

Terminating life-sustaining treatment – recent US developments

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Author's abstract

This paper reviews some recent litigation in the United States which addresses the difficult question of withdrawing food and hydration from both competent and incompetent patients. Whilst the decisions in question have manifested a trend towards favouring patient autonomy, they also indicate an underlying tension between doctors, health care facilities and their dying patients which is not yet close to resolution. The author suggests that the courts in the United States are likely to remain, for the foreseeable future, the final arbiters in that country of disputes relating to the termination of life-sustaining treatment.

Whenever the issue of the termination of life-sustaining medical treatment is discussed, the seminal case of Karen Quinlan (1) inevitably assumes prominence. The unfortunate Miss Quinlan died of pneumonia in June 1985 over ten years after she had suffered severe and irreversible brain damage resulting from oxygen starvation. Having accepted the doctors' diagnosis of permanent vegetative state, Karen's parents asked the New Jersey Court's permission to have the life-sustaining respirator disconnected. In a now famous opinion the Supreme Court of New Jersey acceded to the parents' requests concluding that the decision to disconnect could lawfully be made by Karen's father who had been appointed as her guardian. However, when the respirator was eventually turned off some months after the Supreme Court's ruling, Karen was able to breathe spontaneously owing to the fact that the medical team had successfully weaned their patient from it (2). From then on Karen's parents felt morally unable to consider removal of the nasogastric feeding tube (3) which kept her alive for a period of ten years, although it would appear that when she eventually did die 'antibiotics, which could have fought the pneumonia, were not given' (4).

Although clearly a landmark case, the Quinlan

decision never addressed the question of removal of food and hydration from the patient. However, the New Jersey Supreme Court has recently been called upon to deal with this crucial issue in three important decisions dealing in turn with a competent patient, an incompetent patient whose wishes were well known and an incompetent patient who failed to express any clear opinions on the matter. Each of these decisions, together with some recent cases from other States, will now be considered in order to assess the current state of US law.

The competent patient

Kathleen Farrell (5) began to experience symptoms associated with amyotrophic lateral sclerosis (ALS) in 1982. ALS is a nervous system disorder which destroys the patients' muscles but does not impair mental faculties. The cause of the disease is not known and there is no treatment or cure. Life expectancy, even with life-sustaining treatment, is between one and three years. Eventually Mrs Farrell was admitted to hospital where she underwent a tracheotomy and was connected to a respirator. However, she refused to permit the insertion of a nasogastric tube. In 1983 she was discharged from the hospital because no further medical help could be given. She returned home to live with her husband and two teenage sons, requiring constant nursing care as she was paralysed and bed-ridden.

In November 1985, after experimental treatment failed, Mrs Farrell told her family that she wished to be disconnected from the respirator. Her husband now sought authority to disconnect, together with a declaratory judgement that such action would not attract civil or criminal liability. During the trial, part of which was conducted at her home, Mrs Farrell stated that she wished nature to take its course since she was 'tired of suffering'. Two psychologists testified that she was competent to make this decision.

Ten days later the trial court granted all the relief that Mrs Farrell had requested, but stayed its order pending appellate review. On June 29, 1987 Mrs Farrell died while still connected to the respirator, but owing to the importance of the issues involved the Supreme Court of New Jersey agreed to render a decision.

Key words

Life-sustaining treatment; terminating life-sustaining treatment; removal of food and hydration; competent and incompetent patients.

In a unanimous decision the court built on the principles established in *Quinlan* emphasising that ‘a patient’s right to refuse medical treatment even at the risk of personal injury or death is primarily protected by the common law . . .’ (6). However, the right to refuse life-sustaining medical treatment was not absolute, there being four countervailing interests in sustaining a person’s life, namely preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting innocent third parties. Despite this, none of these interests could be regarded in this case as outweighing Mrs Farrell’s right to self-determination. However, the court did emphasise that in cases of this nature there must be some safeguards in order to ensure that the patient was competent to make such an important decision. It was essential, therefore, that the patient be fully informed about prognosis, medical alternatives, risks involved and that there be a complete lack of coercion. Recognising that this could be more easily achieved in a hospital setting the court, in order to protect the patient at home, required that two independent physicians confirm competency. Provided this is done, no further court action or judicial review is required.

