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Deadline for the May 2005 issue is **1 April, 2005**.

Editorial: Move to Thailand

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This editorial will still surprise a number of readers. It is written on the penultimate day of my 15 years at University of Tsukuba, Japan. For all correspondence please use the new address below. The work at UNESCO is challenging and after a number of years of association as an IBC committee member, and working in an academic role for UN organizations, I took up an offer to join the work of UNESCO, and have already been based in Bangkok for some months. I remain attached as affiliated professor at United Nations University Institute of Advanced Studies.

The opportunity to live in Thailand should prove even more culturally interesting than in Japan, with a wide range of South East Asian cultures to learn from. There are numerous opportunities for intercultural exchange, and we hope that readers of EJAIB will participate in more exchanges of opinion, and debate. This issue has no news section, rather including a number of papers from philosophy of bioethics, reproductive technology, and dying and organ transplants. Readers are invited to send commentaries for publication. News will be reported in future issues, as the transition period between countries of the editorial office has finished.

The Email address printed in the September and November 2004 issues of *EJAIB* was incorrect, and it should be: asianbioethics@yahoo.co.nz

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Wittgensteinian Philosophy, Anthropology and the Ethics of Psychiatry

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Introduction

Discussions of the philosophical base of bioethics too often concentrate on philosophical ethics: utilitarianism, deontology, teleology, Aristotelianism, etc. This approach is too narrow.

Science, philosophy of science, philosophy of logic and language, metaphysics, deeply influenced the ethical philosophies of the great philosophers of the past.

If they were right in putting ethics at the crown of their edifices, and if this is what gave their ethics substance and depth, then perhaps our bioethics, too, must grow out of substantive enquiries into the nature of life, existence, language, logic and science: especially of the health and life sciences. As one example of how this might be done, we want to try to put this ideal into effect by developing an outline of a Wittgensteinian bioethic of psychiatry. We do not intend to create ethics incestuously out of ethics. But we shall start with substantive enquiries into fundamental concepts in Wittgenstein's philosophy.

The philosophy in this paper will not, however, be *Wittgenstein's.* But we hope it will be *Wittgensteinian.* Rather than aiming at historical accuracy about every detail of Wittgenstein's own opinions we shall attempt to draw logical conclusions from some of his doctrines as we understand them.

We shall not try to guess at the bioethic of psychiatry which Wittgenstein "might have written", but rather suggest and discuss a bioethic of psychiatry which is inspired by Wittgenstein's philosophy. First, however, let us clarify further what we mean by saying that ethics develops out of substantive enquiry.

We shall use two examples from the history of philosophy: Hume and Aristotle.

David Hume was highly inspired, as we see in the preface to his *Treatise of Human Nature*, by Newton's success in applying empirical methods to natural philosophy, to what we today call "physics". Hume subtitled his *Treatise*: "an attempt to introduce the experimental method of reasoning into moral subjects. He then devoted the first book of his *Treatise* to substantive philosophy, i.e., epistemology, ontology and philosophy of mind, in which he took the stand that all that can be known to us are impressions and ideas. It naturally follows that an enquiry into ethics can only be based upon an empirical study of the laws of interplay of impressions and ideas within the mind, because impressions and ideas are the only data available to us on which any enquiry, including ethical enquiry, can be based.

In Hume's philosophy ethical praise and blame are passions, i.e. a certain kind of impression. So, ethics has to be a study of impressions. He therefore devoted the second book of his *Treatise* to an experimental and highly introspective study of causal laws governing the passions.

This is part of what is today called "psychology", which is often considered a science. He then applied these doctrines, in the third book of his *Treatise*, to ethics, in a series of empirical generalizations about the etiology of moral praise and moral blame. The ethics was not generated from ethics but directly from epistemology and psychology.

Another example is Aristotle, whose study of scientific method in the *Posterior Analytics* -- with special attention to the geometry which was developing just before Euclid -- lead to the concept of *anchinoya*, the mysterious faculty of "quick wit" or intuitive grasp of the cause of a phenomenon or the explanation of a mathematical proposition.

This mysterious purely intellectual faculty reappeared in the De *Anima* as the "agent intellect" which grasps the explanations of things. (1)

In the *Nicomachean Ethics* this faculty becomes that which distinguishes us from the animals, makes us most similar to and loved by the gods, and the exercise of which is essential to an ethical life.

We think that what we said about Hume and Aristotle can be generalized and that all serious philosophical ethics is based on substantive philosophy, which in turn is, when serious, inspired by the science of the day. But in the interests of brevity, we shall not develop this point with respect to other philosophers of the past.

We shall now turn to Wittgenstein, and to the biomedical sciences which are, in our generation, the "science of the day" just as physics was in Hume's time. The philosophy of Ludwig Wittgenstein was highly influential in Anglophonic and European philosophy in the mid twentieth century.

Some aspects of the Wittgensteinian movement were, more over, typical to the times and similar to movements in other fields, including cultural relativism in anthropology as can be seen in the controversies surrounding Winch's writings , and including, as we shall see, the anti-psychiatry movement in psychiatry. We shall present an admittedly oversimplified and abbreviated statement of some core points in Wittgenstein's philosophy.

Wittgenstein's philosophy is enormously complex and disorderly, made of a vast number of scattered jottings, remarks and students' lecture notes. There are many different schools of interpretation.

Rather than attempting a scholarly interpretation of his philosophy we shall state a relatively workable Wittgensteinian doctrine as a basis for developing bioethical consequences, particularly in the ethics of psychiatry.

We shall discuss four core ideas: the idea of "meaning as use", the idea of a "language game", the connexion between "language and "forms of life", and the well-known Wittgensteinian doctrine that "there can be no private language".

I) *Meaning as use*: Wittgenstein's philosophy of language stands in opposition to the Platonist semantics which ruled in philosophy for many years.

According to Platonist semantics words indicate absolute ideas. The word "good", for example stands for absolute goodness, and things are judged to be good or not-good as they are near to or distant from this absolute standard. According to Wittgensteinian philosophy, on the other hand, words do not represent ideas but are rather like pieces in a game which are used in various ways to accomplish various things in our lives, like expressing our feelings for example.

Words have no permanent, fixed semantic meanings over and above their uses within specific contexts, such as for example, emotional, inter-personal or cultural contexts.

But to appreciate the implications of this doctrine of meaning for psychiatric ethics, we must first discuss the idea of language games.

II) *Language Games*: Just as pieces in chess and balls in football are said to be correctly used if they are used according to rules which constitute their functions in these games, so words of different languages are used according to rules which constitute those languages.

Wittgenstein, however, thought of us as playing various "games" with words. When the word *dog*, for example is used in the "game" of classifying animals into genus and species, it has one use. But when it is used in the "game" of cursing, calling someone a *dog*, it has an entirely different use. If someone curses you by calling you a dog, it would be inappropriate to reply by saying: "But I am not a four-legged mammal". Just as you cannot use a football in a game of tennis, so words in one language game may have entirely different uses within another language game.

An obvious consequence is the cultural relativism which was debated at length by philosophers like Winch and Jarvie and in Elazar Weinryb's Hebrew writings, where attention was given to cultural relativity with respect to scientificity and rationality.

But our concern is bioethics. A clear consequence of the doctrine of language games, which is inseparable from the doctrine of meaning as use, is that ethical words like "good", "bad", "deviant", "cruel" are used according to rules which are determined by a socio-cultural context, and which will be different from culture to culture, and -- perhaps no less so (as was suggested by the International Bioethics Survey (2) -- within each culture.

It follows that there is no universal ethics because uses of ethical words will vary both inter culturally and intra culturally.

Just as you can not judge a move in basketball according to the rules of football, so there can be no basis for members of one culture to judge uses of evaluative words --and their consequences in action -- in foreign cultures. Nor can two people within the same culture always judge the use of evaluative words by others within the same culture.

Perhaps there are consequences for psychiatric ethics. Can't we say that the so-called "mentally ill" are really a culture or sub-culture in-and-of themselves, with their own language games, their own rules for using words: especially in ethical judgments where one decides whether actions are right or wrong? If so then the so-called "mentally ill" are not deviant but only culturally different. They deserve the same respect which we owe to any minority culture.

By this is not meant "toleration", because to tolerate someone is to stoop down to do that persona favour. But according to the conclusion which we are considering, the so-called "mentally ill" are fully equal to everyone else. It would make as much sense to ask them to tolerate us as it would to ask us to tolerate them.

The similarity to doctrines of Szasz, Laing and Foucault should not be surprizing. There seems to have been a spirit of the times. But does it really make sense to call the mentally ill a culture or sub-culture? It has been objected to us: "Of course if the so-called 'mentally ill 'form a radically different culture, we do not understand them, and if we do not understand their language at all, we simply cannot evaluate them. But if we can call some people 'mentally ill', this shows that they are not totally severed from us, and mentally ill or not, we can evaluate agents [who are] different from us in some respects but [who are] in agreement in… [other respects].

"(Anonymous referee).

This is a challenging objection: If they are totally severed from us then it seems that we cannot evaluate them, even to the extent of saying that they deserve respect. But if we can understand them, if only just to the extent that we know that they are thinking beings different from us, then why cannot we evaluate them? In reply, and in continuation of our attempt to develop a "Wittgensteinian" doctrine, we suggest that where the sets of evaluative concepts used by two cultures (or sub-cultures)overlap, then members of one culture may evaluate members of the other with respect to the use of these concepts. But where the sets of concepts don't overlap there can be no evaluation. For example, suppose a person points to a man and says: "This man is very fat, and all very fat people are possessed by evil spirits and ought to be exorcised."

There are two judgments here:

1. "This man is very fat",
2. "All very fat people are possessed by evil spirits and ought to be exorcised".

If we use the word "fat" in the same way as this person, we may evaluate the first judgment and say: "You think this guy is fat?! You should have seen the guy I saw in the Savoy Truffle Restaurant yesterday." But if our own uses of the terms: "evil", "spirit", "ought" and "exorcised" are different from his uses, then we cannot evaluate the second judgment. The common store of concepts, the intersection of the sets of our concepts and theirs, would be the basis of our moral respect for so-called mentally ill people. But more on the idea of respect will be said when we come to discuss private languages below.

First, however, another problem must be discussed. Factually speaking, does it really make sense to say that the mentally ill form a culture in the sense of having a stock of concepts, patterns of thinking and behaving which unite them with one another and separate them from others? Further, is there any such thing as a community among them, with such features as solidarity or mutual loyalty? This is a big question to which an answer cannot be given without going far beyond the scope of this paper.

Perhaps sufferers of a common psychiatric illness or syndrome, like schizophrenia or manic-depression do share a common set of concepts and patterns of thinking and behaving. Otherwise we wouldn't identify them as suffering from the same psychiatric syndrome. There would be no way to identify their syndrome. But do they form a community in the sense of having loyalty to one another? Or in the sense of really communicating with one another? Perhaps they do so in the sense of being part of a segment of the population who are different from others and therefore may feel discriminated-against.

But then they might share this communality with other mentally-ill people who do not share any unique patterns of thinking with them.

Again can we possibly say that psychopathic murderers and pedophiles, on the one hand, form any community with mild and basically decent people who have a tendency to deep depression? Rather than speaking about *the* community of the mentally ill, we should speak instead of subsets of the set of the mentally ill, communities of mentally ill who are sufficiently similar to form a culture.

This line of thinking is leading to the idea of a kind of communities constituted by Wittgensteinian "family resemblances", with members sharing some things, and not others ,with various other members. But further enquiry into this point would require extensive empirical research into what really goes on within groups of mentally-ill people. And that is beyond the scope of this paper.

III) Language *is a Form of Life*: By "language" is not meant Hebrew or Tamil or Japanese, but rather subtle rules for the uses of words. In the present context we are interested especially in evaluative words like "rational", "scientific","good", "ugly" etc.

Wittgenstein may not have said: "Language is a form of life" in these exact words.

But he said enough similar things --like: "to imagine a language means to imagine a form of life"(3) that we may take this saying to represent his view. This famous but obscure idea, that "language is a form of life", is open to a number of interpretations.

One way to understand the phrase is that a language, i.e., a set of rules for uses of words, determines a way of living, which determines a culture, which determines the ethical values of the members of that culture. We think that many Wittgensteinian scholars would understand it this way. But another way to take the phrase would be that instead of saying that a language is the basic factor from which everything else results (like Wittgenstein's students seem to have thought) we shall consider the idea that our language and patterns of behavior, which themselves determine ethical values, are themselves functions of something more basic: our genetic inheritance together with our environment.

Stated a little simplistically, this doctrine would say that the genome of individuals or a group, together with the environment, determines a language (in the normative sense of "language" discussed above) together with patterns of behavior. Our languages together with our patterns of behavior determine the language games which constitute our ethical perceptions of right and wrong. The growing body of genetic research suggesting a significant genetic factor in determining personality traits led us to this suggestion. And of course personality traits can lead to values. Obviously environment has a role, but a biological basis seems definitely to exist. And a biological compatibility among individuals might lead to a community with a shared ethic.

And if such an ethic deviates from what we personally believe to be right or wrong, it would seem that we should treat it nonetheless with respect because it results from genetic and environmental factors which are beyond human control. Similar conclusions apply of course to communities of the so-called mentally ill.

An anonymous referee has objected to our suggestions that a Wittgensteinian bioethic would ascribe a biological basis to language, culture and ethics, and biological bases for differences among people and cultures. According to the objection, Wittgenstein would rather ascribe similarities to biology while ascribing differences to historical and anthropological factors.

This kind of interpretation seems to be quite standard. For example H-J Glock, discussing:" Wittgenstein's claim that he provides 'remarks on the natural history of human beings' (Ref (3) Section 415) " wrote that: "Wittgenstein's naturalism is anthropological rather than biological".(4)

The problem, however, is that when studying a German-speaking philosopher who developed his philosophy during the first half of the 20th century, we cannot ignore the possibility that his thought might have developed to some extent out of the scientific-cultural milieu of the time when anthropology in Germany was inseparable from biology and what they used to call "race science".

Indeed when one reads Wittgenstein's remarks collected in the book, *Culture and Value* (5) it is hard to escape the feeling that one is reading a eugenic polemic. Wittgenstein, among other things, refers to the "unpoetic mentality" of the "Semitic races" He says: "If Jews are said not to have any sense of property, that may be compatible with their liking to be rich since for them money is a particular sort of power, not property. " He refers to the Jews' "secretive and cunning nature." He refers to the Jews as a "sort of disease" a "tumour" in European history. (Ref (3) 6, 21, 22.)

There has been an attempt to explain away Wittgenstein's anti-Semitic remarks by suggesting that he wasn't writing against real Jews; he was only writing against a "metaphysical species" (6) But the phrase, "metaphysical species" is not in our opinion clear enough to make it possible for us to investigate this suggestion.

And this is not the place for detailed research into Wittgenstein's anti-Semitic remarks. (See however the note appended to reference (6) at end of paper.) But it seems to us that if such a study were to take these remarks at face value then it would be natural to understand Wittgenstein to be a believer in Third Reich "race-science", especially with respect to the idea that biology, through the genes, determines the mentality and ethics of a group of people. But if "mentality" is determined by "language", in Wittgenstein's philosophical sense of "language", then our biological interpretation of "language as a form of life" seems to follow naturally.

As Israelis we would have preferred not to go into such an emotion-charged subject as Third Reich science. We certainly are not asking for the sympathy which mention of this subject often provokes when Israelis are present at international conferences. But Wittgenstein's racial remarks in *Culture and Value* make it impossible to avoid this subject in any study of his philosophy. We must also emphasize that in suggesting possible points of similarity between Wittgenstein's philosophy and Third Reich racial science we, while obviously not unaware of the evils of the Third Reich, are not saying that everything in their science was wrong and evil. There has not yet been carried out sufficient historical scholarship to allow us to decide how much of German biology in the l930's and early l940's was evil nonsense, and how much of it was genuine science and an integral part of the process leading to today's genetic medicine.

In suggesting, therefore, a similarity between Wittgenstein's doctrine of language as a form of life and the German biology of his times ,we are simply pointing to one aspect of his doctrine, and not necessarily saying that all aspects of Wittgenstein's doctrine were evil or Nazi.. But Wittgenstein's anti-Semitism seems to go deep enough to suggest a serious connection between his concept of a form of life and racist ideas. But there is another serious problem with this philosophy as we shall see in the next section.

IV) *There can be no Private Language*: This Wittgensteinian slogan is also obscure and many attempts have been made to interpret it. Wittgenstein especially thought that our ability to discuss our feelings and emotions depends upon our being members of a community with shared assumptions as to the use of language. Similarly the Wittgensteinian assumptions which we are exploring would suggest that an individual who idiosyncratically evaluates the world in a way incomprehensible to others is not really evaluating the world, but simply talking nonsense.

This is because values are inseparable from the uses of evaluative words in a language and a language is a communal entity. But although we have been all along using the phrase "the community of the so-called mentally ill", we wonder how many mental patients really communicate with one another.

Are not some of them in a world of their own? And if they are in worlds of their own their linguistic and other behavior would not be worthy of the respect which is due to minority tribes and communities.

For if they are not really communicating with one another then there is no such community and a strict Wittgensteinian would conclude that there is no room to respect their moral judgments because they are just talking nonsense. As has been pointed out to us (anonymous referee), however, if we cannot understand what mental patients are saying to one another, then we have no basis for the conclusion that they are talking nonsense. It seems that we have to give them the benefit of the doubt and assume that there may be some sense there -- perhaps a profound sense -- which is beyond our capacity to understand. This does not mean, of course, that they do not need our help and professional care. Without this care life for them and others can be quite dangerous or at least miserable.

The situation is similar to patients in the persistent vegetative state. We have no evidence of consciousness. But we also have no evidence that they are not conscious, that there are not thoughts and feelings and experiences going on inside and beyond our grasp. This uncertainty about what is going on inside is the basis for the human respect and dignity which has to be allowed these people.

In saying this we disagree with and depart from the Wittgensteinian philosophy, as well as all forms of philosophical and linguistic behaviorism, to which the idea of what is "going on inside" is a foreign and unacceptable idea. We, moreover, recognize the strong genetic factor in both standard and non-standard emotion and behavior.

And we know that we too are also products of our genes and our environments. So even though we allow that society may have to protect itself by restraining the mentally unusual, we think they deserve the same love and respect as everybody else.

Summary and Conclusions

We tried to show in our Introduction that philosophical ethics has traditionally developed out of substantive enquiries, and not incestuously out of ethics. The body of our work was an example of how a Wittgensteinian ethic can be developed in just this way.

We have shown how the idea of *meaning as use,* leads to the concept of *language games* which are so-to-speak isolated from one another by the different rules which constitute them. This led us to the idea of different communities with cultures of their own. We therefore raised the question of whether the mentally ill may be regarded a unique community and culture, or perhaps a unique set of communities. Wittgenstein's idea of language as a form of life led us to speculate about causes, perhaps genetic causes of differing languages and cultures. But we rejected the eugenic ideology which seems to be reflected in Wittgenstein's blatant anti-Semitic remarks. Nor can we agree with Wittgenstein's rejection of 'private languages', and we allow that individuals and small groups may have their unique ways of thinking, their own cultures.

According to the Wittgensteinian philosophy which we tried to develop here, it can be said that the so-called mentally ill form communities constituted by a kind of *family resemblance.* Although it would be hard to imagine psychopathic killers and pedophiles, on the one hand, forming any kind of community with mild and decent people who have a tendency to pathological depression, various subsets of the set of all mentally ill may be hypothesized to share a common language, which is due to patterns of behavior which they learned from their environment, and to their genetic inheritance. They may also share similar ethics which can be seen by their values and perceptions of right and wrong. This conclusion leads us to a recommendation about how to treat the mentally ill. We ought to enable them to develop closed communities instead of hospitalizing them. This does not mean that we should deny them medical treatment, or medical supervision. But we should encourage them to develop communities in and of themselves with rules of their own and values of their own: in other words, shared ethics. We might start by encouraging various moderate degrees of self-governance within mental institutions, and gradually work towards encouraging communities of the de-institutionalized mentally ill. But we shall have to develop the details of this proposal elsewhere. The purpose of this paper has only been to develop the philosophical basis.

Note

This paper is an expanded version of a lecture delivered by H G-D at the Second International Workshop on Israel and Asian Bioethics, Faculty of Health Sciences, Ben Gurion University of the Negev, Beer Sheva, August, l998.

Acknowledgments

The authors wish to thank Dr Haim Marantz and an anonymous referee for challenging and helpful suggestions for revision. We apologize that personal factors caused such a great delay in our re-writing of the paper.

Conflict of Interest

The authors confess to being human beings, sharing the vast majority of their DNA sequences with even the most seriously mentally ill. The authors' attempt to suggest a philosophical basis for respecting these patients' dignity was motivated, therefore, by an interest which conflicts with the ideal of absolutely objective science and scholarship.

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5) Wittgenstein L. *Vermischte Bemerkunger, Culture and Value*. (German and English on facing pages) von Wright GH ed. , Winch P tr. ,Oxford, Basil Blackwell, l980, l984).

6) Lurie Y. Jews as a metaphysical species. *Philosophy* (l989)64:323-347. One of the passages of which Lurie makes use in his attempt to excuse Wittgenstein's anti-Semitic remarks appears in the memoir written by Wittgenstein's student, Norman Malcolm (Malcolm N. *Ludwig Wittgenstein, a Memoir* (Oxford University Press, 1984, 30.) The passage reads: *One time…we saw a newsvendor's sign which announced that the German government had accused the British government of instigating a recent attempt to assassinate Hitler with a bomb. This was in the autumn of 1939. Wittgenstein said of the German claim: 'It wouldn't surprise me if it were true.' I retorted that I couldn't believe that top people in the British government would do such a thing. I meant that the British were too civilized and decent to attempt anything so underhanded; and I added that such a deed was not in keeping with British 'national character'. My remark made Wittgenstein extremely angry. He considered it to be a great stupidity and also an indication that I was not learning anything from the philosophical training that he was trying to give me. He said these things very vehemently, and when I refused to admit that my remark was stupid he would not talk to me any more, and soon after we parted*
Lurie is not at all clear about how he expects such a passage to help him to excuse Wittgenstein's anti-Semitic remarks. In any case, the passage must be seen in its historical context. A reading of British newspapers of the time will reveal that the bomb attempt on Hitler's life was made after the European war had begun and it was known that the Germans had been sinking British merchant ships, and that they had already begun shipping many thousands of Jews "eastward". In such a context it is hard to conceive that any sane person could prefer the life of one mad leader over the lives of the countless soldiers, seamen and civilians who were dying because of that one leader. Yet Wittgenstein and Malcolm seem to have disagreed only on whether or not the British were capable of doing something "so underhanded". But they seem to have both agreed that the attack on Hitler's life was "underhanded". So it is hard to escape the conclusion that Wittgenstein and Malcolm both seem to have held Hitler in some esteem.

