrollment and participation of cognitively impaired subjects since almost all clinical trials whether therapeutic or non-therapeutic carry risks to their participants. Presently, many of these issues are individually

handled by institutional review boards based on their knowledge of existing guidelines and ethical sensitivity (Bonnie, 1997). Kim *et al*., (2004) report that in a recent multicenter survey of the Alzheimer's disease Cooperative Study, 14% of study sites reported restriction from their local institutional review board to accept consent by proxy. Rosamond Rhodes (2005) contends that we are overprotecting our cognitively impaired to their detriment. She notes:

Current policies…presume that all those who can be classified as "vulnerable" should be paternalistically protected from researchers irrespective of whether the individuals in those groups consider their participation as a benefit, whether or not they want to be protected, and regardless of the fact that some, most, or possibly all of the individuals in the so-called "vulnerable" group have the capacity to consent to research participation (p. 12)

Redirecting Our Ethics Perspective

The problem of the cognitively impaired elderly in research revolves around the issue of autonomy. Informed consent is a process by which we document our recognition for our subjects' human dignity. It is through this recognition by which we regard our subjects as persons who are capable of free will and are entitled to the liberty of choosing of what they desire and deem to be in their best interest.

Mental health research involving the cognitively impaired elderly is a balancing act that considers the deepest values of research ethics--that is autonomy, beneficence, and nonmaleficence. This author agrees with Rhodes (2005) that the proper social agenda of clinical research is to advance the knowledge of society for the betterment of its members. In the process of achieving such benefit, subjects regardless of their decisional competency should not be treated merely as means even to such noble ends. To avoid unethical conduct, subjects should be allowed to exercise their autonomy in a manner that is reflective of their personal values, cognizant and considerate to whatever physical, medical or mental condition they are in.

More than respecting autonomy is the concept of acknowledging the rights of individuals to participate in research whether this emanates from an altruistic initiative or from vested personal interests. More often than not, this respect for the rights of individuals to participate in research is ignored (Reynolds, 2002). This is especially true among the elderly who are suffering from psychiatric, neurologic, or medical conditions that may weaken their capacity to assert their preferences. It is tempting to view the elderly with our ageist prejudice and to belittle their capacity to undergo such noble endeavors of contributing to science and humanity.

However, the process of acquiring consent must also be congruent with the values and wishes of the elderly participants. This may be viewed in their values inventory, living will, and advance directives or through their sincere surrogates who could attest to the elderly's personal values and disposition towards research. Attempts to preclude their participation based merely on their age, medical, or mental status devalue their dignity and autonomy. On the other hand, haphazard enrollment may easily imperil the autonomy of such vulnerable individuals given their weakness in articulating their choices and disagreements. It is also the stand of this paper to allow greater surrogate decision making role for research. The arguments for each point will follow in the succeeding paragraphs.

Arguments against Research Participation

Since the 1960's guidelines have been formulated for the purpose of permitting the elderly in research either through advance directives, proxy decision-makers, or legally appointed representatives. This is however easy to say, yet challenging to implement. What is currently being debated in the U.S. is the process of allowing surrogate decision-makers to consent for the cognitively impaired elderly in research. There is currently no consensus as to what extent surrogates should be allowed to exercise their proxy decision-making roles in research.

For one, an advance directive even in the U.S. is already a sensitive issue to tackle with. Only less than a quarter of Americans complete their advance directives for medical care (Emanuel, Barry, & Stoeckle, 1991). All the more, it will be difficult to ask for advance directives for research.

Another problem is the dilemma of weighing risk-benefit assessment in the participation of the cognitively impaired elderly. Many debates now surround the topic of classifying research into either therapeutic or non-therapeutic. There seems to be a persistent hesitation to include cognitively impaired elderly in non-therapeutic research since it does not provide any direct benefit to the participating subjects.

Arguments for Research Participation

Many of the conditions seen in the elderly are difficult to find among the younger age groups. The aged brain has a lot to reveal in terms of preventing, diagnosing and managing mental disorders. By automatically prohibiting the participation of cognitively impaired elderly, we are depriving science the chance to serve the elderly as well as to provide prevention and treatment for the benefit of society. It is not suggested that we take a lax stance on this issue. The elderly are vulnerable thereby necessitating added but appropriate protection without blocking research or trampling upon the autonomy of those who wish to contribute to the noble agenda of rigorous scientific inquiry.

Impaired cognition even among the aged does not necessarily translate to decisional incapacity (Rhodes, 2005; Appelbaum, 2002). To prematurely conclude that the cognitively impaired elderly can not meet an acceptable degree of autonomy would be a moral deficit due to prejudice. It is suggested that society could be best served if investigators and research policy-makers keep an open mind towards potential research participants. Only after sufficient evaluation should elderly participants be labeled as incompetent (Beauchamp, 2005).

Sachs *et al*. (1994), report that many persons with dementia are still capable of participating in health care discussions even if they fall short of the strict regulatory guidelines for informed consent. A systematic review of literature was conducted by Kim, Karlawish, and Caine (2002) covering 32 relevant studies which indicated that many persons with dementia are indeed capable of decision-making either for medical care or research participation. The general view towards mental health research in the U.S. is especially positive among those who have experienced the burden of mental health problems among their loved ones. In a survey covering 246 individuals with family history of Alzheimer's disease, 95% of respondents agreed to participate in clinical trials for dementia even after they have lost their capacity to consent (Wendler *et al*., 2002).

More than just preoccupying ourselves with the process of informed consent, the ethical acceptability of a research protocol involving the cognitively impaired elderly would have to consider the other pertinent facets of research ethics. Respect for subjects does not end with informed consent. Respect for subjects should encompass: respect for subjects' privacy, tolerance to allow subjects to change decisions, assurance of subjects' well-being, and recognition of subjects' contribution to research. Informed consent is necessary in almost all cases, but rarely is it sufficient alone to assure ethical acceptability (Emanuel *et al*., 2000). The focus should go beyond informed consent. Policy-makers and investigators must learn to embrace a more holistic approach to ethical research such as cultural sensitivity, acceptable risk-benefit assessments and humane care of participants.

Non-participation in non-therapeutic research for the reason that it doesn't provide any direct benefit to the elderly participant is a very selfish attitude towards the social benefits of research. Although no one should be compelled to join against his will, society must cultivate a culture of altruism especially among those in special medical or mental conditions with whom humankind may learn about their special situation and possibility derive knowledge to benefit other members of society.

Proxy Decision-Making for Cognitively Impaired Elderly

In the care of the cognitively impaired elderly, health care professionals have customarily turned to families for support and surrogate decision-making roles. This process of proxy consent has always been hampered by social, cultural and legal problems. Yet, it is also a promising frontier for mental health researchers to explore in order to gain greater research opportunities among the elderly in advance stages of cognitive impairment. There are many arguments for and against such practice. Arguments establishing the legitimacy and moral acceptability of family members as surrogate decision-makers emanate from our respect of the family as a basic social unit. In matters that affect its members, the family should be regarded as a responsible decision maker (Emanuel & Emanuel, 1992). This is especially true in Asian cultures where families are collective decision-makers as represented by their elders. By the nature of their intimate relationship to the patient, families are the best judges of the patient's values and attitude towards medical care or research participation. Among the vulnerable groups, the elderly have peculiar characteristics different from legally incompetent minors. Older people have lived long lives, had families, worked, and in one way or the other have developed and expressed their values in life from which family

proxy decision-makers could reflect upon for directions. Hence, traditional surrogate decision-makers for medical care may be entertained as possible proxies even in research.

However, we can not deny instances when the fabric of family ties turns rough and undependable. Family members may have conflicts of interests in the care of their elderly members (Emanuel & Emanuel, 1992). It could be possible that some families may take advantage of research as a means to abandon their elderly patient. They may also consider research as a means to lighten their care-giving load or to gain incentives for their enrollment. Hence, the frail and cognitively impaired elderly may be used merely as a means for the family's end goals. However, the family is still the best trusted decision-maker. A survey by Wendler *et al.* (2002) suggest that 88% of individuals would still allow their families to enroll them in research even in the absence of an advance directive.

Need for Assent

Cognitive impairment in the elderly such as Alzheimer's disease afflicts patients in a spectrum of severity, giving a varied continuum of decisional capacity. Legally, some may fall short of the standards of competence, but may still exhibit certain degrees of appreciation and expression of choice in the things that happen around them. This is called as the capacity to assent. The Helsinki Declaration (1964) states that, "when a subject deemed legally incompetent…is able to assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative" (p.357).

In spite of the Helsinki Declaration, there is still disagreement among existing guidelines on the need to seek assent from incompetent participants. Namely, the New York, Maryland, and the Canadian Tri-Council guidelines require assent for enrollment, while others do not. With regards to dissent, there is consensus among existing guidelines advocating withdrawal of incompetent subjects who express dissent except for the Canadian Tri-Council which would permit continued participation if the protocol offers direct potential benefit to the dissenting subject (Wendler & Prasad, 2001). There is a pressing need for a consensus to establish guidelines with a unified stance regarding the need for assent. It is the opinion of this author that the need for assent must not be a blanket prerequisite. It should be a requirement based on the mental status of the potential subject. If the elderly participant is able to give assent, then it should be sought. The ability to assent entails appreciation of feelings, sensations and outside environment. With assent, comes also the capacity to feel frustration and distress which should be heeded by investigators and proxy decision-makers. Dissent should also be taken in a manner that analyzes the current mental condition of the subject. Investigators should verify if the dissenting behavior is a manifestation of the subject's remaining cognition which desires to withdraw from research or merely an unintelligible act brought about by the deteriorating mental illness.

Conclusion

The cognitively impaired elderly deserve much attention. They are a vulnerable group whose mental health problems are very much still in the process of experimentation and discovery. It is ethically permissible to allow their participation in mental health research for the reasons discussed above. They should not be barred from participation on the sole basis of their vulnerable status. To automatically prohibit research based on such categorical status would be neglectful of the elderly's remaining autonomy and dignity. To hinder a scientific and valid research protocol merely on the basis of the subjects' inability to consent would impede medical advances that would have benefited both the elderly participant and society in general. The elderly should be allowed to contribute and receive whatever advances mental health research has to offer. Their participation should be documented in their advance directives, through surrogate decision-makers who should be protective of the elderly's best interest and cognizant of the elderly's attitude towards research. Appointment of proxies should be as rigorous as that of surrogates for medical treatment or end-of-life decisions. The cognitively impaired elderly whenever possible should be allowed to express assent or dissent in addition to surrogate consent to prevent any distress or undue harm. Research involving the cognitively impaired elderly should be reviewed not only in terms of informed consent but also in consideration of all the facets of research ethics.

Recommendations

It is recommended that stakeholders in geriatric mental health research must encourage clinicians, researchers, patients and families to plan in advance during the initial stages of cognitive impairment. Recruitment in this anticipative manner would encourage discussions on research among those who are still decisionally-capable and interested in contributing to the advances in geriatric mental health. This dialogue regarding future research consent should be culturally-sensitive, and must be shared with the probable surrogate decision-maker as to facilitate better understanding and cooperation. This is a process that may bring about better and more valid informed consents that are truly representative of elderly participants' understanding and desire to participate in research.

References

American College of Physicians. (1989). Position paper: Cognitively impaired subjects. *Annals of Internal Medicine*, 111 (10), 843-848.

