Ethical Decision Making in the Care of the Patient with End-stage Renal Disease (ESRD)

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Ethical decision making in caring for patients with ESRD shares many common elements of ethical decision making with other areas of medicine. There are features unique to the patients with ESRD, however. Because of the frequent complexity and finality of the decisions both patients and nephrologists are asked to make, guidelines have been established to add some uniformity to the thought and advice we are asked to share with patients and their families. These will be reviewed.

Areas of Commonality

Common principles of ethical decision making for all medical care include the following:

- beneficence: defined as doing what is best for the patient,
- nonmalfiecence: defined as doing no harm to the patient,
- patient autonomy: defined as allowing the patient to determine for himself what is best, and
- justice: defined as evolving what is a proper balance between the patient and the environment in which he lives.

Areas of Differences

Features of care for the patient with chronic renal disease which are unique include following:

- the chronicity of survival by artificial means,
- the complexity of the patients' diseases,
- the fact that the burdens of treatment may often outweigh the perceived benefits of treatment, and
- the long-term physical, emotional, and financial cost to the patient, his family, and society.

In establishing guidelines to assist us in advising patients as to for whom dialysis should be considered or in helping advise patients when it is appropriate to consider withdrawal of dialysis, it is important to remember that the guidelines are consensus guidelines evolved from numerous discussions, conferences, and many hours of thought on the part of many people. Although not perfect, they represent an attempt to bring some uniformity to an area of care that has evolved as a result of technology that arrived and was widely implemented before anyone envisioned that its availability might not always be in the best interest of the persons to whom it would be provided.

Ethics and How We React

Ethics is defined as the discipline of dealing with what is good and bad, or right and wrong, or dealing with moral duty and obligation [1]. This definition, in and of itself, allows us to understand the complexity or the situation. None of us knows for certain what is necessarily good or bad, or right or wrong for another person. We certainly might have an opinion about what is right, but we do not know for certain. We have varied opinions regarding moral duty and obligation. Likewise, people's perceptions of life quality vary enormously and when facing the choice between prolongation of life by artificial means vs. imminent death, feelings are tense. Caregivers need to always consider the varied opinion of what is right and be mindful of the emotional intensity of the situations in which we are participants. We are there to give advice as to what can be offered, the projected outcomes of the therapies, and the consequences of the therapies, both good and bad. We are there to offer comfort and support to the patient while he makes the decision, and then we are there to make his decision work in the best manner possible. We are not there to make the decision for the patient. My perception of our moral duty and obligation is that we are there to educate the patient to a level of understanding that allows him to make an appropriate decision for himself. It is then our moral duty and obligation to help make that decision work even if it is different from the one we might have made.

Frequently, we as caregivers feel we have insights that patients do not have. Because of the intensity of what we do, the finality of death, and the awareness that we have the ability to prolong life, we often feel patients do not have the appropriate background to allow them to make the proper decision and thus have a tendency to transfer our feelings of what is right and wrong to them. In my opinion, this is inappropriate. What is appropriate is to educate patients so they make a shared decision with us. This shared decision making is equivalent to informed consent and is a primary goal of ethical decision making in any medical environment.

Evolution of Ethical Decision Making

We concede that defining what is good and bad for another individual is frequently difficult if not impossible. It is equally clear that our collective perceptions of what is good and bad, right and wrong evolve and change as our understanding of our environment changes. Therefore, what we may perceive as right today may be perceived as wrong tomorrow. The decisions each of us make as individuals with our patients daily, however, will when added together decide what decision society eventually makes for itself regarding what is right and wrong. This is the process by which guidelines evolve and policy is determined. The "right to life" issues, living wills, decision making regarding initiation and cessation of dialysis are modern inquiries that did not exist in the pretechnologic era. Collectively, we are still evolving our perception regarding what is right and wrong about these issues. Likewise, the rightness and wrongness of genetic engineering is an area evolving as our understanding of the potential consequences of genetic engineering expands. The choices we are currently making with individual patients will eventually evolve into policy and alter our future perceptions of what is best.

We need to view this ethical evolution as critically as we view our technologic advances. Science evolves by isolating under experimental conditions a particular process so the investigator can observe what nature already knows. By understanding the particular process, the investigator can add this observation to a greater body. Collectively, science, through understanding, can utilize the information to advance itself and hopefully benefit mankind. Likewise, each of our individual decisions with patients should be viewed as a rigorous scientific endeavor in which we and the patients are the natural reactants in the experiment. We are to provide to the patient new information that allows him to realistically understand the outcome of his actions and collectively these *patient made decisions* will determine our evolving policy. Recent practical examples of how juxtaposed technologic and ethical evolution occurs could be considered the advice modification we give patients with regards to survival quality on dialysis before and after the introduction of erythropoietin or advice given to diabetic and systemic lupus erythematosis patients with regards to their chance of survival with transplantation. In both instances, we are able to “upgrade” the potential outlook for the patients as we advise them as to what we feel are appropriate choices.

