The Australian experience of advance directives and possible future directions

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This paper analyses the role that advance directives can play in the formation of advanced care planning. Following on from a review of the legal history of advance directives in Australia, including the common law and statutory regimes, it is argued that schemes for advance directives have not yet proven to be successful. It is proposed that what is needed is a more integrated approach, whereby advance directives are but one mechanism used in a wider concept of advanced care planning. This integrated approach should employ a variety of mechanisms including proxy decision-making, structured concepts of best interests and clearly defined dispute resolution processes.

Introduction

In Australian common law, a patient has the right to control his or her body. This right of self-determination includes a power to make treatment decisions in advance, so that patients’ decisions remain binding after they have lost mental capacity. These decisions about treatment are referred to as ‘living wills’, or, more commonly, ‘advance directives’. Advance directives usually record decisions about life-sustaining treatments, but they can also contain the patient’s preferences and desires about a whole range of treatment matters. In Australia, the right to make an advance directive is enshrined in legislation in most states and territories as detailed below [1].

To date, the rights to make advance directives have not been extensively exercised in Australia. The evidence from Australia, and from other jurisdictions, is that the legal recognition of advance directives does not automatically mean that they are widely understood or employed by patients, or by legal and health professionals. Nevertheless, advance directives have the potential to be very useful tools, particularly given the ageing of the population and the increasing frequency of highly invasive life-sustaining treatments at the end of life.

This article describes the legal basis of advance directives, at common law and under the various pieces of legislation across Australia. It reviews the current use of advance directives and argues that there may be barriers to advance directives being used effectively in Australia. The article concludes with some discussion of future directions and argues that the way forward is not to rely solely on advance directives but to see them as one tool in a range of techniques that are available in advance care planning.

Advance directives at common law

The right to refuse medical treatment is an extension of the right of all persons to control their bodies. This right is a fundamental common law concept reflected in all common law jurisdictions, like Australia, England and Wales, New Zealand, Canada and the United States [1].

Advance directives are one way that a person’s decision to refuse treatment can be exercised. There has been no clear statement from higher courts in Australia about the requirements for making an advance directive at common law. However, the Australian High Court has strongly endorsed the right to control one’s body and the common law principles from other jurisdictions, particularly the United Kingdom, are likely to be adopted in Australia [2]. Three case examples are contained in Box 1.

There is no single approved method of making an advance directive at common law. Rather, the lessons from other jurisdictions show us that there are three main issues to consider at common law when examining the validity of an advance directive [1,2]. They are:

1. Was the patient competent when they made their directive?

   The person must have been mentally competent at the time the decision was made. In Australia most jurisdictions presume that everyone over the age of 16 years is competent to make medical treatment decisions. Therefore, if a patient has made an advance directive when an adult the law presumes that the patient was competent at the time they made the directive [4,5].

   That presumption can be rebutted by evidence showing that patient was not competent when the directive was made. In Australia the test for capacity which is used is the functional competency test, which is based on whether the patient could understand the nature and effects of the treatment being offered, and then weigh those issues together to communicate a decision [5].

2. Was the directive intended to apply in the current situation?

   The issue here is whether the directive should be applied in the current set of circumstances. People considering the applicability of a directive need to look at how the directive was expressed, the language that was used and the seriousness of the decision-maker. Oral directives might be harder to judge in this context...
Statutory recognition of advance directives in Australia (‘statutory directives’)

Queensland [6], South Australia [7], Victoria [8], the ACT [9] and the Northern Territory [10] have legislation which create schemes for advance directives. Interestingly, these statutes preserve common law rights to refuse treatment and work as parallel schemes. This means that a person is able to create an advance directive at common law in these jurisdictions, in addition to being able to create them according to the legislation (although see Qumsieh’s case in Box 1). New South Wales, Tasmania and Western Australia are without legislation in this area and rely on common law.

Who can make a statutory directive?

