
Bioethics Outlook

Plunkett Centre for Ethics

A joint centre of Australian Catholic University and St Vincent's Health Australia (Sydney)

Volume 27, No 2

June, 2016

The Hour of Our Death: Contemporary approaches to end-of-life care

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The contemporary American approach to end-of-life care is captured in an essay by Atul Gawande, M.D., in *The New Yorker* (8/2/10) entitled: "Letting Go! What Should Medicine Do When It Can't Save Your Life?" Dr. Gawande, a surgeon at Boston's Brigham and Women's Hospital and a professor at Harvard Medical School, regrets what is occurring in medical practice. Yet he feels helpless to resist. In his beautifully written essay, Dr. Gawande tells the story of Sara Monopoli, a young woman who was eight months pregnant with her first child when doctors diagnosed her lung cancer. Her husband assured her, "This is going to be O.K. We are going to work through this."

In this issue

First we reprint, with permission, an article which originally appeared in the Jesuit journal, America, in which Dr Paris takes issue with a key principle in the thinking of Dr. Atul Gawande: the idea that, once a patient is overcome by disease, the next thing for the doctor to ascertain is what treatments the patient would and would not want !

Then we present one of the most salient points made by Professor John Haldane in a recent discussion of today's 'transgenderism' movement: the idea that gender is assigned, not discovered.

Finally, we note Daniel Callahan's admiring review of an anthropologist's explanation of why it is almost impossible, in the United States today, to draw a line between enough and too much medical treatment.

The next day Sara delivered a healthy baby. That same day her oncologist informed Sara that the non-small cell lung cancer had metastasized. Her condition was non-operable. There was, however, the possibility of chemotherapy. She was started on an experimental drug that targets a gene mutation found in females with lung cancer. Tests subsequently revealed Sara did not have the mutation that drug targets. She was then changed to a more standard drug. That drug also failed. A third regimen was tried, but it too failed to slow the tumour. All known interventions, including the use of a drug in a Phase I trial, had been utilized without success. Dr. Gawande then asks: "What do we do now?" The question was not about science or medicine. It was, "What does the patient want?" Patient autonomy, for weal or woe, has become the fundamental value in American medicine. It trumps all other values. Gone is the tradition that prevailed from the time of Hippocrates until the middle of the 20th century that the physician determines what should be done in the face of an overwhelming disease.

How did we get to this state of affairs? The late Edmund D. Pellegrino, M.D., described in an essay in the *Journal of the American Medical Association* what he labeled "three eras of medicine:" Hippocrates to 1960; 1960 to 1990; 1990 onward. In the first era physician paternalism prevailed. The doctor decided what was to be done. In later centuries the physician was readily identified by his small black bag. It contained everything

the physician needed to practice—very little. Little could be done and little was attempted. Most people succumbed to death at an early age from an intractable infection. In that era, the rules for the practice of medicine were relatively simple. They were laid out as far back as the Hippocratic Corpus: Alleviate suffering, treat disease where possible and do not impose treatment on the patient "overmastered by disease", because in such cases medicine proves powerless.

Three developments occurred in the years 1960 to 1990 that changed medical practice: technology, third-party payment and loss of trust in institutions. That final factor led to the rise of rights language. The predecessor of the emphasis on the rights of patients is found in Justice Benjamin Cardozo's opinion in the landmark Schloendorff case in 1914 that "every human being of adult years and sound mind has the right to determine what shall be done with his own body." The Schloendorff ruling recognized the competent adult's right to refuse an unwanted medical intervention. It did not confer on a patient the right to determine or demand a treatment, nor was there an obligation on the part of the physician to honour such requests.

Dr. Pellegrino noted that the rise of autonomy transformed the doctor-patient relationship from a joint venture of trust and dependency into a commercial model in which the patient (or proxy) alone determines what is to be done. The

furthest reach of “autonomy” is found in several recent cases in which parents requested and physicians continued life support on an infant born with anencephaly, a condition in which the infant has no brain, or congenital dwarfism such that the child’s small rib cage prevented lung expansion, thus causing suffocation. The most extreme cases were those of a brain-dead child whose parents refused to accept the diagnosis and insisted on continued ventilator support of the child. In all of these cases the treating physicians believed, much like Dr. Gawande, that absent a court ruling to the contrary, they had no option but to follow the treatment decision of the mother.