The decision in *Farrell* is part of a continuing stream of cases which all uphold the patient’s right to refuse life-sustaining treatment as well as confirming that provided a third party acts in good faith in withdrawing such treatment from an informed and competent patient no civil or criminal liability will be incurred even if that person is not a health-care professional. Further, the recent decision of the California Court of Appeal in *Bouvia v Superior Court* (7) confirms that the competent patient need not be terminally ill before he or she may lawfully have life-sustaining treatment terminated. In that case, the patient was quadriplegic and had suffered from severe cerebral palsy since her birth. The medical team being concerned that the patient was not receiving sufficient nourishment to survive, inserted a nasogastric tube against her will. A petition was then filed on the patient’s behalf requesting removal of the tube. In a unanimous decision, the court emphatically confirmed that the ‘decision of the patient was ‘her’s alone’, stating:

‘Here, if force fed, petitioner faces 15 to 20 years of a painful existence, endurable only by the constant administrations of morphine. Her condition is irreversible. There is no cure for her palsy or arthritis. Petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years! Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through physical acts of others. Her mind and spirit may be free to take great flights but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness. We do not believe it is the policy of this State that all and every life must be preserved against the will of the sufferer. It is

incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure, for “15 to 20 years”. We cannot conceive it to be the policy of this State to inflict such an ordeal upon anyone.

‘It is, therefore, immaterial that the removal of the nasogastric tube will hasten or cause *Bouvia*’s eventual death. Being competent she has the right to live out the remainder of her natural life in dignity and peace. It is precisely the aim and purpose of the many decisions upholding the withdrawal of life-support systems to accord and provide as large a measure of dignity, respect and comfort as possible to every patient for the remainder of his days, whatever be their number. This goal is not to hasten death, though its earlier arrival may be an expected and understood likelihood’ (8).

Finally, in connection with competent patients the recent decision of the New York Supreme Court in *In re Brooks* (9) is noteworthy. There an elderly resident of a nursing home, who was not suffering from a serious illness, refused food and water stating that she wished to die of starvation. The director of the nursing home petitioned the court for an order permitting force-feeding on the grounds that the home was under a statutory duty to provide food and drink for its residents and that failure to do so would entail criminal liability for aiding suicide. The court, in denying the petitioner’s application concluded that the competent patient’s right to refuse medical treatment extended to a nursing home resident who was not suffering from any illness or disorder which prevented natural eating.

Incompetent patients

The problems surrounding the withdrawal of life-sustaining treatment from incompetent patients become more acute because their present wishes can no longer be ascertained. However, the New Jersey Supreme Court considered that a distinction should be drawn between those incompetent patients who had expressed clear wishes as to what should be done about the continuation of life-sustaining treatment and those who had not.

In the case of *re Peter* (10), a woman in her early sixties collapsed at the home she shared with a close friend. Although resuscitated, she remained in a persistent vegetative state from the date of her collapse in October 1984. Since January 1985 she had been sustained by nasogastric feeding in a State nursing home. In 1983 Miss Peter had executed a power of attorney authorising the person she lived with to make all health-care decisions on her behalf and to be given full authority to manage and direct her medical care. In October 1985 Ms Peter’s friend was appointed as her guardian and now sought removal of the nasogastric tube. However, before this could be done the approval of the Ombudsman for the Institutionalised Elderly (11) had to be obtained. But this was refused on the basis that although the patient had no hope of recovery,

she might survive in a permanent vegetative state for many years. This problem of life expectancy was considered by the ombudsman to be crucial in the light of the supreme court's earlier decision in *In re Conroy* (12) which concerned an elderly, formerly competent patient who, although not comatose, was expected to die within a year. In the course of that decision, the court had concluded that in the absence of compelling evidence that the patient herself, whilst competent, would have wished termination, a 'best interests' test had to be applied. Thus, medical evidence would be 'essential to establish that the burdens of the treatment to the patient in terms of pain and suffering outweigh the benefits that the patient is experiencing. The medical evidence should make it clear that the treatment would merely prolong the patient's suffering and not provide him with any net benefit' (13). Because Ms Peter was not expected to die within a year the ombudsman decided that the Conroy decision precluded him from approving withdrawal of treatment. The Supreme Court of New Jersey disagreed, concluding that the life-expectancy test could not be applied to patients in persistent vegetative states since 'Life-expectancy analyses assume that there are at least some benefits to be derived from the continued sustenance of an incompetent patient. That assumption . . . is not appropriate in the case of persistent vegetative patients. . . .' (14). Similarly, since such patients could not experience any pain, suffering, joy, satisfaction, or well-being any benefits-burdens analysis was equally inapplicable. The court also confirmed that no distinction should be made 'between the termination of artificial feeding and the termination of other life-sustaining treatment' (15) with regard to both competent and incompetent patients. In conclusion, because there was clear and convincing evidence that the patient had selected a surrogate medical-decision maker, together with equally clear evidence of her medical preference, this subjective approach was the proper way to ensure that the patient's medical preferences were respected.

