Special Section: First Voices

As Time Goes By: Twenty-Five Years of Bioethics

KEVIN O'ROURKE

Like Saint Paul, I was "born out of due time" insofar as the study of bioethics is concerned. (Incidentally, I prefer the term "healthcare ethics" to "bioethics" because the discipline in question addresses issues more far-reaching than medical issues, such as downsizing access to healthcare.) I spent 15 years in teaching and administration at the Aquinas Institute of Theology, then in Dubuque, Iowa, now on the campus of Saint Louis University. I was given a sabbatical study year in 1972–1973 to refresh my mind and spirit. Though my major study and research emphasis prior to the sabbatical study had been in the field of Church law and religious government, I determined to direct my attention to the study of moral theology and ethics, because at that time there was confusion in this area of discipline, especially insofar as the Catholic community was concerned. With this in mind, I chose the University of Chicago as the locale for my study and was awarded a postdoctoral fellowship.

The University of Chicago was attractive because James Gustafson had recently accepted the position of University Professor and my soon-to-be-good-friend Richard McCormick, S.J., was at the nearby Chicago Jesuit School of Theology. From August to January, both of these scholars guided my reading and engaged in provocative discussion. My intention had been to return to Aquinas Institute in June, 1973, and continue my teaching and writing in the wonderful ecumenical consortium that had been developed in Dubuque between Wartburg Seminary, the University of Dubuque Seminary, and Aquinas Institute. Thus my interest was not in the application of ethics to healthcare but rather the study of metaethics.

But in January, 1973, the U.S. Supreme Court set forth the *Roe v. Wade* and *Doe v. Bolton* decisions, which declared that women have a constitutional right to abortion that could not be circumvented by national or state law. The immediate effect of this decision on Catholic hospitals was one of intense concern. Would Catholic hospitals be able to continue to receive government funding through Medicare and Medicaid programs if they refused to perform abortions, as their faith commitment required? The Catholic Hospital Association (CHA), the trade association for Catholic hospitals and nursing homes, realizing it needed someone to respond to the abortion issue and to field questions that were arising in regard to other ethical issues in medicine and healthcare, requested that I join its staff. My provincial agreed to free me for a "couple of years" for this work, and that is how it all began. Almost 30 years later, I can say with alacrity that it has been an interesting "couple of years."

The potential effects of the abortion decision of the Supreme Court were abated insofar as Catholic hospitals were concerned by an Act of Congress in June, 1973

Cambridge Quarterly of Healthcare Ethics (2002), **11**, 380–387. Printed in the USA.

(the Church Amendment named after Senator Church of Idaho) that allowed hospitals sponsored by religious organizations to follow their conscience or faith teaching insofar as abortion was concerned without losing government funding. For this reason, I was mainly involved in other issues arising from the ethical norms of Catholic teaching and the Ethical and Religious Directives of the United States Bishops Conference (UCC). Thus, issues of informed consent, direct sterilizations, and the goals of Catholic healthcare were more prominent than questions concerning abortion insofar as the constituents of CHA were concerned. While I was serving at CHA, the federal government instituted the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1975).[1] The first task of the Commission was to explore experimentation on human fetuses and to recommend norms for such experimentation. With other ethicists, I objected to some of the norms set forth by the Commission[2] and thus began an effort to use natural-law reasoning to consider issues and questions in the field of healthcare ethics. Before I offer an explanation of natural-law ethics, let me observe that the issue of research on human fetuses, especially those created for the purpose of research, is with us still. Because of opposition, which is often described as political, Congress has never approved funding for research on human fetuses unless it is designed to directly benefit the fetuses that are employed in the research. That the opposition is more than "political" is attested to by biological evidence that predicates the beginning of human life, albeit seminal, when ovum and sperm are joined together to form a new living entity. Today, this debate concerning the use of fetal tissue centers around stem cell research,[3] and government funding is still not available. The same arguments in favor of such research are being proposed again. Fundamentally, these arguments maintain that the end of potential help for human suffering justifies the means of creating and destroying human life. Those who oppose this type of research are seeking to protect the worth and concept of human life. With the "doing evil to achieve good" mentality so frequently justified in contemporary society, it is shortsighted to allow destruction of human fetuses even if some benefit may accrue to future generations.

