Legal utility of an advance refusal

SPECIAL ARTICLE

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ABSTRACT

In August 2006, the Law Reform Commission of Hong Kong issued a report on 'Substitute Decision-Making and Advance Directives in Relation to Medical Treatment' ('the Report') in which it recommended, *inter alia*, that advance refusal not be given legislative status, but that instead the use of a 'model form' be widely promoted. This paper looks at the legal benefits, if any, of the model form. It asserts that: first, in relation to those who are terminally ill, the model form adds little to what is currently required by the law; and second, with regard to those who are in a persistent vegetative state, the model form raises the legal question as to whether an application to the court is needed prior to a lawful withdrawal of artificial nutrition and hydration.

Key words: Family; Living wills; Treatment refusal

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INTRODUCTION

In August 2006, the Law Reform Commission of Hong Kong issued a report on 'Substitute Decision-Making and Advance Directives in Relation to Medical Treatment' ('the Report'[1]) in which it recommended, *inter alia*, that advance refusal not be given legislative status, but that instead the use of a 'model form' be widely promoted.[2] In another article, I have argued in favour of giving legislative status to advance refusal. I will not repeat the arguments here.[3]

This paper looks at the legal benefits, if any, of the model form (Appendix). In relation to those who are terminally ill, the model form adds little to what is currently required by the law; second, with regard to those who are in a persistent vegetative state (PVS), the model form raises the legal question as to whether an application to the court is needed prior to a lawful withdrawal of artificial nutrition and hydration.

Advance directive or advance refusal?

The Report defines an advance directive as follows:

> 'An advance directive for health care is a statement, usually in writing, in which a person indicates when mentally competent the form of health care he/she would like to have in a future time when he/she is no longer competent. The development of advance directives is largely derived from the principle of informed consent and the belief in a person's autonomy in health care decisions.' (para 2.1[1])

Although the Report uses the term 'advance directive', I prefer to use the term 'advance refusal'. An advance refusal does not refer to the health care a person would like to have; it instead refers to the treatment (usually life-sustaining) that a person would not like to receive under certain defined circumstances. The difference is crucial. As the Report itself notes, a patient might not legally demand any particular treatment (para 8.44[1]). In fact, if one were to examine the model form itself, it is clear that it addresses only the refusal of life-sustaining treatment (LST) [Appendix[1]]. The importance of advance refusal is emphasised by the law, which protects an individual's right to self-determination. Consequently, I shall continue to use the term 'advance refusal'.

Advance refusal and the right to self-determination

The Report correctly notes the importance of

respecting an individual's right to self-determination, which the common law protects via an advance refusal executed by a competent patient. It quotes Lord Goff:

> 'First, it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that, if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, *even though they do not consider it to be in his best interests* [italics indicate author's emphasis] to do so ... To this extent, *the principle of the sanctity of human life must yield to the principle of self-determination* ... On this basis, it has been held that a patient of sound mind may, if properly informed, require that life support should be discontinued ... Moreover the same principle applies where the *patient's refusal* to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it ...' (para 4.28[1])

TO WHOM THE MODEL FORM APPLY?

The model form states, at its outset, that'I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am *terminally ill or in a persistent vegetative state or a state of irreversible coma*' (clause 1).

At first glance, it appears that the model form applies to three categories of patients. Nevertheless, as I shall explain below, the model form applies to only two categories of patients, as the terms 'PVS' or 'irreversible coma' bear the same meaning.

The model form defines 'terminally ill' to mean those:

> 'suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the month of death'. (This is very similar to the definition given in the Law Reform Commission of Hong Kong Consultation Paper, 'Substitute Decision-Making and Advance Directives in Relation to Medical Treatment' (www.info.gov.hk/hkreform) (July 2004). It stated that terminal illness means 'an incurable condition caused by injury or disease from which there is no reasonable prospect of a temporary or permanent recovery where- (i) death would within reasonable medical judgment be imminent regardless of the application of extraordinary LST; and (ii) the application of LST would only serve to postpone the moment of death.)

Interestingly, the model form does not define the terms 'PVS' or 'a state of irreversible coma'. The Report, however, includes lengthy definitions of the former and it is important to examine it in some detail.

