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Editorial: Oregon Proposal on Resource Allocation	Bernadette Tobin	1
The Babies Doe: Sanctity or Quality of Life ?	John Quilter	4
Just What Are We Doing ? Our Obligations to Comatose Patients	Gerald Gleeson	8
Notebook: Seminar on Resource Allocation		12

RATIONING ACCESS TO HEALTH CARE: THE OREGON WAY

Bernadette Tobin

The Editorial writer of the *New York Times* (August 6, 1992) referred to it as "A Bold Medical Plan, Derailed". What is the "medical plan" and how has it become "derailed"?

The plan was a proposal by the State Government in Oregon to cut back the range of services available through "Medicaid" to the very poor in order to increase the number of people who had access to this government-funded health care programme.¹ The derailment occurred when the Secretary of Health and Human Services in Washington DC (from whom Oregon State needed approval - for the plan involved a change in the use Oregon made of federal funds) declared that the Oregon proposal would discriminate illegally against the disabled.

Whether this rejection is final is not certain. In an election year, it may represent party-politicking rather than any serious view about the ethics of health care distribution. In the meantime, however, it is worth clarifying some of the issues that were - and still are - at stake in the Oregon proposal. The problems that Oregon confronts in the provision of health care are not peculiar to American conditions. The same questions, of economics and of ethics, confront Australian decision-makers.

Health Care for the Poor

Unlike Australia, the United States has no universal health cover. Most health coverage is funded by private insurance or by employer-subsidized

insurance. In 1965, the US Congress announced a health care programme for the poor, the costs of which were to be shared by federal and state governments. Less than twenty years later, Medicaid was struggling to do what it was intended to do. Escalating health costs, an increase in the number of eligible people, a steady stream of requirements from the federal government concerning services to be provided and specific groups to be included, meant that Oregon either had to raise its level of taxation or had to cut into other parts of its budget (education, housing, law enforcement, economic development, environmental protection, etc.) in order to prop up its Medicaid programme. What was Oregon to do?

Organ Transplants

In 1987, the state legislature in Oregon voted to discontinue funding for most organ transplants for people on Medicaid on the grounds that these were high-cost procedures which would benefit only about thirty people during the next two years. The money was to be used to fund, among other things, basic preventive care for nearly three thousand people who were to be added to the Medicaid programme (people who previously been ineligible even though they could not afford to buy their own health insurance).

At first, the legislature's decision went largely unnoticed. Later in that year, however, a young boy with leukaemia, unable to receive state funds to pay for a bone marrow transplant, died while his parents sought public contributions to finance his operation. (His family had raised \$80,000, but needed a further \$20,000.²) Then the public debate began in earnest! According to what health care policy had Oregon made its momentous decision to limit the range of

health care services which would be publicly funded?

It quickly emerged that the state had no policy, that its decision about organ transplants had been a piecemeal attempt to extend the benefits of Medicaid to the "working poor", people who though they had jobs and were thus ineligible for Medicaid were nonetheless unable to pay for (most of) their own health care.

Over the next two years the debate raged. Who should be eligible for Medicaid? Everyone below the federally-defined poverty level (as the original Medicaid legislation intended) or only some percentage of that group? (In Oregon today, only 50% of those below the federal poverty line are eligible. In Florida, the figure is 35%, and in Alabama only 14%.³) Or should the state cut back on its "provider reimbursement rates" (that is, the amount it pays to a hospital (for example) for medical services) even though it knows that that will force some of those providers out of the system and so further reduce access to Medicaid? Should Medicaid cover all "medically-necessary" services (as the federal authorities required) or should some attention be given to measuring the effectiveness (the "outcome") of specific services?

Shift in the Debate

In 1989 the state legislature passed into law the Oregon Basic Health Services Act. It extended Medicaid eligibility to everyone with incomes below the federal poverty level (adding about 77,000 people) and required comparable employment-based coverage for those with incomes just above the level. It thus guaranteed access to health care to virtually everyone in Oregon state. In so doing Oregon shifted the focus of the debate. "Who should be covered?" was no longer the burning question. It was: "What services should be provided?"

How was this to be decided? Oregon Senate established a Health Services Commission to draw up a list of health services ranked in order of importance or necessity (on the basis of the comparative benefits of each service to the entire population covered by Medicaid). To achieve this, the Commission organized and conducted public surveys, open forums, town meetings, and consultations with medical and technical experts. For example, in the months from January to March in 1990 forty-seven public meetings were held throughout the state.⁴ Discussion centred on the relative values of preventive and curative measures, cost-effectiveness (by which was meant the expected outcomes of treatment - prolongation of life, reduction of pain, etc. - related to the cost of that service and the number of patients it would benefit), estimates of how treatments would improve

"quality-of-life", and considerations of fairness and compassion.

As a result of this "community consultation"⁵, the Commission analysed over 1600 health services (from treatments for colds and flu to heart transplants) in terms of their cost-effectiveness. But their first crude listing of services in order of priority for funding caused such a public outcry - the most "important" services turned out to be the cheapest and most simple and the least "important" turned out to be the most expensive and the most complex - that it had to be abandoned, even as a working draft.