Finally, in the case of *In re Jobes* (16) the Supreme Court of New Jersey had to deal with a non-elderly nursing home patient in a persistent vegetative state who, prior to her incompetency, failed to express her attitude towards life-sustaining treatment. The patient had been in this condition since 1980 when she had suffered massive and irreversible brain damage during a surgical operation. In May 1985 Mrs Jobe's husband requested the nursing home to withdraw the jejunostomy tube which provided her with nutrition and hydration. The nursing home refused on moral grounds and so Mr Jobes sought court authority for the withdrawal.

The decision in *Jobes* is significant in that there was some conflicting medical opinion concerning the diagnosis of permanent vegetative state. This was resolved by the court relying upon what they considered to be the more reliable evidence, part of which involved the use of a positron-emission

tomograph scan which indicated 'that blood flow and metabolism in Mrs Jobe's cerebral cortex was only thirty to forty per cent of a normal cognitive brain' (17). As a result the court concluded there was clear and convincing evidence that the patient's condition was that of persistent vegetative state. However, because there was no evidence to indicate Mrs Jobe's personal treatment preference, the subjective test laid down in *re Peters* was inapplicable here. Instead, the correct approach should be that already adopted in *Quinlan*, namely that family members should use their 'substituted judgement' to put into effect as far as possible the decision that the incompetent patient would make if he or she were competent. In order to do this, the surrogate should consider 'the patient's prior statements about and reactions to medical issues, and all the facts of the patient's personality that the surrogate is familiar with – in order to extrapolate what course of medical treatment the patient would choose' (18). In addition, the court laid down a requirement that the surrogate decision-maker secure statements from at least two independent physicians knowledgeable in neurology that the patient was in a persistent vegetative state. Provided this was done, then no legal liability would attach to anyone involved in the surrogate decision to withdraw medical treatment. Only if disagreement arises amongst the parties involved should judicial intervention be required, and this the court considered should be a rare occurrence. Finally, the nursing home where Mrs Jobes had been treated for six years should not be permitted to discharge its patient but must instead continue to care for her even after the withdrawal of the life-sustaining treatment. To hold otherwise would cause immense hardship to the patient and her family. However, despite this aspect of the court's decision, the nursing home, by petitioning other courts, including the US Supreme Court, was able by these legal manoeuvres to delay implementing this decision. The practical result of this delay was that although Mrs Jobes died six weeks after the Supreme Court of New Jersey's decision, her death took place only after she had been transferred to a hospital which was not morally opposed to the withdrawal of the artificial feeding device.

Discussion

The cases referred to are part of a continuing trend (19) which supports a patient's right to self-determination when it comes to the withdrawal of life-sustaining treatment. This combined with the fact that almost all States either already have, or are in the process of considering, living will legislation (20) demonstrates that the problems surrounding life-sustaining treatment are clearly within the public domain in the United States. There are several obvious reasons why this is so. First and foremost is the fact that the process of dying has itself become much more public, in the sense that many more persons, particularly the elderly, are spending their final days in hospitals or nursing