Persistent vegetative state refers to a condition that occurs at the end of a continuum starting with coma. The Report defines this continuum as follows:

> 'Coma is defined as a prolonged state of unconsciousness…When persons experience a brain injury, they can lose consciousness. When the unconscious state is prolonged, it is termed a "coma". A coma is a continued unconscious state that can occur as *part of the natural recovery* for a person who has experienced a severe brain injury…Persons who sustain a severe brain injury and experience coma can *make significant improvements*, but are often left with permanent physical, cognitive or behavioural impairments… The length of a coma cannot be accurately predicted or known.' (para 1.14[1])

The Report also defines a vegetative state as:

> 'A clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which may simulate sleep and waking. This may be *a transient stage in the recovery* from coma or it may persist until death.' (para 1.15[1])

The Report then defines a continuing vegetative state (CVS) as:

> 'When the vegetative state continues for more than four weeks it becomes increasingly *unlikely that the condition is part of a recovery phase* from coma and the diagnosis of a continuing vegetative state can be made.' (para 1.15[1])

Once a vegetative state continues for more than 4 weeks, recovery from a coma becomes increasingly

unlikely; this would typically be considered to be a PVS. The Report defines PVS as:

> 'A patient in a *continuing vegetative state* will enter a permanent vegetative state when the diagnosis of *irreversibility can be established with a high degree of clinical certainty.* It is a diagnosis that is not absolute but based on probabilities. Nevertheless, it may reasonably be made when a patient has been in a continuing vegetative state following head injury for more than 12 months or following other causes of brain damage for more than six months.' (para 1.15[1])

As can be seen from the above definitions, a PVS is the stage at which a coma is regarded to be irreversible. Although a diagnosis of irreversibility can never be certain, it can be done with a 'high degree of certainty'. According to the Report, such a diagnosis can generally be given when a patient has been in a CVS for more than 12 months following head injury, or for more than 6 months following other causes of brain damage.

In light of these definitions, it is submitted that the term in a state of 'irreversible coma' is synonymous with the term in a 'PVS' and they will both be referred to as 'PVS' for the remainder of this paper. This view is supported by the fact that the model form makes it clear that there are two applicable cases: first, 'Case 1 – Terminally ill', and second, 'Case 2 – PVS or a state of irreversible coma'.

What treatment may be refused under the model form?

The model form may be executed by a competent patient over the age of 18 (clause 3). The advance refusal therein may be activated or triggered once such a patient has been diagnosed by two doctors to be terminally ill or in PVS (clause 4), and is unable to participate in decision-making relating to treatment.

> The model form defines LST broadly as:
> 'any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube).'

Basic and palliative care, however, cannot be refused. Although there is no definition of what constitutes basic care, it is well understood to mean nursing care plus non-artificial nutrition and hydration (clause 4).

LEGAL UTILITY

In the event that all the conditions required by the model form have been fulfilled (eg witnessing), and the patient has indicated that no LST be given, a doctor is then bound to follow that instruction.

What utility, if any, does the model form serve? Or, to put it another way: by following a patient's advance refusal in the model form, is a doctor doing anything he or she would not otherwise have been required to do in law?

I propose to examine this question by looking at the two categories of patients separately. First, in relation to a terminally ill patient (eg someone who has reached the advanced cancer stage), the law makes it clear that no medicine that has the ability to shorten life may be administered with the intention of ending life prematurely. Nevertheless, a doctor attending to a dying patient is not under a legal obligation to prolong life; his obligation is to relieve pain and suffering.

Thus, in the English case of *R v Adams*[4] where a doctor was charged with the murder of an 81-year-old stroke patient, it was alleged that the doctor had prescribed and administered such large quantities of morphine that he must have known that the drugs would result in death. In summing up the legal obligation of a doctor attending to the dying (for the jury) Delvin J said:

> 'It did not matter whether Mrs Morrell's death was inevitable and her days were numbered. If her life were cut short by weeks or months it was just as much murder as if it was cut short by years.'

Despite this statement of the law, the judge made

it clear that:

> '... but that did not mean that a doctor who was aiding the sick and dying had to calculate in minutes, or even hours, perhaps, not in days or weeks, the effect on a patient's life of the medicines which he would administer. If the first purpose of medicine – the restoration of health – could no longer be achieved, there was still much for the doctor to do, and he was entitled to do all that was proper and necessary to relieve pain and suffering even if the measures he took might incidentally shorten life by hours or perhaps even longer. The doctor who decided whether or not to administer the drug could not do his job if he were thinking in terms of hours or months of life. The defence in the present case was that the treatment given by Dr Adams was designed to promote comfort, and if it was the right and proper treatment, the fact that it shortened life did not convict him of murder.'[5]

In short, there is no legal obligation to administer LST to a terminally ill patient. Life-sustaining treatment may be lawfully stopped even if there is no written advance refusal. The law only requires a doctor to perform all that is proper and necessary to relieve pain and suffering.

