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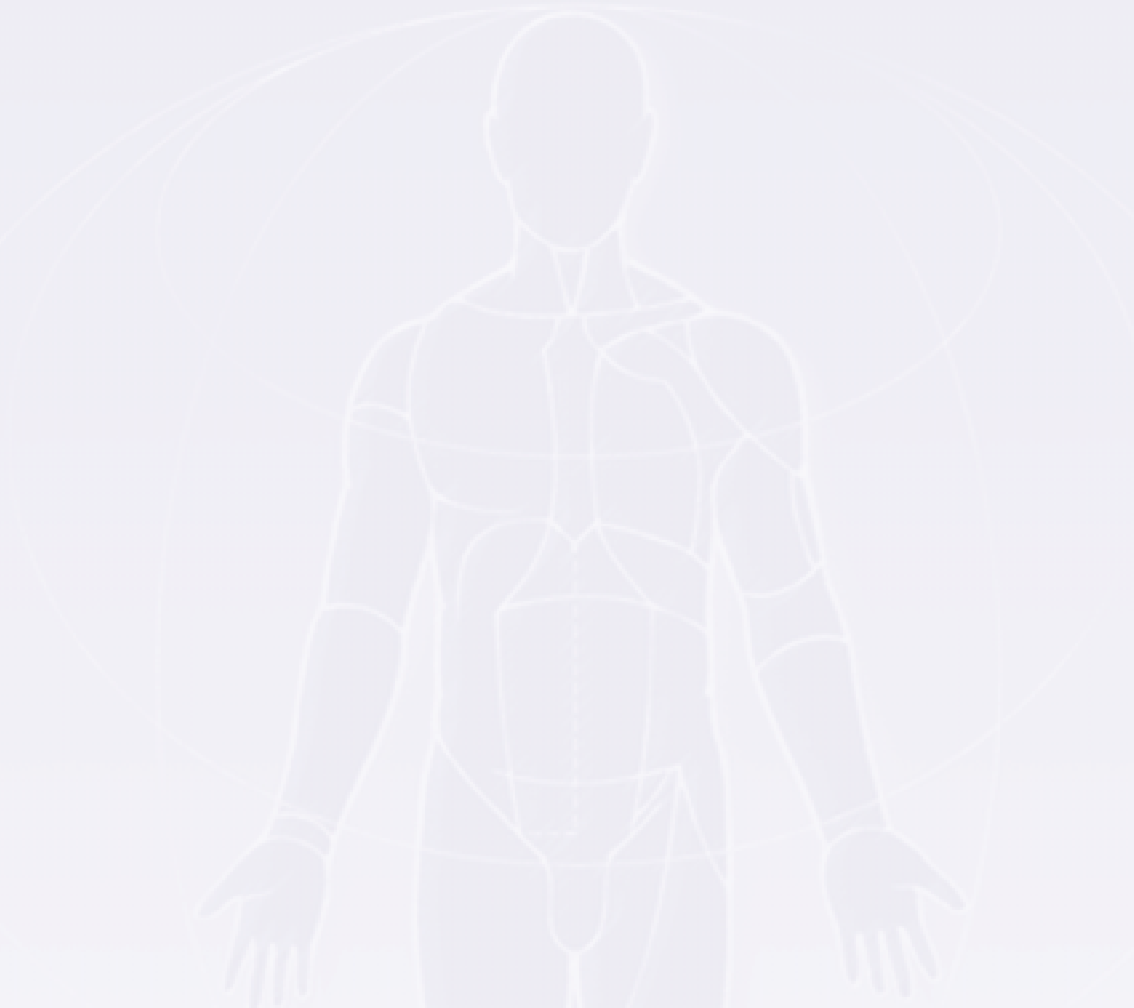

SUMMARY

PRESENTATION

The Víctor Grífols i Lucas Foundation came out in November 1998 at a ceremony which included the three lectures that make up this volume. Besides, this is the first release of a series of bioethical papers initiated by the Foundation itself. The boosting and encouragement of research and training in Bioethics is still a task in its infancy among us which, like so many other things, we have started by tapping the sources from other places that are scientifically stronger and more pioneering. To achieve an international standardisation in such matters and, above all, to stress the fundamental role which bioethics is to play in many of the conflicts posed to us by human life is the Foundation's main objective, which stems from a basic idea: that ethics are not just a must of all times, but that keeping them in mind makes sense both socially and economically. This is the conviction that encouraged Víctor Grífols – father and son – to take the initiative to create the Foundation that bears his name: self-demand and great care for the quality and safety of the products – ethics, in a word – are not at odds with each other but, rather, favour efficiency and the success of any company.

Freedom and health are two primary values of our time. We live in liberal democracies that worship individual liberties as people's primordial right. Health, for its part, is one of the basic assets that the welfare state is duty-bound to guarantee. But it must do so while respecting the freedom of the individual. The social right to health protection must today be seen from the perspective of changes introduced by new technologies. I do not think it either pessimistic or far-fetched to think that these are at the same time a hope and a threat to the autonomy of people who are not always willing to submit themselves to technological breakthroughs of uncertain outcome as seen from the point of view of the their own well-being. Technology must be at the service of human beings and not the other way round. On the other hand, implicit pluralism in liberal democracies often clashes head on with the ideas we have on what it means to be healthy, ideas that have been more or less forced on us by the opinion or the policies of the majority. The diversity of opinions, religions, experiences and situations calls for a continuous and uninterrupted debate as the only way to reach shared decisions without, at the same time, failing to respect the differences and discrepancies between one and the other. The patient's autonomy has to find a way to fit in with that of the healthcare professional in a single search for what has all too ambiguously been called "the common good"...

The fact that there are diverging criteria as to the most suitable way of solving the new problems, or acknowledging the lack of equally satisfactory replies for everyone, does not exempt one from having to take decisions that will solve the challenges posed by scientific and technical discoveries or the need to set up a public health system. Research and healthcare must establish priorities, resources must be allocated to health on an equitable basis and there has to be a basically shared opinion as to the value of technological innovations. Bioethics is the discipline that intends to theoretically approach this host of questions and to establish a suitable framework for a public debate which will not hinder but rather be a guarantee for progress. Many centuries have gone by, yet the first Hippocratic aphorism which, in some way, is the basis of, and at the same time, the first ethic code still applies: "Life is short, art is long, the occasion fleeting, experience uncertain, judgement difficult. It is necessary to do not only what we have to do, but also that the patient, those present and the external circumstances contribute to making it so." That is, ethics – to do what one has to do – is an endeavour only achievable through co-operation, because the questions are complex and all parties involved should contribute not just to finding solutions but, especially, to finding sound approaches to problems. Only through co-operation – or, if you prefer, through real democratic participation – will it be possible to clarify and make it clear to ourselves what value we wish to give to human life. Only if everyone co-operates can the freedom of the individual be respected.

The authors of the three present essays consider the relationship between individual liberties and the public concept of health from three different angles. Hugo T. Engelhardt confronts what he calls the danger of a "lay religion", a new kind of Puritanism that stems from the endeavour to promote health for everyone in a homogeneous way. The harassment of smokers, the obsession with keeping fit or following a healthy diet, sex without any risks, the propaganda in favour of frequent medical check-ups may be, in all cases, a double-edged sword and may respond not just to achieving a common good, but to a trend in society or politics to standardise behaviours and thereby to control them better. Engelhardt insists on social pluralism: the hierarchies of assets and risks are not unanimous and therefore neither is the conception of health. Faced by this diversity, the last thing the state should do is to standardise and impose a single point of view. In democracy, it is the individual who has moral authority.

Stefano Rodotà approaches the relationship between freedom and health from a legal angle. Health legislation not solely aims at guaranteeing the fundamental right to health protection, but to do so by safeguarding at the same time the individual's sovereignty over himself. The world today puts the physician and the patient in a position of having to face a series of questions that have been labelled as "tragic choices". Still, belonging to these question marks, for example, there are most of the questions we currently ask ourselves about genetic information, questions that need to be answered combining two values that cannot be relinquished: the dignity of each individual and the solidarity among people. Increasing the ties of solidarity among citizens, who cannot live like atoms within society, should not, however, mean exercising a greater control over them. It is Rodotà's contention that the so-called "biorights" should mark the development of jurisdiction contributing to establishing the meaning which freedom should have with regard to questions related to bioethic information mentioned earlier, and others no less worrying such as assisted suicide, prioritised patients, compulsory treatment for contagious diseases or the right to free health protection. All of these pose questions that can only be dealt with from the balance that must exist between the indisputable right to health protection and the individual use of freedom.

Finally, Marcelo Palacios reflects upon the physician's freedom. A freedom – he states – that needs to co-exist with that of the other's and, in this case, with that of the patient's, whose right to autonomy has become one of the most developed principles within bioethics. Skilfully mixing the theoretical approach with a series of considerations derived from his personal experience as a physician, Marcelo Palacios refers to the different forms of freedom which the doctor has to make his own: ethical freedom, freedom with regard to law and freedom with regard to practising a profession where doubt and even mistakes need to be accepted if one also accepts contingency and human limitations. To be free is to be responsible and to be both things one has to be above all humble, to contribute, when all things are considered, to demystifying and not placing the physician's power on a pedestal.

It is probably true that human rights are but aspects of a single and fundamental right, namely the right to freedom. Nevertheless, liberties in a democratic and plural society are not an absolute right: they need to answer to some kind of order and organisation, if not, co-existence is impossible. Bioethics may be fully understood as the endeavour of trying to find this order or balance between the individual, his idea of well-being and his private interests, and an idea of the minimum values which need to be shared and acknowledged to be able to live in community. An order built by combining at least the three perspectives of the present lectures: ethical, legal and professional.

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HEALTH, MEDICINE, AND FREEDOM:

A Critical Assessment

H. Tristram Engelhardt, Jr., Ph.d., M.D.

An Introduction to a Temptation: Nationalizing Health

Health, medicine, and freedom are bound in a complex dialectic. Medicine can help liberate us from the forces of nature. First, medicine brings health as liberation from nature's surd threats against our well-being. Second, medicine burdens us with new choices about how to face our finitude. We are by medicine rendered free in the sense of being scientifically informed and technologically empowered to decide about our health in the pursuit of our well-being. Since we will all die and we have only limited resources for decreasing the risks of suffering, disability, and early death, the pursuit of health confronts us with choices regarding our own destinies. The pursuit of health brings us to shoulder the responsibilities of moral agents who must frame health care policy choices about their own well-being. In addition, the lure of health, along with the costs of health care, gives substance to a secular religion of health promotion. This in turn can engender a new puritanism of wholesome living. This puritanism can obscure the diversity of values regarding human well-being and thus threaten freedom.

Health as both a negative notion of freedom from suffering, disability, and early death, as well as health as a positive ideal, are set within value-conditioned expectations. Health as successful adaptation can only be explicated by specifying the goals of adaptation, along with the appropriate reference environment[1]. Since all attempts to be successfully adaptive, to minimize suffering, disability, and to postpone death, are made on the basis of probabilistic knowledge, the pursuit of health is conditioned by different propensities, inclinations, or choices to assume risk. Further, there is a propensity to medicalize problems, thus also encumbering human freedom and human responsibility. In short, medicine's pursuit of health liberates us from nature, imposes new choices on us as free agents, while threatening us with a secular, health-promotional puritanism and an uncritical medicalization of human woes.

