

Three Revolutions: Healing, Power and Ethics

Editor's Note: In observance of the 100th anniversary of the Catholic Health Association, Johnny Cox, who is one of the earliest ethicists in Catholic health care, was asked to reflect on his experience. That reflection follows.

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Indiana Jones, Luke Skywalker and Frodo Baggins couldn't have encountered more adventures than faced me during thirty years doing ethics in American Catholic health care ministry. Like their fictional challenges, most of mine were encounters with power. Power that heals and power that harms, intermixed nearly daily. Thank God, the Force is with us! In my view, three revolutions have tilted the balance of power in favor of healing, two on the edges of life and one central to our Church and professional milieu.

Birth

Our first baby was due in mid-May and my dissertation defense was scheduled for mid-July. 1972 was an exceptional year. Both these events concerned health care ethics, one quite theoretical and the other very, very personal. After all, what could be more personal than childbearing?

Among the many surprises during the months of pregnancy was that only a single physician in that California community had leveraged the local hospital into allowing fathers into the delivery room. My wife and I wanted a family birthing experience so our choice was obvious. The obstetrician was competent,

seemed quite sensitive and made it clear to me during the introductory visit that his professional relationship with my wife did not have room for me! I saw him next while I stood at the opposite end of the delivery table, watching through mirrors as our son was delivered.

My first experience of the power of medicine to fashion the meaning of profound life experiences was only okay. I was thrilled to be there watching a miracle. I participated by coaching and encouraging and being silent as I'd been instructed in Lamaze classes. Joy prevailed. Still something felt incomplete, although I couldn't put my finger on it. Insight began with the next pregnancy.

A year later in another state with an obstetrician who encouraged me to accompany my wife to office visits, a curtain was raising on the medicalization of child birthing. He inquired how I was doing with the pregnancy, anticipating a second child pretty soon after the first. He always provided private time for my wife. He clarified safety parameters and offered options that included a birthing center and nurse midwives. Other family members could participate, if we wanted. Basically this physician used his professional power to fashion gestation and birth as family enriching experiences. Little did I know just how much of a revolution was underway.

That light dawned three years later during my obstetrical rotation as a student nurse. I was assigned to a community hospital in a suburb of a major metropolitan area. The grassroots family birthing revolution was taking off, but at this hospital almost all delivering women were anesthetized and the babies were delivered with forceps. Naively, I inquired of my professor why this practice persisted; she stated the physicians preferred to practice the way they had been trained. I objected that our course textbook taught this previous protocol was no longer scientifically indicated. She looked at me with an expression that spoke volumes. Welcome to the real clinical world of power, politics and ethics. A popular contemporary text examining the first years of nursing was titled *Reality Shock*.

Fortunately, by the end of the seventies, hospitals and physicians were trying to outdo one another on family-friendly processes and environments for carrying and delivering babies. This radical shift of power from the medical establishment to moms and dads occurred just as bioethics was emerging. This revolution catalyzed two important transitions that are unfinished today, one for patients and the other for staff.

The civil rights movement was impacting medical paternalism. In 1973, the American Hospital Association developed its *Patient's Bill of Rights*. The agitation of the 1960s had highlighted disparities between ethical principles and professional practice. The first Directive of CHA's 1949 *Code of Ethical and Religious Directives for Catholic Hospitals* reads: "Even the procedures listed in this section as permissible require the consent, at least reasonably presumed, of the patient or his guardians. *This condition is to be understood in*

all cases" (emphasis in original). But, to modify a currently popular phrase, culture eats principles for lunch! Patients and families docilely followed orders which they presumed, usually correctly, were in their best interests based upon the physician's expertise and beneficence. Many still do but there's been remarkable progress toward patient-centered systems and processes in clinical services. The Internet and electronic medical records help those who use them. Nevertheless today's daily ethical issues in clinics and hospitals challenge us to support patients in exercising their proper decision making prerogatives.

The staff version of patient-centered successes followed a similar trajectory. As I was entering the field, the authority of the physician was akin to the captain of a ship whose word was law. Vestiges of the American hospital's naval roots still include house officers and, of course, orders. Fifty years ago the sailors – nurses, pharmacists, therapists – were expected to salute and obey orders. But then the sailors became officers who were held accountable for their own decisions. Judges no longer accepted the defense that "I followed the doctor's orders." Practice standards and licensure requirements bolstered their professional status and accountability. But they lacked institutional support.

