Comités de Ética Asistencial: de los grandes dilemas a los nuevos desafíos

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Abstract

Health Care Ethics Committees: from great dilemmas to new challenges

Scientific and technological advances have revolutionized the history of medicine. In this article, we aim to provide a brief analysis of the major ethical dilemmas that have emerged since the middle of the twentieth century as a result of technological developments, and analyze the way in which the first bioethics committees approached these issues. Beginning with the Seattle Committee and continuing to consider proposals regarding patient autonomy, we highlight the growing awareness of doctors and patients of new scenarios in which the patient-doctor relationship is no longer dyadic but has expanded to allow the participation of other actors.

Key-words: Committees. Bioethics. Scientific advances.

Resumen

Los avances científicos-tecnológicos revolucionaron la historia de la medicina. En este artículo, procuramos realizar un breve análisis de los principales dilemas éticos que han surgido como consecuencia del desarrollo tecnológico a partir de la mitad del siglo XX, así como focalizarnos en el estudio acerca de cómo han abordado estas cuestiones los primeros comités de bioética en el mundo. Empezando por la Comisión de Seattle hasta considerar las propuestas sobre la autonomía del paciente, se destaca la creciente toma de conciencia sobre los nuevos escenarios en que se desarrolla la relación médico-paciente, la cual paulatinamente ha dejado de ser diádica para dar cabida a la participación de diversos actores.

Palabras-clave: Comités. Bioética. Avances científicos.

Resumo

Dos grandes dilemas da medicina a novos desafios na promoção e proteção da saúde

Os avanços científicos e tecnológicos revolucionaram a história da medicina. Neste trabalho, propomos a fazer uma breve análise dos principais dilemas éticos que surgiram como resultado do desenvolvimento tecnológico desde meados do século XX e se concentrar em um estudo de como os primeiros comitês de bioética no mundo tinham abordado estas questões. Começando com a Comissão de Seattle até considerar as propostas sobre a autonomia do paciente, chamamos a atenção para a crescente conscientização de médicos e pacientes sobre novos cenários em que a relação médico-paciente se desenvolve, tendo em conta que já não é uma relação diádica mas tem sido estendida para permitir a participação de muitos novos atores.

Palavras-chave: Comitê. Bioética. Avanços científicos.

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The scientific and technological advances that began to emerge in the middle of the twentieth century, coupled with the significant advances in communications and computing in the last 20 years, have resulted in biomedical dilemmas that require highly complex moral decisions to be made. As direct witnesses to these dilemmas, hospitals and health care facilities understood that formal mechanisms are needed to address and provide answers to them. The creation of human groups under names such as committee, board, and commission, which would be responsible for dialogue, debate and reflection on the multiplicity of situations generated by medical advances, was therefore a logical development.

This article aims to review the origin of such Committees in line with the techno-scientific developments that have taken place since the 1960s and which have influenced the expansion and consolidation of bioethics up to the present day.

The great dilemmas of the twentieth century

Dilemma 1: Dialysis – 1962

The American doctor Belding Scribner Hibbard (1921-2003) was a pioneer in renal dialysis [1]. Scribner created a small plastic tube, which was placed in an arteriovenous fistula in the arm of Clyde Shields, and connected by a circuit to a machine – previously invented by Dr. W. Kolff in the Netherlands [2] – which could be connected and disconnected as many times as necessary. While this invention allowed Clyde to live for several more years, around 20,000 people in the USA, who also suffered from "terminal" stage chronic renal failure, had no access to this new technological scientific development, as demand far exceeded supply (nine beds) and the cost of the procedure was very high: $10,000 per year in the 1960s.

After the emergence of this new technique questions began to arise about the various and varied concerns that faced *doctors and institutions regarding situations and questions they had not previously imagined. Who should benefit from the new technique? Who would [determine] which patients would benefit and which would not, leading to an irremediable death? Twentieth century doctors were not ready for decision-making of this level. The skills, codes, and individual awareness of the Hippocratic doctor were no longer sufficient. The questions surpassed their knowledge and praxis* [3].

