

**Abstracts Ibero-American Network IAB
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1. Laicism and right to choose at the end of life.

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Reflection on end of life is gaining force in occidental societies. The need to review the sad consequences of pretending the denial of death (neglect, suffering, and indignity that can be avoided), has been an influence to increase the conscience that, sooner or later, everyone will go through this unavoidable outcome. Something can be done to avoid unnecessary suffering and everybody can assume, for himself, the protagonist role at the end of his life.

No doubt, there have been important changes that have contributed to review the needs and rights of patients at the end of their lives. Regarding medical attention (which is the context in which most of the death occur in occidental societies), the paternalistic model has been gradually substituted (although with a lag in many countries) with a new one that privileges the autonomy of patients.

We can observe an increasing number of individuals who are concerned to guarantee for themselves the best possible scenario at the end of their lives. This includes not only the moment in which death occurs, but also the quality of life preceding that moment. Individual freedom must not be sacrificed at the end of life; on the contrary, the need to have this freedom may be crucial at this time. That is why it is important to back the right of an individual to choose at the end of his life.

Every patient has the right to receive the best medical attention when healing therapies are no longer effective; however, not everyone wants the same kind of care, even when they face similar illnesses. Therefore, the importance for them to have the right to choose on which medical treatment to receive and which not, but also, in exceptional cases, their right to ask to be helped in their decision to end their lives if this is the only way to put an end to insufferable pain.

For many individuals, to know they have this right represents the only way to give them a peaceful end of their lives. Other, maybe because their own beliefs do not allow it, will not accept euthanasia. This freedom to choose on very personal and transcendent decisions must be allowed in a lay society. It is inadmissible that religious influences prevent the right of others to take, freely, end of life decisions.

Key words: end of life, euthanasia, laicism, freedom

2. Restoring our humanity: the path for world peace.

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The objective of this study is to discuss the peace proposal presented in 2007 to the United Nations by the philosopher and pacifist Daisaku Ikeda. Despite the sincere and common desire of the peoples of the world in coexisting in a peaceful way, the irrational slaughter of the 20th century persists in this new century in the form of wars between nations and of terrorism motivated by questionable politics, economic and social motives or by organized crime. By using as maximum symbol of this anomaly the production and development of weapons of mass destruction, notably the nuclear ones, Ikeda analyses in its peace proposal the basic causes that lead humankind to oppose the basic right to life of its fellow creatures. Education in the major parts of the world has incited people to nurture a kind of "conscience of its tribe" instead of a "conscience of its species". This peace proposal claims for a deep reflection on the human nature and the role of the people of good faith in the transformation of this tough reality. According to Buddhism, human beings have an inherent destructive power (the state of anger). The function of this power is to annihilate our sense of human solidarity and to plant seeds of suspicion, conflict and hatred. In this sense, this negative condition makes us see other people, cultures and nature as insignificant things and can totally eliminate our concern for the lives of others. The social transformation and the creation of a more humane and positive society can only be realized if each individual improves its humanity. The innate wisdom and benevolence of the life of human beings can overcome the destructive actions of the state of anger. The correct reconfiguration of the negative functions in our inner world, through daily efforts of directing our attitudes (human revolution) toward a positive direction, is the basic element to put humanism into action.

Keywords: Peace proposal; human revolution; humanism

3. Bioethics in an International, Global, Multicultural Society: Some International Legal Aspects.

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It is said that UNESCO's Universal Declaration of Bioethics and Human Rights from 2005 is the way to enter into the international legal sphere of the principles of ethics based on human rights. This point is important since it could allow new subjects into the international legal sphere.

This is an interesting point and focuses a debate on at least two matters:

1. If bioethics is a universal value which must be guaranteed by international legal rules, one must seek the ideal way to guarantee it. The hypothesis we present is to consider ways in international legal systems to create and enforce rules and establish the most appropriate ones to guarantee bioethical principles universally.
2. Linked to the above, but of a different nature, and one that is treated differently, is the question of how international legal rules can provide answers to the growing problems of biomedical research and how this is applied in different fields. These are specific problems whose specific applications are at stake: protecting human rights (on different levels: civil, political, economic, social and cultural, and collective rights...); regulating copyright material; international co-operation for development and the current notion of international security, among others.