Health as a state of liberation from the surd and hostile forces of nature is appreciated within a global culture sustained by medicine. We live in large urban areas such as Barcelona and Houston without fear of frequent

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[1] H.T. Engelhardt, Jr., *The Foundations of Bioethics*, 2nd ed. (New York: Oxford University Press, 1996), chapter 5.

epidemics, not only because of public sanitation, but also because of our technologically mediated abilities to convey active immunity through immunization and effectively maintain uninfected water and food supplies. Immunizations and pharmaceuticals have made the lives of each of us different. Many who read this essay have had operations impossible only a few years ago. Many have had their live saved by medicines unavailable only a few years ago. Medicine has made us free to live in large cities. Medicine has freed us from many concerns about disease, disability, and early death, allowing us to plan life projects with greater security about their realization than was ever possible in the past. Our experience of this relative security is integral to how we regard such human endeavors as professional careers and vocational projects spanning decades. As already noted, this success brings new challenges. Out of considerations of cost containment, we must determine which high-cost, low-yield protections against suffering, disability, and early death should be foregone, as a part of society's basic commitment to health care. As members of high-technology cultures, we are called to fashion policy about how to face our finitude. Since increasing health care investments will only postpone but not avoid death, and since all choices are probabilistic in their nature, health care policy has the character of a free choice about how to gamble regarding the suffering, disability, and early death of society's members. Given our limited resources and the limited character of our knowledge, we must prudently wager with our health in the pursuit of the goods we take to be important.

These choices are further morally challenged by the circumstance that individuals and communities have different attitudes towards risk-taking as well as different orderings of values and harms. This burden of free choice can only be blunted by attempting to slow progress, rather than responsibly to confront choices in the face of finitude. If we take finitude seriously in recognizing the limits of our resources and knowledge, these circumstances have significant implications for health care policy. Moreover, if we take seriously the diversity of human views regarding well-being, this will lead to inequalities in health care and to outcomes many will find tragic in the sense of unwise. This will be the case, for if society respects free choices and if individuals as well as politicians are guided in their choices by a variety of visions regarding appropriate values, there will be different approaches to risk-taking. Consequently, individuals and communities will ensure themselves against risks in different ways. Given particular adverse outcomes, the result will be that some will be protected and others will not. This moral state of affairs is at tension with many cultural forces that incline to a uniformity or equality of outcome. In addition, such policy choices must be made against the background of the emerging centrality of the pursuit of health in our cultures.

The Physician and the State: Nationalizing Health

Over the last half century, investment in health care has taken an ever-increasing proportion of the gross domestic product of most countries[2]. At the same time, most governments have become more involved in paying for health care. Health care has become a major element of public policy, and the maintenance of health an area of broad political concern. The 20th century has witnessed the socialization and politicization of health care. State involvement in health care has become prominent during a period of remarkable scientific and technological progress. For example, over the last four decades, critical care units have emerged as an ordinary part of hospital care. Transplantation has become routine. Intricate forms of coronary surgery have become well established. New and sophisticated drugs are now available to cure disease and to maintain health. We appear on the brink of new breakthroughs mediated by genetic knowledge that promise the better maintenance of health.

In the course of these developments, medicine has been transformed from an art practiced by individual physicians to a scientific collaborative endeavor within high-technology cultures. Health care is now considered a public good to be supported through public resources. It promises to transform our lives through moral scientific insights and technological interventions that offer new security against disease, disability, and premature death. All of this has given medicine a cardinal prominence in most societies. The pursuit of health has been nationalized in the sense of being made a central item of the public

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[2] G.J. Schieber, J.-P. Poullier, and L.M. Greenwald, "Health Spending, Delivery, and Outcomes in OECD Countries," *Health Affairs* 12 (Summer 1993): 120-29. Richard Saltman and Josep Figueras, "Analyzing the Evidence on European Health Care Reforms," *Health Affairs* 17 (March 1998), 85-108.

agenda. Individual behaviors with health consequences have become matters of public concern. A wide range of behaviors are medicalized in the sense of being made the focus of health care professionals. Matters ranging from smoking, drinking, diet, and sexual behavior to domestic violence and criminality have become nested within the province of medicine. Physicians have been transformed into agents of public health care policy, health education, and police authority.

Given the scope of medicine's societal prominence and the force of governmental interests in health outcomes, it is essential to place aspirations to health care promotion in perspective. Although the freedom of patients is enhanced with better information concerning the health consequences of their behaviors, this increased knowledge invites constraints on behalf of individual health in the service of limiting societal costs. Free societies, given the limits of their moral authority, must strive to leave space for deviant choices. There must also be honesty about the actual costs of such deviant behaviors: at times leading a less wholesome life will on sum save money for a society. It is not enough to secure the role of free and informed consent, so that would-be patients can decline unwanted health care interventions. There must in addition be an appreciation of the value-conditioned character of concepts of health, as well as of how different rankings of goods and risks will lead to different understandings of the proper pursuit of health.

Health promotion as a public obligation has deep roots. The idea of medicine as a servant of society and the state became salient with the modern era's turn to secular moral rationality. In the 16th century as the new sciences emerged, modern anatomy took shape, and the promises of medicine for society became alluring. From Giovanni Codronchi's *De Christiana ac tuta medendi ratione* (1591)[3] to Rodericus Castro's *Medicus politicus sive de officiis medicopoliticis* (1614)[4], there has been a growing sense that a rational pursuit of health supports the common weal. In the Enlightenment, this societal pursuit of health was placed under various rubrics, including "medical police". Individuals such as Wolfgang Thomas Rau (1721-1772) argued in favor of the

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[3] Giovanni Codronchi, *De Christiana ac tuta medendi ratione* (Ferrara, 1591).

[4] Rodericus Castro, *Medicus-Politicus: sive de officiis medicopoliticis tractatus* (Hamburg: Frobeniano, 1614).

moral and social duties that physicians should recognize to society's health[5]. An influential synthesis of this view was Johann Peter Frank's *System einer vollständigen medicinischen Polizey* (1777)[6]. The result was a view of medicine as central to a well-ordered society. The state's police authority was then enhanced when it acted plausibly to limit risks to health. However, this faith in the promises of medicine was often exaggerated.

The social promise of medicine was integral to developments in urban hygiene that made cities secure from plagues by safe air, water, and food supplies[7]. Over the 18th, 19th, and early 20th centuries epidemiology acquired knowledge of contagious diseases, which has made life in large-scale cities possible without the threat of regularly recurring, life-endangering plagues[8]. This produced a revolution in human habitation. The world we live in today offers a level of security against unanticipated disease, disability, and death radically unavailable in the past. These changes establish cultural centrality for the biomedical sciences and technologies and for health promotion.

With Success Come Temptations

Most human virtues bring new temptations. The very success of medicine in preserving health suggests that the pursuit of health through medicine and health promotion is a moral obligation that should be enforced by the state. It is such temptations that are the focus of my critical attention. They mark the

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[5] George Rosen, *From Medical Police to Social Medicine: Essays on the History of Health Care* (New York: Science History Publications, 1974); Carlo Cipolla, *Public Health and the Medical Profession in Renaissance Italy* (New York: Cambridge University Press, 1976); Richard Shryock, *The Development of Modern Medicine: An Introduction to the Social and Scientific Factors Involved* (Philadelphia: University of Pennsylvania Press, 1976).

[6] Johann Frank, *A System of Complete Medical Policy* (Baltimore: Johns Hopkins University Press, 1976; German original, 1777).

[7] Max Pettenkofer, *Zur Frage über die Verbreitungsart der Cholera* (Munich: Cotta'schen, 1855).

[8] René Dubos, *Man Adapting* (New Haven: Yale University Press, 1965).

emergence of a new secular Puritanism dedicated to realizing a healthy population. First, one must recognize that the pursuit of health can easily be transformed into an all-encompassing ideology or secular religion of health. After all, the allure of a state committed to health promotion is powerful. Health maintains us in this life and preserves our unimpeded grasp of it. In a post-Christian age, when this life is considered to be everything, anything that can prolong life and preserve health can take on cardinal value. When heaven is no longer recognized as the goal of human life, this life and health in this world can claim a dominating significance. Salvation becomes immanentized in the face of a human finitude that cannot be transcended. The result is often a frenetic pursuit of health and the postponement of death at all costs, a point that Plato already recognized in *The Republic* (*Republic* III, 404-408). The pursuit of health can become an object of individual and cultural ultimate concern.

This displacement of cultural energies to health and the postponement of death is of one fabric with the modern attitude that emerged with the Renaissance and the Reformation's fragmentation of Western Christianity. The traditional Christian world-view found itself confronted by its religious zeal fragmented into numerous religions just as it faced the attractions of an immanent humanism. Cultural energy was displaced from a *studia divinitatis* to a *studia humanitatis.* Unlike many contemporary appreciations of the humanities as set over against the sciences[9], the sciences and technologies were embraced as integral to the fulfillment of that which is truly human. From Magellan's circumnavigation of the world[10], to Copernicus and his *De*

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[9] Many have addressed the current gulf between the humanities and the sciences, in response to the fragmentation of what had been once a unified understanding of human excellence and ability. See, for example, C.P. Snow, "The Two Cultures," *New Statesman* (6 Oct. 1956), 413-14. Subsequently, the lecture was printed as *The Two Cultures and the Scientific Revolution* (Cambridge: Cambridge University Press, 1962). In this work, Snow reflected a view already taken by Matthew Arnold in a previous Reed Lecture. See Arnold, *Literature and Science* (Cambridge: Cambridge University Press, 1882). See also Wolf Lepenies, *Die Drei Kulturen* (Munich: Hanser, 1985), exploring the emerging gulf between the humanities, the social sciences, and the other sciences.

[10] Magellan himself died on April 27, 1521, killed by Lapu Lapu in the Philippines.

Revolutionibus,[11] to Vesalius' *De humani corporis fabrica*[12], a new confidence in science, technology, and human nature came to the fore. Attention was diverted from the pursuit of the kingdom of Heaven to creating a commonwealth for man. It is in this milieu that modern medicine's pursuit of health took shape. It is within this context, as we have seen, that medicine's political service was recognized. Medicine commanded an optimism regarding progress such that Descartes (1596-1650) believed he could extend his life to the age of 100[13]. Health and its pursuit were experienced as goods that all rational men should pursue[14].

This pursuit of health lodges easily within the modern philosophical project of grounding a content-full, canonical account of appropriate behavior through reason. This nesting of the pursuit of health in rational life projects has been enhanced by the success of a discursively rational pursuit of scientific knowledge and technology. As a consequence, the pursuit of health fits congenially within the modern moral philosophical project, which has identified morality with rationality. Insofar as the pursuit of health is integral to the rational life, and insofar as morality can be rationally disclosed, it becomes plausible to expect that a unique rational bioethical understanding of good deportment can undergird a health care policy directed to universal health promotion. It also becomes plausible to assume that rational argument can establish an encompassing canonical account of health and well-being.

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[11] Nikolaus Copernicus, *De Revolutionibus orbium coelestium*, libri VI (Norimbergae: Johannes Petrium, 1543).