Categories of Health Service

The Commission's next step was to develop a set of categories of health services to identify either (a) a specific type of service (such as maternity care) or (b) an expected outcome of service (such as "treatment of life-threatening illness where treatment restores life-expectancy and returns the recipient to previous health"). Seventeen such categories were created. The members of the Commission then ranked these seventeen categories in order of importance according to three criteria: (1) value to the individual, (2) value to society, and (3) whether the category seemed "necessary". Finally, health services were assigned to one of these categories, and then ranked in importance within the category (on the basis of quality-of-life outcomes).

The next step was to estimate the cost of providing each of the services in each of the categories to those who would be likely to need them. Then the Oregon legislature was asked to accept a priority ordering of the categories of health care, and then to draw a line separating those which would be covered in future by Medicaid from those which would not. The final step in the process was the request to the federal government in Washington DC for approval to vary the way Medicaid funds were spent. It was Washington's refusal in August this year which "derailed" Oregon's entire resource allocation plan.

Oregon's Priorities

What were Oregon's priorities? In ranking 609 medical conditions and their treatments, Oregon placed at the top life-threatening conditions which are treatable and which affect large numbers of people and at the bottom conditions which are either fatal but incurable or so trivial that they do not require treatment. Amongst their top ten priorities were the treatment of pneumonia, tuberculosis, peritonitis, foreign bodies in the pharynx, larynx, trachea, bronchus and oesophagus, appendicitis, ruptured intestine, hernia with obstruction and/or gangrene, croup and acute laryngotracheitis, acute

orbital cellulitis, and ectopic pregnancy. Amongst their bottom ten were the benign enlargement of the breast, kidney cyst, terminal HIV disease with less than 10% survival rate at five years (though treatment for earlier stages of HIV disease and comfort care for the terminal stage were listed much higher in their priorities), chronic pancreatitis, superficial wounds without infection and contusions, constitutional aplastic anaemia, prolapsed urethral mucosa, central retinal artery occlusion, extremely low birthweight babies (under 1.3 pounds and under 23 weeks gestation) and anencephaly and similar conditions in which a child is born without a brain.

Washington's refusal to approve the plan has obstructed it, at least for the time being. (The Secretary of Health and Human Services claimed that it would discriminate against the disabled.) No doubt it will come to life again, somewhere, in some modified form. For the problems of justly distributing a community's scarce health resources are being felt not only in Oregon state but in every society, no matter how affluent. Australia is no exception.

Ethical Issues at Stake

The Oregon proposal for widening the group of people who were to be eligible for publicly-funded health care cover to include all the poor by limiting their access to specific treatments raises a host of ethical issues:

- Is health a private or a public good? Has the state a responsibility in justice to provide for all the health care needs of every citizen, or are we to think of health as a private good for which people may save as they are interested and able?

- If we do think that health is a public good (and so that it ought to be available to every citizen whatever his economic status), and yet if we also recognize the necessity for setting limits on what is available through the health care system (because of people's rising expectations of what that system can deliver), where do we set the limits?

- Is it morally-appropriate that decisions about the health care services which are available to the poor should be made not by the poor themselves, nor by their own individual doctors but by bureaucrats (and in particular, by people who work in the health care professions - for in Oregon at least, they were vastly over-represented in the "community" discussion)?

- How far should considerations of cost-effectiveness be used to determine the distribution of health care? Should economic considerations take priority over other considerations (such as the ways in which a genuine community will care for its sick?)

- Must "quality-of-life" considerations be discriminatory against the disabled? How far did Oregon succeed in making discriminations between changes in quality of life (before and after a treatment, regardless of how healthy or disabled that life was) rather than in discriminating between lives on the basis of how healthy or unhealthy, able or disabled, they were?

Here in Australia, we need to think through the ethical issues which Oregon's plan raises. For, although we differ from Oregon in having a universal system of health care, we still have to work out who is to have access to those high-cost treatments which cannot be universally provided.

Notes:

- 1 It is important to distinguish Medicaid from the American programme called "Medicare". The latter covers the cost of all health care for everyone over the age of sixty-five.
- 2 Rossetti, A: "The Oregon Health Care Proposal", unpublished manuscript, 1992
- 3 Kitzhaber, J: "A Healthier Approach to Health Care", *Issues in Science and Technology*, Vol 7, No 2, 1990-1
- 4 Hundreds of such meetings had in fact been held in Oregon in the previous few years.
- 5 On the reliability of these consultations, and for a discussion which raises a range of ethical issues about the Oregon proposal, see Veatch, R: "Should Basic Care Get Priority: Doubts About Rationing the Oregon Way", *Kennedy Institute of Ethics Journal*, Vol 1, No 3, September 1991

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BIOETHICS OUTLOOK

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THE BABIES DOE: SANCTITY OR QUALITY OF LIFE?

John Quilter

1 The Cases

Baby Doe: In April, 1982, a baby boy was born in Bloomington, Indiana, diagnosed with Down's Syndrome and a tracheoesophageal fistula. A complication like this fistula is found frequently among children with Down's Syndrome, much more frequently than among the population as a whole. Reconstructive surgery is normally the "indicated" treatment. Operating on a newborn always involves risk but the prospects of successful restructuring of the malformed passages are good. In most cases of such surgery, the child is able to eat normally. If no treatment were given to the fistula, Baby Doe would not have been able to eat, and stomach fluids would have reached the lungs. Non-treatment would with certainty have led to Baby Doe dying fairly quickly either by starvation or by pneumonia (contracted from the fluids in his lungs). The parents opted to forego the surgery and chose to withhold food and treatment, to "let nature take its course".

