

Eubios Journal of Asian and International Bioethics

EJAIB Vol 17(6) November 2007 ISSN 1173-2571

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Official Journal of the Asian Bioethics Association (ABA)

Contents

	page
Editorial:	161
Arsenic Contamination in Ground Water in Bangladesh: Nature of Awareness in an Arsenic-prone Area	162
- Wardatul Akmam, Sk. Muaj Hurayra Marshad & Md. Fakrul Islam	
BioCosmological Approach in World Bioethics	167
- Konstantin S. Khroutski	
Bioethics Education: A response to Viveka	171
- K. K. Verma & Rashmi Saxena	
Teaching Thanatology: A Qualitative and Quantitative Study	172
- N. Yasemin Oguz, M. Volkan Kavas & Murat Aksu	
Adequacy of informed consent in research carried out in Brazil	177
- José Roberto Goldim, Joaquim Clotet & Jorge Pinto Ribeiro	
Embracing personal and community empowerment: genetic information policy making in Israel	181
- Liza Ireni-Saban	
Neanderthal Range Extended	184
- K. K. Verma & Rashmi Saxena	
Perceptions of Issues in Biotechnology Management in Thailand	185
- Siriyupa Roongrengsuke and Sarote Phornprapha	
Invitation to Join Working Groups on <i>Ethics of Energy Technologies in Asia and the Pacific</i>	190
Asian Bioethics Association (ABA)	191
Conferences	191
Ordering Information	192

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Deadline for the January 2008 issue is **1 December, 2007.**

Preliminary Call for Papers:

The Ninth Asian Bioethics Conference of the Asian Bioethics Association in Yogyakarta, Indonesia, 3-7 November 2008 *Bioethics in Asia: healthy and productive life in harmony with nature*

Research findings, discussion papers, and other contributions dealing with topics in bioethics and related disciplines are welcomed. Papers are invited on, but not limited to, the following themes:

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- Can virtues be taught?
- Islamic Bioethics
- Biomedical and Biosciences Ethics
- Ethical Issues in Disaster Research and Management
- Ethnic Conflicts and Peaceful Co-existence
- Ethical Issues in Biomedical Research
- Ethical Issues on Organ Transplantation
- Ethics and Intellectual Property
- Public Health Ethics
- Technology and Culture
- Ethics of Emerging Technologies / Nanoethics
- Bioethics Education
- Cross-cultural Bioethics
- Environmental Ethics
- Science and Society
- Neuroethics

Preliminary deadline for receipt of abstracts for papers (200 words max)* and proposed sessions (with lists of speakers and titles) is 31 January 2008, to Email: nazif.amruhydari@yahoo.com, amru96@cbn.net.id

The specific objectives of the ABC9 are:

♦ *to identify issues* in the enforcement of law, rules and guidelines and other regulatory means of 'good research practice' of basic and applied researches leading to quality health care involving human subjects in accordance with the universally accepted bioethical norms;

♦ *to interpret and apply* the precautionary approach; where there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation; and

♦ *to recognize and duly support* the vital role in environmental management and development of local communities because of their knowledge and traditional practices.

This event will be organized by the ABA and Indonesian National Bioethics Commission, with the cooperation of UNESCO, WHO, and FAO. The local cooperating bodies and agencies will include industries, universities, and NGOs.

The updated information will be placed on the website: www.kbnindonesia.org

*Persons who wish to apply for limited scholarship support should also submit a letter of explanation and resume. The conference will also make judgments for the best student presentations.

Arsenic Contamination in Ground Water in Bangladesh: Nature of Awareness in an Arsenic-prone Area

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Abstract

Since 1993, a significant proportion of tube wells (the principal source of 'safe' water) have been discovered to be spewing water containing arsenic at a much greater level than is permissible (Bangladesh standard: 0.05mg/litre). According to Dhaka Community Hospital, this has put more than 80 million people at risk of various types of physical and mental diseases, including cancer of the skin and internal organs, gangrene, seizure, convulsions and mental retardation. Given this alarming situation, it is indispensable to make people aware of the imminent danger. Awareness campaigns have been undertaken and implemented by the government and other NGOs. This paper assesses awareness level of the people of a village named Khajadanga, situated in an arsenic-prone area. In this study, awareness has been defined as knowledge of (a) the dangers of drinking arsenic contaminated water, (b) the available alternative options of safe water from which people can choose the one suitable for themselves, (c) what to do if there is an arsenicosis patient in the household, and actual use of that knowledge through using water from safe water sources for drinking and cooking. The findings show that awareness level of the people in the study area was far from satisfactory.

Key words: Tube well, Arsenic contamination, Awareness level.

Introduction

By the early 1990s, most people in Bangladesh (90%) became used to drinking water from tube wells, which was supported and encouraged by the government and world organizations to keep them safe from waterborne diseases like diarrhea and cholera, as tube well water was thought to be pathogen-free (Akmam and Higano 2007). However, when these tube wells were installed, they were not tested for arsenic or other harmful elements. Thus it was neither known to the authorities, nor to the users that the water that they were drinking and using for cooking contained arsenic at a much greater level than was permissible. The permissible level of arsenic in drinking water in Bangladesh is 0.05mg/litre, although the WHO standard is 0.01mg/litre. In 1993, after diagnosing melanosis and keratosis (skin lesions and warts resulting from over-ingestion of arsenic) patients, it was discovered in Chapai Nawabganj district that tube wells were producing arsenic contaminated water (Ahmed 2003).

Arsenic is a carcinogenic and toxic but odorless and tasteless semi-metal element that belongs to the nitrogen family (HVR Arsenic Project 2000). Out of 64 districts in Bangladesh, 53 have been found to have the problem of arsenic contamination in varying degrees (DPHE and BGS 2000). According to Dhaka Community Hospital, arsenic contamination in ground water has put more than 80 million people at risk of various types of physical and mental diseases, including gangrene and cancer of the skin and internal organs, which lead to a relatively slow but painful death, making it the 'greatest mass poisoning in history' (DCH 2002, Smith 2000). Women and children are particularly vulnerable to arsenic toxicity. Pregnant women with high amounts of arsenic in their bodies are likely to pass it on to their babies. Growing children with skin lesions are likely to eventually develop cancer (Zuberi 2003). There is no specific treatment for arsenicosis, but safe water, nutritious food and multi-vitamins could help to make the skin lesions fade away, if diagnosed early (DCH and JU 2000). The alternative sources of drinking and cooking water available in Bangladesh include (1) rainwater harvesting, (2) dug/ring well, (3) deep tube well, (4) pond sand filters, and (5) arsenic removal filters (household and community type) (Ahmed 2002). Production of toxic sludge is a risk that is associated with filtering. However, recently SONO Filter has been declared by the US Environmental Protection Agency as safe from any environmental hazard. Not all of the alternative options may be feasible or suitable for all areas. Thus selection of cost-effective alternative options must be made for specific areas.

Given the alarming situation, it is indispensable to make the people aware of the danger that they are in and they must be persuaded to make changes in habits regarding drinking water, if necessary. In order to disseminate information needed for the masses to address the problem, a national communication strategy had been adopted. This strategy was based on social marketing technique (UNICEF 1999). Social marketing involves designing, implementing and controlling of programs that seek to proliferate the acceptability of a certain social idea, and or practice among targeted groups (Kotler 1975). More simply put, it is a strategy to change behaviour, utilizing advances in marketing skills and communication technology through action framework and integrated planning (Kotler and Roberto 1989). The first phase of the mitigation efforts carried out in a limited number of areas included meetings with community leaders, radio/TV commercial, dramas and workshops for health workers, distribution of leaflets, posters etc. (BAMWSP 2002). NGOs and the local governments were involved in various stages of the programme. All tube wells in the locality were tested and the residents were informed whether their tube wells were safe for them to drink water from. Next, they were helped to choose a safe water option. Village meetings, school meetings, and meetings with elected leaders of local bodies were used to disseminate the messages of the arsenic problem to the people. Workshops to train stakeholders were arranged.

Nevertheless the awareness level of those living in arsenic-prone areas is not at all satisfactory. For example, in Akmam and Islam (2006) it was observed that in spite of having arsenicosis patients in almost all the households, more than 46% of the respondents still used arsenic contaminated water for drinking and cooking. In the study carried out by Zakariya (2000), it was found that in an arsenic prone village that did not have many arsenicosis patients, awareness level was relatively low. Although they knew about the dangers of arsenic they did not bother to drink from safe water sources. In these villages, age, education and income had more influence on awareness. Zuberi (2003) in his study on some areas of Northern Bangladesh has shown that in his seven point awareness scale, the highest level his respondents could reach was 5. The reasons he mentioned for poor

performance of his respondents included (a) illiteracy, (b) non suitable communication materials, (c) non-suitable ways of presenting information (d) non-availability of suitable alternative option at a close distance (e) non-acceptability of prescribed option, and (f) fatalistic beliefs. Hadi (2003) has shown that age, exposure to awareness campaigns, educational status, and exposure to media had significant impact on awareness level. However, he concludes that it is unlikely that only arsenic awareness campaign is going to bring about behavioural change.

Objectives Of The Study

In this paper, we examine awareness level of the inhabitants in a village named Khajadanga. Specific objectives of the study were the following:

1. To depict the overall socio-economic situation of the respondents;
2. To understand the water-use pattern in the study area;
3. To know about the arsenic-related situation in the study village;
4. To find out the respondents' awareness level regarding arsenic problem;
5. To identify the factors that affect awareness level of the respondents.

Methodology

A social survey has been used to carry out the present study. Out of a total of around 1000 households 200 heads of households (the respondents of this study) were selected through simple random sampling. Data were collected by face to face interviews with respondents, using questionnaires that contained both open ended and closed ended questions. The respondents were interviewed in August 2005. Along with heads of households and female heads of households were also interviewed, as collecting water for the household is culturally thought to be 'women's job' in Bangladesh. Household was the unit of analysis. The data were processed manually. Simple statistical methods were used for analysis.

The Study Locale

The locale of this study, Khajadanga, is located in Tilak Shalpo Bahirdia Union within Rupsha Upazilla of Khulna district. This area has been selected for this study as it has been identified in the screening tests carried out by National Arsenic Mitigation Information Centre (NAMIC) as one in which 77% of the tube wells were contaminated with arsenic.

Socio-Economic Condition of the Respondents

Before going on into the water-related aspects observed among the respondents, we shall take a glimpse of the overall socio-economic conditions in the village.

Number of Members in Household

Fifty nine percent of the respondent households (n=118) had 4-7 members. However, a significant number (n=69, 35%) of households had more than 7 members. The reason for this is that in Khajadanga there were relatively more joint households, consisting of members belonging to three or more generations.

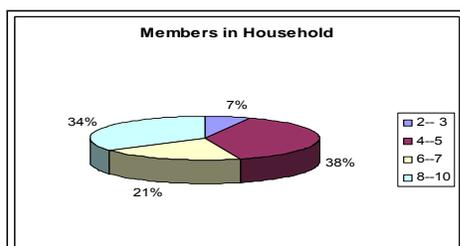


Figure 1: Number of Members in Household

Monthly Income and Occupation

Figure 2 shows occupation and monthly income of the respondent households. We find that 12% (n=24) of the respondent households were dependent on selling their labour only. All the others were principally or partially dependent on agriculture. Twenty six percent (n=52) of them totally depended on agriculture, while 48% (n=96) were depended on agriculture and some form of services. Among the respondents 56 (28%) earned only up to 2000 Taka per month, 51 (25%) earned 2001-4000 Taka, 56 (28%) earned 4001-6000 Taka and 37 (19%) earned more than 6000 Taka per month.

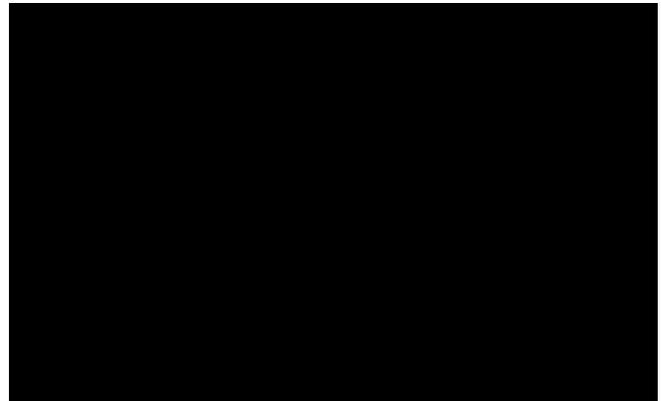


Figure 2: Monthly Income and Occupation of the Households

Amount of Cultivable Land

Figure 3 portrays amount of cultivable land owned by the respondent households. Only 5 (2.5%) of the respondents had no cultivable land. However, 38% (n=75) had more than 3 acres of land.

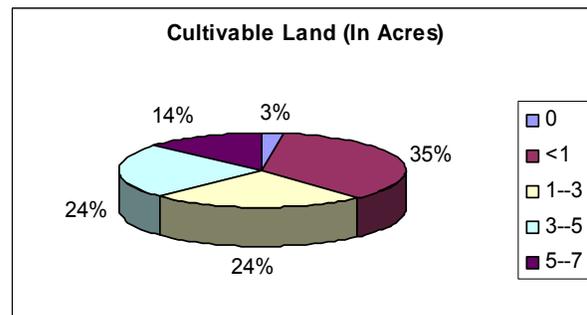


Figure 3: Amount of Cultivable Land

Types of Houses

All the respondents lived in their self-owned houses. Among the respondents, 46% (n=92) lived in kacha houses (made of straw, bamboo, mud etc.), 52.5% (n=105) lived in semi pucca (houses with cemented floor and corrugated iron roof) and only 1.5% (n=3) lived in fully concrete houses (pucca) houses.

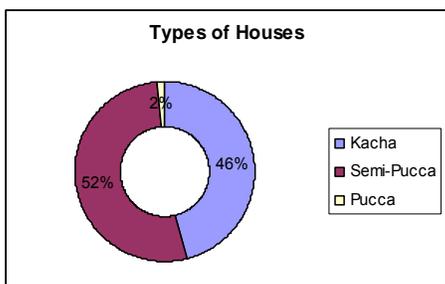


Figure 4: Types of Houses

Average Schooling Years of Households

Average schooling years of each household were calculated by counting the number of years each member of household (aged 7 years or more) attended schools (and colleges, universities etc.) and dividing the sum by the number of members aged 7 years or more. This gives us a better picture of education of the household as a whole. In Khajadanga, 26% of the households had an average of only 0-2 years of schooling, 31% had 2-4 years, 29% had 4-6 years and only 14% had 6-8 years of average schooling.

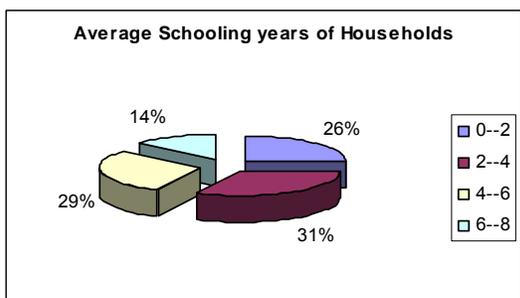


Figure 5: Average Schooling Years of Households

Water-Use In Khajadanga

In Khajadanga, every household used tube well-water for drinking; however, as this water contains too much iron and has a negative effect on taste and colour of food, they all used surface water (from ponds) for cooking. The female heads of households were asked about the distance which they had to walk to procure their drinking water (from tube wells). Their answers are shown in Figure 6. Sixty five percent (n=130) of the households had a tube well within their own home compounds. Thirty nine (20%) had to walk for up to 5 minutes to bring water, and 31 (16%) had to walk for up to 10 minutes.

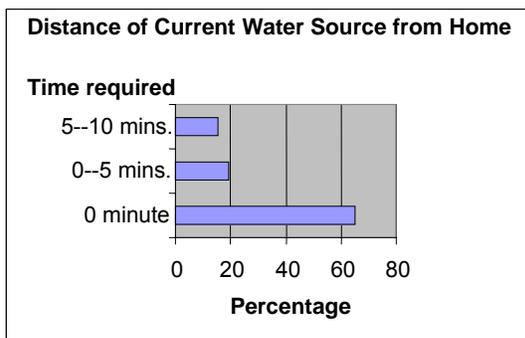


Figure 6: Distance of Current Water Source from Home

Arsenic-Related Situation in Khajadanga

Among the respondents in Khajadanga, 180 (90%) had their tube wells tested for arsenic, but 20 (10%) had not. These households were left out when the screening of tube

wells had taken place. Heads of households, because of their reluctance and ignorance did not take initiatives out of their own accord to have their tube wells tested. Among those tested, 52 (29%) were safe but 128 (71%) were not. Around 20 arsenicosis patients were identified in Khajadanga. Most of them had been taken away from the village to the cities for treatment. Only two of them could be found during the study period, a male and a female. The male patient, after being diagnosed, received treatment at Khulna Medical Hospital. He was recovering. The female patient tried to keep her disease a secret in fear of being abandoned by society. However, when her disease was ultimately exposed (Keratosis), she also sought treatment. She was not ill treated by her family or her community.

In spite of knowing that the water they were drinking was not safe, none had switched to a safe water source. The reasons they pointed out were that (1) they were habituated to drink this water and did not feel it necessary to change that habit (21%), (2) the source of safe water was too far away (22%), and (3) materials/instruments that could make their water arsenic-safe were not available (21%). Thirty six percent of the respondents mentioned all of the three reasons for their drinking unsafe water (see Figure 7).

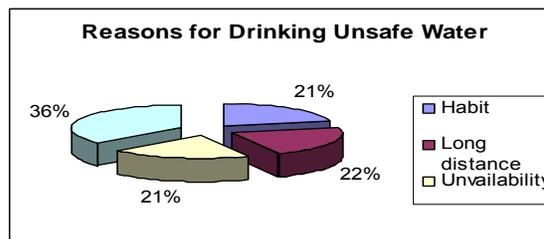


Figure 7: Reasons for drinking unsafe water

Awareness of Arsenic

Concise Oxford Dictionary defines awareness as “knowledge or perception of a situation or fact.” In this particular research, the term refers to knowledge of a situation along with rational changes in behaviour required to show internalization of the knowledge or information. Awareness of arsenic refers to knowledge of the target group on arsenic, its toxicity, mitigation, along with effective efforts to procure drinking and cooking water from safe sources.