[12] Andreas Vesalius, *De humani corporis fabrica* (Basel: A. Operinus, 1543). Vesalius as a humanist wrote this volume in a Ciceronian Latin, largely inaccessible to many of the physicians of the day. See Ludwig Edelstein, "Andreas Vesalius, the Humanist," *Bulletin of the History of Medicine* 14 (December 1943), 547-561.

[13] Rather than living to the age of 100, Descartes died at 54. This provoked at least one unkind obituary that remarked that a fool died in Sweden who claimed to be able to live as long as he wished. *Extra ordinarisse Posttijdinghe* (10 April 1650). For an overview, see G.A. Lindeboom, *Descartes and Medicine* (Amsterdam: Rodopi, 1978), pp. 93-97.

[14] The 16th and 17th centuries were characterized by an interest in recipes for a long life, many of which involved a commitment to various forms of temperate deportment. Ferdinand Sassen, *De reis van Pierre Gassendi in de Nederlanden* (1628-1629) (Amsterdam: Noord-Hollandsche Uitgevers Maatschappij, 1960). See, also, Luigi Cornaro (1467-1565), *Discorsi della vita Sobria* (Padua, 1558).

Were all this so, it would then be possible (1) to dismiss all who disagreed with this project as irrational, and then (2) to justify the imposition of policies of health promotion based on that view, since that policy would restore individuals to their appropriately rational behavior. After all, if one can by reason show how people ought to deport themselves, then the coercive imposition of proper behavior will not be alien to those subject to such coercion. It will instead restore them to the behavior appropriate to them as moral agents. If this were all possible, it should also be possible to disclose a universal moral community of wholesome commitment regarding a content-rich view of health. All rational persons would implicitly belong to this wholesome kingdom of healthy ends. It would only be a matter of philosophers' disclosing the content of this moral commitment, thus providing a justification for the state pursuit of health through bioethically warranted health care policy.

Because we live in a high-technology, electronic culture, there is the additional temptation to accumulate masses of information about each citizen in order to protect against disease by preserving health. Medical records are being computerized, health behaviors monitored, and health outcomes assessed in the pursuit of better health. Better and more complete medical records can then aid in both treating individual patients and assessing the efficacy of particular treatments. An evidence-based medicine can be developed so as cost-effectively to pursue health. In this vision, there is a coincidence among individual good, political aspiration, scientific progress, technological innovation, and financial stewardship, all in the pursuit of good health. After all, everyone should be healthy and the maintenance of health appears to be a good cost-containment strategy on the part of states burdened with ever-increasing health care costs.

This coincidence of the allure of health and of scientific, technological power in a computerized society, in which information can be acquired, stored, and disseminated easily, can be combined to produce an all-encompassing secular religion of health. The temptation is then to enforce health promotion. In this light, it would appear self-evident that the state should require exercise, moderate sobriety, appropriate diet, the eschewal of cigars, the practice of safe sex, the monitoring of citizens by physicians, and the general indoctrination of wholesome behavior. The deviant become the non-compliant, where deviance includes all lifestyle choices and values not in accord with the prevailing view of well-being and health. These may range from traditional Roman Catholics, who may choose not to employ prenatal diagnosis and selective abortion, to those who find benefits in smoking[15], drinking to excess, eschewing exercise in favor of writing books while sipping port, or other risk-affirming lifestyles that set them at an increased jeopardy of suffering, disability, and earlier death. The result can be an encompassing secular Puritanism, this time not in the service of gaining eternal life, but in the pursuit of a very particular view of human flourishing. This puritanical vision gives little space for those who embrace alternative views of the good.

The success of public health policies directed to safe water and food may suggest that this new ethos is unproblematic, that there is a univocal understanding of health along with the moral authority to impose it. In part, this may be a function of assuming that the same moral issues are at stake in impeding the transmission of highly contagious diseases, as are at stake in protecting against the costs of chronic diseases. At closer inspection, this is not plausible. The protection of persons against highly contagious diseases with significant adverse health consequences can be understood as a protection of forbearance rights. If individuals by carrying a disease expose others to more than the ordinary risks of public contacts, they act with a kind of violence against others, to which there may be protective responses without invoking a particular content-full view of proper moral deportment. It is enough to recognize persons as in authority over themselves to the point of refusing contact with persons carrying dangerous disease agents.

Coercive interventions to dissuade persons from behaviors likely to have untoward health costs to themselves is another matter. First, such behaviors do not usually involve the violation of forbearance rights of others. Moreover, if those behaviors do constitute a cost upon others because of all-encompassing state welfare systems, the easiest resolution is to allow exit through private insurance or self-insurance. Also, what is often forgotten is that a wholesome life does not necessarily save money for the state. Postponing death through

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[15] There appear to be benefits other than the pleasure smoking conveys. For example, “Nicotine obtained from tobacco can improve learning and memory on various tasks and has been linked to arousal, attention, rapid information processing, working memory and long term memories....” R. Gray et al., “Hippocampal Synaptic Transmission Enhanced by Low Concentrations of Nicotine,” *Nature* 383 (1996), 713.

engaging in health-promotional activities exposes one to the likelihood of living longer past retirement, requiring longer pension support from the state, not to mention longer health care and likely longer long-term nursing care when one lives longer and develops Alzheimer's. It is for this reason that profligate lifestyles can in fact save the state money. For example, although smokers may impose certain health care costs on the public by dying earlier, they also require fewer pension payments and long-term health care, thus saving money[16]. The commitment to an encompassing therapeutic state also assumes that ideally, out of considerations of justice, equality, and/or the common good, a uniform health care system should be established around a common morality and understanding of health. All of this assumes further that one can realize the Enlightenment aspiration of disclosing a universal canonical moral vision so as to justify a state with a thick understanding of fairness and the common good. This is also not possible.

Beyond the Enlightenment Dream

Modern understandings of polity arose against the fragmentation of the medieval moral and political synthesis that presumed a deep consanguinity of faith and reason. Right reason, it was assumed, could disclose the nature of appropriate conduct, even if one were not a believer. Faced with the bloody fragmentation of Western Christianity, it became plausible to draw upon reason rather than faith for a normative account of human flourishing and to justify a state in authority not only to enforce contracts, resolve coordination problems, but also to achieve the common human good. Against contemporary concerns with foundationalism, there have been attempts to draw from discourse[17] or from the notion of a liberal constitutional

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[16] Virginia Baxter Wright, "Will Quitting Smoking Help Medicare Solve its Financial Problems?" *Inquiry* 23 (Spring 1986), 76-82.

[17] See, for example, Jürgen Habermas, *The Theory of Communicative Action,* trans. Thomas McCarthy (Boston: Beacon Press, 1984).

democracy[18] the rational authority to impose a common understanding of the good. The difficulty with this project lies in the circumstance that, if one in a rationally principled fashion is to draw authority from an account of how humans should deport themselves, or from a common understanding of an appropriate polity, there must already be a background common morality, common understanding of moral rationality, or common understanding of the appropriateness of a particular genre of liberal democratic constitutional government. However, if there are foundationally different accounts of how one ought to weigh cardinal human goods, engage in discourse, or understand constitutional liberal democracy, this project will fail.

This can be illustrated by imagining a consequentialist determining which policies will lead to the best outcome for a state, its members, and its health care policy. Depending on how one ranks the goods of liberty, equality, prosperity, and security, including security against disease, disability, and early death, one will have endorsed a quite different portrayal of the proper structure of the state and its health promotional commitments. The outcome will also be a function of which understanding of appropriate risk-taking one affirms. Crucially, even if one embraces a preference utilitarianism, outcomes differ depending on how one discounts for their satisfaction over time. In health care, this is particularly important, for one must determine how to compare, for example, the good of a youth lived in exuberance, but with risks

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[18] John Rawls, for example, claims to eschew a metaphysical account of his theory of justice in favor of a political conception of justice. See "Justice as Fairness: Political not Metaphysical," *Philosophy and Public Affairs* 14 (Summer 1985), 223-51. Rawls develops these points further in *Political Liberalism* (New York: Columbia University Press, 1993). He introduces this political conception of justice and its tie to modern constitutional democracy in the following fashion: "While such a conception [i.e., a political conception of justice] is, of course, a moral conception, it is a moral conception worked out for a specific kind of subject, namely, for political, social, and economic institutions. In particular, it applies to what I shall call the 'basic structure' of society, which for our present purposes I take to be a modern constitutional democracy. (I use 'constitutional democracy' and 'democratic regime,' and similar phrases interchangeably unless otherwise stated.)" *Political Liberalism*, p. 11. There is considerable ambiguity in the crucial terms he uses such as "modern", "constitutional", and "democracy". It is here that he inserts a very specific content. His recent statement involves a more extensive intrusion of "justice" into families and communities, has appeared as "The Idea of Public Reason Revisited," *University of Chicago Law Review* 64 (Summer 1997), 765-807.

to health in old age, with a much more soberly conducted youth and a greater possibility of a healthy old age? Any definitive comparison presupposes a background normative perspective from which to compare and judge: a guiding set of intuitions, a thin theory of the good, a proper sense of how to balance moral appeals, a canonical appreciation of how to order right-making principles, etc. Of course, in order to establish that background perspective, one needs a further background perspective. In short, one cannot get started without already begging the question, engaging in an infinite regress, or arguing in a circle.

Further difficulties for this project of establishing an all-encompassing pursuit of health promotion lie in the value-determined character of health itself. Concepts of health are not value- or culture-independent. They depend on particular visions of human flourishing and appropriate risk-taking. In a post-modern world such as ours, there are numerous narratives of disease, well-being, and health. No particular narrative is able to claim canonical normativity: any account of health is in the end dependent on an account of adaptation. In turn, an account of what it is to be well adapted requires specifying the relevant environment and the goals of adaptation. In this way, any account of health or adaptation becomes value-infected through the selection of goals, not to mention the specification of the proper environment[19].

Under these circumstances of multiple accounts and narratives of health, the state cannot plausibly claim to be imposing the canonical encompassing view of health. There is no such unambiguous notion of health to discover, which could then uncontroversially guide an encompassing health care policy. After all, concepts of disease bring together the results of complex decisions regarding (1) how one should describe reality, (2) how one should non-morally evaluate human function, grace, proportion, and longevity, (3) how one should select appropriate explanations of diseases, and (4) how properly one should choose therapy warrants on the basis of the first three choices, along with considerations of social and economic costs and benefits. At each step, both epistemic and non-epistemic values play cardinal roles in how one

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[19] H. Tristram Engelhardt, Jr., *The Foundations of Bioethics*, 2nd ed. (New York: Oxford University Press, 1996), chapter 5.

construes the character of medical reality. Apart from the role played by such evaluative judgments, one cannot give an account of health or disease.

Despite these unavoidable ambiguities, over the last two centuries there has been a concerted effort to medicalize moral, social, and other problems, as if one were responding to a society-independent medical reality. At the end of the 18th and the beginning of the 19th centuries, masturbation[20] and alcoholism[21] came to be treated as medical, not just moral difficulties. Subsequently, it has become clear that we can regard as diseases the usual changes of life, ranging from menopause[22] to the disabilities of aging[23]. Currently, this medicalization of human life extends not just to social problems such as smoking and drug addiction[24], but even to domestic violence, indeed, to violence[25] in society in general[26].

With the medicalization of human problems, not only are the responsibilities of patients changed, but so, too, are those of physicians. On the one hand, patients may be excused for persisting in their behavior because it is

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[20] H. Tristram Engelhardt, Jr., "The Disease of Masturbation: Values and the Concept of Disease," *Bulletin of the History of Medicine* 48 (Summer 1974), 234-48.