Baby Jane Doe: In October, 1983, Baby Jane Doe was born in a community hospital in Port Jefferson, New York, and transferred to University Hospital at Stony Brook suffering from spina bifida. She had myelomeningocele, hydrocephalus and microcephaly. Doctors estimated that without any surgery Jane Doe might live for several weeks to two years. She could have easily contracted a fatal infection via the lesion in the back; or death might have followed from the continued pressure on the brain due to the hydrocephaly. Surgery would have included an operation to close the lesion in the spinal column and one to place shunts to drain the excess fluid from her head. With surgery, doctors thought that the baby could survive twenty years though she would have had paralysis and double incontinence, epilepsy, a likelihood of recurrent urinary tract infections and likely repeated operations to clean blocked shunts and replace drainage tubes, along with severe mental retardation. The parents decided against surgery, opting for conservative treatment which included antibiotics to protect against infection.

2 Two Views of the Cases

When people discuss these cases they often divide into two camps. On the one hand, there are those who uphold the idea of the sanctity of life and condemn those who endorse the decisions of the parents in these cases as guilty of discriminating against the handicapped, guilty of treating them unjustly, on the fatuous ground that lives

characterised by handicaps are of insufficient quality to be worth living. On the other hand there are those who, in defending the parents, will allege that their opponents are condemning these children¹ to a life of burdensome, mostly uncompensated drudgery or suffering, lacking what makes human life worth living, all in the name of a principle that not even a humane, kind God could support; a life, moreover, that is likely to put immense strains on the families involved leading to more overall bad consequences than it justifies; and that this is most unfair especially since the sanctity of lifer herself is unlikely to be prepared to take up those strains if the family is unprepared to.²

These two positions represent ends or near-ends of a wide spectrum of views concerning this kind of case. We will not discuss all the relevant issues here. What I propose to focus on here is the thought, illustrated by these two views, that there is a *clash* between upholding the idea of the sanctity of the life of the babies and taking notice of what gets called the quality of life of these infants.

3 The Sanctity of Life

(i) What It is Not

The idea of the sanctity of life is often taken by its critics to imply claims such as that it is wrong *ever* to take human biological life or not to save it where one can, or that all human life is equal on the mere basis of our shared membership of the human biological species. Yet, proponents of the principle generally do allow that one may be justified in taking the life of an attacker (even an insane, and so, innocent one) if that is the only way to defend oneself or protect the innocent. We also allow that it is morally permissible to let someone die under certain conditions, even where we may be able to do something which would keep her biologically alive. A very frail old person who is ready for her dying and for whom further intervention to resuscitate her is unreasonable is an example. While we think that this is morally acceptable, we do not take such judgments to be incompatible with the thought that human life is sacred. In the light of such exceptions to the idea that it is wrong to kill and to let people die, one may justly complain against critics of the principle that they make their destructive job easier by attacking a straw man. The sanctity of lifer does not require that literally everything that can be done to save human biological life must always be done.

(ii) A More Plausible Interpretation

Making this point, however, does raise the question what is distinctive about the principle of the sanctity of life? Does one mean that biological life - the heaving chest of respiration, the flow of blood through the arteries, the electrical activity of the

brain - must be preserved? Or does one mean "life" in the thicker sense of "what makes human living worthwhile" where one has in mind things like friendship, love, intellectual discovery, aesthetic experience, the fruition of one's projects or the like?

I doubt that any of the sorts of thing just suggested is what one is trying to express in the claim that human life is sacred. More to the point is an idea, usually associated with the Prussian philosopher Immanuel Kant, that each human person is a centre of "unconditional worth": that is, unconditionally deserving of at least a minimal level of moral deference and, we might say, awe.

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Part of the thought is that the person's being in this way unconditionally worth our moral solicitude is such as to impose on the way we treat her a moral obstacle to merely using her or, for example, to killing her in the spirit of "putting her out of her misery" in the way one does a sick animal, or for example, to killing a wicked person in the spirit of "ridding the world of vermin"³. Perhaps we could put the idea by saying that each person is a value rather than is valuable because of such and such properties or characteristics: a *person* is worth our moral solicitude unconditionally upon, for example, being rational, having a continuing sense of self, or having good character, or being capable of enjoying things which, as we say, "make life worth living" or the like.

4 The Quality of Life

(i) *Do All Exceptions to the Obligation to Save Life Have Nothing to do with the Person's Quality of Life?*

Those who defend the sanctity of life against the likes of Baby Jane Doe's parents often do so whilst critical of those who endorse the parents' decision on the ground of the poor quality of the baby's life. Thus, the principle of the sanctity of life has commonly been thought to *oppose* the relevance of quality of life considerations in this sort of decision. If this is so, since the sanctity of life does not believe that there is an obligation, literally always and in all possible circumstances, to do everything one might to keep, for example, the biologically-ill alive, the explanation of the apparent exceptions will have to omit all reference to considerations of the patient's quality of life.

There is a variety of gambits proponents of the

sanctity of life use to explain the sorts of exception we have noted. These include appeals to the "futility" of treatment, a distinction between ordinary and extraordinary treatments, "what the reasonable person would decide" or to the applicability of the Principle of the Double Effect. Unfortunately moves such as these, parading as realistic limits on the obligation imposed by the sanctity of life to save lives, often serve only to *conceal* what really is an appeal to quality of life considerations.

