BIOETHICS OUTLOOK

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In this issue

In our first article Dr Gerald Gleeson clarifies one element in the current confusion about medical end-of-life decisions which centres on patient refusals of life-sustaining treatment. If a patient decides to refuse life-sustaining treatment, a doctor may not impose treatment on the patient against the patient's will. However it does not follow from the fact that the patient makes that decision that the decision itself is a wise one.

Our second article is a summary of a recent talk given by Fr Richard McCormick, SJ, which appeared in *Origins*, the CNS Documentary Service. Fr MCCormick outlines eight factors in the current climate in which health care is delivered in Catholic facilities which make it very difficult - if not impossible - for these facilities to live up to their mission.

The third article is the first of two reports by Mr Keith Joseph of this Centre on his recent study tour of Canada. In this article Keith discusses one of the two areas within the ethics of health care on which there are significant differences between Australian and Canadian debates: resource allocation.

The "right" to refuse treatment: *Autonomy vs Responsibility*

Gerald Gleeson

Respect for the freedom with which people make the crucial decisions which shape their lives is one of the chief developments of "modern" civilisation. I do not use the term "modern" disparagingly, but to mark the fact that the positive evaluation of personal freedom is one of the achievements of the "modern" period of western civilisation during its last few centuries. In the "pre-modern" world it was commonly held that "error has no rights" — which meant that a *person* in error, someone who chooses or acts wrongly, had no right to moral respect. Heretics and witches were to be burnt at the stake.

It is an insight of "modern" civilisation that even when a person uses his or her freedom in ways that are judged to be wrong, there is a positive value in the *conscientious* exercise of personal freedom which always deserves recognition. (Of course it does not follow that the "freedom" of the psychopath or the deranged must be respected in the same way.) This positive evaluation of personal freedom

and "authenticity" as inherently valuable underpins the emphasis on personal "autonomy" in contemporary bioethics.

The "right" to refuse treatment

A patient's right to refuse medical treatment is one expression of this autonomy. But does this autonomy also include the right to directly end one's life? In discussion of voluntary euthanasia, the claimed right to directly end one's life is often presented as little more than an extension of the right to refuse treatment that would prolong one's life. So the basis for this so-called "right" deserves closer inspection — as does the notion of patient "autonomy".

I believe there is much confusion about the so-called "right" to refuse treatment. It is quite true that one may not *impose* treatment on a person against his or her will, and it would be a trespass in law to do so. Both legally and ethically, a request by a competent, adequately informed patient — who is not suicidal — that treatment be withheld or withdrawn *ought* to be respected. To the extent that others have an obligation, even a "duty", to respect such a patient's decision, one might speak of the patient having a "right" to refuse treatment. However, it would be more accurate to say that patients have a right to have their decisions respected, taken seriously and not overridden. In respecting their decisions one is acknowledging the "autonomy" of patients, their right to make their own decisions about how their life and health is to be cared for, irrespective of whether one believes a particular patient is making a wise or right decision.

Having a right versus *acting rightly*

Yet, it clearly does not follow that the patient who refuses treatment is certainly acting *rightly*. It would be wrong to override a person's expressed wishes, not because the person is necessarily making a wise decision, but because of one's respect for the *person* whose right it is to make the decision. Respecting personal autonomy does not entail agreeing with a person's judgment. Unfortunately the repeated reference to "patient autonomy" as the fundamental principle in bioethics fosters the mistaken impression that autonomy alone is a sure guarantee of ethical rightness. Although the "intrinsic value" of personal autonomy grounds a person's right to have a decision respected, autonomy alone does not guarantee that the person's decision is right.

To see why this is so, we must undertake a more fundamental inquiry into the goals and goods to which personal autonomy ought be directed. While moral decision-making should be characterised by "autonomy", moral decisions themselves must be directed towards something other than autonomy. Unless autonomy is directed beyond itself, we are left with the bankrupt notion that moral autonomy is concerned only with being autonomous, regardless of the ways in which autonomy is exercised.

Responsibility - the goal of autonomy

What is more fundamental than autonomy is *responsibility* with respect to those goods and goals in the service of which autonomy finds its value. In the case of medical treatment, for example, the goal is health and life, and each person has a moral responsibility to take reasonable steps to care for his or her health and well-being, including — obviously — the responsibility to accept whatever medical treatment is appropriate in the circumstances. A person who declines to accept reasonable treatment that would save his life fails to meet this responsibility. Thus, much as one might respect the autonomy of a person's refusal of treatment, one might also consider the person to be failing in his moral responsibility and lacking, perhaps, the courage to do what he ought to do for the sake of his health.

