REVIEW ARTICLE

THE ADVANCE DIRECTIVE - A REVIEW

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ABSTRACT

The advance directive is a document that enables a competent individual to specify the form of health care he would like to have, in the event that he is unable to make such decisions in the future. This review paper traces the development of the advance directive from 1967, when it was first proposed by Luis Kutner.

The Karen Ann Quinlan case and the Nancy Cruzan case are cited as examples of the case for the advance directive. The argument is that advance directives assist doctors, patients, family members and other carers with the increasingly complex health care decision making. Reservations have been expressed about the anticipatory nature of the decision, possible conflict with personal and religious ethics and the risk of cost containment considerations being over-riding concerns.

The advance directive in America has undergone changes since the California Natural Death Act 1976 was passed. In the 1980s, "terminal" included permanent unconsciousness and advanced dementia. The declarant was also given a wider choice of treatment procedures that they wish to be withheld. Proxy directives were also introduced. In the 1990s, the declarant is even allowed to request the use of life-prolonging procedures. When appropriately implemented, the advance directive can perform its intended functions of clarifying the patient's perspective on life, death and medical care. When it is vague in terminology or applied to patients with uncertain prognoses, it can cause confusion to the patient's carers; and when improperly used, it can become an instrument not of patient's preferences, but of economic purpose, family bias, or physician's values.

Keywords: advance directive, review

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INTRODUCTION

The advance directive is a document that enables a competent individual to specify the form of health care he or she would like to have, in the event that he or she is unable to make such decisions in the future[1]. This document comes into effect when the person who made it (the 'declarant') no longer has the mental capacity to decide on or communicate a treatment decision, usually due to being in the terminal phase of an illness, or being permanently unconscious[2]. It usually specifies that any medical or surgical procedures that are intended to sustain life or to prolong the process of dying should be withheld or withdrawn. Less commonly, the advance directive may state that the declarant wishes to be kept alive for as long as possible[3,4]. Physicians looking after such a patient are then legally bound to act in such ways as instructed by conditions laid down in the documents.

There are two kinds of advance directives. The first are 'instruction directives', or 'instructional directives for end-of-life care', commonly known as 'living wills'. Various other names have been used in the literature, and these include 'medical directives'[5] and 'values histories'[6]. All these detail patients' preferences regarding future treatment decisions.

The second kind of advance directives are 'proxy directives', sometimes known as 'durable powers of attorney for health care', 'health care proxies', 'medical powers of attorney', or 'living will designates'. In these documents, designated individuals are appointed to act on behalf of the declarants, ie to serve as proxy decision makers, in the event of the declarants' incapacity. Such individuals are variously called 'the attorneys', 'the agents', 'the surrogates' or 'the proxies'[7].

Living wills (as opposed to proxy directives) are most appropriate for those persons who do not have someone they can trust [8]. Proxy directives can be used by those who do not want the family members to become their automatic surrogates.

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HISTORICAL DEVELOPMENT OF THE ADVANCE DIRECTIVE

The United States of America

The concept of advance directives originated in the United States of America, from 'the right to die' movement. It was Luis Kutner who first proposed the idea at a meeting of the Euthanasia Society of America in 1967. The term 'living will ' was coined by him in 1969. It is a 'will' because it spells out a person's directions, yet it is 'living' because it takes effect before death[7], though the execution of this 'will' usually hastens death.

The Euthanasia Society took up this proposal in 1969, in preference to advocating active euthanasia, to protect the rights of the terminally ill. The form of the instruction was devised by the Euthanasia Educational Council, later known as 'Concern for Dying'[2].

In 1991, the 'Concern for Dying ' organisation merged with its sister organisation, the Society for the Right to Die, to form the National Council for Death and Dying. This Council devoted much of its effort and resources on educating the public about the living will, and encouraging the states to pass legislation giving formal recognition to the living will.

Legal recognition was deemed necessary because, thus far, clinical decisions about treatment procedures were made by physicians based on ethical principles, such as the doctrine of informed consent. Since 1914, state courts in the USA have repeatedly affirmed the right of competent adults to determine for themselves the kind of health care they wish to receive or

refuse[9], based on the common law of self determination, which dated back to the 19th century. However, common law proved inadequate in face of advancement in medical knowledge and technology, as was demonstrated by certain landmark court cases that took place at that time.

