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Ethical Times

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Ethical Complexity Of Caring For Patients With Brain Tumors

by Albert R. Jonsen, Ph.D.

Americans were distressed by the news that Ted Kennedy, “old lion of the Senate,” was diagnosed with brain cancer. After several

About 10,000 persons are diagnosed with malignant glioma each year.

about 25% still alive after two years. Treatment is usually surgical removal of the tumor, followed by chemotherapy and radiation. About 10,000 persons are diagnosed with malignant glioma each year. Senator Kennedy has reappeared after his initial operation, showing his usual verve, but the country will be watching anxiously over the next months.

Patients with brain tumors face a difficult prospect. The disease affects them in many ways, since the brain sits at the center of sensation, bodily control, communication and comprehension. Their care poses difficult medical decisions that they, their families and their doctors must struggle through. Brain cancer also poses uniquely difficult ethical problems. I will describe these with reference, not to Senator Kennedy, but to a representative fictitious

patient, Mr. RS, a sixty six-year old lawyer, married, with two sons and a daughter, all married. His case is emblematic of many patients who suddenly discover, often after a minor but distressing event, that they have a brain tumor. In Senator

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Program’s Quality Goals Presented To AMA

Last year, the Program in Medicine and Human Values began exploring the role of ethical parameters in quality control measures adopted by the Joint Commission (the federal agency responsible for accrediting hospitals). Seven scholars from around the country joined our staff and assembled at the Program’s headquarters in January of this year. Invited guests included representatives from the Joint Commission and the American Medical Association as well as several health policy authorities. That meeting has generated a groundswell of interest in multiple centers around the country. Dr. Andreck was invited to a May 7th meeting at AMA headquarters in Chicago, to present some of the findings from that conference and explore ways that the AMA’s Ethical Force program can join to promote the incorporation of ethics standards in Quality Assurance protocols.

The Ethicist Is In:

Today's Ethicists are Dr. Albert Jonsen and Reverend James Bretzke

Dr. Michael McG, a general internist, has sought an ethics consultation from bioethicist Dr. Al Jonsen. His patient, Mrs. O' C is 91 years old. She has been relatively healthy until last year when a diagnosis of ovarian cancer was made. She understood her condition and declined any treatment except for comfort. Two days ago, she suffered a serious stroke. In the neurologist's opinion, she has major damage to her brain and is unlikely to recover consciousness. Her three devoted children discuss whether to insert tubes for nutrients and fluids. They, and Dr. McG, were aware that Catholic teaching had generally permitted a patient or the patient's surrogates to omit feeding tubes in terminally ill patients. However, they recently heard that Pope Benedict had reversed this teaching and that nutrients and fluids must be supplied. Their parish priest believes this is correct. Dr. McG asks Dr. Jonsen about this. Dr. Jonsen refers the question to a noted Catholic moral theologian, Father Bretzke.

Here is his answer:

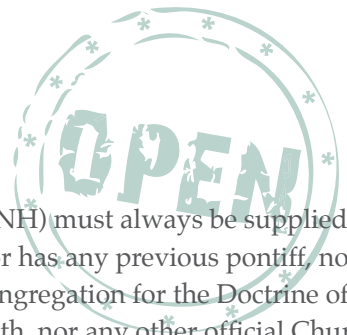
This case involves what Catholic tradition calls the principle of "ordinary" and "extraordinary" forms of treatment (O/E), coupled with the bioethical principle of autonomy, which means respecting the patient's health care wishes, other things being equal. These are long-standing principles taught by Catholic moral theologians. They are expressed in many of the Church's official pronouncements, such as papal encyclicals and statements from the Vatican Congregation of the Doctrine of the Faith.

In general, "ordinary treatment" means "a medical treatment that is morally obligatory and refers to those procedures, drugs, etc. which are not excessively burdensome (including cost) and which offer a reasonable hope of success. "Extraordinary" refers to those procedures that don't meet these criteria for "ordinary" treatment. "Extraordinary" does not mean "extreme" or "heroic," but rather "supplemental" and/or "optional." Since the determination of what is "ordinary" or "extraordinary" depends on the medical situation of a given patient, it is quite possible that an identical treatment for a given malady might be "ordinary" in reference to one patient and be "extraordinary" for another. Thus, it is up to the patient, her doctors, and her family to weigh whether a careful calculation of its relative burdens and benefits shows the treatment as be "ordinary" (in which case it would be morally obligatory), or whether it falls into the "extraordinary" realm, and would then be optional.