Because it is pivotal to the above-mentioned ethical issue, and because this approach has been fundamental in my thinking, teaching, and writing in the field of healthcare ethics, I consider it worthwhile to spend a few words trying to answer the question "What do you mean by natural-law ethics?" I usually start out in my efforts to explain natural-law ethics by saying, "Well, it's the opposite of relativistic ethics; consequentialism and proportionalism." In other words, natural-law ethics concludes that there are some actions that are always good or ethical (nursing the sick, healing the wounded) and some actions that are always bad or unethical (directly and intentionally killing impaired infants, discriminating in employment practices because of ethnic background). Thus, it offers absolute ethical norms. More fundamentally, natural-law ethics predicates that there are certain human goals that are given by nature, for which we must strive if we are to fulfill ourselves as human beings. (Hence the term "natural law"; the goals result from nature, not from our free choice.) In the Catholic tradition, these goals given by nature have been listed by St. Thomas Aquinas: (1) preserving life; (2) generating and procreating children; (3) forming communities, and (4) seeking truth.[4] In secular thought, Abraham Maslow has pointed out the four needs (or goals) of the human person: physiological, psychological, social, and spiritual or creative.[5]

These are not needs or goals that are subject to human choice—they are given by nature—but the manner of fulfilling these goals or needs is subject to our free choice. As we consider these goals or needs, our reason and experience teaches us that some actions of their nature are directed toward fulfilling these goals and some are not, regardless of the circumstances. Some actions will or will not help us achieve the needs or goals in question according to the circumstances in which the actions are performed. From a consideration of the goals or needs of the human person and the human community and the actions that lead toward or away from the attainment of these goals, norms may be formulated that will help individuals and communities reach fulfillment; for example, allowing patients the opportunity for informed consent to medical procedures, paying just wages, respecting the spiritual needs of dying patients. This method of ethical reasoning is not favored by mainstream American bioethicists, who tend toward consequentialism or relativism, but is characteristic of the thought of several leaders who have sought to unite the study of medicine and ethics, such as Edmund Pellegrino and Paul Ramsey. Traces of this method of thinking can also be found in the eight volumes published by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.[6] One of the best expressions of natural-law thinking applied to medicine is the chapter "What Is Medicine?" in Pellegrino and Thomasma's book *The Philosophical Basis for Medical Practice*.[7] Benedict Ashley and I have sought to present the same natural-law approach from a theological perspective in *Health Care Ethics, A Theological Analysis*.[8]

After spending 6 years at CHA, in the spring of 1979, I responded to the request of Fr. Ed Drummond, the president of Saint Louis University, and George Thoma, M.D., the Vice President of the Saint Louis University Medical Center, to found the Center for Health Care Ethics at the Health Sciences Center of the University. At that time, many of the approximately 125 medical schools in the country had some minimal offering in bioethics. However, there were few funded programs or required courses in these medical schools. For 2 years, I spent about 3 hours of every day immersing myself in clinical situations from neonatal care nursery to removing life support in intensive care units. I was present at daily and grand rounds of all clinical services. People often say, "You must know a lot about medicine as a result of your 20 years of experience." I respond, "I don't know much about medicine, but I sure do know a lot about physicians; how they think, and how and why they act." Whenever new members would join our staff at the Center, I would make sure that they were exposed to "the sociology of medicine."

Within a few years of my arrival, with the help of some wisdom figures on the faculty and some medical ethicists who joined our Center, the Center faculty was well funded and offered required courses in all four schools of the Health Sciences Center: the Medical School, the School of Nursing, the School of Allied Health Professions, and the School of Public Health. From the first days of the Center, we published monthly essays on issues in healthcare ethics (since published in four different volumes)[9] and instituted a series of Continuing Education Programs for healthcare professionals across the country, especially for those associated with Catholic healthcare facilities. In 1995–1996, the University Board of Trustees approved a Ph.D. program in healthcare ethics under the direction of the Center. This interdisciplinary program involves the Schools of Medicine, Nursing, Law, and Public Health, as well as the Depart-

ments of Theology and Philosophy. At present, 25 students are enrolled in the program. Many of the faculty members who worked at the Center have gone on to responsible positions in academic centers and healthcare corporations.

