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RPA/ASN POSITION ON QUALITY CARE AT THE END OF LIFE

Executive Summary

The Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) believe there is substantial need to educate all members of the medical community, including patients, families, physicians, and other health care professionals regarding what constitutes quality care at the end of life. This is an especially important concern for nephrologists, because nephrologists often treat patients with end-stage renal disease (ESRD) who either decline or withdraw from dialysis and wish to die naturally. The RPA/ASN believe that competent patients have the right to forgo dialysis based on the ethical principle of respect for patient autonomy and the legal right of self-determination, and that withholding or withdrawing dialysis of a competent patient at the request of the patient does not constitute physician-assisted suicide. It is the opinion of the RPA/ASN that after a decision is made to forgo dialysis, a palliative care approach is the optimal method of patient care. Palliative care includes pain and symptom management, advance care planning, and psychosocial and spiritual support to the patient and family. Nephrologists are encouraged to obtain education and skills in palliative care, so that they are comfortable addressing end-of-life issues with their patients. Dialysis facilities are also urged to develop protocols, policies, and/or programs to ensure that palliative care, including advance care planning, is conducted with their patients.

Background

Over 60,000 ESRD patients die per year with approximately 20 percent of these deaths following a decision by the patient or the patient's surrogate to stop dialysis. The RPA/ASN believe that care at the end of life is an especially important concern for nephrologists, because nephrologists often treat patients with end-stage renal disease who either decline dialysis or withdraw from dialysis. In so doing, these patients express the wish to die naturally. The RPA/ASN believe that care of the dying renal patient is best provided by a multidisciplinary team, and for this reason, the RPA/ASN asked the American Nephrology Nurses' Association, the National Kidney Foundation Council of Nephrology Social Workers, and the Forum of ESRD Networks to work with them in preparing the initial version of this position statement. Similarly, because identifying and respecting patients' wishes is central to providing quality end-of-life care, the RPA/ASN invited the American Association of Kidney Patients to provide input to this position statement.

Definitions

Advance Care Planning- A process of communication among the patient, his/her family and friends, and the health care team in which the patient's preferences for a surrogate and for future medical care are determined prospectively (preferably including the completion of a written advance directive), updated periodically, and respected when the patient no longer has the decision-making capacity to participate in medical decisions.

Advance Directive- An oral or preferably written statement by a patient with decision-making capacity expressing his/her preferences for a surrogate and/or for future medical care in the event he/she becomes unable to participate in medical decision-making. All 50 states have one or more laws recognizing written advance directives and the rights of patients to have their wishes respected. There are two types of written advance directives: a living will (an instruction directive in which the

patient gives directions for future medical care);and a health care proxy (a proxy directive in which the patient designates a person to make decisions for him/her when the patient loses decision-making capacity). In some states the health care proxy is referred to as a medical power of attorney or a durable power of attorney for health care. In some states, both instruction and proxy directives may be combined into one advance directive form. All advance directives must comply with applicable state procedural and substantive laws.

Cardiopulmonary resuscitation- A procedure performed to attempt to support and restore ventilation and circulation in a patient experiencing cardiac arrest (asystole, ventricular fibrillation, or pulseless electrical activity) or respiratory arrest (cessation of respiratory effort). It includes establishment and maintenance of an airway, assisted ventilation, chest compressions, establishment of intravenous access, cardiac monitoring, administration of medications, defibrillation or other control of arrhythmias, and immediate care after resuscitation.

Hospice- A team approach to treatment of the terminally ill patient, usually in the home, that uses the principles of palliative care to help meet the physical, psychological, social, and spiritual needs of the patient and family. Hospice treats the person, not the disease; considers the entire family the unit of care; and provides bereavement counseling for the family after the patient's death. Occasionally hospice is available in a residential facility when the patient is unable to receive hospice in the home because of the lack of a caregiver in the home.

Palliative Care- Comprehensive, interdisciplinary care of patients and families facing a chronic or terminal illness focusing primarily on comfort and support. It affirms life and regards dying as a normal process. It neither hastens nor postpones death. It includes relief from pain and other distressing physical symptoms, and advance care planning. It integrates the psychological and spiritual aspects of patient care, and offers a support system to help the family cope during the patient's illness and in their own bereavement. The goals of palliative care are relief of suffering and maximization of quality of life.

Surrogate- A person who has the legal authority to make decisions for a patient who lacks decision-making capacity. A surrogate is usually a family member, but may be a close friend. A surrogate should make treatment decisions for a patient based on either the patient's expressed wishes, or upon the patient's known values and beliefs (a process known as "substituted judgment"), or when these are unknown, upon the patient's best interests.

Terminal Illness-Illness in which death is expected within six months.

