
Clinical Ethics and Ethics Committees

by William G. Bartholome

Traditionally the field of bioethics has been a paternalistic one, dominated by physicians who made all decisions about patients in clinical settings. The advent of the patients' rights movement, the focus on informed consent, and the emergence of a radically different ethic for non-physician health care providers have all contributed to the collapse of this system. It is being replaced by a rapidly evolving system of shared decision making, embodied in health care ethics committees that educate, help develop policy and help resolve ethical problems arising in the care of patients.

In an introductory essay to his book, *Medical Ethics*, Robert Veatch (1989) traces what he calls "the history of medical ethical systems." He concludes his essay by stating that the primary view of ethics has been "that only people with special skills or knowledge or training can know ethical truths." Many people reject this position, he writes, "in favor of a position acknowledging that all may have moral insight." It is essential to any analysis of developments in the field of clinical ethics, particularly the development of hospital-based ethics committees, that this claim be acknowledged. The traditional approach to the making of ethical decisions in a clinical context has indeed been "rejected." In this essay I will describe how the evolving field of clinical ethics and its embodiment in the ethics committee can be seen as a new "system" for the doing of ethics.

The Traditional System of Medical Ethics

Traditionally, physicians made any decisions about the care of patients in clinical settings. It was assumed that by virtue of their extensive training and experience that physicians were in the best position to make decisions about what "should" be done, that the doctor knew best. It was also assumed that physician behavior was marked by a primary commitment or loyalty to the best interests of the patient, i.e., that the physician intended only the "good of the patient." The practice of medicine was assumed to be a special vocation or calling governed by a well-developed "ethical system." This professional ethic is often referred to as the Hippocratic tradition. In this system, the physician faced with a

decision that involved basic questions of right and wrong or good and bad consulted the accumulated wisdom of the tradition as reflected in ethical codes or statements of principles of medical ethics developed by professional associations. In order to keep the tradition alive and responsive to new developments, professional organizations periodically revised these statements and appointed special committees to study new and changing problems and to propose positions on matters of significant, ethical importance.

In this system, "good" patients were largely passive participants. Their role in the process was evaluated by the extent to which they did or did not comply with the orders of physicians. Other health care professionals did not play an essential role in this ethical system. In fact, the tradition of nursing ethics counseled nursing professionals that their primary duty was one of obedience to the directives of physicians. Health care institutions were merely the site in which this physician-directed system of care operated.

Challenge to Tradition

A detailed history of the collapse of this ethical system has yet to be written. However, some of the major factors that have caused its rejection have been identified and studied in some detail. One of the major forces was

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the emergence of "rights language" in the clinical context. As Americans examined their civil rights, it became obvious that one setting in which their rights were questionable was in their relationships with physicians. The birth and rapid evolution of the patients' rights movement drew attention to the high degree of paternalism in the traditional system. The central focus of the movement became the concept of autonomy, or the right of self-determination. A revealing account of the impact of this movement on traditional physician behavior is provided by Sissela Bok (1979) in her analysis of "lies to the sick and dying." The traditional ethical system directed physicians to dispense truth (or lies) to patients on the basis of whether they judged it to be "good" or "bad" for patients to know. In contrast, the first chapter in John Robertson's (1993) *The Rights of the Critically Ill* is "The Right to Know the Truth and Keeping Confidences." One of the most basic entitlements of this movement for acknowledgment and respect of rights is the right to know, regardless of the judgment of physicians regarding whether such knowing would be good or bad for the patient.

Several works document the second major factor in the collapse of this tradition. Jay Katz (1984), in his brilliant analysis, *The Silent World of Doctor and Patient*, and Ruth Faden and Tom Beauchamp (1986), in their comprehensive book, *A History and Theory of Informed Consent*, provide vivid accounts of how the concept of the informed consent of the patient has challenged the traditional ethical system. Obviously duties of disclosure and informing patients of risks, benefits and alterna-

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tives were not part of the traditional understanding of the ethics of the physician's role. Just as importantly,

the provision for the patient's consent profoundly changed the distribution of power in decision making in the clinical context. With the right to refuse, even to treatments ordered by physicians as "necessary" or "medically indicated," patient autonomy was given formal recognition.