To be sure, one may be unable to persuade a person to do otherwise, to accept the recommended treatment, and one may be powerless to override the person's wishes or impose the treatment upon him — to that extent the person's decision is always to be respected. But the mere fact that a person makes a decision

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Bioethics: Trends in Canada

Keith Joseph

During the January and February 1995 I was fortunate to be able to spend some time in Canada pursuing research. Most of my time was spent at the Westminster Institute for Ethics and Human Values, which is located at the University of Western Ontario. The University is located in the city of London, Ontario, which is the centre of a prosperous area midway between Toronto and Detroit.

In general, the bioethical concerns of Australians and Canadians are similar. The dominant issue in bioethics in Canada at the moment is, as here, euthanasia. The moral and philosophical arguments used are very similar: the main difference is that criminal law in Canada is the responsibility of the federal parliament, rather than provincial (state/territory) legislatures. Consequently the debate is taking place at a national level, and Canadians will be spared the spectacle of political compromise and legislative inconsistency between the states that is likely to mark our approach to this subject.

However, in this article I want to look at an issue on which the Australian and Canadian approaches are significantly different: resource allocation. Here we have much to learn from each other.

In many ways the Canadian political and health care systems are similar to ours: it is certainly more like our system than that of the United States. Health care is slightly more costly than here, being around 10% of Gross Domestic Product (GDP - a nation's total production in a year), compared to 8.5% of GDP in Australia. There are also significant differences in the way in which health care is structured. The following comments are based on the system as it is in Ontario, which is Canada's largest province, and in many ways is to Canada what NSW is to Australia.

The system of allocating health care resources is through funding by the Federal Government to the provinces using a number of funding mechanisms. The provinces then give block grants based on historical costs and political and bureaucratic negotiating to individual hospitals and other institutions, with some special grants for specific projects. Planning is carried out by District Health Councils (DHC), which, typically, may cover a population of 500,000 people. However, these councils are very unlike our Area Health Services: their only job is to present plans and recommendations to the provincial Health Minister, who then allocates resources and is free to (and does) change those plans. There are also no set ways in which the DHC can gain feedback from hospitals or provincial governments. Thus the planning bodies for an area are isolated from the decision making process and the implementation of those plans, which seems to be a significant weakness.

Additionally, Canada has a huge debt and deficit problem. It is one of the most indebted country in the first world: sovereign debt (debt of governments at all levels) is in excess of 88% of GDP, compared to Australia's 25%. The Canadian Federal Government has a deficit this year of $C30,000 million ($C1 = ~$A.95), and the Ontario Government has a deficit of $C10,000 million. In comparison, the governments of NSW and the Commonwealth are running close to having a balanced budget, and are making some effort to retire debt and thus reduce interest payments. Our main problem is with private, rather than public debt. In Canada, only the western provinces such as Alberta and British Columbia are in control of their budgets.

In these financial circumstances the Canadian Federal government is trying to hand much of its responsibilities for health and social welfare to the provinces: in turn, the financial position of the provinces (especially Ontario, Quebec and the Atlantic Maritime provinces) is often not

that much better. Matters are complicated by the issue of Quebec's referendum (due to be held in late 1995) to secede from the Federation: both the Federal and Quebec governments are unable to limit the deficit without adversely affecting their case in the referendum. In such circumstances, financial panic brought on by falling markets and a weak currency, rather than reflective rationing or restructuring, is possibility.

What ethical principles underlie Canadian resource allocation at present? It should be stressed here that what I am writing in this section are short impressions, rather than detailed analysis, and should be viewed in that light.

Firstly, there is the idea, enshrined in law, that all Canadians should have free access to health care. In the past this has meant comprehensive care: however, it seems clear that there will be a scaling down of this, so that care may no longer be as comprehensive as it might have been in the past. How is this to be approached? One suggestion is the Oregon model of community consultation: other trains of thought draw on the work of Callahan and Daniels. Both involve some form of explicit rationing. As can be imagined, much of this is derivative of United States authors.

