

# Bioethics Outlook

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## In this issue

Last issue we published a talk given by Professor Daniel Sulmasy to the Italian Senate on the subject of advance directives. In it, Daniel Sulmasy argued that advance directives are an extension of the tradition of forgoing extraordinary means of care. The first article in this issue builds on that paper: Bernadette Tobin argues that appointing someone to speak on your behalf should you lose the capacity to do so yourself is a better way of executing an advance directive than is writing a living will. In the next issue, in the final of this series of three interrelated papers, Nancy Dubler will spell out the support that hospitals and nursing homes need to provide to people who undertake the onerous role of health care proxy.

In the second article, Dr Helen McCabe addresses questions of justice that arise in relations between indigenous and non-indigenous Australians with respect to health care.

## *More talk, less paper!*

### **Why health care proxies are a better means of extending traditional morality than are living wills**

*Bernadette Tobin*

The topic of 'best practice' in end-of-life care for persons lacking decision-making capacity raises deep questions about a proper reverence for life and for solidarity with the sick, about the ethics of good medical practice, about the responsibilities of people who face the burden of deciding for others, and about wise public policy in a modern pluralist democracy.

Sixty years ago, coma was fatal, post-coma unresponsiveness (the so-called 'persistent vegetative state') was unknown, people who could not breathe or swallow due to neurological impairment simply died. Today, medicine can prolong life, often indefinitely, often in circumstances in which the patient is cut off from family and friends, often in circumstances in which it would be reasonable to judge that the patient had reached the limits of any obligation to preserve his or her life. So, today, there is a need for mechanisms to address medicine's capacity to keep people alive in conditions in which they may not want that to happen.

'Advance directives' can be just such a mechanism. The term 'advance directives' refers to two different ways in which a person can extend the right to forgo extraordinary means of care: appointing a person to act as a health care 'proxy' or 'surrogate' or 'representative' (or giving that person a 'durable power of attorney') and making a 'living will'. In what follows I shall talk of health care proxies and living wills, and argue in favour of the former ('more talk') and against the latter ('less paper'). I will argue that appointing a health care proxy is an effective way of extending traditional morality into contemporary end-of-life situations. I will argue that executing a living will is a less reliable means for so extending traditional morality.

Professor Sulmasy set out the elements of traditional morality from which arose the tradition of recognizing that some forms of treatment and care are non-obligatory or optional or (to use the technical term from philosophy) 'extraordinary'.<sup>1</sup> These elements are: the dignity of the person, the duty to

preserve life, the fact of finitude, the diversity of the human and, associated with these ideas, the immorality of euthanasia and assisted suicide. Medicine has traditionally recognized the fact of human finitude: the Hippocratic Oath requires doctors to use medicine for 'the benefit of the sick' and not to treat patients who are 'over-mastered' by disease. And medicine has traditionally recognized the fact of human diversity: doctors do not treat 'humanity in general' but rather a particular person in particular circumstances. From the recognition of these elements of traditional morality comes the realization that treatment and care can be non-obligatory, optional or 'extraordinary'.

For most of human history the decision as to what treatment and care was obligatory (or 'ordinary') and what was not obligatory (or 'extraordinary') could generally be made by the sick person himself or herself. Now, however, someone else often needs to make that decision.

Let me set before you an example of the ideal circumstances in which someone else makes a decision on behalf of a person who lacks decision-making capacity. Recognizing the elements of the ideal with respect to decision making for someone who has lost that capacity will help to identify the proper role for families, other carers, hospitals and nursing homes, legislation,