Despite the technologic advances, however, we are still confronted with patients for whom we know our current treatment may not offer quality survival. These patients constitute a major dilemma for all and consume an enormous amount of our emotional energy. Again, none of us is empowered to make a decision for another unless we are the legal surrogate for the patient. Our duty remains to educate these patients about what realistically can be offered and expected. When, in our opinion, our treatment does not offer realistic quality survival, we have an obligation to communicate this opinion to the patients. During the same encounter, we are obligated to inform the patient and family that care will be continued in a compassionate manner whether or not technologic intervention is utilized. Historical guidance for appropriate care in this situation has been present since Hippocrates [2] implored us to alleviate the sufferings of the sick and Francis Bacon urged we treat patients’ symptoms only when they might recover [3]. In my opinion, it is only right that we tell patients what to expect and it is our moral duty and obligation to care for them, including the alleviation of suffering, if they choose not to initiate or to withdraw from dialysis.

Guidelines

Because of the enormity of cost, the frequent uncertainty of outcome, the finality of withholding dialysis, and varied opinions as to what is best, the National Kidney Foundation (NKF) set about to establish guidelines for us to use in having discussions with patients. These guidelines have evolved from a series of meetings with medical professionals, legal experts, clergy, ethicists, patients, and academicians. They are not intended to be rules and regulations, but are intended to be utilized as tools in discussing dialysis initiation and withdrawal with patients. The guidelines are based upon the recommendations of the Panel on Initiation and Withdrawal at the NKF Controversies in Quality of Dialysis Care Consensus Conference in 1994 [4].

Recommendation Summary

1. Decisions on whether to initiate or withdraw dialysis therapy are patient specific and *culturally, religiously and ethically sensitive decisions. These decisions can only be made on an informed basis by the individual patient/surrogate after consultation with the care team and others.*

Comment: It is imperative to remember that as healthcare providers, the only unique elements we possess are technologic knowledge and our medical experience. The patient's cultural, religious, ethical values and traditions have as much validity or more than our own. If he is taught to incorporate our technical knowledge and medical experience into his body of information, he will make an appropriate decision for himself.

2. It is unethical to use mandatory standards including a patient's age life expectancy, quality of life, intellectual or physical limitations, socio-economic status or psychological condition in determining whether to initiate or withdraw dialysis.

Comment: All of these issues should be discussed with the patient and family. Certainly, life expectancy needs to be considered and discussed. However, none of these conditions should be used as a mandatory means of exclusion. The issues frequently arise in the consideration of patients for transplantation where there is a shortage of organs for transplant. Even in this setting, it is inappropriate to adopt mandatory exclusion criteria. It is appropriate to advise patients who are elderly or patients with severe coexisting illnesses that certain forms of therapy may be burdensome and ill advised.

3. The patient's values, preferences and goals are major factors, but not absolutely controlling, in the decision making process regarding initiation or continuation of dialysis. While the patient/surrogate has the right to request the initiation or continuation of dialysis treatment, the physician has the right to request the right to refuse to provide treatment which in his/her best professional judgment is the medically useless or futile and unwarranted; for example, where the patient is in a persistent vegetative state or is suffering from severe, irreversible dementia.

Comment: Preservation of patient autonomy is a major goal in ethical decision making. However, in any shared decision different participants may seek autonomous control. If autonomy is the goal of the process, there may be 2 separate decisions. If autonomy is viewed as a constraint, however, a shared common decision may be reached allowing each participant to feel his autonomy has not been violated by the other. In the current health care arena, there is, a third party, society, whose autonomy must be considered. Society, via monetary constraints, is expressing its position loudly. If all 3 participants decide a common goal is the best and most compassionate care for both individuals and majority, dialogue may allow this goal to be achieved. These guidelines represent an attempt to add uniformity to this quest.

4. A patient who has the capacity to make his/her own medical decisions has an absolute right to make a decision not to initiate or to withdraw dialysis therapy. His/her decision in these circumstances should be controlling.

Comment: The right of patient refusal has been upheld by the courts on numerous occasions. We have a duty to do everything possible to help patients understand why we think our therapy is best or not best for them. We do not have the right to force them to receive the therapy if, after proper endeavors, they still do not wish to proceed with therapy. This has to be viewed as an educative process.

We are obligated to improve our education skills to the highest level to optimize the patients' understanding.

5. If quality of life or level of mental functioning is used to justify a decision not to initiate dialysis or to withdrawdialysis and the patient has the capacity tomake medical decisions, it is only the patient's perception of his or her quality of life or level of functioning that should be utilized.

Comment: It is often useful to ask patients and families if they would like a therapy utilized if it would allow the patient to return to a quality of life consistent with what he had in the past or would want in the future. This situation frequently arises acutely when the patient is unable to speak for himself. The guideline serves 2 purposes:

- It allows all of us to realize it is the patient's perception of quality of life that is important.
- In the acute setting, this guideline helps the patient, family and/or surrogate to differentiate between the advisability of an acute intervention vs. a chronic intervention and allows the patient, family and/or surrogate to make a more comprehensible decision regarding what might be best.

