

Review

Ethics review: 'Living wills' and intensive care – an overview of the American experience

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Abstract

Withdrawal and limitation of life support in the intensive care unit is common, although how this decision is reached can be varied and arbitrary. Inevitably, the patient is unable to participate in this discussion because their capacity is limited by the nature of the illness and the effects of its treatment. Physicians often discuss these decisions with relatives in an attempt to respect the patient's wishes despite evidence suggesting that the relatives may not correctly reflect the patient's desires. Advance decisions, commonly known as 'living wills', have been proposed as a way of facilitating the maintenance of an individual's autonomy when they become incapacitated. Others have argued that legalising advance decisions is euthanasia by the back door. In October 2007 in England and Wales, advance decisions will become legally binding as part of the 2005 Mental Capacity Act. This has been the case in the USA for many years. The purpose of the present review is to examine the published literature regarding the effect of advance decisions in relation to the provision of adult critical care.

Introduction

Autonomy, competence and capacity are limited by the nature of the critical illness, or by the effects of treatment. Withdrawing life-support in the intensive care unit (ICU) is common and is often made without the direct involvement of the patient, whose preferences regarding end-of-life treatment are usually unknown [1,2]. Physicians therefore frequently consult relatives regarding the appropriateness of treatment intervention, despite data suggesting that the consulted relatives find this emotionally stressful and do not consistently make decisions that accurately reflect their relative's wishes [3,4].

Advance decisions (ADs), commonly known as 'living wills', have been proposed as a way of facilitating the maintenance of a patient's autonomy if they become incapacitated in the future. In October 2007 in England and Wales, ADs will become legally binding as part of the 2005 Mental Capacity Act. This has been the case in the USA for over 20 years [5].

The 2005 Mental Capacity Act allows a competent person aged over 18 to make an AD that pre-emptively states their treatment preferences or to appoint a lasting power of attorney (LPA) to make decisions for them, if they become incapacitated. There is no set format for an AD (it can be written or verbal) unless it is specifically pertaining to refusing life-sustaining treatment, where it must be written and counter-signed. There is no obligation to seek advice from medical professionals when drawing up an AD, and it can be revoked verbally. If valid to the clinical scenario, an AD will override a LPA if one exists. The LPA must act in the patient's best interests, must be registered with the Office of Public Guardian, and the document must be structured in a statutory form that is counter-signed by an independent third party. The LPA can refuse life-sustaining treatment if it is explicitly stated in the patient's draft, is counter-signed and is deemed to be compatible with the patient's 'best interests'. Where disagreement exists between the attending physicians and either the AD or the LPA regarding their validity to the clinical situation, the Court of Protection can arbitrate [6]. Complying with the patient's preferences will in part depend on the difficult 'diagnosis' of futility and the relevance of the clinical scenario to the AD.

The purpose of the present review is to examine the effects ADs have had for critically ill adults. A MedLine and PubMed search was performed using the search terms 'intensive care', 'advance decisions', 'living wills' and 'surrogates'. Appropriate referenced articles were also included. The bulk of the reviewed literature pertaining to ADs has come from American studies unless specifically stated.

Quality-of-life judgements and advance decisions

The decision to limit therapy in the ICU can be varied depending on the beliefs and local practice variations of the

AD = advance decision; ICU = intensive care unit; LPA = lasting power of attorney; QOL = quality of life.

attending intensivists [7]. Withdrawal is often based on futility or on the perceived prospect that if the patient did survive, it would be with a significantly reduced quality of life (QOL) [1,7]. Determining futility is heavily dependent on determining the outcome, but the likelihood of general nonsurvivability from a critical illness is not an objective or precise tool [8]. There is no perfect measure of QOL [9], and neither is there a correlation between the severity of illness and the health-related QOL at 6 months: the QOL is not predictable from the clinical information at the time of the acute illness [10]. Finally, despite a reduced functional ability after discharge, the majority of survivors were happy with their QOL and would undergo intensive care again, especially the elderly [10-17]. Establishing the appropriateness of ongoing ICU care based in part on issues such as the resulting QOL may therefore become more similar to the patient's wishes if they have given their reasons for refusing certain medical interventions.

