Decisions at the End of Life

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This paper presents a system for making decisions at the end of life. It emphasizes the role of patient autonomy and the importance of patient and family participation with the physician in decision-making. Definitions are presented for the terms: terminal illness, withholding and withdrawing life sustaining treatment, physician assisted suicide and euthanasia. Three cases are briefly described to illustrate the application of the decision-making system. A detailed discussion is then presented of the divergent views expressed by different authors about the moral differences or similarities between forgoing life sustaining treatment and physician assistance in dying. It is concluded that the view that these two actions are fundamentally different, as supported by the United States Supreme Court, in 1997, is the correct one. Physician assisted suicide (PAS) remains a controversial issue. Physicians and societies in individual countries must work out their own approaches to PAS. However, forgoing invasive or intensive life support in terminally ill patients consistent with their wishes is considered appropriate.

Key words: attitude to death; death, assisted; death with dignity; euthanasia; life support care; Oregon; physician-assisted suicide; right to die; suicide, assisted; terminal care

To be or not to be, that is the question.
Hamlet, Shakespeare

Decisions about treatment at the end of life are difficult for physicians, nurses, patients and their families. Thus the question that so troubled Hamlet is indeed relevant to this discussion. In this essay, I will describe and define the questions and the options as they apply in the United States. I will also discuss a method for the complete clinical assessment of the patient that forms the basis on which a discussion of end of life decision can be based. Circumstances will differ from country to country based on social, religious and cultural background. However, the fundamental principles addressed in this essay will likely apply across national boundaries. After presenting three paradigm cases to illustrate the decision-making process, I will review some of the relevant literature that addresses the ethical issues involved in these difficult clinical situations.

In the United States, the right of patients to refuse treatment of any kind, and of treatment to prolong life in particular, is based on a number of important legal decisions going back to the case of Karen Ann Quinlan and that of Cruzan (1,2). In the Quinlan case, the New Jersey Supreme Court ruled that the parents of the patient had the right as surrogates to have life prolonging treatment withdrawn from their daughter, who was in an irreversible persistent vegetative state. In the Cruzan case, the US Supreme Court held that while the individual states had the right to preserve human life, the patient's parents had the right to have life support withdrawn given sufficient evidence of the patient's prior wishes once she was permanently unconscious. In the Cruzan case this was a problem, but the Supreme Court referred the case back to the Missouri courts, who ultimately accepted the parents' contention that the patient would not have wished to be kept alive in this way. The subsequent cases of Bouvia (3) and Perlmutter (4) established the rights of patients who did not have a terminal illness, and were competent, to refuse life sustaining therapy (see also ref. 5).

The basis for suggested policies for physician assisted suicide as adopted in the Oregon Death with Dignity Act is the proposal put forward by Quill et al (6) in an article in 1992. This paper follows the lessons learned in the Netherlands (7). In their paper, Quill et al (6) suggested that a patient who has decision-making capacity, has a terminal illness (as defined below) with intractable suffer-
ing and is free of major depression may request his/her physician for assistance with suicide by providing a prescription for a lethal dose of a sedative, that the patient can use at the time of his or her choosing. The request should be in writing and be repeated after an interval of some weeks and a full discussion with the physician and the patient's family if possible (6).

Before reviewing a suggested method of each analysis and applying this to some paradigmatic cases, it is important to define some basic terms.

1. Terminal Illness – an illness from which a patient is unlikely to recover and which is expected to cause death in less than 6 months.

2. Withholding Life Sustaining Treatment – the decision to allow the disease to take its course, while providing comfort or palliative care (food and drink as tolerated, pain medication and sedation and, optionally, antimicrobial agents). This decision must be based on mutual agreement by the patient or surrogate and the physician.

3. Withdrawing Life Sustaining Treatment – the decision to discontinue measures which are prolonging the patient’s dying process, e.g., ventilator support, tube feeding, pressors and antimicrobial agents. Comfort or palliative care such as pain medications and sedatives are provided. Also included in this category would be stopping hemorrhage or peritoneal dialysis. Again, this decision must be made jointly by the patient or surrogate and the physician.

4. Physician Assisted Suicide – the physician provides the patient with a prescription for a lethal dose of drug which the patient can take at a time of his or his choosing. To qualify the patient must be terminally ill, alert, have intractable suffering and have decision-making capacity and make two written requests for help from the physician at least 3 weeks apart. In addition a second physician must confirm the diagnosis. This is only legal in the State of Oregon at this time, but is currently practiced in the Netherlands under supervision by the State (7-9).