Three Dimensions of Contemporary Bioethics: Western, Global, Cosmist

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Introduction

First of all, I would like to present the definition of the notion "episteme". The latter has been introduced by Michel Foucault in his work *The Order of Things* – to mean the regime of truth that underlay all the discourses of a particular epoch.

However, soon after he abandoned the concept. Nevertheless, the conception of "episteme" has continued its autonomous life in the world-wide science – in the sense of interpreting a history as a number of "discontinuities" and directly meaning a certain global principle of the organization of the all manifestations of human life – the latent universal model (structure) of the construction of human culture and a civilization. The meanings of the notion "episteme" and the notion "paradigm" (Thomas Kuhn) bear a close analogy, but "episteme" is more wide and basic in relation to the entire cultural dispositions of the given civilization, predetermining philosophic and scientific activity as well. More often, at present, the use of the notion "episteme" implies the meaning of "western episteme".

In its turn, the fundamental importance of the "discontinuity principle" in the life (development, ontogeny) of a civilization, society, or person corresponds to the notion "macroshift" by Ervin Laszlo (2001), who is widely regarded as the founder of systems philosophy and general evolution theory (he is also the editor of the journal "World Futures"). Distinctively, however, "discontinuity" reflects the events of the past and present, while "macroshift" serves the future (emergent future, not predictable from the current conditions) evolutionary stages. The following reasoning by Ervin Laszlo deserves attention: "There have been other macroshifts in human history, but they spanned centuries, allowing cultural values, beliefs, and change to occur gradually. Today, technology has reduced our time to adapt; the entire critical period of change is compressed into the lifetime of a generation." (Laszlo, 2001). An outstanding scientist outlines two possible scenarios: "The Breakdown," where we choose to drift without a change in our current direction toward chaos, anarchy, and destruction, or "The Breakthrough," where we collectively transform our thinking and behaviour to produce creative, sustainable solutions to dangerous global problems.

I would like also to lead (readers) to the reasoning of Soraj Hongladarom (*EJAIB* 14/6). It may be objectionable but I might propose the term 'third-order' judgments (in the development of Hongladarom's 'first-order' and 'second-order' judgments). 'Third-order' understandings, herein (like episteme), imply the 'upon' (or 'under', forming the foundation) of "second-order" and "first-order" bioethical judgments and decisions.

Finally, the Behaviourome / Mental Map Project, originated and headed by Darryl Macer, is in accord with the all above mentioned. A new episteme (paradigm, "breakthrough", 'third-order' understandings) in world-wide bioethics – that is what we acutely need for obtaining the effectiveness of the running Behaviourome and, thus, reaching the great aims of the Mental Map Project: To understand ourselves and, if we can make individual mental maps, – to offer persons assistance when making moral decisions (Macer, 2002-2004).

Bioethics, Biopolitics, Biocosmology

"Philosophy is a science and therefore, like every other science, it seeks to establish truths that have been strictly proved and are therefore binding for every thinking being and not only for a particular people or nation."

N.O. Lossky (Lossky, 1951, p.402).

In his bright and key presentation, during the ABC5 – "Globalisation of Bioethics – from the Asian perspective", Prof. Hyakudai Sakamoto brilliantly disclosed the absence of true foundations of global bioethics at present and impossibility of the supremacy of either western or eastern episteme in bioethics on the global level. He introduced an original principle (policy) called by him as 'bargain consensus'. To Prof. Sakamoto's view, precisely this policy (which has been called also as a "Social Tuning Technology"), solely is able to realise the harmony in global bioethics.

At the same time, I am to agree with Soraj Hongladarom who argues "…that decisions as how people from different backgrounds are to co-exist with one another peacefully should be made on an 'overlapping consensus' which is political in nature and which is shorn of the metaphysical basis on what constitutes the good life of the respective groups that enter into the deliberation." (pp. 195-6). Prof. Sakamoto himself does not object against the term "policy", insofar his advanced methodology is the 'dialogue bargain policy' (p. 492).

Prof. Hyakudai Sakamoto has elaborated the entire conception of the harmonious global bioethics by carrying out the panoramic comparison of Western and Eastern civilisations with the revealing of their essential features, and the ultimate elaboration of the 'dialogue bargain policy' – effective instrument in maintaining a sustainable world. He is truly a founder of the scientifically based global bioethics. At the same time I am to stress that the concepts "*Bioethics is Love of Life*" (by Darryl Macer, 1998), "communication-in-trust and cooperation-in-trust" [by Hans-Martin Sass, 1994, (*EJAIB*, 2004)], and the "overlapping consensus" (by Soraj Hongladarom, 2004) are in full accord with the 'dialogue bargain policy'.

Likewise, it cannot be ignored that Van Rensselaer Potter, founder of the science of bioethics, has the similar pre-dispositions in treating the global issues. In the 1999, 'Bridge Bioethics', Potter's new term appeared referring to the key article in 1970 and the book in 1971, in which bioethics was described using the word bridge as a metaphor for the intention to promote human survival (*bridge to the future*) and the intention to link science and philosophy (*bridge between the two cultures*). The cover of Potter's *Global Bioethics* (1988) offers a definition of bioethics as "Biology combined with diverse humanistic knowledge forging a science that sets a system of medical and environmental priorities for acceptable survival." In other words, global bioethics was first described in 1988 as a bridge between medical bioethics and ecological bioethics, in order to achieve a worthwhile long-range human survival. The development of specialized fields of applied ethics is described in terms of the dilemmas that each specialty fails to solve. Each needs to expand from their short-term dilemmas to their long-term obligations by incorporating a holistic bioethics.

It is a very significant thing that Potter's science of bioethics is, in fact, – "***the science of survival***". Hence, modern western bioethics (founded by Potter) is a *teleological* science organized at the achievement of the ultimate goal of survival. To survive – means to resolve the problems that threaten (have the *pathogenic* essence) a person's (and a society's, mankind's) well-being. Potter "bridge to the future" aims at the conservation of the *present* (current) well-being of a person and society. There is no, at all (both in Potter's and Sakamoto's reasoning), the sense of "breakthrough" and macro-evolutionary (emergent) "macroshift" (in Laszlo's meaning).

Therefore, western ('western', traditional) and global ('eastern') bioethics both are *pathocentric*, living in *presentism*, acting in *subject-object* relation to a world ("to achieve a worthwhile long-range human survival", – V.R. Potter; and "to control human evolution", – H. Sakamoto), and are basing on *adaptationism* (*microevolutionism*, *Darwinism*), as well as both are *teleological* disciplines aimed at the ultimate goal of survival (well-being) but lacking the system of own true philosophical fundamentals – for the realisation of understandable (by everyone) universal scientific activity. At the same time, *eastern global bioethics*, the conception of which is elaborated and advanced by Prof. Sakamoto is a true global bioethics, insofar it really pursues the aim (presenting the adequate means) of reaching the holistic harmony in the world "…harmonizing and bridging over all kinds of global ethoses, East and West, South and North" (p. 491).

On the contrary, V.R. Potter was unconvincing in presenting his holistic approach to global bioethics. The latter is natural: Van Rensselaer Potter is an ingenious son of western civilization (western *anthropocentric* episteme). Therefore, the means as much of persuasion as of force were inherent to his mentality. Acting in opposition, Hyakudai Sakamoto stresses: "Look at the reckless abuse of the words "human dignity" and "human rights" in the various texts of "world declaration" (including the UNESCO Declaration) and "world communique" during this period of time without any sincere reflection and regret on the mischief of European and American humanism which eventually caused problems of Asian and African poverty and distress." (pp. 488-489). Following this way of viewing, we might concentrate our attention on the following judgment of Prof. Sakamoto: "We should now establish a new humanism, and also cultivate new sciences and technologies *without human-centrism* (italics mine. – **K.K.**), a new methodology to complement this new humanism, and also cultivate new sciences and technologies to control human evolution, adopting the Asian ethos and wisdom to avoid the European excessive inclination to the manifold natural artificial dualism." (p. 491).

Corollaries

We can treat bioethics from the three perspectives (dimensions): Western, Global, Cosmist.

1. *Western* bioethics – '*bioethics* in essence', which combines (organises) the entire number of natural and humanitarian means: philosophical, scientific, cultural (of any origin: Western, Eastern, Northern, Southern) – for the ultimate achievement of a person's (society's, mankind's) survival (well-being). Western bioethics is a brainchild of Van Rensselaer Potter, a true son of western civilisation (western episteme).

2. *Global* bioethics – '*biopolitics* in essence', likewise organises the entire number of cultural vehicles – for the ultimate achievement of a person's (society's, mankind's) survival (well-being), but doing this on the principally different basis: of a genuine holistic (peaceful and harmonic) basis – reconciling the all involved subjects and "reaching a 'consensus of any kind', even though it might be quite unreasonable or absurd." (Sakamoto, 2004, p. 492). Prof. Sakamoto claims: "Fundamental naturalism is pervasive in every Asian system of thought… the new Global Bioethics should be 'holistic' in contrast to European 'individualistic'." (pp. 490, 491). It is obvious that the true conception of Global Bioethics (due to its substance and readiness) belongs to Prof. Hyakudai Sakamoto, a ingenious son of eastern civilisation (eastern episteme).

At any rate, it is worth mentioning, both *western* and *global* bioethics are basically teleological (eclectic or inter-(cross)-disciplinary) disciplines and directions of human (societal) activity, insofar they are both aimed at the ultimate (of microevolutionary character) goal of survival, naturally attracting and combining, in this order, the use of the very variety of philosophical, scientific, methodological, cultural dispositions and means. All this signifies that both western bioethics and global bioethics are rather the kind of politics than a science, insofar they both are lacking the own proper philosophical substances and, hence, – the possibility of rational (i.e. – universal) scientific activity.

Significantly, the both forms of bioethics (western and global) pass over in silence the evident fact that, in overwhelming significance, the actual bioethical problems of-today are man-made (anthropogenic) problems, in essence, which arise from the unreasonableness (incompetence) of a current philosophy, science and man. We have, as a result, that the general sense of bioethics consists in correction of the consequences of unreasonable activity of man. This is the deepest paradox in the activity of a modern expert in bioethics. Really, bioethics might reach (ay least, aspire to achieve) *natural-natural* character of the activity and to realize *universal generating* approach (by determining the development of science and practice) instead of taking up the duties of secondary (serving, instrumental) activity in the correction of the lacks of unreasonable activity of man (society). What are the factors that prevent experts in bioethics (all together) to put forward the purpose of a philosophical substantiation and scientific (and practical) realization of universal bioethical consideration of the existing actual world – to exclude, in the basis, the *unreasonable* activity of man? Is not it the true necessary and cardinal destination of bioethics (if not bioethics, then who?) – to integrate natural-science ("bios") and humanitarian ("ethike") knowledge and to initiate the creation (and elaboration) of the required philosophical-anthropological bases and the development of the universal theory of a person?

3. Cosmist bioethics – '*biocosmology* in essence' – is precisely the deliberate search for the *universalist* bases in bioethics, which might integrate 'bios' (natural sciences) and 'ethique' (the humanities). Biocosmology might be developed on the fundamentals of Russian (Slavic) philosophy, especially on the basis of Russian cosmism. My variant of biocosmology, an original Cosmist conception in biomedicine and bioethics is substantively exposed in the EJAIB (2002-2004) and the Proceedings of the ABC5 (2004). Its essential characteristic will follow below.

We need universal philosophy (science) in bioethics

"*History is philosophy teaching by example.*"

Dionysius of Halicarnassus

To my mind, the really existing epistema (featured by Prof. Sakamoto), Western and Eastern, are incapable *per se* to provide the universalist bioethics with the needed foundations (universal in substance). Indeed, Western episteme admits the way of feat in spreading the ethical (humanistic) principles (by a brute force and under protest) in resolving the 'ethical' questions (as it was stressed by Prof. Sakamoto and is an evident fact of current global life). Eastern episteme is insufficient 'ex juvantibus' (if to value the consequences), inasmuch as the ultimate result of Sakamoto's biopolitics (harmoniously acceptable "bargain consensus") takes place even if it is absurd. (To underline, once again, the ultimate principle of "bargain consensus" has most likely a political, than philosophical (scientific) significance).

At the same time, if to follow the wisdom of Dionysius, we have objectively and really (behind our philosophical contemplation) the series of indisputable evident, scientifically verified truths. The first: our living world is one universal whole. This truth is known at least since the discovery (in 1953) of the structure of DNA by Watson and Crick. The second truth (in importance): the one whole universal process of life on Earth (including humans and social organisations) has the cosmic origin. Really, in all cases, the energy needed for life on Earth is coming from cosmos (chiefly, the Sun energy); likewise, all the matter of Earth has the cosmic origination. The next and very important evidence: the cosmic universal process of life on Earth (Process or CEPLE, in my abbreviation) has the macro-evolutionary essence: the origin of life, the origin of nucleus-bearing protozoa; the origin of sexually reproducing forms; the rise of sentient animals, with nervous systems and protobrains; the appearance of cogitative animals, namely humans; further occurred the historical emergence of families, social bodies, communities, societies and civilisations; the next integrity naturally should be the whole mankind.

From all this an inescapable conclusion follows; if the life on Earth has the macro-evolutionary substance, then the non-(anti-)macroevolutionary approach is inadmissible and impossible in philosophical and scientific relation. But the fundamentals of western and global bioethics and, accordingly, the approaches of professors Potter and Sakamoto are both anti-macroevolutionary, inasmuch as they both believe in the microevolutionary (Darwinist, of continuous changes) foundations of considering the universal evolution. Therefore, both Potter and Sakamoto uphold unnatural positions in philosophy (science) – artificial, in the essence, and false in scientific relation. Not surprisingly, Prof. Sakamoto, while criticising "the manifold natural artificial dualism" of the western episteme, himself puts forward the line of *artificial* (italics mine.

– **K.K.**) control over evolution: "… demarcation between "natural" and "artificial" will be blurred, and therefore, we might be allowed to "play God" in this third millennium" (p. 487).

Corollary: We sharply need a new episteme, which would provide our philosophy, science and culture with the means of *natural-natural* resolution of bioethical issues. This episteme, as it follows from the above stated, might acquire the substance of *health-centric*, and the *natural-natural* and *subject-subject* pattern of philosophic (scientific) exploration, – of integrating *macro*-evolutionary and *micro*evolutionary processes of a man's (any living subject's) healthy (wholesome, safe, satisfactory) ontogeny (the entire life span). This sought for episteme likewise might have basically the *functionalist* essence, treating every living subject on Earth as the function of Process. From this come my basic principles of the Cosmist conception: Universal Functional Reductionism, Basic Cosmist Functionality, the principle of CosmoBiotypology.

The *major conclusion*:

We have no right to deprive Process (one common cosmic evolutionary process of life on Earth) and, equally, any living subject on Earth (from a molecule – up to mankind, etc.) of his (her, its) emergent (macro-evolutionary) future. Every ontogeny (macro-evolutionary ontogenesis of every living subject on Earth), as well as Process (CEPLE) are self-dependent in the macro-evolutionary ascent (development) and, hence, independent from our viewing and treating the origins and mechanisms of universal evolutionary processes: it is unimportantly, whether we stand on the positions of Darwinism (evolutionism), Creationism, Panspermia hypothesis, Big-Bang concept, etc. Process occurred and develops independently of our consciousness. Process is, because it (he) IS. We can destroy it, but we cannot create it, insofar we are ***internal*** functional elements of this Process (CEPLE), with our (of every man) inherent specific basic (Cosmist, in the term of my theory) functionality. In the same way, every cell of a human's organism has its inherent basic (Cosmist) functionality, like muscle cell, neurocyte, immunocyte, fat (adipose) cell, etc.

Therefore, we need a new cosmos-centric humanism – without fundamental anthropocentrism and naturalism (sociocentrism).

The Challenge of a Cosmist Universal Philosophy: From Bioethics and Biopolitics – to Biocosmology

"Bringing together and integrating the sum of the present time and the past history impressions, it is possible, of course schematically, to express an idea that the peoples of Asia represent a kind of thesis, and Europeans - of antithesis, and that the synthesis is needed which is still in deficiency... I assume that we, Russians, most of all have the inherent qualities of any kind for the achievement of this synthesis, though up to the present only the initial preparation to that is visible".

Dmitrij I. Mendeleev (1905)

In reality, I likewise might confirm this judgment – the philosophical potentials of the needed quality – for the new synthesis in bioethics (as pre-dispositions – pre-paradigms), first belong to Russian (but not Soviet!) philosophy, especially in the form of Russian Cosmism. The major unique property of Russian philosophy consists in its personalising (precisely *personalising*, but not humanising) approach to the consideration of active human life. *Russian personalism* is characterized as energetic, activist personalism, expecting as much self-dependency and activity as responsibility from a person for the actions and the line of life as a whole. In even more exact expression, uniqueness of Russian philosophy and science (and nuclear essence of the entire Slavic culture) consists, above all, in ability to integrate cosmologic (universalising, whole-organising) and personalist (personalising), and also futurological approaches to an evaluation of the position (***active-evolutionary***) of a man in cosmos, i.e. - simultaneous and integrated activation of philosophical *cosmologic, personalist* and *futurological* foundations. Russian universe is *personalising universe*. In the expression of Kireevsky, "... the distinctive type of Russian view on any order … consists in overlapping of personal self-dependency with integrity of the common order …" The reason of a westerner "does not contain order without sameness".

The term "universal" has its origin from Latin *universus* (*uni- + versus), i.e. turned to one*. To my mind, we have, in principle, two basic ways to reach the final aim of creating universal philosophy as science. The first, morpho-centric way, which totally dominates in the contemporary world-wide science, means the reduction of the entire infinite number of living phenomena to a basic element like a micro-organism (germ theory), cell (a cellular theory) or molecule, gene (a molecular theory and modern molecular biology), etc. Morphocentrism leads to the *subject-object* study of the given state of a living phenomena, mainly the disturbance of a normal state (sickness, diseases, mental disorders, as deviations from normal values). Human health, herein, is basically assessed on the data of physiological investigation or the medical certificate from a specialist in psychology (psychiatry).

Hence, it is unable, within morphocentrism, to take into consideration the wholesome satisfactory (healthy) emergent future for a living subject. Morphocentrism is totally based in *presentism* and is *pathocentric* in essence. It investigates the effects, and the causes of the effects (pathogenic events and outcomes) in the past and present, but morpocentrism (or structural-systemic approach) eliminates – from the area of scientific exploration – the natural (cosmic, evolutionary, healthy) course of events in the past, present and, equally, in the emergent (macro-evolutionary) future of a subject’s (a person's, first of all) healthy activity (wholesome, safe, successful, happy life activity). Therefore, morphocentrism, inasmuch as it leads to the study eventually of the given state of a subject's existence (effected by the past and present causes and aims), – evidently has the *anti-evolutionary* and *secondary* essence, in relation to the natural evolutionary course of events on Earth, serving the well-being of a subject (against the external pathogenic influences), but not acting as an agent of the natural evolution of Process (CEPLE) – cosmic evolutionary process of life on Earth.

On the contrary, the proposed Functionalist (Cosmist, functional-systemic) approach establishes the truth that every living subject on Earth (primarily, a man) is a function of the ultimate Process – self-evolving CEPLE. A Functionalist (Cosmist) methodology of attacking the issue of individual's health (wholesome, safe and gratifying life activity) is definitely a *person-centric* approach. In this, primarily a man discloses his/her inherent personal route (vector) of the ascending (macro-evolutionary) implementation of the person's Basic Cosmist Functionality (BCF), mainly possible at his or her mature creative level of personal ontogenesis. Cosmist personalist methodology realises truly universal approach to understanding and explaining individual's health, inasmuch as every subject (a man) on Earth is, ultimately, the function of Process.

The latter thesis can be proved in a sophisticated line of philosophic and scientific arguments (please, see my publications in EJAIB: 12(1), 13(1), 13(3), 14(2); and the Proceedings of the Fifth Asian Bioethics Conference). Concurrently, we have a plain mode of revealing this truth. In fact, every human organism comes into the world from one the same amount (number and mass of molecules – chromosomes) and one the same cell – zygote. As a result of biological development, every cell of the every human organism has its Basic Cosmist Functionality (BCF) – to be a muscle cell, or fat (adipose) cell, or neurocyte, immunocyte, etc. Then, how can it be (where occurs the interruption of the natural logical line) that a human person 'loses' his or her BCF (as an organism, social and cosmic agent on the whole), although coming from the same genotype and the cell (zygote)?

Then, if the Cosmist foundation is true, i.e. – every man has his/her inherent personal Basic Cosmist Functionality (being ultimately a function of one common whole cosmic evolutionary process of life on Earth), we acquire a universal scientific approach to the understanding and explaining every individual's health (wholesome and gratifying fitness of every living subject on Earth). The main point, herein, refers to the effective assistance to a person in the: A) self-dependent personal (re)discovery and the substantive realisation of his/her BCF; and B) its adequate adaptation on the given macro-level of a person's entire healthy ontogenesis. The whole (a. and b.) is needed for C): the ultimate reach of the personal mature creative level of man's ontogeny, constantly transcending (by going beyond, or rising above) biological and societal (societies) macro-levels – and the ultimate execution of a man's specific creative contribution to Process's wellness.

Biocosmology, to my mind, might realise a bioethical task of primary importance.

Conclusion: A New Vista in the Development of the Behaviourome Project

All the three forms of contemporary bioethics are necessary: 1. Western bioethics (*bioethics*) and Global bioethics (*biopolitics*) are the means indispensable in the realisation of a person's (society, mankind on the whole) well-being at the given time and the condition. These two forms of world-wide bioethics have the absolutely necessary *microevolutionary* significance, permitting the resolution of current problems with health (well-being and development) of a human being or society on the given personalist or societal (global) level. Significantly, both forms of contemporary bioethics (western and eastern) carry the qualities of *morphocentrism*, *presentism* and *pathocentrism*, and, thus, both have *anti-evolutionary* (so, unscientific) essence, inasmuch as they both deny primarily the *macro*-evolutionary character of the healthy (wholesome, happy) ontogeny of a subject (man) on the whole – as the healthy 'process of processes': the successful unity of micro-processes (adaptational, on every macro-level of a man's ontogeny) and the macro-process (aimed at the ultimate realisation of his/her BCF – on the mature creative level of a person's ontogeny).