Does the model form add anything to this legal position? Unless it can be shown that doctors routinely provide LST to those who are terminally ill (and in situations where it is unwanted by patients), the fact that a patient has taken the trouble to execute the model form adds nothing to the patient's legal position. However, from a doctor's point of view, the model form serves as evidence documenting the patient's refusal. This may reduce problems arising from unhappy family members.

The second category of patients are those who are in a PVS. As seen from the definition of PVS quoted earlier, when a patient reaches that stage, medically speaking, this is the point of no return. A case that stirred a lot of media attention was the recent Florida Schiavo case. The Report includes an outline of the Schiavo case (para 4.48[1]). Medically and legally, such a patient is alive and is not terminally ill or dying. Such a patient, if given artificial nutrition and hydration, could live for many years. A decision to withhold artificial nutrition and hydration is comparable to starving a hopeless patient to death. Such a decision is thus controversial not only amongst the medical profession but should be a matter of debate for society in general.

From a legal point of view, the law has a role to ensure that there are sufficient safeguards to protect the patient whose life is at stake; by ensuring that there is clear and convincing evidence that the patient's condition has reached a point of no return, and that any medical assessment criteria used are applied consistently and with the highest degree of care. These safeguards are also needed for the family and the medical profession against charges that, for instance, withholding artificial nutrition and hydration has been done to reduce medical costs.

Where PVS patients have left no advance refusal, the common law already provides a stringent legal mechanism for protecting them. In *Airedale NHS Trust v Bland*,[6] an English House of Lords' decision in 1993 (hereafter *Bland*), the House of Lords held that it would be lawful to withhold artificial nutrition and hydration from a PVS patient who obtains no benefit from them (medical futility). Although the Report cites this case, it does not make it clear that the House of Lords was not prepared to allow such an important and controversial issue to be left with the doctors (on the basis of 'doctors know best'), their family members or guardians (as Bland left no advance refusal to artificial nutrition and hydration). The House of Lords made it clear that in the interest of protecting patients, doctors, patients' families and the public, until a body of experience and practice has been built up, application should be made to the court *in every case*[7] (by way of a judicial declaration). Additionally, the House of Lords emphasised the importance of professional guidelines in 'a matter of such importance and sensitivity as discontinuance of life support'. Lord Goff, referring to the discussion paper 'Treatment of Patients in Persistent Vegetative State' issued by the British Medical Association in 1992,[8] said:

> 'Anybody reading this substantial paper will discover for himself the great care with which this topic is being considered by the profession. Mr. Francis, for the respondents, drew to the attention of the Appellate Committee *four safeguards in particular which, in the committee's opinion, should be observed before discontinuing life support* for such patients. They are: (1) every effort should be made at rehabilitation for at least six months after

the injury; (2) the diagnosis of irreversible P.V.S. should not be considered confirmed until at least 12 months after the injury, with the effect that any decision to withhold life-prolonging treatment will be delayed for that period; (3) the diagnosis should be agreed by two other independent doctors; and (4) generally, the wishes of the patient's immediate family will be given great weight.'[9]

As far as I am aware, no case has come before the Hong Kong courts seeking a judicial declaration on the withdrawal of artificial nutrition and hydration of a PVS patient. However, doctors practising in this area may wish to enlighten the public about how these cases are dealt with and whether the professional guidelines quoted above apply in Hong Kong.

Where a PVS patient has signed the model form (refusing artificial nutrition and hydration), the question is whether an application to the court is still needed prior to a lawful withdrawal of artificial nutrition and hydration. Although the decision in *Bland* was based on the fact that Bland left no valid advance refusal, where there is an advance refusal, arguably a judicial declaration is not needed. I submit that this, however, is an unrealistic scenario. The reason is simply this; that most PVS cases involve young persons or adults with severe brain injury, it is unlikely that they have signed an advance refusal. If such a case were to arise, it is submitted that an application to the court should not be required for the following reasons. First, the purpose of the application is to ensure that the treatment is indeed futile (and therefore not in the best interests of the patient). Here futility is linked with two inter-related concerns: sanctity of life and the best interests of the patient. Where the use of artificial nutrition and hydration is likely to provide the patient with a possibility of recovery, removal would clearly be against the principle of sanctity of life and against the best interests of the patient. Where a diagnosis of PVS is not doubted, the patient's clear wishes override what a judicial declaration aims to protect. This is because the principle of the sanctity of life may be overridden by self-determination. However, judicial declaration remains necessary where there are questions as to the validity of the diagnosis or the advance refusal.[10]

What is important to note is that the instruction in the model form (refusing LST) is operative only if the patient is diagnosed as being in PVS. If the professional guidelines quoted above apply in Hong Kong, then they are similar to the Report's own definition of PVS (that is, the diagnosis of an irreversible PVS should not be considered confirmed until at least 12 months after a head injury, or 6 months following other causes of brain damage) with the effect that any decision to withhold life-prolonging treatment will be delayed for that period. Once a diagnosis has been made, the model form allows the doctor to withdraw LST, arguably bypassing the need for a judicial declaration.

