

BIOETHICS AT THE PAN AMERICAN HEALTH ORGANIZATION

Origins, development, and challenges

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Executive summary

Bioethics is the use of dialog for formulating and solving moral dilemmas posed by the progress of science and technology. Concerns about the survival of life on Earth and of the relations between medicine and the humanities were the origins of bioethical thinking. From a conceptual point of view it constitutes a *social process* governed by emotions, a *technical procedure* aimed at correct decision-making, and an *academic product* influencing scholarship. Since its establishment as a technical program at the Pan American Health Organization (PAHO), bioethics has contributed to the training of professionals, to the establishment of committees and commissions, and to the improvement of clinical, research, and administrative practices in the countries of the Americas and the Caribbean. The Bioethics Unit has established advanced programs in five universities, promoted research and advocacy initiatives, and sponsored courses and seminars in 26 countries of the region. After an analysis of its development and evolution, this report does not recommend professionalization of bioethics and proposes further actions to train professionals and researchers, a sustained effort to educate the public, and the assurance of independence from political or economic influences for the Bioethics Unit established at PAHO. The organization should retain its voice in the moral dilemmas and continue providing

not only *evidence-based* but also *value-based* knowledge to its users and all stakeholders in the health sector.

Introduction

The aim of this report is to draw attention to the characteristics and scope of bioethics, a field that has become essential in scientific research, health care and public policy formulation. The work of the Pan American Health Organization (PAHO), pioneer in establishing bioethics in the Region of the Americas and the Caribbean, will be briefly described and evaluated. As a consequence of this analysis, the relevance of bioethics for PAHO, the dangers of its absence, and the challenges for the future will be addressed in a set of recommendations.

Background

The meaning of the term *bioethics* has changed since it was first proposed by Van Rensselaer Potter and André Hellegers in the seventies of the XXth century. For Potter, bioethics was a “science of survival” that should help humankind prevent the ecological disaster pending on life on the Earth. His approach consisted in raising awareness about environmental preservation and the interrelatedness of all living beings. André Hellegers, a Belgian gynaecologist then at the Kennedy Institute of Ethics established at

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Georgetown University, proposed a link between humanistic thinking and the practice of medicine¹.

Both proposals aimed at creating bridges between the hard sciences, with their rationality and purpose, and those traditional concerns of philosophers and thinkers loosely included under the umbrella term “humanities”. This is particularly clear in Van Rensselaer Potter designation of the new field as “bridge to the future”.

The word bioethics seems to be composed of two Greek roots, one of them –“*bios*” – related to human life and the other –“*ethics*”- to custom, character, and human behaviour. This etymological derivation, however, does not indicate what bioethics is to-day and the activities of those who claim to practise it. In fact, bioethics has become a highly practical enterprise useful in *conflict identification*, *decision making* and *policy formulation*.

The importance of bioethics

Bioethics has gained wide attention in academic circles, in the healthcare industry, and in the media. Debates concerning cloning, stem cell research, euthanasia, abortion, end-of life decisions, contraception, to mention a few, are areas in which the public, the scientific establishment and the political leadership dispute over beliefs and decisions which affect the life of people. Scientific advances occurring in industrialized countries do not affect people in other parts of the world directly –for example, improving their quality of life– but indirectly, through their legal, ethical, and social consequences. Even the less affluent countries now pass legislation prohibiting cloning through nuclear transference (the procedure

which originated the famous sheep Dolly) but very few of them possess facilities with the technical capability of actually performing the procedure. Debates on the beginning or the end of human life become blurred by dogmatism from religious groups or prohibitions derived from tradition or popular belief. On the other hand, scientists are sometimes reluctant to have supervision on their work. They contend that the scientific community may suffer from limitations to creativity and progress if too many controls are exercised on its activities.

These and other facts indicate the need of appropriate institutions and procedures for making science and technology accountable to the public and relevant to the pursuit of knowledge and human welfare. Herein lies the importance of bioethics. Its application to these fields in the context of technical cooperation programs is the task of PAHO.

Process, procedure, product

In order to understand the burgeoning field of bioethics, it is useful to consider it in a threefold perspective: as social *process*, as technical *procedure*, and as academic *product*.