In turn, Cosmist bioethics (*biocosmology*) gives back to the entire body of world-wide bioethics its (*macro*)evolutionary essence. Hence, it returns to common bioethics the scientific (universal) status – by restoring the qualities of universal systemic (cosmist, macro-evolutionary) functionalism and cosmist (subjective) evolutionism.

In reality, biocosmology attempts to integrate philosophy with science, to recover to philosophy (ethics) the status of the 'science of sciences'. That is possible, with reference to the Cosmist conception, exclusively on the personalist level of a man's (his or her) health (physiological-personal, societal-personal, and cosmist-personal wellness and fitness), and, obligatory, in relation to the person's entire life - ontogenetic process on the whole.

The introduction of biocosmology also serves the future trends of Behaviourome / Mental Map Project. Here is implied that the insertion of Biocosmology might provide the Behaviourome with the true basis for the realising of the great aim and great challenge of mapping the human mind, proposed by Darryl Macer (2002).

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Body Donation – A need based problem!

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'Death is just a beginning of another life' – Upnishads.

This paper discusses an issue that is likely to emerge as a topic of immense concern in context to Indian scenario in the near future. The terms – Body donation / Anatomical donation / Body bequest- are interchangeable and imply the act of donating the body after death to a facility for a noble cause (education/research purposes). Also, the term 'donor' emphasizes the 'gift to be given away'. In the present scenario, there is awareness to some extent among the masses regarding organic donations such as blood donation, eye donation, hair donation, organ donation and so on. However, the term 'Voluntary Body Donation' is comparatively a recent addition (in India) to the list of organic donations. Presently the term 'Voluntary Body Donation' has become an accepted option though for a small selected segment of the population whereby the subject in complete presence of mind opts for donating his/her body after death with the belief that the living would be benefited by this act of his/her.

What makes 'Body Donation' a unique phenomenon?

Body donation is different from other organic donations in a number of ways. Some of the factors which make it different from conventional organic donations include the following:

People from all walks of life can donate the body: The fact that people from all walks of life can donate the body irrespective of their religious beliefs, social status, cultural bindings etc. attains importance especially in a country like ours which is known for its diversified culture and heritage.

There is no specified age bar: *Unlike other organic donations, there are no age limits for donating a body. However, in some countries like US, the requisite age fixed for a donor has been specified as 18 years or above and the person should be with a sound mind so that he/she is able to sign for himself/herself though in case of a minor, even the parents or the guardians can deed the body for the noble cause.*

No matching is required

Above all, there is no materialistic award for the donor!

But unlike other organic donations, the donated body is *disassembled without any attempt to reconstruct it! And yet it enjoys the status of a high moral act.*

The awareness regarding the subject matter demands urgent attention due to ever increasing imbalance between the demand for cadavers on one hand and their non availability on the other. Whereas the mushrooming of medical schools and other such institutions all over the country contribute to the former part of the equation, the latter part of the equation is being determined by a host of factors such as social, legal, psychological and so on. The end result is a demand – supply mismatch of enormous magnitude with immediate adverse effects on the quality of medical education and health related research activities.

Importance of cadaver teaching / learning

'What we hear, we forget: what we see, we remember: what we do, we understand'. These lines clearly reflect the importance of cadaver teaching / learning in anatomy (the science that deals with the structural organization of the body). Besides the potential to instill long lasting humanistic attitudes towards patient care, the impact regarding structural organization imbibed through the three dimensional visualization during cadaver dissection, remains unparalleled. The age old dictum that 'there is no substitute for human body in teaching human anatomy' stands even today in spite of the revolutionary advancements and technical innovations integrated into learning and teaching media over the recent years (Virtual Anatomy / Visible Human Project etc.)

Anatomy, as such, forms the foundation for a number of related courses. Dentistry, nursing, surgery, orthopedics and ophthalmology are a few to name. Even the advanced imaging procedures (CT, MRI, PET) rely completely on the anatomical knowledge for proper interpretation of results. Hence the cadaver as a teaching / learning tool forms the pivot around which the present day innovative courses dealing with life sciences (medicine, biology, pathology, sports medicine, rehabilitation sciences etc.) revolve.

The majority of medical programmes running throughout the country are in continued need of anatomical material (anatomical gifts) in view of the far reaching pursuits encountered in teaching and research. In a number of places, the student - cadaver ratio (4-5 students : 1 cadaver) advocated by the governing bodies (Medical Council of India – MCI) is hardly met with owing to an acute shortage of cadavers. In most of the medical schools, even more than thirty students get to share only one cadaver for dissection. The paucity of anatomical material is bound to affect the quality of medical education and health related research projects. The process of plastination is currently being used for preserving the bodies in a form that emulates near natural one. Though plastinated bodies / body parts cannot substitute the real cadaveric teaching/learning completely, yet their contribution as real teaching/learning tools cannot be underestimated. Public display of plastinated bodies/body parts (to demystify the human body structure - Van Hagen's Body Worlds – Moore and Brown, 2004) has gained widespread publicity. Though presently, the process is an added demand on donated bodies, however, in the long run, it could help to some extent to combat the acute shortage of the anatomical material.

Awareness needs to be generated amongst the masses regarding the donation of body to science as 'an act that is morally and legally justified'. In the long run, one act of body donation benefits lives of so many other human beings! The ongoing race between medical care becoming more technically oriented on one hand and medical education becoming more procedure focused on the other, has further widened the already existing gap between humanistic values and materialistic values.

Though, in a majority of cases, the objective of body donation is service towards the society, yet there could be examples where donations are made to simply escape the incurring large funeral bills or to avoid the obligation of non caring relations. Hence, the procurement of bodies could either be from voluntary donations or from unclaimed bodies. The old homes and beggar homes, in our country, could be the alternative sources for procurement of bodies provided they are governed by befitting rules and regulations. Equally important in this direction is the identification of receiving centers. Such centers could be declared fit under well framed rules and regulations to receive unclaimed and non medico legal dead bodies for teaching / learning and research purposes. Whatever is the source, of procurement, donation could be denied in the case of autopsied bodies, decomposed bodies, subjects with excessive obesity or extreme emaciation, suicide-homicide bodies or those bodies which have simultaneously been used for organ donations. Hence, whether the body is acceptable as an anatomical gift for study and research purposes, is also determined by the circumstances prevailing at the time of death.

Impediments

The bitter truth that 'death is part of life' has to be accepted. Majority of people do not like talking about death and dying (fear psychosis). Many people think about body donation but only few are able to accomplish it. Also, the reluctance towards the subject matter is compounded both by the emotional as well as the moral bindings. The emotional component has its basis in the bond that holds the family members together and even the mere thought of disfigurement or piecemeal dissection of a loved one shatters their mind. Accordingly, the emotional involvements either on the part of donor itself or the family members might cloud the final judgment. It becomes imperative under these circumstances that thorough discussions of the would be donor with his / her family members regarding the decision to donate should be encouraged. At the same time, the concept that dignity and respect for those who donate is maintained at all the times, is a major source of comfort for the survivors. Many people think about body donation but only few are able to accomplish it.

Whenever a new idea or revised version of an older idea is introduced to the society, there is every possibility of its getting rejected or evoking a negative response. In very sensitive matters, understanding of emotions and perceptions rather than the philosophical and the rationale points determine the response generated. The age old saying goes 'whatever is forced cannot be forceful'. The basic concern, whether the announced idea projects a good image regarding the subject matter or not needs to be addressed. In order to make the concept more acceptable, the publicity policies regarding the subject matter have to be tailored perfectly keeping in mind the architectural design of the society. With time and continued perseverance, even the most vocal critics come to value the importance of the subject matter.

No doubt, it is a marathon job to motivate people for donating the bodies especially when the society is an amalgamated representation of diversified beliefs and blind faiths. However, the development of science and technology has provided the platform for logical and rationale thinking and the logical basis could be used to overcome the religious fanaticism and fundamentalism. Sensitization of masses towards the issue is the key point to be focused at. This could be achieved to some extent by building of trust among the masses. Trust needs to be built within the families as well as amongst the donors. Emphasis has to be laid on sensitive events like proper disposal of the body remains with respect and dignity after the proper utilization of the body for scientific study. Awareness programmes focusing on development of medical science and education and its role in patient care can generate a good response among the masses. This is especially true with a nation like ours where the literacy rate presents major variations from region to region and from state to state. In this direction, movements like 'Deh-Rashtrarpan' launched (Ramesh Satpute at Nagpur, India) with the objective of encouraging body donations in the society, can act as eye openers.

Problem solving

In the present scenario, the concept of 'voluntary body donation' remains a virgin field as yet, with deliberate as well as non-deliberate attempts to leave it untouched. This is the high time when importance of the subject matter demands understanding on priority basis for evaluating measures to enforce its wider dissemination. The need of the hour is to redress the problem by a multi prong approach.

Sensitization towards the subject matter is the key point. Identification of the target groups for evoking meaningful sensitization is an equally important subject. The universal approach of 'catch them young' can help the younger generation, who stand on the verge of facing innumerable dilemmas, to come forward. The government and non government agencies, policy makers, educationists and intellectuals should work together to chart out information dissemination programmes with the objective of targeting the right people in right time.

Counselling: Provision of guidance to people, who find themselves in tough dilematous situations, is one of the primary requirements which can help them in figuring out what to do. However, the guidelines need to be tailored in a fashion that these are acceptable to masses. The propaganda should be embedded in such a language that it carries a universal message (for young and old). Even though the collective action proves more powerful than the individual action, the sense of responsibility needs to be widened on the individual basis as well. At the same time, individual responsibility and individual decision making has to be given equal weightage.

Educational Centres and NGO's will have to put in their heads together to formulate the quantum of information which needs to be either communicated to the donors / families or received. How well informed is the donor / family regarding matters like handling of the body, approximate time period of keeping the body or the rites to be carried out (end of life care) remains the matter of concern. Proper preservation of the body with maintenance of proper records for individual identity is a must. This holds importance as there could always be a possibility of the body / body parts being recognized by a student, staff or laboratory personnel (McNeill PM et al., 2004). Such concerns need to be addressed carefully and adequately and confidentiality regarding identity needs to be maintained.

Legal aspects: Law enforcing bodies need to discuss and formulate laws which are feasible enough to be implemented. As of today there are no foolproof laws especially in case of unclaimed bodies to regulate this aspect. While formulating such laws, innumerable factors inclusive of vast expansion of the society, extreme climatic conditions, provisions for proper dumping of bodies etc. need to be considered.

There is an obligation upon those who formulate various policies to help those who do not have the needed expertise to acquire it. The combined efforts of national policy makers, government and non government agencies can play an important role in setting up the missions for assembling and preserving the bodies followed by their utilization at the expert hands.

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Some Ethical Issues Concerning Medical Reproduction In Portugal

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Abstract

After a brief introduction regarding infertility through the ancient ages up to the modern molecular techniques the authors focus on some proposals issued by the Ethics Council in Portugal which were discussed by the medical and scientifically community although there is a lack of legislation regarding medical reproduction and related issues in Portugal.

Key words: reproduction; ethics; legislation; embryos; stem cells.

Introduction

Infertility goes back to ancient times; paintings and sculptures found in pre- historic caverns link fertility to prosperity; indeed God's commandment to Adam and Eve (according to *Genesis*) quoted: " Be fertile. Multiply and colonize the world ".

In all civilizations the woman was the symbol of fertility but the difficulties to conceive implied different medical attitudes and had different feedbacks according to the woman's status in society. However the recognitions of masculine causes in infertility ranks with the Egyptian pharaoh civilizations when infertility was not considered as a divine punishment but faced as a disease requiring evaluation, diagnosis and treatment.

In the XIX and XX centuries there were remarkable advances in the infertility area. The diagnostic field was marked by modern imaging techniques, both ultrasound and endoscopes; hormonal assays and identification of genetic anomalies; in the surgical area conservative as well as minimal invasive treatments took place with special emphasis to microsurgery techniques and endoscope's surgery; regarding endocrinology reproductions new pharmaceutical tools led to the manipulation of the woman's " endocrine axis" making possible the suppression, induction and stimulation of the ovulation; finally in medical assisted reproduction there is the possibility of performing in vitro fertilization, sperm microinjection, oocytes and embryo culture media, cryo-preservation and different microscopic procedures involving gametes and embryos.

With molecular genetics the pre-implantation diagnosis opened the gates to potential embryo gene therapy. This type of therapy has already been achieved in animal models.

Reproduction and Ethics

Medical assisted reproduction has its implications in the areas of biology, politics and bioethics. There is a great deal of controversy going on but we are still lacking a formula to enable us to deal with all the ethic problems connected with the human reproduction. Infertility is nowadays a serious public health problem concerning around 20% of the worldwide population.

The State of Art in Portugal

Similar to what takes place in other European countries there are hundreds of thousands of Portuguese men and women suffering from reproductive problems and requiring treatment. One way of opposing infertility is no doubt medically assisted reproduction. On this matter the National Council of Ethics and Life for Sciences (CNECV) has already issued in July 2004 some revisited proposals which now need to be backed by the Parliamentary members.

1 . Criticisms to the CNECV proposals.

The CNECV proposals are meeting with a great deal of controversy from the medical and scientific Portuguese community. For example the proposals refer that one should avoid the production of extra embryos either than those meant to be transferred. Thus normally in a 35 or 36 year old woman the physician would only transfer two embryos and therefore only two reproductive ovocytes would undergo further development. With such a sparse number the ovocytes may not evolve into embryos or may originate embryos which may suffer a " developmental blockage"!

The way to bypass this problem would be to culture all viable embryos up to the 5th day of "in vitro" development allowing the medical staff to select which embryo or embryos would have a greater probability of implantation (one should recall that only 40% of the embryos arrive to the blast cyst stage or rather the 5th day of the developmental stage). In short no proposal (according to the Portuguese medical point of view) should define the number of ovocytes that will further develop into embryos! One solution would be to limit the number of embryos to be transferred to the uterus and to freeze the remaining embryos. There is a significant number of embryos that degenerates and such embryos should not be frozen ! The CNECV also states that "scientific research in human embryos is ethically legal but only when done in benefit of the embryos itself ! ". Now this statement doesn't make sense! There is no such thing as " research in benefit of the embryo itself ! " The benefit will only exist within the context of gene therapy ! But then again it won't be " research "! ; therefore this CNECV proposal is also very confusing !

The proposal also states that" the alternative and only faith is that of the embryo destruction" ; now the medical class and scientists definitely do not" destroy embryos"; if an embryo without quality to survive is transferred to a woman's uterus it will disappear ! This should be considered an embryonic death and not an embryonic murder !

2 . Some conclusions to the State Legislation and the Community

The politicians and the lay people should have a knowledge about what type of research may or may not be done with the non viable embryos. These embryos are obviously rejected and this perspective should be considered from the ethical, philosophical and even religious point of view !

At least 60% to 80% of the embryos have anomalies. In the majority of the cases these embryos are not viable. This applies to " in vivo" as well as to " in vitro" embryos. People should know that al least 40% of the ovocytes and about 10% of the sperm have chromosomal anomalies. Matching these with the anomalies that may result from the reproductive procedure, and the first embryonic divisions the conclusion that the majority of embryos are not viable seems pretty much obvious. If they are not viable they should be used to the benefit of Humanity! Embryonic cell evaluation is indispensable when using pre-implantation diagnostic techniques. Therefore there should also be legislation about stem-cell research aimed at the development of new cell and tissue based treatments for a range of diseases.

3. Latest developments

On the 8th National Seminar of the CNECV (November 2004) future proposals regarding stem cell research, pre-implantation diagnosis and cloning was focused. Scientifically and ethical issues viewed the stem cell as the ""hope cell"" having its birth in the crossovers of ideologies, philosophies,religious and moral issues. The stem cell basic properties, potential and limitations were focused; once again the fetal origin implied ethical and logistic problems! Nuclear somatic transference, the so called "cloning therapy" was quoted as one of the forms of obtaining stem cells; it was clarified that embryos not used for reproduction are normally cryo-preserved for donation to other eventual couples or used to derive stem cells to investigate their potential in cell – tissue therapy. From the scientific point of view some of the CNECV members favoured that "life does not begin with fertilization but is evolving continuously among individuals and generations ". On the other hand the philosophers seek the ethical and philosophical dimension of the embryo quoting that "when the embryo is a laboratory tool it becomes an unexpected artefact which one can't easily discharge from a moral circle but that society still doesn't envision how it could be embraced by this same moral circle!". There was also an input of the biotechnology enterprises focusing the use of stem cells in the development of new therapies. However catholic and board members of the CNEVC qualified the stem cell as a "society controversy" triggering a great deal of stress between science and ethics. Once again the legitimacy of abortion was brought up! (Portugal is one of the few European countries where abortion is illegitimate becoming a political issue between the Parliamentary parties). These members admitted that year or decades will be needed before reaching a consensus viewing the recent opening of other European countries to the use of stem cells. It was also quoted that the "resource to cell lineages would imply using lineages resulting from embryos destroyed by others rather than destroying our own embryos "!

4 – Position of the European Committee – EC- for Health Research

The dialogue between Ethics and Science according to the EC (represented by its director at the Meeting) should be based in the following criteria : a rational discussion viewing three landmarks namely: 1- The benefit of the majority of the society (the utilitarian view) 2 – "the Ethics of Human rights" or 3 – the Ethics of the Virtue - a partial compromise in favour of the vulnerable meaning of course the patient" ! Different points of views will "determine different solutions", other criteria will be decided by consensus with " no place whatsoever for a voting by majorities considering the awkward way of making decisions in Politics!"

In short, backing the opinions of other Portuguese colleagues and scientists I feel that not only there is a lack of legislation regarding the above mentioned issues (to be noted that up to this date there is no consensus in Portugal about the " status of the embryo") but that Portugal is postponing such legislation making it difficult for Portuguese scientists to carry on their research projects .

Artificial Reproduction Technologies and Ectogenesis

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Reproduction is highly valued in all cultural traditions; "BE FRUITFUL, MULTIPLY AND FILL THE EARTH" is a basic command that appears already in the first chapter of the book Genesis. This command has influenced the Judeo-Christian tradition ever since and today the right to reproduce is recognized as a basic and fundamental human right. However, there have always been infertile couples; today medically assisted reproduction has solved many problems of infertility among couples that have been unable to have a child naturally. Hence, the development of artificial reproduction technologies (RTs) has enabled people to fulfill one of the most fundamental rights. Yet this welcomed development has created, new concepts of reproduction, challenging settled precepts and established moral values.

The first 'tube baby', Louise Brown, was born in 1987; since then, many other babies were similarly conceived in a petri-dish. Today, conception of a human being is not restricted necessarily to the Fallopian tubes, and/or inside a woman's body, and IVF has become almost a routine medical procedure (Silver 1998; Stock 2002). There has also been an extraordinary development at the end of gestation: Incubators were first used in order to save the lives of newborns in severe distress immediately after delivery. However new knowledge and improved technology have made it possible to redefine the limits between viable and non-viable newborns. Today, incubators may keep embryos of just 500 grams that may have spent only 24 weeks inside a woman's womb (Sills 2003).

Between the fertilization of the ovum (even if this happens in a petri-dish) and delivery (even if this happens prematurely) there is, however, a significant and critical gap, which at present can only be carried out inside a woman's womb. This indispensable stage in embryo development together with IVF technology has produced a new concept of 'host' mothers since only a woman's womb can provide the right environment for an embryo.' Host mothers' have already solved the problem for women who because of physiological difficulties cannot become mothers, or alternatively, for homosexual male couples that may want to rear a child. The notion of 'host mothers' however, has created difficult psychological situations for the parents involved and sometimes difficult questions to be resolved by the legal system (Daniels 2002).

There is no alternative for a woman's womb today; however, it is not unreasonable to think that the idea of 'host' motherhood along with due research and improved technologies may result in the development of the artificial womb (Smith 2002; Butler 2002; Bailey 2003; Mckie 2002; Rae 2002) and eventually, ectogenesis – full gestation outside the womb (Harris 1998). Such a scenario is still hypothetical; it has been used only in science fiction horrors in both novels (Aldous Huxley's 'Brave New World' for example) and movies (George Lucas' 'Phantom Menace'). However, this idea also appears as a matter of fact in some thought experiments (Strong 2002); others regard gestational surrogacy as an actual necessity 'only' until the artificial womb is fully developed (Ber 2000).

To overcome the existing gap between both ends of gestation will not be easy; and an artificial womb still does not mean full ectogenesis. But the development of novel RTs due to the desire to procreate is extreme. These developments have already driven us beyond the theoretical limits of ethics, and formidable work has been done to keep pace reaffirming and re-defining moral values (Glover 1984; Harris 1998; Heyd 1992). But the ethical legal and social implications of full ectogenesis, seem to be a step in RTs that may challenge again almost all universal human values and ethical principles; and, we may now find ourselves confronting full ectogenetic technology before we understand its social consequences, worked out an ethical framework and have had time to elaborate appropriate legal boundaries. Equally, there is the risk that without working out properly the ethics, the social and legal implications of ectogenesis we might apply old precepts to an entirely new problem (Hare 1985).

This paper addresses what appear to be the next steps in RTs, namely the artificial womb and ectogenesis. I will focus mainly on two points: the actual development of an artificial womb and conventional roles of women in reproduction.

The artificial womb.

IVF has permitted to disconnect the fertilization process from the womb that will actually host the fetus. Hence, the idea of surrogate motherhood has become possible. But there have also been cases of pregnant women in persistent vegetative state [PVS] who have reportedly been kept alive until the child is born (Akabayashy and Morioka 1991); thus furthering the idea that the womb is the organ that incubates babies and which just happen to be inside a woman's body. There is already a suggestion to permit the use of wombs for surrogate gestation in cases of PVS, after modifying the organ donation card to include also these instructions (Ber 2000). It is not the aim of this paper to discuss Rosalie Ber's proposal; however, for the purpose of this paper regarding the advent of ectogenesis, Ber's words merit closer attention. She writes:

> In view of the de-personalization of the gestational surrogate mother who functions as a 'womb for rent' … why not permit using the wombs of women in persistent vegetative state [PVS], female bodies kept viable by artificial means, *until technological perfection of an artificial womb is achieved*? (Ber 2000, my italics).

Ber appears to be *certain* the technological perfection of an artificial womb will be achieved, eventually. Of course, she might be wrong, but Rosalie Ber, obviously well acquainted with the subject, explains further:

> The technological perfection of an artificial womb is still in its *elementary stages*. Today's technology enables maintaining the first 2 weeks of the life of a pre-embryo in vitro, as well as maintaining 24 week old premature newborn babies in neonatal intensive care units (albeit with considerable morbidity and mortality) an appropriate artificial womb is needed to bridge at

least the 22 weeks in between. To improve survival the artificial womb it needed for full gestation – i.e., an additional 38 weeks (Ber 2000, my italics).