The morphing of the right of the competent patient to decline an unwanted medical intervention into the right to be provided whatever medical intervention—indifferent to efficacy or cost—the patient (or proxy) demands results in what Dr. Pellegrino described as “the chaos” of present day health care delivery in the United States.

It also led doctors like Dr. Gawande to lament the fact that when physicians today confront patients and families like Sara and her husband, who believe that there is a technological fix for every medical problem, they feel powerless to resist their demands.

The Catholic Mindset

The assessment that patient autonomy is the dominant value in medical practice as well as in bioethics is correct. The Catholic approach to bioethics operates out of a different mindset. Richard McCormick, S.J., the most influential Jesuit moral theologian of the late 20th century, noted in an essay entitled “Bioethics: A Moral Vacuum” (*America*, 5/1/1999) that in our age autonomy has consumed the entire range of bioethics. In doing so, he argued, we have excluded from consideration those goods and values that make choices right or wrong. But those are precisely the factors that make bioethics a moral enterprise. When the rightness or wrongness of a decision is reduced to an individual’s choice, the result is autonomy run amok.

This is captured in a statement by Jack Kevorkian, M.D., (sometimes called Dr. Death) on physician assisted suicide: “In my view the highest principle in medical ethics—in any ethics—is personal autonomy, self-determination.” His approach gives no consideration to the impact of individual choice on family and friends, the medical profession or society.

When contemporary bioethics talks about patients as autonomous persons, it is mostly talking of a pipedream. Such talk leaves the impression that desperately ill and dying patients are in Olympian control. But as we have all experienced, even with something as minor as the flu, illness inevitably means dependence. We

rely on others for whatever we need. This is all the more true of the seriously ill.

Lost in the clutter of clinical details are the “big-picture” issues that concern the patient. Medical costs, for example, have an enormous impact on the sick. But that issue is generally passed over in silence. What are the patients’ fears, hopes and doubts? These rarely appear in the medical chart. Clinical details are noted, but to paraphrase T. S. Eliot, do we measure out our lives in data?

An emphasis on bioethics that reduces the patient to medical details or to the patient’s desires—ignoring big-picture issues like the common good, distributive justice and the spirituality of the patient—misses an understanding of who the patient really is. To achieve that big picture, Catholic moral theology insists we focus on the patient viewed in all his or her complexity—physical, financial, social and spiritual. Patients are not reducible to organ systems, like the heart, liver, lungs or kidneys or, worse, to biochemistry. Rather, we ought to look at what Paul Ramsey famously called “the patient as person” (2002).

A Catholic approach to bioethics begins not with the patient’s autonomous will but with a theological understanding of “the meaning, source and goal of life.” This is seen in Father McCormick’s landmark article in *America*, “To Save or Let Die” (7/7/1974). Although the essay was published simultaneously in a medical journal (*JAMA*), it is replete with theological presuppositions, language and

conclusions. The article is a commentary on a legal case in which Judge David Roberts of the Maine Superior Court ruled that if a patient has a medical need and there is a medically feasible response, that medical treatment must be provided. In Judge Roberts’s words, “The most basic right enjoyed by every human being is the right to life itself.” That pro-life stand might be taken by many as the orthodox Catholic approach to life-death decisions. In utterly unflinching language Father McCormick rejected that reading of the Catholic moral tradition. In his words, such a standard is nothing short of “idolatry.” Human life, he tells us, is a gift of God given for a limited purpose. Its *raison d’être* is not our earthly life but eternal life. As Father McCormick understood the Catholic moral tradition, it is an attempt to formulate a balanced middle ground between “medical vitalism” that acts to preserve life at any cost and “medical pessimism” that kills when life seems frustrating, burdensome or useless.

