December 14, 2009

DRAFT revision of the Renal Physicians Association clinical practice guideline

Shared Decision-Making
in the Appropriate Initiation of and Withdrawal from Dialysis

Notes for reviewers of this document:

1. For the purposes of this working document, the adult patient recommendations and rationales constitute a section of this revision of the Renal Physicians Association (RPA) clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis and the pediatric (neonate, infant, and children) recommendations and rationales constitute a separate section. For the convenience of reviewers, the new text is underlined and in red font. New figures, tables, and boxes are identified with red titles. New text in a box from the original guideline is underlined and in red font. The toolkit has been expanded to include new tools identified in the literature review relevant to the revised recommendations.

2. Please excuse the reference numbering. There are hundreds of new references identified in red font to be added to the 302 references in the original guideline. After receiving the comments of all the reviewers, the reference numbering will be redone. Thank you for your patience.

3. For some recommendations of the workgroups, there was overlap. For example, Workgroup #6 made recommendations with regard to Goals of Care which overlapped with the recommendations of Workgroup #4 with regard to Advance Care Planning. Where there was overlap, an attempt was made to eliminate the redundancy and place the recommendations in the section where they seemed to fit the best.

4. The scope of the guideline has been expanded to include chronic kidney disease (CKD) patients with stage 4 and 5 disease because many elderly stage 4 and 5 CKD patients are dying before the initiation of dialysis. In many cases, they are dying before they ever use their arteriovenous fistula that was inserted to comply with K/DOQI vascular access guideline recommendations. Please see the table below which indicates new guideline topics or ones updated from the original guideline in 2000.

5. Some contributors to this revised guideline have observed that by setting the context of the shared decision-making model on whether or not to withhold dialysis or, once started, whether or not to stop dialysis, this orientation introduces the bias that dialysis is the standard of care (i.e. the default method
of care) for anyone who develops end-stage renal disease (ESRD). This assumption is problematic for the following two reasons.

a. While dialysis may be the standard of care for the vast majority of ESRD patients, it is not necessarily the best care for every patient. This bias may diminish the extent to which nephrologists will consider and/or present conservative, non-dialytic treatment as a reasonable option. The elderly are the fastest growing population on dialysis so it is important to consider whether all elderly started on dialysis are best served by this treatment. There is increasing evidence in the nephrology literature which is presented in this revised guideline that stage 5 chronic kidney disease (CKD) patients over the age of 75 who are not uremic on presentation and who have high comorbidity scores, marked functional dependency, and poor nutritional status may survive about equally as long with conservative, non-dialytic management as with dialysis. The patients managed conservatively are spared dialysis access surgery and the inconvenience and complications of dialysis.

b. It may also diminish the necessary research needed to develop an evidence-base that will tell us whether a given patient would be best served by dialysis or by a non-dialytic, conservative approach.

6. To be most efficient in the guideline revision process, please send your suggestions for additions, corrections, and deletions in a separate document (template attached) with your name and e-mail address and identify your changes by page and line number. For example, page 2, line 22, the font for the word “address” is different than the rest of the text. Please e-mail your comments to amoss@hsc.wvu.edu by January 31, 2010. Thank you.
<table>
<thead>
<tr>
<th><strong>Topic</strong></th>
<th><strong>Implication</strong></th>
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<tr>
<td>Poor prognosis of some elderly stage 4 and 5 CKD patients, many of whom are likely to die prior to initiation of dialysis</td>
<td>Need for counseling regarding &lt;br&gt;1) access placement&lt;br&gt;2) initiation of dialysis vs conservative, non-dialytic management</td>
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<tr>
<td>High prevalence of cognitive impairment in dialysis patients</td>
<td>1) Suggest cognitive testing at start of dialysis and periodically thereafter&lt;br&gt;2) Need to assess decision-making capacity at initiation and yearly thereafter&lt;br&gt;3) Recommend earlier advance care planning</td>
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<tr>
<td>Newer more accurate models for estimating prognosis available</td>
<td>1) Recommend use of “surprise” question with integrated prognostic model&lt;br&gt;2) Refer some patients with poor prognosis for palliative care consultation and/or hospice referral</td>
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<tr>
<td>Inefficacy of advance directives and recognition of advanced care planning as preferred approach for decision-making in the event of incapacity</td>
<td>1) Recommend goals of care discussions&lt;br&gt;2) Recommend use of POLST Paradigm forms where available</td>
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<td>Recognition of undertreatment of pain and other symptoms in dialysis patients</td>
<td>1) Recommend referral to palliative care consultants for pain and symptom management</td>
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<td>Underutilization of hospice in dialysis patients</td>
<td>1) Recommend hospice referral for patients with 6 months or less to live</td>
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<td>Recognition of dialysis patients with distinctly different goals of care: palliative vs rehabilitative</td>
<td>1) Recommend quality measures appropriate for goals of care</td>
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<tr>
<td>Pediatric dialysis decision-making issues distinct from adults</td>
<td>2) Recommend separate chapter in clinical practice guideline on pediatric dialysis decision making</td>
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Section 4. Guideline Recommendations and Their Rationales
for the Treatment of Adult Patients