A third major development has been the emergence of a radically different ethic for non-physician health care providers, most notably a virtual revolution in understanding of nursing ethics. Gerald Winslow analyzed this dramatic change as reflected in the revised "Code for Nurses" adopted by the American Nurses' Association in 1967 (1984). Winslow argues that the new code reflects a fundamental changing of nursing's self-image from a profession dedicated to "loyalty to duty and service" (particularly loyalty to the physician) to a profession dedicated to "advocacy of patients' rights." One important aspect of this revolution in nursing ethics is that nurses now see themselves as playing an essential role in ethical decision making.

Although there are many other factors, these three serve as an adequate basis on which it can be claimed that the traditional, physician-dominated ethical system has collapsed. One interesting way of looking at the extent of this collapse is to reexamine the characteristics of the "good" patient. In the "new" system, the good patient is seen as knowledgeable by virtue of information disclosed and discussed by health care providers; protected by a wide range of rights; served by physicians, nurses and other professionals; and actively involved in decision making (including the ultimate power to authorize or refuse any intervention).

The Emergence of a New Understanding: Clinical Ethics

A very different concept of ethics and doing ethics in a clinical context has emerged. Jonsen, Siegler and Winslade (1982) define clinical ethics as follows: "By clinical ethics, we mean the identification, analysis, and resolution of moral problems that arise in the care of a particular patient." The understanding of ethics reflected in this field of clinical ethics is very different

from that of the traditional approach. Briefly, I will point out some of these important differences.

First, this new understanding of ethics assumes that the care of patients is an ethical or moral enterprise. It assumes that, although medical science, nursing science and other bodies of empirical knowledge are essential, the application of this knowledge and expertise in the care of patients inescapably involves questions of values, of ethics. For example, in an important sense, no course of treatment can be regarded as "medically indicated." All decisions that directly impact the welfare, the lives, the "interests" of patients must be regarded as ethical decisions. In many situations, the ethical aspects are simple and non-controversial. However, in others the empirical aspects are simple and the ethical questions complex, perplexing or highly controversial.

Second, this new understanding assumes that, although ethical decision making may be enhanced by the insights developed by the "professional ethic" of each group of health care providers, it demands a more universal conception of ethics. Clearly each profession—medicine, nursing, social service, pastoral care, various allied health professionals and others—has need of a highly developed professional ethic. This ethic focuses on the special ethical demands associated with playing a particular professional role, and the ethical wisdom relevant to the question of what it means to be a "good" or "virtuous" member of that profession. These traditions of professional ethics must be nurtured and continue as robust expressions of the best reflection and wisdom of the members of each profession regarding what they take to be the special demands associated with their professions. However, no professional group can claim to be the ultimate authority in bedside ethics. The ethical problems which arise in the care of particular patients confront and challenge a patient, his or her family and all those attempting to provide care for the patient.

A third important assumption informing this new understanding of ethics is that ethical problems arise and confront particular physicians, nurses and other

providers, but, most importantly, particular patients and families. Thus clinical ethics is also concerned with personal ethics, with the particular ethical values and beliefs of individuals. This personal, particularistic perspective is a new and radically different ingredient in doing ethics in a clinical context. It demands a new level of involvement of those providing care with those receiving care. It demands a new mode of relating characterized by mutual respect, openness and sustained dialogue concerning what is appropriate, needed, good or right. It demands that a fundamental distinction be made between "disease," the empirically observed pathophysiology, and "illness," the experience of the patient attempting to deal with the disease. The values of the society in which these individuals and professional roles are shaped and nourished by a social ethic inform this dimension of personal ethics.