This study starts from the belief that the basic principles of bioethics and human rights together with biotechnology applications are clearly comprehensive inasmuch as one matter affects or could affect different spheres in international relations and also different subjects which should be regulated.

Bearing this in mind and using as a reference international legal texts linked to this subject, the potential will be assessed and, if necessary, the implicit nature of international legal systems to guarantee the effectiveness of the principles of bioethics based on human rights which adapt to the reality of today's international society characterized by globalization seen from an economic and multi cultural viewpoint and from a human perspective.

Keywords: Human Rights globalization international organizations

4. Sanitary information and active involvement of users

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Objectives:

- To identify active involvement of sanitary system users, in clinical decisions making that affects their health.
- To know the types of information that provides sanitary professionals.
- To identify which is the information that users expect to receive.
- To identify the use that users do of received information.

Methodology

A qualitative methodological approach was used, from semistructured interviews. The information was completed making two interviews to focal groups. A protocol of the interview was made and we prepare two nurses for the individual interviews. The groups were carried out by principal researchers.

Sample:

1. Women with breast cancer, between 30 to 65 years of age, with a disease evolution of one year; 10 for individual interviews and 5 for the discussion group.
2. Men with cardiologic problems, of hypertensive etiology, between 30 to 65 years of age, with a disease evolution of one year; 10 for individual interviews and 5 for the focal groups.
- 3.

Results:

The collected information is presented assembled in 10 categories: the process and obtaining information, the usefulness, the primary target group, the family participation, the informed consent, the qualities of a good informer, the aspects that difficult the information, the participation of the nurses, the role of assistance groups and the missing subjects.

Discussion aspects:

- People want to be informed and to be told the truth, in a sensitive and appropriate way.
- Family members have a role of accompaniment and therefore they need information.
- Is necessary to incorporate the information as an inherent part of all sanitary interventions and to consider the right to be informed as an aim of joint

responsibility among the different professionals either in clinical practice or management.

- It is important to work the personal qualities that promote and contribute to good information, helping professionals to overcome difficulties to carry out relationships that involve an emotional commitment.
- The ethical aspect of informed consent should be worked more thoroughly.
- To introduce the information in management criteria, specifying the sufficient resources.
- To consider that working as a team, that is a guaranty of good attention, may produce feelings of distrust in patients.
- To improve interrelation between sanitary world and no professional associations, with the aim of working as a whole information and assistance to people with health problems that involve high vital risk.

Key words; Patient autonomy, informed consent, trust, caring relationship, bad news

5. Bioethical Observatory: interdisciplinary locus for expert debate and knowledge transference for public understanding and dialogue

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What kind of communication and social dialogue models offers Bioethics to connect expert knowledge to society? Bioethics has been traditionally a reservoir to find, interpret and declare normative principles and assess universal declarations on the risks and benefits of advance research, clinical experiments and biomedical practices. However, the complexity of problem identification in relation to technoscientific innovations and social and environmental impacts impose new demands on public communication and dialogue to create civic co-participation –documents, popular juries, science shops- and its diffusion to media. So that this may also feedback into the expert system for project design and laboratory practices. Are noteworthy the institutional locus for Bioethics at major European universities, attached to research centers and scientific parks, the Bioethical Observatories act as observational systems to breach the gap between scientific and humanistic disciplines as well as faculties divisions and also to procure for the development of dialogue among science, society and media.

Keywords: interdisciplinary teams dialogue intercultural bioethics

6. Rethinking the ethics in journalism

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We are experiencing at the beginning of this millennium a new communicational paradigm. Information is produced in an instantaneous way, spectacular-like and globalized, increasing the risk of breaking ethical values which should rule over the information professionals. This study is part of a general explanation about ethics in the press and its correlation with Bioethics and Philosophy. Today, more than ever, the information professionals are vulnerable, as they need to work with complex and globalized themes that require reflective decision making. Nevertheless, are these professionals prepared to generate journalistically responsible practices?

To answer such a question, we carried out a research involving 100 journalists graduated from seven different brazilian universities. The objective was to evaluate what they think about the importance of ethical reflections, how much they know about this themes and whether their academic background was enough for the ethical practice at their profession. The research evidenced that the lack of ethical preparation of those professionals is overlooked, mainly, by the requirements of their academic formation which has not given proper relevance to such aspect of the profession.

Key words: Ethics, Bioethics; Globalization; Journalism.