Recommendation No. 1: Shared Decision-Making

A patient-physician relationship that promotes shared decision-making is recommended for all patients with acute kidney injury (AKI), stage 4 and 5 chronic kidney disease (CKD), and stage 5 CKD requiring dialysis, referred to in this guideline as end-stage renal disease (ESRD). Participants in shared decision-making should involve at a minimum the patient and the physician. If a patient lacks decision-making capacity, decisions should involve the legal agent. The patient should be encouraged to talk to his/her legal agent to ensure that the legal agent knows the patient’s wishes and agrees to make decisions according to these wishes. With the patient’s consent, shared decision-making may include family members or friends and other members of the renal care team.

Rationale

The recommended process by which providers and patients come to agreement on a specific course of action is shared decision-making. It is based on a common understanding of the goals of treatment and the risks and benefits of the chosen course compared with any reasonable alternative. Ethical principles supporting this process include respect for patient autonomy, beneficence, and nonmaleficence. Observational evidence indicates that shared decision-making, especially the legal requirements for full disclosure and informed decisions, is often not achieved in the dialysis setting. Many patients initiating dialysis receive or perceive inadequate information and may not understand the information they do receive, despite the fact that most dialysis occurs in the setting of progressive CKD where the prognosis is known well before the actual need for dialysis arises. A factor that could limit patients’ understanding of information presented to them and their participation in shared decision-making is cognitive impairment which is severe enough to cause dialysis patients to lose decision-making capacity. Studies have found a high prevalence of cognitive impairment in certain populations of dialysis patients. In two studies in which the dialysis patients were randomly selected, cognitive impairment was found in 30 and 35 percent respectively (Sehgal AR, Am J Kidney Dis 1997; Kurella M, J Am Geriatr Soc 2004). In a study of dialysis patients aged 55 years and older, cognitive impairment was found in 87 percent. It was mild in 14 percent, moderate in 36 percent, and severe in 37 percent (Murray AM, Neurology 2006). The authors of these studies recommend cognitive testing before dialysis initiation and periodically thereafter. Patients with cognitive impairment should be assessed for decision-making capacity. For those patients without decision-making capacity, a legal agent of that patient should be engaged to make decisions, including advance care planning. The high prevalence of cognitive impairment underscores the need for assessing patients’ ability to meaningfully participate in advance care planning. Because of the progression of cognitive impairment over time, earlier and more frequent advance care planning is recommended for the dialysis population. (Elsayed E, Am J Kidney Dis 2007) See recommendation #5.
Recommendation No. 2: Informed Consent or Refusal

Physicians should fully inform AKI, stage 4 and 5 chronic kidney disease (CKD) and ESRD patients about their diagnosis, prognosis, and all treatment options, including: 1) available dialysis modalities and kidney transplantation, 2) not starting dialysis and continuing conservative, non-dialytic management, an option which should incorporate appropriate palliative care, including end-of-life care, 3) a time-limited trial of dialysis, and 4) stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary. The renal care team, in conjunction with the primary care physician, should insure that the patient or legal agent understands the consequences of the decision. Elderly (equal to or greater than 75 years) patients with significant comorbidities, marked functional impairment (e.g., Karnofsky performance status score < 40), and/or severe malnutrition (e.g., serum albumin level < 2.5 g/dL) constitute a special group. They should be informed that dialysis may not confer a survival advantage or improve functional status over conservative, non-dialytic management and that dialysis entails significant burdens which may detract from their quality of life.