[21] Thomas Trotter, *An Essay, Medical, Philosophical, and Clinical, on Drunkenness and Its Effects on the Human Body,* 2nd ed. (London: Longman, Hurst, Rees, and Orine, 1804).

[22] Allan Barnes, "Is Menopause a Disease?" *Consultant* 2 (June 1962), 22-24.

[23] Engelhardt, "Treating Aging: Restructuring the Human Condition," in *Extending the Human Life Span: Social Policy and Social Ethics*, eds. Bernice Neugarten and Robert Havighurt (Washington, D.C.: National Science Foundation, 1977), 33-40.

[24] Thomas Szasz, "The Ethics of Addiction," *The American Journal of Psychiatry* 128 (November 1971), 541-46.

[25] F.I. De Zulueta, "Human Violence: A Treatable Epidemic," *Med Confl Surviv* 14 (January 1998), 46-55; M.M. Von Burg and R.A. Hibbard, "Domestic Violence: A Health Concern," *Indiana Med* 88 (May 1995), 186-90; E.A. deLahunta, "Hidden Trauma: The Mostly Missed Diagnosis of Domestic Violence, *American Journal of Emergency Medicine* 13 (January 1995), 74-6; D. Satcher, "Violence as a Public Health Issues," *Bulletin of the New York Academy of Medicine* 72 (Summer 1995), 46-56.

[26] L.A. Fingerhut, D.D. Inram, and J.J. Feldman, "Firearm Homicide Among Black Teenage Males in Metropolitan Counties," *JAMA* 267 (June 10, 1992), 3054-58; L. Rachuba, B. Stanton, and D. Howard, "Violent Crime in the United States. An Epidemiologic Profile," *Arch Pediatr Adolesc Med* 149 (September 195), 953-60.

no longer a vice, but a disease[27]. On the other hand, physicians become engaged as police to oversee the errant behavior of patients with legal consequences. Increasingly, they are required to report abuse and to function as an extension of the state in solving problems once considered non-medical. As these changes occur, the advice of physicians is no longer an injunction to be weighed by a competent patient. Instead, advice takes on an increasingly legal significance. Health care becomes politicized, with the result that it becomes more difficult for patients simply to decline and choose other measures[28].

Taking Freedom and Diversity Seriously

What remedies exist against the disposition coercively to impose particular ways of realizing health? Given the powerful allure of health and the desire for uniform resolutions to societal problems, how can space for free choice be preserved, and on what basis? How can freedom be recognized as necessary to the democratic pursuit of health? Already answers have been suggested to these questions. In this world of multiple moral visions, all-encompassing attempts to impose a particular view of health promotion are doubly suspect. First, there are numerous visions of how to face risks and to balance the goods that engage humans. Although some visions can be eliminated on grounds such as violating forbearance rights, no one account of the good or of health can be established as canonical without begging foundational questions. Second, in the absence of a canonical content-full vision of morality and health, common

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[27] See Talcott Parsons' account of the sick role in *The Social System* (New York: Free Press, 1951), and "Definitions of Health and Illness in the Light of American Values and Social Structure," in E.G. Jaco (ed.), *Patterns, Physicians and Illness* (Glencoe, Ill.: Free Press, 1958), pp. 165-87.

[28] Physicians, for example, have been enlisted in compelling women to be civilly committed in order best to protect the health of their unborn children. P.H. Soloff, S. Jewell, and L. Roth, "Civil Commitment and the Rights of the Unborn," *American Journal of Psychiatry* 136 (1979), 114-15. See, also, the history of forced cesarean sections: Lawrence Nelson and Nancy Milliken, "Compelled Medical Treatment of Pregnant Women," *Journal of American Medical Association* 259 (Feb. 19, 1988), 1060-66.

moral authority to impose one vision comprehensively cannot be drawn from sound rational argument, but only from the permission of individuals. In this light, one is forced to reconsider the relationship between justifiable, democratic, constitutional governments and health care policy.

The more that one recognizes that by default the authority of government is drawn from the governed, and recognizes as well the diversity of moral visions and understandings of the good life, the more by default justifiable state authority should be placed within the bounds of limited democracies. Enlightenment hopes to the contrary notwithstanding, in the face of a plurality of moral visions, it is freedom, individual permission, not reason, that is cardinal to the moral authority of a generally justifiable secular health care policy[29]. If all do not convert to the view regarding reality[30], and if discursive arguments cannot resolve moral controversies or controversies regarding how best to portray disease and health without already conceding who should be in authority to resolve such disputes or regarding what basic premises should be granted at the outset, it will not be possible to resolve moral controversies with common authority save by agreement. If we cannot draw moral authority from a canonical moral vision, then we must draw it from persons through their permission. It is for this reason that individuals and their free choices are so central in contemporary bioethics and health care policy.

Free and informed consent, the market, and limited democracies with de facto, if not de jure, rights to privacy play the role they do because in general secular terms we cannot discover our way to uniquely correct answers regarding content-full moral controversies or proper accounts of health and disease. Practices that draw their authority from permission have their centrality by default. They are integral to the only available default strategy for gaining general secular moral authority in the face of a moral and value diversity unresolveable by sound rational argument. Under such

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[29] I have explored these issues in greater detail in *The Foundations of Bioethics,* 2nd ed. (New York: Oxford University Press, 1996).

[30] Any accidents to a canonical moral vision could not be through discursive reason, and should not be of the sort that may be imposed by force. See H.T. Engelhardt, Jr., "Moral Content, Tradition, and Grace: Rethinking the Possibility of a Christian Bioethics," *Christian Bioethics* 1 (1995), 29-47.

circumstances, social space for alternative health care approaches and insurance mechanisms becomes morally inescapable. By default, moral space must be given not just for individual choice, but alternative community visions of health and the good life as well.

It is communities whose members share a substantive common understanding of well-being, who can coherently pursue a vision of health. Such communities will likely often draw their vision of values from religious roots, which supply a metaphysical anchoring for their moral commitments. It is here that deep convictions have their roots. Members of such communities can then understand whether abortion, particular forms of third-party-assisted reproduction, and physician-assisted suicide support health or undermine it by being deeply at odds with human well-being[31]. Members of such communities will share a common view of human flourishing. In pursuing this view they will set themselves over against other communities. In comparison to others, they will have different views as to which cost should be borne to lower risks of disease, disability, and early death. The respect of such differences, which amounts to the recognition of the limits of secular moral authority, requires social space for divergent moral choice. It requires acknowledging a kind of moral right of privacy for communities.

The plausible moral limits of a secular pluralist state invite us to take seriously not just moral diversity but a diversity of understandings of well-being. This diversity of visions regarding health involves not just negative understandings of health which require balancing various concerns to avoid diverse risks of disease, disability, and early death. This diversity involves as well competing positive understandings of health, competing visions of human flourishing. In a post-modern, post-traditional world, the cardinal element of health must be that of the freedom of both individuals and communities to act in ways that others will find deeply misguided, as involving a mistaken view of well-being. This is central to the drama of Eden. Freedom is always bound to the possibility of tragedy.

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[31] H. Tristram Engelhardt, Jr., "Physician-Assisted Death: Doctrinal Development vs. Christian Tradition," *Christian Bioethics* 4 (1998), 115-121.

FREEDOM AND HEALTH

Stefano Rodotà

1. The body has long been submitted to absolute forms of external sovereignty: to the therapist (warlock, quack doctor, physician), to collective or public organisations (tribal groups, local community, State), to the employer or to the businessman. Thus, the body has eventually become, and in certain ways still is, a "public place"[1], where the notion of "freedom" has been replaced by that of "cure", and where health is not contemplated with the force of an individual right, but rather as the object of the duty of the medical community and of the protection offered by, to a large extent, public individuals.

Indeed, it is the individual who falls ill, suffers and dies. Yet, often he was even denied knowledge about the illness, its diagnosis and therapy. In some cases, especially women, it even seemed inappropriate to give them information which would enable them to get to know their bodies and, therefore, be responsible for taking care of their own health.

Nevertheless, even though the person appeared to be expropriated, deprived of freedom of choice, this did not get rid of the tensions due to the awareness of pain or the daily handling of the person's physical existence. Literature and iconography[2] not only tell us of the fight between God and the Devil for our soul, but they also depict the patient's invocations, the controversies among different individuals over the body of an excluded or unaware patient. That is, the body and soul seen as an everlasting area of conflict.

However, opposition is not to be found in reality, nor even in history. "The discovery of medicine probably came about as a discovery of the likely alliance of the patient with a man who was able to stand up to and overcome the invisible. Thus the art of healing appeared, and it was conceived as a trichotomy illness-patient-healer"[3]. Thus, the problem is not simply a matter of giving back to each one the right to have a free governance of one's own health, but also of renegotiating the terms of this alliance.

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1 B. Duden uses this term referring to woman in *Der Frauenleib als öffentliche Ort. Vom Missbrauch des Begriffs Leben,* Luchterhand, Hamburg-Zürich, 1991.

2 See for example S. L. Gilman, *Disease and Representation. Images of Illness from Madness to Aids,* Cornell University Press, Ithaca-London, 1988.

3 F. Voltaggio, "Per un'autobiografia della medicina", in P. Donghi – L. Preta (eds.), "*In principio era la cura*", Laterza, Roma-Bari, 1995, 125-126.

However, health does not merely crop up as a right. It may appear in the pressing guise of duty: it is a slave's first and foremost duty not to fall ill so as not to remove his body from the work he must do; illness becomes an excuse for getting out of work. And the social obligation in favour of health is made known when it is possible to prevent and stop the spreading of pathologies or of behaviour patterns considered as a danger to the overall health of the "social" body. This brings about the birth of compulsory vaccinations, the isolation of patients and the quarantine for suspects, the commitment of the demented to prison-like institutions or the ban on alcohol and drugs.

Nevertheless, health could not remain oblivious to human rights, to care, already quite unmanageable, to a sense of body and its individual and social uses. In the great declarations of rights of the XVIIIth century, and also in a large part of the constitutions of later periods, health does not appear. And yet it is only in the most recent considerations that it has become visible as a powerful fundamental right, relevant on a constitutional level and not limited by ordinary legislation[4]. This establishes the premise that, within the framework of the idea of a State characterised by the importance of social rights, health stands as an essential right of the person, and also as one of the prerequisites for democracy, since full citizenship cannot do without a "minimum" of education, employment and especially health. There has been a radical change.