From these words some would perhaps feel relieved, for this shows clearly that the artificial womb is not yet available. Others however, may understand that Ber more than merely hints about the actual development of this new technology. Ber uses the words 'need' regarding artificial wombs - several times. Basically, 'need' is the first step by which any new technology develops and potential profit fuels further development. Surely, the 22-weeks gap might be difficult to overcome and will not occur in one step; but neonatal care, joining other research areas such as gynecology, embryology and stem cell research may finally end up in ectogenesis.

Moreover, the development of an artificial womb may not be controversial because it would center at improving neonatal intensive care. There is already a database that tracks outcomes for 4,127 babies 401 to 500 grams. This weight group of micro-preemie is considered 'experimental' (mortality in this group approached 90%); however, some believe that an 'artificial placenta' can be used. Jack Sills from the Intensive Care Nursery, University of California for instance, observes that,

> [i]t would be ideal to continue the in uterus environment, keeping the premature infant in a warm water bath (free of infection) attached to its artificial placenta. Under ideal physiological conditions the premature would grow and develop normally, free of injury (Sills 2003).

Sills adds cautiously that he does not know if this idea 'is ever going to make its way'; but if it does, there will be little disagreement for using this new technology if it would mean avoiding morbidity, mortality and improving neo natal care.

Infertility and the 'womb factor'.

Whilst it would be difficult to find opponents for developing new ways of care for improving survival and prognosis for 'premies' and even for 'micro-preemies', paradoxically, the beginning of gestation is viewed very differently: Research on human embryos after the 14th day of gestation is not permitted in most countries, yet embryo research in other mammals is not restricted (Knight 2003).

Moreover, today universal rights such as the right for reproductive freedom and the right for privacy have dictated in the US, for instance, constitutional laws that may allow the use of ectogenesis; the framers of such laws did not have ectogenesis in mind when they developed them (Hibbert 2003). Besides, should the desire and the basic right to procreate be *solely* restricted when infertility results from the so called 'womb factor'? This kind of infertility can be due to congenital absence of the womb, primary or secondary anatomo-pathological malformations of the womb, and surgical removal of the womb for various reasons, myomatous uterus and multiple spontaneous abortions (Sperof, Glass and Kase 1994). In this type of infertility both partners usually produce normal gametes, but the only way today these couples can procreate is with the aid of another woman's uterus. Today this can be possible only using a gestational surrogate.

Some countries (the US, for instance) permit private surrogate agreements and do not intervene; other countries (Israel) have formulated clear legislations for surrogacy; still others (Canada) have formulated clear legislation against surrogacy. The Canadian law also has ruled out any research that may 'lead' to Ectogenesis. However, ectogenesis may be the answer for those who cannot reproduce because they lack a womb, for both infertile women and homosexual couples. Moreover, ectogenesis might also appeal to women (and men?) who are perfectly normal. Women who want to develop a career, women that have already developed one and have become too old to bear a baby naturally; finally (or firstly?) to 'just' ordinary women, who until now have not had another choice but to become pregnant if they wanted to have a child. This would certainly imply a revolution in RTs far from the more 'conservative' revolution presently happening in this area.

Present RTs: back to the womb.

In the bible the word 'woman' is used interchangeably with the word 'רחם' which means 'womb' the translation of these passages to English uses the word 'girl' instead (Judges, 5, 30);. However, RTs and especially surrogate gestation where the gestational surrogate functions as a 'womb for rent' remarks vividly and unavoidably that women may still be perceived - and used - as wombs on legs. For RTs the womb has become detached from women bodies, the discussion focusing on the fetus and the future child (Stacey 1992). The womb reappears as an organ inside a woman's body only in the context of the abortion. RTs may have also encouraged women to assume further health risks; yet, reproductive hazards have traditionally been viewed as women's fate and therefore - taken for granted. Candidly in this view, some explain that 'maternity is not a disease' but, 'an essential function that women fulfill for the survival of our species' (Cook, Dickens and Fathalla 2003, 396). The problem with this (correct) definition of maternity is that although this is not a disease, this is not exactly a very 'healthy job' either (I will return to psychological effects in a moment). Although during the last century women's death during or immediately after labor has been dramatically reduced at least in the developed world, pregnancy and birth still compromise women's health. The potential dangers and actual burdens of maternity have been conveniently camouflaged under mystification and decorated further with motherhood appraisal. But the unspoken truth is that women had to accept their role in reproduction because there was not another choice; surely it was preferable to perform the necessary but hazardous task under the incentives of 'added value'.

Future RTs: escaping the womb?

Most tellingly, in Jewish prayers, a man thanks god each morning for not having made him a woman. By contrast, a woman thanks the almighty for having made her 'as HE wishes…'. Obviously, the anonymous writer of these prayers understood the value of being spared the burdens and dangers of 'womanhood'; equally, he knew nothing about 'political correctness' (although the 'orthodox' interpretation of these prayers is the number of commandments incumbent on men as opposed to the fewer numbers on women, slaves and non-Jews). The advent of contraceptives gave some women the opportunity to escape partly from their fate as the carriers of the human womb. Some women welcomed this advance of scientific knowledge in order to plan a family; a new way of life begun for women, in an era in which their womb stopped ruling absolute in their lives. Yet, women could not avoid *all* pregnancies, if they still wanted a child. Would women now want to embrace artificial womb technology if available (and safe)? This would allow women to avoid the burdens and perils of a pregnancy and yet enjoy parenthood - as men do. But whilst this answer may appear satisfactorily unproblematic, it raises immediately a second question: if women choose to walk out from their traditional function as the carriers of the human womb - would it be wrong? Of course, in this complex issue there would be many other questions (one of the most puzzling questions is that men might not need women for reproduction purposes) but for the purpose of this paper I will focus on women's perspective.

Dominant discourses.

Well-established beliefs would certainly play a central role in answering any questions in this issue. Today motherhood is valued rhetorically (even though it has little material and social status) non-motherhood is defined as 'lesser'; equally, dominant discourses concerned with expectations of women, the value of biological identity and power of medical science have joined and support each other (Letherby 2002). The first almost unquestionable assumption is that motherhood and non-motherhood is a significant difference in women's lives (Dowrick and Grundberg 1980). This most probably, is true; yet, women have traditionally been so deeply conditioned into motherhood that non-motherhood has practically been a non-choice. As a female physician explains:

It sounds like I was deciding to have a baby for this reason or that. The fact is that I never decided at all I would or I would not have a baby. I never consciously felt I had a choice. I always assumed I would get married and have a child. It was part of a sequence that was already set up for me. I just knew I would be a mother. Every woman was. …Having a child is still so expected of us, so programmed into our development… (Friday 1979, 433).

Another belief is that women who do not conceive are 'desperate' women; yet many women may play this role if they must, in order to get a child; however, whilst women want a child, it is not necessarily a pregnancy that they want (Letherby 2002). We may find this quite surprising; yet men also enjoy parenthood, without having necessarily to become pregnant. Although some men may claim that they would like to 'experience motherhood' this is easily said because they know they cannot.

Top women and novel RTs.

In 1999, Rosalind Coward suggested that "we need to understand how people are living their lives and making their choices without preconceptions about men being one thing and women another" (Coward 1999, 219). Clearly however, men are one thing; by contrast, women, markedly, are *still* a very different thing: in labor wages, in power and in academic rungs; and, in their extremely demanding reproductive role. Equally, there is a clear connection between women's inequity and their necessary role in reproduction.

The higher price women pay due to their role in reproduction may be seen better from the perspective of women who have ignored the 'ticking clock' of the reproductive years in order to make it to the very top of their careers: 42 percent of women in corporate America are childless at age 40 compared with 25 percent of men. But only 14 percent of women 'planned' to be. This means that a large proportion of these women have become childlessness as a 'creeping non-choice'. Moreover, whilst almost half of all professional women are childless at age forty, the more the woman succeeds in her career the less likely is that she will have a partner or a baby.

For men, the opposite is true: the more successful the man is professionally, the more likely it is that he will be married with children (Hewlett 2002). This is hardly surprising, because at the age of forty, men are still in their fertile prime and for many years - while women at this age have almost reached the age limit for a successful pregnancy. So even though women may have successful careers, the price that too many women are required to pay in order to reach exactly the same goal as men is much higher. Women thus, may find themselves trapped by 'the womb factor' sooner or later, in one way or the other.

Ectogenesis therefore, if safely worked out, may have great appeal to women who want to pursue a successful career without being obstructed by their biological clock from having simultaneously a successful pregnancy and a child. Some women (but not only) might welcome the advent of ectogenesis; other women (but not only) may feel highly threatened by this prospect. While may be inclined automatically to overrule the idea of ectogenesis, the idea contains some merits, particularly related with women's health and equity. If this is so then, as with any other technological development, any danger should be clearly defined.

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What's Morality Got to Do With it? The Need for

Principle in Reproductive Technology and Embryo Research

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Abstract

Recent advances in biology hold out the real possibility of significant progress in the treatment of disease. At the same time however these technological discoveries have posed serious challenges to policy makers, the decision by the UK Court of Appeal in *Zain Hashmi* being a case in point. Judges and legislators have traditionally tried to apply principles of justice in the matters that lie before them. Future issues that involve genetic technology have the potential to involve more than this since they imply an imperative to redefine ethical perimeters. However the new genetics goes beyond this and necessitates redefining human perimeters as well. This paper considers a position broadly known as *consequentialism* – in which outcomes are to be as good as possible - and argues instead on behalf of an approach to bioethical issues which demands consideration of the fairness of the procedures employed.

Within the last decade, dramatic advances in the field of biotechnology (including the Human Genome Project, cloning and stem cell therapy) have raised the prospect of new and radical approaches to curing disease. These developments have also led to significant breakthroughs in the field of human reproductive technology. Bryan Appleyard has recognized the full significance of this and has described the modern genetics project as being nothing short of "a unique combination of philosophy, science and technology that confronts humanity with the most fundamental questions, our answers to which will determine the human future."[2]

Genetics today places us at a vital moment in human history where we can choose not just how we are going to live, but who we are going to be. It is a big global moment, but it is also an intimate, human moment. It affects not only politics, economics and ethics, but equally the most private aspect of our lives. Historically it is unprecedented. [3]

There is no question that these discoveries have been at the center of an insatiable quest for knowledge both in terms of scientific importance as well as popular interest. However after 25 years since the first test tube baby was created, these same scientific breakthroughs have forced legislators, judges, academics as well as those on the edge of medical research to consider a foundational ethics setting out normative perimeters into such areas. Indeed the issues that the new genetics bring involve more than this since they imply an imperative to redefine ethical perimeters. However the new genetics goes beyond this and necessitates redefining human perimeters as well. Furthermore, events do not have a habit of waiting for consensus to be reached about a possible ethical foundation for genetic research or treatment. These issues are forcing courts to deal with them as they develop from these same technological advances.

The recent Court of Appeal decision in the *Zain Hashmi* case is but one instance where conflicting interests resulting from recent medical advances have called for the interpretation of formal rules concerning this rapidly growing and at the same time controversial area of scientific endeavor.[4] While it is not in doubt that laws and regulatory guidelines have already been refined as a result of the rapid developments in biotechnology, the underlying principles upon which such legislation is ultimately to be based, matter greatly. There is no denying that the task of doing so is not an easy one. To quote Lord Phillips of Worth Matravers MR in *Hashmi*, "No one can doubt the difficulty of legislating against a background of fast-moving medical and scientific development. It is not often that Parliament has to frame legislation apt to apply to developments at the advanced edge of science." [5] And the same can be said about judges when confronted by similar developments.

Furthermore, these issues are set not merely against a framework of local or national jurisdiction but within a global one, in which individuals increasingly will seek medical treatment or therapy in whatever location best suits their own perceived needs. It is no longer feasible for legislatures or courts to shut the door on a given procedure or treatment with the expectation that either the technology or the ethical issues that underlie it will go away.

It is vitally important then, that in response to these developments, there be an extensive and rational discussion in which the full implications of these emerging technologies be considered. This paper attempts to contribute to this discussion at a time in which there is great excitement surrounding the prospect of enhancing the quality of human life, but along with this, a growing level of anxiety surrounding not only the implications of science, but over the future of our humanity. I will attempt to focus on the ethical and legal considerations which have arisen as a result of certain related biomedical discoveries, including embryonic stem cell research, and specifically, human leukocyte antigen testing (tissue typing). In this context, I will also consider the wider issues that these technologies imply in terms of consequentialist and deontological approaches to justice.

The *Zain Hashmi* case

The facts in *R (On the Application of Quintavalle) v Human Fertilization and Embryology Authority* (hereinafter *Zain Hashmi*) are as follows: Zain Hashmi was a four year old boy, the fourth of five children born to Raj and Shahana Hashmi. Zain had been born with a serious blood disorder known as beta thalassaemia major (BTM). In order to stay alive, he required regular and intensive treatment including a cocktail of drugs and blood transfusions. However even given this treatment, medical experts determined that his long-term life expectancy was not good. Mrs. Hashmi sought help from physicians who informed her that stem cell tissue taken from the umbilical cord of a sibling with matching genetic material could be used in a bone marrow transplant in order to treat Zain's illness. Wishing to find a suitable match, Mrs. Hashmi subsequently conceived, however prenatal testing found that the embryo also carried the BTM gene. She aborted and later produced another child which was carried to full term. Unfortunately the baby in this instance was not a suitable genetic match for his elder brother, Zain.

Mrs. Hashmi and her husband then explored the possibility of employing in vitro fertilization (IVF) together with a newer technology termed, "pre-implementation genetic diagnosis" (PGD). Here, fertilized eggs created in a laboratory are

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[1] I am grateful to Jean Bethke Elshtain for the title. I am especially indebted to Professor James A. Clapp for comments which he offered to me during the preparation of this paper

[2] B. Appleyard, *Brave New Worlds: Staying Human in the Genetic Future* (Harper Collins 1999) p. 3.

[3] Ibid.

[4] *R (On the application of Quintavalle) v Human Fertilization and Embryology Authority*, [2003] All ER 257; [2003] 3 WLR 878.

[5] *R (On the application of Quintavalle) v Human Fertilization and Embryology Authority*, [2003] All ER 265-66.

screened first for the genes that carry the disease, and then in order to determine whether the embryo is a genetic match with the intended recipient. The screening is done approximately three days following the IVF procedure at a stage where the embryo has divided into eight cells, one of which is removed and tested with a genetic probe. Here the DNA sequence taken from the cell is tested for tissue match and for the thalassaemia disorder. This process involves the use of proteins called, "human leukocyte antigens" (HLA) more commonly referred to in the literature as "tissue typing".

In order for this process to be carried out, the relevant U.K. legislation, the Human Fertilization and Embryology Act (1990) required that a license be issued by the Human Fertilization and Embryology Authority ("the Authority") the statutory body empowered to oversee and regulate matters relating to human fertility and genetic screening.[6] In February 2002, the Authority announced that it would issue a license relating to this matter conditional upon several restrictions. These guidelines included *inter alia* that the condition of the child to be treated was life threatening, that the embryos to be tested should also be at risk from the same condition affecting the child, that (presumably in other cases) the treatment should not be offered where the intended recipient is a patient, that only the umbilical cord be used in the treatment, and that embryos should not be genetically modified in order to find a tissue match. [7]

Mrs. Hashmi made two attempts to conceive a child employing both in vitro fertilization (IVF) and the aforementioned screening process, PGD. However, both of these attempts failed at producing a pregnancy. In December 2001, the claimant, Mrs. Josephine Quintavalle acting on behalf of the group, Comment on Reproductive Ethics (CORE) sought and obtained permission to judicially review the Authority's decision granting the license. The decision issued by Maurice Kay J. in that same month quashed the decision to issue the license permitting the continued genetic screening of embryos for tissue suitability.[8] In setting out its decision, Maurice Kay J. stated "[t]he task of the court is legal rather than ethical". [9] Instead, the court based its decision on the grounds that first genetic analysis of a cell taken from the embryo involved the "use of an embryo" requiring a license under the act. The second question before the court was whether the analysis of a cell for tissue genetic screening and tissue typing "necessary and desirable for the purpose of providing treatment services" under the act. [10]

The court found that regarding the first question, a license was necessary since the procedure did involve the use of an embryo. Regarding the second issue, the court applied a strict definition of applying tissue typing to the ability of a woman to carry an embryo after implementation. It was found that the procedure did not meet the statutory criteria of being "necessary or desirable for assisting women to carry children." [11] The Authority appealed against the decision.

The Court of Appeal decided that the lower court had erred in law by applying too narrow a construction of the definition of "treatment services". The court went on to hold:

Where the object of the treatment is to enable a woman to bear a child confident that it will not carry a heredity defect, an embryo will only be suitable for the purpose of being placed within her if it is free of that defect. PGD is thus designed to secure that that embryo is suitable for that purpose.[12]

The court also pointed out that "[w]hen the Act was passed women who had reason to fear that they would give birth to children with genetic defects were probably the only section of the population for whom it was envisaged that IVF treatment could be justified on this basis". [13] In its conclusion, the court observed that times had changed considerably since the passage of the Human Fertilization and Embryology Act. Establishing that the purpose of the treatment was to (a) create a set of embryos, (b) screen the embryos for instance of genetic defect and (c) screen the embryos for the "desired characteristics" of tissue compatibility with his elder brother, the court argued the following:

[W]hether the PGD has the purpose of producing a child free from genetic defects, or of producing a child with stem cells matching a sick or dying sibling, the IVF treatment that includes the PGD constitutes 'treatment for the purpose of assisting women to bear children'. [14]

As in the initial judicial review, the tone of the decision by the Court of Appeal was very much set by Pannick QC (appearing for the Authority) who asserted that, "the issue (before the court) is *not one of ethics* but of statutory construction (emphasis added)". [15] Indeed, statutory construction (and not ethical questions) provides the basis upon which this case is framed. It would seem then that the decision by the court was very much founded upon a *consequentialist* approach, in other words, that the decision was based on standards that tend to consider the kinds of results that it tends to produce. [16]

It is understandable that in this particular case where the court was faced with a decision that had the potential to save the life of a four year old child, the court felt compelled to rule in the way that it did. But the fact that the court chose to ignore the moral issues involved is significant. Although judges may be reluctant to deal with moral principles in their decisions, there are times when such consideration becomes necessary. Lord Justice Hoffman's judgment in *Airedale NHS Trust v Bland* stands in marked contrast to the reasoning in *Hashmi*. In *Bland*, the House of Lords was asked to decide on whether to allow the withdrawal of life-support treatment. Here, Anthony Bland, a 21 year old man had been put into a persistent vegetative state some four years earlier as a result of being suffocated during the Hilllsborough football stadium tragedy.[17] In his decision Hoffman sets out the reality of the moral issues that confronted the court as well as the public:

People are worried, perhaps not so much about this particular case, but about where it will lead. Is the court to assume the role of God and decide who should live and who should die? Is Anthony Bland to die because the quality of life is so miserable? Does this mean that the court would approve the euthanasia of seriously handicapped people?…This is not an area in which any difference can be allowed to exist between what is legal and what is morally right.[18]

In continuing his reasoning Hoffman set out to insure that the principles on which the judgment was based would not lead to "morally unacceptable decisions in the future". He did so by considering the foundational principle of the sanctity of life along with another fundamental moral principal, that of the respect for individual human autonomy. [19] In upholding a decision to withdraw life-support, Hoffman acknowledges that

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[6] Human Fertilization and Embryology Act 1990, Halsbury's Statutes (4th Edn) (2001) 291, 332.

[7] [2003] 3 All ER 260.

[8] [2002] 2 All ER 105.

[9] [2002] 2 All ER 108.

[10] [2002] 2 All ER 110.

[11] [2002] 2 All ER 111.

[12] [2003] 3 All ER 270.

[13] Ibid.

[14] [2003] 3 All ER 271.

[15] [2003] EWCA Civ 667; [2004] QB 168; Online. LexisNexis® Academic. (21 July 2004).

[16] D. Parfit, *Reasons and Persons* (Oxford UP 1986) 24-5. "There is one ultimate moral aim: that outcomes be as good as possible."

[17] *Airedale NHS Trust v Bland,* [1993] 1 All ER 821.

[18] [1993] 1 All ER 849.

[19] See Dworkin, *Life's Dominion*, (Knopf, 1993) 224: [T]he value of autonomy…derives from the capacity it protects: the capacity to express one's own character-values, commitments, convictions, and critical as well as experimental interests-in the life one leads.

this is a case in which a conflict between these two moral principles required a "painful compromise" to be made. In this case the ultimate compromise was based on the court trying to decide best as to what Anthony Bland himself would have chosen, based upon a respect "to allow him to die and be mourned by his family that to keep him grotesquely alive".[20] It was according to this principle-based mode of reasoning that the *Bland* case was decided. Now as the boundaries of biotechnology expand into ever more controversial areas, there is (like in *Bland*) a corresponding need for systematic ethical thinking regarding the implications and normative issues that these technologies impose on society.

No slippery slopes or free-for-alls

Despite the reluctance to consider the moral implications, the Court of Appeal in *Hashmi* did suggest that this decision was not to be seen as eliminating *all* legal restrictions on genetic tinkering:

> It is (however) plain that while Parliament outlawed certain grotesque possibilities (such as placing a live animal embryo in a woman or a live human embryo in an animal) it otherwise opted for a strict regime of control. No activity within this field was to be left unregulated. *There was to be no free for all* (emphasis added). [21]

But while the learned judge offered the briefest comment on what he considered "grotesque practices" he did not go on to set out what has been referred to in the literature of bioethics as a "bright line" as to enable the evaluation of what practices are acceptable (and what are not). And unlike Hoffman in *Bland*, the *Hashmi* decision did not consider the underlying moral principles. The decision, based as it apparently was on assumptions of a favorable outcome does not offer any real guidance as to the underlying values which serve to establish the ethical quality of those practices. In this respect one must ask, how is this case to set out legal rules in future disputes involving screening for other characteristics?

This problem has now become more than an academic one and the threat of those "morally unacceptable" decisions referred to in Bland is a real one. Already, tissue typing is being carried out in the United States with the intended purpose of sex selection as opposed to screening for life threatening diseases.[22] Beyond these practices, the field of genetic screening offers the promise in the not too distant future, of screening embryos not only for diseases (such as BTM) but for other more fundamental applications as well. The implications of genetic technology are profound. Could a consumer-driven demand for desired traits in children begin to alter the idea of human reproduction? In other words, does the advent of this procedure of tissue typing (or for that matter the project of the new genetics as a whole) pose the ethical "slippery slope" that will potentially lead to the same "grotesque practices" as described by Lord Phillips in *Hashmi*?