Rationale

There is widespread consensus that patients with decision-making capacity should participate in medical decisions if they so choose.47-54 Competent patients have an absolute right to accept or refuse medically indicated treatment. This recommendation is supported by the ethical principle of respect for patient autonomy. Case law requires informed consent or refusal, and state and federal statutes provide for advance directives as written legal documents to be used to make decisions for patients when they lose decision-making capacity. Most states have health care surrogate acts that provide for the selection and authority of a surrogate decision maker when the patient lacks decision-making capacity and has not completed a written advance directive. Treating physicians are ethically and legally obligated to insure that these decisions are well-informed and documented. Observational studies show that patients infrequently think about end-of-life issues, discuss them with family, friends, or the renal care team, or complete advance directives.38-40,42,55-60 (Level B Observational Evidence) Dialysis patients may discuss advance directives more with their families than physicians, but 50 to 90% report no or inadequate discussions with health care professionals about therapeutic options including forgoing dialysis.37-46,51,61,62 (Level B Observational Evidence) Observational studies show most patients want information about their medical conditions and many (75-90%), though not all, desire to participate in care decisions.37,40,42,43,51,56,63-68 (Level B Observational Evidence) A review of shared decision-making in non-dialysis patient populations suggests that increased patient involvement in decision-making can lead to more fully informed consent, shared responsibility for treatment decisions, improved patient compliance, increased patient satisfaction, improved outcomes, and an overall increase in the quality of care.69

Elderly (equal to or greater than 75 years) patients with stage 4 or 5 CKD constitute a special group for whom the informed consent process regarding initiation of dialysis requires special consideration of the risk:benefit ratio. Because of the significant
comorbidities, severe functional impairment, and severe malnutrition of some elderly
CKD patients, research shows that nephrologists should not take an “age neutral”
approach to the management of CKD patients (O’Hare 2007). On the other hand, age
alone should not constitute a contraindication to starting dialysis since comorbidity is the
single most important determinant of outcome in dialysis patients (Davies 2002;
Couchoud 2009; Chandna 1999; Lamping 2000). Age and comorbidity are additive in
predicting dialysis patient survival. Thus, prior to placement of an arteriovenous access,
elderly patients with stage 4 or 5 CKD and significant comorbidities should be
specifically informed that

1) dialysis may not confer a survival advantage;

2) patients with their level of illness are more likely to die than live long enough to
progress to ESRD;

3) life on dialysis entails significant burdens which may detract from their quality of life;

4) the majority of patients in their condition either die or undergo significant functional
decline during the first year after dialysis initiation (Arnold 2009; Jassal 2009; Tamura
2009);

5) the burdens of dialysis include surgery for vascular access placement and
complications from the vascular access, and

6) they may experience adverse physical symptoms on dialysis such as dizziness, fatigue,
and cramping, and a feeling of “unwellness” after dialysis. Further, patients need to be
informed that there will be travel time and expense to and from dialysis, long hours spent
on dialysis, and a reduction in the time available for physical activity and meals
(Dasgupta 2009; Tamura 2009). Dialysis may entail an “unnecessary medicalization of
death” resulting in invasive tests, procedures, and hospitalizations (Smith 2003).

In one study, elderly patients with significant comorbidity treated with dialysis as
opposed to conservative management were more than four times as likely to die in the
hospital as at home and spent 47.5 percent of the days they survived either in the hospital
or at the dialysis clinic (Carson 2009). Such patients should be informed that conservative
management without dialysis is an acceptable alternative that may better achieve
patients’ goals of care. It is active treatment which entails advance care planning,
implementation of patients’ goals, and management of anemia, bone disease, fluid
balance, acidosis, symptoms, and blood pressure. Multiple studies report a median
survival greater than one year for patients managed conservatively (Carson 2009; Wong
2007; Ellam 2009; Murtagh 2007).
Box 1. Suggested Steps for Implementing Recommendation Nos. 1 and 2.