Social process

As a social process, bioethics grew out from sentiments aroused in the public by transgressions of human rights and welfare done in the name of science and medicine. It is not clear that the Nürenberg trial of Nazi doctors had the impact on public conscience historical reconstruction suggests. What is clear is that the so-called “Tuskegee case”, which became public in 1972, attracted wide attention. Starting in 1932, around 300 black individuals from Macon county, Alabama, USA, affected by congenital syphilis, were left untreated for about forty years in order to study what doctors call “the natural history of disease”. In the forty

1 Cf. Lolas, F. *Bioethics. Moral dialog in life sciences*. Santiago de Chile: Editorial Universitaria, 1999.

years elapsed since 1932, penicillin was discovered, the Center for Disease Control –a sophisticated institution for the study of infectious disease- was founded, several papers were published and many physicians did their training with those “cases”. Although many ethical considerations could be made, issues of voluntary participation, informed consent, confidentiality of records, racist discrimination, among others, have become subjects for scrutiny over the years.

This case aroused public interest only after a national newspaper carried the story and presented it to the wider public. Popular outcry was followed by government intervention and commissions were established, first to investigate, and then to take action. A practical product was the Belmont Report, outlining several cardinal principles that since then are used as signposts of careful medical research: *Respect for persons* (including autonomy and informed consent), *non-maleficence*, *beneficence*, and *justice*.

The Tuskegee case was not the only one which combined transgressions of human rights and popular coverage. However, its importance was so great that it has become emblematic of many others.

As a social process, bioethics started as a movement charged with emotions.

Technical procedure

However relevant the emotional origins of bioethics are, the next step was its consolidation as a procedure for making decisions that may affect people. The principles outlined in the Belmont Report were applied to clinical practice, to epidemiological and biomedical research, and to complex issues related to justice in the social field. A new social institution appeared, the “ethics committee”, in

which scientists, patients, doctors, lay people, and donors are represented. The purpose is to have all and every stakeholder in the process of creating knowledge and health sitting around a table and agreeing on purpose and activities.

This second stage in the development of bioethics meant a refinement of argumentative practices and the incorporation of philosophical traditions. Above all, it meant the rational use of dialog for formulating dilemmas and conflicts, for outlining the relevant moral principles, and for finding the most appropriate courses of actions depending on circumstance and goals.

As a technical procedure, bioethics became the rational use of dialog in the formulation, justification, and application of moral principles to science and technology.

Academic product

The development of bioethics led to its “commoditization” as a valuable good that institutions could offer in the marketplace. Research institutions, hospitals, healthcare systems began telling the public that their practices were informed by bioethical principles. International codes of ethics for the professions were seen in a new light. Training persons for participating in ethics committees or simply for being conversation partners in academia, industry, and policymaking became mandatory. Courses were offered, books were published, professional associations were formed, journals with exigent editorial boards were established. One important article in the eighties, reflecting on this development, summarized it with the expression “How medicine saved the life of ethics”. Its author meant to imply that ethics, a complex discipline usually considered the “practical side” of abstruse philosophical systems, had become a tool for formulating and solving practical issues.

As an academic product, bioethics enriched several areas of scholarship and opened new avenues for intellectual inquiry.

Forms of bioethics: discipline versus approach

Throughout the years, a persistent set of questions has been posed. Is bioethics a discipline? Should we convert it into a profession? Are bioethicists destined to be part of the scientific community? How can we evaluate and measure advance and progress in this discipline?

The answer to these and other questions has been yes in some quarters. People demand training because they want to be part of the establishment, earn money, and have power of oversight over research and clinical practice.

However important the transformation of bioethics from social movement to academic product has been, our contention is that it should not be viewed as another discipline or career to be pursued by a group of experts. If bioethical thinking is to have an impact on the sciences, on medicine, on healthcare and on public policies, it should be considered more an approach to the substantive areas in which it can be applied rather than an independent discipline.

This suggestion is based on two observations and one experience. Whenever a discipline becomes established and is converted into a commodity, its practitioners strive at the autonomy of their field. Instead of serving as an ancillary practice helping professionals and scientists, bioethics as a discipline may become entangled in its own development. Power struggle in the university environment, academic evaluation, productivity and concurrence may ensue without due regard to the true needs of the persons and institutions which led to its creation. The type of problems

addressed and work performed by the experts may well respond to their own agenda instead of being relevant to the pursuit of science and global public good.