Thus, for example, when one considers the sanctity of life who agrees that it is permissible to forego artificial ventilation for one who is in an irreversible coma on the grounds that one does not have to apply extraordinary means of life support in such circumstances, the distinction between interventions that are ordinary and those which are extraordinary is one which turns in part on the *benefit to the patient* of such intervention. Consider the classical definition of "extraordinary means" of Fr. Gerald Kelly which makes explicit reference to the idea of "unreasonable burden" to the patient⁴. Whether an intervention is of benefit to the patient or an unreasonable burden is not a morally-neutral judgment but, on the contrary, a moral judgment an aspect of whose form is an answer to the question "will the life the patient will have the opportunity to have if she continues to breathe be valuable enough to her to be worth, for her, the burden or indignity she will have to suffer in our continued intervention to keep her breathing?". That is to say, the distinction between ordinary and extraordinary means of life support is shot through with moral judgments, and one of the things relevant to these judgments is the patient's quality of life prospects.

Alternatively, others who defend the sanctity of life and reject the relevance of quality of life considerations to death and dying issues make appeal to "what the reasonable person in the position of the patient would decide". But here the ruling thought is that of the practically wise person, whose moral thinking is sound. When one asks what such a person looks to in determining whether continued life-supporting intervention is obligatory, mention will be made, correctly, of the benefits to the patient or the lack thereof represented by continued intervention. From here the argument goes as above.

Or again, some will speak of the "futility of further treatment" as if such a consideration is either a morally-neutral fact about someone's medical predicament or a moral feature of the situation that has no relation to the quality of life prospects of the patient. But this is not so. For the application of the life-saving intervention is *not* futile if one's objective is the maintenance of biological life: the ventilator will keep the chest heaving, the blood flowing, the brain firing. The futility of *that* is what is meant by

describing the intervention as futile: for there is inadequate value or quality of life for the patient to compensate the indignity or burden of being kept alive so.

As I have said, there is a variety of strategies that proponents of the sanctity of life employ to explain why it is morally respectable not to apply all interventions that might keep a patient alive without appearing to make appeal to judgments on the quality of life the patient has the prospect of enjoying with continued intervention. I have only mentioned a couple. However I have, I think, said enough to show a connection between the obligation to save life and the patient's quality of life.

(ii) *Understanding Quality of Life Properly*

The fact is that the prospects of a patient for quality of life *are* relevant in the sort of matter we are considering. The quality of a person's life, in this situation, is a measure of the benefit to the patient of continued life-sustaining intervention given the burden to the patient such intervention will represent.

Some may object that the notion of quality of life that I am using is not the one that critics of the sanctity of life employ. To this my reply is that it is not. I agree. Anyone who employs a notion of the quality of life as a *foil* to the idea that all human persons are unconditional values does not have the same concept of quality of life as I do. But it is *similar*. For it takes the question of the value to the person of continued maintenance of biological life to be relevant to our decisions about whether we must do all we can to maintain such life. It also takes the thought seriously that to operate and otherwise treat aggressively many infants suffering from severe problems could well be to condemn them to life that is unreasonably burdensome, whose quality of life may be insufficient to compensate the person the baby is and will become for this burden and indignity. To this extent, I would urge it is more honest of the sanctity of lifer to join her critic in debate *on this common ground* rather than simply to talk past her critic.

One final point of clarification is necessary. "Quality of life" talk is fraught with a temptation that "benefit/burden" talk avoids. For quality comes in degrees ranging from the excellent to the extremely poor. We sometimes think of the latter degree of quality as a negative amount of quality as if a low-quality life is a *harm*. But this is a deep and dangerous mistake. For to say that something lacks the benefits of some conditions is a far remove from saying that it, thereby, suffers harms. The lack of sight is not a good thing for humans, to be sure, and in the Aristotelian tradition of metaphysics it is thought of as a natural evil. But it is not a moral harm to be

blind, it is simply disappointing or the like. So, we do not have to let the blind die because they are suffering a harm by living. Lack of a benefit is not, in general, equivalent to suffering harm. Thus lacking the quality of life of a normal human being is not necessarily to suffer a harm, as low as the quality of life may be. Whether it is or not depends on many other things, conspicuously, the medical condition of the person in other respects.

Lacking the quality of life of a normal human being is not necessarily to suffer a harm, as low as the quality of life may be. Whether it is or not depends on many other things, conspicuously, the medical condition of the person in other respects.

5 Treating Handicapped Newborns

It is now clear where there is an important substantive divide between the critic of the decision of Baby Doe's parents and its defenders. It is in the thought that, in general, a life characterised by mental retardation is of insufficient quality or value to the person the infant is or will become to imply that we have an obligation to do what we reasonably can to save that life where it is threatened. The sanctity of lifer will, rightly, reject this idea. But the *ground* for this rejection is the crucial point. It is not that all human life is sacred in the sense that suggests that all quality of life considerations must be irrelevant⁵. It is rather a difference with the proponents of the baby's parents' decision over what makes life of such a quality as to be of sufficient benefit to the person to be worth living given what is involved in keeping this life going. The critic of the parents of Baby Doe has it in mind that life with mental retardation is sufficient compensation in point of benefit to the patient for the relatively small (though admittedly not inconsequential) burden of surgery to correct the fistula⁶ to justify the surgery. In particular, life for Baby Doe is not a harm just because he is retarded.