- Identify provider(s) who will coordinate communication with the patient or legal agent and family (e.g., nephrologist in conjunction with the primary care provider for ESRD patients or intensivists for AKI).
- Assess patient decision-making capacity and whether it is diminished by major depression, encephalopathy, or other disorder (see Toolkit section for helpful instruments). Obtain psychiatric and/or neurological consultation as appropriate, and institute treatment for conditions impairing decision-making capacity.
- Communicate diagnosis to patient (or legal agent) and family (if the patient agrees).
- Discuss prognosis based upon patient’s medical condition, comorbidities, functional status, and age (see Toolkit section for information about assessing functional status and quality of life, and estimating prognosis).
- Communicate options, taking advantage of educational resources, such as other patients or videotapes and brochures.
- Elicit patient or legal agent and family understanding of information and response.
- Identify the patient’s wishes.
[See Toolkit for National Kidney Foundation (NKF) checklist for initiating dialysis.]
- If the patient wants to forgo dialysis, determine why.
  - Are the patient’s perceptions about dialysis accurate? Does the patient know what to expect if dialysis is not started or discontinued?
  - Does the patient really mean what he/she says or is the decision to refuse or stop dialysis made to get attention, help, or control?
  - Are there changes that might improve quality of life and would the patient be willing to start or continue dialysis while the factors responsible for the patient’s request are addressed?
  - Are there persons (e.g., social worker, chaplain) with whom the patient would be willing to discuss the decision?
(Also, see Toolkit for NKF checklist on withdrawing dialysis.)
- Reach decision based on medical indications and patient’s preferences.
- Encourage patient to discuss end-of-life issues with others such as family, friends, or spiritual advisors (see Toolkit section for helpful questions to use).
- Refer for palliative care and hospice as appropriate.

Recommendation No. 3: Estimating Prognosis

To facilitate informed decisions about starting dialysis for either AKI or ESRD, dated and documented discussions should occur with the patient or legal agent (if the patient lacks decision-making capacity) about life expectancy and quality of life. All patients requiring dialysis should have their prognosis estimated, with the realization that the ability to predict survival in the individual patient is limited. A primary care physician or nephrologist who is familiar with estimating prognosis should conduct these discussions.
The “surprise” question, "Would I be surprised if this patient died in the next year?", can be used together with known risk factors for prediction of short-term survival and poor outcomes: age, comorbidity score; severe malnutrition [low serum albumin]; poor functional status [low Karnofsky Performance Status scale and/or inability to transfer]; calciphylaxis, advanced dementia, severe peripheral vascular disease, and New York Heart Association class 3-4 heart failure.

The estimates of prognosis should be discussed with the patient or legal agent, patient’s family, and among the medical team members to develop a consensus on the goals of care and whether dialysis or a conservative approach to CKD should be used to best achieve these goals for patients with CKD. These discussions should occur as early as possible in the course of the patient’s kidney disease and continue as the kidney disease progresses. For ESRD patients on dialysis who experience major complications that may substantially reduce survival or quality of life, it is appropriate to reassess treatment goals, including consideration of withdrawal from dialysis. For a patient with a poor prognosis who has not started dialysis, the likelihood that dialysis could worsen the patient’s quality of life should be presented and identified as a significant factor in dialysis decision-making.

Rationale

Pertinent ethical principles for this recommendation are respect for patient autonomy, beneficence, and nonmaleficence (see introduction).

When Discussions of Prognosis Should Occur

The majority of chronic kidney diseases have relatively slow courses allowing sufficient time for counseling about treatment options. These counseling sessions should occur prior to the time that dialysis is absolutely necessary. Additionally, the patient's cognitive capacity for decision-making may diminish as CKD worsens, impairing the patient's ability to participate fully in shared decision-making. Furthermore, late referral to nephrology may prevent the nephrologist from developing the therapeutic relationship needed to achieve a consensus regarding the goals of care until after the patient starts dialysis. Several studies suggest that 40-70% of patients with ESRD are either not referred to nephrologists prior to commencing dialysis or have emergent first dialysis sessions rather than electively planned first sessions and/or are using a venous catheter for dialysis access. Several DOPPS patients beginning dialysis in 1996 showed 33% and 21% of patients were first seen by a nephrologist < 3 months and < 1 month, respectively of beginning dialysis. Recent Dialysis Outcomes and Practice Patterns Study (DOPPS) data demonstrated a mortality hazard ratio of 0.65 for patients seen by a nephrologist > 1 month prior to starting dialysis. The REIN study (Couchoud 330) and others found negative consequences of an unplanned start for dialysis (Devins 394, Goldstein 527, Schwenger 1119)(Level B Prognostic Evidence) If the patient has already begun dialysis, a discussion about the long-term plan of care should begin as soon as the nephrologist and the other members of the renal care team determine the patient and/or legal agent can engage in a useful, rational conversation. The occurrence of sentinel events (see below) should also prompt further discussion of prognosis, values, preferences, and treatment goals.
Acute Kidney Injury (AKI)