5. Euthanasia – the physician administers the lethal medication in person. This can be either (a) voluntary – when the patient or appropriate surrogate makes the request for a terminally ill patient, or (b) involuntary – when lethal medication is given by the physician without a request from the patient or surrogate. Euthanasia is not permitted by law and is tantamount to murder in all US jurisdictions, but is possible in the Netherlands under State supervision (7-9).

6. Advance Directive – is a written document that can be a living will and/or a Health Care Proxy (Durable Power of Attorney for Health Care) which indicates the patient’s wishes and/or the person who can represent them, in the event the patient is not capable of doing so in person.

Clinical Decision-making

The process of clinical decision-making which we have used in our Ethics Consultation Service is based on the method of Jonsen et al (10). Sometimes referred to as the four boxes, it consists of four steps:

1. Medical Indications – these include the diagnosis or diagnoses, prognosis, tests that may be required for confirmation of the diagnosis, and their risks, and the therapeutic options with likely benefits and risks and a clear definition of the medical outcomes which are possible for the patient. Arriving at this formulation of the options allows the physician to review the options with the patient and family.

2. Patient (Surrogate) Preferences – these consist of the patient’s wishes, cultural and religious values, and understanding of the clinical situation. If the patient is not able to indicate his or her wishes, a surrogate will be asked to represent him or her. If there is an Advance Directive or a Health Care Proxy, these become effective and very helpful should the patient lack decision-making capacity. Definition of patient preferences and the medical indications usually allows for a consensus about the goals of management.

3. Quality of Life Issues – this covers issues from the patient’s point of view concerning questions of life style, acceptable limitations on activities, burdens of future medical care and family support.

4. Contextual Issues – these include questions of family wishes and their influence on the patient, religious and cultural influences that may impact on decisions, family support and financial matters, and the policy and economic implications for society.

We will now examine how these definitions and methods can be applied to particular kinds of clinical situations. These cases are based on real patient experiences seen by our Ethics Consultation Service.

Case 1 (Withholding Care)

AB, a 65 year old woman with extensive metastatic breast cancer, is brought to the hospital with high fever and septic shock (arterial pH 7.12 and oxygen saturation is 82% on 100% nasal 02 and BP 90/50). Respiration rate is 35 with shallow breathing. Previous efforts at chemotherapy have resulted in severe toxicity and no beneficial response. Her prognosis for long term survival is less than 6 months. Her likelihood of recovery from the present acute illness is less than 50%. She will need intensive care with ventilator support for the present acute situation. The question is: should these measures be initiated or should life support be withheld?

The medical indications are that AB has a terminal illness. Further treatment of her underlying cancer will not be beneficial as noted above. The acute illness may be correctable with intensive
The patient’s preferences are less easy to define. The patient is agitated and confused, but does not want ventilator support. The husband and children state that AB was tired of her suffering and would not want intensive life support. Her quality of life was deteriorating and the burden of illness getting too great. Contextual issues were not of importance in this situation. The decision was made, therefore, by the physician and the family and the nurses, to provide comfort care only and AB died peacefully in a short time.

Case 2 (Withdrawing Care)

Same as 1, but the family asks that a trial of intensive care be given in the hope of a recovery and some months of life and a chance to see her grandson who is coming home from a semester abroad.

The medical indications are the same as in Case 1. Patient preferences have changed as represented by the surrogates, since the patient is confused, and indicate a wish to proceed with intensive care in the hope of temporary recovery. Quality of life issues have changed also in that AB’s grandson is coming home and seeing him again is thought by the family to be very important to her and to compensate for the burdens of treatment. Contextual features are not different from Case 1.

As her physician you feel the family’s wishes are reasonable, but suggest that her response to intensive care be reassessed after a few days to see whether appropriate progress was made. At this reassessment AB is found not to have responded to intensive life support and antimicrobial therapy and now has a right-sided weakness likely due to a stroke or left hemisphere metastasis. The question now arises whether further intensive care can achieve the desired goal as described by the family. At a meeting with the family and AB’s nurses, you raise the question of withdrawing life support in light of the change in medical indications, namely that the likelihood of recovery is diminishing and AB’s status, even if she does recover, is questionable because of the new neurological problem. It is agreed to obtain a head CT to define the cause of the hemiplegia. This shows a probable metastatic lesion. At a further meeting with all those involved in AB’s case, the conclusion is reached that further intensive care cannot achieve the goals set by the family and should, therefore, be discontinued, while ensuring patient comfort with appropriate sedation. Family support was provided by the physician and nurses and by the family’s clergyman at their request. She died peacefully in a few hours.

Case 3 (Physician Assisted Suicide)

Ms. CD with widely metastatic breast cancer including bone lesions, visits her physician to seek his help in committing suicide when her suffering becomes unbearable. She is alert, intelligent, and knows her condition well. Chemotherapy has been ineffective and resulted in severe side effects. Radiation therapy has given only temporary benefit. She needs increasing doses of opiates for pain control. She is sad, but not depressed.