Lucia, an eighty-one year old mother of a large Catholic family, was diagnosed with a fatal brain tumour. Her husband had died many years before and her five sons and three daughters, all adults with their own careers and families, got along well with her and with each other, apart from the normal stresses and strains of family life. Many decisions had to be made: whether to remove the initial tumour, whether to remove its regrowth, whether as death drew close to give Lucia antibiotics for infection, etc. At first, her doctor was able to elicit Lucia own wishes: however, she merely said that she would accept whatever the doctor proposed, so long as that would not cause him too much trouble! The doctor removed the tumour and Lucia seemed content and grateful. As her illness

progressed, her courteous manner remained. But it was increasingly-clear that she had lost her decision-making capacity. So the doctor consulted her family. They were grief-stricken at the prospect of letting their mother go, but they were clear about their role in their conversations with him: it was to represent (that is, to re-present) her to him. The doctor explained her prognosis. The family was able to confirm that her expressed wish, not to be a nuisance to the doctor, said something about her attitude to other people in general: she would not want others to be unduly burdened in taking care of her. The doctor recommended a second surgical removal of the tumour, essentially for palliative reasons, to make her last few months more comfortable. After this surgery she was more subdued, less engaged with those around her. A month or so later a chest infection was not treated with antibiotics, and after a few days Lucia died.

It was part of this family's shared life that they did not shy away from talk about death. Their conversations about death had been prompted by reflection on the death of their father twenty years earlier: they were able to acknowledge what went well and what went badly in the manner of his dying. More recently they had discussed the media attention to a controversial case: they had debated the difference between, on the one hand, refusing care because it would be futile or because the burdens it would impose would be outweighed by its benefits and, on the other, truly suicidal refusals. As a result of their acceptance of death in the midst of life, when their mother began to lose her decision-making capacity, they were able to speak truthfully and helpfully to her doctor.

The other critical part of this ideal was that the doctor's efforts were truly oriented to the 'benefit of the sick'. He was attentive to the proper goal of treatment as she neared the end of her life. He was loath to administer treatment that did not work towards realizing that goal. He was attentive to burdens as well as benefits. He was a doctor who knew that his expertise lay in assessing the medical effectiveness of a treatment for his patient in her particular circumstances. And so he gave his opinion on the following four

questions that came from the family: Would the treatment cure her? Would it reverse the condition she was in? Would it relieve her symptoms? Would it forestall her imminent death? He knew that the burdens of treatment (physical, psychological, social, economic, moral, spiritual) were a matter for his patient, and then for her family, to assess. So he collaborated with them in making decisions. Because of all this talk with them, there was no need for a formal advance directive of any kind. Lucia had conveyed her wishes informally and effectively, and the family was harmoniously committed to ensuring that she died as well as she could.

How does this ideal come about?<sup>22</sup> Over time, through conversations which happen within a family and are conveyed to the doctor. I say 'over time' because people generally need both time and assistance to reflect on the meaning of death in their lives. They need time because a genuine acceptance of one's finitude is a hard-won achievement. They need time because that acceptance raises its own questions about the meaning and significance of life. They need time because there is often a reluctance to consider these matters. And some will need time because they will be challenged to think, in a more mature way, about the meaning and significance of what they were taught in their early religious instruction: that human life is a gift, that they are 'stewards' rather than 'owners' of their lives, that suffering *can* have a positive meaning in their lives.

There are today many more reasons than there ever were why the ideal is unlikely to be realized. Many more people than used to be the case die having lost decision-making capacity. Most people in developed countries have access to advanced medical technology. Many more of those who are hospitalized die after a decision has been made *not* to do something that could have been done: in the United States the data indicate that 80% of deaths are negotiated in some way. And widespread access to technology has increased the anxiety of decision-making felt by those who have to make decisions for others, even in the most harmonious and functional of families. If the ideal is still to

occur, it will now happen only as a result of community efforts to encourage people to reflect on the meaning of death in their lives, to face and resolve personal differences within their families, to ease the burden of decision-making which increasingly falls on others, and indeed to accept that they have a responsibility to assist others in making decisions for them. In this, professional bodies, hospitals and other health care institutions, churches, even a parliament in its role as the setter of community standards, all have a part to play.

Given that the ideal is less and less likely to occur, appointing a health care proxy is a good way of assisting others who are left to make decisions when a person has lost decision-making capacity. We need to help people to see the point of ensuring that someone they trust will be in a position to take on the burden of making decisions for them. We need to encourage people to provide the necessary guidance to that trusted person, to talk about their values and their attitudes to medical treatment and care at the end of life. In short, we need to encourage people to nominate a person who can represent them when they are no longer able to decide for themselves, that is, to appoint a health care proxy. Legislation authorizing the use of health care proxies has a part to play.