Ethical Decision Making as "Shared Decision Making"

One of the most basic and important ways in which clinical ethics departs from the traditional system, namely that the ethical decision making must be *shared* decision making, reflects these three assumptions. I argue that one of the most basic elements of this new system is that doing ethics in a clinical context demands

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the active participation and the moral agency of a primary circle of decision makers, and that no one individual member of this circle can claim ultimate authority or insight into the ethical dimensions of the problem or situation. The patient, by virtue of the "right of consent," has ultimate decisional power, but this power is not the same as ethics. Even though the value of autonomy or the right to self-determination must be re-

spected, many situations exist in which this value or right conflicts with other important rights, duties, obligations and responsibilities. The make-up of this circle of moral agents, of those having the responsibility to face and resolve the ethical aspects of the clinical problem, will vary. Virtually all situations will involve a patient and at least one health care provider. Most hospital situations will include the patient, frequently members of the patient's family, often designated surrogates or court appointed guardians, physician(s), nurse(s), and other professionals involved in the continuous care of that patient, e.g., social worker, pastoral counselor, or respiratory therapist.

Obviously this model of shared decision making assumes that each individual's perspective is essential to making ethical decisions. It assumes that identification, analysis and resolution of the ethical problem require discussion and dialogue; that individuals will bring to this dialogue their own personal values and belief systems; that professionals will bring to the discussion an understanding of their ethical duties and obligations as members of particular professions. It also assumes that the dialogue will be highly sensitive to and respectful of differences in each individual's judgments and beliefs. In a society in which a wide variety of religious and "humanistic" traditions inform ethics, such differences are expected at least in the initial phase of the dialogue. This model requires mechanisms for responding to differences in ethical judgment that persist and seem to be refractory to resolution. Such mechanisms provide a fair hearing for each party and would support and assist in resolving the disagreement.

The Development of Hospital Ethics Committees

This model of shared decision making and its acknowledgment of multiple moral agents and perspectives is the "ethical basis" of a hospital-based ethics committee. A central assumption informing ethics committees is that doing ethics in a free society—of which a hospital community is a reflection—requires praxis and discussion among individuals who bring differing perspectives, beliefs and values to the process. The clinical

care of patients requires multiple providers whose work is informed by differing disciplines and perspectives. Clinical decisions are not merely "medical decisions" made by physicians, nor "nursing decisions" made by nurses, nor "social decisions" made by social workers, nor "administrative decisions" made by hospital administration, nor "legal decisions" made by hospital counsel, nor "moral decisions" made by pastoral counselors. They are also not "consumer decisions" made by patients served by technical providers of "value-free" services. I would argue that they are not merely "ethical decisions" made by ethical experts or "ethicists." They are "human decisions," the outcome of a process for which each involved party accepts responsibility and to which each individual contributes his or her special perspective.

Although these changes in our understanding of ethics and its application in the clinical context have facilitated the evolution of hospital ethics committees, they were also created in response to other forces. Cranford and Doudera (1984) and Rosner (1985) have reviewed these factors. One of the most obvious needs for ethics committees to address is that of providing consultation and review in cases that involve decisions to forgo or discontinue life-sustaining technology in patients who lack the capacity to make such decisions themselves. The judge in the Karen Ann Quinlan case made one of the first formal legal references to this role of an ethics committee. The judge implied that if a committee had been available to review the case and the proposal to discontinue her ventilator support, then formal legal review might not have been necessary. The recommendations made by The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research (1983) further acknowledged this role. The Commission recommended that this "review function" deserved serious consideration as a means by which the hospital could discharge its responsibilities to this population of patients and their families.

However, the emergence of the "Baby Doe" problem ultimately caused the rapid development of hospital ethics committees. This important 1982 case involving a decision to forgo life-sustaining corrective sur-

gery in an infant with Down Syndrome raised serious questions about existing processes for making decisions about handicapped or imperiled newborns. Initially the federal government responded to the case by establishing a reporting system by which incidents of what was called "discriminatory refusal to provide medical treatment" could be reported directly to federal agencies for investigation. Legislation enacted by Congress in 1984 amended existing child abuse and neglect programs to allow incidents of suspected "medical neglect" of handicapped infants to be reported to state programs for investigation and intervention as needed. The major impact of these developments, however, forced the health care community to develop procedures that would allow hospitals to respond to these alleged problems. The American Academy of Pediatrics (1984)