Appelbaum, P. (2002). Involving decisionally impaired subjects in research: The need for legislation. *American Journal of Geriatric Psychiatry*, 10 (2), 120-124.

Beauchamp, T. (2005).How not to rethink research ethics. *The American Journal of Bioethics*, 5 (1), 31-33.

Bonnie, R. (1997). Research with cognitively impaired subjects: Unfinished business in the regulation of human research. *Archives of General Psychiatry*, 54 (2), 105-111.

Centers for Disease Control & Prevention. National Center for Health Statistics Vital statistics. Retrieved May 6, 2005 from http://209.217.72.34/aging/TableViewer/tableView.aspx?ReportId=418

Dunn, L., Lindamer, L., Palmer, B., Golshan, S., Schneiderman, L., & Jeste, D. (2002). Improving understanding of research consent in middle-aged and elderly patients with psychotic disorders. *American Journal of Psychiatry*, 10 (2), 142-150.

Emanuel, E., & Emanuel, L., Proxy decision making for incompetent patients. *Journal of the American Medical Association*, 267 (15), 2067-2071.

Emanuel, L., Barry, M., & Stoeckle J. (1991). Advance directives for medical care-A case for greater use. *New England Journal of Medicine*, 324, 889-895.

Evans D.A., Funkenstein. H., & Albert. M.S., (1989). Prevalence of Alzheimer's disease in a community population of older persons: Higher than previously reported. *Journal of the American Medical Association*, 262, 2551-2556.

Fins, J., Constructing an ethical stereotaxy for severe brain injury: Balancing risks, benefits and access. *Nature Reviews Neuroscience*, 4(4), 323-7.

Grisso, T., & Appelbaum, P.S.(1995).The Macarthur treatment competence study III: Abilities of patients to consent to psychiatric and medical treatments. *Law & Human Behavior*,19, 1449-1474.

Gorelick, P. B. (2004). Risk factors for vascular dementia and Alzheimer disease. *Stroke, 35*(11 Suppl 1), 2620-2622.

Hougham, G. (2005). Waste not, want not: Cognitive Impairment should not preclude research participation. *The American Journal of Bioethics*, 5 (1), 36-37.

Kim, S., Appelbaum, P., Jeste, D., & Olin, J., (2004). Proxy and surrogate consent in geriatric neuropsychiatric research: Update and recommendations. *The American Journal of Psychiatry*, 161(5), 797-806.

Kim, S., Karlawish, J., & Caine, E., (2002). Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry*, 10 (2), 151-165.

Levine, R. (2005).Reflections on "rethinking research ethics". *The American Journal of Bioethics*, 5(1), 1-3.

Macklin R.(2005). Some questionable premises about research ethics. *The American Journal of Bioethics*, 5 (1), 29-31.

Max, W., (1993). The economic impact of Alzheimer's disease. *Neurology*, 43, 6-10.

Sachs, G., Stocking C., Stern, R., Cox, M., Hougham, G., & Sachs, R., Ethical aspects of dementia research: Informed consent and proxy consent. *Clinical Research* 42(3), 403-12.

Reynolds, C., (2002).Advancing research in decision-making capacity. *American Journal of Geriatric Psychiatry*, 10 (2),117-119.

Rhodes, R. (2005).Rethinking research ethics. *The American Journal of Bioethics,* 5(1), 7-28.

Wendler, D., Martinez, R., Fairclough, D., Sutherland, T., & Emanuel, E., (2002) Views of potential subjects toward proposed regulations for clinical research with adults unable to consent. *The American Journal of Psychiatry*, 159 (4), 585-591.

Wendler, D., & Prasad, K., (2001) Core safeguards for clinical research with adults who are unable to consent. *Annals of Internal Medicine*, 135 (7), 514-523.

World Medical Association. (1964).Declaration of Helsinki. In T. Beauchamp & L. Walters (Eds.) *Contemporary issues in bioethics* 6th ed. (pp. 355-357). Belmont, CA: Wadsworth.

Comparison of attitudes towards euthanasia among elderly people in New Zealand and Japan

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Abstract

The purpose of this study is to explore the attitudes towards euthanasia among elderly people in New Zealand and Japan and make comparisons. In-depth interviews were conducted with 25 elderly persons in New Zealand and 25 in Japan separately. All interviews were transcribed verbatim, content analysis method was conducted to examine the key ideas that people had regarding euthanasia. The results showed that 64% Japanese and 24% New Zealand respondents approved of euthanasia. While Japanese hold an idealistic thinking in facing the ethical issues of euthanasia, their concept of euthanasia is mixed with the concept of natural death, that we cannot predict their real judgement of mercy-killing. While seniors of New Zealand are more practical and the availability of effective pain management or palliative care service is the main concern in their end-of-life. I then predict that if the modern medicine can guarantee a pain-free end-of-life, then euthanasia should never be an option for the elderly to accomplish the wish of dying with dignity.

1. Introduction

The ethics of euthanasia is one of the most popular subjects of debate within the health care profession as well as in the public from long time ago until now. The act of euthanasia is today understood as termination of life on the request of a patient and should be under the assistance of the doctor (physician-assisted suicide). Thus, the attitudes of subject who is supposed to give (doctor) and the subject who suppose to take (patient) were thus the focus of most research interest. Few studies, however, have explored the attitude among the population who are supposed to receive euthanasia. Elderly people are assumed to be less remote to their end-of-life, gathering the opinions about euthanasia in their ordinary and healthy days can provide reliable information which may enhance a dialogue on end life issues and make the public improve their maturity to consider euthanasia thoroughly.

Japan and New Zealand are island nations located in the Pacific Ocean. All of them have a universal health care system, long life expectancy and relatively advanced medical care. Moreover, in these relative rich societies, the three leading causes of death among the elderly are the same; that is cancer, cerebral-vascular disease and heart disease. However, there are cultural differences. We predicted that the attitude towards their end-of-life among seniors may be derived from their cultural values. In addition there may be religious factors, the religious affiliations are predominantly Christian in New Zealand and include Confucianism, Shinto and Buddhism in Japan. In addition, there is also an apparent difference of living style that senior people of New Zealand enjoy much a relaxed life; while the characteristic of loyalty and obedience has made most seniors of Japan live precisely. Those may be factors that influence their attitudes toward euthanasia.

Euthanasia is illegal in both Japan and New Zealand, however many studies in both countries have showed that increased medication to alleviate symptoms which may also cause premature death is acceptable among medical staff as well as the public (Akabayashi, 2002; Mitchell, 2004; Mitchell & Owens, 2004; Macer,2003). In Japan “death with dignity” has been a popular idea, while those who have attempted legislative reform have focused on forgoing life-sustaining treatment and the implementation of a living will, not active euthanasia or physician assist suicide (Akabayashi, 2002). At the same time euthanasia has moved into a practical dilemma in Japan when medical doctors have been involved in famous court cases of mercy killing in 1996 and 1995 (Hoshino, 1993, , 1996). In New Zealand, till recently, several attempts have been made to liberalized laws prohibiting euthanasia. However, according to the surveys (Mitchell & Owens, 2004; Mitchell & Owens, 2003); physician-assisted death in New Zealand is occurring. Essentially, both societies haven’t reached a great commitment on the issue of euthanasia except that the establishment of an open dialogue on the subject should be developed.

2. Methodology

This study was part of a larger study of life and death attitudes. A descriptive design was chosen using face-to-face, semi-structured, in-depth interviews.

A. Participants and data collection

Interviews were conducted with 25 seniors in New Zealand in mid-2003 and 25 seniors in Japan in late 2003. Healthy seniors aged 60 years or older were invited as participants. In New Zealand, senior persons were enrolled through approaches in a retirement club, home visits and rest homes, with the introduction of local persons. While in Japan even with some introduction many recruitment attempts were all failed, so home is the only source of interview cases.

Qualitative data was collected through persons who agreed to participate; tape recordings were used during the one to two hour long interviews. No one refused an audio tape recording.

B. Analysis

All interviews were transcribed verbatim, and stored in a computer as data bank. Then, content analysis method was conducted to examine the key ideas that people had regarding euthanasia and life and death questions. The analysis steps began with listening to participants' verbal descriptions, followed by reading and re-reading the verbatim transcriptions or written responses. Significant statements were then identified and extracted. These statements were then recorded in a data management file for ease of ordering later in process. All significant statements in the comments were thus placed into categories depending on different ideas that they contained.

Open-ended interviewing techniques, tape recordings, and verbatim transcriptions from those tapes were used to increase the accuracy of data collection. The transcripts were reviewed and coded independently by two researchers drawing upon their expertise in clinical medicine and bioethics. The qualitative methodology, features of the density of data collection, and the inductive way of analysis were all chosen to maximize the validity of the motifs in order to study seniors' attitudes towards euthanasia.

C. Characteristics of participants

In the New Zealand group, 64% were female, 40% were aged 70-79 years, with 48% older (80-89 32%, 90-99 16%) and 12% younger. All of them were currently living in urban areas. 52% were widowed and 48% were currently married. Different from the Japanese group, only one lived with his children and spouse, 56% were living alone (including 20% in rest home), 40% were living only with their spouse. Most of them (80%) had 2-4 children and 8% had more than 4 children. When asked their religion, all but one identified themselves as Christian.

In Japan, 64% were female too. The average age of the persons in the Japanese sample was lower than New Zealand. Only 44% were higher than 70, which do not correspond to the advanced age population of Japanese society. However, because of the conservative attitude towards talking with strangers among the elderly group, many rejected our interviews or had difficulty to talk directly during the interviews. In Japan, 28% were widowed or singled, 72% were currently married. There is 8% live with children alone. More than half of them lived with their spouse and children (60%). Similar to New Zealand, most of them (80%) had 2-4 children and none of them have more than 4 children. When asked their religion, 10 identified themselves as Buddhism only one as Shinto and eight Christians. Thus we can say there is a slightly Christian bias in this sample. (Table 1).

3. Results

During the semi-structured interview conversations in New Zealand and Japan, 25 seniors from each group were asked to express their opinions about euthanasia. The main categories of response are in Table 2.

In New Zealand, six persons (24%) approved of euthanasia definitely, holding a reason that human should not suffer so much, and life got no value in some situations that Euthanasia should be a right thing for some cases. For example:

"…calling out in pain, begging for the needle…. It's kinder that you slip away and don't have to go through that. I don't think anybody should have to suffer like that. What's the point?"

"If life hasn't got any value, what's the use? When you lose all knowledge, mentally and physically, if it comes to that you're not capable of feeding yourself, of washing yourself or of looking after, euthanasia I believe that's right."