At that time, many if not most, ethics committees allowed only a physician to request an ethics consultation. Through a pioneering policy in 1983, the medical center where I worked gave nurse managers authority to convene mandatory ethics conferences for patients on their units. Within a month, the highest admitting surgeon announced quite loudly that he would not attend a conference

on one of his patients that the nurse manager had scheduled for the next morning. In a way, a gauntlet was thrown. I brought his proclamation to the CEO, who was a living legend of leadership, and listened to her phone call with the surgeon. She simply stated, “Doctor, I understand important decisions for one of your patients will be discussed tomorrow morning. I’ll see you there.” He came. And the word got around. Sadly our three decade track record is, at best, spotty. Once again we find ourselves in the wide gap between principle and practice. In 1992 the first edition of the American College of Physicians *Ethics Manual* stated forthrightly that in ethical matters “even though health professionals have special areas of expertise, each member of the patient care team has equal moral status.” The physician is still captain, but captain of a team of professional colleagues. This conviction is taproot of a culture of mutual respect among professionals that keeps patients at the center of decision making.

Twenty-five years later I am gratified by organizational progress in developing cultures of collaboration and accountability, mostly driven by patient safety and quality initiatives. I am also concerned by the continuing struggles to maintain the gain. Strengthening this culture shift continues to be my top priority.

Death

I stepped into the next revolution during a speaking engagement in 1974. Another speaker was Florence Wald, dean of the Yale School of Nursing and co-founder of America’s first hospice. She raised the curtain on the medicalization of dying and

encouraged me to start a hospice. I was in my twenties and an assistant professor of theology. Within two years Hospice Maran Atha was offering a distinctive way of supporting families to care for their loved ones with terminal illnesses in Spokane, Washington. It was the first hospice providing clinical services in the Northwest and one of the first dozen in the country.

Hospice pioneers introduced a concept of caring, a way of restoring dying persons to homes and families. The goal was not to launch a new health care specialty service but to restore the *ars moriendi*; our message to the community was that dying is a simple, delicate family affair. We sought to integrate this way of caring into existing hospital services but were rebuffed by a medical model of treating disease and the power of vitalism that denied dying as a phase of living.

About the same time, my first years in clinical ethics were also a marathon swim against the swift current of forces that equated the purpose of medicine with treating disease to keep people alive. The stories were poignant. There was a pulmonologist who withdrew from treating a patient on conscience grounds. The patient asked for “comfort only,” the nephrologist and cardiologist agreed “there was nothing left to do.” But the pulmonologist insisted she was professionally obligated to treat the lung infection because it was reversible. There were also those doors to the surgery department beyond which all patients would be resuscitated, no exceptions! Twenty-five years later and closer to home found my mother, an eighty-seven year old with a slowly decompensating heart, who wanted a fairly simple treatment that promised her more strength, but who did not

want to be resuscitated if anything went wrong. The treatment went uneventfully but mom developed a complication and was transferred to the ICU. The nurse manager noted her DNR status and said it would have to be rescinded. My brothers, the priest and clinical social worker, and my sister, the cardiac critical care nurse, held firm. The cardiologist was paged to the unit and declared, “Everyone in this ICU is full code.”

This was a Catholic medical center in 2009. No matter that ethical principles and legal requirements about consent were now clear, no matter that such a practice exposed the professionals and facility to liability risks. The culture of vitalism prevailed. My sophisticated family was adamant and the physician relented. Think of the countless others who were not so fortunate.

Ironically, some years before I had done ethics education on life-sustaining treatment for staff in that very ICU. My family’s experience reinforced the mantra of my friend and colleague, Jack Glaser, that “to educate and hope is a futile strategy.” Without solid organizational architecture, complete with policies and protocols, and courageous executive power to assure accountability for our moral commitments, educational efforts are like seed thrown on rocky soil that looks good when it sprouts but withers as soon as opposition arises. Last year’s report of the Institute of Medicine on *Dying in America* highlighted roughly the same issues and priorities that were front and center in the 1980s.

The power of vitalism is antithetical to the scriptural and theological foundations of our mission as healing ministries of Jesus Christ.

In 1980 the Congregation for the Doctrine of the Faith’s *Declaration on Euthanasia* warned “Today it is very important to protect, at the moment of death, both the dignity of the human person and the Christian concept of life, against a technological attitude that threatens to become an abuse, denying the right to die peacefully with human and Christian dignity.” The recent successes of palliative care programs and services are remarkable precisely because the medical model of treating disease and a culture of vitalism remain deeply embedded in Catholic health care. We are making progress but old habits and new threats persist. Do we name vitalist behavior as social sin? How are our executives supporting physician leaders to curtail those behaviors? Are our oncology groups encouraging drugs that might extend life by a few months rather than suggesting hospice care? How are we applying the principles governing toleration of evil within our own acute care facilities and specialty clinics?