Unfortunately, there is very little clinical evidence to suggest that ADs improve decision-making. One study of patients and doctors given clinical scenarios with and without the presence of an AD suggested that ADs made the physician's decision more compatible with that of the patient [18]. The SUPPORT study of 9,105 seriously ill patients, however, found the AD was associated only with insignificant trends towards improvement in the provision of resuscitation [19]. In the same study, 60% of surrogates stated that the AD helped only a little or not at all for patients who had an AD and died. These findings may be influenced by the fact that, of the patients with an AD, only 12% completed it with physician involvement, and only 25% of physicians were aware that the patient had an AD. There is also no requirement for the individual to state their reasons for refusing a medical intervention, which may explain why ADs have been shown to increase conflict between family members and attending physicians [20]. This conflict can be related to the different interpretations that different relatives and physicians have of the patient's AD and the progress and prognosis of the acute illness. Finally, relatives cannot be relied upon to introduce the AD at the onset of a critical illness: sometimes they have used the AD to initiate less invasive support early on and sometimes the AD has not been made known at all [21].

Cost of intensive care provision and advance decisions

Intensive care is an expensive and limited resource, consuming up to 20% of the entire hospital budget and 1% of the nation's gross domestic product [22]. Overall, 25% of patients that require intensive care die while in the ICU [23]. This is in part due to the aging population, because intensive care is being offered to an older and more unwell group of patients [24]. Patients aged over 65 account for 64.9% of all cases of sepsis and for greater than 50% of the ICU bed occupancy [25,26]. The World Bank population statistics have shown that the over-65 age group has increased

dramatically while the proportion of the older population who remain employed has reduced [27]. In America, the number of patients aged over 85 has increased by 38% from 1990 to 2000 [28].

If elderly patients with a potential critical illness are questioned about end-of-life decisions, up to 41% choose to limit certain life-sustaining therapies including cardiopulmonary resuscitation, ventilation and ICU admission [29,30]. Potentially because of this, the majority of studies analysing the financial effect of ADs have shown reduced expenditure [31]. In one study, the average cost of end-of-life care in a university hospital was reduced from \$95,000 to \$30,000 [32]. These savings were due to shorter durations of ICU stay and hospital stay rather than due to patients with ADs being provided less ICU therapies [33]. Indeed, these patients received the same number or more interventions than those patients without an AD [2,33-36]. One interpretation of this observation is that patients with an AD are receiving full and active treatment but, once it becomes 'futile', treatment is stopped more quickly out of respect for the patient's wishes. Anecdotally, it is easier to withdraw treatment when the family and staff are in agreement that this is what the patient would have wanted.

Incidence of advance decisions in the intensive care unit

ADs have existed in the USA for more than 20 years but the number of people who actually have a written AD remains small [5]. The number of ADs in patients with unanticipated critical illness is especially limited, with only 5–11% of patients having an AD [34,37-39]. In a separate American study of patients with relapsed haematological malignancy, the percentage of patients with an AD only rose to 32% despite the patient having had more time than most people to consider their own mortality and the possibility of requiring critical care [33]. It can therefore be assumed that the number of ADs in those patients with a sudden unexpected, critical illness will be very limited in England and Wales for many years past 2007.

How will the lasting power of attorney be assessed?

The predetermined LPA or surrogate can make decisions on an incompetent patient's behalf that can include the ability to refuse life-sustaining treatment if the document appointing the LPA explicitly acknowledges this. Because the 2005 Mental Capacity Act is statutory law, it will become a criminal offence to ignore the AD or the LPA. This leaves the potential for the physician to be found guilty of the offence of 'Battery' if they do not comply.

The SUPPORT study and the HELP study of elderly and acutely ill inpatients found that, of 1,041 patients who had expressed a clear preference regarding resuscitation, more than 70% said that if they did become incapacitated they

would want the family and physician to make the resuscitation decisions rather than having their own AD followed [40]. Yet the level of agreement between the surrogate's decision and the patient's preference in real and hypothetical seriously ill scenarios was only 68% in a meta-analysis of 16 studies analysing this outcome [41]. To highlight this observation, in an Australian study 83% of patients did not want invasive treatment and 76% of the surrogates agreed invasive treatment was inappropriate, but all surrogates initiated it [42]. Finally, discussing the advance decision with the surrogate and the patient does not improve the surrogate's accuracy. In a study of 717 seriously ill patients and their surrogates, 54% were assigned to the intervention group, which included discussions regarding the prognosis, treatment, resuscitation and ADs, but there was no significant improvement in decision-making on reassessment [43]. These statistics lend weight to the value and importance placed on a surrogate by the patient, but questions their accuracy and detracts from the value of the AD in the first place.