7. Intercultural problems in health care. The Spanish Context

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Recent documents published by the Opinion Group of the Bioethics and Law Observatory at the Barcelona Science Park, University of Barcelona –as the result of consensus between numerous specialists from a range of disciplines- analyze intercultural problems arisen in health care in the Spanish Context: the patient's right to end his or her life under certain circumstances (euthanasia), the refusal of the Jehova's witnesses to accept blood transfusions in accordance with their beliefs and the possibility of health professionals to exercise conscientious objection even if this clash with the right of citizens to receive certain legally-established health service (for example voluntary termination of pregnancy or prescription of the morning-after pill).

However, at present, there is a movement towards promoting individual autonomy, which grants the patient the freedom to accept or refuse the procedures recommended by the physician-introduced by the General Health Law of 1986 and developed by the Law 41/2002 and deontological codes of medical practice-. Acceptance of this principle by health professionals is not uniform and may lead to situations in which the convictions of these professionals are given precedence over those of the patient if life-threatening circumstances develop.

What are the arguments in favour of euthanasia?. Under what circumstances? To what extent is euthanasia accepted by the general public? What is its exact definition? Who is involved? Should the domestic law contain provisions? Should the conscientious objection of health care workers be respected? Should the decisions of the Jehova's witnesses to refuse blood transfusions be respected even when they may put their lives at risk? How should this be done?. There are some of the issues addressed in these documents that wish to participate in the public debate raised by the recognition of the autonomy in health care and helped by globalization that opens a new space with new dilemmas to deal from an interdisciplinary and intercultural point of view, from an intercultural bioethics. Sometimes the proposals have the aim to encourage health institutions to arbitrate and adopt those measures required to avoid a lack of healthcare provisions in certain areas and the repercussions this may have. Sometimes the documents emphasize that the development of the right to take decisions concerning one's own health must also provide concrete contents to the provisions already in place. Conclusions and recommendations will be exposed, they give guidelines to face these challenges in health care nowadays.

Keywords: Intercultural Bioethics, Health care, treatment refusal

8. Scientific groups and their impact on legal regulations.

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One of the purposes of ethic committees is to enrich the debate about medical issues, to allow both society and professionals in health care to make decisions that are respectful of ethical principles and human rights. In order to do so it is important to have media coverage that allows the general public and both health care authorities and professionals to find out about the findings and recommendations issued by ethics committees. The ultimate goal would be to have an impact on legal decision-makers (legislators or judges). The aim of this paper is to present such impact of one particular scientific group in Spain, the Observatory of Bioethics and Law, especially as regards laws on assisted reproduction.

Keywords: scientific groups legal regulations

9. Importance of local contexts for justice in international research

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International research enrolling human subjects has raised an ethical concern regarding the just distribution of benefits between the countries that design the research and the host communities. Although several universal declarations have expressed this concern, a significant divergence exists between the design of the research protocol and the social context where it will be implemented. Many international documents have been created to regulate international research between developed and developing countries, such as the *Declaration of Helsinki*, the *CIOMS Guidelines*, and the *Universal Declaration on Bioethics and Human Rights*. These documents, however, are based on a normative approach to the problem and therefore many social, economic, political, and cultural aspects are overlooked. In the same way, studies of global justice based on human rights or on ideal theories of justice have given important ethical clues to the problem, but the local contexts have remained far from consideration.

Some recent approaches to global justice have a more inclusive and contextual character; they consider the distinct circumstances of the host community and they take into account the capabilities for action of the agents and institutions involved, as well as their limitations for change. These approaches view the human needs that affect human flourishing as a concept that must be understood in an integral way, by taking into account not only the economic circumstances, but also the social and cultural ones, or the so-called social determinants of health.

This work, based on some of the results of a research about just sharing of benefits in Multinational Multicentric Research Protocols realized in one of the largest public health institutions of Mexico, elaborates an approach to justice that takes into account the circumstances of the local context, in particular the social determinants of health in our Latin American countries. A more inclusive and contextual proposal for social justice in international research is made, based on a set of norms that is not simply limited to the duty of not doing harm, but also to the duty to help, so the research will effectively respond to the interests of the sponsoring countries as well as the great health needs of Latin America. The proposal intends to achieve in this way a more equal distribution of benefits among the participants of the research.