Although Saint Louis University is a Catholic University sponsored by the Jesuit Fathers, the student body and the faculty of the various schools constituting the Health Sciences Center are a pluralistic and international community of scholars. Thus, our approach in teaching and writing has been to stress the natural law, not the religious teachings of the Catholic Church. With this perspective, we did not contradict the religious teachings of the Catholic Church but would explain our presentations, especially of such controversial issues as abortion and physician-assisted suicide, through natural-law reasoning. Although not everyone agreed with our presentations, at least we had a firmer basis for rational dialogue than we would have had if we based our ethical presentations on religious dogma, legalistic principles, or some vague effort to arrive at consensus by accepting the lowest common denominator put forth by medical or ethical pundits.

In the late 1980s, our Center became intimately involved in the Nancy Beth Cruzan case.[10] I remember vividly the day in March, 1987, when Lester "Joe" Cruzan called me from Southwest Missouri and asked about ethical treatment for his daughter, Nancy Beth, who had been injured a few years before (1983) in an automobile accident and who doctors said would never regain consciousness. He got my name because I had been quoted in a recent article in *Time*[11] in regard to withdrawing tube feeding from patients who would not recover consciousness; that is, from patients who are in persistent vegetative state (PVS).

I explained to him the theory that had been developed by ethicists and theologians at our Center—namely, that Nancy Beth was still a human person, but because she would never again perform human acts, there was no moral or ethical obligation to prolong her life. (In natural-law thinking, human acts—that is, acts of intellect and will—are necessary for one to strive for the purpose of life. If one does not have the potential or the actual ability to strive for the purpose of life, the person may not be put to death directly, but measures to extend the life of such persons become ethically optional.) Before becoming involved in the case, I visited Nancy Beth in the Missouri State Hospital in Mount Vernon. Ever after the visit, I found it incomprehensible when some of the nurses at the hospital would state that she smiled and responded to conversations.

Throughout the long extended legal proceedings, especially through the Missouri State Supreme Court and the United States Supreme Court, the Cruzans had the excellent legal guidance of William Colby, of the Kansas City firm of Shook, Hardy, and Bacon. And our Center sought to provide the ethical guidance and emotional support that would eventually help them achieve their goal of removing the ineffective therapy and excessive burden that was prolonging Nancy's life. In the course of the legal and political movements organized to thwart the efforts of the Cruzans and William Colby, we sought to offset the pressure coming from the courts and various individuals proposing "life at all costs" opinions with friend of the Court opinions, ethical essays, articles, and court testimony that sought to explain the ethical reasoning on which the Cruzans were basing their pleas. If anyone thinks this was a mere intellectual exercise, recall that Joe Cruzan, a loving and deeply introspective

man, committed suicide as a result of his ordeal. This happened in August, 1996, 6 years after artificial hydration and nutrition (AHN) was finally removed from Nancy Beth in December, 1990. Indications of the severe strain he was under were expressed by a psychologist helping the family, even before the case reached the Missouri Supreme Court.[12]

Somewhat the same situation occurred in the case of Christine Busalacchi, a young girl also injured in an automobile accident and also in PVS when her father, Peter, sought to have life support in the form of artificial hydration and nutrition (AHN) removed from his daughter. Because of the legal precedents established through the Cruzan case, Peter Busalacchi, once again assisted by William Colby, was able to accomplish the removal of the life support more quickly than in the *Cruzan* case. But the opposition of civil and religious "authorities" and voices from the self-appointed guardians of public morals were just as strong and oppressive as they were in the *Cruzan* case. The staff of the Center were present to Peter Busalacchi and his family all the days he kept vigil for his daughter at Barnes Hospital in St. Louis after AHN was removed, and we participated in her memorial service.