There are other significant practical problems regarding how the LPA will be involved in the decision-making process in the ICU. How much needs to be discussed and documented: routine therapy such as fluids or only the more invasive medical procedures? Secondly, the LPA is expected to make decisions in the best interests of the patient. How will their decision-making abilities and decisions be judged to be in the best interests of the patient? In America, if there is doubt or disagreement between staff and the LPA, a second opinion is recommended, followed by an ethics consultation, culminating with legal advice if still unresolved [44]. A similar process including an Independent Mental Capacity Advisor and the Court of Protection will occur in England and Wales.

Interpreting advance decisions in the intensive care unit

The majority of ADs that have been encountered in the intensive care setting are general in nature regarding the limitation of treatment, rather than specific to a particular critical illness [45,46]. The acutely ill patient in critical care does not always have a specific diagnosis initially, which leads to uncertainties regarding the appropriate treatment, its probable efficacy and the prognosis. These factors will combine to significantly increase the difficulty as regards when the AD should be implemented, its true applicability to the clinical situation and how it is interpreted.

Following an AD and withholding treatment may not always appear to be in the person's 'best interests'. A patient's AD, however, needs only conform to their values rather than their 'best medical interests' – the Jehovah's Witness being the classic example. Ignoring the AD because it is thought the reasoning behind it was poor is potentially risky: 'professionals should start from the assumption that a person who has made an AD had capacity to make it' [6].

In a previous case brought before the English Courts in 1994, irrational thought did not equal incompetence when refusing treatment [47]. The case involved a schizophrenic man who was refusing to have his gangrenous toe amputated because he did not consider life without his toe acceptable. The attending surgeons tried to argue that this was irrational, and therefore the patient lacked competence, and were seeking permission to proceed with the amputation. The courts ruled in the patient's favour, however, because he fulfilled the requirements of competence: he had been given and retained the information, he understood and believed the gravity of his decision, and he evaluated the information in relation to his self. It can be seen that a great concern with the AD is not the AD itself, but that it becomes medico-legally easier to follow the AD rather than to strive to keep the patient alive.

Suicide, intensive care and advance decisions

The 2005 Mental Capacity Act expressly rejects an AD that is drawn up to facilitate suicide. A young person completing an AD and subsequently taking a paracetamol overdose to ensure active treatment is withheld is therefore not legally binding: this would be euthanasia by omission because death is the intended outcome and not providing treatment facilitates this outcome.

For many people, however, there are situations where one's own life would not be deemed worthwhile because one's resultant QOL would fall below their own subjective threshold of acceptability. Although made autonomously, it has been said that to knowingly refuse certain treatment because of the probable residual QOL, with the inevitable consequence being death, is morally no different to the decision to actively end one's life because of one's QOL [48]. It is argued that this legalises euthanasia by the back door: 'pre-emptive euthanasia by omission'. The morally correct action of limiting life-sustaining treatment depends on futility and burden. Senior Catholic ethicists have gone as far as to state that self-destructive choices do not necessarily warrant respect: the choices made 'have to be consistent with the fundamental dignity of both the chooser and others' [48]. The counter argument to this is that, because death is not the intended outcome, an AD is not euthanasia by omission: a treatment that provides/maintains an acceptable QOL is wanted, and if therapy cannot achieve this then it is refused.

Conclusion

The present review has shown that there is very little evidence regarding the effect that ADs actually have on the treatment of acutely ill patients in the ICU. The potential benefit of an AD in the ICU includes that it will probably reduce the cost of ICU care, and this will not be secondary to a restriction of therapy offered. The review suggests the AD will not invariably produce treatment that is consistent with the patient's wishes, however, and therefore it cannot be assumed to always facilitate harmonious decision-making at the end of life or to maintain an incapacitated patient's

autonomy. The present review also highlights the problem of how different people interpret and use an AD, and introduces the difficulty of where an AD should be kept if relatives cannot always be relied upon to make them available. A great concern is that it may become easier to follow an AD that will be very unlikely to result in legal action. It will be the far bolder physician who is prepared to interpret and ignore an AD.

Competing interests

The author declares that they have no competing interests.

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