The first of these was the Karen Ann Quinlan Case in 1976. The parents of Karen Ann Quinlan, a young woman who was in persistently vegetative state, petitioned the New Jersey Supreme Court to have her ventilator removed, so that she could die a natural death. The Court granted their petition, and also held that an 'ethics committee' could grant all parties concerned legal immunity for their actions[10]. It did so in the belief that it was the fear of legal liability that prevented Quinlan's physicians from honouring her parents' request.

This widely-publicised case prompted the enactment of the first living will statute in the USA, which was the Natural Death Act of California, in 1976[1]. The Act was considered to be revolutionary at that time, though very narrow by today's standards. It contained a prescribed document which, to be legally enforceable, must be signed by the patient not earlier than 14 days after being diagnosed to be suffering from a terminal condition (defined as one that will cause the patient's death 'imminently'). The 14-day rule was intended to give the declarant a cooling-off period to think about the proposed course of action. It was to remain valid for 5 years, or till the time the patient died, whichever was sooner. The precise format of the document as specified in the Act made it unsuitable for application in many clinical situations. It also did not allow the declarant to express any personal wishes and preferences. In addition, this statute also made no provision for people such as Karen Quinlan, who were 'permanently unconscious', or who were in the 'persistently vegetative state'[2,11].

In 1985, the Uniform Rights to the Terminally Ill Act was approved and recommended by the National Conference of Commissioners on Uniform State Laws. This included a suggested format for the living will. There was no compulsion for any state to follow the recommended format, and each state was at liberty to adopt or reject it. In fact, by 1992, only Maine had adopted this format.

Other states in the USA modified California's Natural Death act to suit local needs. By 1994, 50 States and the District of Columbia had enacted living will legislation. Whilst the laws were not exactly the same in each state, several issues were concurrent. In all these statutes, it was made clear that the enactment of the statutes did not mean condoning or supporting active euthanasia; and that the execution of living wills did not constitute a suicide, but was to allow the natural process of dying to take place. In addition, it was stated that life insurance policies were not to be invalidated by the presence of living wills[1].

In 1990, a second landmark case gave the impetus to the concept of a healthcare proxy. Another young woman, Nancy Cruzan, was left in a persistent vegetative state after a road traffic accident. Nancy's parents sought to have her tube feeding discontinued. The Missouri Court, however, required 'clear and convincing evidence' that this was what the patient would have wished for herself. This proved to be a major stumbling block for the girl's parents, for there was little to indicate what Nancy Cruzan's wishes would have been under such circumstances. The Cruzans' testimony that Nancy had indeed made some general statements indicating a preference to forgo life support in the event of irreversible coma was considered inadequate evidence. On appeal, the US Supreme Court upheld the Missouri Court's ruling to be 'not unconstitutional', while at the same time affirming that patients have a right to refuse any treatment, even though such refusal may lead directly to death. It ruled that when a patient's wishes are unknown, there are no grounds for allowing family members to make decisions. No withdrawal of life support could be allowed. Eventually, though, a lower court accepted additional verbal evidence submitted by Nancy's friends as a valid expression of her wishes. This enabled her care providers in the hospital to stop administering food and fluids, resulting in her death shortly thereafter[12-14].

The US Supreme Court's ruling in this case triggered widespread reaction from the public as well as medical professionals[15,16], calling for legal recognition of living wills and proxy directives, and resulted in the passage of the Patient Self Determination Act on 1 December 1991. This statute states that, as a condition for Medicare and Medicaid reimbursement, all hospitals, nursing homes and hospices must provide all adult patients on admission with written information on their rights in making decisions about medical care, including their right to execute a living will or durable power of attorney[17]. This, however, does not necessarily mean that all patients must have advance directives[18-20], only that they be informed in writing of their legal rights under state laws. Any advance directives made must be documented in the patient's records. Institutions must in addition maintain pertinent policies and procedures and must provide staff and community education on advance directives[17]. The Act also prohibits differential treatment of patients on the basis of the presence or absence of an advance directive.

The United Kingdom

In the United Kingdom, the Voluntary Euthanasia Society have been distributing living wills since the 1970s. It now promotes the Medical Treatment (Advance Directives) Bill, which it proposes to introduce in the House of Lords. This Bill authorises both instruction and proxy directives, and the recommended form of instructions are confined to withholding or withdraw life-sustaining treatment.

