Recommendation Summary

Pediatric Patients

Establishing Family-centered Shared Decision-Making

Recommendation No. 1

Develop a patient-physician relationship that promotes family-centered shared decision-making for all pediatric patients with AKI, CKD, and ESRD.

In addition to involving pediatric patients to the extent that their decision-making capacity allows, the nephrologist should involve parents in determining health care decisions. If the parents request to involve other family members in shared decision-making, this request should be honored. If the treating nephrologist believes that a pediatric patient's parents are making decisions inconsistent with the best interest of their child, the nephrologist should involve medical ethics consultants or hospital ethics committees, mental health professionals, pediatricians specializing in child abuse and neglect, mediators, or conflict resolution specialists. These experts can assist in determining the reason for the parents' treatment choice and in determining an appropriate course of action. It is imperative that the nephrologist take steps to ensure that the pediatric patient has an adult advocate who is capable of participating in health care decision-making. Court involvement to order medical interventions over parental objections should be a last resort.

Family-centered shared decision-making process is recommended for all advance care planning discussions in which treatment options are discussed and treatment decisions are made. Education geared to the cognitive abilities of the parent and pediatric patient about the medical condition, prognosis, and available treatment options is an important component of the family-centered shared decision-making process. The pediatric patient's primary care physician, and in the case of the critically ill pediatric patient, their intensivist should be encouraged to participate in coordinating care related to treatment decisions made by the pediatric patient and his/her family. In the intensive care setting, patients with AKI will usually have multiple medical problems and the concept of shared decision-making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate, and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments.

Informing Patients and Parents

Recommendation No. 2

Fully inform patients with AKI, stage 4 or stage 5 CKD, or ESRD and their parents about the diagnosis, prognosis, and all appropriate treatment options. Inform children and adolescents in a developmentally appropriate manner, and if feasible, seek their assent about treatment decisions.

Treatment options include: 1) initiating or continuing dialysis; 2) transplantation for ESRD; 3) not starting dialysis and continuing optimal medical management; and 4) stopping dialysis and continuing to receive palliative treatment. The nephrologist and the medical team should make every effort to inform parents about the potential benefits and burdens of dialysis initiation or dialysis withdrawal before providing or withdrawing treatment. In the rare circumstances when this is not possible, parents should be informed as soon as possible about the rationale for emergent initiation or withdrawal of dialysis and the efforts that were made to contact the parents before changing the medical plan.As a component of informed permission/informed assent, and in keeping with the on-going process of both shared decision-making and advance care planning, the treating nephrologist may determine that dialysis is no longer providing net benefit (i.e., the risks or burdens outweigh the benefits, the underlying condition is progressive and dialysis is only prolonging the dying process without improving the quality of life during the dying process). In this case, the nephrologist and the medical team should approach the family and discuss the undue burden of dialysis given the patient's medical condition and recommend stopping dialysis and intensifying palliative treatment. This will typically occur in the intensive care setting and intensivists should coordinate the shared decision making in the context of other aspects of supportive care. Children and adolescents should be given the opportunity to communicate their feelings and perceptions regarding the benefits and burdens of dialysis to the extent they desire to do so and their developmental abilities and health status permits. When seeking informed permission/informed assent for discontinuing dialysis, the medical team should explicitly describe comfort measures and other components of palliative treatment that will be offered.

Recommendation No. 3

Facilitate informed decisions about dialysis for pediatric patients with AKI, CKD or ESRD, discuss prognosis, potential complications, and quality of life with the patient, parents, and/or legal guardian.

Nephrologists should rely on population-based survival data, using adjustments for confounders, to discuss prognosis, potential complications, and quality of life with patients, parents, and/or legal guardians. During these discussions, the nephrologist should acknowledge that the ability to predict survival in the individual patient is difficult and should reassure the patient and family that there will be ongoing opportunities for additional discussions regarding prognosis over time. Given the likelihood that health status changes for the better or worse are likely to occur in pediatric patients with AKI, CKD, and ESRD, discussions about survival odds and physical and psychosocial outcomes should be repeated when dramatic changes in health status occur. Each discussion regarding prognostic outcomes and patient/parent decisions regarding treatment should be documented in detail and dated. This documentation should be easily identified and accessible in the medical record. In the event of questionable understanding of the prognostic data, it is recommended that additional resources be offered to the pediatric patient and his or her family to ensure a reasonable understanding of likely outcomes and to allow for informed decision-making regarding treatment (see **Recommendation No. 8**).

Resolving Conflicts about What Dialysis Decisions to Make

Recommendation No. 4

Establish a systematic due process approach for conflict resolution if disagreements occur about dialysis decisions. Use conflict resolution interventions when family members disagree with one another, when children disagree with their parents, when families disagree with the health

care team, or when the health care team disagrees about initiating, not initiating, or withdrawing dialysis.

The following types of interventions are recommended to resolve conflicts: additional medical consultation(s); involvement of pastoral care; palliative care consultation; a multidisciplinary conference including sources of support for the patient/family from within or outside the institution; short-term counseling or psychiatric consultation for the child and/or family and/or consultation with a hospital-based ethics committee. When the health care team believes that non-initiation of dialysis would constitute medical neglect, consultation with available child protection specialists would be appropriate to help determine next steps. Court involvement should be used as an intervention of last resort.