Both alternatives, in Father McCormick’s view, are idolatries. In support of that opinion he quoted Pope Pius XII’s famous allocution to the International Congress of Anestheologists, entitled “Prolongation of Life” (Nov. 24, 1957), stating that we are normally obliged to use only ordinary means to preserve life. In over 500 years of consistent Catholic moral thought, the terms ordinary and extraordinary refer not to hardware or technique but to moral obligation. Ordinary are those things one is obliged to do. Extraordinary

are those things one may do but is not obliged to do in order to save one's soul. Failure to act appropriately is a sin. The punishment for such failure, if not absolved, is eternal damnation. The question then put to the moral theologians was, What exempts an individual from the obligation to undergo a medical technique? The response was that one would be exempt if the treatment were too costly, too burdensome or too painful or if the procedure did not offer a reasonable expectation of benefit to the patient.

A Cog in a Machine

The 1980 Vatican *"Declaration on Euthanasia,"* aware that today the terms ordinary and extraordinary are confused, misused and abused, proposed substituting "proportionate and disproportionate" burden and benefit to the patient. The opening statement of Part IV of the declaration applies that analysis to end-of-life care: "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." An example of such abuse would be the intensive care unit described in Dr. Gawande's "Letting Go," where a patient, tethered to a ventilator with tubes coming from every orifice, is reduced to little more than a cog in a machine.

More morally problematic in today's world of high tech medicine is the notion that "once we start, we cannot stop." It is believed by some that while it might be acceptable to withhold certain treatments, once they have been initiated it would be unethical to shut off a ventilator, stop dialysis or withdraw artificial nutrition and hydration. In the now famous 1973 Quinlan case, for example, both the attorney general of New Jersey and the local district attorney denounced the proposal to withdraw a ventilator from the patient in a persistent vegetative state as state-sanctioned murder.

In the subsequent case, Barber (1993), the Los Angeles district attorney brought first degree murder charges against the chief of surgery and the chief of medicine at Kaiser Permanente Long Beach Hospital for removing, at the request of a patient's wife and seven children, a ventilator and then a feeding tube from a man for whom the physicians had no realistic expectation of restoration to cognitive functioning existence. After a preliminary hearing, a judge dismissed the charges. The district attorney appealed. The California Court of Appeals upheld the dismissal. It framed the question before it thus: "Does a doctor have a duty to keep his patient alive through forced respiration and nutrition?" It responded "No." In doing so the California Court of Appeals determined as a matter of law that artificial respiration as well as artificial nutrition and hydration—*are* extraordinary means of medical support.

Further, it ruled that the decision to withdraw support should be determined in terms of a benefits-versus-burdens analysis as seen from the patient's perspective. Since the patient had indicated he did not want to be maintained by extraordinary means, the court ruled the physician had no duty to provide such measures.

A Jesuit Approach

The Catholic approach to these cases is "back to basics." We reflect on such fundamental questions as "Who are we?" and "Why are we here?" The answer to these questions is found in the old Baltimore Catechism, a standard Catholic school textbook from 1855 to the late 1960s. The responses found there are: "God made us" and "God made us to know love and serve him in this world and to be everlastingly happy with him in the next."

Unpack those penny catechism statements. What do they imply with regard to use of medical interventions to prolong the life of a dying patient? The purpose and goal of life is not the mere prolongation of biological existence. It is rather the attainment of everlasting life with God in heaven. How is that goal achieved? Scripture tells us it is based on "love of God and love of neighbour." Father McCormick's insight in his now classic 1974 essay is that to achieve that goal one must have the capacity to relate. That capacity is severely truncated if all

one's energy is expended on clinging to life in an intensive care unit.

When, one might ask, do life-supporting technologies become so burdensome as to cease to be a moral obligation? The use of an I.C.U. makes sense if it serves to restore the patient to a cognitive functioning, integrated existence. It makes no Christian or human sense when it functions as a high tech hospice. Such a practice, in the words of Ivan Illich's *Medical Nemesis*, is "a world gone mad".