Arsenic Awareness Scale

For this research, a nine-point awareness scale had been developed on the basis of the respondents’ knowledge of the arsenic problem and the actions taken by them in response to their acquired knowledge e.g.,

1. Knowledge that tube well water can be contaminated with high levels of arsenic, for which each tube well has to be tested. If a tested tube well is painted red, it should be avoided and water should be collected from one that is painted green;
2. Knowledge that arsenic is a tasteless, colourless poison that causes various symptoms and diseases including weakness, melanosis, keratosis, gangrene, mental illness and cancer of the skin, liver, kidney and other internal organs;
3. Knowledge that arsenicosis passes on from mother to the baby to be born, and that growing children are most susceptible to arsenic toxicity;
4. Knowledge that toxicity of arsenic does not reduce even after boiling. So, both drinking and cooking water should be procured from arsenic free sources;
5. Knowledge of the alternative safe water options and about the procedure of their use;
6. Knowledge that arsenicosis is neither contagious; nor is it a curse of God; if someone is suspected of having

arsenicosis, he/she must be taken to the hospital for treatment.

7. Knowledge that there is no specific treatment for arsenicosis; drinking from safe water sources is the first step towards cure.

8. To make sure that the tube well from which one procures water is tested; if found not safe, water must be procured from safe water sources.

9. To make others conscious about arsenic toxicity and to encourage and help them to drink from safe water sources.

Respondents who succeeded in fulfilling all the nine factors were considered fully arsenic-aware persons. Along with the awareness campaign that is continuing in the media (radio, T.V.), billboards, school textbooks, newspapers etc., the DPHE (Khulna district) and an NGO named ADAMS also carried out some awareness raising programmes. The DPHE and ADAMS were engaged in the screening program to identify tube wells that were arsenic-affected (spewing water with arsenic 0.05mg/liter or more). They painted the spouts of safe tube wells green and the contaminated ones red and advised villagers to stop drinking water from tube wells that were painted red and share water of the green painted tube wells. However, they did not inform the villagers about the deadliness of arsenic and its multifaceted health-effects. Nor did they provide information on the alternative safe water options, let alone make these available to them. Hence we see that the awareness campaigns to which the respondents were exposed were by no means sufficient for them to attain a high level of arsenic-awareness.

Before going on to awareness level of the respondents, we must know about sources of arsenic information acquired by the respondents. We find that the sources of information were mainly friends, neighbours, DPHE officials, NGO workers, radio and television. It must also be mentioned that these villagers could watch only BTV, the government channel. Satellite TV channels were still out of reach in rural areas.

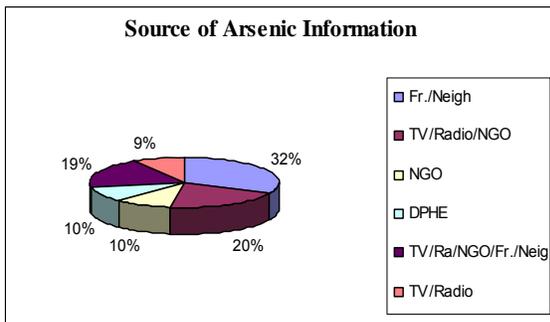


Figure 8: Source of Arsenic Information

The arsenic-awareness level of the respondents is shown in Figure 9. We find that the highest level that the respondents could reach was only 5 (11%, n=22). Although they all heard the word 'arsenic', and most of them had their tube wells tested, many did not know what arsenic was. Thus we find that 38% (n=76) percent of the respondents had acquired the lowest level of awareness. Twenty percent (n=40) acquired level 2, 26% (n=13) acquired level 3 and 36% (n=36) acquired the awareness level of 4. Hence we see that the level of arsenic-awareness of the respondents is a far cry from being satisfactory.

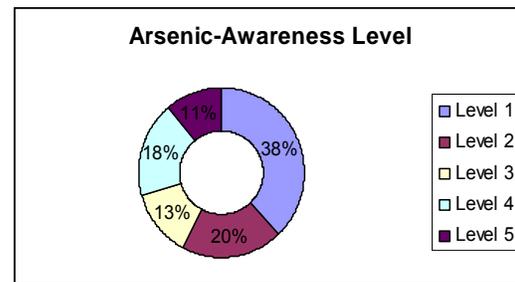


Figure 9: Arsenic Awareness Level among the Respondents

Willingness to pay per month, willingness to donate per month, willingness to walk to bring safe water, and their willingness to give voluntary labour for the purpose of getting safe water are somewhat related to the respondents' awareness level of arsenic. Figure 10 shows us the willingness of the respondents to pay a certain amount of money per month to get safe water. It must be said that people in rural Bangladesh are not used to *paying* for water. Once they had their tube wells installed, they had to spend very little for maintenance. They thought it was duty of the government to provide them with safe water free of cost. However, after knowing that drinking water from contaminated tube wells is a health hazard, most of them agreed to pay a certain amount money to get safe water. Among the respondents, 23 (12%) were not willing to pay at all. In spite of their poverty, 125 (63%) were willing to pay up to 50 Taka, 28 (14%) were willing to pay 50–100, and 24 (12%) were willing to pay up to 200 Taka per month.

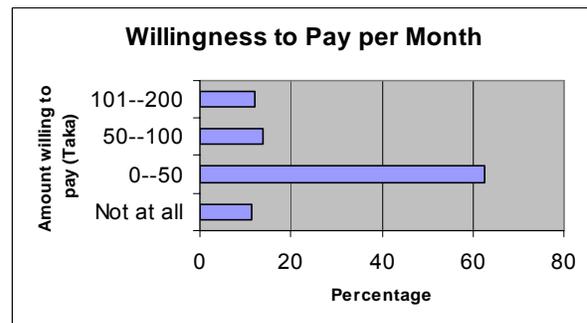


Figure 10: Willingness to Pay per Month

Respondents were also asked about the amount they were willing to donate for the purpose of establishing safe water sources in the village. Their responses are shown in Figure 11. Twelve (6%) of the respondents were not willing to donate at all; maximum number of respondents were willing to donate up to 500 Taka (n=127, 64%). Figure 12 shows the amount of voluntary labour (hours/week) that the respondents were willing to give for the establishment and maintenance of safe water sources. It shows that most of them (n=111, 56%) were willing to give 5–7 hours of labour per week. However, 20 (10%) were not willing to give labour at all. The reason could be their age and ill-health.

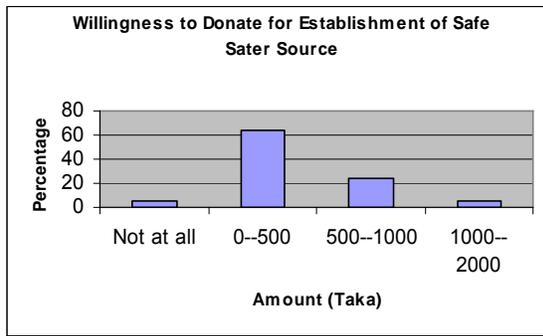


Figure 11: Willingness to Donate for the Establishment of Safe Water Source

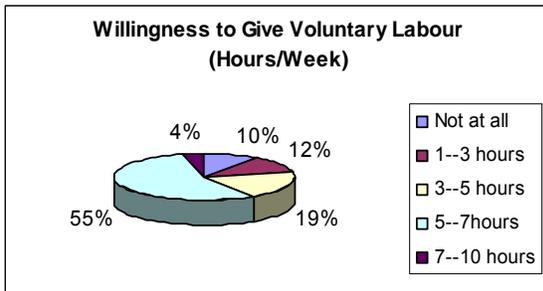


Figure 12: Willingness to give Voluntary Labour

Female heads of each of the respondent households were asked about the distance they were willing to walk to procure safe drinking water. As we see in Figure 6, 65% of the respondent households had tube wells within their home compound. Thus it is not unnatural that almost 25% (n=49, 24.5%) of the respondent women would say that they were not at all willing to walk to get safe water (see Figure 13). Moreover, in rural areas, having to go out of the house to procure water is a symbol of *loss of social status*. A significant proportion of the households however, (n=65, 33%) said that they were willing to walk for up to 10 minutes. As alternative to current tube well water, the respondents would prefer (84%) filtering of tube well water and tap water at home (18%).

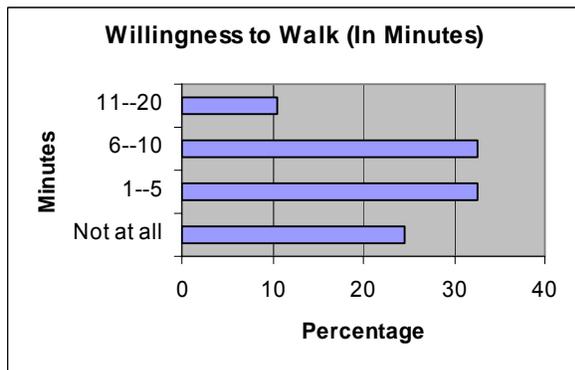


Figure 13: Willingness to Walk (in Minutes)

Factors Affecting Level of Arsenic-Awareness

We tried to find out the factors that were related to the level of arsenic-awareness acquired by the respondents. In Figures 14 and 15 we see how income and average schooling years of household were positively correlated to arsenic-awareness level of respondents (coefficients $r=0.869$ and $r=0.798$ respectively). This means that the higher the monthly income, and average schooling years of household the higher probability there is that the awareness level would be relatively high. In this study we used the variable 'average

schooling years', rather than education level of the respondent. It often occurs that schooling years completed by a certain head of household is low. However, his son/daughter may acquire higher educational level and disseminate information on arsenic contamination to the whole family.

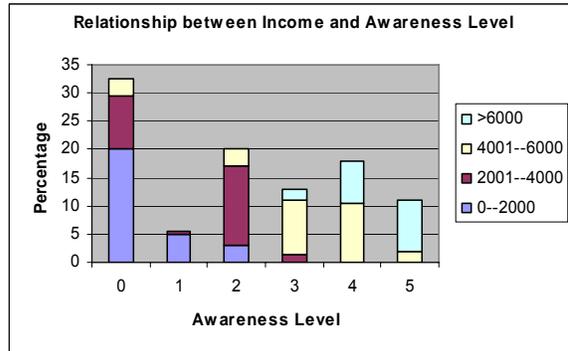


Figure 13: Correlation between Income and Arsenic-Awareness Level

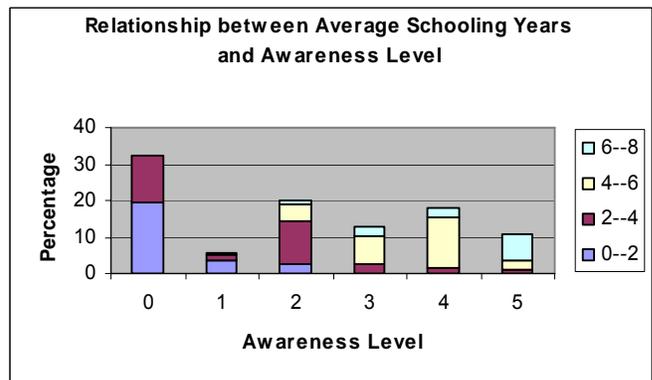


Figure 14: Correlation between Average Schooling Years and Arsenic-Awareness Level

Conclusion

In this paper, we have principally focused on the nature of awareness campaigns and the awareness level attained by inhabitants in an arsenic-prone village named Khajadanga. We observed that the awareness campaigns to which the respondents were exposed were not at all sufficient or suitable for them to grasp the message of danger and respond accordingly. Hence the highest level of awareness acquired by the respondents could reach the level of only five on a nine point scale. The target of all awareness programmes involves some kind of behavioural change. This behavioural change occurs through a certain communication process along with some supporting conditions. The communication process consists of:

- a. Informing
- b. Instructing
- c. Persuading

While informing has a short-range learning goal, instructing involves a long-range learning goal, which is supposed to stimulate the receiver toward some additional activities. In case of persuasion, the receiver is expected to "yield to the point of view advocated by the persuader" (Schramm 1971, p. 44). The first two processes involve clearing of four hurdles (Schramm 1971):

Attention: The message we are trying to convey must be able to attract the attention of those who are targeted;
Acceptance: After gaining attention, the message has to be accepted. Acceptance depends on the face value of the

message and on the credibility of the person/source who is conveying the message;

Interpretation: The targeted person, after accepting a message will interpret it on the basis of his/her stored up experience and built-in values; and

Storing: The interpreted message will thereafter be stored for future use.

In the process of persuasion, the receiver is required to yield the message or point of view advocated by the persuader and act in the direction he/she is persuaded. In this process, the credibility of the persuader is very crucial. Often a threat over which the receiver has no defense (but not so much as to arouse panic), guilt appeal, or even ridicule can help in yielding desired change in behavior. In Bangladesh, a strategic extension campaign on rat control used this tactic (by distributing posters that show trapped men in cages and rats laughing at them from outside), and was highly effective (Adhikarya 1989). Cross-pressure on a specific target can be built by convincing him/her that the two or more persons/groups he/she trusts opine in the opposite direction to his/her opinion, therefore, he/she should also change his/her opinion. This is called "strain toward consistency" (Schramm 1971). This tactic is also worth trying. However, we must ensure that the target group has access to acceptable safe water sources at close distance from which they can procure necessary amounts of water for drinking and cooking.

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BioCosmological Approach in World Bioethics

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"For, truth is rightly named the daughter of time, not of authority. It is not wonderful, therefore, if the bonds of antiquity, authority, and unanimity, have so enchained the power of man, that he is unable (as if bewitched) to become familiar with things themselves."

- Francis Bacon (From his "Aphorisms on the Interpretation of Nature and the Empire of Man")

What is "Cosmos"?

During my presentation of BioCosmological conception, at the Fifth Asian Bioethics Conference (ABC5 in Tsukuba, 2004), Prof. Sang-yong Song inquired of the author about the meaning of the terms in use: "cosmos", "cosmic", "cosmist". It must be admitted that it was not a simple task, particularly taking into account the expectation of colleagues to hear a short and clear reply. Another case of this mysterious attitude was in the XXth conference of European Society for Philosophy of Medicine and Health Care in Helsinki (August, 2006) where my presentation on BioCosmology was put into the session, entitled "Medicine, religion and metaphysics".

Indeed, we might discern at present at least four main meanings of the term "cosmos":

(1) In its primary philosophical sense, a *cosmos* is an orderly or harmonious whole (eventually, as it is perceived by a man). It originates from a Greek term *kóσμoς* meaning "order, orderly arrangement" and is the antithetical concept of *chaos*. Pythagoras is said to have been the first philosopher to apply the term *cosmos* to the Universe. Significantly, in the original (mythological-religious, Eastern philosophical) use the words "absolute", "cosmos", "nature" and "universe" were (and are) employed synonymously to include all that exists.

(2) *Cosmos* – systematic harmonious whole (but distinct to Absolute) held to arise by and persist through the direct intervention of a concrete *divine* or *mystical* power. This relation to "cosmos" leads to the existing range of religious and esoteric cosmologies.

(3) An astronomic (astrophysical) standpoint that is dominating nowadays: *cosmos* is the universe as a whole, considered as complex, well-ordered, and unified system. In cosmic space, as distinct from the Earth, scientists study

celestial objects (such as galaxies, stars, planets, comets, etc.) and phenomena that originate outside the Earth's atmosphere (such as auroras and cosmic background radiation). "Physical cosmos" is an object for modern physical and metaphysical cosmologies. An evident paradox, herein, is that in scientific relation Cosmos is contrasted to the planet Earth, while Earth is ever the integrated and universal part of Cosmos.

(4) Cosmos is a harmonious world of human experience – a subjective harmony within the surrounding world. "Humanistic cosmos" is rooted in the philosophical tradition of ancient Greece, but now it is based on new ontological foundations. Humanistic approach, aiming at the harmony in mutual relations of a subject (human being and his society) with the world around ("the nearest cosmos"), as well as harmonization of the subjective experience of a human (of humankind's historical experience on the whole) – is realized chiefly in the area of philosophical anthropology, modern vitalistic conceptions, including "new age" theories, fundamental ecological approaches, including systems ecology and deep ecology (with Lovelock's Gaia theory), the doctrine of Noosphere by Vernadsky (and its precursors and followers: Bergson, Morgan, Teilhard de Shardin, Steiner, Wilber), as well as the so-called "postneoclassic" science, in the forms of synergetics, conceptions of co-evolution or universal evolutionism (in relation to cosmist issues), that are developed mainly among modern Russian philosophers and scientists (Timofeev-Resovsky, Moiseev, Styopin, Kurdyumov, Knyazeva, Kazyutinsky, Ermolaeva, Liseev).

(Note: the type of "...-brackets or writing with a capital letter is used for the designation of my own terms, metaphors, expressions, etc., whereas "...-type – for citing and the use of generally accepted words).

From the position of original (BioCosmological) exploration, which main distinction is its foundation on the *a posteriori* universal truths (characterized below), author considers it relevant to add one more (*fifth* – Cosmist, realistic) definition: Cosmos is everything that really exists and is the target of our experience – feeling, perceiving, consideration, reasoning, supposition, etc.). For example, ABC8 was a true *cosmic* event.

Every life process (a human's ontogenesis) is the direct subject of BioCosmology

Indeed, the planet Earth itself and the entire evolutionary process of the life on Earth (briefly, *Evolutionary Process* or *EvoProcess*), naturally including every self-dependent life process (biological, personalist, sociological, ecological), – are unconditionally the product and the integrated part of Cosmos, subordinated to the common (universal) Cosmic laws; hence, every life process or event really is the direct subject of BioCosmology (wherein "Bio-" is Greek. "Bios" – Life), including equally the development of ABA or the ontogenesis of a human being (person).

The natural sciences reality of *cosmic* origin of Evolutionary Process (and hence of every current life process, be it biological, personalist or sociological) is simultaneously the Universal objective law of the life on Earth. This law (of Cosmic origination of every life process) does not depend upon any of the existing idealistic (i.e. *a priori* – not validated by natural sciences data) assumptions of origin and (macro)evolution of the life on Earth, like creationism, panspermia, biogenesis and abiogenesis, chemosynthesis, etc.), – at any rate the life on Earth has emerged and been developed always from cosmic matter and energy. Consequently, the life on Earth (EvoProcess, every human ontogenesis, every social history) always is a cosmic phenomenon (process) – this is an objective (naturalistic) fact, *a posteriori* truth.