As a result of my experiences with the Cruzan and Busalacchi families, I am convinced that the opposition to removing life support, especially from religious authorities, arises from two erroneous attitudes. The first attitude is that removing life support from people who could live longer if the life support were not removed will lead to the open practice of euthanasia, the direct killing of persons to remove them from their physical or emotional suffering. But a thorough analysis of the natural-law reasons that allow the removal of life support—namely, no hope of benefit or excessive burden—make clear that the moral object of the act involved in removing life support for either of the aforementioned reasons is not an act of euthanasia. Rather it is an act whose direct and proximate moral object is either to stop doing something that is useless or to remove an excessive burden from the patient. Some people have difficulty distinguishing the foreseen physical effect of the act (death of the patient) from the moral act (benefiting the patient by removing useless or burdensome life support). But understanding such distinctions is the reason why ethics requires intellectual endeavor, rather than emotional response.

The second erroneous attitude arises from the ethos of American medicine that "death is the enemy," not a natural event. Thus the fiction is propagated that any pathology can and should be cured, and that extending life of a patient, for even a few hours, abstracting from the quality of function in the person for whom life is extended, is a great good. Some of my colleagues in the Catholic tradition who disagree with my conclusions in regard to removing life support from people in PVS maintain that "life is an intrinsic good" and for this reason must be prolonged as long as possible no matter what the circumstances. In the sixteenth century, the first theologian to discuss removing life support even though the shortening of life was foreseen, Francis de Vittoria, O.P., declared, "God is not interested in a long life." In other words, simply because one lives a long time does not mean that one achieves the purpose of life any more surely than one who dies young. Only recently, with the Last Acts Movement, has palliative care, as opposed to aggressive care, become part of American medical practice as death approaches. Until palliative care for people with serious and fatal pathologies becomes a common practice in U.S. medi-

cine, we shall have many people believing that it is morally mandated to extend life as long as possible, regardless of the circumstances.

As is evident from this discussion, our conviction that a person in PVS does not have the ability, neither now nor in the future, to perform human acts (as opposed to "acts of man")[13] has generated a great deal of opposition in the Catholic community. Many people, claiming to speak for the Catholic tradition, maintain that AHN must be utilized for PVS patients until it becomes physically useless or an excessive burden. To my knowledge, none of them confront directly the arguments concerning purpose of life. Rather, they prefer to propose that "human life is an intrinsic good" and thus a benefit for the PVS patient and, for that reason, must be prolonged as long as possible, independent of the circumstances. Of course, it is also a firm principal of Catholic thinking that human life is not an absolute good, but this does not factor into their thinking. It is also a firm principle of Catholic theology that the final cause of human activity, to which all other activity should be directed, is "love of God and neighbor." If a person is no longer able to love, what good does it do to prolong mere physiological existence? The teaching authority of the Catholic Church has not issued a definitive statement in regard to the treatment of PVS patients.

Without going into great detail, let me state that some groups of American bishops when proposing general theory in regard to the removal of AHN from PVS patients have allowed for removal of AHN only in cases of excessive burden. Several bishops from Texas are an exception to this trend, having approved the removal of AHN from PVS patients because it offers no hope of benefit. However, when individual bishops have offered moral advice to families who wish to remove life support from PVS patients, they have always approved of the actions of the families without quibbling over the specific reasons for the removal.

Another interesting venture in which our Center was involved was the rewriting of the Ethical and Religious Directives (ERD) for Catholic healthcare facilities.[14] The final statement of this document was promulgated in December, 1994, but the composition of the document was in committee for about 4 years prior to the promulgation. During that time our Center served as consultant to the Committee, held an international conference on the topic of codes for Catholic healthcare facilities, and commented on several drafts of the document. The new ERD seeks to outline theological principles as well as give specific directives for various ethical problems. The six sections of the document are a source for organizational ethics in the Catholic tradition as well as medical ethics in the more traditional sense. Thus, there are sections treating cooperation with other than Catholic facilities and employee rights, as well as sections on patient-physician relationships, care of the dying, and ethical issues that arise at the beginning of life. The ERD seeks to express as succinctly as possible the spiritual ministry, as well as the physiological and psychological ministry, that should be provided to ailing and dying people.