Another organisation, Age Concern England, had also been championing living wills since the 1980s. In 1985, the Enduring Powers of Attorney Act for England and Wales was passed. In 1991, both the English and Scottish Law Commissions published preliminary papers on the adequacy of legal and other procedures for decision-making on behalf of mentally incapacitated adults[21,22].

In 1992, the Terence Higgins Trust produced a 'new' model of the living will, giving the declarant the option 'to kept alive for as long as reasonably possible using whatever forms of medical treatment available.

In November of the same year, the British Medical Association published a statement on advance directives, stating that though it 'strongly supports the principle of an advanced directive, (it) is not in favour of legally binding advanced directives'[23].

In April 1993, the English Law Commission published a paper on 'Medical treatment and research'[24], in which it provisionally recommended that 'legislation should provide for the scope and legal effect of anticipatory decisions'.

In the same year, while the issue was still being debated, what is now known as the 'Bland decision' was made. Tony Bland was 17 years old when he was injured in 1989, while travelling to Hillsborough to watch his team play in the FA Cup semi-final. In deciding whether Tony's life support system should be removed, the Court's decision was that a living will would be recognised as valid and enforceable in English Law, and that the court would also recognise an oral declaration made by a minor. These rights were far wider than those conferred by any American living will statute at that time.

As a result of the Bland decision, a Select Committee on Medical Ethics was established by the House of Lords. Its function was 'to consider the ethical, legal and clinical

implications of a person's right to withhold consent to life prolonging treatment, and the position of persons who are no longer able to give or withhold consent'. To date, no legislation has been enacted in the United Kingdom on advance directives. The House of Lords had ruled that present decision processes on whether to withhold treatment are adequate.

THE CASE FOR ADVANCE DIRECTIVES

Are advance directives necessary? Is it not sufficient to just continue in the way that physicians have always done, that is, to make decisions based on patients' 'best interests'?

Reducing Concerns

Proponents of advance directives argue that this is no longer easy. The world is changing and, as the population becomes more affluent and better educated, there is a shift in attitude away from trust in professional people, including doctors, towards greater emphasis on individual autonomy[25]. There is increasing strong affirmation that patients should have substantial control over their medical care[2], to exercise the right of self-determination. A person who is competent can decide for himself what treatment he wants, but a person no longer competent is unable to do so. Advance directives are, therefore, a means of allowing people to express their individual identity or autonomy at the time of a critical illness, in decisions reflecting their own beliefs and values[14]. Signing the advance directive when the individual is healthy and of sound mind is a tangible expression for him that he has control over events towards the end of his life.

In addition to the assertion of the right of self-determination, there is also widespread concern that artificial prolongation of life may be carried out just because the technical know-how for doing so is available, regardless of whether this is of any medical benefit to the patient, or whether there is any chance of recovery. The advance directive will safeguard the dignity of individuals from being subjected to such procedures.

In the absence of any written direction from the patient, there may be a difference in opinion as to the type and extent of care to be given to a patient who cannot make decisions for himself or herself. Studies have suggested that patients are calling for less, not more, of the costly high-technology treatment often used in terminal phases of illness[3,26-30], and physicians were more willing than patients and family members to withhold or withdraw life-sustaining treatments[31,32]. Family members, on the other hand, were consistently more hesitant to withhold or withdraw life-sustaining treatment than the patients themselves[31-34]. In the event of a dispute, the courts are often the last avenue resorted to for settlement. This can be time consuming, expensive and emotionally draining on all parties involved. In the United States, it is more complicated because the action to be taken differs from state to state. In some states, certain life and death decisions can only be made in court proceedings, while in others, expensive guardianship proceedings must be made before a determination to end certain life-sustaining treatment[35]. In Missouri, it is assumed that the patient wants treatment at any cost, though from various studies, it was noted that the majority of the public do not want treatment at all costs in such circumstances[36].

A fourth area of concern lies within the medical profession. In making decisions about withdrawing life-sustaining treatment, physicians are often uncertain about the range or scope of their authority. They are therefore apprehensive about possible legal liability for actions carried out in good faith[9,37]. In making treatment decisions for patients who no longer have the capacity for doing so, physicians often recourse to what they consider to be in patient's 'best interests', to reduce unnecessary pain and suffering. This may take the form of no active resuscitation, for example, in a patient in advanced stages of malignancy. Such decisions may be contrary to the expectations of the patient's relatives, who may demand for treatment procedures considered inappropriate or futile by the physicians[38-40]. In the event of any difference in opinion, physicians may be taken to task for their actions.