Objective laws of Earth's (Cosmic) life

What are then the objective laws of Earth's (Cosmic) life – its rational true fundamental principles? We might advance five fundamental *a posteriori* (naturalistic) – BioCosmological – principles (truths, laws):

1. *Fundamental cosmism (naturalism)* – undoubtedly planet Earth is the product of Cosmic evolution and a part of real Cosmos, hence all life processes (including the ontogenesis of a person) have the Cosmic origin (are originated from Cosmic energy and matter);

2. *Fundamental universalism*, first of all the structural (morphological)-functional universalism – a natural sciences truth at least since the discovery of the structure of DNA by Watson and Crick, inasmuch as this discovery has proved, first of all, the unity (identity) of basic physical-chemical elements (of proteins, first of all) that constitute any biological organism on Earth, as well as, secondly, has revealed the psychosomatic unity of any conscious organism (the genetic transmission of psychological character by DNA molecules);

3. *Fundamental self-(macro)evolutionism* – every subject of life is the self-(macro)evolutionary process (including the entire biological evolution and social history) and every subject's ontogenesis is the self-dependent emergent evolution;

4. *Fundamental macro-evolutionary cyclic recurrence of life processes* (a kind of *triadicty*), which essence is that diametrically opposed (in relation to the entire life activity of a subject), but successive cycles-stages (like Day-Night-NewDay, or Systole-Diastole-NewSystole, in essence – Thesis-AntiThesis-SynThesis) effectively realize the ontogenesis of every living subject (biological, personalist, sociological, ecological), overruling in evolution each other by turns.

5. *Fundamental evolutionary anthropologism* – precisely BioCosmological '*universal personalist law of evolution*': Since the evolutionary biological emergence of Homo Sapiens, human freedom is a fundamental assumption of all societies and a central experience of all people during the entire social history and every personalist evolution.

All these universal laws, to be underlined once again, are evident *a posteriori* truths corroborated (and not disproved) by natural (social) sciences data.

Crucial principles and notions of BioCosmology

In this fundamental light, what are the crucial BioCosmological conceptions? Herein, the first four chief BioCosmological notions are adduced:

(1) *EvoProcess (Evolutionary Process)* – a *BioCosmological cornerstone* – is the one common whole cosmic evolutionary process of the life on Earth (CEPLE). First of all, CEPLE is a real phenomenon of reality and (meta)naturalistic truth, demonstrated by natural sciences. The conception of EvoProcess is proposed to have the same significance (for the exploration of all forms of life) as the notions of gravity or electromagnetism (for physics) or affinity (for chemistry), etc. EvoProcess is supposed as primary and ultimate substance of all life processes on Earth and, simultaneously, as a scientifically evident phenomenon, therefore this notion integrates *a posteriori* and *a priori* thinking. This is crucially important that EvoProcess is not a belief (conviction, credence, dogma, faith, etc.), but primarily a real phenomenon demonstrable by natural sciences.

(2) *Subject* – a universalizing notion that means every living organism and its/her/his ontogenesis – from a molecule to HumanKind (person, society) and EvoProcess itself.

(3) *HumanKind* – likewise serves as universal equivalent: It stresses that human creative (active-evolutionary) vigor is the leading factor at present of the entire EvoProcess (CEPLE) of the life on Earth, therefore any conscious "*human kind*" subject (as a person, society, civilisation, mankind) is HumanKind as well.

Basic (Cosmist) Functionality (BCF)

(4) Basic (Cosmist) Functionality (BCF). EvoProcess, as we understand it, allows the *universal functionalist reduction of all living subjects. Every living subject on Earth is ultimately the inherent function of EvoProcess – of the all-embracing self-evolving organism of Earth's life.* Hence, every living subject on Earth has its/her/his *basic (ultimate, cosmist) functionality (BCF).* This means that all subjects of life are intrinsically dedicated for the realization and execution ultimately of its/her/his foreordained basic certain function (but which has manifold forms of expression), which is practicable during a subject's (person's, first of all) entire wholesome ontogenesis (at its mature stages).

During the entire life of a subject, as BioCosmology claims, its/her/his *basic functionality* hierarchically organizes (for example) human's biological and social needs in one inherent integral order. This order, in principle, repeats the hierarchy of the main stages of biological and social evolution on Earth. Hence, biological and social needs (and the realized physiological, biosocial and psychological systems of their satisfaction) may be considered as tools for a BCF to implement its self-unfolding and ultimate self-actualization. So to speak, *"we eat to live, but do not live – to eat"*. As it naturally should be, all biological and social needs of humans co-operate on the achievement of the ultimate end of her or his specific functionalist contribution to EvoProcess's wellness. This achievement is mainly possible at the mature *creative levels of social stability* (where the possibilities for free creative activity occur), the culminating stage of man's wholesome ontogenesis.

Cosmos (universe) – uni-versus – “turned to one”

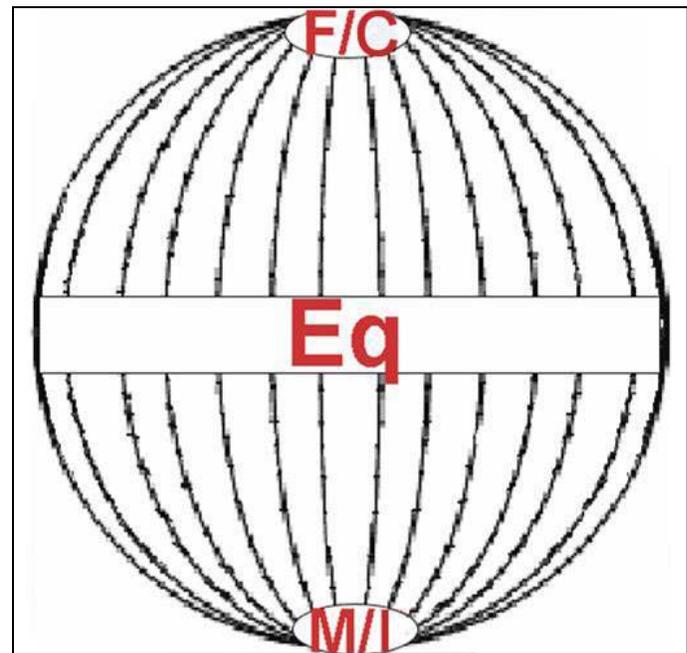
It is important to note that “Cosmos” is synonymic to the terms “Nature” and “Universe”, while the etymology of the latter is from *uni- + versus*, which means “turned into one”.

Significantly, the conception of EvoProcess just serves for universal consideration of world as whole, being a basis for the reduction (to a “Basic Cosmist Functionality” – a “functional organ” – of universal participation of a subject of life in the Cosmist world). It is important that in this quality (of the universal basis for the reduction of the life activity of a subject of life, especially of a HumanKind) it is not farther than quarks (fundamental particles that are explored in modern physics) or genes (morphological units of heredity) or an individual her/himself (which is a common morphological or individualistic reduction, i.e. *methodological reductionism*).

Therefore, *subject* (in BioCosmology) always means an *integrated functionalist subject*, which forever autonomously integrates and hierarchically co-subordinate other subjects of life (to be the functional whole) and, simultaneously, is always functionally integrated by the higher organized subject (organism) that makes good use of the effects of the subject's (person's) inherent functioning, which stem from its/her/his primary intentional (functionalist) activity (the effects of which are demonstrable for the selection by a higher organized subject).

In that way, every subject is a “functional organ”, and the conception of “*functional organ*” (and, further, “*dominant*”) is a long ago established scientific approach, primarily due to the works of Russian scientist and philosopher Aleksey Ukhomsky. Later on his ideas were substantially developed by academicians Petr Anokhin, Aleksandr Ugolev, Pavel Simonov and other.

Herein the scheme is adduced that presents the figurative image of integrated scientific knowledge:

**Designations:**

M/I – the *Morphological-functional* or *Individualist* approach: It reduces everything to “a morpho-” – any objective form or structure, or to the subject of a human being – *the individual*.

F/C – the *Functionalist (Cosmist evolutionary)* approach, which reduces everything to the “*functionalist organ*” and every subject to its/her/his *Basic Cosmist Functionality*.

Eq – “*equator*” of the modern objects of scientific researches: a HumanKind or human organism, animals, plants, microorganisms and their social organizations, as well as their constituting cells, tissues, organs and their system organizations. In the current time, all actual objects of scientific research are chiefly subordinated to the (M/I) pole, leaving indifferently the (F/C) pole – of the one common universal sphere of rational exploration of all phenomena and processes of the life on Earth.

Consonance of BioCosmology with Eastern “fundamental naturalism”

Substantially, BioCosmological concept is concordant with the conception of “fundamental naturalism” (*per se*, “fundamental cosmism”), Prof. Hyakudai Sakamoto used in his presentation of the “Globalization of Bioethics – from the Asian perspective” (at the ABC5 and, previously, in Kiev, 2001). Professor Sakamoto establishes that a new global bioethics should be “holistic” in contrast to European “individualistic” bioethics, and that it requires “some sort of communitarian way of thinking of a non-western or Asian type.” His cornerstone position is as following: “We should now establish a *new humanism without human-centrism*, 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*”.

Virtually, Hyakudai Sakamoto has introduced a new emergent (epistematic, non-western) type of bioethical thinking and a new type of naturalism (based on “Asian ethos”, but not on common Western rational fundamental world-viewing principles) – in the form of his *biopolitical* “bargain consensus” conception and the “Social Tuning Technology”, aimed at the resolution of conflicts of any type and realisation of the harmony in (future) global bioethics.

Asian naturalism vs Western naturalism

So, we might discern Asian naturalism in contrast to Western naturalism and propose the trend of a "Third" naturalism. For instance, Prof. Sakamoto's naturalism is basically distinct from the common modern (global, Western) naturalism.

i. First of all, from the objective point of view, "Asian" naturalism is *realistic* (inasmuch as it treats man and nature as one whole, this is a real truth – natural sciences fact), but *irrational* (rationally unfounded – not reducible to any fundamental rational reason and, thus, existing in Cosmos but missing in Earth's rational life – ACosmist in essence). (Note: My term "ACosmism" has its definite meaning and differs from the accepted ones, like "acosmism" in Hegelian philosophy, or "acosmism" in Hinduism, etc.).

ii. On the contrary, (post)modern Western bioethics is *rational*, but *unrealistic*, inasmuch as it is based on the common (for modern Western philosophy and science) rational fundamental world-viewing principles, but which have "*dualistic*" and "*natural-artificial*" essence – of basic AntiCosmism (dualism of Man and Nature) and absolute *anthropocentrism* (human being is the ultimate creation of the world and, thus, the supreme ultimate epistemic certainty is a person's subjective knowledge about her/himself).

BioCosmology – as a trend of the "Third" evolutionary way in the world bioethics

iii. The proposed BioCosmology might be treated as the form of a "Third" naturalism and Third evolutionary way in contemporary bioethics (and, in the metaphor, mentioned above, – a NewDay, in relation to the Eastern Day and Western Night, which all are the necessary cycles and always existing processes, of revolving experience, of the one whole EvoProcess).

BioCosmology is a *rational* and *realistic* trend of theoretical and practical activity, inasmuch as it is based substantially on a *posteriori* fundamentals, i.e. its fundamental *a priori* notions reflect the real (natural) matter of fact, as it is demonstrated by natural sciences.

In contradistinction, the contemporary Western world-viewing is based on a *a priori* (speculative, abstract) fundamental principles, like British empiricism, Continental (French) rationalism, German idealism, including Kantian (and his followers) transcendentalism, American pragmatism, etc. This is, so to say, naturally (realizing a natural Night-cycle of world development) a not *natural* relation (in the form of *artificial* man-world dualism) to the all-including process (EvoProcess) of the life on Earth, really a "manifold *natural-artificial* dualism" (Sakamoto, 2004).

Three basic questions

A. Do we need the *First* (Eastern or Asian) way of bioethical (and biopolitical) development? Yes, absolutely, we really face a lot of conflicts and problems in various spheres of world development that we need to resolve without delay.

B. Do we need the *Second* – current dominating (Western) – way of bioethical development? Yes, this is likewise our absolute need, inasmuch as we constantly have to cope with the task of crucial importance – protection of the rights of a person and society by neutralizing (minimizing) the possible harmful influences of present-day technologies within contemporary civilizational practice (biomedical, first of all) on regional and global level. (Many of the topical bioethical problems were put on the agenda and tackled during the ABC8).

C. Do we need a Third (Cosmist, "of Real Cosmism") evolutionary way in the world bioethics? Yes, likewise, this is an absolute need, inasmuch as we have a lot of global paradoxes (crises) that might not be solved in neither First (Eastern, of ACosmism) or Second (Western, of AntiCosmism) trends of bioethical activity.

The paradoxes (crises) of the present day

What are the evident paradoxes of up-to-dateness (firstly, on the example of contemporary Russia)? They are:

1) *The loss of a "motivational basis" to procreation* and the directivity on a family with one child in favor of hedonistic models in realizing her or his vital energy (in current Russia we have arrived at the catastrophic surplus of deaths over births – one new-born accounts for two deaths; the objective prognoses of demographers show that already in 50–80 years Russia will meet demographic collapse and disappear from the world scene).

2) *The "social hypersexuality"* as a feature (norm) of social life (at least in present Russia), simultaneously with the decrease of births and inability to realize birth control – uncontrollable growth of a sensuality and pornography in mass-media, aggressive feminism, expansion of homosexuality.

3) *The increase of depressions* concurrently with drug addiction (alcoholism, first of all) – accordantly with the growth of wealth of a democratic society.

4) *The super-popularity of sporting shows* (and super-success of sports industry), alongside (comparatively) with insolubility of many bioethical problems, as well as inaccessibility and inadequacy of (open to general use) qualitative health care, education, conditions of physical culture for the masses, etc.

5) *The current leading role of the philosophy of postmodernism* that affirms basic (*a priori*) pluralism (in the *a posteriori* universal world) – randomness of creativity.

6) *The so-called "anthropological evolutionary paradox"*, in relation to personality: a person is a uterine element of the one common whole cosmic evolutionary process of the life on Earth (that is a natural sciences truth); however we deny the search for universal evolutionary knowledge and rely on the plural (different and often incompatible) sources of knowledge in defining human's nature: biological, sociological, psychological, etc.

7) *The global biomedical paradox*: The inability, in the hi-tech age, to obtain the etiological – curing, remedial (radical) – approaches against chronic non-infectious and non-traumatic diseases.

8) *The global bioethical paradox*: up-to-date bioethics tackles the problems that are the consequences of unreasonable activity of modern science and technologies, while, on the contrary, the present bioethics has no intentions (the aim itself!) to disclose the reason of the existing civilizational unreasonableness! Actually, modern bioethics has fundamentally the *secondary* role (in relation to science) – of "technology assessment" (the term of Prof. Sakamoto, used by him at the ABC5), correcting dangerous (to individual or community health) errors (the consequences of unreasonable application of technological innovations), while the basic role of bioethics (of disclosing and treatment the *primary* reason(s) of unreasonable activity of a man and society) is missed.

9) *The global political paradox*: we are witnessing at present (from rational humanitarian positions) global *senselessness of foreign policy* – i.e. arm-twisting policy of expansion (military intervention), at that the number of billions (trillions) of dollars already having been spent at the aims of senseless (and useless) militarist aggression is ten times enough to resolve the actual bioethical and cultural (aforementioned) problems.

10) Finally, *global civilizational paradox* has evidently intruded on our cultural day-to-day life: Western civilization, although based on rational principles, has arrived at the reality of utmost plural (i.e., *irrational* – irreducible to a common rational basis) global cultural world – constituted of extremely different (frequently opposite) evaluations and reflections (and reactions) to the same issues and problems, arising from the evolution of one common, objectively

universal world – cosmic evolutionary process of the life on Earth (EvoProcess).

Conclusion

In conclusion, if the existing challenge for realization and elaboration of the *Third* evolutionary way in the world bioethics (philosophy, science, culture, civilization) is an objective reality, then has not the time come for us (bioethicists) for the "awakening"?

The discussion on BioCosmology is opened in the special section of the free bi-lingual E-LOGOS: Electronic Journal for Philosophy <<http://nb.vse.cz/kfil/elogos/>> (link to the "BioCosmology"). The participation of every specialist (in all "bio-" sciences) is most welcome!

The detailed characterization of the Cosmist approach is given also in my previous publications in the *EJAIB*: 12(1); 12(3); 13(1); 13(3); 14(2); 15(1); as well as in the: *Challenges for Bioethics in Asia. The Proceedings of the Fifth Asian Bioethics Conference (ABC5)*, 13–16 February, 2004 in Tsukuba Science City, Japan / Darryl R.J. Macer, editor, Christchurch, N.Z.: Eubios Ethics Institute).

Bioethics Education: A response to Viveka

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We have gone through Viveka's philosophical paper on bioethics education with appreciation, and in response would like to offer some comments.

Place of religion and spirituality in Bioethics Education

As Viveka says, religion and spirituality have an important place in Bioethics Education. In fact religion and spirituality are a need of the human species (Verma and Saxena, 2000). Every human population practices some sort of religion. As Macer (1994) has pointed out, most people derive guidance in life from religion rather than from scientific thinking.

Every organized religion has a strong ethical component, and most of it is an expression of altruism. Altruism in humans is heritable, and has been evolving with the evolution of their group living or social life (Hauser, 2006; Saxena and Verma, 2007). This inherited trait of altruism is fine-tuned and shaped for behavioral responses during parental (i.e. informal) and institutional education, in which an extended period of psychological immaturity makes a growing up child impressionable and receptive. Bringing up a child in an unethical cultural environment may partly or wholly block the expression of the inherited altruism.

While need for bioethics education is being widely felt, what should be included in it from religious ethics? This question is specially difficult to answer in a multi-religious, secular and democratic country like India. Obviously to suit this situation a secular bioethics education is needed.

Secular Bioethics Education

While there are several broad principles in common in all the different organized religions, there are also differences in several respects. Viveka (2007) recommends 'dialogue' to come to secular contents of bioethics education. There should

be dialogue among leaders of different religious groups, and the inferences reached should be made available to people through print and electronic media. The feedback, obtained this way, should again be considered by the religious leaders. In bioethics education class-rooms too there should be an open house environment. Students from different religious backgrounds may be allowed and encouraged to express their views, while the teacher is expected to provide guidance and support through "timely and appropriate interventions" (Viveka, 2007). Throughout this process of dialogue is to be carried out in an atmosphere of mutual respect, "harmony and tolerance" (Macer, 1994).

Elements of science in Bioethics Education

People, especially students, often face the dilemma of deciding what is more correct, science or religion. It should be clearly understood that science and religion represent two different attitudes of human mind, and are two non-overlapping areas (Verma, 2006). While science is the attitude of enquiry, religion is a matter of faith. Humans are inquisitive by nature, and wish to investigate and learn about all that is in us and around us. At the same time we have to live by faith, as there are situations, in which we, in spite of all our intelligence and accumulated knowledge, feel lonely and helpless. In such situations faith gives us strength, and the feeling of a superpower guiding and protecting us removes our feeling of loneliness. Thus science and religion are both our needs, and should be taken as separate and non-competing areas.