While dialysis can prolong life expectancy, access to this practice paradoxically entailed an obvious uncertainty of the future. Given the factual impossibility of one person making decisions involving the health and lives of so many people, the Seattle Artificial Kidney Center took the unprecedented decision of forming a group consisting of a pastor, a lawyer, a housewife, a businessman, a labor leader and two non-nephrologist medical specialists, who from their position as laypersons could provide evaluation on a case by case basis, taking into account the personal, social, psychological and economic situation of the candidates for the therapy in order to determine who would be chosen for hemodialysis [4].

The "Seattle Committee" was therefore the first such Committee in the world. On 9 November 1962, a landmark article by Shana Alexander entitled "They decide who lives and who dies" was published in the renowned Life magazine. The journalist has said that writing this article meant immersing herself in a fascinating topic that clearly evinced a growing dispute over how economic, ethical, legal, moral and social decisions should be taken. The publication of this article had such an impact that it was indicated as one of the three most significant events in the genesis of bioethics, along with the formation of the Hospital Ethics Committee in Seattle (in the state of Washington in 1962) and the first heart transplant performed by Christiaan Barnard in South Africa in 1967 [5].

The life of the Seattle Committee was cut short when the US Congress passed a law that provided universal coverage of this treatment. However, its deliberative, interdisciplinary and intercultural character was subsequently replicated throughout the world, but with a greater representation of "specialists" instead of laypersons [6]. During the administration of Lyndon Baines Johnson, who became US President following the death of John Fitzgerald Kennedy in 1964, the Civil Rights Act was passed, which prohibited any kind of discrimination in public establishments and businesses and institutions receiving federal funds. Johnson is credited with having said that the concept of "quality of life" is associated with equal opportunities. The concept of quality of life was popularized in the 1950s by an American economist, meaning that it appears to be linked with the economy: *the concept of quality of life comes from the manufacturing industry and is difficult to define for several reasons. Besides being a value judgment, it is a term used to define other terms* [7].

Dilemma 2: Heart transplants – 1967

The first heart transplants in 1967 posed a hitherto unforeseen problem: how to define clinical

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death. In 1968, the Journal of the American Medical Association (JAMA) published an article by an *ad hoc* committee of the Faculty of Medicine at Harvard University which examined the criterion of "brain death" [8]. In 1975, the request of the parents of Karen Ann Quinlan that the artificial respirator that kept their young daughter in a persistent vegetative state be disconnected generated a legal and social debate about the "right to die with dignity and in peace." It was with these words that the Supreme Court of New Jersey authorized the disconnection [9].

Dilemma 3: in vitro fertilization – 1978

The birth in the UK of the first baby as a result of *in vitro* fertilization and embryo transfer, Louise Brown, caused a revolution in the treatment of certain cases of infertility and also highlighted the need to refer to the "product" of that practice in a way that was descriptive but less stigmatizing than *test-tube baby* [10].

The possibilities that the techniques of assisted fertilization and embryo transfer represented posed great challenges, and the risks they entailed began to be envisioned for the first time. One of the main challenges lay in defining aspects of biological identity. The other important concept continues to be the establishment of the existence of the "human person" in the context assisted fertilization and embryo research. The "pregnancy substitute", also called "surrogate motherhood" and "womb for rent" has generated both support and rejection, while the phantom of "human cloning" is globally seen as a potential danger.

Dilemma 4: Congenital malformations – 1978-1983

A number of perinatal dilemmas – occurring between 1978 and 1983 – gave rise to the formation and consolidation of Healthcare Ethics Committees (HECs) in the United States. It can be said that, for the most part, HECs arose from a strong ethical motivation: the protection of patient autonomy, according to the legal requirements of the time, relating to informed consent of the right of patients (or persons with the right to make surrogate decisions) to refuse a particular treatment, even if the expected outcome of the exercise of this right to self-determination [11] is the subject's death [12]. But the most significant moment regarding the need to establish and strengthen HECs, with special emphasis on perinatal issues, seems to relate to the right to intervene that the powers of the State (in this case the judiciary) maintained in making decisions on the healthcare to be received by newborns with deformities.

With regard to congenital disorders, the first controversial case in the United States took place at the Johns Hopkins Hospital in Baltimore in 1963, when a medical team allowed a newborn with Down's Syndrome and duodenal atresia to die out of respect for the wishes of the baby's parents. The first paradigmatic case occurred in Bloomington (Indiana, USA) in 1982, following the birth of a baby with obvious features of Down syndrome and esophageal atresia. To survive, this newborn required a surgical intervention that would allow him to be fed. However, his parents rejected the recommendation of such treatment and after six days of starvation the baby died. In this short space of time and faced with the refusal of the parents the medical team treating the baby continued, without apparent success, to seek the intervention of the courts in the case that was known worldwide as *Baby Doe* [13].