Indeed, one can reasonably foresee that in the not too distant future, similar screening could theoretically be done regarding height, intelligence, alcoholism and (with the isolation of a "gay gene") being able to screen for the trait of homosexuality. In an effort by parents to have the best possible child, the line between screening for disease and for the "best traits" may well become increasingly blurred. As the philosopher Peter Singer has famously argued in a lecture at Stanford University, "…for most parents, giving their children the best possible start in life is extremely important". [23] According to Singer's reasoning, it is unlikely to suppose that a couple would feel that carrying a child with a disability (such as Downs Syndrome) to term will equip him/her with the best possible start. Singer's conclusion here is that just as it is reasonable to abort fetuses with disabilities such as Downs, it is also just as reasonable to select children for intelligence, height and even aesthetic appeal. Consider Singer's position regarding the prospect of an ethical "slippery slope":

> …to say that the future just sketched is no nightmare, but a better society than we now have, one full of healthier, more intelligent, taller, better-looking – perhaps more ethical? – people. There is therefore no "slippery slope" because the slope is not down to an abyss, but upward to a higher level of civilization than we have achieved so far. [24]

Yet on closer examination, such reasoning is flawed. As F.M. Kamm has pointed out, Singer's application the principle of individual free choice tends to break down when "some are given the right to determine the outcome for another person – namely a child". [25] Furthermore, Singer's claim that what amounts to a form of voluntary eugenics could somehow produce more ethical people is very much open to doubt. But in a wider context Singer's thesis on behalf of a genetically-engineered social upland must be earnestly addressed with regard to the future. This is because of the fact that the frightening legacy of the eugenics movement of the last century cannot easily be ignored. The history of the genetics movement of the last century (brought to its extreme position in the form of Nazi policies of "racial hygiene" that included in its agenda forced sterilization, euthanasia, and ultimately murder) cannot be easily ignored. The legacy of the eugenics movement ought to heighten existing serious concerns over any new introduction of normative notions of "desirability" into the implications of the human genetics project.

Furthermore, as the frontiers of genetic knowledge are pushed back, might we not also become victims of applying human prejudices along with this new genetic technology? A similar application of imperfect knowledge to preconceived bigotry was certainly the case for the (now discredited) eugenics movement of the nineteenth and twentieth centuries. [26] Allan Buchanan, Dan Brook Norman Daniels and Daniel Wikler writing on the implications of the new genetics raise the prospect of, "whether, like the sorcerer's apprentice, we will suffer the consequences of partial knowledge, overestimating our power to predict and control the causal chains we initiate through the application of our newfound knowledge".[27] But at the same time they also consider the need for an accompanying set of values that can clarify what practices are ethical and what are not. The question they raise in this context is, "[e]ven if we were more assured than we should be that out technical control will be complete, we would continue to wonder whether we will be able to distinguish between *what we can do and what we ought to do* (emphasis added)." [28]

The history of the eugenics movement can be ultimately be traced to Plato who argued that far from being created equal, man is born to a particular position in life and the harmonious society is one in which all individuals serve within their own appointed station.[29] A key question to ask here is how closely

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[20] [1993] 1 All ER 853.

[21] [2003] 3 All ER 266.

[22] See the American Society for Reproductive Medicine's Ethics Committee Report on "Preconception gender selection for nonmedical reasons" at: http://www.asrm.org/Media/Ethics/preconceptiongender.pdf .

[23] P. Singer, http://www.petersingerlinks.com/supermarketprint.htm (2 August 2004).

[24] Ibid.

[25] F. Kamm, "Genes, Justice and Obligations to Future People", *Social Philosophy and Policy*, Vol. 19, No. 2, (2002) 365.

[26] Buchanan et al, *From Chance to Choice, Genetics & Justice* (Cambridge UP 2000) 28-46.

[27] Buchanan et al, *From Chance to Choice*, 4.

[28] Ibid.

[29] Plato, *Republic*, Trans. Robin Waterfield (Oxford UP 1993) (Chap. xvi, v 458-59) 172. In the *Republic*, Plato makes reference to "breeding stock" in animals. He then makes the comparison to breeding in human beings and reasons that to allow "unregulated unions" would result in what he calls, "profanation". Plato's concept of profanation is at the heart of twentieth century eugenics (referred to as "degeneration").

does the new project of genetics resemble the old project of eugenics with its own fundamental prejudices? While it is possible to argue that the "old" eugenics was based on imperfect knowledge, the same genuine concerns can be held about the genetics of the twenty-first century.

Foundations of principle

These questions go to the heart of any jurisdiction's policy review concerning biotechnology. In the context of a discussion concerning the issue of ethical foundations upon which any future biotechnology guidelines ought to be based, I argue that in terms of consideration, foremost ought to be that of justice and equal concern for the dignity of persons.

In terms of a philosophical approach to the question of human value, the tradition of belief referred to as Judeo-Christian teaching is based upon the fundamental idea that all persons are equal before God in terms of intrinsic value or moral worth. In Jewish and Christian thought, it is held that all persons have been created in God's own image and all will ultimately be judged according to their deeds and not by birth or social status. This idea, of every person possessing an immortal soul, equal in worth before God had the effect of undermining ancient notions of a hierarchy of human value. Its central principle of the equality before God of all human beings, serves as a bedrock principle for modern institutions of justice.[30] And even though this theist orthodoxy of moral egalitarianism has been exposed to successive challenges by both secular philosophies and the relentless advance of scientific knowledge, it has nonetheless served as a core belief of ethical thought.

Kant and the centrality of the individual

The Categorical Imperative (CI) is intended by Kant as a secular means of establishing moral truth and a basis for right action. In this regard Kant makes his own case for the moral bright line that differentiates between what kinds of actions are ethical and what are not. It carries the significant ethical assertion that if a person is treated merely as a means to an end then such a person is diminished in her own humanity. Only by treating persons as "ends" in themselves do we show proper respect for them. In *Metaphysics of Morals,* Kant makes the equally important distinction between a "Doctrine of Right" and a "Doctrine of Virtue". Referring to the former, Kant argues first and foremost for a right to individual freedom: "Freedom (independence from being constrained by another's choice), insofar as it can coexist with the freedom of every other in accordance with a universal law, is the only original right belonging to every man by virtue of his humanity."[31]

He speaks of an inherent sense of right and wrong which sets human beings apart as morally significant agents. For Kant then, the individual is seen as a moral being who as such possesses a sense of dignity and as such is worthy of respect:

> But a human being regarded as a person, that is, as the subject of a morally practical reason, is exalted above any price; for as a person (*homo noumenon*) he is not to be valued merely as a means to the ends of others or even to his own ends, but as an end in himself, that is, he possesses a dignity (an absolute inner worth) by which he exacts respect for himself and from all rational beings in the world. He can measure himself with every other being of this kind and value himself on a footing of equality with them.[32]

According to this view, human beings are understood as being moral agents that possess an inherent dignity. From this it follows that they possess certain fundamental rights. The significance of this idea is that it helps to establish human rights *as an entitlement,* without resorting to any particular faith or religious doctrine. Yet at the same time this entitlement does not amount to licence. Ian Ward writing on the contemporary Western obsession with rights is correct to point out the error of stressing the Doctrine of Right at the expense of the Doctrine of Virtue.[33] In this regard, Kant expresses this idea in terms of a duty to respect others:

> All duties involve a concept of *constraint* through a law. *Ethical* duties involve a constraint for which only internal lawgiving is possible, whereas duties of right involve a constraint for which external lawgiving is also possible. Both, therefore, involve constraint, whether it be self-constraint or constraint by another. Since the moral capacity to constrain oneself can be called virtue, action springing from such a disposition (respect for the law) can be called virtuous (ethical) action, even though the law lays down a duty of right; for it is the *doctrine of virtue* that commands us to hold the right of human beings sacred.[34]

In further explaining the "Duty of Beneficence" - which Kant regards as the maxim of making others' happiness one's end - he argues that ultimately such a duty is in the common interest of all.[35] What follows from this assertion, is that institutions of power are under a duty to treat people under their various jurisdictions with "equal concern and respect".[36] This same duty, which is owed to people by their governments, is a central part of an overall argument for human rights that has been expressed not only by Kant, but also by successive advocates of liberalism (including John Rawls and Ronald Dworkin). One of the inherent strengths of Kant's moral philosophy is that it is able to accommodate diverse views about what a just society ought to be.

Principle and disagreement

I have made this point previously with regard to Kant's relevance to human rights in the context of a Rortyan world of philosophical pragmatism where the absence of universal moral truth threatens to undermine the core values of humanity upon which any meaningful view of human rights is based.[37] In response, Jean Bethke Elstain has written eloquently about this same issue. She argues that while Rorty's point that "everybody tries to whip up a story according to which he or she did the right thing" and nobody "knowingly does evil" may be allowed, there is an obligation on the part of us all to distinguish between such stories.[38]

And yet it is because people often disagree about justice that societies need what Dworkin has referred to as "principles of fairness".[39] Despite the need for accommodation of dissenting visions of justice, if a state adopts a particular policy which constitutes a rejection of a fundamental respect of its people, it violates their human rights. In this regard, Dworkin attempts to build his case by first employing the views of Bentham as indicated by the inclusion of the vocabulary of sentience: "with *concern*, that is, as human beings who are *capable of suffering and frustration* (emphasis added)". Dworkin combines these views together with those of a Kantian ethic: "with *respect*, that is, as human beings who are *capable*

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[30] Exodus 23.4-9; Matthew 25.31-45

[31] I. Kant, *The Metaphysics of Morals* (Cambridge UP 1996) 30.

[32] Kant, *Metaphysics*, 186-7.

[33] I.Ward, "Imagining Human Rights," *Studies in Law, Politics and Society* 24 (2002): 87-9.

[34] Kant, *Metaphysics*, 156-7.

[35] Kant, *Metaphysics*, 201-2.

[36] R. Dworkin, *Sovereign Virtue*, (Harvard UP 2000) 4-7.

[37] J. Rice, "The End of Human Rights?" *International Journal of Applied Philosophy* 17: 1 (2003) 147.

[38] R. Rorty, "Robustness: A Reply to Jean Bethke Elshtain, " in Daniel W. Conway and John E. Seery, eds., *The Politics of Irony: Essays in Self-Betrayal* (New York: St. Martin's Press, 1992), 219-20; Found in, J. Bethke Elshtain, "What's Morality Got to Do With It? Making the Right Decisions", *Social Philosophy & Policy*, Vol. 21, 1 (2004) 4.

[39] R. Dworkin, *Sovereign Virtue* (Harvard UP 2000) 4-7. Dworkin argues that a government may not necessarily violate human rights if it adopts a view held in good faith of what specific rights follow from this basic duty of equal concern.

of forming and acting on intelligent conceptions of how their lives should be lived (emphasis added)". [40]

Tom Beauchamp and James Childress, propose in regard to disagreement about morality four principles which they categorize as (respect for) autonomy, nonmaleficence, beneficence and justice. [41] They argue that in the lack of agreement about any one moral theory, their four moral principles form the basis for a common set of ethical principles. And in this regard they draw on the contribution of Rawls and his notion of "justice as fairness". [42] In response to the principlism as proposed by Beauchamp and Childress, Donald Ainslie has argued that this is not adequate since such criteria would hardly be accepted by all. For example, it would not be accepted by radical libertarians (or for that matter Nietzcheans). He advances the argument that any ethical theory must not be dogmatic, but instead ought to be able to accommodate an ethical pluralism. [43]

But is a set of moral principles as proposed by Beauchamp and Childress (or for that matter a more general theory of justice as advanced by Rawls) really "oppressive and arbitrary" as Ainslie suggests, given that it cannot accommodate all possible views? Elshtain, argues that the moral point is embedded in the description – "if we get the facts wrong, we will be wrong about ethics too". She cites Stephan Carter who argues that "[w]e must never lose the capacity for judgment, especially the capacity to judge ourselves and our people …[To do] otherwise, at the end of the line lies a pile of garbage." [44] It is argued here that it is this judgmental attribute of morality that has the capability to distinguish that which is garbage from that which is not.

Rawls and the just society

In *A Theory of Justice*, Rawls sets out a discourse of not only justice theory (and issues of disagreement inherent in a pluralist society) but of the wider enterprise of moral and political philosophy as well. In terms of the centrality that liberty plays in his outlook, Rawls follows in the tradition of philosophers such as J. S. Mill, yet at the same time Rawls avoids Mill's utilitarian approach. [45] Instead for Rawls, heavy reliance is placed upon the philosophical methodology and content of Kant. Indeed like Kant, this particular vision of moral philosophy is based not only upon the *a priori*, but also on the empirical realm. And like Kant, Rawls is concerned about the normative, as he is about the positivist claim.

For Rawls, a theory of justice is to be found with just principles. In order to discover what principles are just, one must ask what principles we ourselves would choose for a just society. In his own words, Rawls argues that according to "justice as fairness, men agree to share one another's fate". [46] Rawls' "original position" (which assumes no prior knowledge about race, religion, ethnicity, social standing or natural abilities) is based upon an assumption that one's position in live is in large part a result of what he terms a "natural lottery".[47] Just as one's race, ethnicity, social class or economic standing are factors that have been inherited through no fault or merit on one's own, so also is one's genetic make-up a product of the natural lottery.

Rawls is keen to assert that there is no moral significance that may be properly attached to one's station of birth or inheritance. What *is* important for Rawls is that given the diversity and disparity that exists in any given society, that there also be a set of fair procedures that can be applied to all. For Rawls, the first basic principle of justice is that "[e]ach person has a right to the most extensive total system of equal basic liberties compatible with a similar system for all." [48] What this entails is a system of strict equality with regard to basic liberties compatible with similar liberties for all:

The basic liberties of citizens are, roughly speaking, political liberty (the right to vote and be eligible for public office) together with freedom of speech and assembly; liberty of conscience and freedom of thought; freedom of the person along with the right to hold (personal) property; and freedom from arbitrary arrest and seizure defined by the concept of the rule of law. [49]

The second basic principle of justice that Rawls proposes goes beyond mere negative equality of opportunity. He proposes that "in any social order economic inequalities are to be reasonably to everyone's advantage, and are to be connected to positions, which are open to all." [50] In other words, Rawls advocates a system sensitive to the Principle of Fair Equality of Opportunity. But then he goes further with the inclusion of the "difference principle" whereby society is to be arranged so as to allow the least fortunate in terms of natural differences to do as well as possible.[51] Accordingly, the overall effect of the difference principle would be that the least well off in society would be the best protected. Although Rawls admits that any inequalities of wealth and status would not be totally abolished by policies of favoring the least advantaged, injustices would nevertheless be addressed through the difference principle. In this regard he demonstrates what has been termed as a deontological approach – that is, any given system of justice is to be evaluated in terms *of the fairness of the procedures that it entails*. [52]

Among the most far-reaching of Rawls' claims however, is that minimalist equality of opportunity leaves unresolved the predisposed state of inequality in terms of innate talent (the natural lottery). It is this assertion of the arbitrariness of a natural lottery that forms the basis for Rawls' difference principle, can also be said to extend to genetic endowment. As Thomas Nagel has put it, "[w]hat can be said of being born with a silver spoon in your mouth also goes for being born with golden genes". [53] Nagel's argument in this regard is that a deontological approach to justice places great importance (as does a Kantian ethic) upon individual responsibility. In this regard Nagel argues, "free-choice has the effect of legitimating", while "coercion or discrimination delegitimates". However "that which is left to chance or luck is neutral". [54]

From genetic lottery to genetic equality

In their treatment of justice and genetics, Buchanan (et al) have argued that while basic social institutions already reflect a commitment to intervention in the natural lottery in respect to congenital disease, "presumably any philosophical account of justice must acknowledge the necessity of such interventions". [55] But the writers go further and speculate that in theory, genetic intervention may also be applied even more fundamentally. They consider the situation "where only those whose genetic assets fall within certain parameters tend to develop certain cognitive abilities beyond a certain level": [56]

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[40] Rice, "The End of Human Rights?" 141-42.

[41] T Beauchamp and J. Childress, *Principles of Biomedical Ethics*, ed. 4 (Oxford UP 1994) 38, 100-01.

[42] Beauchamp and Childress, 59-61.

[43] D. Ainslie, "Bioethics and the Problem of Pluralism" *Social Philosophy and Policy* Vol. 19:2 (2002) 3-4.

[44] Elshtain, "What's Morality Got to Do With It?" 5.

[45] Rawls, *A Theory of Justice* (Oxford UP 1971) 184-5.

[46] Rawls, 102.

[47] Rawls, 15-19.

[48] Rawls, 60.

[49] Rawls, 61.

[50] Ibid.

[51] Rawls, 76-80.

[52] Rawls, 30. "(Justice as fairness) is a deontological theory, one that either does not specify the good independently from the right, or does not interpret the right as maximizing the good."

[53] T. Nagel, "Justice and Nature", *Oxford Journal of Legal Studies*, Vol. 17, No. 2, 309.

[54] Nagel, "Justice and Nature", 313.

[55] Buchanan et al, *From Chance to Choice*, 71.

[56] Ibid.

Suppose also that, in general, only those who develop these abilities beyond this level are able to learn the mathematics needed to succeed in all but the very least desirable jobs, in a technologically advanced society. Under such conditions, those whose genetic constitutions prevent them from reaching the needed threshold of abilities will experience significant limitations on their opportunities unless something is done to overcome this impairment. [57]

Philip Kitcher, shares this idea of genetic redistribution of assets. He believes that a voluntary form of eugenics in the form of selection for desired traits in children is inevitable. In his book *The Lives to Come*, argues on behalf of what he terms a future "eugenic utopia" in which the use of genetic information would be obtained in prenatal testing and would be made available to all.[58] His utopian genetically engineered world is however premised upon societies whose decision-makers possess wisdom, beneficence and a "respect for difference" that would seem to reflect not social reality but instead proposes an all too familiar utopian dream.[59]

Could a view of justice based upon a redistribution, not in this instance of resources but of genetic endowment ever gain currency? And if it is possible, then should it ever be done? I would argue that such any attempt at genetic redistribution as a means of distributive justice would be wrong because it would at the same time seek to undermine perhaps the most important moral premise, i.e., that of moral equality.[60] The premise advanced by Kant and its "self-evident truth" so elegantly expressed by Jefferson, "that all men are created equal" is undermined by the scientific claim to the contrary. These types of genetic intervention would be wrong because they would seek to replace a premise of moral equality with a biological one, and in so doing, rob individuals of what it means to be uniquely human. Indeed in this context, genetic equality begins to resemble a form of genetic uniformity. A conceptual shift from moral equality to genetic equality (and correspondingly, inequality) in persons is to assert the latter and deny the former.

Yet the problem remains, which is who is to determine (and indeed by which criteria) what any such equality would be? Who is to say that a genetically "perfect" individual who has been engineered for health, height, intellect and beauty would be "better" than a Ray Charles (blind from birth, yet a great jazz pianist) or for that matter, a Stephen Hawking (severely affected in his twenties by ALS)? That a person who has been screened for gender preference would be better than an Allen Turing or a Walt Whitman? Or, on what basis is one to claim that a genetically engineered tall, attractive blonde who has a cognitive ability to obtain better than average SAT scores, would be preferable to a Robert Johnson (perhaps socially dysfunctional, but probably one of the greatest blues men who ever lived)? [61]

A requirement for principle in judicial decision-making

According to Dworkin's legal and moral theory, principle is required by judges in deciding hard cases without having to fall back on the brutal logic of utilitarianism:

> Arguments of policy justify a political decision by showing that the decision advances of protects a collective goal of the community as a whole…Arguments of principle justify a political decision by showing that the decision respects or secures some individual or group right. [62]

It is important to recall here that the language of Lord Hoffman in *Bland* carries with it this foundational use of moral principle in order to progress toward establishing legal rules. In this way the application of principle provides the theoretical basis through which rights are respected even in the face of collective goals. [63] So too, this same concept of principle is necessary in the realm of evaluating the challenges that scientific advances pose to those human values that have long been the basis for those of our instincts that are among our most humane. The criterion of principle in judicial decision making (sure to come in the wake of *Hashmi*) serves to employ a deontological approach to justice over a consequentialist one.

Although a fundamental *logotaxis* (or inclination toward knowledge) is said to be found at the center of the human condition, along with this need to know, there must also be an evaluation of such knowledge is to be used and applied. As Appleyard warns, science should only ever be a part of the whole, "if it becomes the whole picture, catastrophe ensues". [64]

> …For what must be able to judge and evaluate science; it must be a part of a culture. If we can't, there is nothing to discuss. Whatever science and the scientists say must be right. Step over this cliff, they might say, the fall will do you good, and we can only believe they must be right. [65]

Without doubt, there will in future be more cases such as *Hashmi* and *Bland*. The challenge that exists not only for decision-makers but for all individuals is to constantly apply critical and ethical evaluation to scientific advance. Just as a blind acceptance of ideology has led in the past to totalitarian excess, an uncritical application of science in the absence of moral constraint carries the real potential for catastrophic results. In the final chapter of *Life's Dominion*, Dworkin responds to the "threat or promise" of future scientific developments and the difficult issues that will confront society with and concludes:

> [I]f people retain the self-consciousness and self-respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred, and of the proper place of freedom and its dominion.[66]

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[57] Ibid.

[58] P. Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (Simon and Schuster 1996) 202.

[59] Ibid.

[60] My use of the word "wrong" here, refers to that which is subjectively wrong or blameworthy in the same that Parfit applies the term; Parfit, *Reasons and Persons*, 25: "We need an account of subjective rightness for two reasons. We often do not know what the effects of our acts would be. And we ought to be blamed for doing what is subjectively wrong."

[61] If those advocating this genetic supermarket conception of eugenics were to argue that the issue is not whether a genetically engineered child is "better" than Ray Charles, but whether Ray Charles would have been better off as a sighted person. While his life probably would have been an easier one, who is to say whether he would have been the same artist?

[62] R. Dworkin, *Taking Rights Seriously* (Harvard UP 1977) 83.

[63] *Brown v Board of Education*, Topeka, Shawnee County, Kan., 347 U.S. 115, (U.S. Supreme Court held that public education along racially segregationist lines was unconstitutional). Consider Dworkin's assessment here of consequentialism (and its main paradigm, utilitarianism) in relation to this decision: "A pragmatist justice of a general utilitarian cast of mind would have asked himself whether a decision for the plaintiff children, based on the illegality of all official segregation in schools, was really best for the future, all things considered. He might have decided that it was, but he would have had to consider strong practical arguments to the contrary. It was perfectly sensible to think that such a dramatic change in the social structure of a large part of the country, ordered by a court that is not responsible to any electorate, would produce a backlash that would damage rather than advance education…" (Dworkin, *Law's Empire* (Harvard UP 1986) 220-21).