A prejudice, deeply ingrained in human psyche, is of racism and racial superiority/inferiority. Often the so-called "geographical races" of humans are looked upon as distinct species. But then the different 'races' have successfully interbred producing viable and fertile offspring. In fact much of the present populations are a result of recent 'racial' interbreeding. As Bates (1963) has pointed out, in Mexico 60% of population is a result of marriages between American Red Indians and Europeans, and in Ural most of the population is a result of 'hybridization' between Europeans and Mongoloids. More such example of 'racial hybridization' may be cited. Oliveira and Ferreira (2004) point out that through "extensive genetic studies of several human populations from different continents ... it was verified that the human diversity was higher inside the 'racial' or geographic groups than among them.". The so called human 'races' do not qualify for the category 'species'. They are not reproductively isolated, and reproductive isolation is a necessary feature of a species, as per its biological definition.

Often in biological literature by 'races' is meant 'subspecies'. But the geographical groups of humans, with deep clines or gradients between them, do not qualify for being regarded as subspecies either (Verma and Verma, 2005). Oliveira and Ferreira (2004) have been very correct when they point out that the racial concept is "imprecise" and "subjective". 'Race' has no taxonomic value.

Then how should we refer to the human geographic varying groups with wide clines or gradients between them? Verma and Verma (2005) have suggested a provisional adjective 'parapatric', in view of contiguity of these varying groups.

In the present context it is important to note that recent studies on DNA analyses have shown that frequent gene flow between different regional populations of evolving hominids has been taking place throughout, even from the *Homo erectus* stage (Stone et al., 2006; Templeton, 2007). Human evolution has been trellis like or reticulate due to frequent intermixing of genomes of lineages in different geographical areas.

One strongly founded notion, often circulated, is that war is a biological necessity. A war, in biological terms, is an organized conflict between two groups of individuals

belonging to the same species. War, thus defined, is an extremely rare phenomenon in the animal world (Verma and Saxena, 2000). In addition to humans, wars are known among harvester ants, living in desert like conditions. These ants have the habit of storing in their nests grass seeds, when it is not so dry and there are grasses around. Often individuals of one colony attack another colony of the same species to loot the grass seed store. Perhaps war, in both humans and harvester ants, has in its root the habit of storage and accumulating assets.

Many animals show fight with con-specifics for food, mate, or territory, but such instances are not of organized group conflicts.

Defending one's territory or the phenomenon called territoriality, seen in so many animals, is believed to be in the origin of human wars. While we accept this view, we have to realize that our weapons for offence/defence are now so deadly and extensively destructive that any large scale and wide spreading war may lead to, if not extinction of the human species, extinction of much of human's culture and tradition, accumulated so far, as in a widely destructive war even such institutions as libraries, universities, and museums are not spared.

One way to avoid wars is to opt for a healthy democratic set-up in country states. As Verma and Saxena (2000) point out, "A collective leadership, chosen by people, is to be preferred to monarchy or dictatorship, which involves the risk of a person with psychological repressions, coming up as a leader and behaving as (using expression of Huxley, 1959) "a jealous God" or "an infallible Fuhrer" and creating situations of war." An enlightened voter population ensures choice of right leaders and a healthy democracy.

Concluding remarks

Even an individual failing to realize the need of tolerance and mutual appreciation of cultural and religious differences may lead to "global consequences" (Macer, 1994); hence the urgency of planning and implementation of bioethics education in all countries. Among other ingredients of bioethics education, religion, spirituality, and some scientific facts, which are of general and common interest and which may remove some prejudices and misconceptions, should find place.

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Teaching Thanatology: A Qualitative and Quantitative Study

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Abstract

Objective: To compare the efficacy of two teaching methods for thanatology education.

Design: 60 students were randomized in three groups. After "focus group sessions" with the participants, a validated attitude scale was applied to all. Group I continued with the regular program of the School of Medicine, without any interventions. Group II had seminar studies once every month for six months, each lasting 1.5 hours. Group III established a drama team under the direction of one of the researchers and made rehearsals with the aim of putting a play on the stage whose main theme is the relationships between the dying patients and their relatives. Six months later, the same attitude scale was applied once more in order to assess the difference between the efficacy of teaching methods.

Results: There was a significant difference in each group between pre-test and post-test. Only Group II (the seminar group) showed significant decrease in their scores and became less thanatophobic.

Conclusion: Students' attitudes towards death and dying patients can be changed through education. According to our findings, seminar sessions and small group discussions are the most effective method for this education. Thanatology education through drama sessions needs further research. Our initial hypothesis was that about the drama technique would be more efficient in thanatology education, but our results did not support this hypothesis. On the contrary, although it was not statistically significant, post-test scores of Group III were indicating that they became more thanatophobic.

Key Words: Medical education, thanatology, teaching methods, drama.

Practice Points:

- Attitudes towards death and dying patients can change by education.
- Medical students feel the need of thanatology education and ask for it.
- Seminar sessions are the most effective method for teaching thanatology.
- Though more effective, drama techniques have pitfalls in thanatology education.

Introduction

Over the past few decades, end-of-life (EOL) care issues have been a topic of hot debates especially in the Anglo-Saxon literature. Among the most discussed issues regarding

EOL care is the integration of thanatology education into the medical curricula. (Bishop 2000, Magnani 2002, Wear 2002, Whitcomb 2002, Wood 2002).

Many authors in the field point out that current medical education lacks a comprehensive thanatology teaching system that would provide medical students with relevant knowledge about EOL care and help them gain necessary skills (Magnani 2002, Wear 2002, Whitcomb 2002). When the attitudes of residents and attending physicians towards death and dying are analyzed, it was shown in various studies that most of the physicians and residents have trouble when they have to deal with dying patients. They express that they do not feel comfortable when they find themselves in circumstances such as breaking bad news to patients and their families, discussing with them their treatment options, pain and symptom assessment and management of a terminally ill. (Bradley 2002, Carver 1999, Merrill 2000, Wear 2002)

In modern western medical education, some institutions already began to insert or integrate and implement thanatology education curriculum into their current education programs. (Magnani 2002, Wood 2002) Researchers debate which teaching methodology would best coincide with the goals of such an education and some even offered structured programs composed of subsequent methods.

In Ankara University School of Medicine, where we conducted this study, there used to be no structured education program on EOL care only until very recently. After the conclusion of our study, some programs were offered to be integrated into the undergraduate medical curriculum. By the time we were writing this paper, only two very new additions in the curriculum were noticeable. One of them is a problem-based problem solving workshop of 2 hours on "breaking bad news" in the third grade and the other is a 2-hour "communication with dying patients" session with fourth grade medical students under the supervision of an oncologist and clinical psychologist. (Ankara University School of Medicine 2005).

With this study, we aim to provide some data about the efficacy of some of the teaching methods by which the thanatology education can be given.

Materials and Method:

In our study, we developed and conducted two different thanatology programs. One of these programs consisted of seminar sessions and in the other we used drama methods. We compared the efficacy of these two methods and also compared them with a control group. We tried to figure out which method would be more suitable in reaching the goals of the given education; namely, the relevant attitude of not "escaping" from death and dying patient [thanatophobia]. With the term "thanatophobia" we mean discomfort in addressing patients who are going to die very probably because of the disease they have and difficulty in communicating with their relatives. Whatever the reason might be (for instance; fear of death, fear of one's own death, anxiety for not being able to save one's life (fear of unsuccessfulness), hardness in dealing with loss situations), the term refers to the "abstaining" behavior which becomes visible in one-to-one relationships in daily practice.

We examined three groups each containing a minimum of 16 participants. The participants were randomized among volunteer students at the Ankara University School of Medicine. The participants consented to the study beforehand. The Research Ethics Committee at the Ankara University School of Medicine approved the research study.

We classified the volunteer students according to their semesters and tried to include more or less the same number of the students from each semester in each group. We conducted the research study upon 60 participants. There were 16 participants in Group I, while there were 26

participants in Group II and 18 participants in Group III. We asked the participants their age, gender, level of education (semesters) and experience with a dying person before. We started the research study by conducting "focus group sessions" in order to assess the applicability of the attitude scale to this particular group and comment on the results. (See Appendix 1) Seven focus groups were conducted. Then we applied the "Approach to Death and Dying Patient and Euthanasia Attitude Scale" to all the participants and received the pre-test scores. This scale scores the attitude of physicians' towards death and dying patients, and euthanasia. The test scores were found to be strongly related to the level of competence and empathy, and the sense of anxiety in physicians when confronted with dying patients. As the main objective of the education was to decrease thanatophobia in students when confronted with dying patients, we thought that this attitude scale is an appropriate tool for assessment. The validity and reliability tests of this scale had been completed by Senol *et al.* (Senol 1996) (See Appendix 2)

The first group (Group I) did not take any specific education on EOL care or thanatology and continued the regular medical curriculum (control group). We followed this group's attendance to classes in order to make sure that their attendance rates are within the faculty limits. With Group II, we organized seminar studies for six months once every month each lasting 1.5 hours. In these seminars, we gave the students a structured education on the issues of death and dying patient as well as the concepts regarding to the end of life. This group's attendance to seminar sessions was also followed to make sure that their attendance rates are within the faculty limits. Group III established a drama team under the direction of one of the researchers and made rehearsals with the aim of putting the play named "The Shadow Box" by Michael Cristofer on the stage. (Cristofer 1977) The main theme of this play is strongly attached to the issues of death and the relationships between the dying patients and their relatives. In the play, the members of three very different families face the fact that one member of each family is in the last stages of a terminal illness. To Group III we did not apply any other additional education, but we used a number of drama techniques for empathizing dying patients. The attendants needed to vividly imagine, analyze and recreate the situations, relationships and conditions in which the characters in the play find themselves suddenly and experience how they might feel and how they chose to go over their dilemmas.

We started the study in November 2002 and concluded the seminar sessions and drama work by the end of May 2003. In June 2003, we applied the attitude scale once again to all groups. The qualitative part of the study, which was based on focus group sessions and the quantitative part, which was based on the points derived from attitude scale, were evaluated both together and separately. In this evaluation process, we both compared all the groups among each other and examined each group regarding the inner changes it showed from the beginning to the end of the study.

Nominal variables were assessed by Chi-square test. Comparison between pre-test and post-test was evaluated by Wilcoxon-Signed Ranks test. Differences among three groups for thanatophobia were evaluated by Kruskal-Wallis variance analysis. (Conover 1980)

Table 1: Results of Wilcoxon-Signed Ranks Test

	Pre-Test		Post-Test		P
	X ± SD	Median (Min-Max)	X ± SD	Median (Min-Max)	
Group I	20.2 ± 2.7	20 (17-25)	20.2 ± 2.9	20 (16-25)	0.823
Group II	21 ± 2.7	21.5 (15-27)	18.4 ± 2.9	19 (12-26)	<0.001
Group III	20.8 ± 3.2	19.5 (16-28)	21.3 ± 4.0	21.5 (12-29)	0.429

Table 2: Δ Analysis with Multiple Comparison Test

Groups	Δ	
1 – 2	p=0.009	difference exists
1 – 3	p=0.581	no difference
2 – 3	p= 0.001	difference exists

Results

The participants came from different years ranging from 1st to 6th grades. Each group consisted of participants with various ages coming from different semesters. 23% of the participants (14/60) declared that they had experience regarding death or a dying person at least once before they joined the study. There was no statistically significant difference between groups regarding semester levels (p=0.342), age (which showed a range of 16–27 years, but most of the students were between 18–23 years of age), gender (p=0.260), and experience of death or a dying person among participants in the past (p=0.517). All these analyses showed that there was no significant difference between groups in the beginning of the study for pre-test; so, they were comparable.

Focus Group Sessions

Appendix 1 shows the topics discussed in focus groups. In all focus groups only a few concepts were commonly discussed. These are “loss/to lose”, “preparation for/getting used to death”, “cancer”, “pain”, “to chose/to accept death” and “getting insensitive”. Only in one session, (I-B) “euthanasia” was widely talked about, probably with the biased direction of the moderator. In this session, the participants stressed the approach to death and dying patient only from this one limited point of view. In another session (II-B), the main theme was “conceptualizing death” in medicine. The participants, without stepping out of their physician identity, tried to question how they can act when they confront death. Some participants emphasized that their current medical education was not sufficient to provide them with adequate knowledge, attitudes, and skills towards death and dying patients.

In focus group sessions some ideas which were shared by almost all of the participants, emerged. Most of the participants seemed confused about what “death” can do with medicine. At the beginning of the sessions, they usually tended to view “death” as a situation which has nothing to do with medicine. Medicine would do anything to prevent death; but when it arrives there are other professionals to take care of the situation.

“...if there is something I can do, I never hesitate to do it even for a tiny moment... but if it is beyond what I can do, then, I don't know, I would avoid facing it, I think. Because... I mean... in the end at that point it is also beyond the borders of medicine. At that point I have no active work there.” (Group I-A, Participant No.5)

“It sounds more like unsuccessfulness to me... In the end you do something, you try, but consequently the patient is lost. This is unsuccessfulness in some way.” (Group I-B, Participant No.2)

In these sessions, most of the participants expressed their anxiety and fear about “death.” They told that they usually felt

helpless while communicating with a dying patient or found themselves in situations related to death in some ways. Only some of the participants had a direct experience with death. The latter expressed relatively less anxiety. They argued that experience helped them learn how to deal with “death” and made them think more about it, which eventually provide them with a broader look. Some of the participants shared their observations upon the clinicians facing death in their daily practice. The common idea was that even the experienced ones tend to avoid facing a dying patient.

One of the most controversial points in the sessions was informing the dying patient about her/his prognosis. Some argued that the patient should be informed correctly and completely about her/his possible future, while some strongly disagreed with this idea defending that such an attitude would devastate the person. Some expressed that this issue should be a bedside decision, which can be made by taking different situations into consideration in daily practice.

Many participants pointed out the role of medical education regarding “death”. Most of the participants expressed that medical education should include some issues about “death” and “dying patient”. They argued that this would increase awareness and lessens the feeling of helplessness. They evaluated their current education as unsatisfactory.

“One of my friends' mother was diagnosed with terminal breast cancer. (...) Because that the tumor had metastasis in brain, her condition got worse. My friend told me that the doctor had told her that her mother was in terminal phase. When she asked me what the terminal phase meant, I was really bothered while explaining it to her. (...) Actually I wanted to escape from there.” (Group II-C, Participant No.3)

“To be honest I think that the medical education does not teach us much about death. In my opinion, there is a disease; there are its causes, its etiology, in the end its treatment, its prognosis. I mean it is being instructed to us like that, but what is behind the curtains is actually very different. (...) I mean... to people upon how to deal with death or how they can communicate with a dying patient not much is given. Moreover, nothing is given and maybe because we see death everyday we become insensitive.” (Group II-B, Participant No.7)

“I think the education of medical faculty does not add much to this issue. On the contrary, when I see the approaches of those who already had the education, I think most of the time, I say to myself ‘I should not behave like this.’ (...) I see that some people had already lost their sensitivity and I ask myself if after many years I will be like that.” (Group II-B, Participant No.5)

“Towards the end of the first month during my internship we lost a patient in the intensive care unit. I was following him. (...) And when we lost that patient, there was a huge difference between what I felt and what the specialist physician felt. Then we went to inform the patient's family together; when his family heard the situation, that time, there was a great difference between what his family felt, and we felt.” (Group III-A, Participant No.8)

Derived from these focus group sessions, as a last word, it can be said that almost all the participants pointed out their unease about death and related issues. Some obviously never thought of the issue or even did not think that it was worth discussing before the sessions, since they probably

viewed it as a subject irrelevant to contemporary medicine. However, this attitude can be interpreted as a sign of the general attitude of physicians. Some others, who are the majority, pointed out that their current education lacks a systematic program regarding death and dying patient. Yet most of the participants seemed willing to be informed and adopt appropriate attitudes towards death and dying patient. Some argued that even in these focus group sessions, they realized that this issue should be one of the main topics in the medical curriculum. Finally, the focus group discussions indicated that the attitude scale was applicable to this particular group, because it consisted of the main arguments that came up in the group sessions.

The "Approach to Death and Dying Patient and Euthanasia Attitude Scale"

We assessed whether there was a difference in each group between pre-test and post-test. By this analysis, we found out that only Group II showed significant decrease in their scores, while there was no significant difference for Group I and Group III. (Table 1) As the higher test scores indicate abstaining from the dying patients, only the participants of Group II (the seminar group) happened to change their abstaining attitude towards dying patients significantly and became less thanatophobic.

Change from pre-test to post-test between groups (Δ) was assessed by using Kruskal-Wallis test. There was significant difference between groups ($p=0.003$). Afterwards we applied multiple comparison test and found out that Group II is the one that caused the difference between groups. (Table 2)

Discussion

Thanatology education is an essential part of medical education as well as the end-of-life care education. It is also the most neglected part of the medical curriculum in Turkey, if it exists at all. In accordance with the increasing attention directed to the end-of-life issues, there have been a number of studies conducted on thanatology, especially on the perception of death amongst health care professionals and attitudes towards death and dying patients. The results of these studies showed that it is necessary to include thanatology education in the curriculum of medicine. As death is a very difficult subject to teach, because of the emotional burden it carries, a new task emerged. What is the best method of teaching thanatology? There are few studies on this subject, but many studies are going on.

In Turkey, the studies on the attitudes towards death and dying patients have been conducted since the 1990s. There are studies on the different health care professional groups and on the students of health sciences. These studies showed that the lack of thanatology education causes enormous anxiety for health care professionals when confronted with the death process and it also diminishes the quality of care at the end of life (Abaan 1996, Atac 1996, Deger 1994, Gunduz 1996, Klagsbrun 1988, Oz 1999, Ozaltin 1997, Uysal 1994). Our study is the first study in Turkey which has been conducted for assessing the difference between the efficacies of different educational techniques for thanatology education. After the studies on attitudes towards death and dying patients, we thought that this study would be the second step of introducing a thanatology course to the medical curriculum.

As an attitude scale on death and dying validated for Turkish medical students was lacking, we had to use "Approach to Death and Dying Patient and Euthanasia Attitude Scale." This scale was created for physicians and there was also a modified form available for nurses. We foresaw two negative consequences caused by using a near relevant scale. First of all, our respondents had to assume some situations as they were not practicing physicians yet, and this may have had an effect on their answers. We

expected the students to imagine vividly that they are within particular clinical conditions of medical practice which are mentioned in the scale. However, we did not have the relevant measures to assess how much they could achieve this. Secondly, the euthanasia part of the scale may have a contaminating effect on the answers of the respondents to the rest of the scale. The focus group sessions showed us that the students had distinguished euthanasia debate from attitudes towards death and dying patients. Besides, the term euthanasia is not defined precisely. It might have referred to different meanings and perceptions for different people. For instance; sometimes it means an active act of killing, but sometimes it is the term for withholding futile treatments. Nevertheless, before the study, we emphasized the general conceptual meaning clearly, which is "letting the person die upon her/his will, if she/he has a terminal illness". This expression leaves no room for confusion. Still it remained unclear whether it was perceived in the same way by all the students, as we do not have any measures to assess it. Although attitudes toward euthanasia might not be a good measure of thanatophobia, since only 1/3 items in the scale address euthanasia, we thought that euthanasia sentences will not create serious bias.