Analysis

Most patients with ESRD who refuse dialysis or choose to stop it usually die in less than a month. Patients who stop dialysis die on average eight to twelve days later. By definition, these patients are terminally ill. It is generally agreed that the optimal method of providing end-of-life care for terminally ill patients is a palliative care approach. Nephrologists need to know how to incorporate a palliative approach into their treatment of patients to provide them with the best care possible. This statement describes this approach as it relates to nephrological care under three components: ethical and legal issues, treatment issues, and advance care planning.

Ethical and Legal Issues

Competent patients have the right to forgo dialysis based on the ethical principle of respect for patient autonomy and the legal right of self-determination. To exercise this right, patients need to

have decision-making capacity, be fully informed about and understand the alternatives and the consequences of each, and be free from coercion. When a patient refuses dialysis, nephrologists should also consider whether there are reversible factors such as depression or dissatisfaction with one or more aspects of dialysis that are leading to the patient's request and that could be addressed. If, after examination of these factors and responding to them, when appropriate, the nephrologist is satisfied that the patient's refusal of dialysis is informed and uncoerced, the nephrologist is obligated to respect the patient's wishes.

Withholding or withdrawing dialysis from a competent patient at the request of the patient or of an incompetent patient at the request of the surrogate does **not** constitute physician-assisted suicide. Inherent in the legal doctrine of informed consent is the right of competent patients to refuse unwanted treatments. This doctrine is firmly grounded in common law, constitutional law, and federal statute. Physicians are legally required to honor competent patients' treatment decisions. To do otherwise--for example, to force unwanted dialysis on a competent patient--constitutes medical battery.

Treatment Issues

The wishes of an informed and capable patient or, if the patient lacks decision-making capacity, his/her surrogate, are pivotal concerning dialysis treatment decisions. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to determine why the patient/surrogate is refusing dialysis to be sure the patient/surrogate correctly understands the information that has been presented to him/her and the consequences of the decision.

Questions that may be helpful in this evaluation are as follows:

- 1) Does the patient have decision-making capacity or is the patient's cognitive capacity diminished by depression, encephalopathy, or other disorder?
- 2) Why does the patient want to not initiate or stop dialysis?
- 3) Are the patient's perceptions about the technical or quality-of-life aspects of dialysis accurate?
- 4) Does the patient sincerely mean what he/she says or is the decision to refuse dialysis made to get attention, help, or control?
- 5) Can any changes in treatment or treatment modality be made that might improve life on dialysis for the patient?
- 6) Has the patient discussed this request with family, close friends, and/or clergy? What do they think about the patient's request? Is the patient cognizant of the implications of his/her requests on his/her family and close friends?
- 7) Would the patient be willing to continue dialysis while the factors responsible for the patient's request are being addressed?

Once a decision is made to forgo dialysis, the dialysis team should refer the patient to a hospice or adopt a palliative care approach to patient care. Patients and surrogates should be informed that death from uremia usually takes 8 to 12 days (or occasionally longer) depending on the circumstances, that death from uremia is usually a comfortable one in which the patient becomes increasingly somnolent and then dies, and that if dialysis is not initiated or is withdrawn it will be necessary to maintain salt and fluid restrictions so that pulmonary edema does not occur and mar the comfort of the dying process. Nephrologist/renal team involvement is strongly encouraged to maintain continuity in patient care. The team should take the following steps:

- ❑ encourage the patient to review his/her advance directive for any change that the patient may wish to make;
- ❑ institute whatever means are necessary to ensure patient comfort, including medications and

measures for pain, nausea, agitation, myoclonus, pruritus, and dyspnea;

- ❑ encourage the patient to express his/her preferences with regard to the dying process, including site of death, persons desired to be present, funeral arrangements, etc;
- ❑ issue a Do-Not-Resuscitate order that applies to whatever setting the patient chooses to spend his/her final days;
- ❑ discuss with the patient and family contingencies for the final hours of the patient's life so that family or caregivers do not panic and call emergency medical services when the patient experiences a cardiopulmonary arrest; and
- ❑ address the needs of the family with regard to coping and grieving during the patient's dying process and bereavement after the patient's death.

Advance Care Planning

There is a presumption in favor of starting or continuing life-sustaining treatment, including dialysis, for patients who cannot and have not expressed their wishes. Hence, patients' preferences (and rights) to forgo dialysis in certain situations are usually difficult to respect unless patients have explicitly stated their preferences in advance or named surrogates to speak on their behalf. Therefore, the best way to be sure that a patient's wishes are known and can be respected after the patient loses decision-making capacity is to discuss with the patient (and his/her surrogate) in advance his/her preferences for medical treatment in the future. This discussion is called advance care planning. The product of this discussion is a patient's advance directives which are preferably given in writing but may include oral instructions about a patient's wishes for end-of-life care and designation of a surrogate. If the patient or surrogate gives oral advance directives, it is often helpful for the physician to document them in the progress notes in the patient's chart.