The experience of the social sciences entering the field of clinical care is a case in point. Physicians permitted the incorporation of psychologists, sociologists and other professionals into their field but this led to a reduction in the critical potential of those disciplines confronting the medical establishment. Their practitioners started to wish academic recognition and were neutralized by their desire of academic power in the healthcare field.

In order to avoid lessening the impact of the bioethical discourse, with its emphasis on dialog and deliberation, it should better be considered an *approach* to different kinds of problems rather than a discipline in its own right. This means that instead of creating many experts, the effort should be directed toward enhancing “bioethical literacy” in researchers, clinicians, policymakers and political leaders.

Bioethics as part of international cooperation systems: The role of PAHO

In 1994, the Pan American Health Organization (PAHO), regional office of the World Health Organization (WHO), in association with the University of Chile and the Chilean Government, decided to create a regional program on bioethics. Its purpose was to serve the needs of the 38 countries and territories comprising the Region of the Americas and the Caribbean as they initiated processes of reform of their healthcare systems, improved their scientific infrastructure, and provided medical and sanitary services to the populations.

The PAHO initiative was simultaneous with the establishment of UNESCO’s International Bioethics Commission, created for tackling the

challenges posed by genomic research and the advance of knowledge in the biological sciences. In 2002, a similar unit was created at WHO Headquarters in Geneva, charged with ethics, trade, and human rights.

During the first years appropriate funding was secured for programs aimed at training a cadre of professionals conversant with bioethics in the region of the Americas and the Caribbean. Advanced programs at the master and diplomate levels were established in five universities, with more than 300 students in attendance, and short courses were delivered or sponsored in more than twenty-five countries, exposing more than two hundred professionals to bioethics concepts and procedures. Educational materials were prepared and distributed, including several books now widely used for teaching purposes. A virtual library in bioethics was added to the virtual library in health, a project jointly developed with the *Biblioteca Regional de Medicina*, BIREME, located in Sao Paulo, Brazil.

The initial period also involved legitimizing bioethics in the context of an international service organization. Some critics indicated that in view of more urgent problems, bioethics was in some ways a luxury and to some extent an irrelevant concern, given more pressing and urgent healthcare needs. To respond to this criticism it was necessary to demonstrate how bioethics could be applied in practice and be relevant to actual demands. The real demand that bioethics addresses is quality in the delivery of services, difficult to quantify but essential component of patient satisfaction and correct prioritization of policies.

Aside from training of professionals and opinion leaders in the health field, the Program also responded to demands of information and advocacy on the part of many groups and organizations. The staff of the Program, composed by two professionals, answered

queries and gave advice on matters of public policy and implementation of ethical guidelines. It began publishing a quarterly newsletter and a scholarly journal (*Acta Bioethica*), which in a few years became standard reading for Latin American and Caribbean scholars and practitioners. As part of its dissemination program, bioethical cases were also presented in the form of illustrated stories (comics) for young audiences, useful in the classroom, and employed in five countries of the Region.

Shortly after its establishment, PAHO bioethics program started collecting data on persons and institutions. Comprehensive databases on training opportunities, research projects, and publications were assembled, and surveys were published regarding biomedical publications, funding agencies, ethics codes, and relevant legislations.

With a limited regular budget but an efficient fundraising action, PAHO bioethics program positioned itself as a referent not only in PAHO Region but also in other parts of the world. Viewed in the context of the technical cooperation, the creation of ethics committees for research and clinical care, the establishment of national bioethics commissions, and the training of professionals have been priorities of the bioethics program. They have contributed to a qualitatively better administration of resources, to a widened concept of quality including ethical principles, to increased satisfaction among healthcare researchers and practitioners and to better information of the public about matters of general interest. Bioethics uses dialog to arrive at ethically sustainable decisions and challenges all and every belief, dogma or current of opinion to give answers to the pressing questions posed by science and technology applied to human affairs.

A summary of activities and products of the Bioethics Unit is presented in Table 1.