Finally, it has been suggested that the use of advance directives may contain the escalating health care costs that come with increasing medical sophistication. In the United States of America, studies have consistently shown that 27%-30% of Medicare payments each year are for the 5%-6% of Medicare beneficiaries who die in that year[41,42]. Payments for dying patients increase exponentially as death approaches, and payments during the last month of life constitute 40% of payments during the last year of life, mainly for aggressive and expensive treatment in the intensive care units[41].

It is generally believed that these expenditure are for the care of patients known in advance to be dying, and that interventions for patients whose death is imminent are wasteful, since they neither cure nor ameliorate disease or disability[43]. Thus, reducing expenditure at the end of life seems an easy and readily justifiable way of cutting wasteful spending, and freeing resources to ensure universal access to health care. Advance directives have therefore been proposed as 'just right for transforming good ethics into good health economics', by simultaneously respecting patient autonomy in not wanting to be kept alive if they have irreversible disease, and at the same time saving billions of dollars[44-46].

Conferring Benefits

The use of advance directives is expected to bring about certain benefits. The first of these is that advance directives will greatly assist doctors, patients, family members and other carers with increasingly complex health care decision making. Traditionally, in the absence of a living will or durable power of attorney, decisions about health care are usually made by family and friends. These decisions are not always perfect, as studies have shown[31]. Advance directives will promote patient autonomy while removing onerous decision making from physicians and family members[2].

The presence of an advance directive may also lift the burden of choice from dying persons at a time when they have neither the strength nor the will to worry about alternative forms of care. The moral and legal rights of each individual will be protected. There will be diminished uncertainty about what a patient would want done, thus reducing conflict and anxiety among family members and other care givers about making life and death decisions[8]. The discussion should also bring about improved communication between doctor and patient, and ultimately the greater assurance that treatment accords with the patient's values and preferences[3,7].

Physicians are legally and ethically bound to respect the directions of a patient set forth in an advance directive. This absolves them from the fear of civil and criminal liability when they withhold or withdraw life-sustaining treatment[1]. In fact, the assurance of legal immunity to clinicians for actions in good faith, in accordance to patient's written instructions, is one of the most important features of statutes on advance directives in the United States[37].

The use of the advance directive will enable decision making to be transferred from the courtroom back to the bedside. Application of the advance directive will avoid recourse to the courts to resolve difficulties associated with decision-making for incapacitated patients[9,37], especially if there is a disagreement between the physicians and patient's relatives. It will reduce futile pain and suffering of both the patient and his carers caused by

attempts to preserve life at all costs regardless of quality[14], or to terminate life when it is not the wish of the patient to do so.

THE CASE AGAINST ADVANCE DIRECTIVES

Reservations have been expressed about the meaning, reliability, durability and portability of advance directives[47]. They are anticipatory, and cannot be as precise as an informed decision made by a competent patient at the time of treatment. A patient choosing in advance will usually have a less detailed understanding than a patient facing an immediate and specific decision[17,37]. Many changes can take place between the signing of the document and its execution, including the course and prognosis of the illness as well as the opinion of the physician and his patient. Furthermore, unanticipated therapeutic options might be precluded if these are not specified in the advance directive[8], and physicians or family members would thus be limited in their choice of treatment measures.

Prognostic uncertainty also makes the implementation of the advance directive difficult. As the document may not be specific or detailed enough to fit every clinical situation, the interpretation and implementation of patient's preferences to the situation at hand may be difficult[2,9,17]. There is also no way of ensuring that the document is available at the time when it is needed, as for example in the Emergency Room of a hospital and not in a safe deposit box.

Advance directives are not easy documents for people to sign. These connote death and dying, and many people shy away from planning for healthcare near what may be the end of their lives, as they do not want to be confronted with their own mortality[37]. They may feel that signing the document is psychologically equivalent to admitting that they are giving up and are going to die soon. There is also fear that by executing a directive they will end up getting less treatment than they would desire, or that they will be abandoned by their physicians[36].