homes (21). This phenomenon is inevitably linked to 'the dramatic advances in life-sustaining medical technologies during the past three decades . . . accompanied by rapid expansion in their availability and use' (22). Thus, a recent conservative estimate of the total number of patients in the United States who are the subjects of life-sustaining medical treatment in the form of either mechanical ventilation or nutritional support, put the figures at around 3,775–6,575 for the former and approximately 1,404,500 for the latter (23). It is clear that the number of patients who can be sustained on life-sustaining technologies in their own homes is limited (24). The role and policies of health care institutions thus become crucial whenever the question of the termination of treatment arises. In this connection, it seems apparent that much of the litigation within this area in the United States has been spawned by two factors. First, the health care facility and/or medical team in charge of treatment find it morally unacceptable to accede to the patient's request to terminate treatment. Secondly, there is genuine fear on the health care facilities' part of legal liability (25) should they terminate life-sustaining treatment. The New Jersey Supreme Court attempted to deal with this fear by openly declaring in each of their recent decisions that no civil or criminal liability would attach to any party who in good faith terminated treatment, provided their guidelines had been adhered to. However, it is very doubtful whether these declarations will be of much help since the suggested safeguards are merely procedural recommendations for which there are no new special legal sanctions should they be breached. In short, therefore, the primary test of the legality of any particular termination of treatment remains that of acceptable medical practice and nothing more (26). It is also noticeable that if, as in *Jobes*, the hospital remains adamant that it is morally wrong to terminate treatment there is little or nothing that can be done at present but to transfer the patient.

A particularly important factor that must be considered when dealing with the issue of life-sustaining treatment is the question of cost. The high cost of medical care within this area is undeniable. For example, with regard to a patient in a persistent vegetative state 'costs of \$100,000 to \$200,000 during the first 1 to 2 years of specialised care for these patients are common' (27). With an estimate of between 5,000 to 10,000 of such patients in the United States at the present time (28) it seems obvious that this condition poses 'major ethical dilemmas for society, not only from the standpoint of cost considerations, but, more importantly, the most humane ways of treating the patient . . .' (29). This in turn has led to an argument that persistent vegetative state (PVS) patients should be recognised as legally dead despite being 'biologically alive'. This argument suggests that the current idea of brain stem death is too narrow and that the law should embrace the nature of higher brain (neocortical) death since to do so 'could advance the analysis of the

sensitive issue of foregoing or withdrawing nourishment and artificial life-support systems in cases involving incompetent terminally ill patients (infants and adults) who nevertheless retain cognitive functions by forcing physicians and families to focus on the distinction between patients who are conscious and alive, and patients who are irreversibly noncognitive and, therefore, dead' (30).

Naturally, such an argument brings with it many ethical and legal problems, not least of which would be the problem of declaring a person to be 'dead' who may still be breathing spontaneously and is certainly still 'biologically alive'. It is highly doubtful, therefore, whether the notion of neocortical death could be regarded at present as socially, morally or legally acceptable. Nevertheless, what this type of argument does is to stimulate discussion about the status of PVS patients, who seem neither dead nor alive. Is it any more acceptable to allow such patients to remain 'biologically alive' for many years than it would be to regard them as legally 'dead', in which case life-sustaining treatment could be automatically discontinued? Questions of this nature deserve to be squarely addressed and are likely to become more acute as life-sustaining technology improves and develops.

Finally, the continued litigation in the United States dealing with the termination of life-sustaining measures suggests an underlying tension between health care facilities and their dying patients which is not yet close to resolution. Thus, despite the fact that the decisions of the US courts repeatedly support the patients' autonomy and right to self-determination there seems to be little or no room for complacency. For not only are such cases merely the smallest tip of a massive and growing iceberg but also the findings of the recent US Congress, Office of Technology Assessment Report entitled 'Life-sustaining Technologies and the Elderly' (21) indicate that 'In practice many patients are not involved in decisions about the use of life-sustaining technologies'. The following examples cited in the report (31) give an indication of the scope of the problem:

'In the case of resuscitation, the bias to treat is so strong that the normal presumption about informed consent is reversed. That is, patients (or their surrogates) are likely to be consulted if a DNR order is being considered, but unlikely to be consulted for consent to resuscitate. Antibiotic therapy, especially in the hospital setting, is so routine that health professionals often consider consent unnecessary, and they do not seek it. Also, health professionals' perceptions of some interventions as ordinary or non-invasive mean that, in practice, different treatment modalities for a single life-sustaining technology can involve different decision-making practices. Thus, in many institutions, a nasogastric tube may be placed for the provision of enteral nutrition without the patient's consent – even though formal consent is always required for surgical placement of a gastrostomy tube for enteral nutrition

or a catheter for TPN (total parenteral nutrition, usually intravenous).