However, there is a rejection of the idea that the private sector has a significant role. Unlike Australia, there are virtually no private sector hospitals offering acute care: they are simply not allowed. Given the experiences of the United States, where almost 14% of GDP is spent on health care, but over a quarter of the population has inadequate or no health insurance, private medicine is viewed with what can only be described as deep suspicion. Thus the solutions to be offered in Canada will stress communitarian approaches, rather than free market solutions. Ironically, this stress on communitarianism is in strong distinction to the views of many Canadian moral philosophers, who stress individual rights in a manner similar to their colleagues south of the border.

Like Australia, there is little money spent on preventive and public health measures in comparison with acute care. Similar problems are faced with similar groups - for example, in both countries Aborigines have an appalling health status, and the biggest killer of adolescent males is motor vehicle accidents followed by suicide. However, unlike Australia which is at least focussing on minimising such problems by the development of health outcomes, Canada has not developed such a structure. Health planning is still fairly weak, and in the financial panic that may develop it is not likely to be strengthened.

Therefore, to summarise: there is a recognition of resource allocation problems and, in general, the assumption that communitarian models rather than market models offer the best solutions. There is also a need to improve health planning, so that the outcomes of resource allocation actually address problems, though the political and financial will to do so is fairly weak at present. The strength of Canadian health care resource allocation arguably lies in its communitarian assumptions: however, it has a significant weakness in planning and control, resulting in some inefficiencies and a sense of aimlessness.

The Catholic Hospital Today: Mission Impossible?

Summary of a talk given by Richard McCormick SJ

Recently, a talk given by Fr Richard McCormick SJ on the current state of Catholic hospitals was published in Origins, a documentary service of the Catholic New Service.[1] The talk had been given on 8th March at the Gerorgetown University Medical Centre in Washington, DC. The Catholic hospitals under discussion were, of course, those in the United States. However, their current difficulties, and the challenges facing them, are sufficiently similar to those experienced and faced by Catholic hospitals in Australia for his words to be of more than passing interest to people working in Catholic health care facilities in Australia. In the following article the main themes in Fr McCormick's talk are summarized.

Richard McCormick begins by pointing out that, until recently, religious sisters formed the heart of the Catholic health care system. In 1921, Charles Moulinier wrote: "There is a spirit, a soul, an atmosphere and ideal of service in the sisters' hospitals which they create and maintain and give their lives' best efforts to foster."[2] These sisters were the mission- or culture-bearers.

McCormick then turns to the contemporary scene, and makes two comments on Catholic hospitals today. First, they have beautiful mission statements in which "we read references to continuing the healing mission of Jesus through comprehensive health care. There are statements about caring service for each individual, personalized patient care, the holistic approach which weds competence and compassion. There are assertions about an option for the poor, about continuing Christ's redemptive presence." But, second, "everywhere I go I see Catholics involved in health care doubtful, perplexed, wondering whether they are viable, whether they ought to be in health care, asking about their identity, how they differ from non-Catholic institutions." That is to say, there is a gap between institutional purpose and aim, and personal conviction and involvement. McCormick thinks that a strong argument can be made that the circumstances of late 20th-century United States have weakened and sometimes dissolved the culture of the Catholic health care facility, the strength and transforming power of its vision. To make this point, he draws on Thomas Peters' and Robert Waterman's *In Search of Excellence*:

> *"As we worked on research of our excellent companies, we were struck by the dominant use of story, slogan and legend as people tried to explain the characteristics of their own great institutions ... The vast majority of people who tell stories today about T.J. Watson of IBM have never met the man or had direct experience of the original more mundane reality. These days, people like Watson and A.P. Giannini at Bank of America take on roles of mythic proportions that the real persons would have been hard pressed to fill. Nevertheless, in an organizational sense, these stories, myths and legends appear to be very important because they convey the organization's shared values, or culture."*
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> *"Without exception, the dominance and coherence of culture proved to be an essential quality of the excellent companies. Moreover, the stronger the culture and the more it was directed toward the marketplace, the less need was there for policy manuals, organization charts or detailed procedures and rules. In these companies people way down the line know what they are supposed to do in most situations because the handful of guiding values is crystal clear."*[3]
>
> *"The shared values in the excellent companies are clear, in large measure, because the mythology is rich. Everyone at Hewlett-Packard knows that he or she is supposed to be innovative ... Poorer-performing companies often have strong cultures, too, but*

dysfunctional ones. They are usually focused on internal politics rather than on the product and the people who make and sell it. The top companies, on the other hand, always seem to understand that every person seeks meaning (not just the top 50 who are in the bonus pool)."