Several factors have contributed in producing this result. The notion of health goes beyond any merely biological, purely physical dimension, which

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[4] See art. 43.1 of the Spanish Constitution and art. 64 of the Portuguese Constitution. Art. 32 of the Italian Constitution is the most explicit: "The Republic is the guardian of health as a *fundamental right of the individual* and as a self-interest for all people". Based on this premise, the Italian constitutional Court has denied constitutional legitimacy to the regulations of ordinary laws which limit guardianship over the right to health, for example, those declaring that the damage caused to "health as a property", and particularly to the so-called "biological" damage, (judgement of July 14th, 1986, n. 184) is not liable for compensation. This line of interpretation has been taken up again in Germany which, however, does not have any specific constitutional regulations on the matter, and the Bundesgerichtshof has ruled that non-estate-related damage to health is liable for compensation (judgement of October 13th, 1992). On this point, in general, see P. Häberle, *Die Wesengehaltgarantie des art. 19 Abs. 2 Grundgesetz*, Karlsruhe, 1962; R. Dworkin, *Taking Rights Seriously*, Harvard University Press, Cambridge (Mass.), 1978.

reduces health to simply the absence of illness and illness to a “deviation of the project of species”[5]. It is precisely this criterion that has been adopted by the World Health Organisation, according to which “health is a state of total physical, mental and social well-being, and not merely the absence of pain or disease”[6]. This definition places health beyond pathological confines, it affects the person’s psychophysical integrity and converts health into an element of absolutely free existence. And it specifically contributes to expand women’s freedom, as it is made especially apparent in the laws on abortion, which confer the right of decision-making on their own to women, including guardianship of their own health, understood in the broadest sense as it has just been mentioned.

Furthermore, thanks to the ever more important scientific and technological development, the body appears to have cast off many of the shackles imposed by nature: within the realm of personal decision-making, questions which earlier were exclusively left to chance, to nature, are now raised. And precisely because the body and its functions found their own rules in nature’s laws, it was not necessary to resort very often to man’s laws in the past. In fact, in civil law, which is the authentic rule of individual and social powers, the body was hardly mentioned.

These novelties have a double effect: room for freedom is established where previously there had only been need, and, therefore, one can witness a demand for legal rules in order to regulate situations which have become the object of decisions taken freely. However, the most radical and obvious change takes place with the affirmation of the principle of “informed consent”[7], which not only modifies the relationship between therapist and patient, but places the patient’s will first and foremost and converts health into a fundamental right of the individual, thus making individual rights prevail over those of the

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5 H. R. Wulff-S. A. Pedersen- R. Rosemberg, “*Filosofia della medicina*”, Cortina, Milan, 1995, p. 67.

6 For this definition, see, among others, D. Callahan, “The WHO Definition of Health”, in Hastings Center Report, 1973, p. 77-87.

7 A. Santosuosso (ed.), “*Il consenso informato*”, Cortina, Milan, 1995.

group. Fundamentally, choices related to health – or rather, related to the cycle of life – refer solely to the decisions taken by the person concerned, who, should the therapist intervene, must receive the information needed from the latter.

The strength of this innovation lies in giving back the patient's sovereignty over himself, to such an extent that it has even been seen as the birth of a new "moral individual", instead of just a mere bodily being subject to external decisions.

All of this does not eliminate conflicts: on the contrary, the extension of possible freedom increases them, at least in some cases, the most tricky and thorny ones. Precisely, while health gets a heavier dimension of guardianship within the framework of "third generation" rights, the social rights, formulas are being included in international documents and national constitutions indicating criteria to reconcile individual rights to health with those generally demanded for everyone.

Initially health is not recognised for and by itself, but is considered as being related to other rights. For example, to the right to work and fair remuneration: under art. 25.1 of the United Nations' Universal Declaration of Human Rights (1948), it is stated that "any individual has the right to a level of life guaranteeing health and his own well-being and that of his family's". Or to the right to privacy: art. 8.2 of the European Convention on Human Rights (1950) allows the interference of public authorities in the private sphere of individuals "to safeguard health", considered here not so much with regard to the individual's dimension but to that of the group.

With this considerations – important, albeit still indirect – progressive recognition of the full autonomy of health as a right in national Constitutions is slowly being woven, such as the Italian (art. 32), the Spanish (art. 43.1) and the Portuguese (art. 64), and in documents such as the United Nations' International Pact on Economic, Social and Cultural Rights (1966), by means of which States "recognise any individual's right to enjoy the best physical and mental conditions he may possibly achieve". At the same time and in general terms it states the possibility of limiting even basic rights –among them health–, "to safeguard recognition and respect for the rights and liberties of others and to satisfy the just demands of morality, of public order and overall well-being in a democratic society" (art. 29.2 of the UN Declaration).

2. Hereby health is inserted into the framework of fundamental rights, which introduces a dimension of freedom where previously there had almost only been needs and controls. Nevertheless, the particular nature of the right to health redefines the field of interests to be taken into consideration, which can no longer be boiled down to the simple dichotomy between the individual's and the group's interests.

Yet, what are the confines of this new freedom? What powers are conferred to each one with regard to one's body, its parts and products?

The meaning and scope of these questions are better understood if one bears in mind that the body clearly appears more and more as a "relational object", as a reference point of relationship with other individuals. Reproduction technologies, the opportunities offered by prenatal and preimplant diagnosis or by prenatal therapy force one to take into consideration the interests of the "nasciturus". The growing development of the social uses of the body – from transplants to the circulation of gametes and embryos, to surrogate maternity – brings forward new interrelationships between the lives of different individuals. Health data, especially genetic, demand new criteria to have access to this kind of information and its circulation.

We are faced with great questions, tragic choices[8]. The free choices surrounding health could plunge the body, its parts and products into the flow of trade relations. Modern legal philosophy though, by rejecting the identification of the human body with other material goods, has set it apart from the world of marketable goods[9]. This position is now firmly upheld by the Convention on Biomedicine (art. 21) and by the Universal Declaration of the Human Genome and Human Rights of the UNESCO (art. 4), both in 1997, which adamantly and explicitly exclude that the human body or genome be used as a source of income.

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[8] G. Calabresi-P. Bobbit, *Tragic Choices*, Norton & Company, New York, 1978.

[9] Cf. R. Müller, *Die kommerzielle Nutzung menschlicher Körpersubstanzen*, Duncker & Humbolt, Berlin, 1997.

This standpoint is criticised for its "paternalism", especially by scholars on the economic analysis of law who, for example, consider that the ban on organ trade is an attack against individual freedom and a restriction on the right to health, by reducing the availability of organs and products such as blood and gametes[10]. However, the acceptance of this logic would undoubtedly lead to a new way of discriminating against those most in need, since it would be only these who would go themselves to the market as organ suppliers. Moreover, it should be remembered that the non-marketability of organs or blood or gametes does not go against the person concerned, who, being able to make them available with the due distinction between organs and between their removal before and after death, may benefit others with his organs, providing that these are always donated. The acceptance of market logic would do away with the culture of donation, the ambiguities of which are well-known[11], but which is an essential component of the idea of health included in the principle of solidarity, also understood as a guarantee of the freedom of individual choice. This implies, among other things, a rejection of the social "functionalisation" of the body which, for example, might impose on someone with certain genetic characteristics the obligation of being "a good Samaritan"[12] to save the life of someone in danger.

On the other hand, this does not mean leaving to the blind free will of each one decisions that, in this matter, also concern the health of others. The most recent and eloquent case is that of genetic information, when the person concerned needs to have the data of others belonging to his same biological group to carry out a diagnosis for him, for reasons of preventing or curing a disease or taking decisions on procreation–related matters. Can other members of that group deny him such information, alleging respect for their own privacy, for their right not to know? The answer not only demands

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[10] Cf. essays published in the volume in charge of J. Blumstein-F. Sloane, *Organ Transplant Policy,* Durham, 1990.

[11] See, especially, J. Starobinski, *Largesse*, Éditions de la Réunion des Musées nationaux, Paris, 1994.

[12] G. Calabresi, *Ideals, Beliefs, Attitudes and the Law. Private Law Perspective on a Public Law Problem*, Syracuse University Press, Syracuse N. Y., 1985, p. 103.

redefining the legal status of such information[13], but, above all, acknowledging that, together with the legal concept of family, there comes to light the concept of a "biological group" which shares the genetic data which can be considered as a common heritage to which, and precisely because of this, any member of the group should be able to have access to. A wider perspective opens up under this point: together with the *genetically* shared information there is also all the information which should be shared by the community, such as the information referring to AIDS related to the couple.

3. The subject of genetic information needs to be gone into in more depth, since it is here where the relationship between freedom and health may become particularly controversial. This information happens to be different to any other personal detail due to its structural and permanent nature. Genetic heritage accompanies the individual throughout the length and breadth of his lifetime; it defines the uniqueness of the individual and unequivocally relates him to other individuals; it is the direct link between generations and, as such, it is "immortal", whereas the remaining biological features of the individual, which belong to the somatic domain, die with him.

If one wishes to represent the way in which different pieces of personal information contribute to the formation of the private sphere, one could turn to the following diagram:

private sphere

personal data in general	genetic data
separate	share
share data for social reasons	share data for structural reasons

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[13] Cf., for example, J. Harris (ed.), *Property Problems. From Genes to Pension Funds*, Kluwer, London-The Hague-Boston, 1988; B. M. Knoppers-T. Caufield-T. D. Kinsella, *Legal Rights and Human Genetic Materials*, Edmond Montgomery Publications, Toronto 1996.

Here the relationship between separating and sharing is stressed. A graph of the relationships between the different private spheres shows them as isolated circles, if one examines only the personal data in general. Conversely, if genetic data are considered, one can observe a partial overlapping of the circles which represent the private spheres of those belonging to the same family, understood as a group of individuals based on biological ties. There appears a common area, defined precisely by the genetic data which could, therefore, not be attributed solely to a private sphere more than to another, but rather being an ineluctable link between certain private spheres. Thus, the "genetic body" presents itself as an entity which cannot exclusively be attributed to a single individual.

The consequences of this verification are noteworthy on the level of defining the status of genetic information, and not just in legal terms. This information "can in some cases give a clear indication of the genetic status of other family members"[14]: thus, while analysing *my* genetic data, I am able to get to know the characteristics of the private sphere *of* others; and my asking a blood relation of mine for *his* genetic information may be aimed solely at knowing about *my* private sphere. Is there a need, at this juncture, to talk about common ownership of genetic data?

If we analyse certain significant international documents, we can see a growing and noticeable interest in this aspect. According to the most traditional approach of the Convention on Human Rights and Biomedicine, insofar as referring to the discipline of private life and genetic data goes (arts. 10-14), only the individual's situation which data refer to directly is considered. Quite different is the perspective adopted by the Council of Europe's Recommendation 97 (5), where the following definition is to be found: "the expression 'genetic data' refers to all kinds of data related to a person's hereditary traits or to those that make up the common heritage of a group of people linked by ties of kinship. It also refers to data relative to the exchange of genetic information (genes) that refer to an individual or to a genetic line, whether normal or pathological, identifiable or not. The genetic line is made up of genetic similarities derived from procreation and shared by

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[14] House of Commons. Science and Technology Committee, *Fifth Report: The Cloning of Animals from Adult Cells*, I, The Stationery Office, London 1997.

one or more individuals." Genetic data thus leave the pure individual dimension behind and become "common heritage", which is evidently the point of convergence of the interests of some people identified as belonging to a single genetic line.

A precise definition of the legal status of genetic data, and of the inherent powers of those affected, is also to be found in the documents ruling DNA banks, thus facing the questions of individual and social knowledge of this kind of information. In the *Statement on DNA Sampling: Control and Access* (1997) by the Ethics Committee of the Human Genome Organization it is stated that "special attention is to be given to access made by very close relatives. If there is a high risk of transmission, either of having or transmitting a serious genetic disorder likely to be prevented or cured, closest relatives should have access to genetic data stored so that they can know about their own genetic situation."