Statutory directives can be made by people over the age of 18. They can be made orally or in writing, except in South Australia where they must be solely in writing. Directives to refuse treatment can relate to refusal of treatment generally, or of a particular kind of treatment. However, in some jurisdictions like Victoria, a patient is not able to refuse palliative care using a directive, but may of course do so at common law if the common law has been preserved [1,8].

What types of treatment can be refused?

In Victoria the patient can only refuse treatment which is related to a ‘current condition’ [8]. Unfortunately the meaning of ‘current condition’ is not defined, but presumably it relates to treatment for a medical condition which is being suffered by the patient at the time the directive is completed. This means that these statutory directives are not available to people who would refuse treatment for conditions which they have not yet suffered, for example, strokes, or physical injuries which

than written ones. Obviously, the clearer the language, the easier it will be to judge its applicability. Conversely, directives which use vague expressions, or refer to outdated medical treatments are less likely to be useful [1].

3. Was the patient unduly influenced or pressured into making the directive?

As the Re T case in Box 1 illustrates, the decision to refuse treatment must be free from the undue influence of others. Undue influence may impair the decision-making process of the person and invalidate the decision. As discussed above, when determining whether the influence of a person over a patient was undue, one must look at the strength of will of the patient and the relationship of the patient with the person trying to persuade them to make the directive [3].

Box 1: Three cases of common law advance directives

In Malette v Schulman (1990) 67 DLR (4th) 321, an unconscious woman was rushed into an emergency department after a car accident. The doctor discovered a card on the woman which stated that she was a Jehovah’s Witness and was not to be given blood under any circumstances. The doctor decided to provide blood because he had not had a chance to discuss the issue with the woman. Nevertheless, a court found that the blood transfusion had been given wrongfully. The judge said that a doctor was not free to disregard a patient’s advance instructions any more than he would be free to disregard instructions given at the time of the emergency. The card was a valid advance directive [2].

In the English case Re T (An Adult) (Consent to Medical Treatment) [1992] 2 Fam458, a woman who was not a Jehovah’s Witness had given conflicting messages about whether she consented to a blood transfusion. She finally said ‘no’ and then became unconscious. The patient’s mother was a Jehovah’s Witness and had been exerting considerable pressure on the patient to refuse blood. The Court of Appeal of England and Wales said that the patient had a right to make an advance directive about blood but that the decision had to be the patient’s and not a third party’s. To that extent the court could examine the pressure which had been brought to bear on the patient by her mother. Given the fact that the patient’s mind was weak from pain and drugs, and that the mother’s influence was very strong, the decision to refuse blood products was not truly the patient’s decision and blood could be administered [3].

Qumsieh v Guardianship and Administration Board (1998) 14 VAR 46 – In this case a female Jehovah’s Witness had made a common law advance directive prior to giving birth in which she outlined her objection to blood products. She also had the hospital make notes of her objections. She haemorrhaged after giving birth and lapsed into unconsciousness. The hospital convinced her husband to ignore her wishes and both parties approached the Guardianship Board (now the Victorian Civil and Administration Tribunal) to have the husband appointed guardian for the purpose of giving consent to the transfusion. The Board was not told of the woman’s advance directive. After recovering the woman sought judicial review of the decision to appoint a guardian. The trial judge dismissed the application and did not give reasons. She appealed that decision to the Victorian Court of Appeal. Again the woman’s claims were dismissed. It was said that the issue was now moot and that the Court should not encourage further disagreement between the woman and her husband. Special leave to appeal to the High Court was denied [2].

sustain blood loss. This is quite a severe limitation on the scope of statutory directives.

In the Northern Territory, the direction can be made at any time but only becomes effective when the patient is suffering from a ‘terminal illness’, which is defined as an illness, injury or degeneration of mental or physical faculties –

(a) that death would, if extraordinary measures were not undertaken, be imminent; and

(b) from which there is no reasonable prospect of a temporary or permanent recovery, even if extraordinary measures were taken [10].