The revolution of restoring the *ars moriendi* to patients and families in their own communities has undeniably progressed. The contemporary shift from hospital-centric treatment to population health offers tremendous opportunities for renewing our commitment and investing additional resources. This is a key ethical challenge for the current generation of Catholic ministry leaders.

Conscience

Saint John XXIII opened the Church window that ushered in the breeze igniting the fires of the third revolution. Among its many achievements, the Second Vatican Council

resurrected Catholic tradition about conscience from a century in the tomb of nearly blind obedience to authority. *The Church in the Modern World* proclaimed, “Conscience is the most secret core and sanctuary of a man. There he is alone with God, whose voice echoes in his depths....In fidelity to conscience, Christians are enjoined with the rest of men in the search for truth, and for the genuine solution to the numerous problems which arise in the life of individuals and from social relationships” (16). In 1976, the U. S. bishops reinforced this renewal of Catholic tradition in their pastoral reflection on the moral life, *To Live in Christ Jesus*: “We live in good faith if we act in accord with conscience. Nevertheless our moral decisions still require much effort. We must make decisions of conscience based upon prayer, study, consultation and an understanding of the teachings of the Church” (p. 10).

Even though the following three decades were filled with powerful attempts to squelch these revolutionary fires within the Church, by 2005 nearly every U. S. Catholic health system had established some version of communal conscience formation. Formal discernment protocols or ethical decision making processes were hardwiring our tradition’s teaching on forming conscience within ministry communities. While ordinarily a particular person or group is accountable for a specific decision and its consequences, our tradition emphasizes reaching the decision in community through study, reflection, consultation and prayer together. The richness of our heritage resides within the persons who make up our communities of healing. The wisdom of the Spirit dwells in each and every one gathered together.

Ethicists and moral theologians were simultaneously expanding their repertoire of services into health care board rooms, executive suites and business offices as facilitators for forming organizational conscience and reaching decisions on key issues. The process I helped create and introduce into a Catholic health care system fifteen years ago has three phases, each intended to channel the power of leaders into genuine communal deliberation. Exercise of power is crucial! The first is assembling the appropriate community of reflection to assure those persons and groups who have insight and will be affected by the potential decisions participate. Many leaders tend to exaggerate their own capacity to represent various perspectives, consequently using their power of selection to exclude crucial voices and prejudicing the deliberation. The second phase is the actual decision making process that assures the conversation is focused and participants can share their insights safely and be heard. Some leaders use their power to preempt agendas and even intimidate participants. The third phase is implementation with designated metrics and assigned accountabilities, including a communication plan. It’s a moral imperative to be vigilant against the power to undermine or impede implementation either by opposition or neglect, in effect making a mockery of the entire conscience formation process.

In the present environment, in which Catholic health care is often viewed as an industry or merely a business, it is more important than ever that decisions made by faith-based health ministries are grounded in their communal heritage and moral tradition.

To reach a significant organizational decision without diligent use of an ethical decision making process constitutes moral negligence.

The battle for the healing ministry's soul rages fiercely. The Spirit is at work with and within those gathered to make decisions fashioning the identity and vitality of our ministries. The tools and processes are in place to continue the revolution started by Saint John XXIII. Today's ministry leaders must use their power to fend off current internal and external threats to conscience, the most secret core and sanctuary of healing ministries.

New Revolutions?

So these three revolutions continue with the intermixed powers to fortify and powers to erode Catholic health care ministry. Challenges abound, and who knows what new revolutions are emerging? Whatever arises, patients and their families will need the ministry's support to keep them central to decision making and to integrate the meaning of their health care experiences into their lives – whether birthing, dying or anything in between. Genuine whole person care! Staff, too, will flourish as *moral equals* in decision making and caring only with the support of executives who consistently maintain accountability for organizational conscience through its policies and protocols. True communities of professional integrity! Prayerful discernment processes involving the appropriate community of reflection will keep the Spirit at the heart of strategy and particular decisions to advance the healing love of Jesus. Catholic ministry at its best!

St. Paul reminded the ministry leaders of his day (2 Tim. 1:7) that “God did not give us a spirit of cowardice but rather of power and love and self-control.” Same today and tomorrow, onward into new revolutions. Thank God, the Force is with us!

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