This document confirms the trend towards recognising genetic data as common heritage for many individuals, accessible by all those belonging to a certain group regardless of the individual's will to whom such details refer directly. This brings to light a relevant legal concept of "biological group" which, for the purposes that are being considered here, totally substitutes the concept of family. Within the latter, in fact, individuals who are excluded from the classical family group are in fact included, such as, for example, anonymous or known donors of gametes. The size of this group can be defined in several ways, coinciding with the whole genetic line (European Council Recommendation) or with an imprecise category of "close relatives" (*Statement* by the Ethics Committee of the Human Genome Organization).

In this way, the person and the body are placed together under one dimension which excludes the possibility of total individual isolation. The practical reason for such an acknowledgement is very important, and particularly affects those cases where genetic analysis requires knowing not only the data of the person concerned, but also those of other relatives of his. A refusal on the part of the latter results in the impossibility of the interested party to get to know himself, his own genetic structure, in short, his body as a whole. This explains the fact that the documents mentioned earlier on tend to favour "the right to access" to data by the members of the same biological group. Indeed, knowledge is the premise for deciding freely and consciously.

But, which could be the reasons for refusing? Apart from strictly personal grounds, the reason must once again be looked for in the special nature of genetic information. Indeed, in addition to the characteristics already mentioned, these also have a “predictive” quality, in a sense that they allow us to know beforehand certain aspects of the individual’s biological future (outbreak of certain diseases, predisposition patterns). However, it is precisely the fact of sharing genetic information that may cause a simple request for information to be experienced as a threat by the person requesting such information, to the effect that it reveals that, within the biological group, someone is expressing doubt about his biological destiny: and the common traits of the gene pool immediately cause this doubt to be shared too. This doubt cannot be dissipated by assuring the receiver of the request the “right not to know”, and, therefore, not communicating the result of the analysis. If, for example, the request is related to vital decisions such as marriage or procreation, the simple fact of not marrying or of not having children will reveal to relatives the ill-starred result of the analysis. And this undesired awareness may affect life freedom of the people concerned.

4. Thus are shaped the criteria which must be born in mind when tracing the conditions for the effective exercise of freedom within the domain of health. The specific availability of all the relative information to the person concerned constitutes its obvious premise: and by “availability” not-knowing must also be understood, when derived from a decision taken by the person concerned, who prefers deliberate ignorance to knowledge. Moreover, the framework of principles is compulsorily based on the respect for dignity and equality, in the name of which the individual must also be removed from the growing force of economic influences. And the rules of solidarity must be firmly upheld, based on an adequate consideration of the other’s demands.

Reference to dignity, in particular, has assumed a more noteworthy relevance, even up to the point of talking about human dignity as a “discovery”[15].

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[15] Cf. M.-L. Pavia, “La découverte de la dignité de la personne humaine”, in M.L. Pavia-T. Revet (eds.), “*La dignité de la personne humaine*”, Economica, Paris, 1999.

However, it is one thing to protect the individual against market logic and quite another the attempt to protect him at all costs “against himself”, by adopting prohibition-like systems. One thing is to increase the ties of solidarity among individuals in certain cases and another is to impose overall ways of control for collective reasons, such as mass *screenings*, or the exclusion of procreation for demographic or eugenetic reasons.

This brings to light the need to define freedom, conveying it to a framework of guaranteed rights, in which the concept of health is also defined[16]. The catalogue of the so-called biorights becomes longer. The right of procreation, considering reproduction technologies also as a sterility therapy, so that prohibiting a woman on her own to have access to the same would be equivalent to introducing an unacceptable discrimination just in the area of the right to health, to the detriment of the woman. But also the right to a non-manipulated genetic heritage, except for therapeutic reasons (often, however, influenced by cultural factors also related to eugenetic concerns). The right not to be conceived, as a premise to an action of compensation for the damage to parents who have given birth to a person in precarious physical condition. The right of illness, as a rejection towards discrimination based on pathological situations and as a rejection of duty. The right to uniqueness and diversity, as two sides of the same coin, that is, the free construction of personality. The right to anti-destiny, as a right to full access to predictive medicine, even when taking preventive strategies. The right to know, which can be specified as the right to know one’s own biological origin or get inverted into the right not to know, not to know the information announcing a tragic outcome related to incurable pathologies. The right to privacy, especially genetic. The right to reject cures, to die, to die with dignity, the right to commit assisted suicide.

The thread that links all these different rights, which go to make up a catalogue in constant risk of inflation, is the principle of self-determination[17].

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[16] S. Rodotà, “*Tecnologie e diritti*”, Il Mulino, Bologna, 1995, pp. 143-177.

[17] It is important to follow the reconstruction methods of this principle in the various sectors affected by scientific and technological innovation. In Germany, in particular, an attempt is being made to generalize the model adopted due to the decision on the census of the Bundesverfassungsgericht (15.12.1983), which stated the existence of a “right to informative self-determination” within the framework of the right to personality. This scheme for bioethics is considered by M. Koppernock, *Das Grundrecht auf bioetische Selbstbestimmung*, Nomos Verlag, Baden-Baden, 1997.

The person becomes the full "master" of his own health, and, in fact, of his own life, with certain individuals standing in front of him, first and foremost the doctor, whose duty is to furnish all the information needed, to inform about diagnoses and alternative therapies and to respect all his decisions.

The establishment of a framework of genuine rights reinforces the individual's state of freedom. In fact, freedom does not only show itself in such cases where the individual is faced by the predicament of taking a decision, of choosing, on the basis of the information which the doctor is obliged to give him. Indeed, in reply to the doctor's duty the individual is under no obligation to exercise his rights only in the case of having received such information. The individual has the power to take his own decisions even doing without an item of information that has come from a single authorised source, and this is especially evident in cases where there is no real therapeutic relationship. Total freedom characterises everything related to health management.

What is put forward under this point is the overall problem of the kind of collaboration with the doctor in fulfilling the rights of the person concerned. To the doctor's duty to inform corresponds the patient's right for his instructions to be followed, that fully includes the right to break off treatment, even if the death of the patient might depend on it. In the most well-known decision on this subject, the case of Nancy Cruzan pronounced by the High Court of the United States of America, "the more specific interest in making decisions about how to confront an imminent death" was recognised, which in general was presented as a "liberty interest in refusing unwanted medical treatment" and, in this particular case, it was specified as a "constitutionally protected right to refuse lifesaving hydration and nutrition"[18]. But this is where the question arises: Can one go from the doctor's duty to refrain from an undue treatment, to the former's duty to collaborate in carrying out any of the patient's wishes?

This question, which is usually described within the context of euthanasia, has been put forward very strongly in relation to the right of "assisted suicide",

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[18] *Cruzan v. Director, Missouri Department of Health*, 487 U. S. 261 (1990), p. 279.

taken up by two state courts and later by the Supreme Court of the USA[19]. Here I shall only refer to one essential point in the discussion, inherent to the respect for equality among citizens, expressed precisely under the "equal protection" clause included under the Fourteenth Amendment of the Constitution. Indeed, whereas the person who can survive or survives thanks to some kind of medical treatment has the right to decide to die by rejecting or requesting treatment to be interrupted, this is not possible for a person who is in a situation of even greater suffering, it does not depend on any treatment. The inequality is evident in the damage against the one who does not have the "luck" of having his life depending on a treatment (in this way, the subject of assisted suicide is basically limited to terminal patients, and it is not stated as an absolute right, which would pose the difficult question of assisted suicide for the depressed). That is the reason why the Court of Appeals, Second Circuit, had maintained that "interrupting or rejecting a medical treatment for maintaining life is no other than an assisted suicide", underlining the substantial independence of the different situations and thus extending a person's area of freedom. Nevertheless, the different methods of action by the doctor – indirect in one case, direct in the other – induced the Supreme Court to deny the admissibility of assisted suicide, making the observation, among other things, that "a doctor who assists a suicide necessarily and undoubtedly must have the primary intention of causing the patient's death", which would challenge the legal and medical tradition. But this kind of reasoning is slowly losing strength and, above all, rationality, precisely due to scientific and technological innovations, which force us to retrace or overcome the confines which, in the past, were considered to separate profoundly differing situations. The Supreme Court itself is aware of this which, although its ruling was unfavourable towards the admissibility of assisted suicide, underlined that its decision does not exclude continuing the debate "as it should be in a democratic society", thereby picking up on one of Ronald Dworkin's suggestions.

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[19] Compassion in Dying v. State of Washington, 79 F 3d 790, United Court of Appeals, Ninth Circuit (1996); *Quill v. Vacco*, 80 F. 3d 716, United Court of Appeals, Second Circuit (1996). These judgements were appealed against in the Supreme Court, which gave its judgement on the 26th of June 1997. Among the numerous writings on the subject, see R. Dworkin, "Sex, Death and the Courts", in New York Review of Books, 8th of August 1996.

The subject of assisted suicide poses the question in drastic terms of a new alliance between patient and therapist, within the individual dimension of informed consent, indeed to fully develop the conditions of freedom in the sphere of health. To achieve this, the doctor's collaboration may become essential, by recovering his function of information filter, as contemplated in the European Directive 95/46 on the protection of personal data, which relates the access to health data to the doctor as intermediary [20].

Furthermore, full individual freedom in the field of health may find some specific limits especially in the area of therapeutic and pharmacological experimentation in which, for obvious reasons, the instrument of consent cannot apply for certain categories of individuals (minors, the disabled) and requires a set of rules vouchsafing the necessary guarantees for the person concerned. This brings us to the most general subject of "freedom of cure", which concerns at least three questions:

1) The limits of the doctor's duty to answer any of the patient's requests;

2) The patient's right to have access to any kind of treatment, regardless of the rules which, for example, refer to the testing and authorisation of drugs;

3) The patient's right to have access to any kind of treatment regardless of his personal condition (for example, age and sex).

Indeed, though health is acknowledged as a fundamental right, one cannot escape the system which envisages ways of regulating the exercise of such a right and which act as instruments precisely aimed at the best enforcement of this right. Stated simply, it can be said that one cannot deny the doctor's right to evaluate the patient's requests and, given the case, not to take them up, with the exception of the limits established by regulations specifying the cases in which such proceeding would mean an unlawful rejection to cure. Moreover, since the rules on pharmaceutical experimentation, as well as other regulations, are aimed at safeguarding health, the limit to individual freedom

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[20] Directive 95/46 by the European Parliament and the Council of October 24th, 1995 on the protection of people with reference to handling of personal data and their free circulation: member States may "establish that access to medical data can only be done through medical staff" (item 42).

of choice is presented as a measure aimed at providing the person with all the necessary guarantees when the moment comes to cure. The "paternalism" of these rules is justified precisely because of the specific nature of the interests at stake.

Quite another matter are the possible discriminations related to personal conditions, such as age. The problem resides in the "conflicts which society must come to terms with such as the assignment of tragically scarce resources[21], and one has to differentiate between situations where a specific case of these overall rules is sought to be resolved. The question of age, for example, may arise when the hospital needs to choose between two victims that have come in at the same time and with the same chances of survival for the only resuscitation bed available. In this case, preference for the younger person might be justified. However, if this were to become a general rule and, as it has happened and happens in some States, all patients who are over a certain age are excluded from certain treatments (such as transplants, for example), then a serious violation of human rights is perpetrated, even prior to the principle of equality, thus bringing on a profound modification of social organisation.