This particular case turns on two major considerations: first, just what does the official Catholic teaching authority actually say, and second, how does one interpret and apply these relevant moral principles in this particular case. The first question requires a careful, accurate answer. It points out a real problem, since so often the popular understanding of the actual official Church teaching is partial, misconstrued, or flat out wrong. Despite a fair amount of misleading press coverage, Pope Benedict XVI clearly has not reversed the Church's moral teaching, nor has he said that artificial hydration and nutrition

(ANH) must always be supplied. Nor has any previous pontiff, nor the Congregation for the Doctrine of the Faith, nor any other official Church authority done so. The present Pope has not addressed this issue at all. Previous popes (most notably Pius XII and John Paul II) made a number of pronouncements that support the O/E principle and its application.

In a widely reported address in March 2004, Pope John Paul II said that other things being equal ANH should generally be considered "ordinary means of treatment." Some commentators mistakenly said that now ANH must *always* be administered unless death was clearly imminent. The Pope returned to the issue of health care in end-of-life situations in November of the same year to correct erroneous, over-zealous interpretations of his March Address. In that later Address the Pope stated that "refusal of *aggressive treatment*



is neither a rejection of the patient nor of his or her life." He reiterated the long-standing O/E principle that individual patients can legitimately make a "decision to fore go aggressive treatment (which) is an expression of the respect that is due to the patient at every moment." So it is clear that the various documents have different contexts and emphases and so they must be studied carefully in order to determine first what is actually being addressed by a given document, and then second how the Church teaching is meant to be applied in a given situation.

The Church does not presume to give concrete medical advice or to prescribe specific treatment protocols. The Church recognizes that this is the domain of the medical professionals, who in turn should make these decisions in light of the patient's wishes and the guiding moral principles such as O/E. The Church's role is to enunciate these larger bioethical principles while leaving specific application to the medical experts and the patient him/herself. A most important point in applying the O/E principle is to recognize that its concrete application can only be done in reference to an individual patient, and that there can be no "one size fits all" mandate for a given medical treatment. In short, there is not an absolute Church teaching on concrete health care procedures which must always (or never) be employed.

Dr. Jonsen gave Father Bretzke's note to Dr. McG, who shared it with Mrs. O'B's family and their parish priest. Dr. McG explained the medical consequences of withholding artificial

feeding and hydration, clarifying that it does not cause suffering and leads to a rapid, quiet death. After reflection and prayer, they authorized Dr. McG to withhold artificial feeding and hydration.

We thank Father James T. Bretzke, S.J., S.T.D for his contribution. He is Professor of Moral Theology at the Boston College School of Theology and Ministry. He has taught at the Pontifical Gregorian University in Rome, the Graduate Theological Union, Berkeley, and the University of San Francisco. He can be contacted at Bretzke@bc.edu.



Kennedy's case, that event was a bout of seizures; others experience severe headache, numbness or weakness. RS found himself suddenly inarticulate during an interview with a client (dysphasia). RS saw his primary care physician after a second episode of dysphasia. A CT scan and a biopsy confirmed a glioma in that part of the brain associated with language.

The diagnosis of a brain tumor is a shock because often there have been no prior signs of illness and the patients are otherwise healthy, vigorous persons. Some of those patients are cured since their tumors are of the type that can be totally and effectively extirpated by surgery. Many others follow Mr. RS's path from a so-called "successful surgery," that removes the bulk of the tumor from the brain, to the disappointment, confusion and sometimes despair of a slow demise. As one cancer doctor said, "it always comes back."

This course is distressing and tragic for patient and family. It is medically difficult for physicians and surgeons who provide care. In what sense does it pose a particular ethical problem, different from other conditions? The ethical problems appear when we contrast the most basic principles of medical ethics with the progression of the patient's disease. One of those principles is the autonomy of the patient. This means that the patient has the moral and legal right to determine what course of treatment he or she wishes to receive or, indeed, not to receive. Patients are entitled to a full explanation of their medical condition and of the benefits and risks of any possible treatment. The physician may recommend one or another treatment but only after fully educating the patient. This focus on the autonomy of the patient was a radical break from traditional medi-

cal ethics. In that tradition, a physician would make a diagnosis and, in the language of the past, "order" treatment. The patient was expected, indeed, was thought morally obliged, to follow doctor's orders.