McCormick sums this up: (1) shared values or culture, and values shared throughout the company; (2) values that are crystal clear; (3) values communicated by legends and stories; (4) values that give meaning (motivation and inspiration) to the work of individuals. Culture is essential to the flourishing of institutions, whether they be Catholic hospitals or business corporations. "When the culture is dysfunctional or absent, we usually see a company in disarray. We see a Catholic hospital questioning its identity. More to the point, we see a situation where people's only security comes from where they live on the organization chart. We see people who have jobs, not great causes."

McCormick points out that Catholic hospitals were organized around the "greatest story every told" (of God's engendering deed in Jesus that transforms us and our world). "Catholic hospitals exist to enact in the health care setting what God did in Jesus. Jesus is God's love for us in the flesh. The Catholic hospital exists, therefore, to be Jesus' love for the other in the health care setting. It has the daily vocation of telling every patient — especially the poor — and every employee how great they are, because Jesus told us how great we are and in the process empowered us."

Whether a Catholic health care mission is alive, vibrant and formative depends heavily on the context in which health care is delivered. Here McCormick lists eight key characteristics of this context.

Depersonalization

There are three factors at work in the way we perceive and respond to health care problems. First, there is the growth of technology. Everything from diagnosis through acute care to sending out accounts is done by computer. Check the advertisements in any medical journal and it becomes clear that medicine and the machine are wed. Without decrying medical technology, this gives efficiency but inevitably some impersonality.

"These trends are likely to induce cultural changes in the delivery of care even more revolutionary than any restructuring that is going on today. On-line, computer-assisted communication between patients and medical data bases, and between patients and physicians, promises to replace a substantial amount of the care now delivered in person."[4]

Second, there is cost and cost containment. Spiralling costs are due to many factors (eg. sophistication of services, higher wages, more personnel, cost pass-along systems, paperwork, technology, inflation, fraud). Finally, there is the multiplication of public entities (by which McCormick means lawyers, courts and legislatures).

Together these factors affect the very matrix of the healing profession. This matrix roots in the conviction that patient-management decisions must be tailor-made to the individual, to the individual's condition and values. They are personal decisions that must fit the individual like a glove to a hand. Yet the three factors mentioned above are rather impersonal factors. When they begin to influence treatment, they tend to depersonalize that treatment. A clear sign of this depersonalization is the constant physician complaint about loss of autonomy.

Secularization

The very forces that lead to depersonalization of health care can robustly support the secularization of the medical profession. By *secularization* McCormick means to refer to the divorce of the profession from those values (that culture) that make health care a human service. Or stated somewhat more aggressively, "it is an increasing preoccupation with factors that are peripheral to and distractive from holistic

human care (competition, liability, government controls, finances)."

There are many symptoms of this drift toward secularization. One is the fact that physicians are leaving the profession. Another is the reason given by physicians for their discontent. Basically it is a souring of the physician-patient relationship. Dr. Paul Bearman, director of urgent care at Park Nicollet Medical Center in Minneapolis put it this way: "The ability to have the same kind of relationship I think that's gone. There is the feeling that you could just replace one physician with another, and that's unfortunate."

Behind such an erosion of the physician-patient relationship is the loss of a culture of compassion and care. It is being replaced by a business ethos. Many physicians feel that what they do is "a job." When medicine is reduced to a business, physicians begin acting like business people. As Dr. Edmund Pellegrino has observed, they claim the same rights as the business person — that is, to do business with whom they choose. Medical knowledge is viewed as something that belongs to the physician and that can be dispensed on her own terms in the marketplace, and illness is seen as no different from any other need that requires a service."[5]

Without assigning blame for this secularization of medicine (some physicians would doubtless point to their eroded autonomy (controls), diminished prestige, increased liability exposure, reduced compensation, whilst others would lay the blame squarely on the profession) McCormick simply notes the fact of secularization and the replacement of the professional culture by the business ethos.

"Once the profession is secularized, physicians will begin to make secularized judgments. One such is that the physician is free to treat or not treat AIDS patients. Thirty percent of the physicians polled by the American Medical Association made such a judgment. I can only view this as extremely ominous."