"Not just because I'd rather die, I mean if you're suffering and you don't have a way of getting out of it…and it's terminal…"

Table 1: Characteristics of the sample in New Zealand (NZ) and Japan (J)

Variables	Item	NZ N(25)	NZ %	Japan N(25)	J %
Gender	male	9	36	9	36
	female	16	64	16	64
Source	Family	14	56	25	100
	Community and park	6	24	0	0
	Institution	5	20	0	0
Age	60-69	3	12	14	56
	70-79	10	40	10	40
	80-89	8	32	0	0
	90+	4	16	1	4
Living area	Urban	25	100	25	100
	Rural	0	0	0	0
Religion	Buddhism	0	0	10	40
	Dao	0	0	0	0
	I-Kuan Tao	0	0	0	0
	Folk religion	0	0	0	0
	Christian	23	92	8	32
	Catholic	1	4	0	0
	Shinto	0	0	1	4
	None	0	0	6	24
Marriage status	Single	0	0	2	8
	Married	11	42	18	72
	Widow	14	58	5	20
Living status	Alone	14	56	5	20
	With spouse	10	40	3	12
	With children	0	0	2	8
	With children &spouse	1	4	15	60
Number of children	0	0	0	3	12
	1	1	4	1	4
	2-4	22	88	21	84
	4+	2	8	0	0
Education background	None	1	4	0	0
	Primary school	5	20	0	0
	Middle school	-	-	2	8
	High school	16	64	14	56
	College and above	3	12	9	36
Health satisfaction	Good	18	72	13	52
	Not bad	5	20	9	36
	Not good	2	8	3	12
	Bad or poor	0	0	0	0
Frequency to visit a doctor	More than once a week	0	0	0	0
	1-4 times a month	1	4	8	32
	1-12times a year	22	88	4	16
	Less than once a year	2	8	9	36
	Other	0	0	4	16
ADL scale (Katz Basic Activities of Daily Living Scale)	6	22	88	23	92
	5	1	4	0	0
	4	2	8	1	4
	3	0	0	1	4
	2-0	0	0	0	0

Table 2: Comparisons on views on euthanasia between Japan and New Zealand

Reasons	**Seniors NZ**	**%**	**Seniors Japan**	**%**
N comments/ N respondents	25/25		25/25	
Agree	6	24	16	64
Almost Agree, but…	6	24	2	8
Do not agree	8	32	7	28
Not sure, depends, do not know what to do about it	5	20	0	0

"…people have something incurable and that their health is suffering to the extent it would be better they pass on. I think in quite a few cases, euthanasia should be right."

In addition to those six who "definitely approved", there were another 6 (24%) seniors who felt that euthanasia might be a good idea, but have some other concerns and do not agree with it a hundred percent. All of them expressed that it was a serious event and should be concerned more conservatively. They also have sensed the difficulties in manipulating euthanasia for human's death. They assert it would have to be well controlled and set a strict law to avoid abuse elderly or those who were frail. Within these six, some expressed their doubts to help or to be helped to die and some explained further that even if they are not opposed to it they still prefer to die naturally. For example:

"Ninety percent… I do believe in it. But I do believe it would have to be well controlled, to stop abuse."

"I agree with it to a certain extent but there would have to be some very strict controls, I think people shouldn't be made to suffer for years if they're never going to be better. I would say 60%...,

"Euthanasia is a very, very dicey subject, I mean. If there is absolutely no cure and people are in dreadful pain, yes, I think euthanasia is the answer. But you've got to be so careful about to make it legal, because there are very unscrupulous people in the world…."

"If there's absolutely no hope for a person, why let them suffer for so long…. But I'm afraid it could be dangerous, it could be that people…how do you put it…well its dangerous and it's a big decision and there are few cases that you really think people would be better off, very few I think I'd die a natural death"

"…if I was just living but I wasn't taking part in life, I would just like to be helped to die… I thought I did agree, but I wouldn't want anyone else to have to die…I couldn't ask anyone to do it for me and I couldn't do anybody in"

Eight of 25 (32%) expressed that they were against euthanasia. Most of them held a reason that pain can be controlled; medicine would help lots to relieve pain. According to them, euthanasia is too violent a way to just finish life, they preferred to die on their own and do not want any extra power involved. Some of them regarded people's suffering as part of their life experience, and thought people should be responsible to their life. One was very sure to state that what they approve of is" Natural death" to let go when there in no quality of life, but did not approve of euthanasia. Example comments included:

"…you can relieve the pain totally but not necessarily kill.. Euthanasia is more violent way to do some action to just finish it."

"I think they can control your pain…I think the big thing is, as long as your pain is controlled, it must make a big difference to you, mustn't it?"

"You can accept death easily if you're in pain and you wanted to die. But I don't think we should be helped to be out of this world. Just looked after…"

"I would not like anybody to take my life I would like to die on my own without any help."

"I think that's part of our life experience, I'm definitely against euthanasia. I think we should live our life out…."

"I think I lean more towards what I've done with the living world saying that if there is no possibility of having any quality of life, then stop the medication, let nature take its course. , that's natural death. I don't think I believe in euthanasia".

Five of these 25 seniors (20%) commented they are not sure and are wavering to decide what to do about it. One of the reasons is that they do not face the situation, and they haven't been in that situation to experience like a lot of people. Even though they were not against euthanasia, one of the interviewees stated that she preferred not to put this on his child to make him in a conflict situation and thought that

it was awful to ask his family to face something like that. They concluded that when it comes to them they do not know what to do and this is a very hard decision to make for everyone.

Compared to New Zealand, there are more seniors who approved of euthanasia in Japan (64%). Most of them held a reason that it is good for everyone if it is impossible to get better. In the mean time, they talked about other benefits like saving national resources, releasing the burden of families and removing suffering. Many of them stated that having tubes connected to machines to prolong life is the most terrible thing, it is for sure worse than death. Euthanasia then would be a good thing if only it was decided by patient him/herself. However, many of them defined Euthanasia as to stop the medical treatments or let go the end of life. Only one could clearly distinguish natural death and euthanasia, he said: *"I would emphasize how to release from suffering. Natural death is nice but somehow it is too pain, you just cannot help it but to choose Euthanasia…."*

Similar to New Zealand, in addition to those who "definitely approved", there were another two comments which agree with euthanasia in certain conditions, but they have some other concerns like the feeling of families and the spirit condition of patients. For example:

"If it suffers too much, why not? To relieve is the most important. Nevertheless, my concern is how to cope with family's doubts and emotion? We got to think about the feeling of the families."

Seven of 25 (28%) expressed that they do not approve of euthanasia. None of them mentioned about the practical reason that medicine can help a lot to relieve pain. They focus on the sanctity of life to say that your longevity is a destiny; life should be ended by natural and their feeling of "killing". For example:

"I do not feel well to hear the word Euthanasia; I cannot stop the feeling of murder…."

"I just don't want to be killed by an injection; it is awful to think about that…No, I don't agree…"

"No, just because this is human's longevity (has been decided), …"

"It is better to pass away by nature, Euthanasia is against natural, I don't like it so much."

"It is no necessary to force human die in this way, human will die anyway if his time is up."

None of the seniors we interviewed had uncertainty towards this subject. One thing for sure is they were concerned that they do not want to be put on the machine to prolong their end of life. Euthanasia or Natural death has relieved the anxiety of it that would be accepted easily.

4. Discussion

During the sampling period that the interviews were conducted in New Zealand, there were debates about making euthanasia legal in New Zealand. The private member's parliamentary bill failed in its first reading to proceed to discussion that could have led to legislation; however, deliberate discussions about euthanasia in the public have made citizens improve their maturity to consider this issue thoroughly.

Probably because of the fully discussion through the media during the legislation period, most of seniors we interviewed in New Zealand were very familiar with the subject of euthanasia. They probably cannot imagine all the details of every possible situation of the future death, however at least they have a brief view of the pros and cons over euthanasia and had started to think about what is their wish for their end of life.

Among these seniors, they said they would have different choices between yes or no if we asked them to vote on euthanasia, but there was not only discrepancy in ideas but also diverse concepts can be found over this difficult topic. Whether to approve or not, all of them had a very positive attitude to value human life even in the very difficult stages towards the end of life. What they were most concerned about was if people are in dreadful suffering, can they come out of it? If pain can be controlled only by medical service, that is one solution. Thus the percentages who say yes or no among seniors is not the key point to explain their attitude toward death. Instead, some points of views about euthanasia are worthy to put emphasis on to recognize the context of seniors' preference for their end of life.

First, pain is the key concern, not old age or disability. Many seniors considered euthanasia only for the situation of terrible pain, any other situation especially like very old age, irreversible condition or even "lying there and waiting too long" should not be a reason. To be in pain or not makes a big difference, which many have set as a margin of whether to do or not to do euthanasia. Seniors we interviewed, moreover, stated that they realized that if an old man gets to be bedridden, he might get so tired and fed up with being the way he is (declining, disabled and being a burden of others), it would be possible for him to ask for help to finish life. While, most seniors commented that even if

you can accept death easily and want to die, it does not means you should be helped to be out of the world. "*It is harmful to put your death on to somebody else; you have to think about your family.*"

Some of them approved of euthanasia because of the experience from their families. For example one old lady said *"I heard my mother crying to die with cancer, I hate to see that happening to anybody, so I am all for Euthanasia, if they are in dreadful pain and want to die."* Another said *"I saw my father… and that was enough for me. He's only one of thousands…."*

None of them complained of the situation of their very old age and wanted to die because of old age. They asserted that life is a kind of responsibility, suffering and aging are part of their life experience; people would adjust finally, old and frail, and died of old age naturally.

Strict control may be essential to avoid abuse among the elderly, with either a well disciplined medical profession and guidelines, or legal provisions. Most people would agree that instead of killing the patient to relieve suffering, medicine should made efforts to relieve those in dreadful pain. In New Zealand most patients are able to self-administer morphine to suit the needs for pain control, thus pain control as part of palliative medicine has been given a major role in treatment of terminal illness. Even the result of national survey in New Zealand suggests that palliative care did not meet patients' need and the intent to hasten death does not seem to be a consequence of the non-availability of palliative care (Mitchell & Owens, 2003). While this study shows the availability of aggressive palliative care for the elderly is one determining factor for the attitudes towards euthanasia, since those seniors who stated they were against euthanasia were holding a reason that pain can be controlled and medicine should make the patient feel better.

"Hastening death" and "double effect euthanasia" are welcomed and more easily to be accepted. Regarding the violence of aggressive euthanasia, many elderly preferred to "just give morphine to help the dying along". People feel ease if an action is just under the intention to relieve the pain and not to kill. They believe it exists in hospital and do not feel anything wrong with it, for example one person in their idea of euthanasia said: "*Hospitals are busy, and if someone is in actual pain and helplessly dying, they can just give him a little more morphine to help him along. I don't think there is anything wrong with that."*

Again, pain is an important concern that people can be allowed to deal with it with all efforts; even though it might harm the biological life and hasten their death. For the very sick and suffering patients, the intention to relieve pain would always find its proper place as something that most seniors approved of, to allow death rather than intend to end life in a very struggling condition.

According to the opinion of many seniors, we can understand most seniors do not mind to hasten their death because of the intention to relieve pain. However, other than this, there were some other opinions, for example "I would ask for food to be stopped and drink to be stopped then let me just go and not terminate my life" or "I would just like to be helped to die in a certain state if I was just leaving but I wasn't taking part in life…"etc.. Which makes us consider that the ideas "not prolonging", "hasten death" and "to end life under the name of mercy" can be differentiated by ordinary people like the seniors interviewed here when they were asked to make decisions for their end of life care. Can they make up their mind firmly and express their personal ideas well enough so that the health profession can catch their real intention and follow their instructions with no misinterpretation? Can we find a way to encourage seniors to leave a reliable will during their adult life with good mental function and guarantee that their wishes and preference for their end of life medicine and death management can be accomplished when time is come?

