

FUNDACIÓ
VÍCTOR
GRÍFOLS
i LUCAS

The Three Ages of Medicine and the Doctor Patient Relationship

Mark Siegler

Monographs of the Víctor Grífols i Lucas Foundation
The Three Ages of Medicine and the Doctor Patient Relationship. Nº. 26 (2011)
Edited by: Fundació Víctor Grífols i Lucas. c/ Jesús i Maria, 6 - 08022 Barcelona
fundacio.grifols@grifols.com www.fundaciogrifols.org

ISBN 978-84-694-3182-5

Monographs of
the Víctor Grífols 26
i Lucas Foundation

CONTENTS

	Page
Presentation	
<i>Victòria Camps</i>	7
The Three Ages of Medicine and the Doctor Patient Relationship with Homage to Professor Pedro Laín Entralgo	10
Past and Future Contributions of Clinical Ethics to Patient Care	26
Discussion	46
About the author: Mark Siegler	66
Publications	68

PRESENTATION

This monograph contains the two lectures given by Dr Mark Siegler as the 4th Josep Egozcue Lectures. Dr Siegler's international reputation reflects both his teaching and clinical activity, and his contribution to bioethics. Siegler was responsible for coining and disseminating the expression "clinical ethics", the title of one of the most widely read bioethics texts, to refer to ethics as applied to medical practice. As a practising doctor engaged in treating the sick, Siegler has always been keen to ensure that the ethical challenges raised by the health profession are always linked to clinical practice. In the distinction which is usually drawn in bioethics between "principlists" and "casuists", he is clearly located among the latter.

Siegler surprised his audience by basing his first lecture on the approach of the Spanish historian of medicine, Pedro Laín Entralgo. In his book *Doctor and patient*, Laín Entralgo explains what the relationship between doctor and patient should be like, and argues that it should be based above all on friendship. A good doctor knows how to advise, inspires trust in the patient, and is a person in whose hands the patient is therefore willing to place him or herself. A good doctor usually has good patients. Siegler explained what he means by "the four ages of medicine", marked in chronological order by paternalism, autonomy, bureaucracy and shared decision making. Most of the first lecture addressed the question of how to ensure the survival of shared decision making between doctor and patient in the face of the challenge to it from economic agents ("the payers"). And both the challenge and the continued importance of the doctor-patient relationship itself would seem to confirm Laín Entralgo's thesis of the need for this relationship to be based on friendship.

In his second lecture, Dr Siegler focused on an issue which has been a core theme of his contributions to the field of bioethics: the tension between theory and practice. Siegler distinguishes between philosophical bioethics, which is closely linked to theory, and clinical bioethics, which is born out of practice. It may be something of a cliché to point out that ethics is a practical

science, and indeed Aristotle argued that this lay at the origins of ethical thought. But it is a cliché which needs to be repeated if bioethics is not to become mere theoretical speculation with no real basis and of little help for those who have to deal with daily problems and decide how to resolve them. The book, *Clinical ethics*, of which Mark Siegler is co-author, is intended to be a practical manual for the most common ethical issues in clinical practice. The book fulfils at least two of the requirements which bioethics, as conceived by Siegler, must satisfy: to act as a decision-making guide, and to introduce health professionals to bioethics and support them in their research. The text's widespread use in university departments and institutions in the United States led the Foundation to take the initiative of translating it into Spanish, in cooperation with publishers, Ariel.¹

Siegler's second lecture was followed by a lively debate around many of the issues raised during his talks. These included the bureaucratic age of medicine and the power of the economy in the health system; the importance of hospital and national ethics committees; the construction of patient preferences when taking decisions and the role of the professional in this process; education in bioethics and the role of philosophy in developing this discipline. Thanks to the hard work and dedication of Dr Marius Morlans, who coordinated and chaired the debate and edited the transcript, we are able to offer a summary of these questions and the answers given to them by Mark Siegler.

Victòria Camps
President

Reference

1. Jonsen, A, Siegler M, Winslade W, (prologue by Camps, V.). *Ética Clínica. Aproximación práctica a la toma de decisiones éticas en la medicina clínica*. Ariel: Barcelona, 5th edition.

**The Three Ages
of Medicine and
the Doctor Patient
Relationship with
Homage to Professor
Pedro Laín Entralgo**

I. Introduction

The most complete study of the doctor-patient relationship and medical decision-making in Western medicine was written by the late Dr. Pedro Laín Entralgo, one of the great physician-humanist authors and doctors of the 20th Century. Sadly, only two of Professor Laín's many books have been translated into English. One of the two books translated, which I own and treasure, is called *Doctor and Patient*.¹ It was translated and published in 1969. In this extraordinary work, Professor Laín traces the doctor-patient relationship from its origins in 5th Century Greece through its existence in Roman medicine and in the Middle Ages, to the relationship in the 20th Century.

One of Professor Laín's greatest insights is that the doctor-patient relationship from Greek times to our own has been a relationship that he calls *Philia* or "medical friendship." Professor Laín uses Aristotle's distinction between Eros and *Philia* to distinguish physical love from *Philia*, the origin of which is benevolence to others.

Professor Laín says:

"Insofar as man is a part of nature, and health an aspect of man's nature, the medical relationship ought to be more than mere comradeship – in fact, it should be Philia, friendship. A good doctor has always been a friend to his patient, to all his patients. And the patient also tries to surmount psychological and social barriers to be a true friend to his doctor, and often succeeds."

In 1979, Professor Laín spoke at a conference I helped organize in New York. The topic was: *What does the word "Good" mean in the phrase "Good Patient?"* Professor Laín said: "The sick person is expected to want to get well; to seek out medical advice; to give himself truthfully to the physician; and, in the service of his own health, to cooperate with his doctor." Laín argued that, "The best evidence that a doctor is a good doctor – which means that he or she has both technical competence and the will to help – is the fact that all of his or her patients somehow turn out to be good patients. It does not seem unfair to say to a doctor as a kind of qualifying test: tell me how many good patients you have and I will tell you how good a doctor you are."²

I will return in my conclusion to the important insights of Professor Laín and how they continue to influence our understanding of the modern doctor-patient relationship. At this point, I wish to take you on a brief odyssey that I call the Four Ages of Medicine.

The history of the Doctor-Patient Relationship in Western medicine can be viewed or interpreted conceptually as four ages of medicine: The first age was the period of medical paternalism ("the age of the doctor"); the second age was the period of autonomy ("the age of the patient"); the third age was the period of medical bureaucracy ("the age of the payer"); and the fourth age is the age of shared decision making between doctor and patient.³

II. The Four Ages of Medicine

The Age of Paternalism

The age of paternalism (sometimes called the age of the doctor) lasted thousands of years from about 500 B.C. to the 1960s and represented the traditional authoritarian and sacerdotal strain in medicine. This model of medicine – the physician in control model – was premised on trust in the physician's technical skills and moral stature, on the ethics of beneficence, and was characterized by patient dependency and physician authority.

Medical achievements during this lengthy period were rather modest and not very expensive. Medicine provided symptomatic care rather than cure; it emphasized the power of information (the prognosis), which was a mystery known only to trained physicians; generally, it was better able to deal with psychological than with physical aspects of disease; and it taught principles of hygiene and preventive health care. In this system, the physician provided information, psychological support, and symptomatic relief. In light of the successes of modern scientific medicine, we are often surprised that this older and technically much less effective medical system was respected by men and women for thousands of years. We are thus forced to recognize that for all its limitations, *the age of the doctor*, the traditional and relatively *inef-*

fective system of healing, must have addressed and satisfied many basic human needs for *most* of the patients it served for *thousands* of years.

The Age of Autonomy

The second age, sometimes known as the age of the patient, lasted at most 50 years (1945 to present). In fact, aside from the US, Canada, and some western European countries, it may never have occurred. I refer here largely to my experience in the U.S. Technically, the age of autonomy was an age of extraordinary advances in the understanding of disease, and in the development of remarkable medical and surgical therapies. It was an epoch that emphasized treatment rather than prevention, cure rather than care, and in contrast to the earlier age, proved to be very expensive. In the United States, the cost of care, often paid for by third parties rather than by the patient, was not considered a major concern, especially when balanced against patient autonomy, patient need, or even patient desire.

In the second age, *the age of autonomy*, especially in the United States, the theoretical balance of power shifted from physicians to patients. Many ethicists, legal scholars, and patients began to assert that the foundation of the doctor-patient relationship should be based on patient rights and freedom over the medical practitioners who controlled the first age of medicine. Informed consent was a central clinical and legal concept. The rhetoric of this second age was libertarian and consumerist. An extreme version of the autonomy model suggested that physicians should act as servants, providers or vendors to their patients, to transmit medical information and to use clinical skills as the patient directed, without seeking to influence patient decisions much less to actually make such decisions. My own view is that in most developed countries the second age never existed with the force that it did in the U.S., or if it did, it has now been supplanted by the third age.

The Age of Bureaucracy

The third age, *the age of bureaucracy* (the age of the payer), arrived 30 or 40 years ago, as third parties, often public payers like the government, began

paying for health care. This new era demands cost containment, cost efficiency, and is based on societal cost-benefit analyses. Quality of care for individuals, always so hard to define, is no longer an end in itself, but is now balanced against cost of care for populations, which is much easier to quantify. Physicians in the age of bureaucracy will be divided in their allegiances because they will be serving the conflicting demands of society for efficiency and social justice, and of their patients for personal care.

In the first two eras, the patient's *good* was the dominant concern for physicians. In the age of paternalism, the patient's good was defined as the patient's best *medical interests*. In the age of autonomy, the patient's good was defined as the patient's *freedom and right of self-determination*. In the third age, the age of the payer, however, the patient's good is balanced against other goods such as the needs of society. Decision-making is no longer vested exclusively in the hands of physicians or patients. In contrast to the two earlier ages, the wishes of both patients and physicians are increasingly controlled by the wishes of administrators and bureaucrats. This changes the doctor-patient relationship and represents the greatest challenge to it in 3,000 years.