The pre-test scores of the three groups indicated that there were no statistically significant difference between Group I (control group), II (seminar group) and III (drama group). During the focus group sessions, the participants mainly expressed their concerns about managing dying patient when they had to. They emphasized that they were not comfortable with the concept and as they have not received adequate education on the subject, they were afraid of making mistakes. They pointed out that becoming insensitive and establishing distant relationships with dying patients were two commonly used strategies. These concerns and solutions are in accordance with the existing literature on thanatophobia (Abaan 1996, Atac 1996, Deger 1994, Gunduz 1996, Klagsbrun 1988, Merill 2000, Oz 1999, Ozaltin 1997, Uysal 1994). One of the main arguments, which was common almost in all focus group discussions, was the emphasis put on "doing something." It became quite clear that the participants felt more comfortable when they literally "could do something." Being an observer or assuming a passive role seemed to be intolerable.

Some of the participants argued that "death" was not a concept directly related to medicine, because it was a point beyond medicine. According to them, death is one of the consequences after medicine has done as much as it can. But for the majority of the participants, death indicated the failure of medicine and themselves as professionals. This result is also similar to that of the present literature (Abaan 1996, Atac 1996, Bradley 2002, Carver 1999, Deger 1994, Gunduz 1996, Klagsbrun 1988, Oz 1999, Ozaltin 1997, Senol 1996, Uysal 1994).

The participants put an emphasis on the communication skills and pointed out that it was not just the fear of death, but the necessity of communicating about death that put pressure on them. According to them, thanatology education could not be complete without education on communication skills. They told that even the limited time they spent talking on the issue at the focus group sessions was of help. It became quite obvious during the sessions that the participants were very critical about the attitudes they have observed in the clinics. They said they had found it hard to identify with the medical faculty, because the faculty's attitudes towards dying patients were generally very distant. However, the participants expressed that the clinicians were excusable for their attitudes, as they had to deal with death everyday. Some of the students even said that they were looking forward to become as insensitive as their clinical instructors in order to be liberated from the fear and the anxiety. We may say that

the students view this desensitization as a part of their professional maturation.

The scores we obtained after the educational interventions indicated statistically significant differences. Group II (the seminar group) received a better score than the other two groups. There can be a number of reasons for this result. Firstly, the structure of the seminar can have an effect, as it consisted of both experts and family members of dying patients. In one of these discussions, the participants discussed for one hour upon a suicide case that had happened in the same institution short ago. Secondly, the seminar sessions and small group discussions are routine educational methods for the medical school, so the students were familiar with these methods, where teaching through drama was completely alien to them. There were no special topics on the attitudes towards death and dying patient at the Ankara University School of Medicine by the time we conducted this study. And thirdly, the participants of seminar group had enough time to think over and to observe their environment in the light of what they had been taught.

One interesting finding that is not in accordance with the existing literature and our initial hypothesis is the changes in the scores in Group III (the drama group). Though it is not statistically significant, there is a difference between the pre- and post-test scores of Group III, which indicates that after the education the group developed a more abstaining attitude towards death and dying patient. We think that this result is caused by the content of some of our drama sessions. Staging a play about death and dying patients and their relatives, we thought, would make students gain insight to very difficult human conditions accompanying the state of terminal illness. In this study, actors tried to step out of their individual borders and understand how the dying person or her/his relatives feel by identifying with the characters of the play. Through deep dramaturgic analyses of the text, we tried to reach the essence of people's behaviors and feelings underneath these behaviors. Our hypothesis was that this study would help the students be more empathetic towards their future dying patients, firstly by facing "death" as a concept and dealing with it intensely during the drama study in particular ways; namely reflection, imagination and acting. However, while working with this group, we were often faced the difficulty of separating the emergence of the emotions towards one's own death from the emotions towards the death of dying patient. We realized that it was very complicated to work on the emotions towards one's own death. On the other hand, it was almost impossible to hinder its emergence, since identifying with the character is implicit in the drama's nature. In our study, the main characters were either dying patients or their close relatives. Thus, identifying with the characters fell quite far from wearing the shoes of a physician who confronts death in his/her practice. We think that the drama method we used was the cause of this abnormal result. Other drama techniques must be studied before any final objection towards using drama techniques in thanatology education. Further research using drama techniques should focus on the various unexpected problems that emerge in different ways during the drama activities. We suggest researchers who are willing to work on the efficacy of drama techniques in education to read our experience in its limits and take the points mentioned above into consideration.

There are some limitations that should be mentioned for this study. First of all, we randomized the students who volunteered to participate in this study. They might be interested in the subject or at least sensitive about end of life issues before they participated in this research. This may limit the applicability of the results to the rest of the medical students. Secondly, the performance of Group III (the drama group) can be affected by the text that was chosen. "The Shadow Box" consists of many cultural readings that are unfamiliar for our students. This cultural gap could cause alienation to the text and determine the result. Also at some

point, the students of Group III completely focused on the stage performance, and this anxiety might override the main goal, namely identifying with the dying patient and her relatives.

For the last word, all the points made above show that the issue of death remains to be a taboo in the medical education. What gives hope is that the students are eager to learn more about death and its management in medicine, and they want to adopt appropriate attitudes towards it. A relevant and efficient systematic education can guide them in adopting more humane attitude towards death and the dying patient.

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Acknowledgement

The authors wish to thank Suat Gurcan for his support in translating Michael Cristofer's "The Shadow Box", Atilla Elhan for his contribution to the statistical analysis of the data, Murat Civaner for his enlightening comments during the writing process. Also, we thank all the students who participated in this study.

Appendix 1: Focus Group Sessions Interview Guide

The moderator will introduce himself/herself and the observer to the participants. He/she will ask for permission to use the voice recording device and he/she will explain the objective of the session. After mentioning that the session should last one hour, the participants should introduce themselves. The moderator will open the discussion. The observer will note down the seat numbers and identity information of the participants. He/she will write down short informative/indicative notes about the session by using the signs (O=observer) for himself/herself, (M=moderator) for the moderator.

The main topics of the discussion:

- What do you feel about the death?
- What is your most basic feeling or attitude defining your approach to a dying patient?
- How is death conceptualized in medical profession?
- What kind of attitudes does your current medical education help you acquire regarding death and dying patient?
- In what ways can the knowledge of approaches towards death affect your daily professional life?

Appendix 2: Response questions

The following options existed. To each there were four options: Totally agree. Partially agree, partially disagree, totally disagree.

During clinical treatment, it may be decided that cardiopulmonary resuscitation and other intensive life sustaining treatments are not indicated anymore for a terminally ill patient.

Decisions, as described above, are ethically right.

When a patient of mine dies, I wonder if something could have been done to save her.

I think it is essential that a dying patient be told of the positive and negative aspects of his progress.

I have a clear definition of "euthanasia" in my mind.

In my opinion, euthanasia is a moral equivalent to suicide or homicide.

Telling a person he is going to die is difficult to me.

I find it more difficult to deal with the family of a dying patient than the families of my other patients

In my opinion, keeping a patient alive when we cannot improve his quality of life, causes suffering.

I believe physicians refer terminal patients to other physicians more often than non-terminal patients.

A patient's death does not depress me when I know there was nothing I could do to save him.

In my opinion, euthanasia contradicts the basic philosophy of medicine, which is summarized as "one should show respect to human life under any circumstances."

In my opinion terminal patients don't want to talk about death.

In my opinion, principles for applying euthanasia should be established and it should be decriminalized.

In my opinion, most of the dying patients are afraid of death.

In my opinion, if physicians perform euthanasia, this will cause distrust towards them in the long run.

In my opinion, most of the dying patients have painful deaths.

I might perform euthanasia if one of my patient's requests it.

I would want euthanasia to be performed on a relative of mine, if he has an irreversible terminal illness.

I do not think about death very much.

In my opinion, terminally ill patients consider death as a comfort.

I would perform euthanasia if a committee makes the decision to authorize it.

I try to avoid telling a patient directly that he is dying.

Treating a dying patient is one of the most unpleasant aspects of my profession..

In my opinion, most of the dying patients have a quiet and peaceful death.

I could approve of euthanasia, if it is decided and performed by a committee.

Whenever possible I avoid a person who is dying from an irreversible condition.

I feel as comfortable with a dying patient as I do with any other patients.

I would want euthanasia to be performed on me, if I had an irreversible terminal illness.

In my opinion, most of the dying patients talk openly about dying.

In my opinion, her family is the best support for the terminal patient and they should be always with her.

Adequacy of informed consent in research carried out in Brazil

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Abstract

This cross-sectional study aimed to assess the adequacy of the informed consent process in six research projects carried out at HCPA. The 59 participants were interviewed; all had signed informed consent forms. Most patients were females (relative frequency of 71%); and the mean age was 50.17±15.24. Informed consent adequacy was assessed through the amount of information received and degree of difficulty in understanding the form. Having received previous explanations was reported by 53%, and having had doubts cleared up, by 24%. Comprehension of what was being proposed was reported by 56%, but the text was considered accessible by only 25%. In conclusion, the use of informed consent in research projects should be considered seriously, and Ethics Committees should review all the stages involved. Aspects such as comprehension of information, clearing up of doubts, and access to the investigator should always be guaranteed to participants.

Key words: informed consent, research, Ethics Committees, ethics.

Introduction

The informed consent process involves a relationship between the investigator and the participant that is permeated by mutual respect, dialogue, patience, and persistence.

Beauchamp and Faden (1) established a broad approach to the informed consent process. According to the authors, this process is composed of three stages, and involves seven different elements, involving I - Pre-conditions (Ability to understand and decide, and voluntariness); II - Elements of the information (risks and benefits; the most adequate option; and comprehension); III - Consent elements (option out of at least two alternatives, and authorization).

Several studies have been carried out in different countries about the process of obtaining informed consent in health institutions, not considering the impact of the evaluation carried out by the Ethics Committees.

One study carried out in the United States analyzed the written documents used as the source of information for the obtainment of informed consent in the area of radiology. The study showed that the texts were too complex for the average patient to understand (2). A recent study showed that educational intervention made a difference in comprehension about research risk (3).

In another study, performed in four Veterans Administration hospitals in the United States, 28% of the patients interviewed declared that they were not aware that they were participating in research projects, although all of them had signed specific consent forms prior to the beginning of investigation (4).

In Chile, an assessment was made of 44 research projects submitted to the Ethics Committee of the Medical School at the Pontificia Universidad Católica de Chile during a two-year period. The most frequent problem in the evaluations was absence or inadequacy of the informed consent form (5).

Between 1986 and 1997, a study assessed the use of informed consent in more than 1,348 research projects carried out at Hospital de Clínicas de Porto Alegre (HCPA), Brazil (5). Only 18% of the informed consent forms used in the projects were considered approvable without any repairs. Up to 1993, the most frequent problem at HCPA was the absence of informed consent in most projects; after this date, problems were more related to inadequate information and/or inaccurate writing of the document. It is important to mention that the Ethics Committee of the institution started to work regularly in 1993; before this date, the projects underwent only a methodological evaluation (6).

Up to the present moment, only a few studies about practical aspects related to the process of obtaining informed consent in Brazil have been published. The objective of the present work was to assess the adequacy of the informed consent form used in six health-related research projects carried out at a general hospital in terms of information and consent components. This assessment was accomplished through interviews with the patients.

Methods

Fifty-nine patients taking part in six different research projects at HCPA in the areas of cardiology (n=13), endocrinology (n=14), medical genetics (n=13), gynecology (n=8), and rheumatology (n=11) were interviewed. All the patients had signed informed consent forms. This was a cross-sectional study (patients were interviewed only once).

The selection of projects was done randomly among all the research projects being carried out in the outpatient clinics of the hospital. Six projects were drawn from the ones that had already been approved by the Scientific Commission and by the Ethics Committee. Projects involving patients with psychiatric or neurological diagnoses were excluded from our study.

Most of the 59 individuals studied were females (relative frequency of 71%). In all projects, except for the one on endocrinology, the number of female participants was higher than the number of males. Ages ranged from 25 to 74 years, with an average of 50.17 ± 15.24 years.

The adequacy of the informed consent was assessed according to the amount of information received and the degree of difficulty in understanding the informed consent form. The difficulty in understanding the informed consent forms was assessed by the Flesch-Kincaid and Flesch readability indices. The results obtained with the formula estimate the years of education needed for the adequate comprehension of the text. The most effective values of Flesch-Kincaid's readability index are the ones requiring 6 to 10 years of education. The calculation of the Flesch-Kincaid and Flesch indices was carried out using the Grammatik IV software (7).

The information received and remembered by the participant was assessed with the use of a list for the verification of specific procedures, risks and benefits for each of the projects included in the study. Procedure was defined as any intervention carried out with a research-related aim, such as data collection through an interview, collection of biological material, physical and laboratory tests, use of drugs, and use of placebo. Risk was defined as any probable damage or discomfort resulting from the procedures. Probable benefits to participants ranged from increased information about their state of health or diagnostic characterization to the possibility of alteration in the prognosis due to the use of drugs. Data collected from different projects were standardized so as to allow comparison, in spite of their peculiarities.

The data obtained and/or calculated were analyzed using descriptive and inferential statistics. When data were quantitative and susceptible of being compared to other groups, the ANOVA variance analysis was used. Qualitative data were analyzed using the chi-square test. These analyses were carried out using the EPI-Info software 6.04.

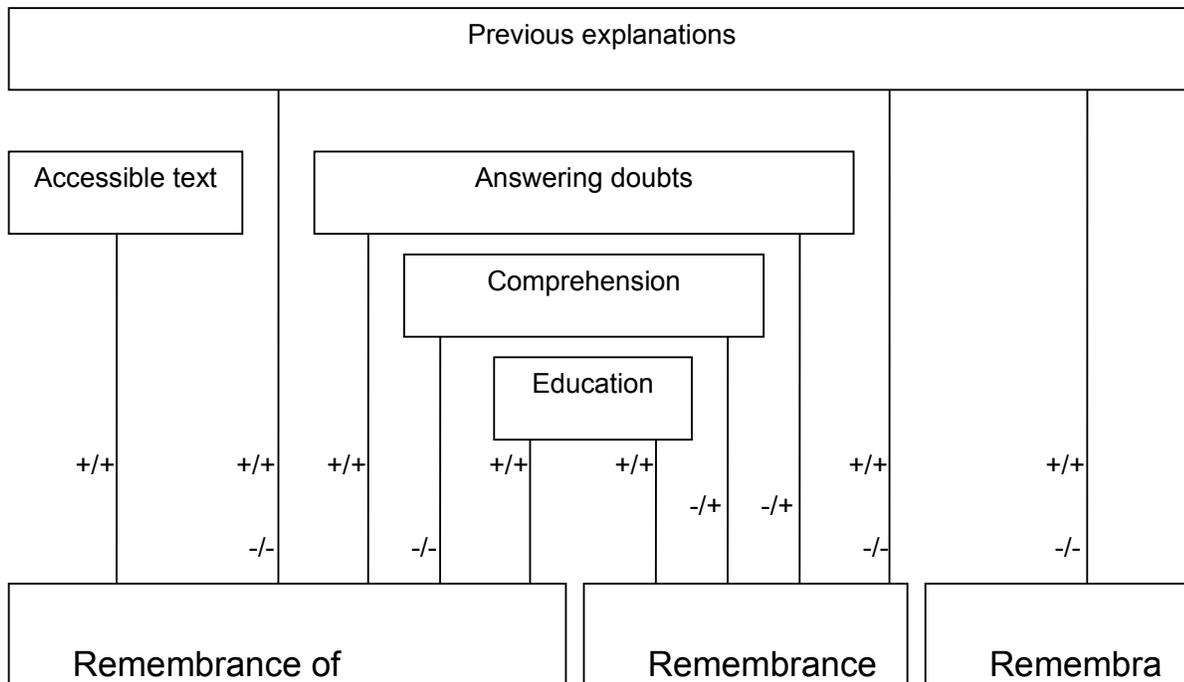
The assessment of multiple interactions between the variables studied was performed through the correspondence analysis (8) which was obtained with the SAS system. The significance level was established at 5%.

The present study assessed only the actual process of obtaining informed consent, and no risks were involved, because only one interview was performed, and the assessment instrument presented no risk of privacy invasion. For these reasons, we asked the Ethics Research Committee at HCPA to be excused from using a written informed consent form, according to item IV.3.f of Resolution 196/96.

Results and Discussion

Values obtained with the Flesch-Kincaid index in the informed consent forms of the six projects ranged from 12 to 18 years of education, with an average of 14.67 ± 2.16 years. The sample's education level varied from illiteracy up to college education. When compared to data about the Rio Grande do Sul population, the education level presented by the sample was slightly higher. This variable was directly and positively associated only with the remembrance of procedures and benefits: the higher the level of education, the higher the remembrance of procedures and benefits. The opposite was not observed: a lower level of education did not make the remembrance more difficult. Luna had already emphasized, in 1995, that illiteracy does not make a person become unable to give informed consent. (9).

Viegas, in 1998, carried out a qualitative study in a sample of six HCPA patients taking part in research projects in the area of oncology.(10) The experiences of these patients in relation to their participation in the projects were analyzed. The author observed that all the participants agreed or refused to participate in the study before reading the informed consent form, based only on previously received information.



Note: (+) represents an assertion, amplification, or a high value; (-) represents a denial, reduction, or a low value

Figure 1. Explanatory model for the informed consent process, based on the Correspondence Analysis.

All six individuals emphasized the importance of information disclosure and clearing up of doubts (10). So, education is not a limiting factor, but a facilitator of the informed consent process.

In our sample of 59 patients, 53% stated that they had received previous explanations. This information alone already indicates inadequate use of informed consent, since almost half of the participants did not remember having received any information before filling out the informed consent form. Another possible interpretation for this result is that informed consent was obtained as an event, and not as a process: the person's authorization was requested based only on the data presented in the forms.

Receiving previous information or not was the variable that presented the highest explanatory power (highest inertia in the correspondence analysis) when associated with obtainment of informed consent. This was the only aspect directly related (either positively or negatively) with all the other variables of the informed consent process, that is, procedures, benefits, and risks. Patients who had received previous explanations were more able to remember the procedures, benefits, and risks involved in the research project. The opposite was also observed: patients who had not received explanations had more difficulty in remembering this information. These associations manifest the paramount importance of this stage in the informed consent process.