From this angle, we may have to leave open the possibility that where an infant's disabilities (be they mental or physical) are severe and may require such a number or nature of interventions as to be so burdensome or such indignities as not to be compensated by the value or quality to the child of its future life, they may be permissibly omitted. Indeed, it may be that, on occasion, this is so as a matter of *honouring* the dignity of the person the infant is. It may be that, depending on the details of the particular case of myelomeningocele spina bifida, a decision like that of the parents of Baby Jane Doe is morally reasonable for the child's sake. One would

have to consider, one by one, the problems of different sorts of birth defect such as Tays-Sachs or Lesch-Nyhan Syndromes, where the prospects for quality of life for the infants is not very great, the merits of the details of these conditions and the treatment options.

The doctrine of the sanctity of life, properly understood in terms of the unconditional worth of the human person, does not imply that quality of life considerations are irrelevant. It ought to be properly understood as a measure of the benefit for the patient of the life made possible by continued interventions, given the burden or indignity these interventions represent for the patient.

Notes:

- 1 Or, following Helga Kuhse and Peter Singer, *Should the Baby Live?*, OUP, 1985, pp. 129-146, the persons these children will become. Many defenders of this view tend to think that the newborn is not a person or perhaps less a person than a self-conscious human being. I do not wish to comment on this issue here. See note 6. For the present point, this question can be ignored.
- 2 cf. Kuhse and Singer, *ibid.*
- 3 These examples are Raimond Gaita's in his *Good and Evil: An Absolute Conception*, Macmillan, London, 1991 discussed in B. Tobin's book note in *Bioethics Outlook*, vol. 2, 1991. I will assume without argument that infants deserve the minimal moral deference and moral solicitude that we owe each other, that is, that they are persons. In an earlier contribution to this forum, I have made a suggestion about the proper understanding of the place the notion of a person has in ordinary thinking (see *Bioethics Outlook*, vol. 2, 1991). It should be noted that I do not think that only human beings must be persons: *maybe* certain higher primates are and *maybe* we will build intelligent systems that turn out to be persons. I cannot be accused of speciesism in this regard, though I do think that there is little reason to be *confident* that any non-human persons exist.
- 4 In his *Medico-Moral Problems*, Catholic Hospital Association, St. Louis, 1958, p. 129.
- 5 cf. G. Grisez and J. Boyle, *Life And Death with Liberty and Justice*, University of Notre Dame Press, London, 1979, chapter 9, *passim*. The authors apply this sort of rational-substitute decision-making to the case of the incompetent who have never been competent. But there surely is nothing to the thought that there is some way such incompetent persons would have thought about their predicament given they have never been able to think at all. At the other end of the spectrum of Catholic moral theology, McCormick does the same thing for young children in arguing that, were they rationally competent, they would see the benefits to others of allowing themselves to be experimental subjects and so one can feel justified in using them as experimental subjects. This strategy, however, assumes what just is not the case: that there is *any* content to the notion of there being some way

such an incompetent would think were he or she competent. One might as well ask what time it is on the sun.

- 6 My claim here requires even more careful formulation. For in the case of many critics of Baby Doe's parents' decisions, the effect of the thought that Baby Doe is a person of unconditional worth is to *silence* the idea that the quality of life of Baby Doe (or the person he will become) is relevant to determining whether we should operate to repair the fistula. (For the idea of one moral consideration's silencing another moral consideration, see John McDowell, "Are Moral Requirements Hypothetical Imperatives?", *Proceedings of the Aristotelian Society Supplementary Volume 52* (1978), 13-29, #9-10.) The important point for our discussion is that this does not imply that quality of life considerations are never relevant to such decisions. They are, though they may not be in this case. In allowing that the weight, relative weight or relevance of a consideration such as quality of life is not constant in moral deliberation across variations in the situations facing it, I part company from Utilitarians or other Consequentialists who think of all moral deliberation as if it were a process of *weighing*. Thus I reject Proportionalism in moral theology.
- 7 There are other divisions between the sanctity of life and the proponent of the Baby Doe's parents' decision. An important disagreement between Kuhse and Singer and the line taken in this paper is the assumption I make about the personhood of the infant. This imposes constraints on permissible ways of thinking about how we may treat the infant that Kuhse and Singer's approach will not have.

TRANSPLANTATION CONFERENCE

Centre For Human Bioethics,
Monash University

This year's annual conference of the Centre for Human Bioethics is **Transplantation: Asking The Hard Questions**. It will be held on Friday 6 November 1992 at Clunies Ross House, Parkville, Melbourne. Topics to be addressed include: ethical problems in organ retrieval; the 'opt out' system; living donors; and organ trade. Papers will be presented by Don Esmore, John McNeil, Nick Tonti-Filippini, Delwyne Hando, Bernadette Tobin, and others.

Cost of full-day registration for the Conference is \$70 (\$60 for Associates of the Human Bioethics Centre). Further information is available from Lynn Gillam at the Centre For Human Bioethics. Ph (03) 565-4278

JUST WHAT ARE WE DOING?