There were many reasons for this radical shift. The 1960s and 70s were the years of protest over the Viet Nam war, over civil rights, women's rights and gay rights. Distrust of "paternalism," the authority of the father of the family, spread to every aspect of life and politics and pushed aside even the benign paternalism of doctors. Also, in the previous decade, a whole range of new technologies had been created. Hemodialysis and ventilator support of breathing gave medicine the power to do what it had never been able to do: sustain endangered life. Effective drugs to banish fatal infection were truly life-saving. Surgery, emboldened by these drugs and guided by skillful visualization, deeply entered the body. It entered the brain more invasively and precisely than ever before.

Why did these medical developments promote the autonomy of patients to so central a place in medical ethics? Simply because the successes of these procedures often left patients alive but did not cure them. A lethal process had been stopped in its tracks but not banished. Surgery and chemotherapy for cancer could stop the invader but was often powerless to prevent its return. Often life was saved and extended, a much desired result, but the reduced quality of saved life might give pause. Autonomy overcame paternalism because while patients might not know the technicalities of their disease and its treatment as well as the doctor, they certainly should know their values and their willingness to live in certain ways much better than the doctor.

Thus, it was thought, patients alone have the right to govern their future and its quality.

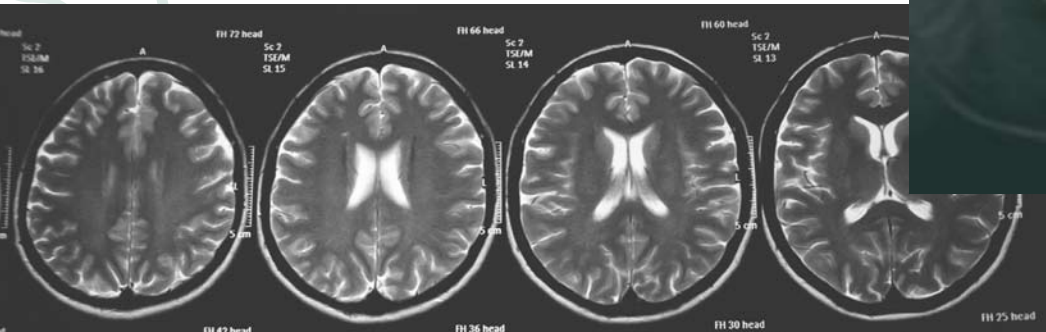
This was a positive reform of medical ethics. However, it had an unfortunate side effect: some physicians repudiated medical paternalism but became, instead, medical commentators. They saw their role to be scientific diagnosticians and technicians, pinpointing the cause of disease and fixing it with the methods they had learned as specialists and subspecialists. Their personal relationship to the patient was primarily as a commentator: informing them of the news about their body and the news about what they could do about it. Like the traffic reporters on the news, they might go beyond comment to suggesting what route to take or to avoid. But their involvement with the patient's own dilemma, distress and above all, future became distant. This is not true, of course, of all physicians but it is a style fostered by the nature of the technologies. Certain fields of medicine, such as family practice rejected this style, but remained at the fringe, rather than at the center of the medical world. The great medical centers literally stood as the center of the medical world.

The complexity of those centers, with their many specialities, their powerful technologies and their arcane financing, move the physician further from the patient. Ironically, patients, newly emancipated and empowered by law and ethics, find themselves wandering confused or shuttled hurriedly through this system. It often brings them great benefits but it also often leaves their most serious needs unmet. They are free but also abandoned.

RS's CT scan was done by a radiologist; he was then referred to a

neurosurgeon who removed the tumor. The neurosurgeon told RS and family that he believed he got the bulk of the tumor, but couldn't "guarantee that he had gotten to all of it." The surgeon then referred RS to one oncologist for chemotherapy and to another radiologist for radiation. Five physicians provided care for RS. Each of them may have done splendidly but they each had isolated, fragmented contact with RS. Notably, his primary care physician whom he had known for twenty years essentially disappears from his care after those early visits.