The Jesuit approach to bioethics goes by the sometimes pejorative term casuistry. As Albert R. Jonsen and Stephen Toulmin demonstrate in *The Abuse of Casuistry*, casuistry is not, as Pascal characterized it, a sly way in which Jesuits twist things to get whatever result is desired. Rather, it is the application of basic theological or philosophical principles to cases or actual situations to discern whether there is a way out of an apparent dilemma.

An example will suffice to see this application in practice. A 75-year-old patient had a recurrent, large cancerous growth on his tongue. The tumour was surgically removed, but it reoccurred. The patient declined further surgery. The problem was that with a tumour the size of an orange on his tongue, if the patient lay on his back and fell asleep, the tumour would block his trachea, which would cause him to cough and wake up. As a result the patient was always sleep deprived. The patient and his family asked if there was anything that could be done to relieve the patient's distress. The

medical resident caring for the patient recommended morphine to keep the patient pain free so he would be able to sleep. With the medication the patient was able to sleep even with the tumour blocking his trachea. But in that position his air supply was inadequate and he died. The nurses believed the resident had “caused” the patient’s death. They wanted to call the police to report a homicide.

In an age in which there is widespread public support for patient autonomy, even to the point of physician-assisted suicide, some argue that the patient’s or proxy’s request for sedation is warrant enough to end the patient’s life. That view contradicts the long tradition in medicine to “do no harm” and the tradition of society’s high barrier against one individual terminating the life of another human being. A Catholic approach to the problem would be to apply the traditional principles of medicine and moral theology to the patient’s situation. Do we accept with utter indifference the suffering of the dying patient? That would not only be inhumane; it would violate the physician’s obligation to “do no harm.” Using the traditional Catholic principle of “double effect,” relief from pain and distress may be provided even if one can foresee, but does not intend, the possible foreshortening of life. Respect for God’s design for life and the God-given dignity of each human being, not deference to the “autonomy” of the patient, is the norm in a Catholic approach to such cases.

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A key issue in the current discussion of 'transgenderism'

Bernadette Tobin

John Haldane, Professor of Philosophy at the University of St Andrews, Scotland, Distinguished Professor of Philosophy at Baylor University in Waco, Texas, and the current Chair of the Royal Institute of Philosophy in London, was a participant in a public debate recently held in Sydney on the question of whether 'society must recognize transgender people's identities'. As the topic has particular significance for healthcare practitioners, in particular psychologists, psychiatrists and others working in youth mental health services, we invited Professor Haldane to address a seminar hosted by the Plunkett Centre at St Vincent's Hospital on the implications of this discussion for the medical profession.

At the outset Professor Haldane pointed out that the current debate about 'transgenderism' is not about how a decent society should respond to those rare individuals with 'intersex' biology. The question of what is appropriate treatment and care for people with this condition is certainly an important one for the medical profession. But that question is not central in current discussions of transgenderism. In fact, Haldane had just one thing to say about the challenges for the medical profession in their treatment

and care of these rare individuals: surgical treatment should not be even considered let alone offered until the individual was able to give his or her genuinely-informed consent ^[1]. Indeed, as Haldane pointed out, whilst it is true that some people identify themselves sexually as other than what is given biologically, one of the main issues of contention is whether or not 'gender dysphoria' is a medical condition.

During the seminar, Haldane identified and explained a key issue in the current public discussion: whether, on the one hand, human beings are sexually differentiated into two genders, male and female, or, on the other hand, the gender of an individual is entirely a matter of choice. In what follows I set out both the claim that gender is a matter for choice, and Haldane's refutation of that claim.

Claim: Gender is different from biological sex

Haldane pointed out that the recent discussion of transgenderism had thrown up two new terms: 'cisgenderism' and 'transgenderism'.

The term 'cisgenderism' refers to the phenomenon whereby one's gender is fixed - by oneself or by others – as the

same as the gender one was assigned at birth. The term 'transgenderism' refers to the phenomenon whereby one's gender is fixed as different from the gender one was assigned at birth.

As Haldane pointed out, embedded in these two terms is a shared assumption: that there is a fundamental difference between an individual's sex and his or her gender. Sex is taken to be a discoverable fact of biology. Gender is taken to be a chosen assignation.