Our Obligations to Comatose Patients

Gerald Gleeson

One of the vexed bioethical questions of the moment concerns the appropriate care of deeply comatose patients [often said to be in a "persistently vegetative state", (PVS)] for whom there is no reasonable hope of recovery. Once a person is actually dying, the focus of our responsibility is primarily comfort (for example, relieving their felt hunger, moistening a dried mouth). However, the death of many comatose patients need not be imminent; even though they are surely terminally ill, they may continue to live for quite some time.

Accordingly, some people argue that there is an obligation to continue to provide food and liquid to such patients (in nourishing quantities and through "artificial" means, for they cannot eat by themselves) despite their inevitable condition. Medically-supplied nutrition and hydration (MNH) is, they claim, really just "ordinary care" and so to deny it to these patients is to "starve them to death". The Bishops of Pennsylvania, for example, have claimed that in the case of such patients: "It is the removal of the nutrition and hydration that brings about the death. This is euthanasia by omission rather than by positive lethal action, but it is just as really euthanasia in its intent".¹

By contrast, others (many bishops and most ethicists) hold that we are not so obligated because, "withholding artificial hydration and nutrition from a patient in an irreversible coma does not induce a new fatal pathology; rather it allows an already existing fatal pathology to take its natural course".² This division of opinion is worth exploring for the light it throws on several aspects of bioethical reasoning.

I.

First, it illustrates the fact that in complex moral matters, sincere and good people may disagree. As will be seen, each side offers serious reasons for its viewpoint. We have what Catholic moral theology has traditionally called two "probable" opinions, that is, two opinions with "probity", with enough good sense behind them for people to be free to follow the judgment which in their conscience they believe appropriate.

In the long run, however, we cannot be content with conflicting "probable opinions". In seeking resolution beyond them, we must bring to bear all the resources of our moral wisdom and sensitivity. This wisdom is typically articulated in the somewhat technical language of moral reasoning, viz. moral

case terms, distinctions, and categories. The "labels" most often heard in this debate include the distinctions between "extraordinary" and "ordinary" means, between "treatment" and "care", and between "withdrawing" and "withholding" treatments.

It is not enough for advocates of the obligation to provide medically-supplied nutrition and hydration to claim that supply of food and liquid to patients is just "ordinary" care.

However, the debate over nutrition and hydration highlights, secondly, the futility of trying to settle complex questions by any mechanical resort to "labelling" and categorisation. Labels are too fluid and too ambiguous to bear the weight of determining the moral outcome. At most these various categories alert us to the relevant moral issues, but do not of themselves determine the extent of our moral obligations.

Thus, it is not enough for advocates of the obligation to provide MNH to claim that supply of food and liquid to patients is just "ordinary" care (even though in the case of PVS patients it is necessarily provided by "medical" means, for example a naso-gastric tube), and need not be unduly "burdensome" in terms of either resources or patient comfort. Nor is it sufficient for their opponents to rely on the description of MNH as "optional" treatment for PVS patients because it is an "artificial" medical procedure, or an "extraordinary" means of providing human nourishment. The really hard questions as to the appropriate criteria for applying these categories remain.

I will argue that although medically provided nutrition and hydration (MNH) is these days in itself a routine and "ordinary" procedure, or even "care" (unlike reliance on an artificial respirator), it does not follow that it is always obligatory. But instead of searching for "labels" that might be supposed to obviate moral reasoning towards this conclusion, I want to present an approach which turns rather on the importance of seeking in each case the most illuminating characterisation of the actions being undertaken. The goal is to state with maximum honesty and clarity just what it is we are doing when we cease to provide MNH for PVS patients.

This focus on the question of "just what we are doing" is relevant to the great debate in Catholic moral theology at present between "absolutists" and "proportionalists". This is the third issue on which the debate over NMH sheds light, and I will examine it before returning to the particular question of care for the comatose patient.

II.

The absolutist position holds that in very many cases it is possible to read off the moral evaluation of an action from a straightforward description of "just what one is doing", irrespective of the circumstances or the further intentions of the agent. For the absolutist, certain kinds of human action (for example killing the innocent, stealing, contraceptive sterilization, etc.), are "intrinsically" evil. The evil resides in the intentional doing of the action itself. All other kinds of actions are either intrinsically good or morally "neutral", and will only become evil if made so by "extrinsic" features such as particular circumstances, intentions, or motives. In the case of PVS patients, some (though not all) absolutists hold that by ceasing MNH one is doing evil because what one is doing amounts to "starving a person to death", clearly something "intrinsically evil".

One need not be a proportionalist in order to deny that there is no obligation to provide MNH for PVS patients. Still, it is worth pausing to consider how a thorough-going proportionalist analysis of this case might run. The proportionalist argues that considered in themselves, kinds of human actions are never definitively good or evil: when I act I may "do - that is, bring about - some evil", but whether I act rightly depends on whether there is a proportion between the evil I do and the good my acting also achieves. Thus, for example, while ceasing nutrition and hydration involves bringing about an evil (death), whether I do wrong in so doing depends on whether in the given circumstances death is proportionately justified by other goods my action serves (for example putting an end to pointless suffering, saving medical resources, etc.).

The proportionalist analysis accurately fits a number of cases, for example amputation of a healthy limb to prevent the spread of disease. Its strength is to alert us to the fact that in trying to understand "just what we are doing" the surrounding circumstances as well as an agent's intentions can actually alter the "intrinsic" nature of what is being done. Thus, medical amputation and mutilation involve utterly different moral characterisations, even though they may be identical as observable physical actions.