If people are to appoint a health care proxy, who should that be? Normally, a member of the family. A family member, who knows and loves the person, is best able to have the right kind of conversation with the doctor. A family member is normally best able to decide, in particular circumstances, whether the sick person would have thought she had reached the limits of her duty to preserve her own life.

Of course, family members can get things wrong, and so it is an over-simplification to say that, if a patient does not have decision-making capacity, then it is a matter of 'what the family wants now'. There are many ways in which the family can go wrong. They may not know the wishes of the sick person. They may find it impossible to let go. They may be too keen to get back to their own lives

unimpeded by responsibilities of caring for a sick relative: if so, they are likely to err on the side of under-treatment. They may focus on whether they themselves can manage the challenges of caring for the patient, rather than on whether the burdens on the patient outweigh its benefit to her: if so, they may err on the side of over-treatment. And they may ask the doctor to act contrary to traditional morality's injunctions and prohibitions. So proxies will often need help.

What if the patient has no family member to appoint? A friend may be able to fulfill the role well. Even an occasional carer. But not, I think, the family doctor, or at least not normally. For that would confuse decision-making at the end of life. A doctor is the proper judge of a person's medical best interests, the proper judge of whether a possible intervention will work or not, relative to whatever specific objective the treatment is aimed at (cure, stabilization, palliation, etc). But a doctor normally needs to be able to consult someone *else* as to whether the burdens of a proposed intervention outweigh its benefits – for this particular patient. The doctor cannot have that conversation with himself.

Nor should an institutional ethics committee take on the role of health care proxy, even in difficult and conflicted cases. Professor Dubler will have more to say not only about best practice in cases of controversy or conflict but also about the proper role for a hospital's ethics committee in these matters.<sup>3</sup> I will say only this. A group of people, the members of an institution's ethics committee, should not be authorized to make treatment decisions in individual cases. Doctors might seek advice from such a committee, proxies may seek advice, even patients may seek advice. But the advice a committee may legitimately give in response to a particular case can only be in terms of general ethical principles applicable to like cases. Ethics committees have a key role to play, but it is not to *decide* particular cases.

I have argued that the appointment of a health care proxy is generally an effective way of extending traditional morality's recognition that treatments and care may be

non-obligatory. I would now like to explain why I do not think the same of living wills. In my judgment, they are a very unsatisfactory alternative to the use of health care proxies, at best a back-up to be recommended only in circumstances in which there is no proxy.

Let me begin with the story of my most recent experience of a living will. It reveals some of the problems associated with living wills. Anna, a seventy-one year old woman who had breast cancer with liver metastases, respiratory failure and scoliosis, was to be admitted to a Catholic hospital for the insertion of a ureteral stent to help her to urinate more easily and so to relieve the pain and pressure she felt in her abdomen. Anna had a living will which directed that, if she suffered from any one of a number of conditions including 'advanced disseminated malignant disease', and if two doctors were of the opinion that she was unlikely to recover from illness or would suffer impairment involving severe distress or incapacity for rational existence, then 'I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life' and that 'any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesia...)'.

Anna rang the hospital a few days before her operation to check that her living will would be observed. The Director of Nursing, who promised to read the living will carefully and call her back, quickly saw a problem. The procedure to relieve Anna's pain and discomfort would itself de-hydrate her. The doctors would insert a canula and use it not only for anaesthetizing her during the procedure but also for re-hydrating her after the procedure was finished. And so, if Anna's living will were followed literally, it would preclude doctors from giving her ordinary post-operative care. Fortunately, Anna was a sensible and intelligent woman. When the Director of Nursing rang her back, and talked the matter over with her, it became clear that Anna had not understood what the standardized living will she had filled in really meant. Once she did, and once she understood that re-hydration was a necessary part of post-operative care, she readily discarded that living

will. All she asked was that, if her heart were to stop beating during surgery, she would not be resuscitated. The Director of Nursing promised that that wish would be respected, and wrote it in the notes. Anna withdrew her formal living will, successfully underwent the surgery, and as it happens died a few weeks later.