Having received answers to doubts was referred by 24% of the patients, but it is not easy to interpret the complementary value of this result. The fact that 76% of the patients did not receive answers to their doubts may be seen as a deficiency in the informed consent process, or it may be due to the absence of questions on the patient's part, either because he/she did not want to ask questions or because he/she did not feel comfortable in doing so. This issue is not well understood yet. Answers to doubts made the remembrance of procedures easier and the remembrance of

benefits more difficult. This apparent contradiction may be explained by the difference in the added value of this information. Procedures are concrete actions, which occur if the patient agrees to participate in the research project, so clearing up a doubt related to the procedure reinforces the certainty of its occurrence. Benefits, on the other hand, are a probability. When a doubt related to a certain benefit is cleared up, this may calm the person and even be decisive in the process of making decisions. If the benefit does not occur, this remembrance may be lost.

Comprehension of what was being proposed in the research project was reported by 56% of the patients. Data regarding this characteristic allowed us to assert that in 44% of the sample, the informed consent was considered morally contestable. According to the results, non-comprehension made the remembrance of procedures more difficult and the remembrance of benefits easier. These people authorized their inclusion in the research project without an exact notion of what would be done, perhaps focused only on the possibility of obtaining some benefit out of the experience.

A similar situation was observed in 1975, in a study involving the informed consent given by 41 volunteers in non-clinical research projects.(11) In this sample, 14 people gave consent without having been adequately informed and without having understood exactly what would be done during the research project. It is worth noting that in the study performed in 1975, only five people, all with medical education, adequately understood what was being proposed in the forms. This professional selection shows that the information was not accessible to most participants in the North American project; it reinforces what had been previously discussed regarding the fact that investigators write according to their pattern of reading.

The text of the informed consent forms was considered accessible by only 25.4% of the participants. This characteristic was associated only with the remembrance of

procedures. Coherently, texts considered accessible made the remembrance of procedures easier, while those considered non-accessible made it more difficult. This value was numerically similar to the number of participants that had an education level compatible with readability indices. Participants with at least high school education constituted 29% of the sample. There was, however, no significant correlation between readability and education level. Similarly, differences between the Flesch-Kincaid and Flesch indices for groups that considered the text accessible and non-accessible were not significant. These results confirm those already observed when education level was assessed.

The analysis of the results obtained with the three elements of the informed consent - procedures, risks, and benefits - also presented some associations that deserve to be analyzed.

Remembrance of procedures was the main element of the informed consent, according to the correspondence analysis. They were remembered in 48% of the cases, which means that 53% of the patients either did not remember what had been proposed and performed with them, or, perhaps, did not consider such situations as being related to the research. The remembrance or not of procedures had no relationship with the time elapsed between the obtainment of the consent and the present data collection. Having received previous explanations and answers to doubts, having considered the text accessible and having an education level superior to elementary school were facilitators for the remembrance of procedures. Not having received previous information, not having understood it, or not having understood what was being proposed, made remembrance become more difficult.

Benefits were remembered in 48% of the cases. Having an education level above elementary school and having received previous explanations contributed to this remembrance. The absence of previous explanations, on the other hand, made the remembrance more difficult. There were two inverse associations: the non-comprehension of information made the remembrance of benefits easier, and the absence of doubts on the patient's part was associated with difficulty in remembering benefits. Although apparently contradictory, both inversions have the same explanation. The non-comprehension may be the result of a non-clarified doubt, which generates insecurity and uncertainty. Remembering benefits may be one way of dealing with this insecurity, even if the benefits are not adequately understood. Complementarily, those who had their doubts clarified and felt more secure were not even able to remember the benefits reported. It is important to emphasize that the participants who did not seek answers for their doubts may have experienced an embarrassing situation, caused by the establishment of a dependence relationship with the investigator.

Remembrance of risks had a considerably lower index than the other aspects, since only 22% of the patients reported it. This means that 88% of the participants did not remember the risks they had taken when authorizing their inclusion in the research project. An important aspect is that only the risks indicated in the informed consent form signed by all subjects were taken into consideration. Only one association was observed between remembrance of risks and another variable: having received previous explanations made it easier to remember risks; the absence of previous explanations made it more difficult. The low rate of remembrance of risks may be a sign that the patient is denying the negative aspects associated with the research project in which he/she agreed to participate.

The results obtained with the remembrance of procedures, benefits, and risks showed that the participants selectively differentiate between these data during the obtainment of informed consent. People preferentially remember what will actually be carried out or what benefits the research can bring to them. Since risks have a negative

character and are only probabilities, they are remembered in a lower incidence. None of these characteristics - procedures, benefits, or risks - had an association with the time elapsed between the obtainment of informed consent and the data collection.

The low remembrance of risks may be at least partially explained by the studies carried out by Hofstede, who used another trans-cultural variable: the form by which society deals with conflicts and uncertainties (12). This characteristic may clarify the discussion about the lower remembrance of risks. The Brazilian population was classified into the group of countries that most avoid situations involving uncertainties. This way, information about a risk associated with the research project may generate such anxiety that the risk is denied or forgotten. Procedures, on the other hand, constitute a certainty; as they had already been performed when the present data collection started, they were more easily remembered. Benefits represent favorable information, which was probably decisive for the people to authorize their inclusion in the project. Even constituting a probability or an uncertainty, benefits do not generate insecurity; on the contrary, they make people hope that they are really going to happen.

These results show that it is really necessary that the use of the informed consent in research projects be the object of deep reflections in all instances involved. It is of paramount importance that the informed consent form not be used as a means of responsibility exemption by investigators, research institutes, and sponsors. Ethics Committees play an important role in reviewing all the stages involved in the informed consent process, and not only the text adequacy of the form, as is usual in Brazil. The access to and comprehension of information, the clearing up of patients' doubts, the familiarity with and access to an investigator who is able to clear up potential doubts are conditions that should be formally guaranteed to candidates to participate in research projects.

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Embracing personal and community empowerment: genetic information policy making in Israel

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Introduction

Thirty years ago, researchers from an American group collected blood and DNA samples from Indian Amazon tribes and sold it to scientists around the world for \$85 a sample. In 1996, another team came to collect more blood samples in exchange to medicine. Recently, Karitiana and other Amazon tribes have decided to demand compensation and to stop the distribution of their blood and DNA by American private companies (Rohter, 2007). Similarly, during the 1990s, researchers from the U.S. National Institutes of Health indicated that Ashkenazi Jews had an extremely strong history of breast cancer. This was the first genetic mutation positively associated with cancer risk in a particular ethnic group. Some leaders within Ashkenazi Jewish community have expressed concerns that these research findings linking a racial or ethnic population to a disease or disorder might stigmatize the group involved or the Jewish community (Hodge and Harris, 2001).

The participation of individuals and social or ethnic groups in genetic research raises some concerns, such as discrimination, stigmatization, and breaches of privacy. Thus, this article offers to view regulatory guidelines that apply specifically to genetic testing and data handling including privacy and confidentiality of genetic test results, research profits and benefits sharing, and avoidance of the misuse of genetic technologies and information in employment or insurance as an appropriate response to specific public concerns.

This paper suggests that the key strategic concept guiding such regulations is empowerment (Zimmerman and Rappaport, 1988). Empowerment aims at the improvement of individual and collective skills to regain control over living and working conditions and their impact on well-being (Henderson and Thomas, 1987). In public policy studies, empowerment refers to a constant process of enabling individuals and groups to enhance their individual and collective skills and to take part in collective action (Rochefort and Cobb, 1994). It is suggested that in the case of genetic information, empowerment is manifest in the dilemma between one's interest in protecting sensitive personal information and the general will to obtain this information, for instance, in order to undertake research for the benefit of the society as a whole (Rochefort and Cobb, 1994; Gottweis, 2005).

Indeed, regulation of the use of genetic information needs to assess the basic questions concerning the relations between state and society. The questions here became more complicated during recent decades due to the shifting role of the state. These changes are often explained by the growing influence of international actors, private actors, and civil society actors (Coleman and Skogstad, 1990; Atkinson and Coleman, 1989).

The present paper aims to analyze how the state's relationship with non-governmental actors influences individual and community empowerment in the field of genetic information regulation. This paper suggests that legal protection for individuals and communities should follow the social nature of genetic information. Moreover, growing

empowerment can result in a policy network exemplified by the state as a dominant actor whereby the state consciously tries to exclude organized interests from policy-making. As such, it should be emphasized that states should enact laws to protect individuals and ethnic communities from genetic discrimination instead of self-imposed regulation in the insurance market.

This article is divided into two sections. The first section briefly outlines the nature and implications of genetic information, the second will examine the relationship between state and non-governmental actors in designing genetic information regulation in Israel.

Genetic Information vs. Medical Information

Mapping and identifying human genes enables obtaining information concerning each person. Genetic information has been seen to be different from other kinds of information concerning our health and lives in general, in that genetic information has a probabilistic character in which health risks can be accurately predicted by genetic test (Beskow et al., 2001; Issa, 2002). Moreover, medical information is considered to be uniquely personal while genetic information is usually – by its very nature – a social (family) concern. Genetic information can reveal information not only on a particular, unique individual, but about those who are genetically related to him or her, such as members of a particular family (parents, children, siblings), or an even larger ethnic or racial population. In the context of political and legal decision-making, this paper will briefly outline three main aspects which guide the ethical grounds behind the legislation calling for special regulation where genetic information is concerned: genetic privacy protection, sharing in research profits and advantages, and avoiding misuse of genetic information by private sectors.

Genetic Information and Privacy Protection

The use of genetic information invokes policy debate over the ethical grounds behind the special legislation for genetic information. Some believe that parts of existing medical information privacy laws could be interpreted to include genetic information privacy (Lemmens, 1999). They claim that the same argumentation that is relevant to the use of genetic information is, in many ways, relevant also to other kinds of health information which reveals illness or probabilities of particular health conditions for people. Others claim that the use of genetic information challenges a number of existing legal tools such as intellectual property, privacy, and informed consent in private-funding research (Wolf, 1995). As such, they suggest that as part of the disclosure for consent, individuals must be informed of possible future uses of the specimen, whether identifiers will be retained, and, if so, whether the individual will be re-contacted. However, in multiplex genetic testing for more than one condition, there is no possible way to re-contact participants and obtain informed consent from them for each test (Rechtes, 2003).

Genetic Information and Research Benefits Sharing

With the rapid development of high-throughput technologies allowing for the screening of very large numbers of samples, and with growing recognition of the important role genetic variation can play, there has been a tendency to try to generate large national population collections in various countries (Iceland, Estonia, Latvia, Sweden and the UK, for example), or to investigate sub-populations with defined characteristics (in Italy and Finland, for instance). These collections, considered as national research resources, are usually supported with private funds in combination with public funding, although they are occasionally supported with private funds alone. Thus collections which are partly held by the private sector could be set up on a commercial basis,

using tissue collected from hospitals or extra tissue taken from a medical research trial, processed for research, and sold to pharmaceutical, diagnostic, or biotechnology industries. Therefore, ownership of the data becomes a significant question that needs to be addressed by both researchers and communities. It is argued that the concept of ownership (e.g., of research results or human tissue) needs to be clarified, and that ownership of data should be defined to include the communities providing the data, as well as the researchers studying the data.

Genetic Information and Discrimination

Expansion of the range of genetic tests and other genetic information available to physicians, insurance companies, employers, and the general public could lead to genetic discrimination based solely on the nature of an individual's genotype. The practice of genetic discrimination has the potential to create a new group of disadvantaged people who would need the same protections now accorded those suffering from racial and sex discrimination (Billings et al., 1992; Natowicz et al., 1992; Alper et al., 1994).

The tragedies of race and sex discrimination illustrate the dangers of basing employment decisions on inborn characteristics. Like these, discrimination on the basis of genetics ignores the present abilities and health status of workers and substitutes questionable stereotypes about future performance. Less absenteeism, reduced life and health insurance costs, and longer returns on investments in employee training all reduce the costs of labor. Insurance companies also face strong economic incentives to identify individuals perceived to be at increased risk for ill health in the future in order to raise the premium.¹ Despite the extension of using the self-regulation model by the private sector, some states in the U.S.A., such as Texas, Georgia, Virginia, and New Jersey, have enacted laws which prohibit the use of genetic information by employers and insurance companies.²

In the future, the extent to which government will be able to influence the distribution of goods and services will depend on achieving coordination and control among these disparate actors. (Orenlicher, 1995; Brownsword et al., 1998; O'Neill, 1998; Hall and Rich, 2000; Murray et al., 2001; Annas, 2002) Coordination of multiple actors becomes an important precondition for the increasing capability of government to perform an active role in designing genetic testing policy. Therefore, this paper claims that a state's relationship with non-governmental actors provides a fertile field for analysts who wish to investigate the structure and decision modes of governments, the interaction between government and groups, the types of policies which result from such interactions, and their impact on non-discriminatory genetic policy.

The Israeli Genetic Information Policy Making

The unique characteristics of the genetic information presented above will be strengthened if it can be supported by empirical data. In this section, we will examine how state-civil society relations affects policy outcomes, namely providing support for individuals' and communities' empowerment or leading individuals and communities to become more vulnerable to potential risks from the use of genetic technology.

Israel was faster than other states to respond to the concerns about commercial use of genetic information. In fact, the special nature of DNA and genetic information with respect to individual rights has been recognized in the law on

genetic information, adopted in Israel in 2000.³ The Genetic Information Law 5761-2000 and other existing ethical guidelines cover most issues of informed consent, confidentiality, and rules of accession relating to either identified or non-identified DNA samples or genetic information in the usual individual or family-based, small scale, collections. The law indicated a communitarian approach in addressing the issues of genetic testing, which set boundaries within which personal autonomy was to be exercised. The specific responsibilities and goals set out in the new legislation provided inter-relationships of individual values, rights, and needs with communal values, civic duties, and responsibility and public welfare.⁴

In 2000, the Genetic Information Law was enacted in Israel. The law as a government regulation initiative contains protection from genetic discrimination in insurance and in applying for employment (see esp. sections 23 and 24). However, genetic information policy-making did not end in preliminary legislation. Other ethical and legal aspects of the use of genetic information were being further considered by the Knesset Committee of Scientific and Technology Research and Development. One of the Committee's challenging regulatory issues was the management of DNA sample collections from Ashkenazi Jews by the Israeli commercial company IDgene Pharmaceuticals Ltd. IDgene is a privately owned population genomics company focused on identifying the genetic basis of common diseases.

The commercial interest of IDgene in the use of genetic information raised public concerns over the regulation of large population-based genetic studies. During 2001, this issue was reviewed in two reports: One was issued by the Bioethics Advisory Committee of the National Academy of Sciences, headed by Prof. Michael Ravel and the second was issued by the Ethics Bureau of the Medical Association, headed by Prof. Avinoam Reches. (Reches, 2003) Most of the recommendations specified in these reports are similar, especially in their call for the establishment of new statutory authority, which will assure quality control of both the collections and the ethical management of genetic databases. Such authority will be implemented to evaluate and monitor the current use of existing biobanks throughout the state and constitute a biobank of its own. The report of the Israel Academy Bioethics Committee emphasized the concern of groups' genetic discrimination in research: "Genetic profiling of a collectivity that can be defined by ethnic or national origins could lead to risks of stigmatization of all those who belong to the collective. Worse, this could lead to discrimination in various forms – moral, physical or economic."⁵ The deliberations of the Ethics Bureau of the Medical Association were aimed at defining a broader set of principles, dealing in balancing the privacy of genetic information and the benefit of research to improve public health of ethnic communities and society as a whole. Prof. Kasher, one of the members of the Israel Academy Bioethics Committee, suggested considering the community from which the samples are collected as the owner of such information. According to Kasher, "...it is actually the community property."

The description of the Israeli network in genetic information policy-making enables us to specify the influence of state regulation on individuals' and communities' empowerment. A practical investigation of the Israeli policy can be found in the responses of an Arab Bedouin community

¹ <http://www.managed-care/mag.com/archives/9701/9701/genetics.shtml> Date last accessed: 27 March 2006.

² I refer to Information Nondiscrimination Act of 2003: <http://www.gene-watch.org/programs/privacy/genetic-disc-position.htm> Date last accessed: 27 March 2006.

³ Passed by the Knesset on 16 Kislev 5761 (December 13, 2000); bill and explanatory memorandum published in *Hatsaot Chok* 2786, 11 Tevet 5759 (December 30, 1998), p. 290. *Kovetz HaTakanot* 5741, p. 292.

⁴ Knesset protocol no. 71, Science and Technology Committee meeting (19 November 2001); Knesset protocol no.1041, Research and Technology Development Committee meeting (8 November 2004).

⁵ <http://www.academy.ac.il/bioethics/hebrew/report2/report2-h.html> Date last accessed: 20 November 2006.

in Israel to a genetic counseling program for spouse selection. While health professionals designed the program to fit local norms such as consanguinity, matchmaking, and the Muslim ban on abortion, for the Bedouin, it also meant the medicalization of marriage arrangements and family planning. Research has shown that during the last decade, the Bedouin infant mortality rate was 15.3% of 1,000 new births compared to 3.3% in the Jewish community. In 1994, Soroka Hospital in collaboration with the Institute of Genetics at Ben-Gurion University of the Negev and Ministry of Health, decided to implement a Premarital Carrier Screening program of couples at risk. (BGU, 2000) In 2002, inborn defect was the explaining cause of 36% of infant mortality. Another community-based premarital program that uses carrier matching is *Dor Yeshorim*, a program developed by the ultra-orthodox Ashkenazi Jewish community. The Tay-Sachs genetic screening program was established to follow the ultra-orthodox Ashkenazi Jewish community's law under which birth control and abortion are forbidden and engagements are pre-arranged through matchmaking procedures. The program tests young adults for disease carrier testing before they begin matchmaking procedure so the engagement can be canceled at the earliest possible stage. The success of *Dor Yeshorim* screening program derives from the strong support of the religious leaders of the Jewish community, the confidentiality of the storage data and the availability of shared biomedical information with community members. According to Raz, "The compliance rate with *Dor Yeshorim* is over 90 percent; in recent years hardly any children affected with Tay-Sachs or cystic fibrosis have been born in this community to couples who married during the last decade." (Raz, 2005: 18) Although, The Bedouin program was drawn upon *Dor Yeshorim* model, with which professionals at the local medical center were quite familiar, the genetic screening program for the Bedouin community did not require community involvement in all aspects of this research, including follow-up with the results (Raz, 2003). When obtaining community empowerment, special attention must be given to preliminary research to identify potential issues and problems that may cause turmoil in the community. Researchers also should strive to select community partners (leaders, organizations) knowledgeably and carefully to ensure that these individuals can adequately represent the multiple and diverse views within a community. These regulatory mechanisms are crucial to obtaining community empowerment in participation in genetic screening programs and to promote general welfare instead of narrow private interests.