Where proportionalism becomes problematic is in the extension of this kind of analysis to moral evaluation in general. The analysis fits well cases like amputation, organ transplantation, stealing in time of famine, or lying to a homicidal maniac, in which the evil done and the good achieved fall within a recognisable "total good" (saving life; sharing bodily tissue; the universal right to material necessities; the nature of human communication.)

If the pattern of proportionately justifying the doing of evil is generalised across all moral decision-making, several problems arise. First, there is the commensurability problem: how are goods and evils which do not fall within some overarching "totality" to be compared with each other? Secondly, if proportionate weighing of goods is always an option, then there is little room for the idea that some actions are "morally unthinkable" (for example rape, murder of the innocent, adultery) in the sense that the question of whether "in these circumstances" they might be justified is one that a virtuous moral agent never allows to arise. While a proportionalist might believe that the circumstances which would justify killing the innocent would be rare in the extreme, in principle at least, and in general, the question of justifying doing evil remains open.

One strength of the absolutist position is that it takes seriously the matter of "just what we are doing", just what actions we are choosing and intending as means to our ends. The absolutist believes that if it is an accurate description of "just what one is doing" that one is doing evil, then one's action can never be justified or made right. By intentionally doing evil in some form (for example by killing the innocent) one's will (one's "heart") is set upon evil; one is in personal complicity with the evil one is doing, and "justifying" appeals to extenuating circumstances or to one's further good intentions are in vain. (Of course, one's evil-doing might be subjectively excused, but it can never on this view be justified.)

The absolutist view challenges us to recognise the intentionality of our action: in acting wrongly, I do not just bring about evil, I do evil, and that makes me evil. If withdrawing nutrition and hydration from PVS patients amounts to "starving them to death", it could never be justified.

"Starving someone to death" cannot be re-described as "ending his suffering". We ought not fudge the descriptions of our actions ...

The absolutist account upholds the straightforward reading of the injunction that "a good end never justifies an evil means". For the absolutist, moral agents are capable of understanding that an action chosen as a means to an end may be evil even before they consider its relation to that end and irrespective of all but a few specified circumstances. Just as we cannot mean whatever we like by the words we use, so our actions cannot bear just any interpretation we chose ("starving someone to death" cannot be re-described as "ending his suffering"). We ought not fudge the descriptions of our actions by eliding them

into our further intentions so as to evacuate the straightforwardly moral evil that certain kinds of action involve. Once such evil is identified, then it can never be justified as a means to an end.

For the proportionalist, however, the injunction that the end does not justify the means is always subject to the qualification that what appears to be an evil means (removing a healthy kidney, killing an innocent person) might not be always morally evil, because of its special proportional justification in a given situation (saving the life of a recipient, saving many innocent lives?).

For the proportionalist, talk of the moral evil of a means is incoherent apart from its relation to a good end and to the surrounding circumstances. The proportionalist argues that those terms by which the absolutist designates certain kinds of actions as intrinsically evil (for example, "murder", "rape"), involve both a generalising abstraction from particular cases, and a presumptive judgment as to which circumstances might justify the evil brought about. For the proportionalist, talk about some kinds of action (for example, starving someone to death) as "intrinsically evil" presupposes that, for example, the "someone" is not already dying, and that apart from this special circumstance, justifying circumstances or good ends are virtually unimaginable.

Circumstances can and do make an objective difference to the morality of actions by making objective differences to the accurate description of "just what we are doing."

Nonetheless, in principle the question remains open: perhaps there are circumstances (other than imminent death) which would make the cessation of nutrition and hydration not amount to starving someone to death, and so not a (morally-) evil means to some good end. The proportionalist does not think that our standard moral case terms and the moral evaluations they include can ever be more than presumptive. The "intrinsic" morality of actions, therefore, is always in principle open to modification by new circumstances and purposes of action. There is no way of determining in advance what these circumstances may be, or of separating relevant from irrelevant circumstances.

A potential incommensurability between the evils and the goods an action brings about in the circumstances is thus inevitable. But it is not in principle insurmountable simply because we know that human beings are always discriminating between, and prioritising, different kinds of good,

often without much difficulty.

My aim is not to settle the absolutist/proportionalist debate here. By noting the strengths of each position, I have tried to highlight the importance of lucidly understanding just what human action in a given situation amounts to.

The attractive strength of the more cautious opinion is its forcing us to name our actions honestly, and so, for example, to take stock of the seemingly-accurate description of "just what we are doing" in ceasing nutrition and hydration as "starving someone to death". On the other hand, the proportionalist point is that any action-description will presuppose certain "standard" circumstances and cannot be just read off from a physical action-description. The application of "starving someone to death" in the case of a PVS patient with fatal pathology is surely problematic.

Circumstances can and do make an objective difference to the morality of actions by making objective differences to the accurate description of "just what we are doing": for example, donation of tissue by a live donor need not be "mutilation", taking another's property in time of famine may not be "stealing", marriage in a confused post-war situation in which one's spouse may be presumed dead may not be "adultery", etc. These action kinds ought to remain "morally unthinkable", but in some circumstances the unthinkable becomes thinkable provided we can truly come to understand that "just what we're doing" here does not fall under some category of action we ought still regard as intrinsically evil.