The first reason why living wills are a poor instrument for extending traditional morality into new situations is that they require careful interpretation: they are not self-explanatory.<sup>4</sup> The course of illness is generally unpredictable and a doctor needs to be able to provide good care in the actual circumstances of a patient's illness as they occur, guided by conversations with a health care proxy about the burdens and benefits of treatment, but not constrained by anything that curtails the exercise of his medical judgment. Anna's living will refused artificial hydration in all circumstances. That refusal would have prevented her doctors from doing what she actually wanted them to do: look after her properly during and after a palliative procedure.

Even when a patient has a progressive illness with a predictable course, unanticipated circumstances may arise. In fact, the following questions need to be asked of any living will: Do the present circumstances correspond to the situation that the patient imagined when he or she recorded his or her wishes or values? Do the treatment and care options that are available correspond to those the patient imagined would be available when drawing up the living will? Do the effects of implementing the patient's living will correspond to the effects that the person understood would be their consequence? Are there any new or changed factors in the present circumstances that the patient may not have taken into account but might have wanted to be considered in the present circumstances? Living wills don't come with their own answers to these questions.

The second reason why living wills are a poor instrument for extending traditional morality into new situations is that they privilege past wishes over the provision of reasonable care.<sup>5</sup> The logic of a living will is this: once a person

becomes unable to decide for herself, it is her past assessments and directives that prevail over any signs as to what she wants now, however urgently expressed, and over any assessment of what is reasonable care in the circumstances that may be made by family, friends, attending doctors and nurses. People's assessment of their own interests often varies with circumstances. What seemed a good idea to Anna when she executed the living will no longer seemed so when the procedure she was to undergo was explained to her.

The third reason why living wills are a poor instrument for extending traditional morality into new situations follows from the second.<sup>6</sup> There is a crucial difference between what traditional morality requires and what living will legislation may authorize. Traditional morality recognizes that a refusal of treatment because it is futile or too burdensome involves no suicidal intention and, correspondingly, that a doctor's decision to act accordingly involves no homicidal intention (even though the foreseeable result may be the death of the patient). But traditional morality's respect for the individual's right to forgo treatment and care comes in a framework that excludes both suicide and homicide. Since attempts to enshrine living wills in legislation sometimes ignore the significance of intention, living will legislation may blur the critical distinction between refusing treatment that is futile or too burdensome treatment *in order to avoid its futility or burdensomeness* and refusing treatment in order to eliminate one's own life.

The fourth reason why living wills are a poor instrument for extending traditional morality into new situations is that they simply do not work!<sup>7</sup> A recent analysis of living wills summarizes why they have failed: few people have them, few people can predict their preferences accurately, few people can articulate their preferences clearly, and they are often not available when they are needed.

After twenty five years in which legislatures, courts, administrative agencies and professional associations around the world have promoted them, very few people have actually executed

living wills. Most Americans do not have them, most Australians have never heard of them. There are many explanations. Some people say they have not executed a living will because they do not know enough about them, others because they do not think that they will need one. Some say they care less about what decisions are made than they do that the decisions are made by people they trust, others say that living wills are incompatible with their cultural traditions. One way or another, people overwhelmingly just do not want to execute them.

For living will legislation to work, people need to be able to predict their preferences accurately. But, as Anna's case shows, people are generally not able to this. People misunderstand crucial background facts about medical treatment: for example, they regularly over-estimate the effectiveness of cardio-pulmonary resuscitation. And they fail to recognize just how unstable their preferences are likely to be at different times in their lives and in different states of health. People who are healthy often say that they would not wish to live with disability: but the studies show that they frequently change their minds when they have experienced living with a disability.

For living will legislation to work, people need to be able to articulate their future treatment decisions accurately and lucidly. Few people can. The living will document that Anna used was pre-prepared for her. So as to simplify things for her, it gave her few choices. But, even so, she did not understand its meaning. And there is no reason to think that she would have been able to articulate her preference any better had the document allowed her to go into more detail. In addition, living wills often specify that they apply only in the circumstances of 'terminal illness': yet it is common enough that difficult decisions have to be made about treatments that respond to conditions that are not in themselves 'terminal'.