[64] Appleyard, *Brave New Worlds*, 160.

[65] Ibid.

[66] Dworkin, *Life's Dominion*, 241.

Do we need a Thanatoethics?

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People from all over the world belonging to various ethno cultural groups share the same respect for the dead. Reasons vary from one culture to another. I shall comment on short only a few traditions' attitude towards dead bodies.

Jewish tradition claims respect for the dead body because once it harbored life which originates from God and, of course, much more important because man was created in God's image.

It is a sacred duty to bury deceased people and no one should be left without a grave. Members of the community also bury unclaimed bodies. In order to understand how important such things are we have to mention the fact that even though Jewish priests are not allowed to make contact with cadavers it still is of their duty to put in the ground any unknown deceased if there is no one else to do that.

Bodies are washed, dressed in a simple shroud meant to show that in front of death we are all equal and buried as soon as possible. They have to return fast to ashes we all were created from. Autopsy, dissection, incineration or embalming is in principle forbidden.

Christians share the same belief about man as a bearer of God's image and about life as a divine gift. God's most beloved creature, candidate to redemption, called to enjoy together with his Maker the beauties of the world man is dual by nature, both material and immaterial. Body and soul form an undividable harmony since the very beginning of each person's life. We come to life by God's will. He is the one that embeds life and the soul within an earthly shell and He is the one that decides when they will separate, for the shell to return to ashes and the soul to get onto the other world to face God's judgment.

After death, body has to be treated with respect, as it once was a temple of the Holy Spirit, as God has created it out of His immense love and it served the soul for an entire life. Bodies have to be washed, which reminds of baptism. Incineration is not allowed, as garbage gets incinerated, not human bodies. The main idea of funeral rites in Orthodox Christianity is that the dead body remains under God's protection as it used to be when alive. It is buried with love and care under the sign of hope for resurrection in Christ.

Islam also teaches respect for the death. It is of very bad taste, not appropriate to carry a body using a vehicle or an animal, as if it was a piece of luggage. The body has to be carried by four persons or if it is light enough (a child's body, for example) by one person only that has to hold it with both his hands.

It is everyone's duty to bury the deceased. If an anonymous is found death in Muslim lands the body is buried and a funeral prayer has to be pronounced. Dead bodies have to be carefully washed, perfumed with camphor and dressed with specific ritual clothing.

In Islam there are even special percepts that explicitly forbid enemies' bodies to be desecrated for example by mutilation. Transplant from a dead body is not allowed for the same reason that it equals desecration of the body.

Hinduism also treats the body with respect even though that is not as apparent as for the other mentioned religions because of the incineration rites. Nevertheless, incineration does not reflect a lack of respect for the "human shell". It is required in order to free the soul more quickly so that it could go on with its karmic cycle.

The body is however important and embalming or autopsy have to be avoided as cutting the body open might trouble the soul that is still around in the first few days after death. Hindu people respect dead bodies, they would not leave them to be eaten by animals or desecrated by disrespectful people by any means.

One attitude I particularly find deeply moral and wise was that of the Mongols that put no sign on someone's grave so that the body could by no means be found and desecrated. The deceased could therefore rest in peace. Mongols have always been showing respect to the dead of every nation and religion, not allowing anyone break not even into ancient anonymous graves that had practically nothing to do with their own history and that very well might have contained valuable pieces. Their disgust towards Archaeology disturbing the rest of the dead is visible up to the present.

So, in theory we can expect that all over the world most part of the people would feel quite similar about our "shell" being unproperly treated. And here a big question pops up - *what does "unproperly" mean*?

Times have changed, people have changed, the world is continuously changing but... old habits dye hard and some things never change. Among those, the irrepressible interest for others' dead bodies that we seem to share since immemorial times.

As I underlined above religion teaches us to regard both living and dead bodies with respect. Taking care of our departed neighbors is a moral duty to us whether we are Christians, Hindu, Jews or Muslims. Still, a dark fascination lies somewhere in our head or soul, beneath the beautiful layers of our moral self. When it comes about dead bodies it seems that contemporary people are at least as tempted as their Middle Age ancestors to set foot over that thin red line between decency and - let's say so - extravagancy. Gruesome news with gruesome pictures makes magnificent audience, as any good news anchor knows. Many people look for the thrill of watching more or less bloodied human remains. Some of those death consumers claim to be horrified by such scenes but they still look, eyes wide open and their heart pumping like crazy.

In the few last years new and imaginative manners of making out of death a source of entertainment emerged.

There are thousands of websites offering horrible pictures to anyone that might be interested. Net nannies watch carefully for children not to set eyes on sex pictures (not that I do not agree with this policy). Meanwhile, children may freely watch horrors and get some awesome material for future nightmares.

While looking for material for this paper I visited only one of the "gruesome" websites. It proudly advertised being "the sickest place on the web for 6 years!" In my humble opinion, it deserved some credit, indeed. I had to leave my desk for a while in order to get into my senses. And not that I have a weak stomach, I studied biology and dealt with each and every possible piece of human and animal dead bodies. I always felt sad watching the human remains we used as practice material back in faculty but never got sick. No one was really mocking those remains. There were a few jokes but no one exceeded measure.

Getting sick in this particular case is not about pictures of dead bodies more or less scattered to pieces, it is about the evil that seems to lie beneath exposing a person's remains under some circumstances. It is not about images but about comments and scenery. Some might call devilish whatever drives people to create such websites. Most will probably call it sick. I call it sad. It is really sad to see people become intellectualist hyenas. A taste for grotesque is often considered to reveal a person's refinement, it very well suits people of culture. Count Dracula continues to be a romantic fascinating figure.

A trendy matter in the field is plastination. Plastination is an original preservation method intended to serve teaching and research by keeping parts of dead bodies into an outstandingly good condition. Replacing water and body fat with a resin can do this.

The technique has been invented about 20 years ago by Dr. Gunther von Hagens at Heidelberg. Its results are outstanding; the anatomical specimens look very realistic (they ARE real, as a matter of fact), not suffering a bit from the signs of decay.

I have to admit that von Hagens' invention was an outbreak in the field of preparing study material for Biology and Medicine actual or future specialists. Yet, many people do not seem so eager to develop a taste for it at least not in its "public event" dimension.

When plastination got public in the USA someone called the supposed travelling exhibit of dead bodies "a public road show of Uncle Joe and Aunt Matilda." Harsh but sadly true. Nevertheless, scientists became to have doubts about the event they were planning only when reminded that the six bodies that were intended to be exposed belonged to unconsenting anonymous that no one had claimed from the morgue.

It seems that we are rapidly moving from traditional values to the culture of the (informed) consent, misperceived as a chaotic space where anyone can break rules and trash "taboos" as long as certainty about his/her free, informed choice is assured.

If plastination specialists would have been limited to science I guess there wouldn't have been any great fuss about it. But at some point they tried to make a new art out of it. A macabre art that has not exactly met the taste of a few churches, citizens' organisations, scholars, public figures and ordinary people that felt outraged of what plastinators called art.

When von Hagens started to expose artistry made out of dead bodies he aroused many voices. If displaying anatomic specimens with educational purposes was (almost) acceptable, the sight of a dead man travelling through eternity on (dead) horseback or that of a dead woman unveiling for the public the mystery of the dead child in her plastinated womb definitely upset many people. I have to admit that I sympathise with them. The whole thing has a strange, infernal glitter.

It is interesting to watch how plastination gets sometimes semi-rejected and semi-defended altogether, by the same person in accordance with personal views beyond the subject. A comment published on a socialist website contested plastination's artistic dimension while defending it against the "rigid" attitude of some Christian denominations. It is one individual approach that I found quite intriguing by its core of atheist-intellectualist objectivity and sense of equity.

Meanwhile the large public that hates plastination rules with a few good percents- an on-line poll reveals that about 56% of the voters find plastination "disgusting and wrong" in total opposition to those that think about it as "a good educational tool" (43%).

As if intended to prove the fact that nothing is good or wrong by itself but by the way you use or apply it, a very imaginative application of dr von Hagens' technique flourished recently. There is a company that offers to plastinate male intimate parts so that devoted wives or girlfriends can keep them when the rightful owner dies. They call it an "intimate memento", that is "sterile, non-toxic, very durable, and safe to handle and display as you see fit." No further comments.

So, aren't traditional moral values enough any more, with Bioethics added to the defendant mechanisms intended to protect human dignity in these troubled days we live?

Do we need something especially designed, a "Thanatoethics" in order to refrain from treating human dead bodies as if they were shells or starfish that we may joyfully use as decorations?

I will not however conclude symmetrically, with my own question that also stands for title but with a comment someone else has made on-line, in the middle of his story about how fascinating and educative a plastinated bodies exhibit was to him:

I can't help but wonder what HR Giger (the surrealist artist that created *Alien* "life forms") *might do if he knew how to do plastination*.

Neither can I...

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Are the dead really departed when we remove their organs ?

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1. Premise

As the discussion regarding the subject about the beginning of life has recently jumped in our country, in connection with the disputed passing of the artificial reproduction law (law nº40, 2004); On a subject concerning the end of life, and that is particularly the matter of the removal of organs from "corpses", the debate seems to be finished immediately after the passing of the new law on transplantations (law nº 91, 1999). This law has been passed by the majority in Parliament. However the debate on this law has been mainly held on an issue – on the other hand, a long term one – and that is the norm introduced for the declaration of will, known as "informed silent-assent." (see sec. nº 4).

In my opinion, a quite questionable norm, even though it was much more questionable, how the then Health Secretary Rosy Bindi got round the law, by sending the Italian citizens a card (*donor card*). This card wasn't not only provided for by the law in any way, but actually it obstructed its application at the crucial point.

In fact today it's five years since the law was in effect and we are still in a transient phase (governed by sec. nº 23), that we can just go on defining so in euphemisms. But now I don't want to dwell long on this point.[67]

Here I would like to raise another doubt and this doesn't concern so much with the law about transplantations itself as with the assumption it is based on; and that is to say whether the donor is already a "corpse", when the organs are about to be removed. Are we really sure of it?[68] I will begin from an obvious remark that appears immediately clear by the comparison between the two laws I have just mentioned.

We thought it proper to defend with a series of prohibitions a pin-sized being contained in vitro (e.g. by prohibiting its freezing or its killing or even by forbidding the preimplant antenatal diagnosis), on the contrary, with a human being in the flesh, whose temperature is about 37º C, with a rosy complexion and a not voluntary heart beat and breathing but kept alive by mechanical ventilators, we can do everything is permitted to do with a corpse. You might observe: the matter is only apparently perplexing. Since their earliest formation, however, the embryos are already alive (and this explains why they draw great attention), on the contrary, once brain death has been established, the patient isn't any longer alive, but dead: a corpse that looks like still alive, but it actually lives no more. This conclusion is introduced as a scientific datum, which was acquired once and for all at the end of the Sixties, when a Committee, founded at Harvard medical school in order to discuss the problem, managed to compare in a famous report to all intents and purposes the irreversible coma diagnosis (made with accurate clinical tests, that had to determine the permanent loss of brain functions) to brain death and this to the actual death.[69]

A new definition of death derived and in the succeeding years it was very successful. And this happened for various reasons. First of all, this definition reflected the then scientific knowledge, that seemed to prove the theory that the patients in a irreversible coma were destined to die of a cardiac arrest in a short time, anyway; secondly such a definition gave the best help to the development of the technics of transplanting, that have just begun at that time (we have to remember that the first heart transplant was done by Barnard in December 1967); thirdly it could have the problem of euthanasia got around: if the patient, whose brain had completely stopped working, was dead, removing its heart or breaking off the artificial breathing didn't correspond to kill him. As you can see, right from the start, not only scientific reasons urged to redefine death. Even if you examine the laws, the connection between the new definition of death and transplantations is very evident. We restrict ourselves to our country, but the matter, at least to a certain extent, could be generalized to other juridical experiences. Back in 1969 the criterion of brain death was introduced with the Health Secretary's decree law of the 11th August, and with the following one of the 9th January 1970. This criterion was introduced (using the Harvard standards for all practical purposes) exactly with a direct reference to the problem of the removal of organs for transplantations. And it is remarkable that, in a very short time, on the 5th February 1970, one of the President of the Republic's decree laws (the nº 78 one), introduced by the Health Secretary, authorized for the first time in Italy the removal of heart and of its parts.[4] Since then the law-maker confined himself to indicate the various methods for the confirmation of death and he didn't even dare define it in the first methodical law regarding transplantations (law nº 644, 1975). This happened in 1993 only with the law nº 578 (and with next year's related execute ministerial decree [5]). According to this law death <<corresponds to the irreversible cessation of every brain function>> (sec.1)

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[67] I have already dwelt on it on many other occasions, I confine myself here to mention: P. Becchi, P. Donadoni, *Informazione e consenso all'espianto di organi da cadavere,* in <<Politica del diritto>> XXXII, n. 2, 2001, pp. 257-287; P. Becchi, *Tra(i)pianti, Spunti critici intorno alla legge in materia di donazione degli organi e alla sua applicazione,* in <<Ragion pratica>>,18, 2002, pp. 275-288. e P. Becchi, *Information und Einwilligung zur Organspende. Das neue italienische Gesetz und seine "ewige" Überganspha*se in *Hirntod und Organspende,* edited by A.Bondolfi, U.Kostka, K.Seelmann, Basel, Schwabe, 2003, pp.149-161.

[68] For a more exhaustive attempt to answer the raised question, I want to refer to an anthology that I edited in association with Rosangela Barcaro, *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti,* Napoli, E.S.I, 2004,. This anthology includes writings by Carlo Alberto Defanti, John Finnis, Amir Halevy e Baruch Brody, Hans Jonas, Josef Seifert, Alan Shewmon, Peter Singer, Ralf Stoecker, Robert Truog and it reproduces in the appendix the document of the *Danish Council of Ethics* dedicated to the discussion on death criteria.

[69] See *A definition of irreversibile coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine Brain Death,* in <<Journal of the American Medical Association>>, 205, 1968, pp. 337-340. For the critical discussion on the document see for instance: M. Giacomini, *A Change of Hearth and a Change of Mind? Technology and the Redefinition of Death in 1968,* in <<Social Science and Medicine>>, 44, 1997, pp.1465-1482; R.M. Veatch, *Transplantation Ethics,* Washington D.C., Georgetown University Press, 2000; G. Belkin; *Brain Death and the Historical Understanding of Bioethics,* in <<Journal of the History of Medicine>>, 58, 2003, pp. 325-361; in Italian see C.A. Defanti, *Vivo o morto? La storia della morte nella medicina moderna,* Milano, Zadig, 1999, pp.65-75. See P. Mollaret, M. Goulon, *Le coma dépassé. Mémoire préliminaire,* in <<Revue Neurologique>>, 101, 1959, pp.3-15. The importance of this study has been ignored for a long time because Harvard Committee has put, as to speak, the previous papers in the shade. Nowadays Mollaret and Goulon's work is recognized as one of the most significant moment in the irreversible coma research. See for example E.F.M.Wijdicks, *The Landmark <<Le Coma Depassé>>, in* E.F.M.Wijdicks (edited by), *Brain Death,* Philadelphia, 2001, pp.1-4.

[4] All the quoted regulatory documents are quoted in the appendix of the important essay by F. Mantovani, *I trapianti e la sperimentazione umana nel diritto italiano e straniero,* Padova, Cedam, 1974, pp. 851-853.

[5] See, on this subject, also for the regulatory documents attached in the appendix: U.G. Nannini, *Valori della persona e definizione legale di morte,* Padova, Cedam, 1996.

This law introduces not only the definition of total brain death, but also – changing route with respect to one of 1975 – extends the use of the norms for the determination of death from the persons suffering from brain injuries and who are subjected to resuscitative measures to all those who are in that condition, regardless of they are donor or not. Even though this law is formally separated from the transplantation problem, since this law was brought in, it has changed the conditions for the removal of organs. And the latest transplant law, that has been in effect since 1999, only accepts it completely from this viewpoint. The transplant law[6] has indeed changed the methods to get the consent, it has made it easier (and this is already partly true in the present transient phase), but this law has kept the definition of death and the standard methods for its determination unchanged, as so they had been established in 1993/94, and therefore they are now the assumption for the removal of organs legitimacy .

2. The moral-philosophical debate on brain death.

Even just during the Nineties, while in our country – like in many others – brain death was not only accepted, but its definition was even introduced by a law; in the country where this definition was firstly given, The United States of America, a strong reconsideration of it started developing. Actually strong philosophical doubts about the new definition of death raised immediately. As everybody knows a great twentieth-century philosopher, as well as one of the most important figures in the contemporary bioethical discussion, Hans Jonas, after a month since Harvard report publishing, during a conference about the experiments on human beings raised his strong objection to it. The *leitmotiv* was the following: we don't know exactly the borderline between life and death and a definition – inter alia introduced with the clear intention to encourage the removals of organs – can't replace that cognitive deficit for sure. When brain has completely stopped working we can break off the artificial life-support treatments (on the contrary – as Jonas claimed later on – we must do that because keeping a human being in that condition would be opposite to the human being's dignity), not only because the patient is dead, but also because making his/her life longer in that condition is absurd. In Jonas' opinion we can already find the dilemma – well emphasized by Jonsen[7]– which derives from the debate on brain death. Should we break off the life-support to let the patient die or should we turn off the respirator connected to a body, which is already dead? As everybody knows the second one has been chosen and as a dead human being's respirator was turned off, why not, on the contrary, keep it turned on a little to encourage transplantations?

According to Jonas, instead, the first option had to be taken and the criticism on the new definition of death became his strong point. His most famous writing, printed in 1974, is entitled *Against the Stream,* now it has become a classic.[8] Less known – and that's why I'd like here also to draw attention to this – is the fact that Jonas, just before his death, came back to this problem again in his correspondence to a German doctor he was friend with. The matter is worth briefly mentioning.

In October 1992 after a car crash a young woman went into a coma of which she would never come out and, after the standard clinical tests, she was declared brain dead. With her parents' permission her organs were going to be removed. The arrangements for the removal of organs were stopped and the doctors decided to go forward with the pregnancy, when the doctors realized she was pregnant. The debate on brain death began in Germany and then a lot of people wondered how a "corpse" could go forward with the pregnancy and even – as it happened – how it could "decide" to terminate a pregnancy with a spontaneous abortion when the foetus was no longer alive. I'd like to quote on this subject a passage from Jonas' interjection, taken from his correspondence with one of the doctors involved in the case:

"Whether you like or not, you, my friend, or better you (the doctors) were contrary to the contemporary declaration of death of her object with your well-considered decision. You have said: with the ventilation (and the other treatments) we want to prevent Marion's body from becoming a corpse, so that it can go forward with the pregnancy. As you thought it was able to go forward with it, or as you wanted to give it this chance, you relied on the life remaining that was in it - and that was Marion's life remaining! But the body is just as much Marion's body, as the brain was Marion's brain. This time the failure of the experiment (it seems to have already been successful in previous less extreme situations) can't be taken so much as a confirmation that it is admissible, just as a spontaneous abortion shows that a pregnancy in general isn't possible. You believed sincerely in the chance of its success, and that is to say you believed in the functional capability of the cerebrally dead body which to that end was necessary and was kept alive by your talent- and that is to say you believed in her LIFE that was temporarily prolonged for the child. You aren't allowed to dismiss this belief in other coma cases for other purposes. [9]*"*

You might say: this incident interestingly concerns itself with showing the author's great coherence. This is undoubtedly true for Jonas' biography, but meantime his "old" position had become current again and it started to be much more popular than it was before. Not only Jonas' writings, but also Josef Seifert's ones[10], and more recently Robert Spaeman's ones[11],

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[6] For a comment on the new law here I restrict myself to referring to the miscellaneous book: *La disciplina giuridica dei trapianti. Legge 1º aprile 1999 n. 91,* edited by P. Stanzione, Milano, Giuffrè, 2000; in the appendix the law text is also quoted. For a critical interpretation see P. Becchi, *La morte nell'età della tecnica. Lineamenti di tanatologia etica e giuridica,* Genova, Compagnia dei Librai, 2002 e ora P. Sommaggio, *Il dono preteso. Il problema del trapianto di organi: legislazione e principi,* Padova, Cedam, 2004.

[7] See A.R. Jonsen, *The Birth of Bioethics,* New York, Oxford University Press, 1998, p.240.

[8] Jonas' reaction to the Harvard Committee report has been quick : it goes back indeed to September 1968 and it was put forward by the author during his speech in the lecture about the experiments on human beings. The most famous essay *Against the Stream* followed it, this writing was printed in 1974 (but composed in 1970). Jonas discusses in it the objections that had been raised by some Committee doctors, meanwhile he came into contact with. Two postscripts of 1976 and of 1985 followed this essay, a symptom of the steady Jonas' attention paid to this subject. All the writings have been collected by Jonas in *Technik, Medizin und Ethik. Zur Praxis des Prinzips Verantwortung* (1985). Italian translation., *Tecnica, medicina ed etica, Prassi del principio responsabilità,* Torino, Einaudi, 1997, pp. 166-184. Now the article is also in the anthology edited by R. Barcaro and P.Becchi, *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti* (in the press). For a first attempt to introduce Hans Jonas' figure and works in our country see fascicle nº 15 monographic section of <<Ragion pratica>> of 2000, dedicated to him. See also P.Becchi, *Tecnica ed etica in Hans Jonas* in <<Annali della Facoltà di Giurisprudenza di Genova>>, XXV, 1993/94, pp. 280-314 and now P.Becchi, *Hans Jonas e il ritorno alla metafisica,* in <<MicroMega>>, 5, 2003, pp. 82-109.

[9] See H. Jonas, *Brief an Hans-Bernhard Wuermeling,* in *Wann ist der Mensch tot? Organverpflanzung und Hirntodkriterium,* edited by J. Hoff e J. in der Schmitten, Reinbek bei Hamburg, Rowohlt, 1994, pp. 21-27. The letter text is now translated into Italian in the anthology: *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti*, (already quoted)

[10] See J. Seifert, *Leib und Seele. Ein Beitrag zur philosophischen Anthropologie,* Salzburg, 1973; J. Seifert, *Das Leib-Seele Problem und die gegenwärtige philosophische Diskussion. Eine kritisch-systematische Analyse,* Darmstadt, 1979, (A second edition of this book was published in 1989); J. Seifert, *What is Life ?On the Originality, Irreducibility and Value of Life,* edited by H.G. Callaway, Amsterdam, 1997; J. Seifert, *Is "brain death" actually death? A critique of redefining man's death in terms of "brain death",* in R.J. White, H. Angstwurm, I. Carrasco de Paula, (edited by), *Working Group on the Determination of Brain Death and its Relationship to Human Death, 10-*

too would be worth considering. Both Joseph Seifert and Robert Spaeman (two authors with a Catholic background) now share similar intellectual ideas to Jonas. All these authors subscribe to the idea that given the uncertainty or impossibility to test that a person is definitively dead, you should treat him/her as if he/she were still alive.