In the process of advance care planning, some of the issues that need to be specifically discussed are the following:

- ❑ circumstances when advance directives should be followed or ignored; and the degree of leeway the patient would wish to give his surrogate and physician in following or not following the advance directive explicitly, particularly when a new treatment becomes available;
- ❑ wishes for withdrawal or continuation of dialysis under various medical conditions;
- ❑ medical decisions surrogates are likely to face during the patient's incapacity such as whether to use cardiopulmonary resuscitation, mechanical ventilation, and tube feedings;
- ❑ the patient's values about independence, control, quality of life, suffering, additional treatment to reduce uncertainty about prognosis, and being a burden on the family; and
- ❑ the setting and circumstances under which the patient would prefer to die, i.e, at home versus in the hospital, a palliative care approach versus an aggressive approach, etc.

Because advance directives are needed to be able to respect incompetent patients' wishes, dialysis facilities have been strongly encouraged to develop protocols, policies, and/or programs for providing advance care planning to their patients. To be sure that advance care planning has occurred prior to a medical crisis, dialysis facilities are urged to incorporate advance care planning into the ongoing discussion with patients of their long-term care plan and to update the planning, as needed, whenever patients' medical conditions change. Patients generally expect that their

nephrologist will introduce the topic, but other members of the renal team need to be involved in the educational process necessary to prepare the patient and surrogate for the discussion. For advance care planning to be effective, research has shown that the renal team must be educated so that they are comfortable in addressing end-of-life issues.

To respect the wishes of patients who prefer not to undergo cardiopulmonary resuscitation, nephrologists shall issue do-not-resuscitate orders for their patients who request them. These orders shall be issued in the dialysis unit in a manner that respects patient confidentiality and yet ensures that those treating the patient are aware of them. As noted above, physicians are legally required to honor competent patients' treatment decisions. To do otherwise, ie, to perform unwanted cardiopulmonary resuscitation on a competent patient, constitutes medical battery. It is important to note, however, that a do-not resuscitate order does not preclude other standard measures in dialysis treatment such as fluid resuscitation for intradialytic hypotension. A do-not-resuscitate order only becomes effective when the patient has experienced a cardiac or respiratory arrest (see Definitions section under cardiopulmonary resuscitation). When a patient with a DNR order is hospitalized or admitted to a nursing home, the existence of the DNR order shall be communicated to the ambulance transport team and to the receiving facility to ensure respect for the patient's wishes.

Research studies of cardiopulmonary resuscitation in patients with renal disease, including ESRD, have indicated that the outcomes of cardiopulmonary resuscitation for these patients are usually poor. Many dialysis patients are misinformed about the outcomes of cardiopulmonary resuscitation because of what they have seen on television. Therefore it is necessary for nephrologists and other members of the renal team to educate dialysis patients about the likely outcome of cardiopulmonary resuscitation based on patients' particular medical conditions.

Recommendations

- 1. All members of the renal health care team including nephrologists, nephrology nurses, nephrology social workers, and renal dietitians should obtain education and skills in the principles of palliative care to ensure that ESRD patients and families receive multidimensional, compassionate, and competent care at the end of life.**
- 2. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to determine, if possible, why the patient/surrogate has decided to forgo dialysis to be sure the patient/surrogate correctly understands the information that has been presented to him/her and the consequences of the decision. Once the nephrologist is satisfied that the patient's decision to forgo dialysis is informed and uncoerced, the nephrologist should respect the wishes of the patient/surrogate.**
- 3. After a decision is made to forgo dialysis, the renal team should refer the patient to a hospice or adopt a palliative care approach to patient care. In either case, the nephrologist and other members of the renal team should remain active in the patient's care to maintain continuity of relationships and treatment.**
- 4. Nephrologists and other members of the renal team should obtain education and skills in advance care planning so that they are comfortable addressing end-of-life issues with their patients.**
- 5. Dialysis facilities should develop protocols, policies, and/or programs to ensure that advance care planning is conducted with their patients.**

6. Nephrologists should explicitly include in their advance care planning with patients/surrogates information about the outcomes of cardiopulmonary resuscitation for patients with ESRD and a discussion of patients' preferences regarding cardiopulmonary resuscitation if cardiac arrest were to occur while patients are undergoing a dialysis treatment. The RPA/ASN encourages dialysis facilities to develop policies and procedures for respecting the wishes of dialysis patients with regard to cardiopulmonary resuscitation in all settings including in the dialysis unit.

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