For living will legislation to work, these wills need to be available, at the crucial time, to those who have to make treatment decisions for patients who cannot do so for themselves. Often they are not. They get lost. People

forget their existence. They are not transferred with the patient to hospital. They are not transferred from one clinical team to another, etc. The most efficient bureaucratic procedures in the world are unlikely to improve things.

Finally, for living will legislation to work, those who have to interpret the instructions in living wills need to be good at analyzing their instructions and applying them in the actual circumstances of the patient. For the reasons given earlier, they are not. And living wills do not, indeed cannot, automatically apply themselves to the patient's present circumstances.

For all these reasons, living wills are a poor instrument for extending traditional morality into new circumstances. So, I respectfully recommend that a parliament does three things to institute advance directives: (1) authorizes in law a decision-making role for a health care proxy as representative of the patient, (2) fosters measures which address the health care proxy's need for advice and support, and (3) addresses remaining issues raised by patients who do not have health care proxies, and those who have neither a proxy nor a living will, *in a manner which does not undermine the centrality of the doctor-proxy relationship*.

A word or two about the third recommendation. There are patients who do not, and likely will not, have proxies. It is critical that we grapple with how best to ensure that the treatment and care such patients receive at the end of life is faithful to their wishes without undermining the primacy of the institution of 'the proxy as decision-maker' as public policy. Here I will make two suggestions:

(a) In the case of patients who do not wish to appoint a health care proxy, a parliament should authorize the use of living wills. It should, however, make it clear that such living wills are not literally 'binding directives' but rather 'statements of the patient's wishes'. It should encourage the use of language which focuses on the patient's needs, values and goals at the end of life and avoid any language which encourages the patient to reject specific treatments.

(b) In the case of patients who have neither a proxy nor a living will, a parliament will need to devise some less-than-perfect solution. I recommend that it authorizes hospitals and nursing homes to make their own, local, arrangements to ensure that patients and residents are not kept alive in circumstances in which they would not want that to happen: for example, a hospital could have an arrangement with some trusted members of its local community (someone who serves the needs of the elderly, someone who serves the needs of the mentally ill, a member of the clergy, ...) who would be prepared to be available to collaborate with the doctor in deciding whether the limits of appropriate treatment and care had been reached in a particular case. This less-than-perfect solution would build on the law's recognition of the individual's right to refuse futile and overly-burdensome treatment and to accept treatments chosen to address the symptoms of illness even though they may happen to hasten death. It would need to be backed up by the establishment of ethics consultation services and ethics committees which foster good professional practice at the end of life. Though less than perfect, it would be a better solution, in my judgment, than would be referring such cases to juridical or semi-judicial decision-making (by public guardian, tutelary judge, etc). In addition to being remote from the patient, those bureaucratic solutions tend to be lengthy, cumbersome, public, expensive, and (worst of all) open to the vagaries of politics!

Today, we need to accept that we are more likely than ever to die in circumstances in which we are not able to participate in decision-making about treatment and care at the end of our lives. We need to accept a responsibility, in advance, to assist those who are likely to have to bear the burdens and anguish of making those decisions for us. So the law should encourage the use of health care proxies as decision-makers in the case of patients who have lost decision-making capacity. And professions and institutions must meet the challenge of ensuring that the new relationship between professional and proxy is true to Hippocrates' covenant: 'the benefit of the sick'.<sup>8</sup>

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# What has indigenous health got to do with reconciliation?

Helen McCabe

In February of this year, the Australian Prime Minister formally apologised to Australia's Aboriginal and Torres Strait Islander people for the 'grief, suffering and loss' which has accompanied what is now a former officially-sanctioned practice of removing indigenous children from the care of their families and communities. In acknowledging the injustice suffered by indigenous Australians, Mr Rudd said 'sorry' and resolved that such activities must 'never, never happen again'. In issuing this apology, a step towards reconciling relations between the so-called 'stolen generation' and non-indigenous Australians was taken.