To give mercy is not easy at all in practice. Although most people really think there are few cases that would be better to be helped to off the world, but for themselves they prefer not, and feel awful to put their family in the difficult situation to have to consider such a procedure or end. They supposed that to ask their family member or anyone to do that is unfair. Also, as one person stated *"I could never help a person to die, but I probably could help myself."* Since they couldn't ask anyone to do it for them and couldn't *"do anybody in"*. The doctor, having a professional image involved in decisions relating to human's life and death, and the power to prescribe drugs, could thus be regarded as the appropriate, and most available, person to do so. It sounds reasonable as one said she wouldn't mind asking her doctor because she is not related to him. Nevertheless, as a matter of fact,

it is a great imposition of one person upon another to ask them to help terminate their life. As a doctor, he might feel that if it is mercy to give, why restrict its performance only to doctor? As Dr. Tan coded from Shakespeare's in his article *"Why I do not believe in Mercy-Killing", "Mercy is twice blessed; it bless him that give, and him that takes?"*(Tan, 1996). People approve of euthanasia to be merciful and a right thing to protect human dignity. Then why do they protect their loved one from doing it or facing this confused situation? There must have many doubts about its rightness and goodness. To be merciful is not easy and to benefit patients cannot give a full reason to perform mercy like euthanasia. We can see it very clearly from the opinions of seniors in New Zealand.

In general, euthanasia is accepted to be applied only when people can speak of unbearable and hopeless suffering. Thus, the request of a dying patient is the prerequisite to make euthanasia put in practice. Voluntary euthanasia should exclude the personal emotion of depression, feeling of worthlessness, guilty, anger and confusion. Gathering the opinions of elderly people in their ordinary and healthy days can provide reliable information which is the most reasonable to protect a right to die rather than imposing a duty to die.

Compared to New Zealand, there were more seniors who approved of euthanasia in Japan and held a reason that it is good for everyone. The benefits would be, for example, saving national resources, releasing the burden of families and eliminating the suffering of the patients. Again, many respondents stated that having tubes connected to a machine to prolong life is the most terrible thing, it is for sure worse than death. However, many of them defined euthanasia as to stop the medical treatments or let go the end of life. According to the studies, Japanese doctors were affirmative for life-sustaining treatment (Asai, Fukuhara, & Lo, 1995), and tend to adhere to the principle of prolonging life when their patient has not directly expressed his or her will (Akabayashi, 2002). Because of these, Japanese seniors might have much worry being treated in a wrong way when dying. To express their approval of euthanasia might be just a way to mitigate their worry.

Different from New Zealand, there was no wavering comments or uncertain talks about euthanasia in the Japanese group. This might confirm that the in-depth thinking of benefit and risk on this subject are not sufficient in seniors group of Japan compared to New Zealand. As Shinagawa (2000) said in his book of *Tradition, Ethics and Medicine in Japan*, "*Curiously enough, virtually almost no formal discussion has even taken place in Japan on euthanasia, mercy killing, death with dignity, "do not resuscitate" order and so on*." In spite that the situation is taboo to discuss these issues in Japan, the unitary concern of not encumbering another and keeping an intact dignity of elderly life might have predominated their attitude towards euthanasia. It showed that in this moment, Japanese society was not ready to be concerned seriously about the necessity of legislation on euthanasia, regardless of the fact that Japan has the world's longest life expectancy.

5. Conclusion

Compared to New Zealand, seniors of Japanese hold an idealistic thinking in facing the ethical issues of euthanasia. In the non-approving group, none of them mentioned about the practical reason that medicine can help a lot to relieve pain. They focus on the imperative that "life is sanctity" and "do not kill". Those who approved of euthanasia sometimes included a dramatic thinking towards it since the meaning of the words "Anrakushi" (euthanasia in Japanese) has inferred a meaning of "peaceful and happily death" and gave a image that euthanasia accorded with a "perfect" human death. The finding of the interviews is consistent with the view point of Lock (1995) that Japanese's concept of euthanasia is mixed with the concept of natural death, so it may be of the utmost priority to differentiate between euthanasia and natural death to the public that we can explore the real judgement of "Mercy Killing".

Different from Japan, seniors in New Zealand who stated they were against euthanasia were holding a practical reason that pain can be controlled and medicine should make the patient feel better. The availability of effective pain management or palliative care service is the main concern for elderly in their end-of-life. If the modern medicine can guarantee a pain-free end-of-life, then euthanasia should never be an option for the elderly to accomplish the wish of dying with dignity. The only question left is first how seniors can differentiate between "not prolonging" and "to end life under the name of mercy", and then to make up their mind firmly and express their personal ideas well enough so that the health profession can catch their real intention and follow their instructions with no misinterpretation?

6. References

Akabayashi, A. (2002). Euthanasia, assisted suicide, and cessation of life support: Japan's policy, law, and an analysis of whistle blowing in two recent mercy killing cases. *Soc Sci Med, 55*(4), 517-527.

Asai, A., Fukuhara, S., & Lo, B. (1995). Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet, 346*(8971), 356-359.

Hoshino, K. (1993). Euthanasia: current problems in Japan. *Camb Q Healthc Ethics, 2*(1), 45-47.

Hoshino, K. (1996). Euthanasia in Japan: update (CQ Vol 2, No 1) by Kazumasa Hoshino. *Camb Q Healthcare Ethics, 5*(1), 144.

Lock, M. 1995. "Contesting the natural in Japan: Moral dilemmas and technologies of dying", *Culture, Medicine and Psychiatry* 19:1-38.

Macer, D. R. J. "Japanese Bioethics" pp321-337 in Peppin, J.F. et al., eds., *The annuals of Bioethics Regional Perspectives in Bioethics.* Swets &Zeitlinger; 2003

Mitchell, K. (2004). Physician commitment in end of life care--perspectives from New Zealand and the Netherlands. *Soc Sci Med, 59*(4), 775-785.

Mitchell, K., & Owens, G. (2004). End of life decision-making by New Zealand general practitioners: a national survey. *N Z Med J, 117*(1196), U934.

Mitchell, K., & Owens, R. G. (2003). National survey of medical decisions at end of life made by New Zealand general practitioners. *Bmj, 327*(7408), 202-203.

Shinagawa, S. *Tradition, ethics and medicine in Japan*. Berlin: Humanitas Verlag; 2000.

Tan, S. Y. (1996). Why I do not believe in mercy-killing. *Hawaii Med J, 55*(12), 273, 303.

Considerations about Termination of Pregnancy in Portugal: Seven Answers to Seven Questions

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Abstract

Regarding abortion there is a great deal of controversy going on in Portugal. Unlike the other European countries, the exception being Cyprus, Poland, Spain and Ireland abortion or voluntary termination of pregnancy is illegal in Portugal. The authors focus on seven questions and related answers, which are a matter of debate at the Portuguese Parliament in the threshold of a referendum to be carried on viewing the public poles about such a delicate problem.

1 - What's the Actual Juridical Regime of Abortion In Portugal?

Abortion or voluntary termination of pregnancy is defined by the Penal Code as crime against intra-uterine life (articles 140º and 141º). The Penal Code also states the situations when it is admissible (article 142º). The person that performs the abortion is faced with a prison penalty of 2 to 8 years (if against her will, articles 140º/nº1) or a up to 3 years (if according to her will, article 140º/nº2). The limits of the penalty are increased in one third when the abortion or the means utilized result in dead or offense to the physical integrity of the pregnant women and when the agent is involved in frequent practice of abortion or performs it with intention of profit (article 141º/nºs 1 and 2). The pregnant woman that carries out an abortion is punished with a prison penalty up to 3 years (article 141º/nº3). The people who whelp her (friends, family or others) may be judged for complicity (article 27º). If the sentence applies a prison penalty inferior to 6 months it is replaced by a fine or other penalty not affecting freedom (artº 44º). Abortion is a public crime; so the judicial procedure does no depend on previous denunciation.

Abortion is not punished when (causes of exclusion of illegality– article 142º) it is performed by a physician or under his orientation, in an official health establishment or officially recognized, with the consent of the pregnant women, in the following situations:

a) If it is the only mean to remove danger of death or serious and irreversible lesion to the body or to physical or mental health of the pregnant women or if the fetus in unviable – there is no limit to time of pregnancy.

b) If it is shown that is the best method to avoid danger of death or serious and lasting lesion of the body or of the physical and mental health of the pregnant women and it is performed in the first 12 weeks of pregnancy.

c) If there are strong motives to believe that the newborn will suffer, in an incurable way, from serious disease or congenital malformation (eugenic abortion) and it is performed in the first 24 weeks of pregnancy.

d) If the pregnancy results from crime against freedom or sexual auto determination (for example, rape) and the termination of pregnancy is performed in the first 16 weeks.

2 – Is Portugal Included in the Countries with More Restrictive Legislation?

The laws concerning termination of pregnancy are very restrictive in Cyprus, Poland, Spain, Portugal and Ireland. In a general matter, abortion is permitted only in cases of violation, malformations of the fetus and protection of the physical or mental health of the woman. Ireland is the only country in the EU (European Union) where abortion is, in the face of law, forbidden in any circumstance. In 1992, Ireland signed the Maastrict Treaty and received guaranties that the restrictive laws in abortion matters would not be affected. Portugal does not contemplate economic and social reasons as cause to terminate pregnancy, contrary to the majority of other European countries and the interpretation of the law by the medical services is too restrictive, justifying the low number of abortions performed under the law.

3- What are the Differences in the Application of the Portuguese and Spanish Penal Laws?

The Spanish penal law is very similar to the Portuguese law, and was in fact based on it. Nonetheless, the Spanish law as some more restrictive aspects, for example, the stated periods to eugenic abortion, 22 weeks, and to abortion in sequence of rape, 12 weeks. In spite of the more restrictive interpretation of the law by the public services, private clinics perform the large majority of pregnancy terminations in Spain (about 97% of the abortions take place in private clinics). The Spanish law does not punish the women that carry out a clandestine abortion in the cases when is practiced by the motives permitted (by law), however the physicians, mid-wives and others are punished. Since February 2000, Spain authorized the utilization of the abortive pill in the public health services permitting the fastening of attendance in those services. The accreditation of the private health services to the practice of pregnancy termination and the exigencies necessary (specialists, facilities, medical practices, etc.) are predicted in the law.

4- What are the Recent International Recommendations Concerning Abortion?

Several entities, including the UN (United Nations Organization), the WHO (World Health Organization), the United Nations Fund for the Population (UNPF, the European Parliament and the International Association for Family Planning have alerted to the consequences of clandestine abortion in women's health. CEDAW (Committee of the Nations for the Elimination of Discrimination Against Women) in January 2002 recommended to Portugal:

"The Committee is worried with the restrictive abortion laws in Portugal, in particular because clandestine abortions have serious negative impact in the women's health and in their well-being." The Committee recommends that the state member (Portugal) facilitate the national dialog about reproductive health in women, including the restrictive laws on abortion. It also asks the Government to promote the improvement of the family planning services, permitting the access to all women and men, including adolescents and youth. The committee asks the state member to include information about deaths and/ or related diseases in consequence of clandestine abortion."

The European Parliament approved, in July 2003, a resolution about rights in the matter of sexual and reproductive health, from which we enhance: "We recommend that in order to protect the reproductive health and the rights of women, the voluntary termination of pregnancy should be legal, safe and universally accessible." We recommend the governments of the State members and those of the countries candidates to join, to abstain, in all circumstances, to act judicially against women that performed illegal abortions."

5 –Are there Statistics Concerning Abortion in Portugal ?