Alasdair MacIntyre

Some years ago, Alasdair MacIntyre suggested that historically the physician played three simultaneous and intersecting roles in the doctor-patient relationship: 1) the physician was a magical healer; 2) the physician was an applied scientist; and 3) the physician was a bureaucratic administrator.⁴ MacIntyre's view is an accurate description of the evolution of the doctor-patient relationship in the three Ages of Medicine as I have just described them. In earlier times, before the scientific revolution, the physician's primary role was as a magical healer; in the scientific era, the role increasingly became that of applied scientist; and in our modern era, the physician plays an increasingly complex role as applied scientist and bureaucratic administrator.

In describing the physician as bureaucratic administrator, MacIntyre anticipated one of the major problems in the third era of medicine (the age of the

payer) and that is, who has the right to determine the patient's goals and preferences: the patient, the physician, or the bureaucracy?

III. The Fourth Age of Medicine – Shared Decision-Making Between Patient and Physician

This problem of who has the right to determine the patient's goals and preferences and who has the power to make decisions was an issue that I worked on 30 years ago, in the early 1980s. At that time, I recognized that the apparent tensions between physicians and patients that were reflected in the debates about physician paternalism and patient autonomy were not an accurate description of most medical encounters. At their extremes, both of these models implied an adversarial relationship between physician and patient on the crucial question of where the ultimate authority in the doctor-patient relationship should rest. But based on my clinical work as a medical practitioner, this adversarial tension between doctor and patient seemed artificial and certainly did not reflect my own experiences in caring for patients. My direct experiences with patients suggested to me that in most clinical encounters the physician and patient work together in a process of shared decision-making. They worked cooperatively as partners toward a common goal which was to help the patient who had come to the physician asking for help.

Based on this insight derived from my own clinical experience, I began to search for a compromise, a middle ground between physician paternalism and patient autonomy. In the early 1980s, I developed a model that I called the doctor-patient accommodation model, which I believed to be a better description of the actual clinical encounters between most patients and their physicians.⁵ The doctor-patient accommodation model that I developed relied heavily on communication, discussion and negotiation between doctor and patient. The doctor and patient decided what rights and responsibilities each wished to retain and which would be relinquished in the context of their

medical relationship. The accommodation process depended on all the details of the medical encounter including the attitudes and personalities of the doctor and patient, as well as the type and acuity of the medical problem, and the setting in which the doctor-patient encounter took place (whether in the doctor's office, the patient's home, or in a hospital). Rather than the doctor and patient knowing in advance what decision was best for the patient, the doctor-patient accommodation model provided a means to search for the best decision for the patient and this became a central goal of the doctor-patient encounter. As I wrote in 1981: "The doctor-patient accommodation model focuses upon the process by which *this* physician and *this* patient under *these* circumstances negotiate *this* doctor-patient relationship committed toward *these* ends."

In 1982, the year after I published my paper on the doctor-patient accommodation model, the U.S. President's Commission for the Study of Ethical Problems in Medicine asked me to present my views to them, as they were working on a report on the Doctor-Patient Relationship. The report they published in 1982 was based closely on my presentation and on my 1981 paper. For example, the President's Commission stated:

"The paternalism-autonomy debate has increasingly become an arid exercise. In this Report, the Commission attempts to shift the terms of the discussion toward how to foster a relationship between patients and professionals characterized by mutual participation and respect and by shared decision-making."

"The Commission's view is intended to encompass a multitude of different realities, each one shaped by the particular medical encounter and each one subject to change as the participants move toward accommodation through the process of shared decision-making."⁶

Since the mid-1980s, the prevailing model of the doctor-patient relationship in the United States has become the model of shared decision-making and this represents the fourth age of medicine. Different terms have been used to capture the shared decision-making model but they each involve doctors and patients working closely together. Some of the terms that are used to describe

this fourth age of medicine, the age of shared decision-making, include: patient centered care, participatory decision-making, preference-sensitive decision-making, collaborative medicine, and the enhanced autonomy model.

Empirical studies have now shown that shared decision-making leads to improvements in patient care in each of the following ways:

- patients have greater trust and confidence in their doctors
- patients cooperate better on treatment plans that they have agreed upon with their doctor
- doctors and patients reach financially appropriate decisions
- patients have greater satisfaction with their care
- patients experience better outcomes in a number of chronic diseases, including hypertension, diabetes, peptic ulcer disease and rheumatoid arthritis

IV. Tensions Between the Third Age of Medicine (The Age of the Payer) and the Fourth Age of Medicine (The Age of Shared Decision Making)

Between 1950 and 1980, the paternalistic model of medicine (the first age) competed with the autonomy model (the second age). We have seen how these tensions were resolved temporarily since the 1980s by the emergence of the shared decision-making model that acknowledges the legitimate roles for both patients and physicians. Now, however, there is a new tension emerging between the third age of medicine, the age of the payer, and the fourth age, the age of shared decision-making. The question is who will have the final authority to make decisions: the doctor, the patient, the doctor *and* the patient, or the payer. The central issue is whether patients and their physicians can make *any* decision they choose or whether such decisions will be reviewed by payers who may approve or disapprove the decision.

In the Hippocratic tradition (that is, the first and second age of medicine) doctors and patients always attempted to maximize benefits for the patient, even if the patient had only a slight chance of benefitting from a treatment. But payers, especially public payers, wish to conserve financial resources by not spending large amounts of money on care that is not likely to help a patient and to use those funds to improve the health of other people who would be more likely to benefit from a treatment.

One of the most controversial aspects of the Obama administration's health reform plan is the establishment of panels to determine the "comparative effectiveness" of certain treatments. While no one exactly knows what is meant by "comparative effectiveness", it appears that this is a kind of cost-effectiveness measure to determine whether people will be allowed to receive certain kinds of care even if they and their doctors indicate they want such care. The development of "comparative effectiveness" panels will be a critical test of the shared decision-making model that has emerged as the new model of the doctor-patient relationship in the United States during the past 30 years. The question is now whether the shared decision-making model – and for that matter the doctor-patient relationship – will survive the challenge by payers, or will the doctor-patient relationship become a kind of romantic vision of an age of medicine that no longer exists?

V. Will the Doctor-Patient Relationship Survive?

There are three reasons why I believe the doctor-patient relationship and shared decision-making will survive even the current challenges from public and private payers:

- medicine serves a universal and unchanging human need
- medicine has an unchanging central goal to help patients
- most medical help is delivered in the direct encounter between patient and physician: that is, within the doctor-patient relationship

1. Medicine serves a universal and unchanging human need

Medicine deals with the most fundamental aspects of the human condition: birth, life, health, physical functioning, vulnerability, loss, and death. These are the eternal problems for which patients have always sought help from doctors in all countries at all times. Regardless of advances in medical science or changes in politics, these fundamental aspects of the human condition will always be with us.

When people are ill, they turn for help to the doctor or healer in their society. That clinical encounter between the patient and the healer is the *unchanging event in medicine*, the constant. In this sense, medicine is the most universal and unchanging of the sciences. Regardless of the social, economic, scientific, and political changes that have affected how medicine is organized over the last 3,000 years, the clinical encounter of the doctor-patient relationship, remains virtually unchanged. I don't think that sophisticated technology or computers will eliminate the need for a personal and caring physician.

2. Medicine has an unchanging goal – to help those who ask us for help and to improve patient's quality of life

The second paragraph of the Hippocratic Oath makes this point: *I will use treatment to help the sick according to my ability and judgment; I will keep them from harm and injustice.* Medicine achieves this unchanging goal of helping patients in a variety of ways – by talking to people and hearing their fears and concerns; by caring for people and treating them with dignity and respect; by relieving their distress; by treating physical pain and psychological suffering; by restoring their ability to function; and sometimes by curing disease. Most of these functions of medicine are delivered in the context of a doctor-patient relationship.

Today, we physicians know far more than our predecessors knew about the science of medicine. The biological revolution since World War II has been

one of the great intellectual flourishings in human history – comparable to Greece of the 5th century B.C., or Spain in the Golden Age, or 15th century Florence under the Medicis. Yet, despite the advances in the science of medicine, the central goal of medicine – to help a patient and to improve the patient's quality of life – has not changed.

3. Most medical help is delivered in the direct encounter between patient and physician, the doctor-patient relationship

There are many ways to help people through the practice of medicine. Since I completed medical school, researchers have developed many new pharmaceuticals (including antibiotics, antihypertensives, cancer chemotherapy), new surgical approaches (for example, for cardiac disease and organ transplantation), and astounding diagnostic tools to image previously hidden parts of the body, not to mention newer developments in reproductive technology, genetics, and molecular biology. All of these scientific and technical achievements benefit our patients.

But at some point, these new research developments have to be applied in a face-to-face encounter between the person asking for help and the doctor who is prepared to respond. This is the practice of clinical medicine, this is the heart of the doctor-patient relationship, and for 40 years this has been my greatest joy in practicing medicine. The doctor-patient relationship and shared decision-making are the best method discovered to provide high quality and cost-effective patient care.

VI. Is Shared Decision-Making a New Concept?

Let me conclude my paper today by asking whether the shared decision-making model that emerged in the United States in the 1980s and that has

been the dominant model for the past 30 years is an entirely new concept or whether it builds upon history and tradition in Western medicine. To answer this question I will refer to two sources: Plato and, once again, Professor Pedro Laín Entralgo.

Plato

Almost 2,500 years ago, in a remark in Book IV of *The Laws*, Plato recognized that good doctor-patient relationships were required to achieve the goals of medicine. Plato began by describing what he viewed as inadequate or poor doctor-patient relationships, what he called “*slave medicine*.”⁷ Here is what Plato said about slave medicine:

“The physician never gives the slave an account of his problems nor asks for any. He gives some empiric treatment with an air of knowledge in the brusque fashion of a dictator and then rushes off in haste to attend to the next ailing slave.”