Some commentators have dismissed the occasion as 'merely' symbolic, pointing out that simply saying sorry would not rectify the marked disadvantages suffered by indigenous people with regard to measures of well-being, such as standards of health. They believe that any sincere and worthwhile attempt to reconcile relations must involve efforts aimed at achieving greater measures of equality between the two groups, such as more equal 'health outcomes'.

So, how are we to think about relations between indigenous and non-indigenous Australians? What does justice require? And what do we do about the poor standards of health among indigenous people? Answering these questions involves distinguishing four different senses of justice - retributive justice, reparatory justice, restorative justice and distributive justice - and then understanding what each requires of us.

## Retributive Justice

The demands of justice which most obviously occupy the attentions of law enforcement agencies are those concerned with retributive justice - with either punishment or rehabilitation or, indeed, with both of these things. In relation to the removal of indigenous children from their families, however, the requirements of retributive justice do not apply in any clear sense, given that those involved in removing those children acted within the law. Of course, it does not

follow that, in relation to those practices, the law itself was just: both those commentators who supported 'the apology' and those who did not concur, for the most part, on this view. What it does mean, however, is that no-one can be tried for breaking a law because no-one did.

The injustice suffered by indigenous families cannot, then, be addressed under the terms of retributive justice. For this reason, those wronged by past laws and policies cannot seek redress in the courts or have their suffering acknowledged in this more usual and public way. They must look elsewhere.

## Reparative and restorative justice

Since the release of the *Bringing Them Home Report*,<sup>1</sup> indigenous Australians have asked that a formal apology be made and that it include the word 'sorry'. Ultimately, on February 13th, this came to pass when Mr Rudd apologised 'for the laws and policies of successive Parliaments and governments'<sup>2</sup> and, in a subsequent speech, said 'sorry' himself.

The use of the English word 'sorry' is by no means straightforward. To be sure, it can be used in a form of apology when one is admitting direct responsibility for harm caused to another. However, we can also use the word 'sorry' to describe a kind of 'feeling with' or 'feeling for' those who suffer. Indigenous Australians understand the word 'sorry' to mean 'having empathy, compassion and understanding'.<sup>3</sup> Saying 'sorry', then, means more than simply apologising or regretting; it means 'being afflicted' by what was suffered or 'sorrowing with' those who have suffered injustice. It means more, that is, than simply upholding rights and duties.

And it means more than acknowledging disparities in measures of material well-being between indigenous and non-indigenous people. Indeed, saying 'sorry' for the infliction of injustice itself is necessary given that any suffering of a material or psychological kind is compounded by injustice in ways that differ from human suffering that is consequent to a



natural disaster, for instance, or an accident. In other words, forms of suffering 'matter differently and more' when they are caused by injustice, rather than something else.<sup>4</sup>

Saying sorry is really a first step in reconciling relations between indigenous and non-indigenous Australians; for this reason, it is also a first step in abiding by the terms of reparative justice. For the proper aim of reparation is reconciliation. Some commentators would insist that reparative justice also requires us to make efforts at restoring what was lost (or its equivalent). However, this requirement is demanded, instead, by the terms of *restorative* justice and must be upheld in addition to the terms of reparative justice. Of course, in this case, it is not possible to restore to the 'stolen generation' what was unjustly taken; indeed, restorative efforts can only be realised in cases where harm done was limited to violations of property.<sup>5</sup> Nonetheless, some kind of compensation ought to be offered even if this is the case.

Some commentators have worried that the issuing of a formal apology would obfuscate the need to address the inequalities which continue to afflict indigenous Australians, such as unequal standards of health. They point to official records which reveal the higher incidence of morbidity, considerably shorter life expectancy rates and higher infant mortality rates among indigenous people,<sup>6</sup> suggesting that reconciliation would be realised if we simply 'closed the gap' that exists between standards of indigenous health and those of the wider community. However, while they are right to be so concerned about the poorer health standards of indigenous Australians, it does not follow that 'closing the gap' in this respect will contribute to reconciliation as such.