Key words: international research, justice, local contexts, Latin America, social determinants of health

10. Personal Point: Social Bioethics as a contribution to the world, from Latin America

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The place where Bioethics moves inside social sciences and technology is growing everyday and so becoming a great tool to move inside this matter with real certainty.

Since its first appearance in public in late 70's, as a bridge between different areas of knowledge, there had been so many progress and changes in the world that the newborn once in our hands is now a little girl that grows and grows and wants to know more and more everyday.

Of course Latin America has not been immune to this growing that seems to be logarithmic if we keep in mind that our strong matter is not biotechnology, but social sciences; a field that is frequently consigned to oblivion in the joyride of progress, because of her low rating in media, compared with subjects like abortion, in vitro fertilization, euthanasia or stem cells investigation.

The subject of human sciences as a "science" that permanently changes and whose rapid change could be quantified is a very rare concept in our environment, in which most effective measurement are those quantitatives but not those qualitatives, and all because the second ones take more time to be collected, are difficult to measure and translate to easy terms that can show their utility. Humanistic and social knowledge are more difficult to notice and so on, frequently forgotten and leaved out of the way.

Key Words: Bioethics, Latin America, Social

11. Proposal: informed consent adaptation to the cultural context

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Researchers and professionals who work on research projects with human beings must guide the informed consents in two directions: a technical one partly formed by research protocols as a basic requirement of ethics assessment, and another direction for contents adaptation for the use of non-informed participant communities.

The objective of this study is focused on the description of structures in documents of informed consent, proposed in twenty protocols present in the Chilean Metropolitan Area. An analytic descriptive method is applied with an emphasis on conceptual revisions and the qualitative examination of material. The material will be given an anonymous treatment eliminating names of sponsor, code and drug; each analysis will have its own assessment criteria.

The revision to the construction of the narrative technique in informed consents is carried out through text analysis.

The analysis of text comprehension in informed consents documents is conducted through focus group with members from the local community.

The results of this revision and analysis provide us with guidelines to carry out the application of informed consents from a technical point of view with a contextualised adaptability to people who take part in biomedical research.

Key Word: Informed assent, narrative Adjustment, Local Cultures

12. Fertility of different women in Spain: a not so large gap

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ABSTRACT: The shadow of a great gap in fertility comes again to the panorama of the population increase in Europe. People have been afraid of “Barbars”. The question of the proportion in natural increase of foreign population have been a “leit motif” in the last century in Demographic and other disciplines. Fear do not release in the number of members of a family; that means the quantity of children that foreign women can have in their lives, but in the long term consequences of this matter. The question that hurts susceptibilities is based in the proportion that new and future generations will have foreign fathers or origins.

Differential fertility; that means children borned of women of a certain population, have been defended and condemned equally. Even, conclusions of the principal researchs express contradictions in the final apportionment and results. If we pay attention to the methodological question, differences will arise obviously. A study on the fertility of foreign women living in Spain in comparison with the whole, will show the proximity of the results in fertility indicators. The principal difference that have been observed till the present, consist in the moment in which women have their children and not in the final number of them.

The aim of this paper is to measure fertility in the whole society and in the foreign women group that live in the country, in the same moment. The hypothesis considers the gap between measures of fertility is not so large as other not accurate indicators have showed in the near past.

To make the point, two methods are proposed. In one hand, the Fertility Survey of 1999 where the number of children ever borned for each woman are measured. In the other hand, the TFR (Total Fertility Rate) will be estimate from the last year that data is published. This measure show the number of children that a woman will have in their own life. That means that is a model to make comparisons, not a measure of the future and what could come. Finally, a methodological discussion is presented because each measure represent a different aspect of fertility. Women that lives in Spain are near in the final number of children ever borned (*quantum*) but not in the distribution on time, earlier or later, in their own life (*momento*).

Key words: Differential fertility- Spain-Foreign women

13. Following the tracks of the official speech, prejudices go...

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Is it possible to inform about new scientific findings without generating false hope among Persons Living with HIV/AIDS (PLWHA) and their loved ones neither increasing fear, risk behaviors, or discrimination among the general population?. Which are the interfaces between bioethics, jurisprudence and written press hidden behind the use of the language?