CONCLUSION

I have shown that in the case of the terminally ill, the model form is likely to serve little legal purpose. In the case of the PVS, the use of the model form, which is likely to be most rare, will raise legal questions that the Law Reform Commission may wish to address in due course.

Nonetheless, I believe that the current discussion on the use of advance refusal is productive. It heightens general awareness of the issues relating to end-of-life treatment and the futility of certain LST. It has also provided a meaningful platform for medical practitioners to consider how their practice may change via advance care planning[11] in catering to the needs of their patients.

Looking ahead, it is unclear how many people will use the model form. Although the Report rejects giving advance refusal legislative status for the time being, this is an area that requires continuous study and review. As the Report states:

'We have duly considered the view of the majority of respondents [to our Consultation paper] that the promotion of the concept of advance directives by non-legislative means should be an interim measure. We agree with this approach and suggest that the position *should be reviewed by the Government* in due course once the community is more generally familiar with the concept of advance directives.' (para 8.40[1])

References

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4. [1957] Crim.L.R. 365.
5. [1957] Crim.L.R. 365, p.375-6.
6. [1993] 2 WLR 316.
7. *Ibid, per* Lord Keith, p.363.
8. General Medical Council. *Withholding and withdrawing life-prolonging treatments: good practice in decision-making* (www.gmc-uk.org/guidance/library); British Medical Association. *Treatment decisions for patients in persistent vegetative state* (www.bma.org.uk). Accessed on 17 Nov 2006.
9. [1993] 2 WLR 316 at p373 *per* Lord Goff, author's emphasis.
10. para 4.40; similarly if the dispute is about a person's competence to make a valid advance refusal, *see* para 4.43.
11. Au D. Advance directive: how clinical practice may change. Hong Kong Geriatrics Society Annual Scientific Meeting, 16 Jun 2007.

Appendix
With pemission from *Hong Kong Lawyer*

Annex 1

Proposed model form of advance directive

ADVANCE DIRECTIVE

Section I : Personal details of the maker of this advance directive

Name : (Note: Please use capital letters)

Identity document No.:

Sex : Male / Female

Date of birth : ____/____/____ (Day) (Month) (Year)

Home Address :

Home Telephone No. :

Office Telephone No. :

Mobile Telephone No. :

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.
2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.

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3. I, _____ *(please print name)* being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.

4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my wishes in relation to my medical care and treatment are as follows :

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

(A) ***Case 1 – Terminally ill***

(Note: In this instruction -

"terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

I do not want to be given the following treatment:

☐

☐

(B) ***Case 2 – Persistent vegetative state or a state of irreversible coma***

(Note: In this instruction -

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

I do not want to be given the following treatment:

☐

☐

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under :

(i) my will; or
(ii) any policy of insurance held by me; or
(iii) any other instrument made by me or on my behalf.

_____ _____
Signature of the maker of this advance directive **Date**

Section III : *Witnesses*

Notes for witness *:*

A witness must be a person who is not a beneficiary under –

(i) the will of the maker of this advance directive; or
(ii) any policy of insurance held by the maker of this advance directive; or
(iii) any other instrument made by or on behalf of the maker of this advance directive.

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

(1) I, _____ *(please print name)* sign below as witness.

(a) as far as I know, the maker of this directive has made the directive voluntarily; and

(b) I have explained to the maker of this directive the nature and implications of making this directive.

(2) I declare that this directive is made and signed in my presence together with the second witness named below.

_____ _____
(Signature of 1st witness) **(Date)**

Name :

Identity document No. / Medical Council Registration No.

Office address :

Office Tel. No. :

Second witness

(Note: This witness must be at least 18 years of age)

(1) I, _____ *(please print name)* sign below as a witness.

(2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

_____ _____
(Signature of 2nd witness) **(Date)**

Name :

Identity document No. :

Home address / Contact address :

Home Tel. No. / Contact No. :