Talk of equality and restoration characterises aspects of justice concerned with obligations and rights. However, another aspect of justice is characterised by talk of 'apology, forgiveness, contrition, atonement and reconciliation',<sup>7</sup> or those things necessary to restoring and maintaining dignified human *relations*. It is this aspect of justice that is required *in addition* to attention to welfare needs (such as health care) if justice is to be realised in its richer sense. Indeed, even if we managed to improve the health standards of indigenous people such that they emulated the highest

standards achievable in a modern, Western society, we could not claim, at the same time, to have realised all aspects of justice if relations between indigenous and non-indigenous Australians continued to await atonement and reconciliation. To this end, it was necessary to make a public apology, to say 'sorry', and to commit to pursue respectful, peaceful, cooperative relations.

If we have acted to reconcile the relevant relations and, also, offered some kind of compensatory measure in what must be a symbolic attempt at restoration, we are still left to attend to the health and other welfare needs of indigenous Australians. Attention to this latter concern is addressed by the requirements of distributive justice, a matter that is by no means straightforward.

### **Distributive Justice and Indigenous Health**

In addition to genetic endowment, public health and safety standards, degree of economic prosperity, and so-called 'lifestyle choices', health standards will be influenced by the way in which the resources of health care are distributed. In particular, the distributive criterion selected will determine, to a considerable extent, who gains access to the resources of health care, on what condition(s) and in what quantities. A consideration of diverse philosophical theories reveals differing distributive criteria which, in turn, are informed by a range of different values and dissimilar beliefs concerning entitlements (or otherwise) to the resources of health care.

#### *The Utilitarian Approach*

Utilitarians want to provide those kinds of health care measures which contribute to 'maximising' benefits (or, possibly, 'health outcomes') while minimising burdens (or costs to the community). To this end, they have provided such measures as the 'quality-adjusted-life-years' (QALYS) administrative model, a calculative approach to determining the value of providing particular treatments or services when compared with other spending options. In this sense, they want to distribute resources in accordance with the calculative outcomes of a cost-benefit analysis.

However, even if such determinations were a straightforward, technical matter (and they are not), it must follow from a utilitarian approach that some (the minority) will unavoidably be

denied access to necessary resources should the cost of meeting their needs detract from an overarching quest for 'maximising' (usually unspecified) benefits. In this way, utilitarians are prepared to forsake those whose needs, should they be met, are likely to detract from the project of meeting the preferences, desires or choices of the majority.

Under a utilitarian scheme, the health care needs of indigenous people living in remote communities would most likely be neglected, given the additional cost of providing both (expensive forms of) transport to treatment facilities and, as well, of treating what are oftentimes more complex expressions of illness. For example, the incidence of co-morbidities (such as diabetes and its complications) is much higher among the indigenous population; accordingly, the treatment of some diseases (e.g. cancer) would be complicated by such associated conditions as nephropathy and peripheral vascular disease.<sup>8</sup> In other words, it is less expensive (and more likely to meet pre-determined benchmarks) to treat cancer in people who are otherwise healthy and who, also, live close to sophisticated health care facilities than it is to treat the same disease in those who live remote to those facilities, who suffer more medically complex conditions, and who also need additional (costly) treatment, such as renal dialysis.

Generally, in a utilitarian world, the goal of efficiency takes precedence over that of meeting health care need. Or so it seems. Accordingly, on this approach, the likelihood that additional resources will be made available to indigenous people is doubtful, no matter how dire their need.

#### *The Libertarian Approach*

Libertarians pursue what they understand to be a 'right to self-determination'; the values of autonomy, 'freedom', and 'choice' take uppermost place within this worldview such that 'patterned' systems of distribution are ruled out. Hence, tax-payer funded health care systems would be an anomaly in a libertarian world where, if such a world exists at all, the cost of health care services is borne by those individuals who 'choose' to purchase such goods. The libertarian worldview is at odds, then, with approaches which give rise to universal health insurance schemes, such as Medicare.