A year later, the US Department of Health and Human Services sought a ruling that, as an instrument of evaluation, was intended for use in the treatment of children with disabilities (physical or mental). It also proposed the direct intervention of the State in these type of cases in which decisions prove complex and highly controversial [14]. The American Academy of Pediatrics (AAP) responded rapidly, and Infant Bioethical Review Committees were created.

A second similar case occurred in the USA in October 1983, which once again dealt with the birth in New York of a child known as Baby Jane Doe. In this new case, Jane had a multiplicity of "defects": spina bifida, microcephaly, hydrocephalus and severe neurological disorders. The medical team suggested that the clinical profile of Baby Jane Doe could be reversed considerably if she was immediately subjected to surgery in order to avoid infections. Her parents, however, refused the intervention and opted for more conservative treatment, understanding that although new infections would be prevented, nothing could be done about the basic medical profile of the child (congenital malformations). A Court ruling noted that the surgery in question was vital and therefore should be carried out, but the verdict was overturned by the Court of Appeals of the State of New York. The girl was taken home without any surgical treatment [15]. This situation demonstrates the tension between a collegial, deliberate and flexible decision and the legal perspective of a Court based on a legal rationale with formal support, and which can be exegetical.

In February 1984, the Department of Health and Human Services of the United States ordered the

investigation of parental decisions that denied treatment to infants with disabilities. A telephone hotline was created to report cases of neglect in which the involvement of the parents of a child could be inferred. On May 23 of the same year Judge Charles L. Brieant of the district of Manhattan stated in a summary judgment that the federal rules known as the Baby Doe Rules were invalid and illegal, and should be set aside due to the fact they violated the medical duty of *confidentiality* and the *right of parents to privacy*. The judge was responding to the demands of the American Medical Association (AMA), the American Hospital Association (AHA), and many other scientific societies. This decision, partially accepted by the US Department of Health and Human Services, offered freedom in decision-making in hospitals that possessed an institutional childcare review committee [16].

In the United States, the Department of Health and Human Services (DHHS), the former Department of Health, Education and Welfare (DHEW) and the American Academy of Pediatrics, recommended the creation of bioethics committees in hospitals, for the study of ethical issues in neonatology, case reviews, the teaching of medical personnel and the development of institutional standards [16].

Dilemma 5: Decisions in patients without autonomy – 1980

In 1980 a Commission [17] created by Jimmy Carter, then President of the United States was formed, with the aim of reporting to Congress on the question of a uniform definition of death. In July 1981, the Commission finally presented its findings on "Death Definition" and recommended the adoption of the Uniform Definition of Death Act, which was developed in collaboration with the American Bar Association, the American Medical Association and the National Conference of Commissioners on Uniform State Laws [17]. During this project, the Commission noted that many people were concerned about the uncertainties relating to the proper care that should be provided to patients with severe deficiencies in the higher brain functions. As a result, they produced a report recommending committees created within hospitals to make ethically correct decisions in cases of mentally incapable and unconscious patients and critically ill newborns [18]. There were three options relating to the controversy over decisions in the case of the third category:

a) the therapeutic options applicable to a particular baby should be agreed between the parents of the child and the treating medical team [15];
b) implement the intervention and direct control of the State in issues affecting the private sphere, to prevent any initiative that would result in little or no possibility of life to a newborn;
c) refer cases in which controversy exists to the Courts.

New challenges at the beginning of the twenty-first century

The twenty-first century has brought new technologies, therapeutic alternatives, and uncertainties. These include reflections on the new dilemmas that have arisen around post-research benefits in the protocols of pharmacological, pharmacogenomic and pharmacogenetic studies; on excessive population growth and migration, with the correlative economic and political questions over who should take charge of the access to health care of "foreigners"; on decisions related to climate change and avoidable natural disasters which in turn affect aspects of health; on research in neuroscience, which has to a subspecialty in "neurobioethics" and its possible link with potential thought control and manipulation of the decisions of societies.