III.

In the case of comatose patients, I propose that ethical decisions as to their appropriate care turn on two critical issues: first, the anticipated outcomes of the various courses of action, and secondly, the dignity of the patient as person. The appropriateness of nutrition and hydration ought to be determined in accord with these two factors.

Thus, assuming that there is no reasonable hope of recovery for a patient, no form of treatment will be of any benefit beyond that of sustaining physical life. Some ethicists argue that "benefit" is the wrong term here.³ MNH, for example, may have the "effect" of extending a comatose patient's life, but it will be of no (personal) benefit to her. Others claim that physical life is something good in itself, and so ought always to be sustained irrespective of the comatose patient's inability to enjoy any of the other goods of personal life. They fear that the former view makes physical life merely an "instrumental" good, to be discarded once it no longer benefits personal

existence.

However, physical life can be understood as in certain ways subordinate to personal life without thereby being "instrumentalised". Personal human existence is indeed embodied in physical living; the body is not "an instrument" of the soul. Being physically alive both makes possible, and - more importantly - finds its fulfilment in, the flourishing of personal and spiritual life.

When personal flourishing has been rendered impossible, the mere prolongation of physical life loses (most of) its significance. Once this point is reached, MNH may not be indicated simply because it has become futile with respect to that which matters most, and so is not in principle an obligatory element in the care of terminally-comatose patients.

When we cease nutrition and hydration for comatose patients, we are recognising that their lives are coming to an end, and that to prolong their physical existence alone, divorced from the possibilities of personal existence, is simply to prolong their dying.

This conclusion may be strengthened by considering a paradoxical twist in the arguments of those who believe MNH is always obligatory. The latter claim that one reason why MNH is not an "extraordinary" means of treatment is that it is not burdensome to the patient (who is, after all, unconscious). Yet, they admit that were the patient conscious (or, prior to his becoming unconscious) he could in some instances justifiably decline such treatment on the grounds of its burdensomeness to himself. The irony is that on this view, MNH which may not be of benefit to a conscious patient, can be of benefit to a comatose patient even though (just because?) he or she is unconscious.

It follows that consciousness is not on its own the critical issue with respect to the appropriateness of MNH. Once a person is diagnosed as surely terminally ill, no treatment will bear the meaning of **benefiting recovery**. But just because a treatment may be futile from that viewpoint, it does not follow that it is never required. A patient's terminal condition - though it removes one source of obligation for certain treatments - is no ground for our simply abandoning him or her to die (for example, by starving to death).

The focus of our response now becomes care for the person in this last stage of her life with a view to

not only easing her pain and suffering, but also to the "personal" elements in human living - the significance she finds in continuing to live, in her relationships with others and in her appropriation of the meaning of her dying.

The dignity and worth of personal life demands that, among other things, food and drink, the ordinary means and symbol of participation in the human community, continue to be provided while the sustaining of physical life has personal significance. In the case of those who are conscious, this significance ought include the easing of felt discomfort and pain. In many cases it may be sufficient to provide oral feeding in small amounts which palliate a patient's hunger, even though the quantities will be too small to provide sustained nourishment.

In some cases, continued feeding (even by nasogastric tube) has significance because of uncertainties as to the patient's precise state of consciousness, or the chances of short term improvements in consciousness. But to the extent that medically-supplied nutrition and hydration neither benefits recovery nor adds to the quality of a dying person's life, nor reflects the obligation always to treat a person with dignity, it is inappropriate. None of these conditions is typically met in the case of persistently comatose patients.

What, then, are we doing when we cease nutrition and hydration for comatose patients? We need not be "starving them to death". Rather, we may be recognising that their lives are coming to an end, and that to prolong their physical existence alone, divorced from the possibilities of personal existence, is simply to prolong their dying. Because we value these patients to the very end of their lives, we must continue to palliate their pain, as well as any felt hunger or thirst. But we are not bound to ensure (by quite elaborate means) that they receive sufficient nourishment to go on "living" indefinitely. Circumstances do make an objective difference to the "intrinsic" morality of actions.

Notes:

- 1 Quoted by Richard A. McCormick, "Moral Considerations" III Considered', *America*, March 14 (1992), p. 210.
- 2 Kevin O'Rourke, quoted in McCormick, *ibid*, p. 213.
- 3 cf. McCormick, p. 214.

NOTEBOOK

RESOURCE ALLOCATION: THE ETHICAL ISSUES

Seminar Sponsored by the John Plunkett Centre For Ethics

Venue:

Douglas Miller Lecture Theatre
St Vincent's Hospital
Darlinghurst, Sydney

Time:

Tuesday 27 October 1992
3.30pm - 6.30pm
(Followed by drinks)

The seminar will consist of two sessions:

1. Making The Hard Choices Today:

Assoc Prof James Biggs	Physician
Dr Terence O'Connor	Surgeon
Prof Don Chisholm	Medical Researcher
Mr George Jepson	Hospital Administrator
Prof Darty Glover	Dean - Faculty of Medicine
Mr Richard Gilbert	Economist/Planner

2. Justice in the Allocation of Resources:

Dr Robert Young	Reader in Philosophy La Trobe University
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The Seminar is free and open to all who are interested.

For catering purposes, we would like to know if you are coming. Please contact:

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