Plato contrasted this inadequate or poor doctor-patient relationship with what he called the physician-patient relationship for free men. In good doctor-patient relationships, Plato said:

“The physician treats the patient’s disease by going into things thoroughly from the beginning in a scientific way. He takes the patient and family into his confidence. Thus, the physician learns from the patient. He never gives treatments until he has won the patient’s trust, and when he has done so, he aims to produce complete restoration to health by persuading the patient to cooperate with the treatment.”

This quote from Plato suggests that when patients are noncompliant, or do not cooperate with the physician’s recommendation, it is not primarily the patient’s fault. Rather, it is the fault of the physician who fails to earn the patient’s trust before proposing a treatment plan. It is amazing how similar the views of Plato are to those of Professor Laín who is quoted at the beginning of my paper as saying that good patients are often found in the practices of good doctors.

2,500 years ago, Plato believed that the best clinical medicine is practiced when the physician and patient have established a doctor-patient relationship in which the scientific aspects of care are placed in the context of a personal relationship, a relationship that reminds us very much of shared decision making. Only in this human relationship can the benefits of modern scientific medicine be provided to meet patient needs, which have remained essentially unchanged since the times of Hippocrates and Plato. Not only have patient needs stayed the same, but the effectiveness of the doctor-patient relationship has hardly changed between Plato’s time and our own.

Professor Pedro Laín Entralgo

As I noted at the start of this paper, Professor Laín has taught us that the doctor-patient relationship has existed in Western medicine for more than 2,500 years. Professor Laín believes that such a relationship is needed to achieve the clinical and psychological goals of medicine, which are to help the patient. Further, Professor Laín’s view is that the ideal doctor-patient relationship requires a model of friendship, which he calls *philia*, between the patient and doctor and this helps us to understand why the shared decision-making model of the past 30 years more closely conforms to the history of the doctor-patient relationship than a model that establishes an adversarial relationship between doctor and patient. In the United States, in the face of contemporary health reform including comparative effectiveness panels, we are likely to see a continuing struggle in the next decade to retain the essential elements of the doctor-patient relationship and shared decision-making and the model of medical *philia* that Professor Laín has taught us to respect. I am confident that the United States and Europe will preserve the doctor-patient relationship as described by Professor Laín because it remains the most effective, most efficient, most elegant, and least expensive way to provide high quality health care and improve health for all of our people.

References

1. Laín Entralgo, Pedro. *Doctor and Patient*. New York: McGraw-Hill, 1969.
2. Laín Entralgo, Pedro. *What Does the Word Good Mean in Good Patient? Changing Values in Medicine*. Ed. Cassell, E. J., Siegler, M. University Publication of America, 1979.
3. Siegler, Mark. "The Progression of Medicine: From Physician Paternalism to Patient Autonomy to Bureaucratic Parsimony". *Arch Intern Med*-Vol 1 145, April 1985.
4. MacIntyre, Alasdair. *Medicine Aimed at the Care of Persons Rather than What...? Changing Values in Medicine*. Ed. Cassell, E. J., Siegler, M. University Publication of America, 1979.
5. Siegler, Mark. "Searching for moral certainty in medicine: a proposal for a new model of the doctor-patient encounter." *Bull. NY Acad. Medicine* 57.1 (1981): 56-69.
6. Making Health Care Decisions: A report on the ethical and legal implications of informed consent in the patient-practitioner relationship. Washington, D.C.: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982.
7. Plato. *The Laws*. Taylor, A.E., translator. London: Dent, 1934.

**Past and Future
Contributions of Clinical
Ethics to Patient Care**

Introduction

The title of my paper, “The Past and Future Contributions of Clinical Ethics to Patient Care,” emphasizes that it is essential that clinical ethics contribute in a positive and constructive way to improving patient care. But the notion that ethics should encompass medical issues and contribute to patient care has not always been accepted as a major role for bioethics. This, in fact, remains one of the major differences between bioethics and clinical ethics.

For the past fifty years, the bioethics movement has systematically examined the moral basis of clinical and research practices and has contributed a valuable perspective to medicine. Bioethics used the focus of theological ethics in the 1960s and philosophical ethics and law since the 1970s to probe and constructively criticize medicine. The bioethics movement emphasized patient autonomy, patient rights, and broad public policy concerns such as distributive justice in health care. On the whole, bioethicists have been “loving critics” of medicine and their goal has always been to improve medicine, at least in theory. But what about another goal, improving medicine in practice, that is, improving patient care? Here, unfortunately, the contributions of bioethics are less clear. In 1978, when I originally described the field of clinical ethics, I wrote: “Whatever else medical ethics is, it must have something to do with the practice of clinical medicine, or at least it should.”¹ Others disagree. For example, Dan Callahan, the former director of the Hastings Center on Bioethics, and an earlier lecturer on the Josep Egozcue Lectures (October, 2007)² has written: “While I would hardly want to overlook the needs of the physician practitioner, I now wonder if that is the right place to center our attention. Does reality lie in the particularity of individual cases where most clinicians think it does or in a more general abstract and universal realm?”³

In response to Callahan’s emphasis on bioethics theory, Leon Kass has criticized the ethics movement for being *too* theoretical, philosophical, hyperrational, and ideological, while at the same time failing to examine routine practice issues and failing to consider the habits and behaviors of physicians

and the profession. Kass considered the issue and wrote: “Though originally intended to improve our deeds, the practice of ethics, if truth be told, has, at best, improved our speech. The real action in practicing ethics will begin when we again see ethics as practice, as the combining of character and custom, in conduct that both creates and manifests the human agent, negotiating the many challenges of the human condition.”⁴

This tension between the theoretical and the practical remains one of the central differences between traditional bioethics and the modern movement in clinical medical ethics.

This paper will focus on the new discipline of clinical ethics and will explore its contributions to patient care. The paper is divided into the following three major sections:

- Part I. Three reasons for the increased importance of clinical ethics in the United States and Europe during the past fifty years;
- Part II. How clinical ethics currently contributes to patient care; and
- Part III. How clinical ethics will contribute in the future to patient care.

Part I. Three reasons for the increased importance of clinical ethics during the past fifty years

The three reasons I have selected to explain the increased importance of clinical ethics during the past fifty years are:

1. Recent medical achievements that gave physicians a new control over birth and death;
2. Abuses in medical research and the need to protect human subjects in medical research; and
3. A new understanding, worldwide, about human rights.

1. Recent medical achievements that gave physicians a new control over birth and death

In this section of the paper, I have chosen to discuss three scientific-technological developments that have changed medicine and its capacities. The three developments I will examine are:

- a) Organ transplantation (1954);
- b) Mechanical ventilation (~1975); and
- c) Reproductive technology (1978)

Please note that each of these developments is relatively recent, the oldest among them, organ transplantation, having been done successfully less than sixty years ago, and the most recent one, reproductive technology, having started as recently as thirty years ago. Further, two of these extraordinary scientific achievements (transplantation and mechanical ventilation) have given physicians a new power that has never before existed in the history of mankind, the ability to save lives by reversing critical end-organ failure. The third development, reproductive technology, enables man to create babies outside of the body. Taken together, these three technologies have given physicians and scientists Promethean power over death and life, perhaps not quite equivalent to Prometheus stealing fire from the Gods, but nevertheless a form of scientific and clinical control that man has never before possessed.

Let us briefly examine these three scientific developments that have changed medicine's capacity.

- a) *Organ transplantation (1954)*. The first successful organ transplantation was a kidney transplant between identical twin brothers in 1954, performed in Boston at the Peter Bent Brigham Hospital, under the direction of Dr. Francis Moore, the Chair of the Harvard Department of Surgery. This successful operation established a "Proof of Principle" that medicine was able to reverse end-organ failure in man. When effective immunosuppressive medication became available, first in the 1960s and later in the 1980s, surgeons were able to perform not only kidney transplanta-

tion, but also liver, heart, lung, pancreas, and small intestinal transplantations. At last, many end-organ diseases could be reversed and cured.

- b) *Mechanical ventilation*. The second example I will discuss is the use of mechanical ventilators. In 1972, I developed one of the first medical intensive care units in the City of Chicago. In those days, the breathing machines available to us were ineffective pressure ventilators. These machines would break or the lungs would not tolerate the pressure after a few days. They were useful only for short-term ventilatory support. Three years later, however, by 1975, a new type of ventilator, the volume ventilator, became widely available. These new ventilators permitted indefinite ventilatory support, and would work for weeks, months or even years. That was an enormous change in the technology of medicine, because now we could keep people alive who were not able to breathe on their own for a very long time.
- c) *Reproductive technology*. My third example is reproductive technology. In 1978, Dr. Patrick Steptoe and Robert Edwards created the first so-called "test tube baby," Louise Brown, who has now conceived naturally and has given birth to her own child. On 2010, Dr. Robert Edwards received the Nobel Prize for his pioneering work in reproductive technology.

My reason for showing these three revolutionary developments in modern medical science – organ transplantation, mechanical ventilation, and reproductive technology – is to establish the point that these kinds of dramatic changes in medicine over the past two generations have created new and profound questions for clinical medical ethics and have thus increased the importance and relevance of clinical ethics and ethical analysis.

2. Medical research and the need to protect human subjects

The second reason for the increased importance of clinical ethics has to do with medical research and the need to protect human subjects. This effort began with the recognition that there were abuses of human subjects that took place in the context of medical research. The most egregious of these

atrocities was the work of the Nazi doctors during World War II. After the war, the Nazi doctors were put on trial at Nuremberg. A code of ethics was developed after the Nuremberg trials, the so-called Nuremberg code of 1947. That code has remained the foundation of all the later ethical research codes. There are ten principles included in the Nuremberg code but I will mention just three of them here.