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played a leadership role in developing a formal proposal for the establishment of what it called "Infant Bioethics Committees." Congress modified and incorporated this proposal into its Amendment of the Child Abuse and Neglect Act of 1984 as a recommendation for the establishment of "Infant Care Review Committees." The Academy felt that these committees could provide consultation and review, ensuring that sensitive treatment decisions were made in a reasoned, informed and caring manner. It recommended that parents and physicians consult with an institutional ethics committee when contemplating decisions that involved forgoing life-sustaining treatment from an imperiled newborn. This concept of review and consultation with a hospital-based ethics committee was also endorsed by the American Medical Association (1985) and has been actively supported by the American Hospital Association (1986).

The Roles of a Hospital Ethics Committee

The proliferation of ethics committees has been dramatic. A "progress report" in the *Hastings Center Report* (Gibson et al. 1986) claims that they are now "firmly in place." The majority of hospitals with greater than 200 beds have established such committees. Only a handful of academically affiliated medical centers lacks committees. A number of purposes or roles for ethics committees have been suggested. I will briefly review four of these roles and their relationship to the field of clinical ethics. One of the more elementary roles of an ethics committee is to serve as a "forum," as a "safe place" to which individual members of the hospital staff bring their concerns, questions and problems related to ethical issues which arise in the care of patients. Although individual cases can raise special if not unique ethical problems, the vast majority of ethical issues that arise in the care of patients are recurrent sources of anxiety, frustration and stress for highly dedicated and deeply committed care providers. An ethics committee provides members of the staff with a sounding board that acknowledges, shares and discusses these perceptions and experiences with members of the same hospital community.

A second major role of an ethics committee is to serve as a means through which an institution can undertake effective educational programming in clinical ethics. Members of the committee serve as a planning committee for a wide variety of conferences, seminars, courses, in-service programs, rounds and the like. They can also serve as a multidisciplinary "faculty" for educational programs in their own departments or divisions and for hospital-wide programs. By means of their combined and individual efforts, the members of the ethics committee play a key role in catalyzing and sustaining an ethical dialogue throughout many departments, disciplines and programs of a complex health care institution.

A third critical role is that of policy review and development. Although development of policy for dealing with recurrent ethical problems requires meticulous ethical analysis, such as that which might be pro-

vided by an individual with advanced training in philosophy and/or theology, it is also clear that policy development must be multidisciplinary. Since policies in this area guide the work of all those providing care to the patient, it is essential that members of the involved disciplines have a voice in shaping policy. Each discipline brings to the process of policy formation a unique perspective informed by the special ethical duties and obligations facing members of that discipline. Since the care of patients involves many cooperating professionals working in a "horizontal" organizational structure, members of each profession must be represented at the policy making table. From a purely pragmatic perspective it can also be argued that in order for policy to be effective in guiding behavior and "accepted" by those involved, it must be seen as in some sense the "product" of this democratic process.

The fourth role is the most challenging: consultation with patients, families and providers who are facing serious ethical problems. Some might argue that consultation with a committee of ten or twelve members is a highly cumbersome and impractical vehicle for consultation. If consultation regarding some technical aspect of a patient's care was needed, that argument would carry a great deal of weight. However, a central assumption of clinical ethics is that no one individual or discipline or "expert" has ethical truth or wisdom to bring to the patient or staff facing such an ethical quandary. Although a very experienced clinician or an individual with formal training in clinical ethics might be of considerable assistance in such a situation, a much more thorough and comprehensive consultation would involve discussion and analysis of the issues from the wide range of perspectives represented on a multi-disciplinary ethics committee, i.e., medical, nursing, social, psychological, legal, administrative, religious, ethical, and so on.