"Another judgment that could easily convey a full-blown secularization is the following: "I will not impose my values on my patient." Of course, there is a perfectly healthy and orthodox understanding of this statement. It is: In designing patient-management regimes, I will take appropriate account of the patient's background, education, age, values, preferences, etc. The noxious and secularized reading is this: I will do anything the patient prefers and requests. Here the physician is reduced to a technological tool of the patient, conscripted to do the patient's bidding for a price."

3 Emergence of Public Partnerships and Public Morality

The term *public morality* suggests that the pursuit of the basic goods that define our well-being has increasingly been shifted from private one-on-one acts and has been put into the public sphere. That means that bioethics will have to have much more to say at the level of policy-making than it has. Until quite recently it has been much more concerned with the level of individual decision. "But," as Daniel Callahan correctly notes, "on a national scale those decisions are going to be overshadowed by large structural, moral and political decisions. It is these decisions that will eventually shape the individual decisions."[6] This suggests that whenever other values (than the patient's) are the legitimate concern of the mediator of health care, the good of the individual patient becomes one of several values in competition for priority. It further suggests that the individual is in danger of being subordinated to these values.

As McCormick understands the term, *public morality* is the pursuit of these other values without violating the needs and integrity of the individual. It is a harmonizing of public concerns with individual needs. These "other values and concerns" constitute the public dimension of bio-medicine because they represent concerns other than and beyond the individual. In Callahan's words: "Ways will have to be found to balance that ethic [patient-centered] off against the legitimate interests of the public."

Callahan argues that the allocation of resources, the development of a just health care delivery system, the adjudication of the rights and claims of different competing groups "are and will be the important moral problems of the future." These problems will "force biomedical ethics to move into the mainstream of political and social theory, beyond the model of the individual decision maker and into the thicket of important vested and legitimate private and group interests." Establishing the proper balance between individual patient-centered concerns and other legitimate interests is what McCormick means by the term 'public morality'.

The Market-Driven Health Care System

"No margin, no mission". The vocabulary of the market which surrounds hospital policy and decision making is relatively recent: downsizing, market share, utilization review, mergers, joint ventures, networking, acquisitions, integrated delivery networks, capitation, etc. Much of this institutional manoeuvring is driven by the survival instinct. Are things different in the Catholic context ? Patricia Cahill calls it a "destabilizing truth" that

"Catholic sponsors don't trust one another ... There is a great fear of giving something up to one another on the one hand and the almost naive willingness to cut the same deal with a non-Catholic entity."[7]

The Cultural Denial of Mortality

Of course, it is impossible to deny mortality. But sometimes health care seems to be organized on a rejection of the fact. Once again, McCormick quotes Daniel Callahan:

"Our toughest problem is not that of a need to ration health care, though that will be necessary. It is that we have failed, in our understandable eagerness to vanquish illness and disability, to accept the implications of an insight available to all: We are bounded and finite beings, ineluctably subject to aging, decline and death. We have tried to put that truth out of mind in designing a modern health care system, one that wants to conquer all diseases and stay the hand of death."[8]

Efficient Rescue Medicine v Health Promotion and Disease Prevention

When people think of health care they usually think of sick care. An experienced observer puts it as follows:

"Heart disease is America's No. 1 killer. Daily newspapers and television dramas give the impression that coronary bypass surgery, modern cardio-pulmonary techniques, miracle hypertension pills, human heart transplants, and in the future, animal and artificial heart transplants are the way to battle heart disease. Right ? Couldn't be more wrong. Since 1970 our nation has experienced a dramatic 25 percent decline in deaths from coronary heart disease. The major reasons ? Improved eating habits — the reduction in cholesterol — accounted for almost one-third of the drop. The decline in cigarette smoking was responsible for another quarter. So individuals, by changing personal habits, were responsible for more than half the decline in deaths from heart disease. In contrast, coronary care units accounted for only 13.5 percent; cardio-pulmonary resuscitation, 4 percent; bypass surgery, 3.5 percent; and the widely used hypertension pills, only 9 percent. Deaths from stroke are also sharply down for much the same reasons."[9]

Our bias toward acute care means not only neglect of health care, but a one-sided emphasis on cure to the neglect of care, and that at the very time when what is needed in an aging society is more caring. This distortion of health care led Cardinal Joseph Bernardin to assert that in the contemporary climate Catholic health care providers "are being asked to leave behind their attachment to acute care institutions and to forge a new future in the world of community-based networks."[10]

Expanding Notions of Disease and Health

The term *disease* has had an interesting evolutionary history and, therefore, so has the term *health*.