In Portugal, the legal termination of pregnancy is a residual margin in the universe of pregnancy terminations. Women continue to perform illegal abortions in private clinics and doctor offices (sometimes in other places with no conditions, like garages) and auto-abortion with the use of Cytotec (a medication for stomach problems). It is estimated that, in each year, about 20,000 to 40,000 clandestine abortions take place in Portugal, 5,000 women being hospitalized in consequence of

complications and 15 dying. It is estimated that one in every four Portuguese women did a clandestine abortion (our population is under 10 million). In young women between fifteen and nineteen years old, one in 200 did an abortion and in the young adults aged nineteen the proportion rises to 5% (one in 50). In the last six years approximately 9,000 women went to Spain to abort in private clinics.

In 2002, according to official data, 11,000 women had hospital urgencies and 5 died in consequence of abortion. The police authorities investigated 49 cases of abortion in 1998 and 1999 and 23 cases in 2000. In 1998/1999 eight persons were convicted. In 2002, in a trial nationally and internationally followed, 17 women were judged for abortion and one was condemned.

In the decade of 84/94 the hospitals performed 716 legal abortions and received 730 cases of complications of illegal abortions!! For the same decade, 46 deaths of women victim of clandestine abortion were reported. A study conducted in 1999 in the Portuguese district hospitals (by the Association for the Family Planning) concluded that the majority of the hospitals conducts less than ten voluntary terminations of pregnancy per year and that the principal cause is the fetal malformation or disease (65-70%). The same study reports a low number of pregnancy terminations related to the physical or psychological health of the pregnant woman (21%) showing that the interpretation of the law is very strict, namely in the case of psychological health. The same study also concluded that the hospitals don't maintain statistics about the number of attendances in consequence of clandestine abortions.

A paper published in 2004 (by ISEG – Superior Institute of Economy and Management) concluded that are still "no data about the reality of abortion in Portugal", "the number of clandestine abortions remains incognito" and that "there are various figures pointed out but the truth is that there are no feasible studies to national level that reveal with rigor the reality of abortion in Portugal".

6 – What are the Consequences of the Referendum that took place in 1998?

In June 1998 Portugal held a referendum about abortion, approved by the Assembly of the Republic in consequence of accordance between the two larger Parties of the Left and Right Wing (PS – Socialist Party and PSD – Social Democratic Party). The question was: "Do you agree with the legalization of voluntary termination of pregnancy, if done by option (of the woman) in the first 10 weeks, in a legalized health establishment?". Half, 50.9% voted against the law and 49.1% in favor. The referendum was not validated because only 31.9% of the electors voted (to be validated more than half of the electors had to vote - Law nº15-A/98, April 3). Consequently, the Assembly can now decide for a new referendum or wait for a project of law (concerning legalization of abortion) to be subject to approval. For a referendum to take place a proposal with more than 75 000 electors' signatures must be delivered to the Assembly of the Republic (AR), the competent Committee and ultimately the President have to accept the proposal and finally the AR has to appreciate and vote it. If it is approved the President submits it to the Constitutional Court and if accepted the President has the final decision to the realization of the referendum.

7 – What is the Present Political Scenario around Voluntary Termination of Pregnancy?

The present government (now in the hands of PS) wants to convoke a new referendum. The proposal to the Assembly was delivered in April 2005 being supported by the other left wing parties (PCP – Portuguese Communist Party, BE - Left Block and PEV – Green Ecologist Party). The President Sampaio is personally favorable to the evolution of the law. However, the decision of the President, known in May, was against the referendum, not for political reasons but because the referendum (legally) would have to take place in a Sunday in the month of July, month of holidays for many Portuguese. He considered that "minimal conditions to a significant participation of the Portuguese were not gathered". A survey conducted in April 2005, revealed right after the position of the President, indicates that 54,3% of the Portuguese are in favor of the legalization of abortion, against 28,6% that make the "No" option. The other 16% didn't have an opinion or did not wanted to answer.

There were different reactions to the President decision: PCP defends that the left wing majority permits the approval of the legalization of abortion in the Assembly without the necessity of a new referendum. Probably the PCP will be against a new proposal to public consultation. In face of the decision of the President the BE also defends the approval of the law in the Parliament. The PSD and CDS-PP (Popular Party), both right wing parties, approved the decision of the President because they

consider that it is not a priority question in face of other political questions. The Government promised that it would bring back the question about the presentation of a new proposal to a referendum, but the PSD (major opposition party) and CDS-PP were against the referendum before the end of 2005, proposing it to the spring of 2006, after the presidential elections.

Conclusions

Regarding Portugal and up to this date, abortion is considered a crime according to the Portuguese penal code. Abortion may not be punished if it proves to be the only means to avoid irreversible lesions of the fetus or the physical or mental health of the pregnant woman.

Statistics have proved that in the countries that waived abortion penalty abortion rate as not raised. The risks of abortion without the surveillance of health professionals may be severe. The referendum may not be the best way to tackle such a delicate situation. The Government however, through the Members of Parliament should endeavor such difficult task by issuing the right legislation. According to the questions in the present article one may anticipate that the addressed Parliament debate, although not meeting the consensus of the different parties, will prove to be righteous in introducing the necessary changes in the present legislation.

From Human Rights to Patient Rights

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Abstract

Right is an authority given and protected by law. Human rights, highlighted with French Human Rights in 1791, were promulgated in Turkey during the Ottoman Empire with the Gulhane Royal Edict (Gulhane Hatti Humayunu) in 1839, the Reform Edict (Islahat Fermani) in 1856 and the Royal Constitution (Kanun-i Esasi) between 1876 and 1878. In the Republican period, human rights were assessed parallel to patient rights. In the West, Thomas Percival introduced ethical rules in modern medicine in his book, "Medical Ethics" in 1803. The international patient rights declaration, the Lisbon Declaration, was published in 1981. "The Medical Deontology Regulation" promulgated in Turkey in 1960 mentioned patient rights in its 4th, 5th, 6th and 14th articles. The subject was again exclusively dealt with in the Patient Rights Regulation promulgated in 1998.

A right is acknowledged and protected by law. The wide variety of interests, under the protection of law, indicates the existence a variety of rights such as rights of creditors, rights of being, right to own property, right to vote etc. The protection of rights by private law is called *private rights* whereas their protection by public law is called *public rights* (9). The rights to vote and to be voted, to propagandise for a line of ideology, to participate in meetings etc. are assessed amongst private law. On the other hand, the basic rights of individuals are dealt within Constitutional law (12). The most fundamental human right is the right to survive since the violation of the right leaves the other rights null and void.

The first written rules regarding human rights are the French Human Rights Declaration in 1789. According to the 16 article declaration:

Article 1 - All men are born and remain free and equal in rights. The social distinctions can be founded only on the common utility.

Article 2 - The aim of any political association is the conservation of the natural and imprescriptible rights of the man. These rights are freedom, the property, safety and resistance to oppression.

Article 3 - The principle of any sovereignty lies primarily in the Nation. No body, no individual cannot exert authority, which does not emanate from it expressly.

Article 4 - Freedom consists in being able to do all that does not harm others: thus, the exercise of the natural rights of each man has terminals only those which ensure the other members of the company the pleasure of these same rights. These terminals can be given only by the law.

Article 5 - The law has the right to defend only the harmful shares of the company. All that is not defended by the law cannot be prevented.

Article 6 - The law is the expression of the general will. All the citizens have right to contribute personally or by their representatives to his formation.

Article 7 - No man can be marked, be stopped or held that in the cases determined by the law and according to forms' which it prescribed.

Article 8 - The law should establish only sorrows strictly and obviously necessary and no one can be punished only under the terms of one law established and promulgated before with the offence, and legally applied.

Article 9 - Any man being supposed innocent until be was declared guilty, if it is considered it essential to stop him, any rigour which would not be necessary to be ensured of its person must severely be repressed by the law.

Article 10 - No one should not be worried for his opinions, religion, provided that their demonstration does not disturb the law and order established by the law.
Article 11 - The free communication of the thoughts and the opinions is one of the most invaluable rights of the man; any citizen can thus speak, write, print freely, except answering of the abuse this freedom in the cases determined by the law.
Article 12 - The guarantee of the humans right and of the citizen requires a police force; this force is thus instituted for the advantage of all, and not for the particular utility of those to which it is entrusted.
Article 13 - For the conversation of the police force, and for the expenditure of administration, a common contribution is essential; it must be also distributed between the citizens, because of their faculties.
Article 14 - The citizens have the right to note, by themselves or their representatives, the need for the public contribution, to agree it voluntarily, to follow employment of it, and to determine of it the share, the balance, covering and the duration.
Article 15 - The company has the right to request account from any public agent of its administration.
Article 16 - Any company in which the guarantee of the rights is not assured nor the determined separation of the capacities, does not have a Constitution.
Article 17 - The property being a foolproof and crowned right, no one cannot be private from it, if it is not when public need, legally noted, requires it obviously, and under the condition of a Just and preliminary allowance.

The cry for human rights with the French Human Rights Declaration was echoed in different times and countries in the world. Human rights were handled in the Ottoman Empire on various occasions such as the *Gulhane Royal Edict* (*Gulhane Hatti Humayunu*) in 1839, the *Reform Edict* (*Islahat Fermani*) in 1856 and the *Royal Constitution* (*Kanuni Esasi*) between 1876 and 1878. The chronological order of these activities is as follows:

1. 1839 Gulhane Royal Edict Principles

The fundamental laws constituting the backbone of running the state are the protection of right to survive, to lead a honorary life and to own property.

2. 1856 Reform Edict Principles

- The freedom to adopt any religion and a sect within the religion is secured. The people of different nationalities living in the Ottoman land have the right to be state officials regardless of their gender and religious background.
- Convention of the Supreme Assembly
- No one in the Ottoman Empire will be forced not to perform his or her religious obligations or to adopt a different religion.
- Tax is to be equally distributed among the members of the society.

3. The Articles of the 1876-78 Constitution

- All the Ottoman people have their individual rights and are bound by law not to violate others' rights.
- All the Ottoman people are equal before law and they are also equal according to their religions and religious obligations.
- For the first time, a new type of management, parliament is established.
- No citizen shall receive punishment for any other reason or outside the framework of law.
- The religion of state is Islam. All religions in the Ottoman land can be freely adopted and their obligations can be freely performed.
- Tax cannot be collected or distributed without an article of law ordering it.
- The budget shall be discussed and determined in the Parliament.
- Not a single article of the Constitution (*Kanuni Esasi*) can be violated or omitted.

The subject of human rights was placed exclusively on the agenda of the world as a matter of discussion following the establishment of Nurnberg War Tribunal after the World War II. The discussions have not come to an end yet and they seem to continue to be on the agenda of the world. The Universal Declaration of Human Rights (1948) and its European version, European Convention to Protect Human Rights and Basic Freedoms (1954), and similar regional documents in America and Africa can be assessed as other examples in this regard (8).