The existence of regulations does not necessarily imply that they are known or applied rationally or consistently. Much remains to be done in Latin America and the Caribbean to apply and adhere to those guidelines and statements that emphasize the need to avoid stigmatizing or discriminatory language when referring to HIV infection or PLWHA.

Achieve original knowledge since a perspective that “adapts” to the time, place and socio-cultural status of people claiming their rights requires responsibility, conviction, and constant monitoring regarding the consequences produced by certain actions and speeches in order to avoid a new category of vulnerability based on lack of concern and knowledge on a foreign language.

Key words: Very Personal Rights, HIV/AIDS, Vulnerability

14. Are there any differences of attitude among ovum donors from different nationalities?

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According to the data of the Spanish Society of Fertility between 15-20% of the Spanish couples, at reproductive age, undergo some type of sterility. An important factor resides on the delay of maternity, causing that more couples or single women go to the fertility treatments being in many cases necessary a procedure of ovum donation to obtain pregnancy.

Actually, the most frequent profile of the donors who come to our clinic to donate are of 18-35 years of age and are from Spain, Latin America and European East countries.

The main motivations that encourage these women to donate their oocytes are the following:

- Altruism: The women who donate by this motivation usually are the ones who already have their own children, that comes from reconstituted families, those who are friends of women suffering from infertility, who have had a voluntary interruption of pregnancy, which increases sensitivity towards the infertility.

European women seems to be related to the women who come from separated parents as well as with women who have had a voluntary interruption of pregnancy.

For Latin Americans, this motivation could be related to the fact that women already have children.

- Economic (students and/or women with low remunerations that need an extra economic contribution) : In case of European women, it can be related to the fact that there are more unmarried women in comparison with Latin American women.

- Both reasons giving preference to one or to the other independently.

These motivations differ depending on the origin of the donor, which give us some idea of the different attitudes that these women show with respect to the donation from a familiar, social and ethical point of view.

In this way, what has been concluded with reference to evaluation of the donors to be admitted in a Reproduction Centre, we should not only consider the clinical aspects like genetic compatibility and sanguineous group with the receiving ones, but also to evaluate the familiar and personal file, emotional support as well as other social aspects of the donor, that we think may produce a major adhesion to the treatment and a better experience of it.

In conclusion, the necessity of ovum donors is increasing as a result of the delay of maternity. The donors are from different nationalities which causes more genetic diversity.

Key words: Oocyte donation, motivations.

15. Bioethics and laicism (laïcité). Some references to the current situation in Mexico

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We are proposing a conception of laicism (laïcité) as a cognitive method in the individual sphere and as a democratic decision making method in the public sphere using discursive procedures. The secular State must fully embrace the sector in which the moral (values) dimension is preeminent, but most emphatically, the one regarding the religious dimension. In this sense, secular bioethics in the public sphere should incorporate the autonomy that the State has or should have in front of the religious doctrine and norms as well as respecting the individuals' privacy and freedom of conscience. Through out this paper the reader will find various recent examples in which the laïcité principle has been questioned in Mexico, as well as some possible solutions.

Key words: laicism (laïcité), tolerance, pluralism, democratic, freedom of conscience and privacy.

16. Language and reality in Latin America.

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From the ninetieth, it is considered politically correct to use a language that includes human rights and the bioethical principles of liberty and equity. This situation permitted to recognize the rights of minority groups like black peoples, women, youths, and people with incapacity. For the implementation of positive actions, these groups were unified by the concept of “vulnerability” that in fact was a new handicap. From another point of view, the fragmentation of these groups to study their characteristics, favored the evacuation of the discussions about their basic causes for the profit of considerations about their effects or secondary causes. For the governing people and for many bioethical organizations, equity is limited to partial solutions without a correct implementation because of lack of planning and joint actions with other public policies. They talk about human development, but public policies are designated for economic development and inequities are more profound. In this situation, Latin American bioethics is divided. In many countries, the biometrical model predominates in the investigations and ecology, and social bioethics is considered as political deviation. Under the influence of the North-American bioethics, these groups are centered in the problems of science and technology, and do not consider human rights as part of bioethics. In their analysis of bioethics problems, the application of justice and equity are restricted to the clinical field or to the health services. They are frequently localized in hospitals or in universities, and their proposals are palliative, as they cannot be applied out of these ambits, as they do not take account the situation of inequality in the country. At the same time, they refuse the global bioethics as philosophical concept and as part of economical and cultural globalization. The similitude of words is facilitating the confusion and is permitting to evacuate the discussion. But the utilization of this language by politics and the lack of its application in facts are producing more confusion that do not benefit to the Latin American bioethics.