The physicians, in turn, may also feel it inappropriate to discuss such issues when their patients are fit and well[35]. Some physicians are not accustomed to receiving from their patients written instructions as to what they, the physicians, should do in terms of medical care[2]. Others may find the advance directive contrary to their personal ethics or religious beliefs.

By definition, advance directives can only be made by competent adults and they will therefore have no place in the care of minors, infants or psychiatric patients[48].

Ethical questions have been raised about the use of advance directives for cost containment. Advance directives are expected to decrease provider costs, assuming that many patients - especially the elderly - will opt to limit the expensive, intensive treatment they may receive in the hospital[49]. This caution about the unethical use of advance directives to contain costs is critical[37]. Potential financial conflicts of interests may arise, as providers may attempt to exert some form of 'undue influence', or subtle coercion, to promote the use of the advance directive to limit health care inappropriately, in order to meet institutional economic goals, such as minimising medical insurance payouts, to the patient's disadvantage. Patients who are poverty stricken, illiterate or unaware of the precise meaning of advance directives may be asked to make choices about which they have little understandable information[9,50].

PROGRESS WITH THE ADVANCE DIRECTIVE

It has been almost 20 years since the passage of California's Natural Death Act in 1976, and 4 years since the Patient Self Determination Act became law in the United States. Most of the practical experience with advance directives are from the USA, as are most of the published studies evaluating their usefulness.

Three Generations of Advance Directives

Since the introduction of the California Natural Death Act in 1976, the advance directive has undergone changes in form in what can be identified as different 'generations'[1]. The prototype of first generation directives was the Natural Death Act. In addition to being narrow in scope and specification mentioned above, there was no provision for penalty if health care providers did not honour these documents. The documents were also perceived to be difficult to implement because physicians were required to make decisions on the basis of their interpretation of what was written, rather than a discussion of the treatment options with a person acting on behalf of the patient[18].

These inadequacies led to the development of second generation directives in the 1980s. The scope was broadened, with a more expansive definition of 'terminal condition' to include permanent unconsciousness and advanced dementia. The declarant was also given a wider choice of treatment procedures that they would wish to be withheld or withdrawn.

Proxy directives were also introduced at this time. These allow a competent adult (the 'principal') to choose another person (the 'proxy' or 'agent') to make treatment decisions for him or her, if he or she becomes incompetent to make them. The agent has the same authority to make decisions that the principal himself would have should he be still competent. These directives take effect from the moment the principal is incapacitated, but not necessarily terminally ill. The goal of proxy directives is to simplify the process of decision making and to make it more likely that the patient's wishes are followed[7]. As for living wills, there has also been much discussion in the literature concerning the advantages and disadvantages of using proxies, and the comparison between the use of proxy decision makers with that of documents[7,8,17,31,51,52].

In the 1990s, there was increasing recognition that withholding or withdrawing life-support is not the only option that people can choose. This saw the emergence of third generation advance directives, for example Indiana's Living Wills or a 'life-prolonging Procedures Act, which recommends two alternatives: either a living will or a 'life-prolonging procedures declaration', which allows the declarant to request the use of life-prolonging procedures that would extend his life in the event of an incurable disease or injury or a terminal condition. Some physicians are not comfortable with this modifications, as it may be against the physician's own clinical judgement, and does not take into consideration, the futility of the treatment or the consumption of available resources[53].

Practical aspects in implementation

In the administration of the advance directive, it was felt that the process should be a clinical and not an administrative one[37]. Patients need to discuss with someone knowledgeable about the role of an advance directive in their care. It is therefore the job of the doctors and not the admission clerk to discuss this with their patients. The timing of the first and subsequent discussions about advance directives, as well as the types of patients judged to be 'suitable' or receptive were also subjects of much thought[3,54]. Some authors suggested that, ideally, initial discussion should take place in the outpatient setting before the patient experiences the dislocation that often attended inpatient admission[17,35]. Patients also preferred the discussions to be held earlier, while they are still ambulatory[55,56]. In order to lessen the awkwardness of the subject, doctors should integrate discussion of directives into their ongoing dialogue with patients about current health status and future care. A discussion of hypothetical cases was suggested as a means to facilitate an understanding of the different clinical scenarios and the treatment

procedures available, so that patients can make their decisions intelligently[57-59].