6. Use of medical treatment, including dialysis, is not legally or ethically required where the patient will receive no substantive benefits from such therapy.

Comment: Again, this protects physician autonomy but encourages out of necessity the education of the patient about realistic expectations and outcomes. It also reverts back to the admonitions of Hippocrates and Bacon. Frequently, second opinions regarding the futility of a contemplated treatment will help patients understand complex issues.

7. In circumstances where a patient with ESRD is being evaluated for initiation of dialysis, it is recommended that dialysis be withheld where the patient:

- *a: is adequately diagnosed to be in a persistent vegetative state.*
- *b: has an irreversible and severe mental disorder that results in the patient being unable to react to or interact with his/her environment (e.g. advanced Alzheimer's disease or severe stroke).*

Comment: The key phrase in this guideline is "adequately diagnosed". Nothing breeds distrust of our profession more than authoritative advice given to patients when our basis for the certainty of the diagnosis is based on soft data. When advising against dialysis in the above setting, it is imperative to know the patient has an irreversible condition.

- *c: is expected to die within 60 days from a primary, non-renal disease, unless the patient has an overriding short term life goal that could be met by initiation of dialysis therapy.*

Comment: We are all terminal. The arbitrary number of 60 days is a guideline. Certainly, patients with longer life expectancies but with painful comorbid conditions may be advised against initiating dialysis. The use of dialysis for the achievement of short-term goals is very reasonable.

8. In cases where the benefits and burdens of initiation of dialysis for the patient are unclear, it is appropriate to recommend a trial period of dialysis of approximately 30 days.

Comment: Again, the quality of life issue is addressed. Frequently neither the caregiver nor the patient, family and/or surrogate knows what is best. A trial period is sometimes needed in order for us all to be educated.

9. A reassessment of all patients initiated on dialysis is appropriate after approximately 90 days of dialysis.

Comment: We have all encountered outcomes we did not predict. It is very appropriate to counsel all patients preemptively that a trial of dialysis is just that. It is a way of giving permission to someone to change his mind. We all need that permission.

10. In circumstances where a patient is on dialysis, it is recommended that dialysis be withdrawn for a patient:

- *a: adequately diagnosed to be in a persistent vegetative state.*
- *b: with an irreversible and severe mental disorder that results in the patient being unable to react to or interact with his/her environment (e.g. advanced Alzheimer's disease or severe stroke).*

Comment: Natural circumstances frequently dictate that a decision made under initial conditions might be different from one made under new conditions.

11. In cases where the patient/surrogate is considering or desires to withdrawdialysis and the health care team believes that there are possible interventive measures which could reverse the patient/surrogate's desire to withdraw, it is appropriate to recommend a trial period of 30 days, or such time as is necessary for an assessment of the effectiveness of the interventive measures.

Comment: This recommendation allows for the same latitude of uncertainty that exists frequently when dialysis is contemplated initially.

12. There are no Federal or state laws or judicial decisions which permit the health care team and/dialysis facilities to unilaterally withdraw dialysis therapy from a patient who is abusive, persistently disruptive or "non-adherent" with his/her dialysis regimen.

Comment: Abusive people exist everywhere. We are not allowed to care exclusively for people who are nonabusive. We do have our rights however. Appropriate disciplinary care for the abusive patient is within our rights. Withdrawal of care is not. It is also inappropriate for one individual to jeopardize the care of many because of the individual's abusive behavior.

13. The medical personnel treating the patient have continuing responsibilities to the patient/others after a decision is made not to initiate/withdraw dialysis therapy.

Comment: Hippocrates and Bacon would be proud of our remembering their admonitions.

We, as individuals and as a society, are in an evolutionary process. Since we are a part of nature ourselves, it is appropriate to view ourselves as unfinished parts of a greater whole that will continue to evolve to a more finished product. The development of guidelines, based on ethical decision-making principles for care of patients with ESRD, is an appropriate manner in which to continue this process. It is also clear that the guidelines will change as technology advances and our understanding of the consequences of new technology advances.

References

[1] Webster's Third New International Dictionary. 1961 Merriam-Webster, Springfield, MA p 780

[2] Selections from the Hippocratic Corpus 1977 In: Reiser SJ, Dyck AJ, Curran WJ (eds.): Ethics in medicine: Historical perspective and contemporary concerns. MIT Press, Cambridge, MA pp 1-9

[3] *Bacon F, Spedding E, Spedding J 1905* trans. De dignitatae et augmentis scientiarum. In: Robertson JM (ed): The Philosophical Works of Francis Bacon. EP Dutton, New York, NY 2:487

[4] *National Kidney Foundation, Inc.* 1996 Summary of Recommendations in initiation or withdrawal of dialysis in end stage renal disease: guidelines for the health care team. New York, NY, pp iii-iv