Although, as a universal concept, human rights is protected and tried to be applied in real life situations over declarations, announcements, agreements and articles of law, the violations seem to prevail with growing pace, and unfortunately the data at hand indicates that the situation gets worse everyday. Since it is obvious that the problem can only be solved through education, regarding courses are scheduled in course programmes of various schools. The first course about human rights in medicine was initiated at Harvard University in 1991-92, and it was repeated in the 1994-95 period. Similar courses were scheduled afterwards at John Hopkins in 1993, at California University, Yale University and Boston University in 1994. In a research conducted in the US in 1996,

the importance paid to the subject of human rights was researched in post-graduate public health courses, and some suggestions were put forth in this regard. In an article published in the "Health and Human Rights" magazine, the research results as to whether 28 public health schools in the US and 15 other schools scheduling public health courses as MBA programmes were scheduling "human rights" courses. Thus, the schedules of these schools were scrutinised in detail, besides public health programmes of other 34 countries were studied. While 5 out of 28 schools stated that they scheduled "Human Rights and Health" courses; the rest declared that they lacked these courses (1).

Two Sample Health and Human Rights Courses:
The School of Public Health, Boston University
Title of the Course: *Health and Human Rights*
Scheduled by: *Department of Medical Law*
Main Subjects: *Human Rights Philosophy in Health, Human Rights Law, Health and Rights, Risqué, Human Rights and Public Health Applications, Women Health and Human Rights, Health and Human Rights in Times of War, AIDS and Human Rights, Experiment on Human Beings, Doctor's Stand Against Human Rights Violations, Sanctions, Non-governmental Organisations and Human Rights.*

The School of Public Health, Harvard University
Title of the Course: *Health and Human Rights*
Scheduled by: *Department of International Health and Population*
Main Subjects: *Part 1: Introduction to Human Rights, History of Human Rights, Law of Human Rights, Relevant Institutions, Monitoring, Sanction, Universalism and Relativity, Responsibilities and Restrictions in Rights.*

Patient rights means in a way the application of human rights in medical services and it takes its reference directly from basic documents regarding the human rights. Fundamental human rights such as determining the way to lead a life, leading a secure life, receiving respect from others as a human being, showing respect to others, etc., constitutes the core of patient rights. After it was determined that the basic rights which can be taken under the protection of law within the framework of the legal system were the right to be autonomous and the right to determine one's own way of life, the legal structure of patient rights, that is the relation between patient and doctor which is mainly conducted in line with ethics and defined with trust, was defined again. In fact, the principle of equally remains incomplete when it is defined within the framework of trust relationship, which is a situation that can only be overcome with the internalisation of the principle of equality.

The main objection to be followed in re-defining patient rights within modern law and placing them under the protection of law is to set a ground where patients can actively and equally participate in their relations with the doctor. To determine the legal framework of patient rights we should take into consideration the national law, which includes approximately 47 law articles, 16 regulations and 10 statutes as a medical work of legislation. There are some problems regarding the legal framework of relations between the patient and doctor in effectively applying patient rights, in drawing the lines of legal responsibility of the doctor, and active application of rights by the patient. In fact, in determining the framework of doctor's legal and penal responsibility the effective application of patient rights is regarded as a criterion (5).

The History of Patient Rights

Patient rights follow almost the same historical pattern with individual rights. Individual rights are the rights which separate the person from other members of the society, and they can only be used by the specific person. The development of these rights brought about important and new aspects to the doctor-patient relationship. Previously, the doctor applied the traditional way which we label as paternalistic behaviour or manner where, under the guidance of scientific facts and researches, he conducted the treatment and diagnosis by him/herself. The traditional way leaves aside informing the patient about the quality of medical application, side effects, development, alternatives etc. and other demands from the patient are not taken into consideration. When the nature of relationship is concerned, it seems that the only individual the patient can claim his/her right is the doctor. The ethical aspect of doctor-patient relationship has been thought to be the "responsibility of the doctor" since the time of Hippocrates until the last 25-30 years. Consequently, within the axis of responsibilities and rights, patient rights have been neglected (2).

The responsibility of doctor, as to its historical dimension, dates back to ancient times. In pre-historic and ancient times, generally magicians and

religious men were busy with medicine, and they prepared drugs using hashish and performing sorcery to treat patients. As a part of these activities, it was a generally accepted principle that in times of wrong-doing or not being able to cure patients the religious men conducting medicine were not deemed responsible for their deeds. On the other hand, it was also clear that in times of making obvious mistakes the doctor could not benefit from a state of absolute non-punishment. Some documents surviving from ancient times mention the art or treatment and the rules regarding the responsibilities of doctors in Babel, Sumerian, Hittite, and Ancient India. These rules can also be found at written documents such as the Hammurabi Rules (1800-1750 BC) of the Mesopotamian Civilisation. While famous thinkers such as Hippocrates (470-399 BC), and Aristotle (384-322 BC) defended the view that the doctor should be held responsible for wrong-doings, Plato (428-348 BC), on the other hand, defended the opposite suggesting that the doctor should have immunity in times of wrong-doing (7).

There are examples indicating that in ancient times the doctor was held responsible for his deeds when he avoided paying his patients appropriate attention, or neglected them. The most striking example in this regard belongs to Alexander the Great (356-333 BC). Alexander the Great sentenced the doctor to death for being responsible for his lover's death due to negligence. In addition to many books about medicine, the famous thinkers of the Islam world such as Ar-Razi (854-932), Farabi (870-950), Biruni (973-1051) and Ibn Sina (980-1037) wrote books and thoughts dealing with medical ethics. In the Seljukian and Ottoman periods, medical ethics held the doctor responsible against his conscience.

The following is a dialogue, which took place between A. Pare, a renowned surgeon of his time, and Charles IX:

During the Ruen Siege the King asks:

- I hope you will treat your king better than a poor citizen.

- No your majesty. I beg your pardon but that is impossible.

- Why is that?

- Because I treat a poor citizen like s/he is a king.

In the West, on the other hand, the foundation of codes of modern medical ethics was laid by Thomas Percival. His views were published under the title "Medical Ethics". The Medical Academy of Paris adopted the view in 1829 that the doctor conducting treatment in line with his/her own limits of conscience should not be held responsible for his deeds. American Medical Associations accepted in a meeting in Philadelphia in 1874 the medical ethics, and demanded the application of them during medical education. The French Deontology Law was regulated positively with written principles and published in the official gazette (6). The doctor-patient relationship, which is dealt with within the framework of "the responsibility of doctor" in its historical dimension, has changed in a way that enabled the patient to claim his/her rights not only from the doctor, but also from all members working in medical field. The trend, which even leaves out the responsibility of doctors and other members of medicine, regards today the hospital as the responsible institution. Consequently, not only doctors or medical workers, but also executives have crucial responsibilities in securing patient rights (3).

As a concept patient rights is a completely new subject in our country. Thus, doctors are not quite knowledgeable about it, which brings along a limited level of interest. When public interest is concerned, there is nothing much to mention; patient rights are put on the agenda when patients suffering from a wrongdoing are covered by mass-media channels.

In Turkey patient rights, as a concept, are handled within the framework of health-care rights. Although patient rights and health-care rights seem to be close to each other, they are completely different concepts. Patient rights originates from the relationship between the doctor-patient and hospital whereas health-care right from state and individual (4).

The rights of patients are stated in the Constitution of 1982 (17/2) as follows: "Except for medical necessities and rights stated in codes of law, the integrity of an individual's body cannot be touched, and cannot be exposed to scientific and medical experiments without the individual's consent." and the realisation of health-care right is given as a responsibility to the state.

"Patient Rights Regulations", promulgated in 1998, are the most important achievement in Turkey when human rights is concerned. Due to bearing the phrase "patient rights" in its title, every subject placed in the regulations should be accepted as patient rights and applied in real life situations. The first article of regulations mentions the general approach regarding the concept of patient rights. The first article is as follows: The regulation was

prepared in order to enable every individual to benefit from "patient rights" which are the reflection of human rights and are mentioned initially in the Constitution of Turkey and in various international legal documents and agreements, to be protected against violations of rights and to use legal channels in the event of any violation, in a way that protects human dignity." On the other hand, Article 48 puts forth an important aspect as to application.

The regulation bears the underlying reason to make every relevant individual aware of patient rights. It requires the preparation of leaflets and information boards, which include proper and complete information about subjects in medical institutions. It is stipulated in Article 48 that all official executives in medical institutions are responsible for placing the patient rights as a list on an open environment allowing easy access to patients, the personnel of institutions, and visitors, aiming at being helpful in realising the basic principles of patient rights.

The 4th, 5th, 6th and 14th articles of the "Medical Deontology Regulation", which has been in force since 1960, has many aspects in common with the 1st, 2nd, and 4th articles of the Lisbon Declaration, a declaration issued by the World Medical Association in 1981. The articles mentioned in the Medical Deontology Regulation 21 years before the international patient rights declaration can be regarded as the importance given to patient rights in Turkey.

Bibliography

1. Amato,Z.: Toplum ve Hekim C.11 Sayı 75-756,1996p.115-116
2. Aydın,E..: Tıp Etiğine Giriş, Öncü Basımevi, Ankara 2001 p.115-129
4. Aydın,E.: a.e.g p.126
5. Balkır,G.: Hasta Haklarının Yasal Boyutları I.Uluslararası Tıbbi Etik Kongresi Bildiriler Kitabı, Ed: N.Ersoy. ,Ü.N. Gündoğmuş, Kocaeli, 1999 p.11-16
6. Başağaoğlu,İ.: Adliyeye İntikal Eden Tıp Deontolojisine ait Vakaların Hukuki ve Deontolojik Yönlerinin Değerlendirilmesii.Yayınlanmamış Doktora Tezi, İstanbul, 1988 s.25
7. Başağaoğlu,İ.: İstanbul Tabip Odasına İntikal Eden Etik Sorunlar. Medikal Etiik 2 (İlkeler ve Sorunlar) Ed.H.Hatemi, Sökmen Matbaacılık, İstanbul 2000,p.75-76
8. Izzard,R.: Toplum ve Hekim, C.ll Sayı:75-76 1996 p.112-114
9. Köprülü,B.: Medeni Hukuk Genel Prensipleri. Kişinin Hukuku (1-2 Kitapl) Fakülteler Matbaası, İstanbul 1947 p.5-2
10. Sayek,F.: Sağlıkla İlgili Uluslararası Belgeler (T.T.B) Ankara 1998 p.27
11. Seber,E.: Hekim, Hasta Hakları ve Hekim Sırrı, Tıbbi Etik Yıllığı Ed.Arslan Terzioğlu, İstanbul, 2000, p.14-20
12. Tekinay,S.S.: Medeni Hukuka Giriş Dersleri. Sulhi Garan Matbaacılık İstanbul, 1979, p,128-140

News in Bioethics & Biotechnology

http://www2.unescobkk.org/eubios /NBB.htm

Please note that since 2005 the News review does not include news searches from popular journals such as *Nature, New Scientist, Science*, nor Medical Journals, as other search engines will easily pick up bioethics news articles in those journals.

Engineering Ethics

Papers on integrating ethics into engineering and science courses are in *Science & Engineering Ethics* 11 (2005), 631-70. The ethics of earthquake prediction are discussed in *Science & Engineering Ethics* 10 (2004), 655-66.

Ethics and Physical Sciences

A series of papers on Einstein, space and time, evolution and philosophy are in *Revista Portuguesa de Filosofia* 61 (2005), 3-223. **Nanoethics** is discussed in *Science & Engineering Ethics* 10 (2004), 627-38; 11 (2005), 521-34. On ethical and legal issues of nanotechnology, *Health Law Review* 12 (3) (2004), 3-77; *Law and the Human Genome Review* 22 (Jan. 2005), 27-48; *Health Law J.* 12 (2004), 103-24.