Table 1. Summary of activities and products of the Bioethics Unit

Courses	Publications	Interventions	Alliances	Other activities
Training / Specialization/ Curriculum development	Scholarly journal/ Newsletter/ Books	Response to inquiries / Establishment of ethics committees	Academic institutions/ Other agencies/ Industry	Advocacy / Surveys / Data bases / Public dissemination of information

In the context of the Region of the Americas and the Caribbean, the role of bioethical thinking and the practice of bioethical deliberation is particularly relevant. Some of the countries in this Region show the highest inequity in access to healthcare, poverty affects almost half of the population, and corruption of public services is a continuing threat. Political instability and the pervasive influence of transnational capital affect the continuity of governmental decisions. Professionals engaged in health care and health research tend to experience frustration and anger for not having enough resources for fulfilling adequately their role.

Some of the historical developments outlined above have taken place in some countries and with less intensity or salience in others. Bioethics has become a standard expression and institutions request advice and guidance. The establishment of national commissions and ethics committees is a good measure of the impact of the work of PAHO and other agencies. Better practices in research and cooperation also indicate the importance of bioethics.

Currently, the Bioethics Program is engaged in actions for quality assurance of the programs offered by academic institutions in Latin America and the Caribbean, establishes new educational and research programs in the less advanced countries of the Region, promotes the creation of facilities and helps interested parties to prepare research proposals for international funding agencies.

Recommendations and challenges for bioethics at PAHO

The Pan American Health Organization demonstrated by its pioneering effort to develop bioethics that it had identified a real need and responded to it in an appropriate form.

In order to continue fulfilling its role, PAHO should strengthened its presence by showing that it constitutes a knowledge-based organization that not only fosters the acquisition and application of relevant information but also that it cares about the moral implications of knowledge and efficient action. This can only be possible if it maintains a professional unit composed by respected practitioners in the field of bioethics and funds it adequately. A limited amount of resources should suffice as seed money for continuing the successful fundraising activity of PAHO bioethics unit.

It is not necessary to increase personnel or to hire permanent consultants. The relations between PAHO Representatives and the bioethics program are excellent and are an example of concerted effort to develop country-focused action. Specialized help is now available in the majority of the countries thanks to the action of the bioethics program.

When presenting programmatic documents, PAHO should show that it really cares about the ethical quality of the work it performs and the product it delivers. The bioethical outlook

provided by professionals trained in bioethics program can be of help in this regard.

PAHO without bioethics? An undesirable scenario

In fulfilling its mission of public service, the Pan American Health Organization has rightly interpreted one important need in the Region of the Americas and the Caribbean. However, in order to continue exerting a positive influence on research and health care, several considerations are necessary.

By establishing bioethics as a legitimate field of intellectual activity and source of guidance for proper action, the risk of creating a group of people convinced of their superiority in matters of moral judgment and in need of recognition is high. Professionalization of bioethics, as indicated above, is not our recommendation at this point in the development of the field. Training of professionals in bioethical deliberation and dissemination of its principles among populations are responses to this risk.

Education of the population is part of the bioethical enterprise. Since its fundament is dialog, individuals should acquire the capability of entering dialog. This implies a concerted effort on the part of experts, academic institutions, self-help groups, and public services. People must realize that health is a societal and personal construction aided by professional work. A well-educated community does not pose unreal

demands on the providers of services, is more informed and confident about its own resources, and develops a sense of solidarity that is a precondition for a good quality of life.

Bioethics at PAHO should continue and receive appropriate support based on the recommendations made above. Its presence in the moral debate and an increase in its visibility are justified on several grounds. Radical groups may use bioethics to sustain their arguments or disseminate particular beliefs. Industry may find bioethical arguments useful for backing up aggressive interventions rendering economic gains. Governments may employ bioethical discourse for legitimizing inappropriate or authoritarian practices. As a technical cooperation agency, PAHO guarantees expert neutrality in matters of common interest to minorities and majorities. It may help reduce the danger of misuse of moral arguments in the service of economic or political power. If bioethics is no longer part of PAHO message, an important voice would be missing in the debate.

The challenge ahead is to perform a service for the common good of the inhabitants of the Americas and the Caribbean that is free from economic or political constraints, that enjoys respectability among those whom it addresses and does not create an artificial distinction between those who know and those who ignore. Because in matters of health everybody counts, the aim continues to be "Health for all, by all, with all".