However the most remarkable point – and that's why I want to dwell on – is that, also in a line of thought which is poles apart from what I referred to, it is now openly recognized that "brain death" was only a "bold trick" human beings was declared dead with, but they weren't at all.

This is the conclusion a philosopher, Peter Singer, well-known also in our country for his strong utilitarian ideas, came to.

Also on this occasion it's worth retracing briefly the path he took.[12] At the beginning of the nineties Singer – at that time professor in Melbourne – was called by an important hospital in that town to join a Committee that had to deal with some moral questions connected to the problem of consent; among these also the ones connected to anencephaly. The babies suffering from this severe deformation can't become completely conscious, as they lack their brain upper part (that is the cerebral hemispheres, cerebral cortex included) and their cranial vault, whose function is to hold it, whereas their "lower" part, which is composed of brainstem, is often undamaged, even though sometimes not very developed. So the anencephalic child can breathe spontaneously, as this activity depends on the brainstem, but the baby's disease has a gloomy diagnosis: these children survive for changeable time from a few days to few weeks, before dying of a cardio-circulatory arrest.[13]

Singer, who in the previous years had been, in general, "total brain death" promoter, coped then with the following problem: why not pass from that idea of death to the cortical one in order to declare dead the anencephalic subjects, too?

Some Committee members wanted to take that course, but Singer, leaving the others a little dumbfounded, didn't follow them. The reasons for his disagreement are expressed clearly in one of his books, *Rethinking Life and Death,* brought out in 1994 and shortly afterwards translated into Italian. At least one paragraph of this book is worth quoting completely:

"The resolutions of the Committee I sat on got me to consider brain death more strongly. The Harvard Committee on brain death had to cope with two great problems. A lot of patients in a very despairing condition lived thanks to ventilators and nobody dared turn off the devices that kept them alive. Organs which could have been used to save human lives were unusable because, to remove them, you had to wait for the cessation of the likely donors' circulation of the blood. The Committee had supposed to solve both problems, resorting to a bold expedient and that was to declare dead all the individuals whose brain stopped, at least partly, working. This redefinition of death had so clearly expected consequences that it met with very few objections and it was almost universally accepted. Nevertheless, it was invalid from the start. The practice to solve the problems turning to redefinitions rarely works, and this incident wasn't an exception of the rule.[14]

Of course the conclusion that Singer draws from the cerebral "crisis" is very different from the previously quoted philosophers' one. For these people, if "the brain dead patients" are still alive during the explantation, this means that we just kill them doing it and we must not do any explantation, according to Singer, on the contrary, it is allowed to do it because life isn't a sacred and inviolable value. Also in this case (like in other ones) there is a third possibility, as usual this is the most difficult one, I tried to describe it on another occasion[15]; here I'm interested in underlining another point: that is to say that, despite the different moral conclusions, all the quoted authors have started from the same objection to brain death idea. You could wonder what has got Singer to share Jonas', Seifert's and Spaemann's opinions on this subject. These authors were very distant from him and he didn't almost seem to have known them at all. We can find an indirect answer by reading his latest contribution to the subject, *Morte cerebrale ed etica della sacralità della vita,* where the author reveals his sources.[16] And it deals with scientific sources of great importance, that together with others, contributed to define that state, the new idea of death based on completely neurological criteria, not only from the philosophical viewpoint but also from the medical-scientific one, has sunk in.

14/12/1989, the Vatican City, 1992, pp.95-143; J. Seifert, *Is "brain death" actually death ?*, in <<Monist>>, 76, 1993, pp. 175-202, see now, translated into Italian, J. Seifert, *La morte cerebrale non è la morte di fatto. Argomentazioni filosofiche,* in R. Barcaro, P. Becchi (edited by), *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti,* Naples, (in the press).

[11] I recommend Spaeman's clear interjection during an international bioethical conference, which took place in Rome in October 2002. His interjection text is now brought out in Italian and it's entitled *La morte della persona e la morte dell'essere umano,* in <<Lepanto>>, n. 162, XXI, December 2002, (Dossier: Ai confini della vita/ At the boundaries of Life)

[12] For a more precise study I'm allowed to refer to P. Becchi, *Un passo indietro e due avanti. Peter Singer e i trapianti,* in <<Bioetica>>, X, 2, 2002, pp. 226-247.

[13] For a detailed description see for instance The Medical Task Force on Anencephaly, *The infant with anencephaly,* in <<New England Journal of Medicine>>, 322, 10, 1990, pp. 669-674. It is however observed that more recent surveys carried out by D.A. Shewmon are inclined to show, in some cases, how the remarkable brain plasticity enables the brainstem to perform some functions, which, otherwise, would be cortical. The doctrine of the neuroanatomical basis of consciousness is questioned. See on this subject D.A. Shewmon, *Recovery from "Brain Death": A Neurologist's Apologia,* in <<Linacre Quarterly>>, February, 1997, pp.30-96. (The Italian reader on the anencephalic problem can read M. Caporale, *Al confine tra la vita e la morte,* Milan, Vita e Pensiero, 1997, pp.22-23).

[14] See P. Singer, *Rethinking Life and Death***,** *The Collapse of Our Traditional Ethics* (1994), Italian translation, *Ripensare la vita. La vecchia morale non serve più,* Milano, 1996 (reprinted, with another subhead: *Ripensare la vita. Tecnologia e bioetica: una nuova morale per il mondo moderno,* Milano, 2000, p. 65)

[15] See P. Becchi, *La morte. La questione irrisolta,* in <<Ragion pratica>>, 19, 2002, pp. 179-218.

[16] See P. Singer, *Morte cerebrale ed etica della sacralità della vita,* in <<Bioetica>>. VIII, 1, 200, pp.31-49. Singer's essay has been the theme of an interesting John Finnis' reply, which has till now been unpublished. Singer's contribution, with this reply, are now included in the book edited by R. Barcaro, P. Becchi, *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti,* (already quoted).

3. The medical-scientific discussion about brain death

Although I hadn't a doctor's expertise, at least let me stress two crucial points on this subject.[17] The first one concerns with the possibility to check total brain death on the basis of the norms and the tests which are now in use; the second one should prove the theory that brain death is a tale–tell symptom of the near brain death of the whole human body.

The first point was well-considered by two U.S. medical doctors, Robert Truog and James Flacker, in an essay brought out in 1992 and which is entitled: *Rethinking brain death.*[18] According to these authors, proved scientific researches show that the patients, who respond to the current clinical criteria and neurological tests for the brain death, don't necessarily lose *all* brain functions and this would prove that the complete cessation of these wouldn't be diagnosable on the basis of the standard tests in use.

In order to support their theory, the two doctors raise four different subjects, which can be summarized as follows. First of all, their endocrine-hypothalamic function doesn't fail those patients, who were declared in brain death according to the tests then in use. That is to say, in some patients declared brain dead the hormonal activity of the hypophysis gland and of the nerve centre that governs this (hypothalamus) is persisting, and therefore, they have still a regular hormonal activity; secondly a weak electrical activity can be registered in a lot of patients in such a condition. This activity is concentrated in some areas of the cerebral cortex, and it's destined to stop after 24-48 hours. Thirdly some patients unexpectedly go on responding to the external stimuli, as, for example, after the surgical cut before the removal of organs the rise in heart rate and in blood pressure shows; (These observations refer to patients declared brain dead on the basis of only clinical British criteria, which refer to the brainstem condition); fourthly, a lot of declared brain dead patients have still the spinal reflexes, which were very important when the definition of brain death was given and in the immediate succeeding years. And, in my opinion, it's right to consider them, as spinal marrow and brainstem are joined to each other, and therefore you can't rule out lower brainstem involvement in spinal marrow activity for sure.

On the basis of a careful analysis of these four elements the two authors came to the conclusion that the current clinical means can't prove the cessation of each function, but only of some, and actually they can diagnose, at the most, cortical death.

The second point has been illustrated above all by Alan Shewmon, an authoritative American neurologist, who, inter alia, changed his mind during his career, at first he had been a total brain death strong supporter then he was highly critical of it.

Like the two previous authors' incident, the starting point is also in this case an empirical examination: organisms declared dead using the current neurological standards survive much longer than it could be imagined, and this presumes that brain is not so essential to the human body's integrated working, as, on the contrary, it was considered. Against the prevailing opinion in the medical field, according to which brain is the organ responsible for the integrative functioning of different body parts, and, as such, it represents the body "critical system", Shewon formulates his own theory: our body "critical system" isn't limited to one single organ, even if it's as important as brain. According to the neurologist this theory could give an explanation for the declared in brain dead individuals' prolonged existences (a patient, who survived till over 14 years, set up the record). These persons, most of them child patients, keep undamaged some functions that were thought to pertain to brain, such as body temperature control, fluids homeostasis, the reaction to infections, the bodily growth, which are symptoms that an integrative functioning is persisting.

Shewon concludes that it's completely wrong to consider brain death a signal of the near death of the whole human body. One of the pillars brain death is based on, that's the opinion that brain is "our body central integrator ", has been completely disputed. Brain death doesn't cause body disintegration, such a disintegration is rather consequence of damages which involve more organs and the achievement of a critical level, "the point of no return", that determines death process start and makes ineffective any medical operation aimed at avoiding *the exitus.* Therefore, according to Shewmon the clinical condition of brain death shouldn't be diagnosed as unique condition for the determination of death, but you should refer to more than one parameters, such as those which are connected to the respiratory, circulatory and neurological

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[17] For a more detailed discussion see R. Bancaro, P. Becchi, *Morte celebrale e trapianto di organi,* in *Bioetica chirurgica e medica,* edited by L. Battaglia e G. Macellari, Noceto, (PR), Essebiemme, pp. 87-103 and Id., *La "morte cerebrale" è entrata in crisi irreversibile ?.* in <<Politica del diritto>>, XXXIV, 4, 2003, pp. 653-679. On the German debate see for example: H. Thomas, *Sind Hirntote Lebende ohne Hirnfunktionen oder Tote mit erhaltenen Körperfunktionen ?*, in <<Ethik in der Medizin>>, 6, 1994, pp.189-207, J. Hoff, J. in der Schmitten (edited by), *Wann ist der Mensch tot? Organverpflanzung und Hirntodkriterium,* Reinbeck bei Hamburg, 1994; M. Klein, *Hirntod: Vollständiger und irreversibler Verlust aller Hirnfunktionen?*, in <<Ethik in der Medizin>>, 7, 1995, pp.6-15, C. Wiesemann, *Hirntod und Gesellschaft. Argumente für einen pragmatischen Skeptizismus,* in <<Ethik in der Medizin>>, 7, 1995, pp. 16-28; K. Stapenhorst, *Über die biologisch-naturwissenschaftlich unzulässige Gleichsetzung von Hirntod und Individualtod und ihre Folgen für die Medizin*, in <<Ethik in der Medizin>>, 8, 1996, pp.79-89, W. Höfling, S. Rixen, *Verfassungsfragen der Transplantationsmedizin. Hirntodkriterium und Transplantationsgesetzt in Deutschland,* Tübingen, 1996; G. Höglinger, S. Kleiner (edited by), *Hirntod und Organtransplantation,* Berlin, 1998, F. Oduncu, *Hirntod und Organtransplantation. Medizinische juristische und ethische Fragen,* Göttingen, 1998; R. Stoecker, *Der Hirntod. Ein medizinethisches Problem und seine moralphilosophische Transformation,* Freiburg, 1999; T. Schlich, *Ethik und Geschichte: Die Hirntoddebatte als Streit um die Vergangenheit,* in <<Ethik in der Medizin>>, 11, 1999, pp.79-88; G. Brudermüller, K. Seelmann (edited by), *Hirntod. Zur Kulturgeschichte der Todesfeststellung,* Frankfurt a. M., 2001.
On the Japanese debate see: H. Kawaguchi, *Strafrechtliche Probleme der Organtransplantation in Japan,* Freiburg i. B., 2000; M. Morioka, *Reconsidering Brain Death: A Lesson from Japan's Fifteen Years of Experience,* in <<Hastings Center Report>>, 31, 4, 2001, pp.41-46. The debate diffusion, also in the general opinion, is clear by the daily press analysis. See for instance: *Transplants from brain-dead patients burdensome: study*, in <<Japan Economic Newswire>> (International News), Tokio, 8 maggio 2002; *Transplants of organs from brain-dead man begin*, in <<Japan Economic Newswire>>(International News), Osaka, 12 novembre 2002; *Organs from Wakayama brain-dead man transplanted,* in <<Japan Economic Newswire>>(International News), Osaka, 13 Novembre 2002; *Flawed test for brain death <<violated law>>,* in <<The Yomiuri Shimbun/Daily Yomiuri>>, 25 Febbraio 2003.

[18] See R.D. Truog, J.C. Fackler, *Rethinking brain death,* in <<Critical Care Medicine>>, 20, n. 12, 1992, pp.1705-1713. Starting from the results he achieved with this article, Truog has dealt with brain death problem more than one time. In an article of 1997 (R.D. Trough, *Is It Time to Abandon Brain Death ?*, in <<Hastings Center Report>>, 27, 1, 1997, pp. 29-37) instead of putting forward the proposal of the replacement of brain death with the cortical one, as he did when he wrote with Facler in 1992, Troug hopes for the traditional cardio-respiratory standard comeback in order to declare death and, at the same time, he hopes for a separation between transplantations problem and the debate on brain death. He thinks that doing transplantation might be only carried on by finding a different excuse from that one given till now by a definition of brain death, which is more and more at a turning-point. And it was exactly with the attention drawn to the need to give transplantations a moral basis that Troug wrote a new article: R.D. Troug, *Organ Transplantation Without Brain Death,* in <<Annals of the New York Academy of Science>>, 913, 2000, pp. 229-239.

activity. [19] If the point of no return had been clearly exceeded, the patient would have been disconnected from the artificial ventilation devices, and after twenty minutes' wait – a time which is considered necessary by Shewmon to get sure that the subject vital functions can't spontaneously recover – you could proceed with the death declaration.

Therefore, Shewmon comes to the same Jonas' conclusion in a different way. The big question that you can pose here is, whether these norms were respected, transplantations would be still successfully possible. The physical conditions aren't for sure any longer ideal, and the advantages are more limited, too; but now we have to wonder whether the organs – as the latest medical studies prove – are removed from donors who are in a borderland between death and life, in this case the explantation itself causes them to die. The legislations which admitted brain death are based on the assumption that the patient is already dead when the organs are removed, but if, from the beginning, this assumption could be arguable from the philosophical viewpoint, in the end it turned out to be baseless from the scientific viewpoint, too. If the legal premise for the removal of organs is that they are extracted from persons who definitively lost their brain functions, then it must be recognized that a lot of organs are removed breaking the law openly. Instead of going on operating deceptively, we'd like to discuss openly whether removing organs, in a condition you can't get over from, but that it doesn't correspond to death yet[20], is admissible or not.

In the end, like in the artificial insemination also in organs transplantation issues, the application of advanced medical technologies raise new, difficult moral doubts about it. The removing organs technical possibility urged us to use patients, whose fate was decided, like spare material for other human beings; similarly the in vitro insemination technical possibility could encourage us (even though in this case the Italian law-maker bucked the trend) to use so-called extra embryos – destroying them – for some diseases treatment. In this case the problem was: "What about the patients, who, although they have been subjected to resuscitation, won't be able to get over any longer because their brain stopped working?" In the end, we expected to solve it in an oversimplified way, and that's to declare them dead, even if their human body can continue working well and (for a long time) with the ventilation support, perhaps it might work better than those few in vitro embryonic cells, which have no brain yet, anyway.

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[19] See for example D.A. Shewmon, "*Brainstem Death" , "Brain Death" and Death: A Critical Re-Evaluation of the Purported Equivalence,* in <<Issues in Law & Medicine>>, 14, 2, 1998, pp.125-145 (now translated into Italian and it's entitled *" Morte del tronco cerebrale", "morte cerebrale" e morte: un riesame critico della presunta equivalenza,* in the book edited by R.Barcaro, P. Becchi, *Questioni mortali. L'attuale dibattito sulla morte cerebrale e il problema dei trapianti,* Naples, in the press and the latest one: D.A. Shewmon, *The Brain and Somatic Integration: Insights Into the Standard Biological Rationale for Equating "Brain Death" With Death,* in <<Journal of Medicine and Philosophy>>, 26, 5, 2001, pp. 457-478.

[20] The problem has been clearly illustrated by two American scientists: S.J. Youngner, R.M. Arnold, *Philosophical Debates About the Definition of Death: Who Cares?,*in <<Journal of Medicine and Philosophy>>, 26, 5, 2001, pp.527-537.

Commentary on Becchi

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Today, it has become widely known among specialists that current brain death criteria are far from perfect. First, it became clear that some brain functions still remain after a "brain death" diagnosis. In many countries, brain death is defined as "the total loss of function of the whole brain," hence if we maintain this definition, it is clear that the current criteria fail to determine true "brain death." This may be shocking to lay people, because they usually believe that the brain dead person's brain stops functioning, and they believe this to be a persuasive ground for permitting organ transplants. When Professor Paolo Becchi gave a lecture at Kansai University in 2004, a legal specialist commented that he had never known this fact, and it might influence his attitude toward brain death and organ transplantation.

Second, as Paolo Becchi referred to in his paper, the hearts of many brain dead people continue beating more than several weeks after the diagnosis of brain death. In the longest case it has lasted more than 14 years, which was reported in Allan Shewmon's paper in 1998, and in this case the parents have cared for their brain dead son at their home. This was made possible because the integral function of the brain dead body became very stable after the diagnosis of brain death. Similar case was reported in Japan, in which case a virtually brain dead baby "lived" for 4 years in a hospital (I talked about this case in (1)). These findings are sharply contrasted to ordinary people's beliefs on brain death. Many people believed that the heart of a brain dead person stops functioning within a week after the diagnosis. I suppose they have never imagined a case in which the heart continues beating for more than a month/year.

Becchi talks about Hans Jonas and his contributions to contemporary bioethical discussions. Jonas was a philosopher who was staying outside the mainstream of bioethics, but I believe we have yet to learn a lot of things from his philosophy on life and nature. As Paolo writes in his paper, Jonas saw "life" in the midst of the brain dead body of a pregnant woman. The pregnant woman was losing consciousness in the state of brain death, but Jonas saw something very precious in the warm brain dead body of the woman who continued maintaining another "life" in her uterus. For Jonas, the essence of human life doesn't consist in brain function, nor warm body itself the brain dead person maintains. I presume Jonas wanted to say that the essence of human life is something that lurks behind the warm living human body and makes it something more than a mere body. Human life is something that adds "dignity" to a brain dead body. This is, I think, what Hans Jonas tried to say in his letters on brain death. It is time to rethink Hans Jonas's philosophy of life in terms of bioethics and life studies.

(1) Masahiro Morioka, "Current Debate on the Ethical Issues of Brain Death," *Proceedings of International Congress on Ethical Issues in Brain Death and Organ Transplantation*, University of Tsukuba, (2004):57-59.
http://www.lifestudies.org/braindeath02.html

Bioethics thick and thin: A review of *Genomics In Asia: A Clash of Bioethical Interests?* edited by M. Sleeboom.

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To what extent can we speak of a distinctly ‘Asian attitude’ towards genomics and bioethics? What social and political factors shape the reception of biotechnology in Asia? Do class interests impact access to clinical services? What are the processes by which bioethical policies in Asia are formulated and what are the linkages between political authority, population polices, and the use of biomedical technology?

These are some of the questions explored in this volume, which is a result of the *Genomics in Asia* conference held in March 2002 at the International Institute of Asian Studies (IIAS) in Leiden. Readers of *EJAIB* will be familiar with many of the topics and authors. Contributions are by: Anwar Nasim; Gursatej Gandhi; Santishree Pandit; Soraj Hongladarom; Noritoshi Tanida; Hyakudai Sakamoto; Shui Chuen Lee; Yu Kam Por; Masahiro; Min Jiayin; Norio Fujiki; Mary Ann Chen Ng and Darryl Macer; Yanguang Wang; and Chan Chee Khoon.

It is clear from the contributions that we cannot speak of a distinctly ‘Asian’ position towards genetics any more than we can identify a unified ‘Western’ perspective. *Genomics in Asia* presents a diverse range of viewpoints from the humanities and social and natural sciences. Issues include gene therapy, the moral status of nature, eugenics, cloning, genetic counselling, female infanticide, and the proper role of bioethics in the global community. Topics are considered from Islamic, Christian, Hindu, Sikh, Confucian, Shinto, and Buddhist perspectives. Thus, *Genomics in Asia* shows the range of claims made in the area of bioethics in Asia and is to be recommended as a good introductory reader to the variety of religious, philosophical and cultural problems raised by biomedicine.

Despite its value, however, the volume’s analysis of bioethics and genomics remains rather thin in at least two ways. First, while the book addresses a diverse set of issues from a wide range of viewpoints, it nonetheless suffers from a paucity of methods. That is, it lacks the sort of interpretive analysis that Clifford Geertz advocated in his account of effective research. In his example of winking, Geertz emphasized the importance of distinguishing between a meaningful social gesture and a mere twitch of the eye. His argument was that we must move beyond a simple description of winking as a physical act to the particular social understanding of winking as a gesture. In other words, a ‘thin description’ is the mere wink. A ‘thick description’ includes the meaning behind the wink and its symbolic import between communicators, as well as the wider society.

Genomics in Asia is ‘thin’ in that much emphasis is given to normative claims and assumptions but little use is made of empirical data. When qualitative methods are used, it is in the form of surveys (eg Part III Genomics and Practices in Asia). But surveys, as a method, are highly problematic since one never knows how respondents have interpreted the questions. Surveys have their use when combined with other methods but on their own tend to decontextualize knowledge. In short, surveys cannot gain access to the richness (indeed messiness) of lived experience. These are shortcomings that the editor recognizes. Sleeboom writes that ‘more qualitative research’ and ‘more empirical data from a comparative perspective’ is needed to better understand the issues at hand (p. 20). I’d fully agree and note that the IIAS’s new Genomics in Asia Research Programme is designed to accomplish just this.