Principle one required the voluntary consent of the human subject. No experiment could be performed without the permission of a human subject. The fourth Nuremberg principle said that medical experiments should be conducted so as to avoid all unnecessary physical and mental suffering and injury. The ninth Nuremberg principle said that during the experiment, the human subject should always have the freedom to end the experiment and to withdraw from participation. The Nuremberg principles did not have any official standing. In 1964, however, the World Medical Association, meeting in Helsinki, Finland, adopted the Nuremberg Code as the basis for the first code of research ethics. That code, the so-called Declaration of Helsinki of 1964, became the basis for all subsequent international research standards for conducting human research. The Helsinki Declaration has been amended eight times since 1964, but the fundamental principles, the ones that originated at Nuremberg and that were incorporated into the Helsinki Declaration, have remained in force to the present time.

Unfortunately, the Nazi physicians were not the only ones to abuse human subjects in the context of research. In 1966, Dr. Henry Beecher, writing in the *New England Journal of Medicine*, highlighted more than twenty instances in the United States of unethical research conduct by physician-investigators.⁵ And in later years, revelations about Willowbrook and Tuskegee in the United States demonstrated conclusively that unethical research studies were being done on human subjects, often on vulnerable human subjects. In recent months, new information has emerged that U.S. physicians conducted unethical syphilis experiments involving prisoners and patients with mental illness in Guatemala in the late 1940s.

Recently, I was asked to comment on the Guatemala experiments by the *New York Times*, and I stated that it was appalling that at the same time that the

United States was prosecuting Nazi doctors for crimes against humanity at the Nuremberg trials, the United States government was supporting research in Guatemala that placed human subjects at enormous risk. In the Tuskegee study, the African-American men who were being studied had developed syphilis through sexual contact and were not properly treated. In Guatemala, the syphilis was injected into research subjects by inducing sores and scrapes on their skin and then injecting syphilis into the skin or directly onto the penis in order to give the men syphilis. The Tuskegee and the Guatemala experiments were both evil and unethical.

Thus, a worldwide focus on medical research and on protecting the rights of human subjects is a second major reason for the increased interests in clinical ethics during the past fifty years.

3. A new understanding of human rights

The third reason for the increase in interest in medical ethics is what I call a new understanding of human rights. After World War II, in both the United States and Europe, there were new understandings of civil rights, racial rights, student rights, and women's rights. Patient rights were part of this general movement toward redefining the appropriate relationship of individuals and professional authority structures. Many of the changes in medical ethics during the past fifty years have come about because of this redefinition of patient rights. These changes include the importance of telling the truth to patients about their diagnosis, the importance of obtaining informed consent from patients before treating them, and the general movement away from paternalistic-authoritarian medicine.

In conclusion, my view is that, during the past fifty years, advances in medical science, concerns about protecting human subjects during medical research, and profound changes in human rights, have together made clinical medical ethics increasingly important in the United States, Canada and Europe.

Part II. How clinical ethics currently contributes to patient care

In this section of the paper, I will begin by describing the field of clinical medical ethics – its goals, methods, and the range of issues it deals with, and will then discuss the following four ways in which clinical ethics contributes to improving patient care:

- by providing a decision-making approach,
- by direct patient services,
- by teaching clinical ethics, and
- by doing clinical ethics research.

1. What is Clinical Medical Ethics?

Clinical ethics is a practical field – practical as opposed to theoretical – that helps patients, families and health professionals reach good clinical decisions by taking into account both the medical facts of the situation and the patient’s personal preferences, values, and wishes. Clinical ethics emphasizes the importance of integrating the medical issues and medical details of a particular case with the personal preferences and values of the individual patient. The goal of clinical ethics is a very practical goal: to improve patient care and patient outcome. One other ancillary goal is to improve the comfort and the satisfaction of the health professional – the doctor and the nurse – by helping them feel they are working effectively with the patient and the family.

By what methods does clinical ethics achieve this goal? One method is to incorporate ethical considerations and patient choice in reaching healthcare decisions, thus allowing the patient to become an active participant in decisions. And the second method is by emphasizing the ethical obligations of the health professional, both doctors and nurses. These obligations include clinical competence, honesty, compassion, and respect for the patient. These are the methods that clinical ethics uses.

Another way to look at clinical ethics is to think of its content and the range of issues it addresses. The content of clinical ethics includes the study of the doctor-patient relationship and also the study of specific ethical issues. Thus, clinical ethics must include a focus on the ethos of the professional and on the character and virtues of the physician, who is expected by the public to demonstrate these character qualities. In addition, clinical ethics examines specific ethical issues including truth telling, informed consent, confidentiality, end of life care, pain management, palliative care, allocation of clinical resources, and the ethics of medical research and innovation.

How is clinical medical ethics different from philosophical bioethics? First, as previously noted, clinical medical ethics is practical, not theoretical. Further, the foundation of clinical medical ethics derives from medicine rather than philosophy, theology, or the law. Additionally, clinical medical ethics must be practiced by clinicians – by physicians and nurses – at the bedside or in the office.

Kierkegaard captured the crucial distinction between those who operate in the real world of practical experience and those who offer theories but are not themselves practitioners. Although Kierkegaard uses, for his example, a ship captain, the same distinction would apply to a clinical ethicist who practices medicine as compared to a bioethicist who views medicine from a theoretical perspective.

“Let us imagine a ship captain who had passed every examination with distinction, but that he had never been at sea. Imagine him in a storm; he knows everything he ought to do, but he has not known before how terror grips the sailor when the stars are lost in the blackness of night; he has not known sense of impotence that comes when the captain sees the wheel in his hand become a plaything for the waves; he has not known how the blood rushes to the head when one tries to make calculations at such a moment; in short he has had no conception of the change that takes place in the knower when he has to apply his knowledge.”

The distinction that Kierkegaard makes here is between theorists of bioethics and the doctor and nurse in the intensive care unit or in the emergency

department who is faced with a real patient and a real crisis and must use all of his or her skills and ethical and clinical knowledge to provide the best care for that person.

2. Four ways in which clinical medical ethics contributes directly to patient care

With this background describing the field of clinical medical ethics, I now wish to examine four ways in which clinical medical ethics contributes directly to patient care.

a) Clinical medical ethics provides a structured approach to ethical decision making

In 1980, in writing our book *Clinical Ethics: A Practical Approach To Ethical Decisions In Clinical Medicine*, Al Jonsen, William Winslade, and I developed what we called a four-box model to help with ethical decisions as well as clinical decisions. The four boxes are arranged in a rectangle with two of them being above a horizontal line and two below. Above the horizontal line, the critical issues are the medical facts in a case, the medical indications, and then, also above the line, the preferences and wishes of the patient. Each of these boxes reflects certain principles in medical ethics. For example, beneficence, one of the oldest of ethical principles, is reflected in the medical indications box, and autonomy, the right of choice for patients, is reflected in the patient preference box. Most medical decisions are reached using these two “above the line” factors: medical indications and patient preferences. The other two boxes in the rectangle are below the line: quality of life for the patient, and the social and economic issues. These are the four considerations that doctors should think about in trying to reach good decisions between themselves and the patients. We have structured our book in such a way that each of the four chapters discusses one of the four boxes and one of the four ethical principles involved. In 2005, Professor Victòria Camps wrote a prologue to the Fifth edition of our book and it was translated into Spanish with assistance from the Gri-

ffols Foundation.⁶ The seventh edition of the book was released in the United States recently.⁷

Just a few final points about the four-box model. Most decisions in the United States and Europe continue to be reached above-the-line based on medical indications and patient preferences. When clinicians must go below the line to reach decisions, clinical ethical problems intensify and become more complicated. Most decisions above the line are not controversial and are not adversarial, but rather they use a process of negotiation that we call “shared decision making” between the doctor and the patient to arrive at a clinical choice, a clinical decision. This decision-making approach described in our book is one of the current ways that clinical ethics contributes to improving patient decisions and patient care.

b) Clinical Ethics provides direct patient services

The principal way that clinical ethics provides direct patient services is by organizing ethics committees and ethics consulting teams. In order to be accredited and approved, all U.S. hospitals are now required to have committees or consultants who can address ethical dilemmas that may arise while taking care of patients.

Ethics consultations and committees can serve four functions: to educate the staff, to set institutional policy, to provide a non-judicial mechanism for the review and resolution of cases involving conflicts, and to directly influence patient care decisions. Committees and consultants improve clinical ethics decision-making by educating the hospital staff and by developing rational and sensitive institutional policy on ethics matters, such as brain death, ‘do not resuscitate’ orders, living wills, and organ transplantation. It is hoped that institutional ethics committees can assist in conflict resolution and thus spare the various parties the time, expense, and anguish of litigation and judicial intervention. A critical question still facing ethics committees and consultants, however, is whether they improve the process and outcome of clinical-ethical decision making when they become directly involved in individual patient care decisions.⁸

Who should staff ethics committees or consultations services? The consultant clinical ethicist must be able to “do” ethics under fire in ambiguous situations. This requires not only a broad knowledge of ethics but also objectivity, compassion, and a capacity to counsel and psychologically support the participants without imposing one’s own moral values upon them. The clinical ethics consultant must be available and accessible to colleagues when crucial decisions are made. He or she must be familiar with not only ethical theories and principles but also relevant policy statement, legal cases, and published research. The consultant must be knowledgeable in the clinical details of the situation and must be ready to apply clinical judgment and discernment to the case at hand.

A physician who is competent as a clinician and has been trained in medical ethics is particularly effective as a consultant. Such persons enjoy the advantages of a firm grasp of the factual tripod on which ethical decision must rest: diagnosis, prognosis, and therapy. They also have experience in making clinical decisions that are urgent, complex, emotionally charged, and filled with uncertainty; in addition, they are accustomed to counseling patients.