Here is the ethical irony: the success of medical technology that promotes autonomy into a central principle of ethics now reveals its inadequacy. The brain tumor patient is saved from quick death but faces death inevitably and probably soon. Patients with brain tumors are quite lucid, rational and mentally competent (although often distressed) at the onset of their disease. They should be vigorous decision-makers in their own behalf, choosing treatments and directing their doctors.



However, many patients gradually slip into deep confusion, dementia, memory loss or some other psychiatric states. Even after "successful surgery" radical changes in personality may appear which make the final months of a patient's life a hell for patient and family. Yet, as these deficits occur, the patient is often faced, as was RS, with decisions about whether to continue therapy, to change therapy, or to become an experimental subject for innovative treatments. As their competence to make decisions is more and more compromised, the decisions that they are offered may become more complex.

When any patient loses this competence, it is customary to turn to immediate family or to appointed surrogates to make decisions. For brain tumor patients, the slip into incapacity is gradual and often not easily recognized. Their family is deeply involved in their treatment and progress, taking every positive moment as a signal of victory. The patient's gradual shifts in personality are profoundly linked to their familial and social environments, which often need as much attention as does the patient.

In brain cancer, the autonomy of the patient is compromised slowly and

often subtly. While many conditions, such as Alzheimer's, are marked by slow, subtle degeneration of decision-making capacity, few demand the continual revision of treatment programs that brain cancer does. In brain cancer, there are continual questions about continuing aggressive treatment or turning to new treatments. Treating physicians are often guided by the technical probabilities of success more than by the signs of dimmer and dimmer futures. They do so, not only because they are masters of the technologies but because they are reluctant to tarnish the hope of patient and family. The ethical question now is whether this

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Happenings

situation imposes new duties on the physicians and on the system of care through which RS is fitfully moving. Is respect for autonomy a satisfactory ethic? Should we revive the old “paternalism” and, if we do, how can it function in a medicine that has become so impersonal and so superspecialized? Even if physicians should act more authoritatively, which physician, among the phalanx of physicians caring for seriously ill patients should assume that role? Can we be assured that the medical recommendations will hew to the best interests of the patient and not pursue every route out of futility? Brain cancer raises these questions very poignantly. Sometime soon, in the wind-washed rooms of a house in Hyannisport or the sterile wards of Massachusetts General Hospital, these questions will be asked and will have to be answered somehow.

International Bioethics Retreat – Paris 2008

This year’s International Bioethics Retreat, co-sponsored by the Program in Medicine and Human Values, was hosted by France’s prestigious “Sciences Po”, June 23-27. Countries represented: Argentina, Canada, Finland, France, Germany, Monaco, Italy, The Netherlands, Qatar, the United Kingdom, and the United States. William Andereck and Wes McGaughey presented, “Conducting a Value Audit: Assessing the Ethical Climate of a US Community Hospital,” and Katrina Bramstedt presented, “Exploring the Ethical Complexities of Organ Tourism.”

A highlight of the meeting was a panel discussion on “American Healthcare: Practice not Theory,” chaired by Dr. Andereck and presented for invited French health professionals and the media. Next year’s Retreat will be held in Lausanne, Switzerland, hosted by the University of Lausanne.

Bramstedt Interviews and Lectures:

Throughout this spring, Dr. Katrina Bramstedt was asked to give interviews both for local as well as national print and television news on topics as far-ranging as: termination of treatment questions, ethical issues

surrounding organ transplants, sperm banking and donor privacy, and physician conflicts of conscience. Additionally, Dr. Bramstedt gave two lectures in April: first in Chicago for the Frontiers in Ethics Transplantation conference on “Defending Psychosocial Exclusion Criteria for Transplantation” and in Boston to the International Society for Heart & Lung Transplantation on the transplantation of foreign nationals.

Other lectures:

Three other local presentations were given by Program staff; Dr. Andereck lectured on Commodified Care at the Asian Ophthalmology Society in San Francisco. Dr. Jonsen delivered a lecture titled “History of the Knights Hospitaller of St. John” to the San Francisco History of Medical Society, presented Grand Rounds to the UCSF Department of Clinical Pharmacy on the ethics of enhancement, and also addressed the International Convention of Head and Neck Cancer Surgery. Steve Heilig stood in for Dr. Larry Schneiderman at the annual Stanford Bioethics Summer Camp, contributing to a panel discussion on health care reform.