The story goes as follows: At birth, adults take a look and discover that the newborn child has either male or female biology.^[2] Adults then choose which gender to assign to the child. If the child has male genitalia, they assign male gender. If the child has female genitalia, they assign female gender. Mostly, this assigning of gender is uncontroversial. The child with male genitalia grows up feeling comfortable with the gender that was assigned to him. The child with female genitalia grows up feeling comfortable with the gender that was assigned to her. In this way, most of us are 'cisgender': we grow up comfortable with the gender which was assigned to us at birth. But note that the assigned gender was a matter of the adults' choice, a choice which may be rejected later by the individual concerned: thus the phenomenon of transgenderism.

Cisgenderism and transgenderism share this assumption: that gender is assigned, not discovered, at birth. The use of the terms 'cisgender' and 'transgender'

implies a rejection of Freud's idea that biology is destiny. They both say that biology is not destiny, that we should distinguish anatomical (or physiological or sexual) identity from gender identity.

In addition, so the story continues, in the current debate, anatomy is not what matters. A person's anatomical identity is not his or her gender identity, and the claim that it *is* is no more than a cultural convention. Chosen gender identity is key to personal identity. What matters is what gender you choose to associate with: you might be cisgender or transgender, depending on which assignment you make. (Once again, Haldane reminds us, it is important to note that there are cases of genuine sexual ambiguity; there is a small group of people for whom the matter of sexual identity is a real and significant problem. But transgenderism - as a social movement - is not about them.)

Reply: Human beings are sexually differentiated into male and female

In replying to this claim, Haldane re-asserted the traditional idea that human beings are sexually differentiated into male and female, but insisted on the importance of how that idea is understood. It is a *generic* statement, that is, a statement about the genus, or kind, of creature a human being is. But there are at least three different kinds of generic statements: 'essential', 'contingent' and 'normal'.

Consider the following generic statement: 'Human beings use tools.' If you think that using tools is a part of the essence of what it is to be human, then were you to come across someone who does not use tools, you would have to say that he or she was not a human being. But that seems too strong. For we do come across people who are not tool users. Or, again, take the generic statement: 'Human beings are language users.' If you think that using language is a part of the essence of what it is to be human, then were you to come across someone who does not use language, you would have to say that he or she was not a human being. Once again, it seems wrong. There are people who do not speak.

On the other hand, Haldane pointed out that if you think these features have nothing to do with the kind of creature a human being is, that they are accidental features that human beings just happen to have by chance, that they are merely contingences, that too seems wrong. It is too weak. For there does seem to be some serious connection between being a human being and using tools and speaking a language.

The most reasonable view, says Haldane, is to think of these properties not as essential features, not as contingent features, but as *normal* features of a human being, part of the nature of what it is to be a human being, but which admit of exceptions. Normally, human beings

are users of tools, but some are not. Normally, human beings are language users, but some are not.^[3]

The same, Haldane argued, can be said of gender identity. A specific gender identity, connected with biology, is not an essential feature of human beings, for it is a fact that there are people whose biology, and thus gender identity, is uncertain. Nor is gender identity merely an accidental feature of human beings, changeable at will. Rather, biology and thus gender identity is normally discovered at birth. We take a look and can confidently say: 'That is a boy' or 'That is a girl'.^[4]

To conclude. Michael Jackson, who underwent skin bleaching and nose reshaping, seemed to think that he was a Caucasian who happened to have been born into the wrong body. Rachel Dolezal, an American girl born to white parents, who became president of the National Association for the Advancement of Colored People (NAACP) in Spokane, said that she 'identified' as African-American. Her parents said that she was profoundly confused, but she said: 'For me, how I feel is more powerful than how I was born.'^[5]

Activists in the current debate insist that gender identity is similarly – always and everywhere – a matter of how an individual happens to feel.^[6] Against this, John Haldane argued, we need to recover – and to hold on to – the idea that gender identity is – normally – discovered at birth. (*Footnotes are on page 12.*)

Enough and too much.