The properly trained and clinically acculturated professional ethicists should be able to meet many of these same requirements. This would, of course, mean that the professional ethicist must assimilate many elements of a medical education in order to approach the synthesis of technical and moral capability. The best professional ethicists today have done just this.

c) Clinical Ethics Teaches Physicians Practical Clinical Ethics Knowledge

The main goal in teaching clinical ethics is not to produce professional ethicists but is rather to produce ethically knowledgeable physicians and thus improve the quality of patient care. We teach clinical ethics because physicians must know something about ethics in order to practice competent, high quality medicine. The modern standard of care requires a practical working knowledge about such ethical subjects as informed consent, truth-telling, confidentiality, end-of-life decisions, surrogate decision-making, the use of

innovative, non-standard treatments, and physicians’ ethical responsibilities when working within health care bureaucracies such as managed care organizations. The modern physician is not able to practice good medicine without some working knowledge about these topics. Further, patients and society expect physicians to have not only technical proficiency but also the practical ability to recognize and respond to ethical issues such as those mentioned.

Regarding the question of how ethics should be taught, our own approach emphasizes that teaching be clinically based, use real cases, be continuous throughout the medical curriculum, and also be coordinated with students’ other learning objectives. Such teaching can be provided through lectures or in practice settings such as rounds, conferences, or case conferences. The best teachers of this material are clinicians who themselves are responsible for patient care and for clinical teaching.

d) Clinical Ethics Conducts Research Designed to Improve Patient Care

Clinical ethics research aims to improve patient care by examining how patients make their own choices and decisions. Clinical medical ethics research may be divided into two broad categories, analytical and empirical research.⁹ Analytical research uses the methods of legal and philosophical reasoning to examine conceptual issues and to develop defensible recommendations for ethically acceptable practice. Empirical research in clinical medical ethics involves the collection and analysis of clinical data to describe the way clinical decisions are in fact made by patients, by physicians and within the patient-physician relationship. Empirical research examines the values that are used in reaching clinical decisions, how they are used, by whom and under what conditions. This type of research uses the methods of the social sciences, decision analysis, clinical epidemiology, and health services research. This latter type of research is quite different from the legal philosophical research of analytical medical ethics. Empirical research may help to understand the ethos of professionals and the preferences and values of patient regarding a wide range of ethical issues in medicine. This type of research has helped clarify end-of-life issues and advance directives, good

care of the dying, decisions making in AIDS, patients' views on quality of life, and the value of ethics consultations.

Some of the most important clinical ethics research of the past fifteen years has explored aspects of the doctor-patient relationship, including communication, patient empowerment, and shared decision-making. We have learned from ethicists and health service researchers that patients who enjoy good doctor-patient relationships and who interact actively with physicians to reach a shared health care decision have greater trust in their doctor, have greater loyalty to the doctor-patient relationship, co-operate more fully to implement the shared decision, tend to make financially conservative decisions, express greater satisfaction with their health care, and have improved outcomes, at least for four chronic conditions: hypertension, diabetes, peptic ulcer disease, and rheumatoid arthritis.

Recently, Wennberg made a statement that could serve as a future research agenda for the field of clinical ethics: "It is the job of the evaluative sciences to conduct technology assessment and outcomes research to estimate the probability for outcomes that matter to patients and to elucidate the important of patient preferences in choosing treatment."¹⁰

Part III. How Clinical Ethics will Contribute in the Future to Patient Care

In the future, Clinical ethics will contribute to patient care in the following ways:

1. By balancing community and individual needs

In modern medicine, there are often tensions, sometimes even conflicts, between what is best for individuals and what is best for whole communities or populations. At times, difficult trade-offs must be made that take account of potential competing interests. These tensions can arise over questions of contagious disease, vaccine policy, confidentiality, and even questions relat-

ed to bioterrorism. In each of these cases, clinical ethics may help to achieve reasonable and practical balances between the medical needs of individuals and those of the community.

2. Global health and disparities

Disparities in health care and in health status at the global level are not only social and political challenges but are bioethical challenges as well. Preventable death and disabilities from disease such as malaria, TB, HIV, and diarrheal diseases demand a response from the clinical ethics community. These issues directly engage the energy of many clinical ethics experts.

3. By strengthening the doctor-patient relationship

Clinical Ethics aims to re-establish the alliance between patients and physicians that traditional medical ethics may have helped weaken by artificially driving a wedge between the doctor and patient on the false dichotomy of autonomy and paternalism and by distorting the doctor-patient relationship in considering it an adversarial relationship. In the vast majority of clinical encounters, the patient and physician are not adversarial but are allies and the agreement is that the goals of the patient who seeks help and of the physician who offers to help coincide. The doctor-patient relationship, at the heart of medicine and at the heart of clinical ethics, will survive for the following reasons:

- a) medicine services an unchanging human need;
- b) medicine's goals have not changed since Hippocratic times; and
- c) physicians continue to be respected and wanted by patients

The best clinical medicine, is practiced when physician and patient have established a fully human relationship in which the technical and scientific aspects of care are placed in the context of the doctor-patient relationship. Only in this human relationship can the benefits of modern medicine be provided in ways that patients want and in ways the physician believes to

be in the patient's best interest. The contribution of clinical ethics will be to strengthen, nurture and improve this vitally important relationship.

4. How clinical ethics will contribute in the future to patient care

One of my former students, Dr. Preston Reynolds, has defined medical professionalism as follows: "A set of professional values, attitudes, and behaviors that result in serving the interests of patients and society before the physician's own interest."¹¹ The key concept in medical professionalism is that medical professionals should be motivated primarily by the needs of the patient – a kind of altruism – and not primarily by self-interest, either economic or other self-interest.

In 2006, the Spanish physician, Dr. Garcia Sabrido, responded to some Americans who had criticized him for treating Fidel Castro. In defending his actions, Dr. Sabrido referred to his professional duty: "When a physician is called upon as a physician, his duty is to be a physician. If I am asked my opinion about a patient, I don't ask about his religion or his political ideas. I am a professional doctor and I devote myself to that. For me, President Castro is an exceptional patient, but he's still a patient." This is the essence of professionalism.

Writing in 1927, an American physician, Dr. Francis Peabody, had spoken about the physician's professional qualities: "The good physician knows his patients through and through and his knowledge is bought dearly. Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient."¹²

The great Spanish physician, Dr. Pedro Laín-Entralgo, has written: "Insofar as man is a part of nature and health and aspect of man's nature, the medical relationship ought to be more than mere comradeship. In fact it should be *phillia*, friendship. A good doctor has always been a friend to his patient, to

all his patients, and a patient also tries to be a true friend to his doctor, and often succeeds."

This is the language of professionalism, something that has become increasingly important in the United States as we struggle to redeem the qualities of medicine and doctoring that seemed to have been lost in the last generation. As medical science has made great progress, there seems to have been an attenuation of the relationship between doctors and patients. Clinical ethics hopes now and in the future to help restore that critical balance by strengthening professionalism and by strengthening the doctor-patient relationship.

References

1. Siegler, M. A Legacy of Osler: "Teaching clinical ethics at the bedside". *JAMA* 1978; 239: 951-956.
2. Callahan D. *El bien individual y el bien común en bioética*. Barcelona: Fundació Víctor Grífols i Lucas, 2010.
3. Callahan D. *On Living (well) within Limits*. Hastings Center Report, November-December 1996; 16-19.
4. Kass LR. *Practicing ethics: Where's the action?* Hastings Center Report 1990; 20: 5-12.
5. Beecher HK. "Ethics and clinical research". *N Engl J Med*. 1966; 274: 1354-60.
6. Jonsen, A, Siegler M, Winslade W, (prologue by Camps, V.) *Ética Clínica: Aproximación práctica a la toma de decisiones éticas en la medicina clínica*. Ariel: Barcelona, 5th ed.
7. Jonsen, A, Siegler, M, Winslade, W. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. McGraw Hill Medical, 7th edition.

8. Siegler M. and Singer P.S. "Clinical Ethics Consultation: Godsend or God Squad?" *American Journal of Medicine* 85 (1988):759-760
9. Singer PA et al. "Research in clinical medical ethics". *J. Clin. Ethics* 1990; 1: 95-99.
10. Wennberg J. Health Outcomes. Wyngaarten JB, Plum F, and Bennett C eds.; *Cecil Textbook of Medicine*. 20th Edition Philadelphia: WB Saunders, 1996.
11. Kelley, W. *Textbook of Internal Medicine*. 4rd Ed. Lippincott-Raven, 1997: 7.
12. Peabody FW. "The care of the patient". *JAMA*. 1927; 88:877-82.

Discussion

This is a summary of the discussion session in which participants considered some of the issues raised during the lectures, and had the opportunity to put questions to Mark Siegler. The session, chaired by Màrius Morlans, Member of the Ethics Committee of the Vall d'Hebron University Hospital, touched on a range of issues related to the doctor-patient relationship and bioethics. These included the concerns of many health professionals as to the need for ethics committees, together with issues such as the efficiency of public health systems, child patients, research into patient preferences, teaching and the role of philosophy in medical ethics.

The doctor-patient relationship

Eduard Prats, Sant Joan University Hospital, Reus

I found the notion of the four eras of the doctor-patient relationship very interesting: the era of paternalism, the era of autonomy, the era of bureaucracy (which we might also call the era of management) and the fourth era of consensus and negotiation between doctor and patient. In your lectures, you presented this as a chronological progression. With some patients, the relationship is based on dialog, with consensus and shared decision making, but at times one has to be paternalistic or bureaucratic. Do you believe that it is possible to mix these four styles of relating to patients in the daily practice of medical care?