Conclusion

This paper has indicated that the possibility of individual and community empowerment depends on the extended role of governmental actors in genetic information policy making. The Israeli case of genetic information policy-making demonstrates that the existence of state's autonomy in which jurisdictions found that the benefits of a comprehensive, coherent, and principled regime would displace the perceived need (as well as the political pressure) to treat genetic information distinctly from other types of data. Indeed, civil servants are liable to include provisions of accountability and responsibility in policy-making. These provisions might include entailing "collective" termination to privacy rights and informed consent due to the fact that the collection and the use of genetic information do not concern only those individuals from whom samples are collected; requiring researchers, in their research grant proposals, to justify their selection and definition of communities; demonstrate sensitivity for the larger ethical, legal, and social implications of their research; anticipate potential group harms; specify actions to educate and inform the community about the research and to obtain consensus for the study; indicate ways

to communicate research results back to the community for the benefit of the society as a whole. In the context of individuals and community empowerment, it urges the need to create a distinct corpus of rules specific to genetic information. For that, this policy has the obvious advantages of providing additional and more tailored protections specific to this type of information, while also addressing some of the familial and communal interests in that information.

It is argued that in the future, National Bioethics Advisory committees will take a leading role in shaping genetic information regulation. The fact that these committees' members are coming from different disciplines – ethics, law, science, religion, etc. – promotes dialogue with the public about the ethical, legal, and social implications of genetics research. Indeed, growing public involvement in the meetings and deliberations of the National Bioethics Advisory Commission and the broad dissemination of the Commission's reports to researchers and the public is essential for justifying public participation in research on the one hand and commercial investment on the other, for the sake of society's welfare as a whole.

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through DNA sequencing data, inferred "that the DNA sequences from these fossils fall within the European Neanderthal mt-DNA variation. Thus, the geographic range of Neanderthals is likely to have extended at least 2000 km further to the east than commonly assumed".

Krause et al. (2007) have estimated the date of an adult and a subadult humerus bones by the ¹⁴C technique as nearly 35,000 years old.

In an e-mail letter to Wade (2007) Paabo has said, "We now know that they (Neanderthals) are ('were' would have been better) on the doorstep of Mongolia and even China...".

Neanderthal features started appearing in evolving hominids in Europe about 400,000 years back. The Neanderthals first appeared in western Asia 150,000 years ago. As noted above, the Neanderthal presence in more eastern Asia has been estimated to have been about 35,000 years back. These time estimations suggest eastward migration of Neanderthals after their European origin.

After their movement out of Africa the modern humans were in the Indian subcontinent about 65,000 years back (Verma, 2006). Hence 35,000 years ago presence of moderns in more eastern parts of Asia is quite expected. In fact the museum bony remains from the Uzbekistan and Siberian caves, used by Krause and his team for DNA extraction, were badly contaminated with modern human DNA. Krause et al. (2007) say, "The high ratio of modern human DNA to Neanderthal DNA for the subadult Okladnikov and the Teshik Tash specimens are in agreement with previous observations that modern human mtDNA occurs in most fossil bones.". These facts suggest coexistence of moderns and Neanderthals over a long period (more than 10,000 years in Europe, Verma and Saxena, 2007) in a large geographic range (extending from Gibraltar to the Altai Mountains in south Siberia). This further increases the possibility of some interbreeding between moderns and Neanderthals and assimilation of Neanderthal contribution in the modern human's genome (vide Verma and Saxena, 2007).

Neanderthal Range Extended

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In an earlier communication (Verma and Saxena, 2007), on fate of Neanderthals, it has been said that Neanderthals lived in Europe and south-west Asia. That was the knowledge then. Now the range of distribution of this species of *Homo* is known to be considerably more extensive (Krause et al., 2007).

Before the work of Krause et al. (2007) there were some indications of Neanderthals in more eastern parts of Asia. In the Teshik-Tash Cave in Uzbekistan some hominid bones and artifacts were found; the latter included Mousterian tools, which are associated with Neanderthals. In the Okladnikov Cave in the Altai Mountains in South Siberia some hominid teeth were found, which looked neanderthaline. But these finds were not conclusive evidences in favour of Neanderthal existence in those parts in the past.

In the Krause's team was included S. Paabo, who had experience of sequencing and analyzing Neanderthal DNA from European sites (Wade, 2007). Taking advantage of his experience Krause's team planned to identify Neanderthal mt-DNA in the DNA samples extracted from bony remains from the Teshik-Tash and the Okladnikov Caves. Krause et al.,

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Perceptions of Issues in Biotechnology Management in Thailand

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Introduction

Over the past century, biotechnology has created great promise and new opportunities for the human community as a whole. Despite the advantages, biotechnology raises important ethical issues emerging from the manner in which the technology is developed, designed, and implemented worldwide.

In terms of management, the most important question may be – are managers in biotechnology business specifically and properly educated and prepared to deal with all of the above questions? (Hoyte and Weiskel, 2004). In the case of a developing country such as Thailand, there has been no curriculum of graduate study of biotechnology management offered by any university when this project started in 2005.

To establish good governance in biotechnology management in Thailand, this research study, as part of the EU-Lemlife Project, was funded by the European Union to develop a curriculum for Biotechnology Management course, the first curriculum to be offered in Thailand at the graduate level.

To design a curriculum to develop Thai managers' knowledge and skills to manage biotechnology business at the local and international arenas, the curriculum should reflect both local and international concerns. The study was thus divided into 5 parts:

Part I: Presentation of background information on biotechnology in Thailand, concept of corporate governance, ethical issues in biotechnology companies, and stakeholder concept in biotechnology business.

Part II: Presentation of topics to be included in the draft of curriculum of biotechnology management. The draft of the curriculum was the outcome of the integration of reviews of the concepts listed in Part I, together with the information obtained from the survey of biotechnology management curricula offered by a number of leading universities.

Part III: Data Collection from interviews with experts, executives, and managers from leading biotechnology companies, and managers from non-biotechnology companies regarding the topics to be covered in the curriculum. Opinions from the public were also surveyed to provide a broader picture for the curriculum development.

Part IV: Presentation of results.

Part V: Conclusion and recommendations

Biotechnology in Thailand (1983-2007)

Before the economic crisis in 1997, the Thai government aimed to push Thailand to be named one of the Asian Newly Industrialized Countries (NICs) with an average economic growth rate at 8-9 percent during 1993-1995. In 1983, the Thai Government established the National Center for Genetic Engineering and Biotechnology (BIOTEC) under the Ministry for Science, Technology and Energy. Nevertheless, when compared with India and China, biotechnology in Thailand has progressed at a lesser extent despite the fact that

Thailand has abundance of unique genetic resources of plants, animals and micro-organisms (Tanticharoen et al. 2003).

After the economic crisis, efforts have been made by both the government and private sectors to revive the economy via the development of science and technology. In 2001, the total of the Government's R&D expenditures provided to the universities in Thailand amounted to approximately C\$40.6 million. The expenditure on R&D was allocated mainly on development of agriculture, forestry and fishing, with lesser amounts on promotion of industrial development, environment, and healthcare (Agri-Food Trade Service: Market Information Southeast Asia, 2002).

At present, Thailand has a number of agencies that work in the field of biotechnology: the National Science and Technology Development Agency (NSTDA, established in 1991), the Thailand Institute of Scientific and Technological Research (TISTR), the National Research Fund, the National Research Council of Thailand, together with many of the major universities such as Chulalongkorn, Mahidol, Kasetsart, Chiangmai, etc. (Business-in-Asia.com, 2005).

In 2002, the biotechnology industry in Thailand was considered very much in its infancy since only a few products were commercialized and the technology used by the private sector was mainly imported (Agri-Food Trade Service: Market Information Southeast Asia, 2002).

To strengthen biotechnology as a key driver for national development, the Thaksin Shinawatra Government launched an initiative to formulate Thailand's National Biotechnology Policy Framework. Therefore, the National Economic and Social Development Board (NESDB), in collaboration with BIOTEC, and the NSTDA prepared the National Biotechnology Policy Framework, an eight-year road map (2004-2011) which was endorsed by the National Biotechnology Policy Committee in 2003. The policy framework aims to achieve the following goals by the year 2011:

1. Development of new bio-business.
2. Biotechnology promotes Thailand as Kitchen of the World
3. Thailand represents Healthy Community and Healthcare Center of Asia.
4. Utilization of biotechnology to conserve the environment and to produce clean energy.
5. Biotechnology as the key factor for self-sufficient economy
6. Development of qualified human resource system.

The Government could not stay long enough to realize the policy framework set to be achieved by 2011 as the Royal Thai Army staged a pronunciamiento against the government on 19 September, 2006. The interim Government was then formulated mainly to set up the election by the end of 2007. Under the new Government, the status of these goals is not clear.

Nevertheless, U-sarat Bunnag (2007) views that the overall picture of biotechnology in Thailand 2007 is not so poor. The agricultural biotechnology sector now employs various technologies ranging from industrial fermentation and marker assisted selective breeding technology, to recombinant DNA techniques.

In the medical biotechnology sector, it seems that Thailand is becoming well known for being a regional hub for healthcare with more than 1 million foreigners coming last year to use its health facilities and services. Now, this sector's focus is to create leverage on biodiversity, Thailand's strength, to discover bioactive substances from natural products and micro-organisms to develop new drugs.

For food biotechnology, this sector provides many untapped opportunities for investment. It was forecasted that the processed food sector will grow at a satisfactory level this year.

Although biotechnology is well developed in most universities and research institutes in Thailand, there is inadequate number of personnel in biotechnology. Seventeen universities in Thailand could accept only up to 600 biotechnology students annually (Tanticharoen et al., 2003). In 2007, among 70 universities in Thailand, 20 offer biotechnology science. However, none of them offer a Master Degree in Biotechnology Management (Ministry of University Affairs, 2007).

Corporate Governance and Ethical Issues in Biotechnology Companies

The field of biotechnology is advancing so rapidly it poses challenging problems not just only for the lawmakers, consumers, and government, but also for corporations since this area obviously faces a lack of informed public debate and consensus on key questions. Under such circumstance, even well-intentioned corporations may find themselves lacking the moral standard essential for responsible corporate citizenship (MacDonald, 2002).

From the point of view of Pradhan (2003), 'good governance' must have the following characteristics:

- Decision makers are held accountable through voice of stakeholders
- Policy making and implementation processes are transparent and efficient
- Decisions are contestable
- Rules and regulations are predictable.

Oman (1999) proposed that corporate governance is perceived as a system by which business corporations are directed and controlled via organization structure that identifies the distribution of rights and possibilities among different participants in the corporation, such as, the board, managers, shareholders and other stakeholders, and spells out the rules and procedures for making decisions on corporate affairs. By doing this, company can achieve its established objectives and can monitor its performance.

From another perspective, Mathiesen (2002) argued that corporate governance is "a field in economics that investigates how to secure/motivate efficient management of corporations by the use of incentive mechanisms, such as contracts, organizational designs and legislation. This is often limited to the question of improving financial performance, for example, how the corporate owners can secure/motivate that the corporate managers will deliver a competitive rate of return."

Regarding how biotechnology firms deal with ethical issues, Kato and Macer (2003) conducted a survey of 559 biotechnology companies in the USA, UK, France, Canada, and Germany to investigate how they respond to bioethical issues. Their survey revealed that in companies involved in biotechnology, bioethical problems did occur. However, they responded to the issues differently and their practices for handling such issues were quite diverse. For instance, only 11 per cent of companies reported that they had codes of ethics, then, another 11 per cent responded that they had a policy or policy statement on ethical issues, and 5 per cent informed that they had general codes of conduct not especially about bioethics.

Given the different types and levels of companies' approaches in dealing with ethical issues, it can be seen that even biotechnology companies in the developed countries lack standards in managing ethical issues.

The Stakeholder Concept in Biotechnology

Chris MacDonald (2004) claimed that the stakeholder concept was one of the most attractive conceptual devices in business ethics. Accordingly it has been seized upon by theorists in business ethics as a way of explaining the idea that businesses have obligations to a broad range of parties, beyond the stockholders to whom corporate executives were traditionally thought to be beholden (Goodpaster, 1991).

For Freeman (2001), stakeholders simply refer to those groups who have a stake in or claim on the firm including suppliers, customers, employees, stockholders, and the firm's local community. The stakeholder concept gives due credit to the fact that the motives of agents in business are relatively complicated and the conflict between those varied motives has been a central issue in the business ethics literature. Therefore, the process defined as "stakeholder analysis" "can provide biotechnology companies with a lens through which to pay attention to the full range of interested parties" (MacDonald, 2004).

A simplified stakeholder analysis process was developed by Weiss (2003) for a biotech firm as follows:

Phase I: Descriptive Analysis. This involves the listing of parties having a stake in the issue which might include employees, stockholders, providers of biological resources, local communities, competitors, firms in related fields, government agencies, and university-based researchers, and others. Then, the assessment of each stakeholder's interest should be conducted.

Phase II: Normative Analysis. This includes an assessment of the types and levels of obligation that the firm has to each stakeholder. This phase is aimed to accurately locate the firm as enmeshed in a continuum of ethically relationships.

In conclusion, the aim of stakeholder analysis is to understand the awareness, knowledge, perceptions, interests, and expectations that shape debates among stakeholders on biotechnology in order that firms can better develop management strategies and practices in handling new technologies.

Topics/Issues in Biotechnology Management

In addition to reviews of concepts of corporate governance, biotechnology business ethics, and stakeholder analysis for the biotechnology industry, the researchers have reviewed a number of biotechnology management curricula offered by some leading universities (see Appendix 1: List of Selected Universities that offer Biotechnology Management Course). Then, a number of studies and articles on management knowledge, skills, and issues related to effective biotechnology management were also reviewed.

From the sources of information mentioned above, it seemed that the most frequent topics appeared in the curricula surveyed and the academicians' concerns include:

1. Fundamental knowledge of principles of management and strategic management for biotechnology industry (Burgelman et al., 2003; Christensen, 1999; Dodgson, 2000; Roberts, 1995).
2. Fundamental knowledge in biotechnology industry (Raeburn 2000; Grace, 1997; Oliver, 2000)
3. Understanding entrepreneurial mindset in startup and large companies. (Meyer et al., 1986; Roberts, 1991)
4. Finance: financing for biotechnology business, grant proposal strategies and management (Blandford, 1991; Hale, 1994; Ries and Leukefeld, 1998).
5. Marketing: market analysis, marketing strategies for biotechnology products (Moore, 1991; Wansink and Kim, 2001; Zimmerman et al., 1994).
6. Regulatory issues in biotechnology industry such as clinical trial process for both devices and drugs, FDA approvals, etc.
7. Intellectual property and commercialization (Besend and Raskind, 1991; Reitzig, 2004)
8. Product development and transition to business units (Cooper et al., 1999; Wheelwright and Clark, 1992)
9. Bioethics and legal issues. (Bulger et al., 1993; Colley et al., 2003.)
10. Stakeholder analysis and corporate governance (Aerni, 2001; Macdonald, 2004; Monks and Minow, 2001, Wallace and Zinkin, 2005).

Research Methodology

Based on the topics listed in the previous part, a draft for a curriculum of the course "Principles of Management in Biotechnology" was developed for comments by experts, managers in biotechnology industry, and managers in non-biotechnology industry.

At the outset, the researchers planned to collect data via interviews and questionnaire. However, when we pilot tested our questionnaire, we found that respondents who were not in the field of biotechnology did not understand the term "biotechnology" and had very little knowledge about it. Therefore, we selected personal interview and focus-group interview as major tools to collect the data because they could provide richer information and unclear questions could be clarified during the interview.

Populations:

Group 1: Experts

Personal interviews were conducted with 5 experts (academicians and researchers) in biotechnology.

Group 2: Top Management and Middle Managers of Biotechnology Companies

Twenty-one top managers from 14 biotechnology companies were interviewed. Among the 14 companies, 2 companies were from agricultural industry, 3 companies from food industry, 4 companies from healthcare industry, and 2 from pharmaceutical industry.

Then, focus-group interviews were conducted with 42 middle managers from those 14 biotechnology companies mentioned above (3 managers for each company).

Group 3: Twenty-five middle managers from 12 non-biotechnology companies were asked for comments on the draft of the curriculum and on other issues of concerns regarding the management of biotechnology industry on focus-group interviews.

Group 4: Fifty people from Bangkok metropolitan area representing "the public" were asked for a short interview (about 5-10 minutes) to survey general awareness and perceptions of biotechnology. These people were not asked to review the draft of the curriculum. The interviewees included passers-by and/or shoppers from 4 shopping centers in Siam Square area, Thonburi area, Srinakarindra area, and Rama III area).

Overall results

Most interviewees agreed that the development of biotechnology management course should include the following topics:

Rank no. 1: Marketing of biotechnology invention

Rank no. 2: Corporate governance for biotechnology business (bioethics and legal issues)

Rank no. 3: Managing conflicts of interests and safety issues in biotechnology companies

Rank no. 4: Fundamentals of management, strategic management, entrepreneurship in biotechnology industry

Rank no. 5: Financial management and grant management

Rank no. 6: Management for invention and innovation

Rank no. 7: Intellectual property of biotechnology products

Rank no. 8: Creating and managing human resource in biotechnology business

The above ranking shows the perception of the importance of each topic as perceived by all respondents. Each respondent was allowed to select more than one topic perceived as important.

The marketing of biotechnology invention was regarded by most respondents as the most important area to be offered in the curriculum. This may be resulted from the concern about their quality of life that might be at risk by consuming the products they were not well informed about, e.g. GMOs

(such as soybean), agricultural product adulteration (such as rice). Their concern maybe emerged from their ignorance about biotechnology, its products, benefits, and risks.

The detailed results from each group's interviews are discussed below.

Results from Group 1

Overall, this group perceived biotechnology as critical mechanism to drive national development and growth if used properly and ethically. They expressed their concern about the level of public awareness and understanding of biotechnology which seemed so minimal and superficial.

"When people don't know biotechnology and are not educated about it, it is very easy for some NGOs to run any propaganda against GMOs, or other biomedical research by painting biotechnology to look like a monster that will take away people's lives quietly!," said one of the experts. Another expert shared his view that, "Although the former Government had laid out the policy framework for biotechnology development, they did not do a good job to educate the public about biotechnology. I think the government themselves do not quite understand it (biotechnology) as well. Some ministers think that it sounds so modern to include biotech in their policy!"

The experts perceived that good management or good governance in the fast-growing biotechnology industry is very much in need because "The technology changes so fast and there are a lot of problems regarding biosafety guidelines for laboratory work and for field work such as the issue of the release of genetically improved organisms (GIOs) into the environment."