The medical indications are clear. She has far advanced cancer and is not likely to live for more than 6 months. Further tests are not going to provide useful information. Standard chemotherapy has failed. The options are a trial of experimental drugs or possibly autologous bone marrow transplantation. You present these considerations to her. She states that her preference is not to try high technology treatments. She is tired and wants to enjoy her family while she can and then die at home in peace. You and she live in Oregon and you agree to consider her request. You ask her to have a consultation with an oncologist for confirmation of the diagnosis. You also ask her to put her request in writing and to arrange a meeting with her family.

Her quality of life is acceptable to her at the present time, but it is clear that further progression of her disease with worsening pain would make it unacceptable. The contextual features are that she has a supportive and loving family, some of whom live nearby and that the patient lives in a state where physician aid in suicide is legally allowed.

The consultant confirms your diagnosis, and the family, while saddened by CD’s situation, support her wishes. A month later you receive her second written request for help in suicide. You agree to provide this in case your efforts at palliation prove unsuccessful. You provide a prescription for Phenobarbital which CD fills and keeps in her safe as agreed between you. Your palliative care plan, however, proves effective. CD and her family have time to settle all their issues and she dies at home with her family at her side and her Phenobarbital in her safe and not used. But she knew that it was there, if she needed it.

Discussion

The case histories discussed above lay much emphasis on patient autonomy, exercised either directly by the patient herself or by the duly appointed proxy or a surrogate. Patient autonomy is the dominant principle governing patient care decisions in the USA at the present time. It is based on the assumption that the patient or surrogate have a clear understanding of the clinical situation, the management options and their likely outcomes, risks, and benefits. There have been those that have interpreted this as limiting the physician to simply laying out the options and then accepting the patient’s decision without discussion. Several authors have challenged this position (11-13). Thus Pellegrino and Thomasma (11) have argued strongly for doctor-patient relationship based on beneficence-in-trust, in which the physician consults with the patient and guides the patient toward a decision consistent with good medical care and the patient’s values. A similar position has been advocated by Emanuel and Emanuel (12) who argued for physician guidance of a fully informed patient in medical decisions. Balint and Shelton (13) and Quill and Brodie (14) have es-
posed a similar position. These views are consistent with the cooperative model first suggested by Szasz and Hollender (15). This collaborative process of joint decision-making requires mutual respect, understanding and trust, which can mitigate the power disequilibrium between patient and physician.

Sometimes this collaboration and consensus is difficult to achieve, because the patient or the surrogate clinging to unrealistic expectations of what medical care can accomplish. At other times, the problem is that the physician is the one wanting to keep trying for a cure when the burden of treatment is greater than the patient can accept. In these cases one has to deal with issues of medical futility, which can be physiological or value judgments (16). These are extremely difficult issues to resolve, since they are problems more of beliefs, values and hopes than of medical facts. It is in these settings that an ethics consultation can prove very valuable in enabling all the participants to work through their emotions, concerns, hopes, fears, and sometimes feelings of guilt, with the help of a “third party” which can act as a mediator to reach consensus.

There has been much debate in the literature of medical ethics about issues of withholding or withdrawing life support, that some have called “forgoing life support,” as opposed to physician assisted suicide (17-21). Indeed, some authors have even gone further and equated physician assisted suicide with euthanasia (7-9). In 1989, Wanzer et al (22) in discussing a physician’s duty to provide adequate palliative care for a terminally ill patient, even at the risk of shortening life, suggested that physician assisted suicide may be a legitimate consideration in some rare instances. Two years later Quill (23) described the case of Diane in which he described how he and the patient had after very full discussion agreed that he would provide Diane with a lethal dose of barbiturate to use at a time of her choosing. She was dying of acute leukemia. Brock (17) has argued strongly that withdrawal of life support and physician assisted suicide are equivalent. In his view the act of removing life support from a dying patient is in fact ending that patient’s life, just as providing a prescription for lethal dose of a sedative or injecting a lethal dose of drug (17). He further argues that these would be socially acceptable acts on the part of a physician at the patient’s request and with the patient’s fully informed consent (17). Rachels has made the same argument (18). Earlier Gaylin et al (24) had taken a strong position against physician assisted suicide or physician assistance in dying, but differentiated these actions from withdrawing life support. Several authors have strongly supported the view that forgoing life support and, thereby, allowing the disease to take its course and permitting the patient to die with dignity uncumbered by high technology equipment if that is their wish, is appropriate and is not “killing” (19-21,25). The argument presented by these writers is that in forgoing life support, such as mechanical ventilation or even hemodialysis, the physician is letting the disease take its course and not actively hastening death. Both McCormick (19) and Annas (20) argue for the importance of clear distinctions, and that we should not allow the availability of modern technology to observe the difference between a natural event, such as dying imminently of a terminal illness, and intervening in the form of providing a lethal drug to enable a patient to die, even though both actions are undertaken at the patient’s clear and informed request. In 1997, the US Supreme Court in their decisions on the appeals from Washington State (26) and New York State (27) upheld this distinction, which had been overruled by the lower courts.