- The word *disease* first meant an identifiable degenerative or inflammatory process which if unchecked would lead to serious organic illness and sometimes eventually to death.
- The next stage of development was statistical: At least some diseases were identified by deviation from a supposed statistical norm. Thus we referred to hyper-thyroidism or hyper-cholesterolemia, hypo-glycemia, etc. One was said to be unhealthy, to have a disease, if he or she were *hypo-* or *hyper-*anything. The person was unhealthy not in the sense of an existing, tangible degenerative process, but in the sense that the individual was more likely than others to suffer some untoward event (which a colleague of McCormick called *"hyper-untowardeventitis"*).
- The third notion defines disease as inability to function in society. For instance, a good deal of surgery is being performed to enlarge breasts, to shrink buttocks, to tuck tummies, to remove wrinkles — in brief, to conform to someone's notion of the attractive and eventually of the tolerable. We live in a society that cannot tolerate aging. At some point, then, this question arises: Who is the patient here? Who is sick — the individual or society? This broad understanding of health can too easily reflect the sickness in society's judgments about the meaning of the person. In our time and in some societies, peoples are hospitalized because of nonconformity.
- The final stage of development is the definition of *health* popularized by the World Health Organization. According to WHO, health is a "state of complete physical, mental and social well-being, not simply the absence of illness and disease." This description of health was adopted in the 1973 abortion decisions of the U.S. Supreme Court. The court stated that the "medical judgment may be exercised in the light of all factors — physical, emotional, psychological, familial and the woman's age — relevant to the well-being of the patient."

Through the expansion of the notions of health and disease, some basic human problems are being medicalized. This means, of course, that medicine is being plunged ever more deeply into the economic priorities of a leisure-luxury society.

The Obsolescence of the Hospital

Today in the United States, three quarters of all surgery is done on an outpatient basis (it was less than one quarter in 1984). Hospital outpatient revenue has grown two to four times faster than in-patient revenue. The American Medical News concluded: "In virtually every area of medicine, the hospital is becoming less and less necessary. A growing number of services are being delivered just as well or better on the outside, and it's cheaper to boot."[11]

Conclusion

McCormick sums up the difficulties for Catholic hospitals: they are asked to sustain a Catholic culture in a depersonalized atmosphere, in which medicine is increasingly viewed and lived as a business, at a time of powerful market and competitive pressures that send patients home quicker and sicker, in a culture that tries to transcend mortality, invests substantial resources in sick care and medicalizes more basic human problems, and at a time of the hospital's diminishing importance and religious influence.

Is the mission possible? McCormick finishes with the question asked by Charles Dougherty, Director of the Center for Health Policy and Ethics at Creighton University: "How do we save the souls of these institutions as they manoeuvre through a competitive minefield?"[12]

Notes

[1] ***Origins*, CNS Documentary Service, Vol 25, No 1, May 18, 1995.**

[2] **Cited in *Health Progress* 76 (Jan-Feb 1995) 57.**

[3] J. Peters and Robert H. Waterman Jr., *In Search of Excellence: Lessons from America's Best Run Companies*, New York: Harper & Row, 1982, 75.

[4] Jerome P. Kassirer, M.D., "The Next Transformation in the Delivery of Health Care," *New England Journal of Medicine* 332, Jan. 5, 1995, p. 52.

[5] Edmund Pellegrino, "Altruism, Self-Interest and Medical Ethics," *Journal of the American Medical Association* 258, 1987, pp. 1939-1940.

[6] Daniel Callahan, "Shattuck Lecture: Contemporary Biomedical Ethics," *New England Journal of Medicine* 302, 1980, p. 1232.

[7] Patricia Cahill "Collaboration Among Catholic Health Providers," *Origins* 24, Sept. 1 1994, p. 213.

[8] Daniel Callahan, *What Kind of Life; The Limits of Medical Progress*, New York: Simon and, Schuster, 1990, p. 23.

[9] Califano, *America's Health Care Revolution*, New York, Random House, 1986, p. 187.

[10] Joseph Bernardin, "The Catholic Moment," *Health Progress* 76, Jan-Feb 1995, p. 25.

[11] *American Medical News*, Jan. 9, 1995, p. 11.

[12] *The New York Times*, Jan. 4, 1995, C5.

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The "right" to refuse treatment: Autonomy vs Responsibility

(contd. from page 2)

— the simple exercise of "autonomy" — does not guarantee the rightness of the decision.