This point cannot be overemphasized. The assumption is that "truth" or "wisdom" in matters of clinical ethics is approached best not by seeking the ethical expert or the most qualified moral judge, but rather by creating an opportunity for dialogue within a community of informed individuals who are committed to ex-

amination and analysis of ethical issues from their own personal and professional vantage points or points of view. Patients, families and those caregivers responsible for the patient's care are best served by meeting with and engaging in dialogue with such a "community." I used the word "community" rather than "committee" to underscore that an ethics committee is a means by

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which a community of health care providers and an institution can discharge a community responsibility to patients, families and its members. Most proposals for such committees suggest that "lay" or "community" members be appointed to call attention to this link to the larger community. If significant ethical problems or disagreements or cases involving forgoing life-sustaining treatment are not brought to the legal system, some "community" must assume responsibility for attempting to play this critical social role. The committee is an acknowledgment of this communal responsibility to protect, support and service its members and its patients.

Conclusion

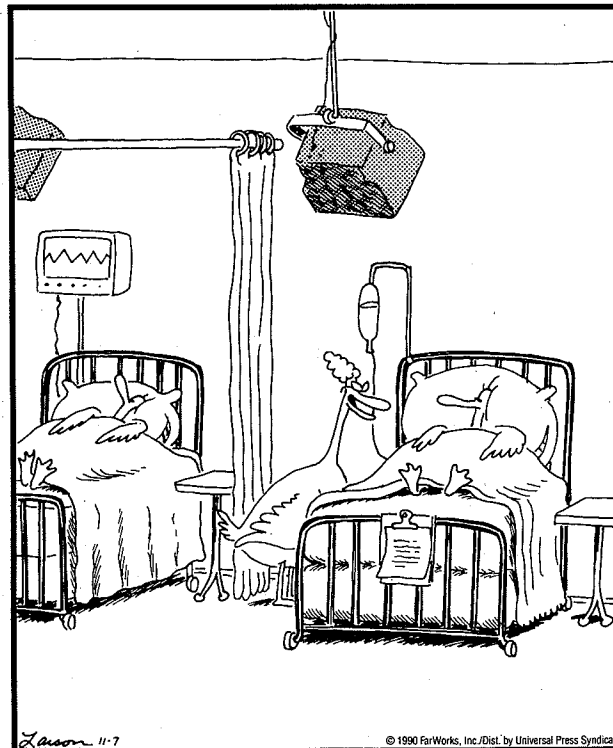
A virtual revolution has taken place in the "system" by which ethical issues are identified and addressed in a clinical contest. The traditional, physician-dominated system of "medical ethics" has been rejected in favor of a more universal conception of ethics, an evolving system of "clinical ethics." I have also argued that this rapidly evolving understanding has been embodied or institutionalized in the creation of hospital-based ethics committees which can serve in a wide variety of capacities to assist health care institutions in identification, analysis and resolution of ethical problems that arise in the care of patients.

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THE FAR SIDE

By GARY LARSON



"It's just a miracle you pulled through, George. . . .
Why, it was only a few hours ago the whole
family was deliberating on whether or not to
wring your neck."

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Ms. Wicher supports ethics programs; monitors compliance with values and ethical conduct guidelines; facilitates an open environment in which employees feel comfortable bringing ethical issues forward; enhances the visibility of topics related to human subjects in health research, health law and policy for research; and offers training and professional development across departmental disciplines. She also chairs the Institute's Corporate Ethics & Clinical Ethics Committee and the Institutional Conflicts of Interest Committee. She co-Chairs the Joint University of Buffalo/Roswell Park Cancer Institute's Institutional Ethics Committee. Ethics committees have played clinically relevant roles in U.S. healthcare contexts since the 1960s. At that time, some hospitals established committees to approve requests for abortion and sterilization and to allocate scarce dialysis machines. Universities and hospitals created human subjects committees to scrutinize research protocols and consent forms; in the 1970s, these committees became federally mandated institutional review boards (IRBs). Source for information on Clinical Ethics: III. Institutional Ethics Committees: Encyclopedia of Bioethics and Clinical Ethics continues to focus on the needs of professionals who are actually engaged in making difficult ethical decisions in health care. With an international editorial board, it features increasing coverage of developments around the globe. This journal is a member of the Committee on Publication Ethics (COPE). Clinical Ethics is an important journal devoted to the discussion of key issues surrounding the application of ethics in clinical practice, research and policy. Published quarterly, the journal publishes peer-reviewed articles under the headings of Case Studies, Public Policy and