There are also other questions that could be raised:

- Could indiscriminate coverage of assisted fertilization techniques by healthcare benefit systems lead to their collapse in the medium term, considering the large demand and the high cost of the procedures?;
- Do patient databases exist for epidemiological, discriminatory or profit-based purposes?;
- Is it correct to use the potential extension of the life expectancy of a person to recommend continuous hemodialysis, while knowing that this could affect the patient's lifestyle and life projections, condemning him or her to be connected to a machine to survive, without which death would be inevitable? What is the cost – beyond the economic – of subjecting a person to a life that is dependent on a machine? What is the psychological impact of being a member of a group that gradually reduces in size, where one ceases to be a "patient" and becomes instead a "survivor"?;
- Is the establishment of databases and biological samples (including genetic data) aimed at determining, in the medium and long term, possible associations between disease and indicative

markers or to deny health coverage to those who suffer from certain diseases?

Final considerations

Based on the dilemmas discussed and the alternatives presented the growing importance of hospital ethics committees in assisting health professionals in decision-making in critical or complex situations can be seen. Despite this phenomenon, however, final decisions are frequently taken by the hospital authorities and/or by persons from the legal field, who are often far removed from the deliberative, dialogical and plural environment that the exercise of ethics and bioethics require.

And while the intention of such decisions was to recognize that healthcare practitioners could operate in such an important area of activity, subsequently established in both the Presidential Commission document (1983)[18] and the American Academy of Pediatrics declaration (1984)[5], the mere citing of such statements or principles is insufficient when considering concepts such as human beings, life, death, vulnerability, quality of life, non-discrimination and respect for persons.

The facts analyzed and the emergence of concepts that supported practices in which it was intended to "save the patient" through the technological imperative and/or the therapeutic furor, demonstrated by the progress of the so-called techno-sciences. This illustrates the need to deliberate on dilemmas and ethical and medical problems as the health professional alone and in isolation cannot, should not and should not want to act in a paternalistic manner for several reasons: the emergence of the Patient's Bill of Rights (1972) in the US, the increasing criminalization of medical activities as a result of "defensive medicine" practices[19], and the requirement in modern law to respect the will of the patient.

In summary, *an ethics committee analyzes, thinks, talks, reviews, compares, contrasts and values. Value is not the same as judge*[20]. Consequently decisions made within this framework will tend to involve an interdisciplinary dialogue and intersectoral deliberation, contributing to the fields of both healthcare and research, to: ensure that individuals fully understand the potential risks and benefits to which they are exposed; avoid duress, coercion, undue influence or seduction; ensure no harm is done and thus the potential benefits are maximized and exposure to potential damage is minimized, providing fair and equitable treatment to all individuals and groups[21].

Finally, there is a growing awareness among doctors and patients of the new scenarios that surround the clinical relationship, in which the connection is no longer merely dyadic but instead involves the participation of many people. The presence of so many actors who, in one way or another, are involved in the decision-making (clinical or research) process leads us to believe that *due to the absence of applicable rules in Positive Law, the remaining guidelines demonstrate failings in their texts and difficulties of interpretation which prevent or at least hinder their proper application*[22], representing an important reason for articulating the current regulations in the context of practical reality, with special emphasis on the here and now and the individual characteristics of the recipients. *Biological and pharmacological medical progress in recent years, along with the development of new technologies for clinical application, have forced health care agents to develop their sense of social responsibility and alerted the public about these new powers which represent progress for human life and quality of life*[23].

Being part of an ethics committee generates obligations and responsibilities (even in the case of *pro bono* work). Ultimately, these Committees must take up the challenge of promoting ethical awareness by fulfilling their educational and advisory roles, encouraging the qualification of all their members in terms of values, skills and attitudes. Only the interdisciplinary, inter-sectoral and inter-generational dialogue within a Committee will allow, after a comprehensive, respectful and transparent democratic debate, shared decision-making to be achieved. Such decisions, if prudent and contextualized in time and place, will mean not only avoid having to resort to the judicialization of medical consultations, but also will gradually modify the widely-held idea in the vast social centers of Latin America that the only mission and vision of a bioethics committee is associated with its regulatory role.

Ultimately, Ethics Committees today face the challenge of promoting ethical awareness and social responsibility, given that techno-scientific progress must be based on the *recognition of the dignity of the human person, and the universal respect for and observance of human rights and fundamental freedoms*[24].

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