Genetic Engineering of Plants

Use of oil palms for energy production is discussed in *The Ram's Horn* 235 (2006), 1-2. The World Bank has supported the planting of 1.4 million GM popular trees in a large experiment in China, *The Ram's Horn* 225 (2004), 2-3. Argentina is now the world's second largest producer of soybean and most is GM, *The Ram's Horn* 229 (2005), 1-3.

Genetic Engineering of Animals

Designer Molecules

Biotechnology & the Public

A genetics bill of rights is suggested in *GeneWatch* 18 (Jan. 2005), 12-4.

Regulation & Field Trials of GMOs

A French court in the city of Orleans dismissed charges of criminal vandalism against activists who uprooted GM corn planted by Monsanto in 2004-2005 in that region, *The Ram's Horn* 236 (2006), 3. India rules on GMOs are discussed in *Asian Biotechnology and Development Review* 7 (2005), 33-42.

The ethics of **biowarfare** is discussed in *CQHE* 14 (2005), 306-21; *GeneWatch* 17 (Nov. 2004), 1-21; 18 (Sept. 2005), 9-11. The ethics of all sorts of new **weapons** raise serious questions, *Science & Engineering Ethics* 10 (2004), 667-92. A review of Beam, TE. Et al., eds., *Military Medical Ethics* is *BME* 210 (2005), 20-28.

Vaccines & Diseases

Ethics of vaccination of infants is discussed in Italian, *Bioetica e Cultura* 28 (2005), 65-72. MMR ethics is discussed in *Nursing Ethics* 12 (2005), 43-58.

AIDS & Sexually Transmitted Diseases

Bioethics in Tanzania with special reference to HIV is discussed in *CQHE* 14 (2005), 256-67. On HIV in Malawi, *Nursing Ethics* 12 (2005), 187-92. A Catholic perspective on the use of condoms to prevent HIV is in *National Catholic Bioethics Quarterly* 5 (2005), 37-50. Public disclosure of HIV status is discussed in *Nursing Ethics* 12 (2005), 288-95. Ethical issues in HIV vaccine trails in India are reviewed in *Indian J. Med. Ethics* 1 (2005), 109-112.

Microbes & Pollution Remedies

Environmental Issues

A report from the World Commission on the Ethics of Science and Technology (COMEST) on the Precautionary Principle is available to download from the UNESCO homepage, www.unesco.org/shs/ethics There are increasing stories of violence over water shortages, and traditional methods may be used to preserve water resources, *Honey Bee* 16 (April 2005), 4-6.

Biodiversity

Biological diversity can also be preserved while preserving human culture as well, *Honey Bee* 15 (July 2005), 12-3. Biodiversity contests are also ways to preserve biodiversity being used in India, *Honey Bee* 16 (July 2005), 4-7.

Animal Rights

The ethics of behavioural research on captive animals is discussed in *Science & Engineering Ethics* 10 (2004), 717-34.

The ethics of **pet cloning** are discussed in *HCR* 35 (Nov. 2005), 34-9. Use of animal organs for transplants is discussed in *Turkish J. Medical Ethics* 12 (2004), 242-7.

Brain function

Two papers on ethics of neuroscience are in *Science and Christian Belief* 16 (2004), 98-156. Neuroethics is also discussed in *BME* 210 (2005), 3-4.

Safety of Recombinant DNA Products

Food safety

Laws on GM food in the USA are discussed in *GeneWatch* 18 (Jan. 2005), 15-8. The right to food is argued for in *The Ram's Horn* 232 (2005), 1-2. A registry of alleged GM food contamination is online at <www.gmcontaminationregister.org>

Disease Risks & Drugs

Some sensitive public health data is buried from public view, *Science & Engineering Ethics* 10 (2004), 597-614. FDA in the USA is considering reform of drug safety testing, *HCR* 35 (May 2005), 10-11.

Patenting & Business

Ownership rights of the body are discussed in *CQHE* 15 (2006), 89-100. Papers on the ethics of IPR from the 5th International Conference on Bioethics, The Ethics of Intellectual Property Rights and Patents, Warsaw, Poland, 23-24 April, 2004; are in *Science & Engineering Ethics* 11 (2005), 1-160. One alternative is open source biotechnology, *GeneWatch* 18 (Jan. 2005), 6-11. Anonymity and property rights are discussed in *Law and the Human Genome Review* 22 (Jan. 2005), 153-78.

Bioethics and business are discussed in *HCR* 34 (Sept. 2004), 14-36; *The Ram's Horn* 236 (2006), 1-3. There has been controversy over patent applications by Monsanto which relate to breeding of pigs, *The Ram's Horn* 232 (2005), 7. *On the Canadian Supreme Court decision in Monsanto v. Schmeiser, Health Law Review* 13 (1) (2004), 44-7. Papers on patenting of biotechnology in India are in *Asian Biotechnology and Development Review* 7 (2005), 1-108.

Birth Control

The ethics of sterilization of young, competent adults is discussed in *BMJ* 330 (2005), 1323-5. The Indian Supreme Court has made an announcement on sterilization, *Indian J. Med. Ethics* 2 (2005), 40-1. A paper on the sense of autonomy in Chinese reproductive policies is *New Genetics and Society* 24 (2005), 15-30.

Embryo Status

A new book reviewing the history of abortion in **China** and providing interview data on the current opinions is Nie, Jing-Bao, *Behind the Silence: Chinese Voices on Abortion* (Lanham, Rowman & Littlefield Pub. 2005, ISBN 0-7425-2371-3; 294pp.). A supplement to *Reproductive Health Matters* 12 (2004), is Berer, M., ed., *Abortion Law, Policy and Practice*, 234pp. On abortion in **Canada**, *CQHE* 14 (2005), 287-91. Abortion in Australia is reviewed in *MJA* 182 (2005), 447-52. Papers on power, money and reproductive autonomy are in *Reproductive Health Matters* 12 (2004), 6-137. Links between abortion and breast cancer are reviewed in *National Catholic Bioethics Quarterly* 5 (2005), 303-30.

The symbolic value of embryos in debates on ethics is discussed in *CQHE* 15 (2006), 22-35. Difficulties of legislating in human embryo and cloning research are discussed in *J. Law & Medicine* 12 (2005), 483-93. The possibility of making an artificial womb and its affect upon abortion debates is discussed in *National Catholic Bioethics Quarterly* 5 (2005), 283-302. Deciding the fate of frozen embryos is debated in *Medical Law Review* 13 (2005), 244-56. A critique of Health Canada's proposals on consent for human embryo research is *Health Law Review* 14 (2) (2005), 19-27.

Cloning and stem cells

The **ethics** of ES cell cloning are discussed in *CQHE* 15 (2006), 7-21; *National Catholic Bioethics Quarterly* 5 (2005), 249-282; *KIEJ* 15 (2005), 269-88; *Science & Engineering Ethics* 11 (2005), 589-616; *HCR* 35 (Nov. 2005), 15-9; *GeneWatch* 18 (Sept. 2005), 12-5; *Science and Christian Belief* 17 (2005), 199-222; *New Genetics and Society* 24 (2005), 1-14; *Law and the Human Genome Review* 21 (July 2004), 51-66. On the ethics of creating and sacrificing embryos for stem cells, *JME* 31 (2005), 366-70. ES cell banks in the UK are discussed in *Law and the Human Genome Review* 20 (Jan. 2004), 147-62.Stem cell research in Islamic countries is discussed in *JME* 31 (2005), 399-403. The cloning debate in the UK is reviewed in *CQHE* 14 (2005), 268-76. The ethics of oocyte-assisted stem cell research from a Catholic perspective is discussed in *National Catholic Bioethics Quarterly* 5 (2005), 465-70, 579-86. The future uses of stem cells may affect the way we view human life, *HCR* 35 (March 2005), 25-33.

There was much controversy over the scientific fraud of Prof. **Hwang Wook-suk**, who has been fired on 20 March 2006 from Seoul National University and suspended for five years from receiving Korean government funding in science for his fabrication of stem cell research papers, which have been withdrawn from the journal *Science*. More articles will be introduced in future issues.

Assisted Reproductive Technology (ART)

On ethics of ART, *F&S* 83 (2005), 1612-21. Use of fertility treatment in patients with psychiatric illness is debated in Italian, *Bioetica e Cultura* 27 (2005), 43-54. A series of papers on human embryo transfer are in *National Catholic Bioethics Quarterly* 5 (2005), 51-152. A review of commercial surrogacy is *Health Care Analysis* 13 (2005), 11-31. On equity of access, *JME* 31 (2005), 280-5. Ethics of **sex selection** is discussed in *JME* 31 (2005), 291-4. Attitudes to ART in Sri Lanka are presented in *New Genetics and Society* 24 (2005), 99-118. onsultation on the UK HFEA is called for in the UK, *BME* 210 (2005), 10-3.

A review of options for preserving fertility in women is in *NEJM* 353 (2005), 64-73. The psychological risks of multiple births resulting from ART are reviewed in *F&S* 83 (2005), 1422-8. Competition can increase the rates of multiple pregnancy, *F&S* 83 (2005), 1429-34. Frozen sperm and frozen oocytes can give rise to embryos, *F&S* 83 (2005), 1547-56. The ethics of reproductive ectogenesis are discussed in *Science & Engineering Ethics* 10 (2004), 615-26. Dangers of egg donation are discussed in *GeneWatch* 18 (Sept. 2005), 6-8, 16. Reproductive **tourism** in

Europe is reviewed sin *Reproductive Health Matters* 13 (2005), 120-8.

Fetal Environment & Neonates

Papers on implementing ICPD and maternal health are in *Reproductive Health Matters* 13 (2005), 6-119. Ethics of relating during childbirth for midwives are discussed in *Nursing Ethics* 12 (2005), 606-621. Ethics in pediatrics is discussed in *Nursing Ethics* 12 (2005), 223-252. Prevention of neural tube defects in Europe is discussed in *BMJ* 330 (2005), 574-5.

Genetic Disease Markers

Genetic Screening Methodology

Imaging and **neuroethics** is discussed in *American J. Bioethics* 5 (2005), 5-38. Mandatory drug testing in urine of physicians is debated in *J. Clinical Ethics* 16 (2005), 85-96. A review of techniques and ethics of preimplantation diagnosis is *F&S* 83 (2005), 1347-53.

DNA Fingerprinting & Privacy

Patient's **privacy** and human rights are discussed in *Nursing Ethics* 12 (2005), 273-95; *HCR* 35 (Nov. 2005), 49; *Health Law Review* 14 (1) (2005), 3-50. Obligations of human genetic data are raised in Macer, D. "Privacy, openness, and obligations of personal human genetic data", *Dharma Deepika* 10 (2006), 85-94. Laws to protect against genetic discrimination are discussed in *HCR* 35 (Nov. 2005), 27-33; *Law and the Human Genome Review* 21 (July 2004), 103-26.

Ethics & Genetic Screening

Genetic testing of **children** for late onset disease is discussed in *CQHE* 14 (2005), 47-56; and on genetic testing after breast cancer diagnosis, *CQHE* 13 (2004), 417-19. Prenatal testing and disability in the context of autonomy are reviewed in *CQHE* 14 (2005), 65-82. Newborn screening is discussed in *JME* 31 (2005), 393-8. Syrian women's perceptions of ultrasound screening in pregnancy are reported in *Reproductive Health Matters* 13 (2005), 6 147-54.