Mark Siegler

Yes, I do. What I have described chronologically speaking as the four eras of medicine would clearly be more accurately represented as a series of lines which cross over one another. The era of paternalism was very important during the 1950s but is now in decline, while the era of autonomy, which began in the 1960s and 1970s, arguably peaked during the 1980s, together with shared decision making. They are lines which cross over; it's not that one disappears and another one starts. You are absolutely right when you say that, for some doctors and patients, in some circumstances, a paternalistic

model may be the correct approach to a particular situation. Indeed, in my experience, I know that many patients prefer this type of paternalistic relationship. There are people who don't want to take decisions. They say, "Look, I've come to see you, doctor, because you're the expert. Please help me. Tell me what I need to do. What would you do if I was your mother?" That is an invitation to reply in a paternalistic manner. One still occasionally comes across very strong, very independent people who ask the doctor for information but then take their own decisions. Normally, their decisions are good ones, but sometimes they make mistakes. And then we ask, what should the doctor do? How should the doctor intervene to suggest that maybe the patient should consider an alternative to his or her decision? In that case, I would opt for the overcrossing lines. At any moment in time, during the 1980s, the 1990s, even today, one could find all sorts of doctors and patients.

Health management

Joan Manel Salmerón, Hospital Clínic, Barcelona

I would like to focus on management. When we talk about the bureaucratic era or the era of funding, we must consider the concept of efficiency. In your lecture it seemed as if this was just an obstacle which got in the way of, even distorted, the doctor-patient relationship. However, those of us who have always enjoyed the benefits of a public health system, as is the case in Europe where such health systems are very advanced, understand that efficiency is a duty. In your vision, it seems as if this is in the hands of others: of bureaucrats and administrative staff. Don't you think that health staff, in this case medical staff, even if their key relationship is with the patient, should always be aware of the concept of efficiency within the process of negotiating and taking shared decisions?

Mark Siegler

Yes, I strongly believe that. I refer to bureaucracy from two perspectives. One is that suggested by Professor MacIntyre, who argues that the modern doctor

is a manager, the person who controls access to a very complex system of services: to diagnostic procedures, treatment, admission to hospital, medicines etc. From this perspective, the modern doctor must function as an administrator, as a manager, as a bureaucrat, because the system is very complicated and someone has to enable the patient to access it and receive benefits from such a complex system. This is Professor MacIntyre's idea. In my lecture, when I talked about the age of bureaucracy, I suggested that it differed from the Hippocratic tradition in which there is an individual relationship between doctor and patient. This involved people working in an isolated manner to care for patients, but the modern system which, as I said, is a complex one, requires somebody to look out for public health needs, the needs of the community, of the financial system, of whoever pays the bills. And also, in the final instance, doctors control society's resources through the individual decisions they take.

In answer to your question, I believe it is essential that the doctor be a skilled guide who knows how to manage social resources: that is, the money available to provide healthcare to the whole community, to the whole population. Doctors must take decisions which are in the patient's interests, while remaining aware of, indeed responsible for, their public consequences and repercussions. As I said in the lecture, this is a different role for the modern doctor. I believe you have detected a slightly negative attitude, a slight wavering on my part, when I described the glorious days of the past, a time when these financial and fiscal realities were not always so present. No doubt they also existed, but I established a certain tension between the ancient tradition and a modern one which is more social and communal. This role is characteristic of most health systems, both European and Canadian, for example, and increasingly of the system in the United States. I continue to trust in the shared relationship between doctor and patient. As I mentioned in the lectures, if only in passing, if you allow shared decision making you often realize that the relationship between the two will give rise to medicine which is more economically efficient, more coherent, with decisions which have been more carefully considered and are not excessively onerous. Even if they are not taken on a purely economic basis but rather on the basis of patient needs, I believe that between the two of them doctors and patients arrive at decisions

which many of us consider appropriate and reasonable. And this encourages us to establish this system of negotiating shared decisions. Often, this is the right model and, from a social perspective, the one which enables the best decision to be taken.

Ethics committees

Pablo Hernando, *Corporació Sanitària Parc Taulí, Sabadell*

When I first became interested in ethics committees, back in 1991, I read an article of yours which made a big impression on me, published in 1986 in the journal of the Hastings Center. It was called, "Decisions by Bureaucracy"¹ and heavily criticized these committees. I see that you have changed your opinion somewhat since then. My question is, what is the situation regarding these committees in the United States, in light of Kuczewski's 1999 article which talked of *failure to thrive*² and appeared to be reporting a crisis? What is your experience of consultations? When I heard the figure of 150 per year, I was surprised. The average number of consultations in Spain is three per year, and according to the studies I've seen, the figures are similar in the United States. I would appreciate it if you could talk about ethics committees. I imagine your position has changed since 1986, but I would be grateful if you could give me your opinion on this issue.

Mark Siegler

I have two perspectives. To be honest, I'm not sure which to choose. In 1986, in the publication to which you refer, I said that ethics committees run the risk of taking decisions which are not good for the patient. This is because committees consist of a group of people who talk to each other but do not include either the doctor or the patient, the people most directly involved. Perhaps you remember that in that publication I said that my hope for the long term was that ethics committees would cease to exist, because they had already clarified the essential aspects of clinical ethics for both doctors and patients and that, therefore, there would be no need for experts or advisers.

Doctors, nurses and patients would be capable of resolving all these problems. In fact, I recall that at the end of that article I referred to quite a curious case. I said that real experience in ethical issues, taking hospitals as an example, is located in small units.

Dr Morlans is a nephrologist and, if I want to know something about the ethical problems associated with kidney disease or transplant, him and his colleagues in surgery, nursing and social support who work in the field of renal pathology, are the ones who best understand this issue. In a hospital which performs a whole range of different types of transplant operation, the ethical issues associated with each are so different that I would consult Dr Morlans and his colleagues about kidney-related issues, but if I needed to know about heart transplants then I would talk to experts in that area. This is where doctors have the most thorough knowledge of the issue. And the same could be said of neonatal care. We shouldn't talk to an intensive care doctor if the issue at question concerns childbirth, for example. In sum, the experts are experts, and ethical discussion with these teams of experts would replace discussion within the ethics committee. This has not happened as rapidly as I had expected, particularly if we remember that we are talking about 25 years ago. I am confident that, if this idea were to become a reality, we would train enough doctors and nurses to understand these ethical decisions, and in particular those affecting their own work, and the decisions they take every day. As a result, the need for ethics committees would be reduced. Unfortunately, perhaps because of the rapid advance of technology, new ethical problems continue to arise which mean that ethics committees will continue to be necessary for some time.

Another issue which concerns me is the need to consult committees even when the problem has been resolved (at least in theory), such as in the case of good care at the end of life. I believe that during the last thirty years we have made a lot of progress, providing better care to patients who are close to death: palliative care, pain relief, the right to take decisions, etc. All of this, in theory, has been achieved. However, in daily practice, at least in my hospital, it is surprising to observe how old questions about care at the end of life come up time and time again. It is as if doctors and nurses who know and

understand at a theoretical level what they have to do, how far they can go, want the committee to come and say, "Yes, go ahead, no problem. Go ahead, you can do it. It's acceptable, it's appropriate, it's reasonable." They know before they are told, but they want the stamp of approval from the committee, as if it provided external authorization for decisions which they know have to be taken, and which they take well. We have advanced, but we still have a long way to go, there is some ambivalence between what I would like to happen, the disappearance of these committees, and the actual day to day situation which makes them useful.

Pediatric patients

Josep Lloret, Hospital Universitari Vall d'Hebron, Barcelona

I am a pediatric surgeon, and I would like to know if everything you have said with regard to the doctor-patient relationship can also be applied to patients who are minors and their parents or guardians. I would like to hear if you think this model also applies to such cases, or if there are peculiarities when the patient is a minor and is unable to express his or her interests or life project.

Mark Siegler

This is a very important issue. Everything I have said has been based on my experience as a doctor working with adults, but when children are involved the situation changes a lot. Clearly, babies require total protection: usually this is provided by their parents, and sometimes by society. We cannot ask them to express their preferences or desires for themselves, regardless of whether what is being proposed is major surgery or protective vaccination of the type given to all children. As children grow, they become capable of ensuring that their wishes are respected; they need to be encouraged to express their preferences, and we need to get into the habit of listening to them. In the United States (I don't know about Spain) we use the rule of seven. A child aged between 0 and 7 years is listened to, but does not decide. Between 7 and 14 years, as the child

nears 14, he or she has more and more say in treatment. And between 14 and 21 years, we take very seriously everything the individual says. In the United States the age of majority is 18 years and, as the individual nears this age, he or she has more power to decide upon treatment. But there is also a peculiar exception with regard to issues relating to contraception and the control of fertility. In this case, from 14 years of age, children can express their wishes and be heard. As I said, paediatrics is complicated, and this completely changes the situation. There are also lots of types of parent: some are very good parents, but others are less interested in the wellbeing of their children, and when that happens you have to find somebody else to protect the child – the state, the government or whatever. That's why I mainly work with adults, because in my opinion paediatrics is a very complicated area.

Investigating patient preferences

Joan Córdoba, Vall d'Hebron University Hospital, Barcelona

I am an internal medicine doctor. For me, as somebody who works with patients, your lectures will help me to take decisions in complex situations. I was particularly interested in the investigation of patient preferences. You have shown how patients' preferences change and, in particular, with respect to cardiopulmonary resuscitation, how preferences change over time. Sometimes doctors tend to think that once a patient has taken a decision, it is forever, while the type of investigation you have undertaken shows that preferences, the decisions taken by the patient at a given time, can change. In this regard, I would like to know if anyone has analyzed whether this change in preferences is associated with other variables. That is, if there are factors which cause patients to change their decisions and whether this sort of analysis could have an influence on their preferences. If we find that preferences depend on certain factors, then we could influence and direct the patient. I suppose I am worried that studying patients' interests is double-edged: are we really thinking about patients, or are we studying their preferences in order to be able to influence them?