Another issue about the field testing of transgenic plants in Thailand was mentioned by an expert that, "Generally, Thailand, like other developing countries, lacks the standard infrastructures for most operational steps regarding the field testing procedures. Although NBC (the National Biosafety Committee) had developed Biosafety Guidelines, but they are just only guidelines not law. If scientists or companies do not follow the guidelines, there are no penalties. So the development of business ethics and social responsibilities in biotechnology management program is really important."

Another feedback was about the need to develop management skills in innovation management, financial management, and entrepreneurial skills in scientists who were promoted to take management role.

With regard to intellectual property, the experts said that now Thai scientists better realized about this issue than a decade ago. "But it's still a good idea to include this topic in the curriculum," concluded an expert.

Results from Group 2

About one-third of the managers interviewed had their degree in business administration and according to them, "Biotechnology is just another kind of business. So the management concepts we learned from school can be applied in managing this business. With some more study about the biotechnology industry in terms of legal issues, and operations guidelines, we can manage it."

Regarding the topic of human resource management, the majority of the managers agreed that the most important problem confronting their companies was the inadequate pool of qualified personnel in biotechnology and the retention of these people.

Another important issue mentioned was about the intellectual property of biotechnology products. More than half of them similarly said that the field of biotechnology is new but it grows very fast, therefore the intellectual property law found a hard time to catch up with technologies.

For top management, more than half of them commented that advertisement and marketing was important because certain biotechnology products or service could be perceived

and/or received differently in different society. "Now it is not clear how society will deal with the growing ability of researchers to manipulate genomes. What kind of marketing strategy should be used to ethically promote genetics services available in hospital in the future?," said a private hospital administrator.

Another important issue identified by these managers is the intellectual property of biotechnology products. More than half of them similarly said that the field of biotechnology is new but it grows very fast, therefore the intellectual property law found a hard time to catch up with technologies.

The last issue addressed by top management was about the management of new products or innovation in biotechnology. They realized that only good ideas or even discoveries of new products were not sufficient to create business. Scientists must be trained to be market-oriented, customer-oriented, cost-efficiency oriented, and fast enough to be the first to launch the product.

Results from Group 3

About 90% of managers from non-biotechnology companies were not familiar with the term "biotechnology," and were not certain about what the term really meant. Most of the managers interviewed had at least a Bachelor Degree and some of them hold Master Degree. These people admitted that they knew very little about biotechnology products and/or inventions. All of them heard about GMOs and animal cloning from newspaper and from some TV programs but did not paid much attention to such information since biotechnology sounds not related to their daily life.

However, when the interviewees were provided with some introductory information from the researchers, they then realized how close biotechnology was to their life. They became more involved in giving comments. Their priority concern was about bioethics, biosafety, and how their rights as consumers should be protected. According to them, marketing management of biotechnology played a critical role in introducing/communicating the products to the consumers.

They voiced their opinion that, "We understand that biotechnology yields both benefits, and also, risks. We hope that the government will do a better job in educating the public about biotechnology and we expect the business sector to have social responsibilities in providing accurate information to the consumers via advertisement, product labeling, and don't just providing only the good side of their merchandises or services."

Another comment was about the term "biotechnology" itself. Many said that, "I just don't get it, I just know that it is a sort of technology. Can anyone come up with a simpler term that people walking down the street can understand?"

Although the marketing issue attracted much attention from these managers, they insisted that the curriculum should include fundamentals of management, finance, innovation management, and knowledge of intellectual property. With reference to intellectual property, a few managers commented that, "Thailand had bad reputation about copyright as we like to sell fake brand name merchandises. And when we can invent something new, we are so naïve and slow in getting a patent. We have to improve on this. Developed countries like the US, Japan, have more experience than Thailand about protecting their intellectual property and they are very fast in doing this. So we got to be careful about this matter or we will lose our competitiveness."

Results from Group 4

The public were not asked to review the draft of the curriculum but they were interviewed to assess their awareness and understanding of biotechnology in general. Among 50 people interviewed, 78% said that they had never heard of the term "biotechnology", 11% heard of the term "biotechnology" but did not understand the meaning, and the

rest 11% heard of the term and understood the meaning and importance of biotechnology.

Although about two-third of this group never heard of the term "biotechnology," however, when asked about GMOs, 81% heard about this term because they heard the discussion about GM-crops such as soybean and papaya. And even they heard about GMOs, they did not clearly understand what the term GMOs meant, they just understood that GM-crops were different from normal (natural) crops but they did not know what the differences were.

From the interviews, the researchers felt that there was a high level of anxiety about biosafety. Some of the respondents said that, "We don't know if the 'Somtam' (Thai papaya salad) we have everyday is cooked from genetically engineered papaya or not. We don't know if the genetically engineered papaya will cause any sickness in our body in the long run or not." They requested that the genetically modified (GM)food should be clearly labeled as "GM-food" so they would be able to decide to consume or not.

The public also requested that the Government should take more pro-active effort to inform and educate the public more frequently about biotechnology by using simpler terms and examples. "The Government should do more PR about the concept via radio program or television just like the way they did the PR for election or about measures to prevent the bird-flu or dengue fever," one interviewee suggested.

Despite the limited knowledge on biotechnology, the majority of the public agreed that a good curriculum specifically designed for biotechnology management is certainly needed.

Conclusion

Most interviewees agreed that a curriculum for biotechnology management curriculum is necessary for Thailand to speed its process of economic growth through good governance of the technology which takes all stakeholders' concerns into consideration.

Marketing issues, biosafety, and bioethics received most of the attention from the interviewees because they were worried about the risks and their quality of life. The researchers also learned that the less people know about biotechnology, the more they are anxious or afraid of it.

Although this research surveyed only a small number of samples, the results signifies an important issue about the low level of public awareness and understanding of biotechnology that might have some impact on the speed of development of this technology and the speed of national development by using this technology.

Recommendations

Based on the research findings, the Biotechnology Management curriculum for Thailand should reflect the needs of 2 groups of people: the scientists who lack management skills but are promoted to take managerial role and the managers who were trained in management but lack the knowledge in biotechnology industry. In addition, the curriculum should involve other ethics-laden topics which may concern both groups, e.g. general business social ethics and responsibilities, ethics for biotechnology industry in particular, ethics in marketing, managing (and educating) stakeholders, etc.

Successful development and utilization of biotechnology depends on several factors including clear government policy and up-to-date law, research funding from both government and private sectors, responsible and knowledgeable researchers, effective and ethical business, and, most importantly, well informed public.

The development and successful implementation of biotechnology management program can hardly be realized if the public, one of the stakeholders, are not sufficiently educated about technology. If the public or the consumers do not understand the benefits and risks of biotechnology, they

will not know their rights. And when the public do not know their rights (to be protected), they can hardly justify or control other major stakeholders --the Government and the business.

A good curriculum can develop qualified graduates, but cannot guarantee effective and ethical managers. Effective and ethical managers are the consequences of several variables including good family, good school, good organization culture and management, good and smart government, good laws, and well-informed citizen to watch the business. Therefore, the public must be adequately educated about biotechnology so they will become more active citizen and consumers. Unreasonable fears and myths about biotechnology will be eradicated. More demands of biotechnology products and services will naturally increase and it will then spur the inventions from the business and researchers.

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Appendix 1: List of Selected Universities that offer Biotechnology Management Course

- Biomolecular Science Center, University of Central Florida
- Biotechnology and Health Industry Management, Graduate School, Penn State Great Valley
- Biotechnology Graduate Programs, McGill University
- Biotechnology Management Program, Southern Illinois University Edwardsville
- Biotechnology Program, College of Life Science, Peking University
- Biotechnology Program, Faculty of Sciences, The University of Hong Kong
- Biotechnology Project Management, Massachusetts Biotechnology Council (MBC)
- Business & Management, University of California Extension, Santa Cruz
- Center for Biotechnology Management, Kellogg School of Management at Northwestern University
- Chemistry and Biotechnology Department, Graduate Courses, The University of Tokyo
- Decision Sciences Department, NUS Business School, National University of Singapore
- Department of Biomedical Engineering, Rensselaer Polytechnic Institute
- Department of Biotechnology, School of Bioscience and Biotechnology, Tokyo Institute of Technology
- Department of Food Technology, Faculty of Science, Chulalongkorn University, Thailand
- Graduate Programs in Biotechnology, University of Maryland, Baltimore County
- Institute of Biotechnology, Technische Universität Berlin, Germany

- Management of Biotechnology, University of California, Davis Graduate School of Management
- Master of Biotechnology, The Wharton School of the University of Pennsylvania
- Master of Science in Biotechnology Program, University of Wisconsin
- Modern Biotechnology Management, AIT Extension, Asian Institute of Technology, Thailand
- Molecular Biotechnology, Faculty of Science, The Chinese University of Hong Kong
- School of Biotechnology, Madurai Kamaraj University
- School of Business, McMaster University
- School of Management, University at Buffalo, The State University of New York
- Technology and the Bio-environment, University of Maryland University College Europe
- The Business of Biotechnology, Haas School of Business, The University of California at Berkeley
- The Institute for Biotechnology and Life Science Technologies, Cornell University
- The School of Agricultural Biotechnology, Seoul National University
- Cost-benefit analysis and economic constructions
- Adoption & development of energy technologies (state of the art review)
- Ethical frameworks for research agendas and policy
- Educational frameworks for environmental ethics
- Nuclear dialogues
- Energy flow, environment, and ethical implications of meat production
- Water ethics and water resource management

The aim of the working groups is to develop dialogue around these particular issues with a focus on environmental ethics and human security. Each group will produce a report that can be used by policy makers, scientists and researchers to consider the ethical dimensions of energy policy.

Who are we looking for?

We are looking for people interested in participating in the working groups with a diverse range of experience in energy and environmental ethics, from fields including but not limited to engineering, government, institutional advisory bodies, civil society organizations, energy-related industries, education, and academia. The people participate as individuals in the highest standards of intellectual vigor and integrity, and the reports will be subject to peer review, and will not represent the views of partner organizations.

We are also looking for organizations with an interest in this project to help support the process of deliberation, consultations and dialogue.

Working group members are not paid for their time although there may be funds available through UNESCO Bangkok and project partners for physical and virtual meetings and other resources.

Want to know more?

For further information on the project please contact Dr. Darryl Macer, Regional Unit in Social and Human Sciences in Asia and the Pacific (RUSHSAP) at UNESCO Bangkok on +66(0) 2391 0577, extension 147 or email d.macer@unesco.org.

There is a yahoo group, unesco_eet@yahoo.com

Description of Working Groups

Universalism and environmental values

Environmental values in the Asia Pacific region are drawn from a diversity of rich philosophical and religious heritages. To what extent can common ground be found within a United Nations system that seeks to implement universal rights and dialogue among different values? Is it appropriate to seek universal or pluralist environmental values? Is there such a thing as an 'Asian environmental ethos' that might be the foundation for building and promoting a more sustainable economic growth?

Ethical worldviews of nature

Are there worldviews inherent in philosophical and religious traditions of the Asia Pacific that shape ethical relationships with the natural world? Are these anthropocentric, biocentric, ecocentric or cosmocentric worldviews? How do our worldviews allocate value and meaning to people, plants, animals and the biosphere? What are the relationships between such worldviews and actual decisions made by policymakers or the daily lives of the people they represent?

Visions and hopes of the future

What is the most appropriate timescale to consider problems of environmental ethics – years, decades, centuries, or generations? Is there a common vision of where we would like society to go beyond MDGs? How to balance economic growth, quality of life, and other future aspirations in a holistic vision?

Representation and who decides

What are the rights of nation states to decide on energy technologies for their people, when such decisions may pose an environmental or security risk to neighboring countries, to the region or to all countries? What are rights of provinces, communities and ethnic groups with regards to energy infrastructure in their geographic area?

Community engagement

How can we engage communities in the decision-making process? Are communities being given a chance to articulate their environmental values? Do communities have adequate access to information about energy technologies and their risks and benefits? What is the role of education in assisting communities to make decisions about their future? Are women and young people being engaged? What are the appropriate stages of an energy project for community consultation? Is there a trade-off between adequate consultation time and expedient implementation of a project? How can we develop the 'not in my backyard' view when it comes to large-scale energy

Invitation to Join Working Groups on *Ethics of Energy Technologies in Asia and the Pacific*

UNESCO Bangkok, on behalf of project partners (including the Ministry for Science and technology and the Ministry of Energy, of Thailand), invites interested individuals and organizations to participate in working groups for the Ethics of Energy Technologies in Asia and the Pacific project.

About the project

Energy is intimately related to our environment and use of its resources, as well as to almost every sphere of economic activity. As policy makers around the world grapple with climate change, choices about energy generation and consumption will have a significant impact on levels of greenhouse gas emissions and on environmental health, as well as people's ability to access energy to heat and cool their homes, travel, work and enjoy leisure time.

This project is not intended to duplicate the numerous meetings being held on energy and environment, but to open up ethical and value questions that have often been neglected. It aims to depoliticize discussions on environmental ethics to produce substantive cross-cultural and multidisciplinary outputs that will be relevant for long-term policy making.

The Asia Pacific region is experiencing the fastest annual growth in energy demand in the world and meeting this demand over the next two decades will be a tremendous challenge. As oil prices continue to climb, countries face increasing pressure to articulate their energy policies and achieve energy security. The ethics of all energy choices, including fossil fuels, biofuels, nuclear energy, fuel cells, renewables, etc., need be considered holistically. How will energy production affect the environment and other living organisms? How will rising energy prices affect the poor? What are our ethical obligations for consultation with local people? What are our ethical obligations to future generations and what vision for the future do we hold? Do environmental values held in Asian philosophical and religious traditions affect the sustainability of our relationships with our environment?

The project was launched in September 2007 with a three day conference at the Imperial Tara Hotel, Bangkok. Hosted by UNESCO Bangkok in collaboration with the Ministry of Science and Technology and the Ministry of Energy, Thailand, it was attended by a hundred people from about 20 countries, from many sectors and backgrounds, with a range of views on these issues.

About the working groups

Following on from the conference fourteen provisional working groups have been formed on the following topics (more details below):

- Universalism and environmental values
- Ethical worldviews of nature
- Visions and hopes of the future
- Representation and who decides
- Community engagement
- Stakeholder responsibilities
- Energy equity and human security

infrastructure? How can community engagement reflect the emerging paradigm shift from principles of paternalism through those of informed consent to informed choice?

Stakeholder responsibilities

What are stakeholders' responsibilities towards the environment and to future generations? Is a rights' based framework really appropriate for environmental ethics, when an emphasis on responsibilities may be more important? When regional or global consensus cannot be reached, do countries have a responsibility to do what is 'ethically correct', even if no-one else will? The group will articulate the responsibilities of scientists, policy makers (funding and regulation), the public (including consumers and non-consumers of different products), investors, companies, institutions, particular interest groups (e.g. geographically close to a power plant, occupational groups, faith groups), and other living organisms, as examples in a cross-cultural perspective.

Energy equity and human security

While energy generation supports economic growth and a higher standard of living, it also has financial and environmental costs. How do we reconcile the disproportionate consumption of energy by developed countries with increasing demand for energy in developing countries, and particularly across the Asia Pacific region? Is it appropriate for rich countries to encourage less developed countries to limit their energy consumption and shun luxury lifestyles? Is there a way for developing countries to access the technology and expertise that permits more efficient energy generation in the developed world? At the social level, should governments provide concessions to make energy more affordable and accessible for lower-income people? Do government subsidies for energy run the risk of subsidizing inefficient use of energy?

Cost-benefit analysis and economic constructions

How can environmental and cultural values best be incorporated into cost-benefit analyses for energy projects? What are the real costs of 'cheap energy'? What are the costs of any form of energy if we consider the opportunity costs of infrastructure construction or land surface area, and total energy costs over the lifecycle of a product, including waste, disposal and security?

Adoption & development of energy technologies (state of the art review)

This review of energy alternatives for local and national scale projects will focus on the ethical implications inherent in different research options for energy production and delivery. It will include development of innovation in new science and translational research, diffusion of technology, and energy diversity. It will also consider global networking and IT. It will analyze points of different alternatives.

Ethical frameworks for research agendas and policy

What criteria do policymakers use in deciding to adopt energy technologies, and how are ethical considerations taken into account? How should policy makers identify and employ the precautionary principle? How can they ensure appropriate gender-sensitive aspects in policy formulation from planning through implementation and impact assessment, emphasizing that women in a society are assets (UNEP) in environmental and energy management?

This group will examine the different understanding of ethical frameworks by looking at critical ethical issues including: codes of ethics for researchers, societal values, rights of all participants (stakeholders), rights of indigenous peoples, religious values, legal issues and take account of the conclusions of the specialized working groups above. After a review of all policies it will analyze the ethical frameworks inherent in the documents to draw up a model ethical framework.

Educational frameworks for environmental ethics

This working group will link to ongoing efforts to develop and test environmental ethics education materials and strategies with pilot trials. The topics link to the coverage of all the above working groups.

Nuclear dialogues

This group will look at the particular sensitivities of the nuclear energy debates from an ethical perspective.

Energy flow, environment, and ethical implications of meat production

Meat, as a food, is a form of energy for humans, but in order to produce enough meat to satisfy global demand huge reserves of energy are required in the form of feed, fertilizers, pharmaceutical production, transport and refrigeration. This group will examine the consumption of energy, particularly fossil fuels, in the meat production industry, and ethical implications for humans and the environment.

Water ethics and water resource management

The ethical issues associated with water resource management, including its uses in energy and other domains are a priority area in many countries. There are also issues over equity of access, ways to conserve water, and privatization of what many consider to be a common resource.

Erratum: Gabriela Marodin, Diana Monti Atik, Danielle Beheregaray Schulz, José Roberto Goldim, Risk Information Assessment in Pharmacological Projects, *EJAIB* 17 (July 2007), p. 109-112. The editor regrets that the captions for Figure 1 and Figure 2 on pages 110-111 were switched, and should be reversed. The on-line pdf version was corrected.

News in Bioethics & Biotechnology

<http://eubios.info/NBB.htm>

International Bioethics Education Project News

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

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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Asian Bioethics Association (ABA)

The website for ABA is <eubios.info/ABA.htm>

Conferences

A bioethics conference calendar website is: <http://www.who.int/ethics/events/en/>

For a list of some ethics meetings in Asia and Pacific: http://www.unescobkk.org/index.php?id=current_and_future_events
UNESCO-University of Kumamoto Joint Bioethics Roundtable: Self-Determination in Asia

15-16 December, 2007 University of Kumamoto, Japan
 Contact: Dr. Darryl Macer, Prof. Takao Takahashi

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