South Australia has similar restrictions to the Northern Territory. The direction only becomes operative when the patient is in a terminal phase of a terminal illness, and is no longer competent [7].

In Queensland the directive generally becomes effective on incapacity but a direction to withhold life-sustaining treatment will not operate unless:

(a) the principal is terminally ill and is not expected to live more than a year, or is in a persistent vegetative state, or is permanently unconscious, or has a severe illness with no reasonable prospect of being able to live without the continued application of life-sustaining measures; and

(b) (if the direction concerns artificial hydration or nutrition) the life sustaining measure would be contrary to good medical practice;

(c) and the patient has no reasonable prospect of regaining capacity for health matters [6].

What form must the directive take?

All statutory directives have a prescribed form which varies across the jurisdictions. In Victoria the form is referred to as a ‘refusal of treatment certificate’. In Queensland it is called an ‘advance health directive’ and in the ACT and South Australia statutory directives are called ‘directions.’ They must be signed, but if the patient is unable to do so, some Acts allow for another person to sign in the presence of the patient at their direction.

Written directives must be witnessed. Some statutes require one or two witnesses to the directive, neither of whom needs to be medically qualified [9,10]. In the Territories directives must be witnessed by both a registered medical practitioner and an ‘other person’ who need not be a medical practitioner [8]. In Victoria, both witnesses must sign the certificate and be satisfied that:

(a) the patient was of sound mind and was 18 years of age or over when they made the decision;

(b) the decision is voluntary and made without inducement or compulsion;

(c) the patient was informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about a particular treatment or medical treatment generally;

(d) and the patient appeared to understand the information about the medical treatment [8].

Queensland requires the witness and a doctor to certify that the patient had the capacity to make the decision at the time it was made [6].

Some scheduled certificates provide a space for the patient to sign the certificate but they do not have to sign it in all jurisdictions for it to be valid [8]. Some forms also require the witnessing medical practitioner to give details of the current condition [8].

If a directive is made by means other than writing, some statutes require that it be witnessed by two health professionals [9].

How can a directive be cancelled?

In most jurisdictions, a patient can cancel a directive, whether made orally or in writing, by clearly expressing or indicating their wish to a registered medical practitioner or another person. Space is provided on some certificates for the patient to record their wish for the directive to be cancelled. However, it is not necessary for them to do so. In Queensland, where directives can only be made in writing, the ‘principal’ (i.e. the patient) can only revoke the directive in writing [6].

In some statutes, a directive will cease to operate if the medical condition of the patient changes to such an extent that it no longer reflects the condition recorded in the directive [9].

Are doctors bound to follow a statutory directive?

Some statutes state that the doctor is not bound to honour the directive if he or she is in doubt about whether the directive complies with the statute or whether it had been revoked, or whether the patient had in any way changed his or her decision regarding the directive. In Queensland, the health provider may act inconsistently with a directive if the directive is uncertain, contrary to good medical practice or if circumstances have changed to the extent that the direction is inappropriate [6].

Apart from these situations, a directive must be respected even if the doctor believes that treatment is in the patient’s best interests and that treatment should be given as part of the doctor’s duty to take reasonable care. To treat in the face of a valid directive is to commit an assault in criminal law and a battery in tort law [11]. Under the Victorian statute, a doctor who treats a patient despite a valid certificate commits the offence of ‘medical trespass’ [8].

Generally, health professionals are granted immunity from civil claims, criminal charges or professional misconduct.
proceedings in cases where they follow advance directives, and can demonstrate that they have acted in good faith, on reasonable grounds and without negligence. Criminal and civil liability is also effectively abrogated in some jurisdictions by sections which state that the withdrawal or withholding of treatment in accordance with a statute is not the cause of death.

The use of advance directives in Australia
There has been little research into the use of advance directives in Australia, but what evidence we have shows that advance directives are not generally known about, understood or commonly employed. In their survey of residential care facilities in the Hunter region, Nair et al. found that only 0.2% of residents had formal advance directives [12].