Facilitating Advance Care Planning

Recommendation No. 5

Institute family-centered advance care planning for children and adolescents with AKI, CKD, and ESRD. The plan should establish treatment goals based on a child's medical condition and prognosis.

Family-centered advance care planning is recommended for infants with poorly functioning or nonfunctioning kidneys due to genetic conditions and those with a non-reversible urological or kidney abnormality. In the event that the health care team has information that the viability of a fetus with suspected multisystem organ involvement is questionable, family-centered advance care planning should occur before the birth of the baby. This will allow the health care team to be able to act decisively in light of the neonate's health status and prognosis at the time of delivery.

Advance care planning should be an ongoing process in which treatment goals are determined and revised based on observed benefits and burdens of dialysis and the values of the pediatric patient and the family. The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be *strongly* encouraged to talk to their parents to ensure that they know the patient's wishes and agrees to make decisions according to these wishes. Ongoing discussions that include reestablishing goals of care based on the child's response to medical treatment and optimal quality of life is the mechanism by which advance care planning occurs. Discussions should include the pros and cons of dialysis as well as potential morbidity associated with dialysis. Kidney transplantation should be discussed if appropriate.

Children and adolescents should be allowed to participate in advance care planning commensurate with their preference and developmental status. Parent or pediatric patient questions regarding discontinuation of dialysis if the patient's medical condition becomes irreversible and non-responsive to currently available treatments should be addressed frankly. Such questions can be used as a springboard for obtaining information about parent and child wishes regarding end-of-life care. Assurance should be given that the pediatric patient's comfort is paramount in the event that dialysis is discontinued. In addition, such questions should be used as an opportunity to explicitly describe comfort measures and other components of palliative care.

Making a Decision to Not Initiate or to Discontinue Dialysis

Recommendation No. 6

Forgo dialysis if initiating or continuing dialysis is deemed to be harmful, of no benefit, or merely prolongs a child's dying process. The decision to forgo dialysis must be made in consultation with the child's parents. Give children and adolescents the opportunity to participate in the decision to forgo dialysis to the extent that their developmental abilities and health status allow.

An example of a clinical situation in which forgoing dialysis is often considered is an infant with multisystem organ failure for whom dialysis would be burdensome and would serve only to prolong dying. Forgoing dialysis should also be considered for a pediatric patient whose kidney failure is a consequence of a primary health condition that is non-reversible, non-treatable, and terminal and for whom dialysis would cause undue suffering. Infants or children who would otherwise be expected to survive for years with conditions causing severe neurologic impairment and who develop ESRD should ordinarily not undergo dialysis or transplant. Examples might be an infant with anencephaly or severe porencephaly, or a child with a severe progressive demyelinating condition. In children with severe developmental disabilities, clinicians will need to discuss with parents the balance of the benefits to burdens of prolonging life with dialysis. An intensification of palliative care treatment should occur in conjunction with any decision to forgo dialysis.

Recommendation No. 7

Consider forgoing dialysis in a patient with a terminal illness whose long-term prognosis is poor if the patient and the family are in agreement with the physician that dialysis would not be of benefit or the burdens would outweigh the benefit.

In pediatric patients who experience major complications from dialysis that may substantially reduce survival or quality of life, it is appropriate to discuss and/or reassess treatment goals, including considering forgoing dialysis or withdrawing dialysis and initiating or increasing the emphasis on goals commensurate with palliative care. Alternatively, it is reasonable to initiate dialysis for patients with AKI or ESRD who have chronic illness from a non-kidney cause in whom outcome studies have been favorable. For example in HIV-associated nephropathy, dialysis has the potential to improve the quality of life in children.

Recommendation No. 8

Consider the use of a time-limited trial of dialysis in neonates, infants, children, and adolescents with AKI or ESRD to allow for the assessment of extent of recovery from an underlying disorder.

In an intensive care setting, neonates, infants, children and adolescents with AKI or ESRD as a result of an underlying disorder may be candidates for initiating time-limited trials of dialysis. The purpose of such a trial would be to establish the extent of recovery from the underlying disorder and/or to determine the balance of benefits to burdens that continued life enabled by dialysis provides to the child. The initiation of dialysis in conjunction with extra-corporeal membrane oxygenation (ECMO) is an example of a time-limited trial. It is considered time-limited in that the dialysis is most often discontinued when ECMO is withdrawn due to patient non-viability.

Providing Effective Palliative Care

Recommendation No. 9

Develop a palliative care plan for all pediatric patients with ESRD from the time of diagnosis and for children with AKI who forgo dialysis. The development of a palliative care plan is a continuation of the process of advance care planning and should be family-centered.

The terminally ill child, family and child's physician(s) should be involved in developing and executing a palliative care plan, based on their preferences concerning goals of care and decisions regarding testing, monitoring, and treatment. With the patient and family's permission, health care professionals with expertise in hospice and palliative medicine should be involved in co-managing the medical, psychosocial, and spiritual aspects of end-of-life care for the child and family. The nephrology team along with the child's pediatrician and other medical providers should offer bereavement support to the patient's family. In the case of a long-standing relationship with the pediatric patient, nephrology team members are encouraged to send a condolence card to the patient's family. Nephrology team members should be given complete autonomy regarding attendance at a pediatric patient's funeral or memorial service. Nephrologists and the child's health care team are strongly encouraged to seek support, in dealing with the child's dying process and death in the event that that the situation causes significant stress that interferes with baseline functioning at work or home.