Key words: language, concepts, facts, bioethics.

17. Challenges of an intercultural bioethics in the cultural transition

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This paper will enter upon an anthropological perspective about the different values given to the scientific and technologic knowledge on life, in the multicultural societies prevailing in our countries. For sure, in those aspects where believes or experiences on knowledge, and explanation on organic and inorganic life —as well as their control— become disputed. It is supposed that the said perspective must be entered upon the cultural change —the transition— which is based in the transformations stirred up by the contemporaneous world —as said by Hottois. Of course this is due to the increasing power of the techno-scientific intervention in the entourage of the organic life (cfr. Hottois 1991:170).

The proposal will be organized in two parts: the first, as an ample reflection; and the second, the corollary, as an open proposal. It would be an investigation question — consequent – hypothesis. Then the first would be the analysis of the reason for introducing the cultural dimension and some of its implications in bioethics; the second would be the concomitant factor: the introduction of the cultural dimension in bioethics, permitting judiciously to talk about the possibility of an intercultural bioethics. In substance, it is intended to channel the bioethic reflection to the question about the possibility for us to be understood ourselves, nevertheless being culturally and morally different.

In an early study about the cultural dimensions in bioethics, as an approximation to an intercultural bioethics (Zambrano, 2006), it was defined that *“the intercultural perspective of bioethics is an approximation to the proaction of the moral, ethic and techno-scientific phenomena permitting to understand, intervene, reproduce and transform the practices and the institutions committed in the administration, conduction, and restructuring of knowledge, sense and hypothesis on life”*. Such would be the anthropological vision of bioethics, which would be attached to the idea after which the ethical transitions are possible, due to the cultural changes (in meaning or belief) and to the relations with the administrations of sense in a society (renewal or transformation).

This work takes distance from those who relate the anthropological analysis with statements of indigenous and exotic experiences; and it also moves away from those who understand anthropology as a look for ontological human universals.

Key words: Intercultural bioethics, cultural transition, culture.

18. Who Decides? The Concept of Autonomy in Mexican Cancer Patients.

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Introduction

The current norm in medical practice entails shared decision-making between physician and patient. Grounded in the ethical principles of autonomy, the physician must convey to the patient the relevant information needed to make medical decisions, and has the obligation to obtain the patient consent to treatment. A valid consent requires three essential components: disclosure, capacity and voluntariness.

With the purpose to evaluate the patient's perception about the information provided to make an informed consent we conducted an investigation at the INCan in Mexico.

Methodology

An initial socioeconomic evaluation was obtained from 300 randomly selected electronic charts of patients seen during 2007.

Patients and relatives waiting at the hospital were invited to participate in focal groups' interviews using a semi-structured questionnaire. Thirty two patients and 16 patient-relatives were included, and four groups with eight patients each and two groups with eight relatives were conformed. After explaining the purpose, procedures and obtaining permission to tape the interviews, questions related to the information provided about their disease, treatment, prognosis were ask and each patient or relative was encouraged to participate, after a period of two an d half hours in average, final comments were allowed.

Results

Most patients admitted to the institution were had and average daily income of \$1.50 USD;, without a formal employment; 30% illiterate and 47% had six or less years of education.

The patient's concerns changed along with the disease. At diagnosis the main concern was: Will I be eligible to be treated at this institution? "the disease", how advanced it was, and the possibility of being cured. Patients being treated for longer periods were confused about the different types of treatments and concern about death. All the patients were grateful to their physician/s and consider that they had been informed and physician-guided-family decisions were the rule. Relatives had a clearer view of the disease and their main concerns were financially related. Complains about information, and lack of shared decision making was mostly expressed by relatives with long term treated patients.

Discussion

In the scope of cultural bioethics the provision of health cannot be structurally disengaged from the sociopolitical processes. Patients respond to illness and make health care decisions within a unique personal context shaped by culture.

This study shows that right to self-determination cornerstone of patient's autonomy in the West is different from the Mexican family-based decision-making.

According to these results, proper measures have to be implemented to guarantee a culturally - appropriated informed decision.

Key Words: Autonomy, Informed Consent