What is reasonable treatment

Thus the critical ethical question is not so much about autonomy but about what constitutes "reasonable and appropriate" treatment *in the circumstances for a particular patient*. That is a judgment which properly belongs *to the patient* in two ways: first, the patient is the one responsible for *making the judgment*, and secondly, the patient is the one who is best able to determine *what the responsibility* for health and life *requires*. It follows, too, that the patient may err in that judgment for a variety of reasons, and may err more or less culpably.

While there are fairly "objective" medical indications about what would be reasonable and appropriate treatment in most situations, there are also "personal" indications unique to the individual concerned. For example, a man might be struck down by an ailment that could be alleviated were he to move to a vastly different climate, in a distant country, away from family and friends, where he would be unable to speak the language or gain employment. It would not normally be reasonable to expect a person to go to such lengths in order to responsibly care for his health.

For treatment to be reasonable and appropriate, it must be likely to be *effective* (not "futile"), with its benefits *proportionate* to its burdens (not unduly "burdensome") — both on the patient and the available human and medical resources (not unduly "costly"). In taking "reasonable" measures to care for one's health, a person is not required to do what would be "unduly burdensome" or "extraordinary". In refusing such treatment a person is not choosing to remain ill, or to die, but is choosing to forgo that which is not, in the

circumstances, obligatory. Moreover, a treatment option that would be burdensome for one patient might not be for another. Hence there is usually a range of reasonable judgments that might be made in similar circumstances. In short, personal autonomy — one's responsibility to make a decision — is in the service of the reasonable judgments one is called upon to make.

Consider the case of a young man who is left quadriplegic after a diving accident, only able to remain alive with the help of a ventilator assisting his breathing. May he request that the ventilator be removed, knowing that he will die soon after? That he forgo such a means of prolonging his life would seem reasonable. He might choose to prolong his life, but his refusal to do so would not necessarily indicate a failure to meet his general responsibility to preserve his health and life.

The need for the virtues

Once the notion of responsibility is taken as fundamental, the crucial role of the traditional moral virtues becomes evident. In making a sound judgment about how one ought meet one's responsibility for one's health, one needs to be courageous, temperate, just and prudent.

Courageous: one's judgment should not be swayed either by fear of the difficulties involved in treatment, nor by reckless indifference to the real dangers it may entail.

Temperate: one's judgment should not be swayed either by distaste for the discomforts of treatment, nor by delight at the prospect of being the pampered victim of illness (!).

Just: one's judgment should take into account the impact of treatment options on one's relationships with others, both with those who depend on one, and those one depends upon.

Prudent: one needs to ensure one's judgment is sensitive to all the relevant and particular circumstances of one's situation, so as to integrate the claims of courage, temperance, and justice within the final decision one reaches.

No right to end one's life

Once personal autonomy is situated in relation to one's more fundamental moral responsibilities, it is evident that the limited sense in which one has a "right" to refuse treatment in no way licences the claim that one has a "right" to deliberately end one's life or request others to end it. The refusal of treatment can be morally justified because one is only obliged to do what is reasonable to preserve one's life and health.

There are limits to what is reasonable precisely because physical life does not have to be prolonged *at any cost*, — not at the cost of one's emotional and spiritual well-being, nor at the cost of impoverishing one's family, nor at the cost of imposing disproportionate burdens on oneself or others.

By contrast, deliberately ending one's life could never be a reasonable way of meeting one's responsibility for one's life and well-being, because taking life undermines not only life but all the other dimensions of personal existence. The responsibility for one's health and life is more fundamental than the autonomy with which one must exercise that responsibility.

Because autonomy is subordinate to responsibility, autonomy could never be *rightly* exercised to undermine the very object of one's responsibility, namely the good of one's life. The limited sense in which one has a "right" to refuse treatment does not imply that one's refusals are always right and virtuous, let alone that one also has a "right" to end one's life. There is no valid argument from patient autonomy to voluntary euthanasia.

NOTEBOOK

Proceedings of a Seminar held in November 1994

EUTHANASIA

Jan Remmelink, Attorney-General, The Netherlands	***The Legal Position on Euthanasia in The Netherlands***
Lynn Gillam, Centre for Human Bioethics, Monash University	***Medical End-of-Life Decisions: The Law in Australia***
John Quiter, John Plunkett Centre for Ethics	***Against Legal Protection of Voluntary Active Euthanasia***

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