Public opinion is surveyed in Elger, BS. "Attitudes of future lawyers and psychologists to the use of genetic testing for **criminal** behavior", *CQHE* 14 (2005), 329-45. The use of genetic defenses for criminal cases is discussed in *Health Law J.* 12 (2004), 35-70. In Germany the debates on reprogenetics include the meaning of ethics, *HCR* 35 (May 2005), 42-49. Reflections on Habermas related to **eugenics** are in *HCR* 35 (Nov. 2005), 31-42. Race and genes are discussed in *GeneWatch* 18 (Jan. 2005), 3-17.

Gene Therapy

A Rawlsian perspective on ethics of human genetic engineering is in *CQHE* 15 (2006), 35-41. Design constraints on a post-human future are discussed in *Monash Bioethics Review* 24 (2005), 10-19; and letters on the post-human future are *HCR* 35 (Nov. 2005), 4-7. Seven papers on justice and genetic **enhancement** are in *KIEJ* 15 (2005), 1-106. The concept of authenticity in enhancement are common, *HCR* 35 (May 2005), 34-41. A review of the licensed gene therapy in China is in *GeneWatch* 18 (Nov. 2005), 10-3.

Human Genome Project (HGP)

The withdrawal of samples from a population genetic project is discussed in *JME* 31 (2005), 385-92. Ethics and the epigenome, including methylation of DNA, is discussed in *GeneWatch* 18 (Sept. 2005), 3-5. A review of the Harvard case of Xu Xuping is *New Genetics and Society* 24 (2005), 57-78. On ethics of biobanks, *Law and the Human Genome Review* 22 (Jan. 2005), 103-114. A paper by Sir John Sulston on society and the human genome is *Law and the Human Genome Review* 20 (Jan. 2004), 25-36.

General Medical Ethics

Medical ethics and culture are discussed in *CQHE* 14 (2005), 7-46, 100-6, 355-443; Moazam, F. & Jafarey, A. "**Pakistan** and biomedical ethics: Report from a Muslim country", *CQHE* 14 (2005), 249-55. Codes and values on caring in **Australia** are reviewed in *Nursing Ethics* 13 (2006), 5-16.Reviews of the *Nuovo Dizionario di Bioetica* (New Dictionary of Bioethics) are in Italian, *Bioetica e Cultura* 13 (2004), 187-206. A paper on ancient ethics is Takemura, E. "Approaches to the Samurai ethic in the Bakumatsu Era", *Bulletin of the International Research Center for Japanese Studies* 31 (Oct. 2005), 47-68 (in Japanese with English summary). A book review of Walter, JK. & Klein, EP., *The Story of Bioethics: From Seminal Works to Contemporary* Explorations (Georgetown University press, 2003) is *HCR* 35 (May 2005), 50-1.

Two new reports describing various models for ethics committees are available to download from the UNESCO homepage, www.unesco.org/shs/bioethics Papers on ethics committees are in *IJB* 15 (2004), 13-129. On research ethics in China, *Turkish J. Medical Ethics* 12 (2004), 253-5. Inclusion of ethnic minorities in research is called for in *BME* 211 (2005), 22-4. Complications are still found in UK consent, *BME* 210 (2005), 15-9.

Patient ethics is discussed in 6 papers in *CQHE* 14 (2005), 131-190. Natural law and moral theology is discussed in *Alpha Omega* 8 (2005), 163-98. A series of papers on Kant in Portuguese are in *Revista Portuguesa de Filosofia* 61 (2005), 347-607; 651-1096. The Christian origin of medical compassion is discussed in *National Catholic Bioethics Quarterly* 5 (2005), 243-8. A demand for **religious** care in Taiwanese health care is seen, *Nursing Ethics* 13 (2006), 163-79. Papers on Christian approaches to ethics are in *Dharma Deepika* 10 (2006), 2-94. A series of papers on religious and cultural influences on behaviour are in *Nursing Ethics* 12 (2005), 557-605. Research in tribal communities is discussed in *Indian J. Med. Ethics* 1 (2005), 122-5.

A review of trends in nursing ethics over the first 11 years of *Nursing Ethics* journal is *Nursing Ethics* 13 (2006), 65-85. Medical ethics and interrogation are discussed in *HCR* 35 (Nov. 2005), 17-22. Bioethics and armed conflict are reviewed in *HCR* 34 (Nov. 2004), 3, 11-12, 22-30.

Bioethics Education

The resource book or text-book, Darryl Macer, ed., *A Cross-Cultural Introduction to Bioethics*, Eubios Ethics Institute 2006, is available in hard copy and on the website <http://www.unescobkk.org/index.php?id=2508>

A call for teaching medical and nursing students together is made in *Nursing Ethics* 12 (2005), 167-77. Nursing ethics education is discussed in *Nursing Ethics* 12 (2005), 5-18. Ethics education is also needed for ethics committee members, *KIEJ* 14 (2004), 395-406. A series of papers on public deliberation in bioethics taken by the US President's Council are *KIEJ* 15 (2005), 219-322. How the public values bioethics commissions in the USA as public forums is debated in *KIEJ* 14 (2004), 333-60. Teaching of medical ethics in University of Londrina is reviewed in *Turkish J. Medical Ethics* 12 (2004), 230-3.

A paper explaining a methodology of keyword analysis for assessment of student reports is Maekawa, F. & Macer, D. "How Japanese students reason about agricultural biotechnology", *Science & Engineering Ethics* 10 (2004), 705-16. Indian views on WHO teaching guidelines are in *Indian J. Med. Ethics* 11 (2005), 54.

Twenty papers on **web-based** education in science and engineering ethics are in *Science & Engineering Ethics* 11 (2005), 323-511. The use of electronic discussion boards to teach responsible conduct of research is also possible, *Science & Engineering Ethics* 11 (2005), 617-30. Reflection and ethics education are discussed in *HCR* 34 (Nov. 2004), 31-8.

Law & Medical Ethics

Direct to the consumer **advertising** of medicines is debated in *CQHE* 15 (2006), 42-9; *Health Law Review* 14 (2) (2005), 28-33. A paper on bioethics in bureaucracy is *CQHE* 14 (2005),379-84. Papers on ethical limits on human subjects **research** are in *CQHE* 13 (2004), 313-416; *HCR* 35 (Sept. 2005), 12-3, 16-19, 20-43. Papers on Canadian governance for ethical research on humans are in *Health Law Review* 13 (2&3) (2005), 5-116; *Health Law J.* 12 (2004), 125-200. Roles of nurses in clinical trials are discussed in

Nursing Ethics 13 (2006), 180-6. Papers on expanding the roles of nurses are in *Nursing Ethics* 12 (2005), 431-452. The ethics of proxy consent for neonatal care is debated in *Health Care Analysis* 13 (2005), 1-9.

Papers on medical **malpractice** in the USA are in *HCR* 35 (March 2005), 15-24; and in India, *Indian J. Med. Ethics* 2 (2005), 60-1. An ethics of saying sorry for mistakes is called for in *Nursing Ethics* 11 (2004), 568-76, 577-86. The risks of clinical trials are discussed in *KIEJ* 14 (2004), 369-94. A critique of bioethics is *Health Care Analysis* 13 (2005), 73-86. Papers on the responsible conduct of basic and clinical research from the 6th International Conference on Bioethics, Warsaw, Poland, 3-4 June 2005 are in *Science & Engineering Ethics* 12 (2006), 1-200.

Prospects for reform of the United Nations are discussed by Ioan Voicu in *ABAC Journal* 25 (Sept. 2005), 1-28. A report on the January 2005 **UNESCO** consultation meetings on the Declaration on Bioethics and Human Rights is *HCR* 35 (March 2005), 8. An editorial on the Declaration is *BME* 211 (2005), 1. Papers on law and bioethics are in *IJB* 15 (2004), 15-174.

Scientific Ethics

A Japanese perspective on conflict of interest is in *CQHE* 14 (2005), 277-80. Conflicts of interest are discussed in *Science & Engineering Ethics* 11 (2005), 515-7, 553-74; *HCR* 35 (March 2005), 13-4.

Euthanasia & Terminal Care

Causation and active euthanasia are discussed in *CQHE* 15 (2006), 71-80; *JME* 31 (2005), 311-7; *HCR* 35 (May 2005), 53. On terminal sedation in Italian, *Bioetica e Cultura* 29 (2005), 213-20. PVS is discussed in Italian, *Bioetica e Cultura* 28 (2005), 94-101.Papers on the distinction between ordinary and extraordinary treatment are in *National Catholic Bioethics Quarterly* 5 (2005), 471-578; 4 (2004), 773-784. The Oregon state Death with Dignity Act is discussed in *National Catholic Bioethics Quarterly* 4 (2004), 739-54. Assisted suicide in Belgium is discussed in *European J. Health Law* 12 (2005), 39-41; and in Switzerland in *European J. Health Law* 12 (2005), 25-38. The legal case of Theresa Marie **Schiavo** in the USA is reviewed in *HCR* 35 (May 2005), 16-33; *JAMA* 293 (2005), 2403-7; also in *JME* 31 (2005), 376-8.

The results of surveys are in Hsin, D. & Macer, D. "Confucian and Taoist influences on the images of life among seniors in **Taiwan**", *Turkish J. Medical Ethics* 12 (2004), 211-25. Long term nursing of elderly persons in Finland is reviewed in *Nursing Ethics* 13 (2006), 116-29. A good life for dementia patients is discussed in *Nursing Ethics* 12 (2005), 30-42. On end of life care, *JAMA* 293 (2005), 2265-71; 294 (2005), 359-65. Advance directives in **New Zealand** are discussed in *Nursing Ethics* 12 (2005), 349-59. Ethics in geriatric management and clinical research are discussed in *JME* 31 (2005), 355-9. Policies on end of life care in USA are reviewed in *J. Law, Medicine & Ethics* 33 (2005), 294-309. Implications of end of life care in India are discussed in *Indian J. Med. Ethics* 2 (2005), 76-8, 79-85.

Organ Transplants & Brain Death

The preferences to donate organs inside groups is discussed in *CQHE* 15 (2006), 50-9. Living donor liver transplantation is discussed in *Indian J. Med. Ethics* 2 (2005), 89-93. On organ trade, *CQHE* 15 (2006), 60-70; *JME* 31 (2005), 269-72, 362-5. Presumed consent is debated in *CQHE* 14 (2005), 107-118. On the future regulation of human tissue in the UK, *Medical Law Review* 13 (2005), 170-223. A paper on brain donation for research is *BME* 211 (2005), 17-21. A series of papers on US public **attitudes** to death and organ procurement are in *KIEJ* 15 (2005), 211-32. **Brain death** is questioned in Chiong, W. "Brain death without definitions", *HCR* 35 (Nov. 2005), 20-30.

Health Costs

Justice and public health are discussed in *CQHE* 14 (2005), 13-26. Age-based decisions on distribution of health care are debated in *CQHE* 14 (2005), 83-99. Consent and limiting healthcare costs are discussed in *JME* 31 (2005), 424-6. The challenges of global consumption and governance of pharmaceuticals in the UK are reviewed in *BMJ* 331 (2005), 40-2. A review is Hammonds, R. & Ooms, G. "World Bank policies and the obligation of its members to respect, protect and fulfill the right to health", *Health & Human Rights* 8 (2004), 26-60.

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