Effect of AKI on Prognosis and Decision-making

The nephrologist can play a critical role in determining the aggressiveness of care for patients with AKI. AKI requiring renal replacement therapy provides a natural break point in the escalation of care. Discussions regarding the patient’s ability to withstand dialytic therapy can give family members a feeling that “everything” reasonable has been done to provide for the recovery of the patient. Multiple prospective and retrospective studies have documented intensive care unit (ICU) and in-hospital mortality rates of approximately 50 to 75% for patients with AKI receiving dialysis.73-121 (758 Landori) Medical and surgical patients had roughly similar mortality rates in these studies. A recent meta-analysis demonstrated the long-term morbidity and mortality after AKI (Coca 3012). The one retrospective study in bone marrow transplant patients showed a mortality rate of 85% with AKI-requiring dialysis and variable mortality risks depending on the type of bone marrow transplant. (970 Palevsky, 977 Parikh). In one large intensive care unit study, AKI requiring dialysis was found often to reflect the severity of underlying illness, impact overall survival negatively, and be associated with more frequent withdrawal from life support. (1235 Swartz) Withdrawal of life support in the ICU was studied in 584 pts in Switzerland (Gerstel 3003). This article found that family satisfaction was higher if withdrawal of life support took place over a longer period of days and if extubation occurred as part of the process of life-support withdrawal.

Prognosis Tools for Patients with AKI

Mortality prognosis can be quantified using routinely available measurement tools and scoring systems.80,118,120-131 (2 Abosaif, 110 Barrantes, 639 Jenq, 729 Kuitunen, 761 Leacche, 788 Lima, 796 Lins, 819 Maccariello, 956 Ostermann, 961 Ozturk, 991 Perez, 1296 Uchino, 1298 Uchino, 1337 Wald) Development of such measurement tools and prognostic scores has involved various multivariate modeling techniques and testing of over 75 potential prognostic variables. Variables most often independently associated with increased mortality have been liver failure, mechanical ventilation, and multiorgan failure.73,74,76-78,80,121,132 Two retrospective and three prospective studies, with sample sizes ranging from 100 to 500, have shown prognostic models do not have better than 80 to 85% discriminating ability in identifying individual patients with poor prognosis.74-77,80 In dialysis-dependent patients with AKI, general scoring systems may underestimate mortality risk. (Clermont G et al. KI;2002; Rocha E et al. NDT; 2009, Strijack, 2009) Recognizing the inability to precisely predict individual prognosis, the Working Group supported provision of gross estimates of prognosis based on the belief that this information facilitates realistic patient and family expectations and promotes informed decision-making.

Recovery Rate from AKI

Collective studies are inconclusive regarding the rate of recovery from AKI. Several studies report dialysis-free rates of approximately 70% to 90% among survivors of AKI that required renal replacement therapy.73,77,78,81,82,87,91,98-101,105,106,119 (87 Bagshaw, 89
Bagshaw) (Level B Prognostic and Observational Evidence) Most of these studies were small, retrospective, and only followed patients to hospital discharge. Two more recent clinical trials have shown widely disparate rates of recovery of kidney function ranging from 75% to 95% at 2-3 months of follow up. (Palevsky et al in Critical Care; The Renal Replacement Therapy Study Investigators, 2009). Complete recovery of kidney function to within 0.5 mg/dL of baseline serum creatinine concentration at 28 days after the initiation of renal replacement therapy was observed in fewer than 30% of patients surviving an episode of severe AKI in one clinical trial (VA/NIH Acute Renal Failure Trial Network, 2008). Adequate evidence regarding how many patients recover normal function and how long it takes for them to recover function was not found. In a study by Wald, the risk of developing ESRD after an episode of AKI requiring dialysis was 2.63/100 person years, nearly triple that of the control group (0.91/100 person years) who did not have AKI (Wald 3046) (Figure 1 & Table 1). The Working Group recommended that patients with AKI who no longer require dialysis but who still have significant kidney dysfunction continue to be followed by a renal care team. The follow-up care should be individualized to the patient’s needs and community resources. It may be provided by the patient’s primary care physician in conjunction with a renal care team. The Working Group agreed that patients with AKI of duration greater than two months have a strong likelihood of ESRD. They should be told that they have ESRD and counseled accordingly within six months.