Why an American anthropologist thinks it is increasingly difficult to draw the line

Daniel Callahan has long been an outstanding contributor to public understanding of the ethical issues at stake in a society's healthcare system. Not surprisingly, his attention has generally focussed on those issues as they arise in the United States. Since there are increasing commonalities between their system of healthcare provision and the Australian system - both because with their *Affordable Health Care Act* they are becoming a little more like us and with the onward march of the market into healthcare in Australia we are becoming much more like them - it was with interest that I read, in a recent edition of the *Hastings Center Report*, Callahan recommending the argument of a thoughtful anthropologist, Professor Sharon Kaufman, on this subject.

The bad health of the system

Kaufman sets out three separate but inter-related features of the cultural background to American healthcare system which are symptoms of its own bad health: the increase and influence of the industry, the rapidly increasing number of treatment options to which

patients have access and which are hard to deny to them, and the 'American perspective on aging and the timing of death' whose most notable feature is that most deaths, regardless of a person's age, have come to be considered premature.

Hidden 'out in the open'

Against this cultural background, Kaufman identifies four 'hidden' forces - links in a chain - within the American healthcare system, especially healthcare for the elderly, that make it 'difficult if not impossible to see the line [of care] between *enough* life-giving treatment and *too much*'.¹ First is the biomedical research industry with its 'clinical trial engine that churns out evidence of effective therapies at an unprecedented rate'. Second is that of the various committees that set both the Medicare (in the US, this is the health insurance program for Americans aged 65 and older) and private insurance company policy which decide which therapies are reimbursable and that in turn determine what doctors will prescribe and what

¹ Daniel Callahan. Invisible Chains and Unwitting Captivity: American Health Care. A review of *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*, Sharon R. Kaufman, Duke University Press, 2015, in *Hastings Center Report*, March-April 2016.

patients will want. Third is the phenomenon whereby what become reimbursable instantly becomes a standard of care. And fourth is the predictable corollary of the third: once a therapy becomes standard, it becomes 'ethically necessary' and therefore difficult if not impossible for doctors, patients and families to refuse.

Callahan admires what the 'wide lens' of Kaufman's view which enables Kaufman to reveal how all Americans become unwitting victims of forces which are linked in a culturally-supported chain that is so tight that patients and families (and sometimes doctors) do not *decide* about treatments so much as *yield* to procedures that the chain has made normal and ordinary.

And Callahan himself adds that this combination of factors helps to explain much of the naiveté that marks the too-often careless invocation of patient (or family) autonomy as the 'high, clean, and well-lighted road to take when ethical decisions have to be made'. The chain makes it inherently hard to decide, generating more and more options and fewer criteria for choosing among them. He ends: *'When the weight of a complex, flawed, yet insistent culture is dropped on a critically ill patient and family, perhaps the best we can hope for is that they will bring with them Aristotle's virtue of prudence – recognizing that we have yet to devise what a wise use of autonomy might mean.'*

Footnotes from page 10

1 *In this regard, the experience of Dr John McHugh at Johns Hopkins Hospital in the United States is telling. Dr McHugh was the first to do re-assignment surgery in 1960s. He later abandoned it because five or six years after having undergone the surgery, the individuals so treated seemed to show no significant improvement and exhibited the same kind of distress as did those who had not had the surgery. In addition, Dr McHugh came to think that the surgery itself might be a form of 'mutilation'.*

2 *On the whole and by and large. In this discussion, Haldane was not talking about those rare individuals with genitalia which is ambiguous (or 'intersex').*

3 *In Aquinas's thought, which he picked up from Aristotle, they are 'proper to' or 'proprium', that is, predicable properties of the members of a kind but which do not constitute part of the definition of that kind.*

4 *Indeed, Haldane added, that human beings are heterosexual is neither essential nor contingent but 'proprium'.*

5 *The Guardian, online Australian edition, 14th December 2015*

6 *It is important to note that Haldane was not talking about those rare individuals with genuine gender dysphoria. He was talking about ideas found in the current movement dubbed 'transgenderism'.*

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