It is now possible to re-examine the first two cases discussed earlier. In the first case a decision was reached not to institute intensive care with ventilatory support. That is the decision to withdraw life support. This decision was based on her poor prognosis for quality of life because of the far-advanced metastatic breast cancer and because her surrogates felt she would not want such intensive care. She was, therefore, provided comfort care and allowed to say her farewells and to die peacefully. That is, the terminal disease was allowed to run its course, and patient autonomy was respected. In the second case, while the prognosis is equally grave, the physician and the surrogates agreed to try to prolong the patient’s life with intensive life support because of her expressed wish to see her grandson. However, after a few days, Mrs. AB had not responded and in fact had developed a cerebral metastasis. A further family conference with the physician was held and it was obvious that the patient’s wishes were no longer attainable and that, therefore, further intensive care would be medically futile. The decision was, therefore, made to withdraw life support, provide comfort care to patient and family and allow her to die peacefully. This process again provided full respect for patient autonomy. In both these cases, the physician provided advice and guidance to the family as surrogates to allow them to exercise their substituted judgment on the patient’s behalf. These decisions are entirely in line with the positions taken by Wanzer et al (22) and others (19-21).

The issues surrounding physician assisted suicide are even more complex than those involved in forgoing life support. The positions taken by highly respected ethicists, legal scholars, and politicians are literally poles apart. They range from the position taken by Gaylin et al (24) that “doctors must not kill”, to the situation in the Netherlands (7-9) and the suggestions of Quill et al (6) for policy allowing physician assisted suicide in the USA. Oregon has now had a more than one year of experience with physician assisted suicide (28,29). The experience reported from Oregon is similar to that which has been accumulated in the Netherlands (7-9,30) in that the number of cases of physician assisted deaths is very small compared to total deaths. In Oregon, there have been 1–3 cases of physician assisted suicide each month out of 2,400 total deaths,
i.e., 0.1% of all deaths (28,29). In the Netherlands the figures are one order of magnitude higher at 3.5% in 1995 (8). It is important to note that this figure is unchanged from the 1990 data (7). There are, however, important differences between Oregon and the Netherlands situations. In Oregon only physician assisted suicide, as defined in this paper, is permitted, while in the Netherlands physician assisted suicide and euthanasia are not differentiated (7-9,28). Furthermore, there is evidence that in the Netherlands only 40–50% of physician assisted dying is reported (9). This is obviously of great concern. Oregon and the Netherlands are similar in another respect, in that both have an ethnically relatively homogeneous population and have health care systems that come close to providing universal access to health care (30). It is, therefore, not clear whether allowing physician assisted suicide in a less homogeneous societies or one with limited access to health care would be safe or lead to abuse and injustice.

Even if these matters of justice and policy could be resolved, we will be left with the unanswered question of the morality and ethics of physician assistance in dying. In the USA, some 70% of hospital deaths are reported to follow a decision to forgo intensive care (30). A recent survey cited by Angell (30) suggests that in Washington State 16% of physicians have been asked for help in dying and about 25% of the requests were granted. Thus, there is a small but significant proportion of patients who feel the need for such assistance and some physicians who are willing to help them. For me this remains a difficult issue. In my 50 years of medical practice, I have received only 3 requests for aid in dying. I believe that if the physician has a strong long standing relationship with a patient and the patient, the family and the physician feel that the patient’s request, like that of Diane (23) is justified, then providing such assistance is ethically and morally appropriate. We as physicians and our respective nations or states need to make our own decisions on this issue over time.

Euthanasia in any form is contrary to law in the United States and almost all other countries and has, therefore, not been discussed in this essay. Investigators in the Netherlands have published their findings in this area in the context of their experience (8,9). These raise several concerns such as the high proportion of cases of involuntary euthanasia and the uncertainty about the extent of unreported cases of physician assisted suicide and euthanasia (8,9). They noted the absence of patient or surrogate consent in almost one third of the cases and a rate of reporting of cases below 50%. While these concerns may be acceptable within a homogeneous society with a national health service, they could present a major problem in a pluralistic, diverse society with for profit private health insurance, and in many nations with strong religious traditions and beliefs in the sanctity of life.

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