Summer Workshop III:

The methods of assessing the ability of patients to make decisions in their own behalf, a problem frequently encountered in Emergency Rooms, Intensive Care Units and Extended Care settings, was chosen as topic for our third annual Summer Workshop in Medical Ethics thanks in



part to feedback received last year. Proof of interest in this critical subject was shown by the attendance of the largest group yet to participate in this one day workshop. The majority of attendees were staff and ethics committee members from multiple Sutter institutions throughout northern California. In addition to our own Clinical Ethicist, Dr. Bramstedt, we had four guest lecturers: Mark Sullivan, MD, PhD, University of Washington; Douglas White, MD, University of California, San Francisco; Jonathan Canick, PhD, CPMC; and Katharine Ettinger, JD, a member of our CPMC ethics committee. Our Program extends thanks to Robert Fordham and the Fromm Institute for the use of Fromm Hall at U.S.F. We look forward to continuing this suc-

cessful training event in June 2009. Exact date and topic will soon be announced.

Summer Seminar '08:

The University of Washington welcomed Dr. Jonsen to their 21st annual week long seminar, Summer Seminar in Clinical Ethics, which he founded in 1988. Dr. Jonsen lectured on multiple topics to bioethicists from throughout the country.

Recent Publications:

Dr. Bramstedt had a paper titled "Deactivating implanted cardiac devices in terminally ill patients: Practices and attitudes," placed in *Pacing and Clinical Electrophysiology (P.A.C.E.)* journal. Our former



*Physician panel at Sciences Po:
Richard O'Brien, MD and Henry Perkins, MD.*

intern, Alon Neidich, who is now studying for medical school, had an essay cited in the President's Council on Bioethics' working paper, on the future of newborn screening.



Stop Talking Medicaese

"Uncle Charles smoked cigarettes until he was 78, then he got a tumor on his lung. The doctors were able to remove it, but a few years later he came down with liver cancer. He survived that one too. Last March, he got brain cancer, and that killed him quick."

The words are spoken by a layperson, not a doctor. The speaker is using terms common in discussions about cancer. Unfortunately, these terms are confusing and vague. Doctors themselves use them, hoping not to upset a patient, and that well-intentioned vagueness often worsens the confusion and anxiety around the diagnosis. So, let's try to get precise.

The word **tumor** is the most general term in the group. It refers to any growth or swelling of the body. It is derived from the Latin root "tumeo" — to swell. Some tumors consist of abnormal cells that proliferate more rapidly than normal cells and do not respond to the bodily chemistry that stops unregulated growth. Such tumors are called **neoplasms**. Neoplasms can be **benign**, meaning that their growth is limited to the site of origin. The only way they will hurt you is by growing larger and crowding out adjacent organs or tissue. Other neoplasms are **malignant**, meaning that they not only have the property of invasive and destructive local growth, but that they can also spread through the

blood stream, or the lymph nodes, to invade and grow in other tissue, far removed from the original site. This travel of a malignant neoplasm from one site to another is called **metastasis**. The sites of metastatic tumor spread are the lymph nodes themselves, the bones, the liver and the lung. The brain is involved less frequently, but more often than the adrenal glands, or the skin. Some neoplasms have a propensity to spread to particular organs, like prostate tumors to the bones, or colon tumors to the liver, but other neoplasms, like breast and pancreas, are less picky.

So now we are ready to define **Cancer**. The Greek physician Galen

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noted that some rapidly growing tumors would develop swollen veins that would spread out in a pattern that reminded him of the legs of a crab, “karkinos” in Greek, “cancer” in Latin. In the modern world, cancer refers to any neoplasm that contains malignant cells and has the potential to metastasize. It does not have to spread to become a cancer, only to have the potential to do so. This is why even cancers that are successfully removed are often treated with subsequent chemotherapy, in an attempt to treat any cells that may have already traveled undetected into the body.

So, we now can see that Uncle Charles did not have three cancers, but a neoplasm that spread from one site, the lung, to brain and liver. He developed a malignant neoplasm of the lung due to years of smoking. Although the primary site in the lung was removed at surgery, the tumor had metastasized to his liver and brain, appearing clinically, a bit later. It was the lung cancer that spread to his brain that caused his death, although the liver cancer would have done the same thing if he had survived a bit longer.

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