However, *Genomics in Asia* is also ‘thin’ in its treatment of ethics. Here, I adopt Michael Walzer’s distinction. For Walzer, thin morality is that which is universal and refers to humanity in a broad sense. Thick morality, on the other hand, is dependent on specifics and adapts to social circumstances. In this sense, morality gets its thickness only within the context of social and cultural relationships. In *Genomics in Asia* too little weight is placed on specifics. As the book shows, part of the danger of relying on a thin analysis is that you get unsubstantiated and rather poorly thought out arguments. Some chapters simply claim too much. For instance, it is poor academic writing to assert that ‘there is no tradition of racism in China’ or that ‘there are no Chinese who think that they are superior to particular minorities’ (p. 287). Again, it must be said the editor seems well aware of these problems and rightfully faults some of the contributors for mistaking their own views as being widely representative when in fact they are not.

But the reader should not let my critical tone put them off to *Genomics in Asia*. Given the growth of genetic research in Asia, bioethical reflection is sorely needed. In this respect, the volume helps to fill a gap in the literature and provides a good start to the analysis of the issues. Overall then, the volume is useful as far as it goes – but its greatest value may be in bringing attention to just how much work is needed yet in the field of genomics and bioethics in the Asian context.

I end on a note of caution. Unfortunately, chapter numbers referred to in the editor’s introduction do not correspond to the actual text which can be confusing for the more discerning reader. And finally, the volume does not contain an index, which is regrettable in light of Kegan Paul’s list price of £75.00.

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Perceptions of interpersonal relationships held by patients with obstinate disease

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Abstract

The objective of this study was to reveal the problems related to interpersonal relationships which patients with obstinate diseases face, and consider the behavior, attitude and medical intervention that healthcare and healthcare-related professions should take in regards to these problems. Semi-structured individual interviews were conducted with patients with obstinate neurological diseases and observation of outpatient care was also conducted. Data were analyzed by qualitative content analysis. Patient diseases included Parkinson Disease (PD), Amyotrophic Lateral Sclerosis (ALS), myasthenia gravis, spinocerebellar ataxia (SCA), and progressive supranuclear palsy (PSP). Findings highlighted that patients’ disease and suffering was not understood fully by patients’ families, that patients feel a lack of family support and cooperation, and that society’s level of understanding of their disease was also insufficient. Again, findings revealed that patients recognized their inability to perform personal activities and to behave competently within the contexts of family and society. This lowered their self evaluation. These findings highlight three needs: “the need for empathy,” “the need for self

esteem," and "the need for support." In this report, we discuss the "the need for empathy" and "the need for self esteem."

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Introduction

In order for patients with obstinate diseases to receive a high level of medical care, strong interpersonal relationships with friends, family and healthcare providers are necessary. Several previous studies have shown that the patient-healthcare professional relationship is not always adequate, which leaves the patient unsatisfied with his or her relationships. It has been suggested that healthcare professionals are unable to provide sufficient psychological support to the patient, lack the ability to empathize, do not disclose enough information and often do not encourage patients to participate in medical decision making (1,2). This has fostered discussions on how healthcare professionals should approach the patient-healthcare professional relationship. Education on communication skills and exploration on building better relationships are also underway.

Certainly enough, a patient's interpersonal relationships go beyond those with one's healthcare provider. Patients live and exist with their families as part of society. According to Kleinman, illness is not merely a personal experience; it is a mutual, communicative and, ultimately, a social experience (3). As described above, we surmise that similar to, or even more than, how the patient-health professional relationship has an impact on a patient's lifestyle, a patient's interpersonal relationships with his or her family and community – with which they spend the majority of their time – have a significant influence on patient's QOL and welfare. In particular, medical care for patients with obstinate diseases who are physically limited by their disease necessitate social welfare and constant family support. The quality of care for patients with obstinate diseases depends largely on a patient's interpersonal relationships as well as on other's attitudes and behavior. Accordingly, a survey study is needed on how patients with obstinate diseases maintain their relationships with family and society, and how patients' families and communities recognize and accept a patient's disease and disabilities.

Even today in the field of psychiatry, families of patients with depression hold a fixed idea that depression is "a disease of idleness" as a result of being unable to understand that depression is a disease which requires careful consideration of a patient's condition. Accordingly, this necessitates healthcare professionals to help patients' families in understanding the patient and his or her disease (4). There are also cases when a patient's family suffers directly from a patient's disease and becomes physically tired and emotionally unstable (3). As a result, a family's emotional and physical capacities to understand the patient's suffering are lost leading to possible breakdown of familial relations. Even within a patient's community, prejudice continues to exist against patients infected with HIV or Hansen's Disease (leprosy) (5). Relationships of prejudice perhaps inflict a great deal of emotional and social harm on the discriminated persons.

In Japan, as for as we know, there exist neither studies on how patients with chronic obstinate diseases perceive their personal and social interpersonal relationships nor on the types of problems patient face in those interpersonal relationships. We believe that an understanding of how patients perceive their relationships will allow us to reveal part of the problems inherent to these relationships and propose a possible way of dealing with these problems from a medical perspective. Accordingly, this study's objective is to reveal the problems that patients with obstinate diseases face in their interpersonal relationships. Based on our findings, we then consider the behavior, attitude and medical intervention that healthcare and healthcare-related professions should take regarding these problems.

Methods

Between May and November, 2003, we conducted semi-structured interviews with outpatients of the Department of Neurology at the Mie University Hospital. A convenient sample was taken of patients whom the attending physician (YN) judged to be physically capable of participating in an interview, whom were adults with decision-making capacity, whom could communicate effectively, and whom provided their informed consent to participate. Interviews were conducted in a room at an arranged time following the patient's check-up on a different floor than the Neurology ward.

Interview questions focused on the following items: lifestyle problems that the patient has faced as a result of his or her obstinate neurological disorder, the patient's family, local community, medical requests, and any problems at the time of medical decision making. Data on participants' age, sex, diagnosis, marital history, occupation and religion were collected at the time of the interview.

Interviews were conducted primarily by one investigator (AA). However, the attending physician (YN) had conducted interviews on two patients with Amyotrophic Lateral Sclerosis (ALS) in the medical examination room immediately following their medical appointments. In regards to these two patients, the attending physician judged that it would be too strenuous for these patients to participate in an interview separate from their medical appointments. An interview conducted by the attending physician was more appropriate on the following basis: one patient was male with advanced ALS who was physically disabled and had difficulty speaking; the other patient was female who had difficultly breathing and required written communication due to a tracheotomy. Upon obtaining informed consent, observation on patient interaction via audio tape was also conducted in order to compare with interview data. This was conducted by the attending physician who participated in this study (YN).

Observation and interview recordings were transcribed verbatim and analyzed using qualitative content analysis (6). This consisted of, first, selecting portions of the transcription that related to everyday interpersonal relationship problems and to the patients' perception of their family and other people, next, coding these portions and, lastly, creating categories based on the association between codes. The qualitative content analysis was initially conducted by three investigator (AA, YN, and EN). The remaining investigators reviewed these preliminary results to further verify reliability of findings. Research team discussions were also used to select interviewees' representative statements.

Content analysis validity was ensured by comparison of interview responses and observation recordings as well as by content analysis being conducted by multiple investigators. When we compared each patient's interview responses with the patient's utterances during his or her medical checkup, no incongruities were found regarding patient symptoms, limits of ADL, home environment, state of social welfare, primary complaints and other lifestyle problems. No differences existed in codes and categories created respectively by investigators. Given the sensitive issues related to interpersonal relationships, member checking interviews were not conducted with patients due to possible psychological harm. This study was approved by the Mie University School of Medicine Ethics Committee. All investigators have participated in the conception and design of this study, discussed the accuracy of the lists of codes and categories, and joined the writing of the final version of the paper.

Table 1 Interview Participants' background

Sex	
Female	6

	Male	4
Age (range)	40 to 70	
Diagnosis		
	Parkinson disease	4
	amyotrophic lateral sclerosis	3
	myasthenia gravis	1
	spinocerebellar ataxia	1
	progressive supranuclear palsy	1
Religion		
	Buddhist	6
	Christian	1
	None	3
Living with their families		10

Results

Interview Participants

A total of 12 patients among outpatients with obstinate neurological disorders were asked to participate. Ten patients provided their informed consent to participate in a semi-structured interview and to have the interview recorded. The two patients who chose not to participate were female with Parkinson Disease.

Table 1 shows participants' background. Our sample consisted of six males and four females ranging in age between 40 and 70 years old; all participants were living with their families. Six participants were Buddhist and one was Christian. Diseases included Parkinson Disease (PD, n=4), Amyotrophic Lateral Sclerosis (ALS) (n=3), myasthenia gravis (MG) (n=1) spinocerebellar ataxia (SCA) (n=1), and progressive supranuclear palsy (PSP) (n=1). In five of the interviews, patients were accompanied by their spouses (ALS (n=3), MG (n=1), and PSP (n=1)).

Findings are based on content analyses of interviews conducted with patients (n=10) who had provided their informed consent. This study focused on problems related to interpersonal relationship that patients with obstinate neurological disorders face. In our description of results presented below, codes are represented by single quotes, categories are represented by double quotes and excerpts from interviews are in *italics.*

Problems with interpersonal relationships with family members (household interpersonal problems)

1. "A lack of understanding from one's family"

Participants felt that their pain and suffering from disease was not sufficiently understood by their families. Patients felt that they were blamed for "faking being ill" in times of family conflict especially in cases of PD with fluctuation or when their family acted insensitively towards the physical constraints or failures brought about by their disease. That is, patients' families would 'behave bitterly' toward behavioral constraints or failures due to one's disease, and familial relationships would become complicated when patients were blamed for 'playing sick.' While we cannot say that this demonstrates a causal relationship, a fraction of participants felt that their disease had caused a great deal of stress for their family and, thus, had caused 'family strain.'

Dissatisfaction… I would probably say it lies in how much my family understands. I move around a lot and my family probably thinks that not much is wrong. Thus, I guess it is unlikely that my family understands my position. (Male in his 50's、SCA).

In getting sick, all my worries are family-related. How can I say this? In becoming disabled like this, my family assumes that I brought my Parkinson Disease on myself (female in her 60's, PD).

2. "An inability to carry out one's role as a family member"

Obstinate neurological diseases make it difficult for patients to carry out their role as a family member. Interview participants could not play their 'role as one of the bread makers' or their 'role as the women in the family' and would consider themselves as 'a disturbance.' This caused many participants to feel 'a sense of inferiority' and/or to feel 'reserved' towards family members.

Being unemployed in itself. (Male in his 40's, ALS).

I can't clean or do my house chores as I please. Although my daughter in law does a lot of the chores and cleaning for me, I feel so reserved. (Female in her 70's, PD).

3. "A lack of family support"

Patients' needs were not always prioritized within the family. 'Family circumstances' were quite influential. For instance, remodeling one's home for easier movement was impossible because of a child's resistance to live at home together or adequate family support was not available when only husband and wife lived together due to one's child having grown-up and now living away from home. Other examples include families that have to deal with another family member being sick. Psychological harm as a result of 'awareness of male and female roles inside the house' also existed. Results described that in the case of female patients, husbands would not actively do the house chores.

I want my daughter who lives in Tokyo and has yet to marry to return home, but it is impossible to find work around here; she is a high school teacher and would have to retake the licensing examination. There are a lot of things to consider. (Male in his 60's, ALS)

There are times when I have to carry a small package or something, and I thought my husband would do it for me, but… with my mother in law around, he just won't do anything. Unlike the children today who would immediately take notice and offer to carry it for me, my husband will not do it even if I ask him. (50 year-old female, PD).

Problems related to interpersonal relationships with people outside of the family

4. "A lack of understanding from society"

Participants felt that, similar to their feelings toward their own family, society did not understand their pain and suffering brought about by their disease. Society is defined here as those interpersonal relationships outside of the family. Many participants suffered from people being 'cold' and 'not understanding.' They wished that people would 'be kind' and 'be considerate.' While no concrete examples were provided, many participants felt a sense of 'discrimination, prejudice.' Other patients felt the need to 'personally explain' one's disease and raise people's awareness since society 'lacked awareness and understanding of disease'. Even though people did not see a patient's symptoms to be severe enough to be fully recognized and to be treated kindly, symptoms were indeed quite painful for the patient him or herself.

(Interviewer asks, "Do you have any requests towards your family or the people around you?") That would be to be kind. To be kind is my first wish. My grandchild already hates me. He sometimes says, "When grandma comes, we can't do anything; you don't need to come grandma." My daughter in law does a great deal for me, but… even with her, I feel that I am a trouble. I feel that I am a bother. If I go out with them, they have to walk slowly and lag behind. *No matter what I do, I always need other people's* help. (70 year-old female, PD).

Ultimately I guess I want society to have some consideration for my disease… It would be hard to answer how to do this, but ultimately (in order to have people understand), one has to confess to be sick and get people to understand. (50 year-old male, SCA).

5. "Inability to participate in society"

The fact that patients could not perform the same tasks as a healthy individual –'we cannot do anything together' – limited patients' ability to participate in society. In regards to specific activities daily living (ADL), participants often felt distress because of their 'inability to do something alone' and the need 'to tolerate' having always to go places and do things with caregivers.

Even with walking, this does not work. So when walking, I bend all the way over. Unless I lean to the side, I can't go forward. My physician says to stop walking for a little while when that happens and then to start walking again. So I stop for a little while and struggle walking with my cane while everyone just passes by and goes ahead. Why did I have to get sick like this… (60 year-old female, PD).

6. "The eye of others"

The inability to participate in society due to constraints on one's everyday movements was extremely stressful. However, having people watch one's each and every movement made it even more difficult to live with an obstinate neurological disorder. Participants would always 'feel conscientious of others' and 'different from other people.' For instance, when a patient would fall down in public, he or she would feel conscience of 'looking bad' while also worrying about physical harm. Participants would 'worry (feel concerned)' about 'being a trouble to others' and about one's bodily movements seeming 'unpleasant' to others. Similar to how participants felt towards their family members, many felt 'a sense of inferiority' in society. Even patients with myasthenia gravis who are free from most symptoms felt 'different from other people'.

If I were to fall while on a trip or out shopping, I think "oh, this looks bad" (Interviewer comments, "While, in fact, your body is much more important than looking bad"). "Looking bad" is also a consideration. (60 year-old female, PD).

Now, my lifestyle is very much like the lifestyle of a normal person. I try not to become tired. But when I do get tired, I either take a morning nap or an afternoon nap. When I am really busy, I am up all day, but… well, I try to lay down either in the morning or early afternoon. (40 year-old female, MG).

Discussion

Findings highlighted that patients' disease and suffering are not understood fully by their families, that patients feel a lack of family support and cooperation, and that society's understanding of disease was also insufficient. Again, findings revealed that patients recognized their inability to perform personal activities and to behave satisfactorily within the contexts of family and society. Ultimately, this lowered their self evaluation.

Before we assess the above findings, we would like to confirm this study's limitations and problems. Firstly, the final sample consisted of ten patients. Although we used qualitative interviews in which sample size inherently does not affect study quality, our sample size was limited when compared to similar studies that have been conducted abroad. Accordingly, this study serves as a preliminary survey. Problems beyond the items referred to by interview participants may exist. Secondly, it is possible that the five patients who were accompanied by their spouses at the time of the interview were unable to express their honest opinion regarding their spouse's behavior and attitude. However, we were able to gain sufficient understanding of patients' feelings towards their families from patients who were not accompanied by their families. Thirdly, this study's sample consisted of patients with obstinate neurological disorders who were able to visit the hospital on their own or with additional help in order to receive outpatient care. Accordingly, it is possible that perceptions of interpersonal relationships differed among patients whose disease was too advanced to receive outpatient care. It is also possible that perceptions of interpersonal relationships differed among patients with a non-neurological chronic obstinate disease. Lastly, and most importantly, results are ultimately based on patients' subjective perceptions and do not reflect the actual degree of understanding and support among patient families and society. Findings consist of "what patients feel" and "what patients think" and do not provide an objective account of what is actually occurring in a patient's surroundings. This study included neither interviews with patient families nor observation of what occurs outside the examination room, which could have substantiated patient's views. Accordingly, this study does not contain data analyzed from a third-person perspective on patient-family or patient-community relationships.

After considering these limitations and based on the items expressed by patients related to relationships with family, community and oneself, we would like to discuss the type of training healthcare professionals should receive and what can be done. There are several lessons that healthcare professionals should learn from this study' findings, but we have summarized these lessons in the following three needs: "the need for empathy," "the need for self esteem," and "the need for support." In light of the excessive literature on the need to support patients with obstinate neurological disease in the areas of social welfare, care giving, nursing and medicine, this report focuses on "the need for empathy," "the need for self esteem."

Certainly empathy is essential to interpersonal relationships. Perhaps all people have experienced the pain of "no one understands" or the happiness of "being understood." Even if one can not heal a patient's disease, a healthcare professional can ease a patient's suffering just by sharing their pain. Nevertheless, it is impossible to understand fully another person. In particular, it is extremely difficult to share the suffering of pain which one has never experienced. Suffering of disease is similar to QOL from the perspective that both depend on a patient's subjective perspective. The everyday pain of patients with obstinate diseases is immeasurable. It is even difficult for a patient's family to understand the feelings of patients whom live day-in and day-out with disease. Interpersonal relationships that are unable to provide and, thus, lack empathy are sources of pain.

Accordingly, health professionals need to ask themselves constantly, "Am I understanding the patient's suffering?" Vital questions include, "Am I able to stand in the other's shoes?" "Am I able to see things as the other does?" and "Am I interacting with consideration?" So the question remains as to how we can be empathetic human beings. Ethically speaking, this question can be restated as how we can acquire the virtue of "empathy." This report will not pursue this difficult query, but rather seeks to confirm the absolute need to maintain an empathetic demeanor in the context of patient care. Enrichment of medical education within this area is also desirable.

As Kleinman has pointed out, disease alters a patient's world and disease destroys patient families (3). Maintaining healthy relationships is difficult inherently, but a patient's disease and the disabilities that accompany that disease further complicate that relationship. It is easy to imagine the difficulty for a family to understand a patient's suffering and fully empathize with that patient in a household where the familial relationship is dysfunctional. Likewise, we should not forget that it is difficult for healthcare professionals to understand the feelings of a family who is caring for such a patient. Under these circumstances, a healthcare professional is able to educate families on how to understand a patient's disease as well as able to support families who face physical, psychological and economic stress by living with the patient. Policies that promote caregiver support, consideration of burden, and improvement of caregiver QOL are important. For instance, given that physical constraints are inherent to several neurological diseases, it is necessary for healthcare professionals to explain to the family that, as a result of the disease, the patient's condition will worsen no matter how hard he or she tries in rehabilitation and that regardless of a treatment's quality, the patient's prognosis will remain poor. It is also valuable to inform families of social resources such as caregivers and social welfare. Likewise, we believe that it is important for healthcare professionals to be empathetic towards the suffering that a patient's family experiences. However, further exploration is needed on whether health professional can and, if so, how far they should intervene in family problems which, ultimately, are private – except domestic abuse to the patient.

In regards to a lack of understanding in one's community, we recognize that discrimination and outright disregard derives from ignorance and illogical hate. This highlights the importance of further spreading the concepts of human rights and promoting general education on disabilities and medical care. However, a societal lack of understanding for disabilities and disease cannot be cured by medical care alone. A change in behavior toward society's weak is needed.

This study revealed that patients severely lose self-esteem. Patients feel ashamed as a result of not being able to fulfill their roles, which consequently instills feelings of self-insufficiency and makes patients conscientious of others. Feelings of inferiority also arrive as a result of not being able to participate in society. That is, this can be summarized by a self-image of I am 'abnormal and unworthy.' Kleinman described that it is an indispensable necessity for healthcare providers to be highly sensitive to stigma and feelings of shame (3). Healthcare professionals should consider how to preserve a patient's self-esteem in the contexts of a patient-healthcare professional relationship and a medical care approach. Healthcare professionals cannot forget that imprudent behavior and communication can easily hurt a patient. Medical care is merely not providing benefits to patients. Rather medical care is based on "never causing injury" and "never harming." Therefore, medical education on the modality of the patient-healthcare professional relationship and on the fulfillment of professional ethics is indispensable.

The ultimate question, however, is what can healthcare professionals do in regards to the sense of shame and inferiority felt by patients with obstinate disease in their private and social lives? Unquestionably, this challenge is quite difficult to meet with only a medical approach. Today in Japan, there are currently no effective policies to eradicate a patient's self-perception of being 'abnormal and unworthy.' But, if patients, their families and friends, healthcare professionals and the community fundamentally change their standards of self-evaluation and the significance of and value in human existence, this social state may improve. Hence, a first step to recovering patients' loss of self-esteem could be found in a societal sharing of awareness. This awareness would recognize that the significance of and value in human existence can be determined not by being able to do something but in ways which maintain a patient's human dignity, that the concept of normality itself is strictly illusionary, that one needs neither to be identical with another nor to be self-conscientious, that, regardless of differences among individuals, a person can not live without the support of one's community and others, and, accordingly, that one does not need to lower themselves just because they receive support from family and community.

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News in Bioethics & Biotechnology

http://www.biol.tsukuba.ac.jp/~macer/NBB.html

News will appear in some future issues of EJAIB.

International Bioethics Education Project News

yahoo listserve
<http://groups.yahoo.com/group/Bioethicseducation/>)

Human Behaviourome Project

The new list of total papers on the mental mapping project, is online: http://www.biol.tsukuba.ac.jp/~macer/ menmap.htm

IAB Genetics & Bioethics Network: On-line

The complete address list is updated on the Internet. Send all changes to Darryl Macer.

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Persons who want to confirm their membership of the ABA must send their completed membership form and fees to the secretary if your name does not appear in the list on-line, Darryl Macer, (by Email, fax or airmail). An updated ABA membership list will be placed in mid-March 2005 on the new website linked through http://www.unescobkk.org/index.php?id=41

Conferences

A bioethics conference calendar website is:

http://www.who.int/ethics/events/en/

First Bangkok Workshop on Ethics Partnerships for Asia-Pacific Region, 21-22 March 2005, UNESCO Bangkok, Thailand. Contact: d.macer@unescobkk.org

Fourth Session of UNESCO COMEST, 23-25 March 2005, Bangkok, Thailand. Contact: d.macer@unescobkk.org Website: http://www.unescobkk.org/

Sixth Asian Bioethics Conference, 14-18 November, 2005, Sanliurfa, Turkey. Contact: saksoy@harran.edu.tr Website: http://www.jointbioethics.org

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