Decisions about the treatment of a life-threatening infection, even in severely debilitated and terminally ill people, frequently focus on choice of the appropriate antibiotic and omit explicit consideration of whether or not to treat.

A patient preference that runs counter to the advice of health professionals is often interpreted as "irrational", and efforts will be made to change the patient's mind or to circumvent the patient's request. In such cases, the patient's decision-making capability may be called into question, and efforts made to appoint a surrogate or a guardian.'

A possible solution to these problems would be to move towards standardised decision-making guidelines and in this connection it is important to note that in June 1987, the Joint Commission on the Accreditation of Hospitals adopted a standard requiring hospitals and nursing homes to have a policy for decisions about resuscitation by 1988 (32). However, whilst there may be some consistency surrounding the issue of decision-making within resuscitation, the same cannot be said for decisions about the use of life-sustaining treatment in general. It seems likely, therefore, that within the foreseeable future the courts will continue to be the final arbiters in the United States of the types of disputes which recently taxed the New Jersey Supreme Court. In short, the controversies surrounding the question of terminating life-sustaining treatment seem destined to range on indefinitely; but at what price to dying patients?

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References

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- (2) The weaning process appears to have been performed without objection from the patient's guardian, see Quinlan J and J. Karen Ann, *The Quinlans tell their story*. New York: Doubleday & Co, 1977: 284-289.
- (3) See reference (2): 282.
- (4) Rachels J. The end of life, euthanasia and morality. Oxford: Oxford University Press, 1986: 101.
- (5) In the Matter of Kathleen Farrell, 529 A 2d 404 (1987).
- (6) See reference (5): 410.
- (7) 179 Cal App 3d 1127, 225 Cal Rptr 297 (1986).
- (8) See reference (7): 305.
- (9) New York Supreme Court, Albany County, June 14, 1987.
- (10) In the Matter of Hilda M Peter, 529 A 2d 419 (1987).
- (11) An officer of the State of New Jersey who guards against abuse of patients or residents over 60 years of age who are clients of institutions offering health or health-related services.
- (12) 98 N J 321, 486 A 2d 1209 (1985).
- (13) See reference (12): 365.
- (14) 529 A2d at 424.
- (15) See reference (14): 427.
- (16) In the Matter of Nancy Ellen Jobes, 529 A 2d 434 (1987).
- (17) See reference (16): 439.
- (18) See reference (16): 444.
- (19) For detailed discussion see Weir R F, ed. *Ethical issues in death and dying*. (2nd ed) New York: Columbia University Press, 1986, and Lynn J, ed. *By no extraordinary means, the choice to forego life-sustaining food and water*. Bloomington and Indianapolis: Indiana University Press, 1986.
- (20) As of July 1987 there were enacted laws in 39 States including the District of Columbia, whilst 11 other States had legislation under consideration, although in two of these latter States the bills had failed in House. See: *News from Society for the Right to Die NY 1987*; Jul 24.
- (21) See US Congress, Office of Technology Assessment. *Life-sustaining technologies and the elderly*, OTA-BA-306. Washington, DC: US Government Printing Office, 1987 Jul, which remarks at page 45: 'The shift to hospitals or other institutions as a place to die began about the time of or just after World War II. . . . By the 1970s, more than 70 per cent of all deaths occurred in hospitals or other institutions, and the percentage may be even higher now.'
- (22) See reference (21): 3.
- (23) See reference (21): 11, table 1-1.
- (24) See reference (21): 14.
- (25) Nor is this fear confined to possible civil liability. See, for example, *Barber v Superior Court*, 147 Cal App 3d 1006, 195 Cal Rptr 484 (1983) where a prosecution of doctors for terminating a patient's life-sustaining treatment was eventually only prevented by an appellate court.
- (26) Annas. In thunder, lightning or in rain: what three doctors can do. *Hastings Center Report 1987*; 4: 28.
- (27) Cranford R. Termination of treatment in the persistent vegetative state. *Seminars in neurology 1984*; 36. Also see reference (21): 13, table 1-2.
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- (30) Smith D R. Legal recognition of neocortical death. *Cornell law review 1986*; 71: 850-862.
- (31) See reference (21): 22-25.
- (32) Joint Commission on the Accreditation of Hospitals. Proposed standards for policy in resuscitation of patients. *Accreditation manual for hospitals*. Chicago, Illinois 1988.