Most patients wanted to discuss their preferences for future treatment[3,31,58,60,61]. However, the methods for eliciting patients' wishes differed from individual to individual, and from centre to centre[14]. Some authors believed it best to have patients give a general indication, while others believed that it was better to describe a series of specific situations and treatments and ask people to choose which treatment they would want in which situation[5]. Opinions differed also as to the usefulness of comprehensive checklists with alternative scenarios. In was felt by some to be too confusing and abstract to be useful to either patient or healthcare providers[3,5]. One author reported that the use of detailed directives, coupled with a supportive proxy and discussion with the physician was reliable[62]. Good counselling by physicians, therefore, should be an important part in the process of patient education about end-of-life decisions.

In order to write the advance directive, the specifics of many issues relating to each individual still need clarification. These include certainty regarding the diagnosis, the type and phase of illness, the degree of severity and imminence of death, the patients' wishes regarding the type of treatment expected or anticipated.

Interpretation of what is written is another aspect open to much difference in opinion. It is almost impossible to write a directive that leaves no room for interpretation[17]. Changes in the patient's wishes, deterioration of the patient-physician or patient-proxy relationship, and the emergence of new treatment alternatives are factors that make these directives difficult to interpret. A strictly abstract or literal interpretation of the patient's intentions is not satisfactory. One needs to know why the choice was made, and in what context. This can be achieved if the physicians and patients can discuss together the patient's wishes and intentions as stated in the documents. They can then reach an agreement on the extent and nature of care during terminal illness. Otherwise, without the intent being clarified, physicians may be uncertain about how to carry out patients' wishes even though they sincerely desire to do so[2].

As circumstances can change with time, physicians should re-examine directives periodically with their patients so as to be updated as and when patients change their minds[17]. Available data, though, suggest that there is considerable stability in patients' preferences concerning life-sustaining treatment[28,57,63,64].

Difficulties in implementation

Since the introduction of legislation on advance directives in the USA, it was noted that there was a big difference between the large percentage of people who indicated a desire to die without heroic measures and the small percentage who have executed advance directives[36]. Estimates ranged from 4% to 24%[34,37,60]. Of those who have completed advance directives, many did not fully understand them[65].

What are some of the reasons for these problems? Firstly, it was felt that acute care hospitals and nursing homes are not optimal settings for first discussions of advance directives[37]. As mentioned above, studies have shown that both physicians and patients were of the opinion that discussions about treatment preferences should take place prior to a critical or terminal phase of illness, when patients are well and during a routine office visit[60]. However, this was not found to be the case in practice. Many physicians still have reservations about advance directives[5,9,13,26,37,57,61]. Physicians and providers have viewed such directives as a patient responsibility instead of a professional or institutional one. While some doctors remained reluctant, and believed that patients should be the ones to ask about, or initiate, discussions about life-sustaining treatment[37,54,60,66,67], most patients believed that physicians should be the ones to initiate this[58,61,67]. Also, many younger, healthy patients and their physicians were of the opinion that advance directives are only for the elderly or the chronically ill[3]. Patient and physician, therefore, each waited for the other to raise the subject. Communication was often postponed until the patient was no longer capable of participating in the decision-making process.

Physician discomfort about discussing life-sustaining treatment was often based on misconceptions about the consequences of initiating a discussion[27]. Some physicians believed that patients would become discouraged and that their recovery would be delayed if negative information was provided. Most patients, however, actually wanted information about risks and benefits of treatment outcome in issues pertaining to their own medical care[68], and would prefer that physicians be straightforward and honest with them[56].

Another reason for this was that a lot of time was needed for the discussion of advance directives, and that special training and competence on the part of the health care provider was felt to be required[17]. It was estimated that 15 minutes would be needed for the initial discussion of a structured advance directive document, with a description of alternative medical scenarios[3]. Further discussions might be necessary as a follow-up. Unfortunately, patients generally did not write advance directives after discussion with their physicians[60,69,70].

Even if the directives were written, their execution was by no means a certainty, as many events and changes can take place in the intervening period of time. In one study, most hospitalised patients' preferences remained stable for a month after their transfer form the intensive care unit[28]. By contrast, in another study, 13% of 65 nursing home residents who had advance directives limiting their care changed their decisions in favour of more care[63].