Mark Siegler

That's a very useful question. Yes, people are studying preferences or values. Economists call them utilities. But the amount of work still to be done is enormous. There are some groups studying those aspects which bring about change, but very few groups studying the changes themselves. And your question about which aspects cause the values and preferences of patients to be modified raises an issue which is still poorly understood. A while back we studied amyotrophic lateral sclerosis. With this pathology, we started with a hypothesis. We thought that the crucial modifiers were the progression of the illness, together with growing knowledge of the disease and accepting the reality which suffering from it entailed. In another example, that of pregnant women, the modifier was the difference between thinking about childbirth, and actually being in labor. Here, we have a change of state together with a change in how that state itself is experienced.

We have also done a study of terminal kidney disease, because it is possible to perform a longitudinal study as patients enter the terminal phase of kidney disease and have to be treated with dialysis. We looked at the types of choices to be taken in favor of and against dialysis, in favor of and against aggressive treatment. Using clinical markers to differentiate the stages of development of the disease, we then studied other people with the same pathology to see how their decisions developed or changed over time. All of this work was completed during the 1990s, but the truth is that not many investigators have followed up the work of our group in Chicago. I think it's a very rich area. There's a very good group in Dartmouth, and John Wennberg, one of the founders of this group, has been asked to advise the Obama administration. For thirty years he studied the separate but related problem of variability in healthcare practice.

In the United States there are 50 states. Each one consists of small communities, small towns, cities etc. When Wennberg and his colleagues studied, for example, bladder surgery, or hip replacements, or carotid endarterectomies, they discovered that there were massive differences between different states, sometimes as much as ten times the order of magnitude of the number of interventions per the same number of inhabitants. And within individual

states, they studied neighboring communities. In these studies, they observed that a given operation (gall bladder surgery, for example) could be five times more frequent in one community than in a neighboring one.

There did not appear to be differences with regard to the number of patients with gall bladder disease. Instead, other variables were causing surgery to be five, six or even ten times more frequent in one community than in its neighbor. The Wennberg group's question is to what degree this variability was determined by the doctor, the surgeon who performed this bladder operation, and to what degree it was determined by the patient who wanted the operation to be performed.

This effort continues, and the Obama administration is very interested in understanding the huge variability which exists in health care. And that brings me back to the issue of public health in general: identifying the optimum rate, the lowest rate, the highest rate, the median rate, and the reasons for these variations. A lot of work is being undertaken in this area, and there is a lot more still to do.

National ethics committees and the clinical relationship

Marc Antoni Broggi, *Germans Trias i Pujol Hospital, Badalona*

I am a surgeon and chair of the Bioethics Committee of Catalonia. I would like to put two questions to you. The first concerns your opinion of national committees. Here, in Europe, they are quite common and seek to provide guidelines or recommendations which transcend, for example, the local preferences or ideologies of individual surgeons and of hospitals or centers. Their purpose is to reflect upon issues which are of interest to the community.

The second question relates to the clinical relationship. My concern has always been that, in the shift from paternalistic medicine to contractual medicine, the relationship has become more distant. So, how can we teach future doctors that, even if the relationship is a contractual one for practical

reasons, it should be modified in the direction of a relationship based on *philia*, one which is friendly, horizontal and more intimate in complex situations? I think this variability is complicated, and brings with it a real risk of falling back onto practicing defensive medicine. Just now, at least for us, that's the danger. How can we teach all of that?

Mark Siegler

You have raised two very difficult questions. I will try to start with the first one, about the role of national ethics committees. A lot of countries have these committees. In the United States, when the president is elected, he usually appoints a new committee or presidential commission to resolve specific issues which have a big impact on the world of ethics. The danger of these committees, at least in the the United States, is that, because they are appointed by the president, their agendas are usually party political. And in Europe these committees sometimes have agendas of a religious nature. However, if we can ensure that a national committee is open-minded, that it is not subject to excessive political influence, then it can have an important role.

It would be of vital importance when deciding on or recommending public policies, particularly with regard to progress in medical technology, for example. The current Presidential Commission, appointed by President Obama, was asked, as its first task, to study the ethical problems associated with synthetic life. I don't know if you have followed the controversy, but there are people who are experimenting with the creation of life in a test tube. From an ethical perspective, this raises a whole host of interesting if at times recondite questions. In any case, there certainly are important issues at the national level, such as the allocation of resources, whether medicine should be publicly or privately funded, issues relating to medical care at the end of life, etc. I believe that a committee can do great work in these areas.

The second question you raise is a fascinating one. How do we teach people? How should we prepare our young people, the doctors of the future, so that they understand that at some times and in some situations they will wish to maintain a doctor-patient relationship which, as you note, is contractual in

nature, while at other times and under other circumstances, a relationship based on *philia*, on friendship, will be more appropriate. It's what we said before, what Professor Laín Entralgo said. I believe that, while it is not an easy task, young people should be taught that medicine consists, in large part, of applying specific details. I will explain myself. Of course, medicine is based on science, but the application of medicine also lies in the details, in each individual case, in individual circumstances. To be a good doctor, the young person must know how to change his or her attitude according to the needs of the patient, of this patient, in these circumstances, and at this time. And I don't know how to say this, I've been doing medicine, practicing medicine for over forty years, and I'm still learning and I hope that most doctors of my age are still learning. And let's hope that's the case. This is a profession which makes you humble, because you never manage to get things completely right. You try, but you only rarely achieve it. And it will be a long time before the doctors of the future reach my age and commit errors, something we do constantly. But the ideal is to offer them the foundations, the basics, the essentials so they can adapt to circumstances.

Araceli Teixidó, Hospital Sant Jaume, Calella

I am a psychologist and psychoanalyst. I was very interested in what you said about the article "Decisions by bureaucracy". I wasn't familiar with it, but I'm going to look it out because it sounded very encouraging. I also really liked the example you gave about the captain in the middle of a storm. And how you see things differently when you're caught up in a storm. I think that what you were describing was also touched upon in the discussion. The ethics committee seeks to resolve – or help to resolve – something which is experienced much more intensely by the doctor. And I think sometimes the doctor's position can be compared with that of a captain in the middle of a storm.

The decisions the doctor has to take are very important. The ethics committee, from a greater distance, gives its opinion and analyzes what is taking place. You raised the hope that ethics committees might disappear some day. However, I believe that what is preventing this from happening – and perhaps this is what we need to address – is that there is really a gulf, a huge gap,

between what the committee decides or what it can say, and the doctor taking the decision and putting it into practice. Because there is this element which you compared to the storm, and which goes beyond what is reasonable.

Mark Siegler

Perhaps we will never manage to completely resolve this conflict. You are absolutely right to bring up my views on ethics committees. What I would like to make very clear is that, so long as these committees exist, it is very important that they are treated as advisory committees, not final decision-makers. I think your question also allows me to stress something that perhaps I haven't made as clear as I would have liked: that the final decision lies with the patient and the doctor, or the patient and the psychoanalyst. Those are the people who have to take the decisions. Ethics committees, as you have said, may support and advise the doctor. That's their role, rather than acting as a tribunal which issues a definitive ruling. "This is the court's decision and there is nothing more to be said." That is not what an ethics committee should do.

When I said that, ultimately, I would like it if ethics committees ceased to exist, perhaps I was overstating the case. What I would really like would be to democratize ethics. And when I talk about democratizing ethics, I mean making it part of everybody's baggage, of all health professionals and patients. So that doctors, nurses and social workers would know enough about ethics not to have to turn to the committee for guidelines. I understand your concern, because that moment has not yet arrived, and maybe it's some distance away. In other words, I share your concern about the need for these committees in the future.

Philosophy and medical ethics

Victòria Camps, Víctor Grífols i Lucas Foundation, Barcelona

I am a professor of Philosophy, and I would like you to explain what role there could be for philosophers in medical ethics. I completely share your

argument, that ethics is a practical rather than a theoretical issue, and that it is acquired through day to day experience. When you spoke about the search for medical ethics, you said there were two routes: the empirical and the conceptual. I understand that the empirical route is the one which is pursued in hospitals and health centers, while the conceptual route is more theoretical. Do you think these two routes can be joined and can work together? Or do you believe they are two parallel routes, that is, that every now and then philosophers can offer doctors an interesting idea, like Kierkegaard, who wasn't thinking directly about doctors but who provided certain insights, as indeed did Shakespeare? Does philosophy have a specific role with regard to medical ethics?

Mark Siegler

I believe that philosophers have a lot to contribute to the development of medical ethics, and in a lot of areas. One might think of the foundations of medical ethics which, as I have said, lie within the sphere of medicine, and of the history of philosophy and the traditions of the west. I am not so familiar with eastern philosophy, but I am familiar with the western version and how these traditions have evolved. Our analysis, above all with regard to aspects related to cost-efficiency and the use of resources, derive from a utilitarian analysis. Our attitudes to informed consent, telling the patient the truth, and respecting patients, all come from a very ancient tradition of individualism and autonomy. Including the virtues of Aristotle, to which I referred. All of this forms part of the tradition of modern ethics; so I would almost consider philosophy to be one of the basic sciences of medical ethics, if not the fundamental one.

In response to your question about the relationship between empirical research, based on data, and conceptual research, if this was a lecture with slides I would have answered with a slide, because it's really a circular relationship, as you have implied. That is, data collection, that way of conducting research into ethics, provides us with a description of what people believe, of what doctors, nurses and the family think. At the same time, it raises interesting questions which the ethicist or the analytical philosopher must address in

response to the descriptive ethics which reveals this data; however, once the analysis has been completed, it feeds back and raises new questions which whoever is collecting the data then has to reconsider. Therefore, there is clearly a substantial link between the theoretical and the analytical and, in fact, as I try to describe it here, I see it as a circuit where one form of investigation raises questions about the other which, at the same time, raises new questions about the first and so on. In other words, there is a very close relationship.

I dedicated the first 10 or 15 years of my profession to conducting analytical research, collecting data on ethical aspects. The lecture to which Dr Morlans referred, about the doctor-patient relationship, is not based solely on data but on direct experience and personal reflection. During the 1980s, the techniques of social science were integrated into ethics, and I think this has helped us to understand a little better some of the real problems faced by doctors and patients. In addition, this has also raised new regulatory, philosophical and analytical questions.