Discriminatory policies may also be based on sex, as it is the case when women are excluded from having access to certain techniques of assisted reproduction (such as fertilisation with the semen of a donor) or a limit is placed on reproduction technologies available only for married women or women who have a "steady" partner. Apart from any other judgement of principle, procreative prohibitionism may seriously violate the right to health itself, which has been defined by the World Health Organisation as "reproductive health". Indeed, especially if reproduction technologies are considered from the viewpoint of curing sterility, the prohibition on having access to such technologies is also seen as a violation of the right to health under constitutional rights, and that, therefore, cannot be limited by ordinary laws, and those of the principle of equality, since discrimination against citizens based on "personal conditions" is not admissible (Italian Constitution, art. 3) simply because of the fact that the woman is not married.

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[21] This is the subtitle of the book by G. Calabresi-P. Bobbit, *Tragic Choices*, cit.

The curb on women's freedom in this area also appears as an attempt to close a room of freedom, which has been opened above all because of the technical possibilities of contraception and the recognition of a substantial right to self-determination with regard to abortion. Behind this kind of restrictive methods one can clearly make out the wish to deny women the freedom of decision-making and to reassume the control of reproductive power. This is what is trying to be imposed on anything related to a woman's body which, once again, is being placed under strict medical control and helping to link reproduction with the family model.

Once again, the fundamental right to health appears as an element which contributes to defining the citizen's real condition. It is not enough just to proclaim freedom of choice: this must be specifically converted into the possibility of getting the necessary treatments so that health can be protected effectively. This statement clearly points to the link between formal recognition of the right and the existence of the material conditions which guarantee its effectiveness.

Having reached this far, another problem arises. The right to receive medical treatment, does this also imply the right to free cures? If, in answer to this question, certain constitutional provisions are examined, one can immediately see that the right to health and free cures do not coincide. The Italian Constitution, for example, only guarantees free cures to "the needy" (art. 32), and the Austrian Constitution states that the "the Republic safeguards the health of the individual, *also* by means of free cures". Therefore, if it is clear that the right to free cures can be stated in absolute terms only for certain categories or in special situations, this does not mean, on the one hand, that it cannot be extended beyond the weakest economic segments of the population, as shown by the universalised systems of the welfare state; and, on the other, that the right to be cured can be excluded at a reasonable cost. Thus, recognition of health as a right becomes a way for the authorities to act, whose duty is to assign adequate resources to fulfil such a right.

Indeed, the most insidious curbs on equality appear when cuts in social expenditure bring about a decrease in the right to health through progressive cancellation of the public guarantee systems. If health is included among the goods that have to be acquired on the market, each one will only have the amount of health which his economic means enable him to have. And if health helps to define citizens' rights, this means that new ways of excluding the citizenry are being introduced, analogous to those which in the past excluded those less well off to the right to vote.

The definition of freedom of our contemporaries and of future generations is therefore influenced by the specific possibilities offered to each one to fulfil health as a right.

5. The analysis of the specific conditions for effectively safeguarding health, understood in the broadest sense of the meaning stated above, also demands taking into consideration the context in which individuals act. This implies, above all, the subject of the relationship between the individual dimension and the social or group dimension of the right to health. We have already underlined that the right to health also includes the right to refuse a cure, which particularly shows up "negative freedom". Nevertheless, it may find a limit in the need to protect the health of other individuals, as it happens, for example, in the case of infectious diseases, which may bring with them the obligation to undergo obligatory or compulsory treatment. Evidently, in this case, the strong curtailment of freedom demands the respect for very specific conditions, which are effectively summed up under art. 32.2 of the Italian Constitution: "no one can be submitted forcefully to certain health treatments unless provided for by law. The law cannot under any circumstances violate the limits imposed by respect for human beings".

Thus, the right to health remains within a complex balance of interests that are constitutionally relevant, which becomes particularly significant when analysing the relationship between health and work and, more generally, between health and economic freedom. Once again, this brings to light the subject of the limits of market logic: business cannot be done in such a way as to jeopardise a person's freedom and dignity, as shown by the ever-stricter health regulations in the work place.

This point of view also acknowledges the "right to a healthy environment", as a premise for safeguarding health and as a necessary condition to effectively protect the psychophysical safety of the individual. This new right is duly recognised by many laws and decisions and has also acquired specific constitutional relevance, for example in Austria, where the law of the 28th of November 1984 amended the Constitution by stating that "the Republic safeguards the health of individuals, also by means of free cures, and the healthiness of the environment in life and at work, as fundamental rights of the human being and in the interest of the community".

Furthermore, the liberation of the body, thanks to scientific and technological innovation and to the relevance acquired by the knowledge which any person should be able to have, would not really bring about a condition of freedom if it were possible to use this information in violation of the individual's privacy, to curtail his rights. It is precisely this preoccupation that has led international documents[22] and domestic laws to list information on health among "sensitive data", and what is more, to submit information in this category to particularly strong surveillance. The purpose of this line of action is to protect the individual against social stigmatisation and any discrimination that may be based on genetic characters or other health-related factors.

The risk of discrimination becomes critical when knowledge of personal data is mixed with business, especially with the aim of insurance companies and employers to find out about the genetic characteristics of anyone wishing to take out an insurance policy or looking for a job. Here the maliciousness of biological reductionism is very large, since a person's current or future health might become the basis of ruthless discrimination, with the advent of categories of non-insurable individuals or who cannot be employed. Faced by the possibility of a new society of castes, it continues to be fundamental to fully state the value of equality, not subordinated to simple economic calculations.

Once again, freedom and health cross their paths. And full respect for the person in itself helps to determine the way in which each one is specifically a citizen.

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[22] For further particulars, Convention of the Council of Europe on protecting people against automat personal data processing (1981), art. 6.

THE DOCTOR'S FREEDOM

Marcelo Palacios

First of all, let me congratulate the Grifols Foundation Board for its valuable initiative which today begins, basically concerned with bioethical reflection, and which we applaud. My most sincere acknowledgement to them and also to professor Camps for their invitation to take part in such an important event.

Organisations such as these, of which there are precious few, that include in their activities bioethical considerations such as those which underlie the spirit of the Foundation and convene us here today to a public event, for the first time. Hence my congratulations, and although these include everyone I wish to express my personal congratulations to Mr. Víctor Grifols and at the same time offer the International Bioethical Society, the Scientific Committee of which I have the honour of presiding, for any future collaboration that will hopefully be open and fruitful.

Since Bioethics is at the core of this meeting I cannot simply brush it aside, and consequently must briefly mention some considerations, firstly raising the question what bioethics is in fact. The term was coined in 1970 and understood by van Ranselaer Potter as deepening our knowledge of biology so as to improve the quality of life; it is, as you can hear and probably know, still a very young discipline and therefore still maturing. For this reason, and because of the varied and surprising "daily menu" which for some years now technological breakthroughs have been offering us – especially those derived from biological sciences and medicine –, the development of bioethics can be seen to be rapidly boosted and to lend itself to **practical and timely orientations** for any situation, and, obviously, to avail itself of the pertinent **language** too. Orientations – postulates or principles, for those who wish to call them that – and a language which is obviously needed and which has to be developed by all of us. Let us now enter, according to my criteria, into what will be the Century of Bioethics, an assertion which is backed up by outstanding examples, such as the cloning of somatic cell nuclei after their transfer to previously denucleated oocytes (initially to improve animals, or those to which genes are added which will later result in useful products, etc.), or that of "stem-cells" or mother cells of unlimited division, discovered in adult body tissues, and which will give rise to cell, tissue and maybe to autologous organ deposits or banks, "inherent" to those from which they proceed and without immunity risks which can be induced by strange or heterologous materials. These procedures will change the dynamics used in transplants and will solve the underlying rejection problems, or, on quite a different plane, when the debate begins on euthanasia, the definition of which in my opinion is taintedly burdened down by such actions (active, indirect, passive) which euthanasia is not, and which confuse the issue on such a tricky topic and influence legal decision-making. The coming century will not only be that, but it will necessarily be one in which bioethics will become an indispensable instrument of co-existence, a joining bridge with which to try and harmonise, by means of intercommunication and dialogue without any alibis, two fundamental rights: the one that aims to protect human dignity and any which might arise from it, and the one that safeguards each one's to participate in scientific progress and to benefit from it.

Without prolonging my line of argument too much, I consider that Bioethics was doomed to be born in a century which will soon come to an end, held to be the "blackest" in our history, and, as I see it, at least the most contradictory. In synthesis, it is this century that sees the proclamation of the rights and liberties of man (unfortunately, even today already forgotten or enforced incompletely in many parts of the World), the breakthrough and development of science and technology (in the first half predominantly by mathematics and physics and, in the second, mainly by biology, biochemistry and medicine) to limits that were difficult to imagine beforehand, unbridled demographic explosion (almost tripling the world's population from 1900 up to the present day) and physical and spiritual violence here and there in its most harmful and refined forms (wars, hunger, preventable diseases, discrimination against women, child abuse, environmental pollution, desertification, aggression against biodiversity, etc.).

We do not have the time to linger on with this or much else, but let what has been said suffice to uphold the previous statement, that amidst such greatness and misfortune, so much progress (?) and backward movement, in tune and confronted, the bioethic germ found the suitable breeding ground in which to take root and grow. And it did just that, acquiring such importance that I would currently define Bioethics as "the ethical discipline which involves itself in a committed, social and practical way, and if possible beforehand, in all problems that derive or may derive from the applications of science and technology to the **bios,** to life in general, and especially to human life, with the aim of helping to stop its abusive use".

The bioethical language to which I referred to does not need many novel concepts (except those that belong to scientific and technical jargon), which means that it can be structured with already-existing terms and values (freedom, autonomy, responsibility, democracy, pluralism, rationality, exchange, consensus, modernity, co-operation, settling of disputes, respect, solidarity, humanity, anti-violence, public debate and so many others) which can be used to peacefully define the operational "bioethic body" – generally and specifically – that needs to be expressed. In some areas worth mentioning, the Bellmon Report has been resorted to so as to furnish Bioethics with certain bases and, without any further intention other than that of constructive criticism, I believe that its contribution is neither enough nor the most appropriate, even if it were only for the fact that the document in question only deals with medical experimentation and, therefore, accepting its real value, it precisely points out contradictions or limitations to its conceptual nature.

There will be occasion for going into and comparing what has been said, although I think that bioethical language should have **no frontiers** with regard to approaches, it should be **universal** as to commonly-held matters, **current** (the classical legacy of ethics and later contributions are important, yet far more important are the bioethic postulates which we all may build today for all current scientific and technical affairs, naturally without forgetting the forecasts for the near future) and the consequence of **sufficient knowledge of the events** it is concerned with, **intercommunication** and a **comparing consideration on aims.** I would suggest that we should try to find a way **not to limit bioethics just to medical science** –there are signs that this is happening–, and though healthcare and medicine are some of its great topics, they are not the only ones.