The presence of advance directive also did not increase the likelihood that patients' wishes would be followed. Their existence were not always known to the physician[72]. In 25 out of 71 cases, the advance directive did not make it to the patients' hospital chart when the patients were transferred from nursing home to hospital[26]. Physicians often did not ask their patients whether they have completed advance directives. A survey conducted reported that only 4% of personnel working in acute care hospitals routinely enquired about the existence of advance directives at the time of admission[54]; and patients who have completed advance directives often did not tell the hospital employees[37]. There was also evidence that advance directives were overridden or ignored one fourth of the time[26].

When the terms stated in the documents were not specific enough, these would be open to many ways of interpretation. The ambiguity of the documents would allow the staff to project their own attitudes and feelings regarding treatment protocols, resulting in conflict and controversy[73]. When proxy decision makers are involved, advance directives cannot in themselves entirely safeguard patients from the questionable motives, conflicts of interest, or unreasonable requests on the part of the surrogate decision makers[9].

On the other hand, a checklist of interventions was also found to be not useful. The intervention-focused directives run the risk of promoting the selection or rejection of interventions just because of their inherent characteristics, and not because of their suitability in a particular situation. Moreover, listing of possible interventions may shift attention away from overall treatment goals and may lead to prescription of inappropriate medical care[13].

Have the objectives been met?

In view of all these, it is pertinent to examine whether the perceived needs for introducing the advance directive have been met.

It was reported in literature that patients who have completed advance directives generally found their existence to be comforting[37]. One study of a retirement community of non-terminally ill residents with living wills showed that specific planning decreased anxiety about death[66]. In another study of nursing home residents, support of living wills was significantly correlated to a feeling of internal control[75]. Thus the right of patient self-determination was fulfilled.

Whilst the writing of advance directives was a pshychological boost to some individuals, the outcome of implementing them was not so clearly beneficial. Schneiderman et al[76] have shown, in a prospective randomised clinical trial, that executing the California Durable Power of Attorney for Health Care, and having a summary copy placed in the patient's medical record, had no significant positive or negative effect on a patient's well-being, health status, medical treatments, or medical charges. Schneiderman also found that there was no discernable reduction in treatments or costs, though most patients chose to limit life-sustaining treatments. There should be caution about generalising these findings, though, since most patients studied retained their decision-making capacity through their declining states of health, and the advance directive was invoked in only 3 cases[50].

Another group, Teno et al[77], reported a study involving 854 patients who died at 5 medical centres. They found that executing an advance directive did not significantly affect the cost of patients' terminal hospitalisations. In contrast, in a more recent study by Weeks et al[78] on 336 consecutive patients who died at a University tertiary care medical centre, it was reported that patients without advance directives had significantly higher terminal hospitalisation charges than those with advance directives.

The conflicting conclusions in these studies suggest that additional studies are needed to determine whether there is indeed cost saving in the use of advance directives. Whatever the result, though, it is not envisaged that any such savings would restrain the rate of growth in health care spending over time in the United States[79]. Callahan, in his book entitled 'What kind of life: the limits of medical progress', sees the two potentially synergistic connection between patient autonomy and cost containment to be on a collision course. He cites the 'powerful, unremitting public demand for better health and a longer life' as a major obstacle to limiting health care costs[80].

Several reasons have been proposed as to why, despite the high cost of dying documented for Medicare beneficiaries in the United States, was there not much cost saving from the use of advance directives, and the use of fewer high technology interventions. One explanation was that the Medicare data presented a distorted image of the cost of dying. Medicare data should not be extrapolated to the whole health care system in the US because <1% of the total American population die each year, compared to 5%-6% of Medicare beneficiaries. The 5% of Medicare beneficiaries actually account for 27% of Medicare payments, whereas the total number of Americans who die annually (2.17 million) are estimated to account for only about 10%-12% of health care expenditures[43].

Another explanation may lie in that even when patients refuse life-sustaining interventions, they do not necessarily require less medical care, just a different kind of care[43], and this may cost just as much in terms of skilled personnel and costly equipment for palliative care outside the hospital.

The unpredictability of the timing of death is also another reason why there may be no reduction in health care costs. It is impossible for doctors to predict the duration before death, and determine which patients will benefit from the intensive care and which ones will receive 'wasted' care[43]. In other words, it is difficult to know in advance what costs are for care at the end of life and what costs are for saving a life[81]. Only in retrospect, after the patient died, can one identify the last month or year of patient's life. This means, therefore, that patients are kept on high technology resources for as long as there is uncertainty about the prognosis, as neither physicians nor family members are willing to take the responsibility of invoking the advance directive when there may be a chance of improvement in the patient's condition.