Presently, as in Europe, a tension is discernible in Australian arrangements for health care provision where, increasingly, the market has entered a realm previously protected within the public and not-for-profit social realms. That this is so is of concern for those who suffer heavier burdens of illness and injury, as do indigenous Australians, and for those who lack sufficient pecuniary resources. Indeed, as Michael Walzer notes, such a market in health care becomes dangerous, given that those burdened with poor health are oftentimes those who are least able to afford the cost of health care. And, moreover, given the kind of society in which we live, a market for health care is also degrading.<sup>9</sup> Ultimately, those who suffer illness and who are also poorer must rely, in times of health care need, on the 'charity' of others.

#### *The Egalitarian Solution*

Egalitarians (among others) rightly worry over such arrangements given that charity can be revealed as 'an attitude of condescension towards the poor',<sup>10</sup> depending, of course, on the spirit in which it is offered. Walzer notes the way in which the poor who are also sick suffer a 'double loss' in a libertarian world: their health and their social standing.<sup>11</sup> Indeed, this concern is reflected in egalitarian theories in which distributive justice is ordered by a criterion of equality, usually equality of opportunity. For the most part, egalitarians value health inasmuch as its possession affords opportunities to achieve other things, such as improved employment prospects, higher incomes, and other measures of well-being.<sup>12</sup>

Morbidity and mortality statistics provide some kind of 'snapshot' of health standards in a given population. That marked disparities exist in this respect between indigenous and non-indigenous Australians is a concern around which there has been considerable attention in recent years; the 'close the gap' campaign, for instance, represents a political approach to rectifying this anomaly. Practically, a list of objectives has been specified to achieve this goal, such as a reduction in the incidence of diabetes and of cancer, so that, in turn, greater equality is realised between indigenous and non-indigenous Australians. Ultimately, should such aims be realised, it is the hope of egalitarians that indigenous Australians come to enjoy the same opportunities for well-being as do the non-indigenous.

However, while such efforts are indeed worthy, it is also the case that if we restrict our efforts to providing only those treatments and services likely to improve opportunities of well-being, then we are likely to neglect a range of activities that meet such needs as for pain and other symptom relief, rehabilitation and for alleviating the suffering and other effects of mental illness (including that attributed to the forced removal of children from family and culture) and organic brain damage, such as results from alcohol misuse, 'petrol sniffing' and other substance misuse. As well, health care activities that are not amenable to measurement and which are not likely to improve life's opportunities, such as those provided to the seriously chronically ill and (in particular) the dying, are likely to be forsaken in the quest for reaching designated standards of equality. In other words, the gap we close is unlikely to include a range of conditions which require serious, creative and culturally appropriate responses.

If resources are to be distributed fairly, they must be distributed in accordance with the criterion of actual health care need, and not propensity to 'maximise' overall benefits (as utilitarians would have it), nor ability to pay (as libertarians would insist), nor to bring about some kind of equality of opportunity (as many egalitarians would propose). Further, in addressing health care need, we will also need to be patient; improvements in standards of health will take longer than what can be captured in the short time-frames of electoral terms. As well, if we are to go beyond the measurable standards of health to include what are oftentimes more urgent needs, such as for pain relief for the chronically ill and dying, then we must include those kinds of services that do not necessarily contribute to meeting the blunt tools of public accountability assessments. And, to do this, we will need (at least) to reinforce our somewhat tenuous right to health care.

### In Conclusion

An incipient but important undertaking to reconcile relations between indigenous and non-indigenous Australians was realised on 'sorry day' when a public apology was offered, when the prime minister of Australia said 'sorry', and when a commitment was made to avoid similar injustices in the future. To this extent, the terms of reparatory justice have been honoured. While the

terms of compensation await deliberation and agreement, it must be said that whatever is decided, it will not be possible to restore what was lost. And whatever is decided in this respect, it does not follow either that the provision of additional health care resources will meet the requirements of restorative justice. For health care resources are *already* owed indigenous people by virtue of their higher actual health care need, and not of past injustice as such. Nonetheless, all aspects of justice are more likely to be realized under the influence of those virtues most meaningful to indigenous Australians: empathy, compassion and understanding. Hence, our success in upholding all the terms of justice relies, then, upon the extent to which we are truly sorry.

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