Teaching in bioethics

Joan Manel Salmerón, *Hospital Clínic, Barcelona*

I am sure that nobody would doubt that students of Medicine or the Health Sciences should receive training in Bioethics, but experience tells us that it is only when they are practicing their profession, after graduating in Medicine, that they really have the sensitivity and experience they need to benefit from such education. I would like to ask Dr Siegler what he thinks about the potential need, especially in hospitals and healthcare centers, for specific training programs in bioethics aimed not solely at doctors and nurses – who are at the center of the care process – but also to all the staff who work there because they come into contact with the patient and contribute to the final outcome of the service provided.

Mark Siegler

I think this sort of training would be very valuable, probably even essential. I believe there can never be too much education in a clinical environment, not just classroom theory. I think that some kind of introduction to this area through a lecture course or a basic text is essential. That would definitely be useful, but even more important is the opportunity and the capacity to apply this information to the clinical setting. Ethical aspects, and the experience of young doctors, of the nurse or the paediatrician are very different from that of the experienced doctor in the oncology or surgery unit, or a general surgery or emergency department.

We need teachers who are able to teach students wherever they come from. And for me, as a minimum, the ideal way of organizing this would be to set up a short program covering the basic elements of bioethics, and then give plenty of opportunities during clinical practice to apply this knowledge and work on specific cases. To do this well, we need teachers who are trained in emergency care, paediatrics, geriatrics etc., and able to take on this commitment. In some places, there are even philosophers who give classes to intensive care doctors, and offer their opinions on issues. Philosophers also acquire a lot of knowledge of clinical problems when they discuss cases with doctors. I am in favor of direct, practical applications. Obviously, when young doctors start to specialize, when they go into paediatrics, surgery or oncology, or when nurses start to say they want to go into the operating theater or intensive care units, there is another opportunity to offer this ethical experience on the ground.

Conclusions and closing remarks

Màrius Morlans, *Vall d'Hebron University Hospital, Barcelona*

I would like to bring together the ideas which have been expressed here about the need for ethics committees. I would be happy if clinical ethics committees in hospitals and health centers were to disappear once one of their funda-

mental tasks had been achieved: that of providing training in ethics for all the professionals in the center. I share Dr Siegler's belief that ethics should be more closely linked to services and care units, that it should be practiced at the patient's bedside. I share this aim. Probably, when everyone incorporates decision-making based on ethical principles and personal values into their daily practice, ethics committees will be unnecessary. But we still have a long way to go. Meanwhile, perhaps ethics committees need to be more accessible.

Dr Siegler noted that, as we all know, the advice offered by these committees is not binding. People need to see the members of the committee as colleagues to be consulted, just as one might with a problem in one's daily life. In such cases, one asks a friend for advice. This does not involve somebody imposing his values upon us. We know they will say what they think and give us the best advice because they care about us, and we also know that if we do not have to follow this advice our friend will not become angry or scold us. Therefore, the *philia* which we are calling for in the relationship between doctor and patient is the same feeling which we should inspire in the members of ethics committees. It is important that people do not see us as a separate body which is distant and bureaucratic, but rather as companions who dedicate part of their time to helping their colleagues. Perhaps this would be the best way of bringing committees closer to health professionals and ordinary people. And these committees, here in Catalonia, have an important job to do.

References

1. Siegler, M., "Decisions by bureaucracy", *The Hastings Center Report*, vol. 16, n°. 3, June 1986, pp. 22-24.
2. Kuczewski, M., "When your healthcare ethics committee 'fails to thrive'", *Hec Forum*, 1999, n°. 11 (3), pp. 197-207.

List of participants in the discussion

Chairperson

- Màrius Morlans, Vall d'Hebron University Hospital, Barcelona.

Participants

- Marc Antoni Broggi, surgeon, Germans Trias i Pujol Hospital, Badalona.
- Victòria Camps, President of the Víctor Grífols i Lucas Foundation.
- Joan Córdoba, internal doctor, Vall d'Hebron University Hospital, Barcelona.
- Pablo Hernando, Corporació Sanitària Parc Taulí, Sabadell.
- Josep Lloret, pediatric surgeon, Vall d'Hebron University Hospital, Barcelona.
- Eduard Prats, Sant Joan University Hospital, Reus.
- Joan Manel Salmerón, Chair of the Clinical Ethics Committee, Hospital Clínic, Barcelona.
- Araceli Teixidó, Psychologist, Hospital Sant Jaume, Calella.

About the author: *Mark Siegler*

Mark Siegler, M.D., is the Lindy Bergman Distinguished Service Professor of Medicine and Surgery at the University of Chicago and the Director of the MacLean Center for Clinical Medical Ethics.

An honors graduate of Princeton University, he received his medical degree in 1967 from The University of Chicago. He was intern, resident and Chief Resident in Medicine at The University of Chicago, followed by a year of advanced training at the Hammersmith-Royal Postgraduate Hospital in London, England. In 1972 he joined the University of Chicago faculty, organizing and directing one of the early medical intensive care units. This experience with critically ill patients introduced him to a range of ethical problems that he continues to investigate, teach and write about to the present time.

“Clinical Ethics” was a term originally developed in 1973 by Siegler and his mentor, the late Alvan Feinstein, M.D. to highlight the patient-centered focus in both Siegler’s early work in “clinical” ethics and in Feinstein’s pioneering work in creating “clinical” epidemiology. Clinical ethics has both practical and theoretical dimensions. As a practical field, it aims to improve patient care and health outcomes by involving physicians and health professionals in the analysis and resolution of ethical problems such as informed consent, end of life care, and decision making within the doctor patient relationship. When these issues arise in clinical practice, ethics consultation and casuistic analysis are often used to help resolve them. The theoretical grounding of clinical ethics is found in medicine not ethics, and its intellectual foundation derives from the doctor-patient encounter rather than from abstract ethical theory based on philosophy, theology or law.

In 1984, the University of Chicago established the MacLean Center for Clinical Medical Ethics, the first program in the nation devoted to this clinical specialty, and appointed Dr. Siegler as the Center’s Director. In its first decade, the MacLean Center was chosen by U.S. News and World Report for three consecutive years as the leading medical ethics program in the country.

Since then, the MacLean Center has become the largest program in clinical ethics in the world, a program that now has an endowment of more than \$20 million and includes five endowed University chairs in clinical ethics. More than 250 physicians and other health professionals have trained at the MacLean Center, many of whom now direct ethics programs in the U.S., Canada and Europe. The research conducted by these fellows helped open the bioethics field to a new research approach that has been described as “the empirical turn” in bioethics.

Dr. Siegler has practiced general internal medicine on Chicago’s south side for more than 40 years and is one of the few physicians who combines expertise in medical ethics with an active medical practice. He has published more than 200 journal articles, 50 book chapters and five books. His textbook, co-authored with Al Jonsen and William Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 7th Edition (2010), has been translated into eight languages and is widely used by physicians and health professionals around the world.

Dr. Siegler’s research interests include the ethics of surgical innovation, living donor organ transplantation, end of life care, ethics consultation, and decision making within the doctor-patient relationship. Siegler’s seminal 1981 paper, “Searching for Moral Certainty in Medicine: A Proposal for a New Model of the Doctor Patient Encounter,” was cited repeatedly by the President’s Commission in their 1983 report, *Making Health Care Decisions*, as the basis for recommending a shared decision making approach for doctors and patients, an approach that has since become the standard model for the doctor patient relationship in the U.S.

Dr. Siegler is a Fellow of the Hastings Center, an elected member of the Association of American Physicians (AAP), and recently completed serving on the Board of Trustees of Princeton University. For six years, Dr. Siegler served as Chair of the Ethics Committee of the NIH-sponsored Immune Tolerance Network and has also served on the Ethics Committee of the American College of Physicians. He has been on the Ethics Committee of the American College of Surgeons for the past 18 years. Dr. Siegler was 2010 winner of the Lifetime Achievement Award from the American Society for Bioethics and Humanities.

Publications

Bioethics monographs:

26. *The three ages of medicine and the doctor-patient relationship*
25. *Ethics: an essential element of scientific and medical communication*
24. *Maleficence in prevention programmes*
23. *Ethics and clinical research*
22. *Consentimiento por representación (Consent by representation)*
21. *Ethics in care services for people with severe mental disability*
20. *Ethical challenges of e-health*
19. *The person as the subject of medicine*
18. *Waiting lists: can we improve them?*
17. *Individual Good and Common Good in Bioethics*
16. *Autonomy and Dependency in Old Age*
15. *Informed consent and cultural diversity*
14. *Addressing the problem of patient competency*
13. *Health information and the active participation of users*
12. *The management of nursing care*
11. *Los fines de la medicina (Spanish translation of The goals of medicine)*
10. *Corresponsabilidad empresarial en el desarrollo sostenible (Corporate responsibility in sustainable development)*
9. *Ethics and sedation at the close of life*
8. *The rational use of medication. Ethical aspects*
7. *The management of medical errors*

6. *The ethics of medical communication*
5. *Practical problems of informed consent*
4. *Predictive medicine and discrimination*
3. *The pharmaceutical industry and medical progress*
2. *Ethical and scientific standards in research*
1. *Freedom and Health*

Reports:

4. *Las prestaciones privadas en las organizaciones sanitarias públicas (Private services in public health organizations)*
3. *Therapeutic Cloning: scientific, legal and ethical perspectives*
2. *An ethical framework for cooperation between companies and research centres*
1. *The Social Perception of Biotechnology*

Ethical questions:

3. *Surrogate pregnancy: an analysis of the current situation*
2. *Sexuality and the emotions: can they be taught?*
1. *What should we do with persistent sexual offenders?*

For more information visit: www.fundaciogrifols.org

FUNDACIÓ
VÍCTOR
GRÍFOLS
i LUCAS