Added to that, a small minority of patients consistently want treatment even after they become incompetent or have a low chance of survival. These are reflected in the third generation advance directives, in which provisions are made for individuals with such view. Needless to say, health care costs will not be reduced in these cases.

IS THERE A NEED FOR THE ADVANCE DIRECTIVE?

Taking into consideration all the above, should physicians then advocate the use of advance directives, or should they stay status quo and manage as they have always done? Is there a need for the advance directive?

In advocating the legislation of the advance directive, one author expressed reservations that there might be unintended negative effects in trying to make formal a process that was previously informal, in that all the certification requirements must be met before action can be taken. The current, widely accepted, informal mechanisms of consent to 'do not resuscitate' orders appear to work quite well, and do not present the difficulty of the perceived legal barriers limiting the aggressive treatment for certain patients[36].

In the absence of advance directives, treatment decisions are often made by family members and relatives. In those with close and intact families, the advance directive may be unnecessary. Many elderly individuals may be more comfortable with established patterns of deference to their physicians, than with the use of legal documents. Moreover, some cultures and religions would find this method of personal decision making highly repugnant[9].

As for saving health care costs, cost containment is not an unethical motive in and of itself. The issue is rather who decides what costs are contained and when[9]. The crucial ethical responsibility is to ensure that the patient, and not the institution, the third party payers, or even the patient's (interested) relatives make this decision.

It was mentioned that few Americans have executed advance directives. In fact, only about 25% of people in the U.S. have executed even ordinary wills[36]. The failure to prepare wills does not create major problems for the remaining 75% of the population because the law creates a reasonable 'fall-back' or 'default' position for such cases. Although few Americans have expressed their treatment preferences in writing, decisions to withhold or withdraw treatment are common in the United States[82-85]. In the absence of the advance directive, the 'fall-back' would be to make treatment decisions by considering the patient's 'best interests' as defined by 'objective, socially shared criteria'[35]. The patient's best interests are determined by weighing the potential benefits and burdens of treatment, including such factors as the relief of suffering, the quality and extent of life sustained, and the effect of the decision on the patient's loved ones. The decision, though, weighs heavily on the social mores of preserving life, regardless of the prognosis for recovery.

One way of making this decision-making process more

formalised, and yet not instituting it in the form of legal statute, would be for health care facilities to develop formal treatment guidelines that are based on the consensus of the surrounding community based on religious affiliation and other social considerations[86]. One argument against this is that there is no uniformity, and patients will get different treatment depending on which facility they make use of. Then again, is there a need for uniformity of treatment for all? Are professional and community guidelines adequate in shaping such a care plan? There are as yet no studies on the adequacy of this process.

CONCLUSION

It can be seen that the issue of advance directives is not an easy one to resolve. Much has been written and without doubt much more opinions will be forthcoming. There would always be advocates and objectors. Courts and ethicists have argued for years about patient preferences as the key to treatment decisions.

In a developed nation, as the population ages, and the proportion of elderly people becomes larger, the issue of withholding and withdrawing expensive forms of care will gain even more prominence[50]. In the context of terminal care, doctors have a number of duties which may at times be in conflict. These include the preservation of life, the relief of suffering, obedience to the law as it stands, and a general conformity to accepted ethical standards[14,25]. The physician's job may be made easier with the presence of an advance directive.

Whatever the opinion, one should bear in mind that the underlying philosophy of an advance directive is not the right to live or to die, but the right of self-determination, that is, 'patient autonomy', and the advance directive reinforces the primacy of patient preferences in treatment decisions[37].

When appropriately implemented, the advance directive can perform its intended functions. When it is vague in terminology or applied to patients with uncertain prognoses, it can cause confusion for the patient's carers[2]; and when improperly used, they can become instruments not of patient preferences, but of economic purpose, family bias, or physician's values[8]. Its main objective of clarifying the patient's perspective about life, death, and medical care[13] should be the central guiding light.

In the final analysis, the *concept* of advance directive has definite advantages and a useful role in the care of patients in the terminal stages of disease. It is the *implementation* of it that is not easy or simple, which makes one wonder if the age-old, well-accepted practices should be left to carry on as they are at the present.

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