The evidence from Victoria is similar. In a study of 403 emergency department patients with a mean age of 73, Taylor et al. found that 7.9% of patient had an advance directive, while 82.6% of patients surveyed thought they were a good idea [13]. It is also worth noting that Taylor's definition of 'advance directive' includes other forms of surrogate decision-making such as medical powers of attorney and enduring guardianship so the figures for advance directives (as defined above) may be lower again (see below for discussion of surrogate decision-making).

In Queensland, which has the most recently acquired legislative scheme, Cartwright et al. found that a high proportion (> 73%) of the health professionals surveyed, including doctors, nurses and social workers, had heard of advance directives, but only 25% of community members had even heard of them. Fewer than half of all the groups surveyed knew that the directives were accepted at law; such knowledge was reported by 48% of doctors, 35% of nurses, 45% of social workers and only 10% of community members. Not surprisingly, this study also found that all groups said that lack of knowledge about advance directives was a major barrier to their adoption [14].

Research from the United States shows that lack of information is not the only problem: health care professionals may also be resistant to patient choices, particularly in acute settings. The US Federal Patient Self Determination Act 1990 required health care institutions to provide written information to each patient which outlined their rights to make advance directives and yet it has manifestly failed to raise the level of knowledge of or support for advance directives in health professionals [15].

Similarly, the famously well funded SUPPORT trial (Study to Understand Prognosis and Risks of Treatment) was also a failure. SUPPORT sought to improve end-of-life decision-making and reduce the frequency of prolonged dying caused by mechanical intervention by increasing the level of patient–family involvement in decision-making. Nurse facilitators were used to provide advice and information as well as document patient and family preferences. At the end of five years, there was no noticeable improvement in the control of patients over their treatment [16].

The experience of the Patient Self-Determination Act and the SUPPORT trial highlight the importance of cultural change in the health professions to the success of advance directives.

Advance directives as part of a wider culture of advance care planning
Further research is needed in Australia to determine whether advance directives can become a more useful mechanism for communicating patient choices. It may be that even with large scale educational programs, only a small percentage of patients will employ an advance directive, such as patients with chronic conditions, or those with specific religious objections to types of treatments. If that is the case it might be argued, as it has by some in the United States, that advance directives have proven to be a waste of time and resources [17].

Nevertheless, there are good reasons to be interested in advance directives, even in the face of such criticism. First, the fact that most people have not made an advance directive does not mean that they do not want the right to make one. Many of the important civil rights in Australia are never exercised by the majority of the population but they are fundamental rights which Australians expect to have access to if needed, for example, rights to trial, rights to freedom of movement and rights to protest. The right to make an advance directive is also a fundamental right and for that reason it is worthy of our respect.

Second, regimes which merely create forms of advance directive will fail to improve the correspondence of patients’ preferences with the treatment they actually receive. Creating a legal structure for advance directives is only the first step in making advance directives useful tools for patients and health professionals. What is needed in addition to a legal structure is a culture of advance care planning, where patients and health professionals ‘engage in a process of reflection, discussion and communication of treatment preferences for end-of-life care that proceeds, and may lead to, an advance directive’ [18].

Finally, if a wider culture of advance care planning is the ultimate goal, it needs to be emphasised that advance directives are only one legal tool for end-of-life decision-making. Equally important, and perhaps potentially more popular with patients, are legal regimes for surrogate decision-making. At present most States and Territories allow for the patient to appoint an enduring attorney or guardian for health care matters and in some States, such as NSW, the appointment document can refer to the patient’s preferences about treatment [19]. Additionally, relatives and carers of patients in some jurisdictions have rights to consent to treatment as ‘persons responsible’ or as ‘statutory health attorneys’. These methods of surrogate decision-making are equally as important as advance directives in end-of-life decision-making but again it must be emphasised that the potential of these legal tools will never be realised unless a culture of advance care planning is fostered and takes root.
References
7. Consent to Medical Treatment and Palliative Care Act 1995 (SA).