While starting this lecture I have been wondering whether there is any dilemma in approaching two different, yet converging, paths. The first is concerned with expounding on freedom according to its essential, philosophical and theoretical perspective, which I will only touch upon briefly, since it is up to others who are more versed in these matters and under different circumstances. The second, from personal experience, that is, that of someone who has performed thousands of operations using the scalpel with certainty – not exempt of certain doubts that have occasionally overcome me – in the vicinity of the most noble of tissues such as the backbone marrow and others that were equally important and delicate; that of someone who on many occasions prescribed pharmaceutical formulae or decided to withdraw them due to their uselessness in view of the patient's terminal state; that of someone who followed up and controlled restoration and standardisation protocols of haemodynamic and biochemical constants; that of someone who suffered, and why not admit it, died just a little bit with the adverse result and death of a patient, until he understood that it was time to limit such states of mind and so became aware of the significance of his task from the point of view of ethics and professionalism (yet it must be said in passing, without fully achieving it and troubled by the horizons of his freedom as a doctor).

From a point of view of protecting health, insofar as it concerns healthcare – and even if the system of care is made up of a complex network of implications and conditioning interests (economic, political, denominational, public, private, group or individual) – by the **main characters in healthcare matters,** I shall concern myself specifically with the **physician** – the other is the **citizen insofar as being a potential** or actual **user** (patient) of the health system- and, as stated at the beginning, I shall refer to his **freedom** of action.

Freedom is, all things considered, a concept which includes quite varying forms of freedom, yet not because of this are they tinier or of lesser rank. First of all we should ask ourselves what "to be free" consists in or means, since it is obviously not only limited to "being free". Freedom is understood as the human being's natural faculty **to act** – or not to act – in one way or another, and he is therefore **responsible** for his actions; thus man exercises his freedom with "free will" or legal authority to act and **choose** upon **reflection**. (Let us then introduce some elements – to act, responsibility, choice, reflection – which will play a special role in the doctor's relationship with the individual and the group, especially in the relationship doctor/patient) It is a way of acting through the **conscious process** (stimuli, sensations, perceptions, affects, emotions, ever-sharper feelings, analyses, discussions, judgements, reactions and, finally, behaviour patterns produced by the body structures in which these processes are developed), and not in fact through **freedom of thought** conscience which is derived from the moral judgements of **the former**.

It is said that the freedom of each one ends where that of others begins, something which though a lot is not everything. Freedom cannot just be limited to being a simple barrier against the liberties of others, but rather it must be theoretically seen as imbued with a **willingness to consider and strengthen** the freedom of his kin, a willingness which will in turn reinforce his own. Thus, genuine freedom, in this case that of the doctor, does not have to be unilateral and centrifugal, radiated from the doctor towards others; quite the opposite, it must be shared as a **living experience** as far as possible, as a positive way of **interaction**, showing solidarity, understanding and constancy and with positive individual and social repercussions. Respect for the patient's rights and autonomy, informed consent, to expect efficient care (which does not exempt the doctor of his co-responsibility in the search for a balance between the quality of care and its cost, and, as a result of this, of an active participation in the overall aspect of healthcare, to which I will refer later on), these are important realisations of such a wish and understanding which I shall only mention.

There is something else which ties in with what we are dealing with. In democratic and properly ruled nations freedom is a faculty which is enjoyed either in deed or verbally, so that the individual will not go against **good manners and laws.** We are thus recalling what is already well-known, and which will no doubt be tackled by other speakers: that liberties, like other fundamental rights, are based on the one hand on **moral values** and **ethical principles** the origin and foundation of which is to be found in **human dignity,** and, on the other, that they are therefore **not absolute** and as a matter of fact have their limitations. And the fact that the doctor's freedom is not absolute either forces him to find out when it is not, so as to experience his freedom correspondingly. (Thus, there appear new elements which have to be kept well in mind in professional dealings: the ethics of applying medical know-how to human life – included in **bioethics** – and rules – the **bio-laws,** among others, from the development of which, whether or not indirectly, the doctor should not be excluded – which are sometimes necessary to regulate certain actions and to indicate a framework or perimeter for professional freedom).

Let us briefly go over the doctor's liberties. Prior to his status and licence (though not his prerogative) to practice in this profession he had the freedom to choose it, which in itself should imply a vocational attitude and, supposedly, a **humanistic** tendency, which I take for granted and which I will not go into again (it would be useful here to point out that in mentioning the doctor's freedom we are generalising, since in actual life doctors' activities are very diverse and, all things considered, this freedom increases its variables, with certain exceptions). Thus, the doctor is a person with his university training and later specialities, and who obtained his degrees which authorise him to act accordingly. And since the profession is a social reality, one has to consider the doctor's freedom from the point of view of practising it, and more specifically of his most direct actions, which are not other than his dealings with the user or patient, and which also include the social community. It is my intention to insist on the fact that the doctor does not act in an isolated way, but that his action is very closely linked to the other protagonist of health (the citizen, whether patient or not). So, if we go directly to the most frequent interaction between both, **the relationship doctor/patient,** this seems to confirm that the former is an **active actor** (what he largely is) and the latter, a **passive actor** (today only in relative terms, since his gains in autonomy and possibilities of choice have increased considerably over the past decades), whose condition of patient or sufferer forces the doctor to heighten his responsibility which in turn will guide his freedom. Consequently, although we are briefly dealing with the doctor's liberties here and now, it is obvious that we cannot separate them from the real ones of the one who requires the doctor's help, and that the liberties of the patient must be rigorously supplemented with the respect of other fundamental rights, such as: those that are related to **life,** to the **protection of health,** to **safety,** to **privacy** and not to suffer any **torture or inhuman or degrading treatment.**

I mentioned earlier that for many years I had an intense and continuous professional activity. First, and for a short time, as a general practitioner, and later as a surgical specialist in Spanish and foreign hospital organizations. Allow me, therefore, to talk from the viewpoint and perspective of a professional freedom based substantially on experiences I have had, the decisions taken – usually as a protocol –, since my approach is not merely theoretical, and the states of mind in taking more or less important steps. One might think that in making this statement I am not talking about the doctor's freedom, that is, the freedom of all doctors, but rather of my own, and I partly admit this. Yet, due to having generally worked in a team and thanks to this baggage of experiences, I take the liberty of establishing behavioural analogies with most of them, if not with all of them. I shall therefore refer to freedom within professional practice from several approaches which I consider fundamental, while at the same time I shall insert certain experiences I have had which will inextricably involve freedom.

A) **Purely formal freedom** (acting according to legal regulations, which have to be made available to the doctor for his understanding).

We doctors show very little interest for the laws which regulate our activity and even less if they are not at hand (in the healthcare organization which I preside, doctors have easy access to a handout prepared to this effect, which include the General Laws on Health, Drugs, Public Health and Criminal Law, and the Decree Laws on a free choice of doctor, temporary disability, etc.), and this ought to be amended, for the good of the group we treat and for our own.

What I am saying with this is that the healthcare professional, the biologist, the biochemist and other scientists ought not to adopt passive attitudes or merely of complaint (management does not act or does so hopelessly badly, politicians have no idea or make mistakes, etc.), but should rather adopt a permanent heterocritical attitude, which begins with the analysis of the planned or standardised reality and in making positive and fact-based proposals; another is the attitude of seeing the mote in another's eye and not the beam in one's own, which is like talking to a brick wall, – let me give you an example: the donation of tissues, organs, reproductive cells or blood requires reconsideration by everyone, with certain clarifications; the component of solidarity seems obvious, and legal cautions are well-intentioned, but it is no less true that they also curb the number of donations, all in all, to the detriment of those who need them, namely the patients. Matters such as those contemplated under article 2 of Law 30/79, article 5 of Law 35/88 or article 21 of the Asturias Convention on Bioethics ("the human body or its parts may not be the object of gain") should be considered from the perspective of the real meaning of "gain", and should be given a reasoned and pertinent solution –. To put it in a nutshell, legal rules in force in any given period of history are not permanent, and if it could be demanded for the good of and in the interest of the patient and the group, these should be adapted to the requirements of the changing times, demands of which healthcare staff should make a point.

With reference to what has been said before, and for freedom to be exercised in a responsible manner, the following is pertinent:

- Strict adherence to the opportunities as given by the degree.
- Knowledge of the laws and others (principles, limitations, sanctions, etc.) insofar as it concerns: medical prescriptions (types, formulas financed by the public health system, generics, reference prices, etc.) and a catalogue of medical services offered (general, orthoprothesic, healthcare transport, etc.); clinical tests; cell, tissue and organ transplants; the disabled who cannot fend for themselves (children, patients under anaesthesia, mentally-ill patients, etc.) and many other dimensions (assisted reproduction, genetic technology and engineering).

B) **Strictly professional freedom** to work according to each one's specific training and tasks (freedom of diagnosis, of prescription, of indications and surgical-medical operations, of research).

*) I had the good fortune to initiate and develop one of my specialities under an eminent German professor, a specialist in vascular surgery, in whose department surgery was done from below the renal arteries down to the lower limbs, proximally to the leg. Well, anyway, by using the streapper in thromboses of the femoral artery, there was a moment, and some of these have left their mark on me and to a large extent have made me what I am, in which while looking at me he asked: “Shall we go on?” He was asking me, his trainee assistant, whether or not he should go on advancing with the streapper as far as the popliteal artery, knowing full well that the operation would be incomplete if he did not do it and, on the other hand, that the posterior thrombosis would almost certainly be there if he were to enter with the plunger in that highly dangerous terrain, at knee level. In the end he did not risk it, but I shall never forget the sparkle in his eyes, full of honesty, a certain worry and his self-control to put a brake on what his wish demanded, guided by his balanced freedom.

*) On one occasion I attended a Surgery Congress in Stuttgart where, as in most of them, new techniques, the effects of certain drugs, etc. were presented. To be honest, the most authentic lesson I ever learnt was through the speech delivered by a well-known Austrian professor, in which he did not give an account of his success but a series of unsuccessful lines of research, with the aim, he pointed out, of making them known so as not to repeat them nor to waste any more time pursuing them. During one of the breaks I went to greet

him and, to be honest, when shaking hands I hoped that some of his immense freedom, which allowed him to accept his errors and to be self-critical aloud, would rub off on me.

C) **Bioethically-based freedom** to guide ones actions according to decisions taken with full **awareness and freedom of thought:** I am referring to one's own actions and those that are shared (on bioethical Committees), and the list is not yet comprehensive, to careful attention and respect for and information given to the user/client, intercommunication and professional co-operation.

To the intrinsic ethical root in which all true freedom resides, and as far as the doctor is concerned, the freedom derived from his specific activity must be added, so that whenever he performs an action he must justly value to what extent his professional actions affect health and the well-being and dignity of others. All things considered, I believe that freedom from a medical point of view must commit itself to and work on the basis of:

– SELF-CRITICISM, taking as a fundamental idea that one should not act medically beyond what one knows or what one can do under certain circumstances and with the means available.

– RESPONSIBILITY, based on on-going and sufficient medical information and training, on evaluating the advantages and risks of the operation; and with a view to the outside world by means of reasoned hetero-criticism.

To end this talk, I think that the doctor's freedom, on top of being based on self-criticism and a sense of responsibility, has HUMILITY as one of its most important supports. And I am not referring to humility as a show of false modesty or as having a prudish look – however sincere -, but rather as the objective acceptance of the power conferred upon the doctor by his knowledge, his ascendancy over the patient and his possibilities of action, and as an anticipated acknowledgement of how his actions can affect others, either directly or by way of his proposals to decision makers. And when all is said and done, I believe freedom to be an attitude demystifying that power, to confine it to those areas where freedom plays out its role as humanly as possible.

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