Perhaps the most insightful and helpful part of the ERD is in Section Five, Care of the Dying. Even though I have written and lectured frequently on this part of the ERD, and even though for more than 25 years I have helped people with the question of removing life support, I am always reluctant to rush people into the act of removing life support from loved ones. Faced with the actual experience of removing life support from a loved one, people are filled

with doubts and confusion. The principles are well worked out, but applying them is a deeply emotional experience. When Mom or Dad is near death, or when the life of a sibling or child is in question, it is almost impossible to step back from the scene and use general principles in a rational manner. "If life support does not offer hope of benefit, or imposes an excessive burden, we may forgo it," traditional natural-law ethics and theological thinking tell us. "*But this is my mother!* Isn't there any hope?" The most poignant story depicting the pain of death that I have ever heard concerned a nurse-ethicist friend of mine, whose mother was severely impaired with advanced Alzheimer's disease. Her mother was a continual concern to my friend, who nursed her alone for 2 years. When her mother died, several friends said to her, "What a blessing. She is now better off. You are now relieved of that burden of caring for her." But my friend replied, "Her death is not a blessing. I took care of her because I loved her, and I would want her back even in that terrible condition so I could still show my love for her." Love often transforms our reasoned analysis of situations, lifting our aspirations and attitudes to levels beyond the human. Coming from a religious tradition that is so imbued with a belief in eternal life and the mercy of God, I have a difficult time when meditating on death to look on it as an unmitigated evil, but when the death of a family member or a dear friend occurs, my religious faith is often beclouded by the emotional sense of loss and pain that ensues.

What does the future hold for bioethics, for healthcare ethics? Having seen the "birth of bioethics" and its survival into adolescence and maturity, I wonder about its continuing vitality. Words attributed to Daniel Callahan, perhaps erroneously, often come to mind: "Do bioethicists ever say no?" There seems to be an overpowering inclination among bioethicists to propose conclusions that are more likely to please the scientific and business communities than to protect the rights of the weak and powerless. Every time an ethical panel or committee is asked for an opinion by the federal government or a governmental agency, the method of discernment looks more to the effect than to the nature of the action that brings about the effect. One disturbing aspect of the present healthcare situation is the lack of opposition to investor-owned, for-profit healthcare corporations.

If healthcare is necessary to fulfill one of those basic goals or needs discussed in the excursus on natural-law ethics, then it should be available to all, not treated as a commodity but as a right or service that fosters individual well-being and the common good. Do we hear many bioethicists declaring that healthcare is not a commodity; that the market system is not the setting for ethical decisions that concern healthcare? We also hear of research facilities, often working in close contact with bioethicists at the same facilities, being penalized by the federal government because they do not observe even the legalistic norms governing research, let alone the ethical norms that should be imbued in researchers working with human subjects.

Finally, I wonder about the qualifications of people who are called bioethicists. Lawyers, physicians, nurses, accountants, and any number of other professions have a certification process that enables them to practice as a professional in their area of expertise. But how do bioethicists qualify for their profession? How many of them are acquainted with the art of medicine that comes from intense clinical experience? It seems that all one has to do to achieve the status as a bioethicist is to get behind a podium and declare publicly that one is a bioethicist. No board or

examination specifies capability; there are no requirements for clinical experience. If this method of "certification" continues, I see little hope of a future for bioethics as worthwhile adjunct to the profession of medicine as it has been in the immediate past.

Notes

1. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1975.
2. O'Rourke K. *Linacre Quarterly* 1976.
3. Racing toward immortality. *New York Times Magazine* 2000 Jan 30:35.
4. Aquinas T. *Summa Theologica*, I–II, q. 94, a. 2.
5. Maslow A. *Motivation and Personality*, 2nd ed. New York: Harpers, 1970.
6. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1981–1983.
7. Pellegrino E, Thomasma D. *The Philosophical Basis for Medical Practice*. New York: Oxford University Press, 1981.
8. Ashley B, O'Rourke K. *Health Care Ethics: A Theological Analysis*, 4th ed. Washington, D.C.: Georgetown University Press.
9. Center for Health Care Ethics. Monthly essays on issues in health care ethics, since published in four volumes. Washington, D.C.: Georgetown University Press.
10. *Nancy Beth Cruzan*.
11. *Time* 1987 Feb 23.
12. *The Joplin Globe* 1988 Mar 11.
13. Aquinas T. *Summa Theologica*, I–II q. I, a.
14. Center for Health Care Ethics. *Ethical and Religious Directives for Catholic Health Care Facilities*. St. Louis, Mo.: Saint Louis University 1994.