Figure 1. Risk of Chronic Kidney Disease Requiring Dialysis in Association with Acute Kidney Injury and Dialysis During Index Hospitalization

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Table 1. Risk of Chronic Dialysis and All-Cause Mortality by Group

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Acute Kidney Injury and Dialysis at Index Hospitalization (n = 3769)</th>
<th>Without Acute Kidney Injury or Dialysis at Index Hospitalization (n = 13568)</th>
<th>Hazard Ratio (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Incidence Rate Per 100 Person-Years</td>
<td>No. of Events (%)</td>
<td>Incidence Rate Per 100 Person-Years</td>
</tr>
<tr>
<td>Chronic dialysis</td>
<td>322 (8.5)</td>
<td>2.63</td>
<td>400 (3.0)</td>
</tr>
<tr>
<td>All-cause mortality</td>
<td>1311 (34.8)</td>
<td>10.10</td>
<td>4884 (35.9)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Reflects the effect of acute kidney injury and dialysis vs matched individuals without acute kidney injury.

<sup>b</sup> Further adjusted for age (continuous in years) and the propensity score for acute kidney injury and dialysis.

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Stage 4 and 5 CKD

Recent studies have shed light on the poor prognosis of many CKD patients. Studies have demonstrated that CKD patients are more likely to die rather than reach dialysis, due to increasing cardiovascular mortality with higher stages of CKD (Roderick 3013, O’Hare). In one study, patients greater than 85 years of age had no baseline glomerular filtration rate at which they were more likely to progress to dialysis than die. Studies of conservative management of CKD patients, where palliative care is given rather than dialysis for selected sicker patients, have usually demonstrated a small survival benefit to dialysis versus conservative management but not uniformly so (Couchoud, Carson 3026, Murtagh 3027, Joly 3028, Brunori 217, Ellam, Smith Clin Nephron Pract 2003). (Table 2) In a study by Murtagh, patients greater than 75 years of age with ischemic heart disease or greater than 1 comorbidity had no survival benefit from dialysis (Figure 2) (Murtagh 3027). Likewise, in a study of patients with more comorbidities and lower functional status who had been recommended a non-dialytic approach to management but chose dialysis instead, there was not a significant survival advantage for these patients (Smith Clin Nephron Pract 2003). (Level B Observational Evidence) Couchoud developed and validated a simple clinical tool to predict 6-month mortality in elderly CKD patients starting dialysis (Couchoud).
Figure 2. Comparative Survival of CKD Patients over 75 Years with High Comorbidity Score with and without Dialysis

Kaplan-Meier survival curves for those with high comorbidity (score=2), comparing dialysis and conservative groups (log rank statistics <0.001, df 1, $P$=0.98.

Reprinted with permission from Murtagh 3027
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Dialysis</th>
<th>CM*</th>
<th>Median survival</th>
<th>Independent Predictors of Conservative Management Recommendation</th>
<th>Age (yrs)</th>
<th>GFR (ml/min)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smith 2003</td>
<td>321</td>
<td>258</td>
<td>63</td>
<td>RRT CM</td>
<td>Age</td>
<td>Mean 61.5</td>
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<td>8.3 vs. 6.3 months=NS (10 patients vs. 26 patients)</td>
<td>KPS</td>
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<td>RRT group 80% 4 yr survival</td>
<td>Diabetes</td>
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<tr>
<td>Joly 2003</td>
<td>144</td>
<td>107</td>
<td>37</td>
<td>RRT CM</td>
<td>KPS</td>
<td>Mean 83</td>
<td>&lt;10 CG</td>
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<td>28.9 vs. 8.9 months P&lt;.001</td>
<td>Social Isolation</td>
<td>Cut off ≥ 80</td>
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<td>Late Referral</td>
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<td>Low BMI</td>
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<td>Carson 2009</td>
<td>202</td>
<td>173</td>
<td>29</td>
<td>RRT CM</td>
<td>Age</td>
<td>≥70</td>
<td>≤30</td>
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<td></td>
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<td>37.8 vs. 13.9 months P&lt;.001</td>
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<td>Cut off</td>
<td></td>
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<td>Murtagh 2007</td>
<td>129</td>
<td>52</td>
<td>77</td>
<td>RRT CM</td>
<td>Age</td>
<td>&gt;75 yrs</td>
<td>&lt; 15 Stage 5</td>
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<td></td>
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<td>84% vs. 68% at 1 yr (P&lt;.001)</td>
<td>Comorbidity</td>
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<td>CM only 18 months</td>
<td>Ischemic Heart Disease</td>
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<td></td>
<td>No survival advantage for RRT patients with high comorbidity score or ischemic heart disease.</td>
<td>excluded Late Referrals and GFR &lt;15)</td>
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<tr>
<td>Wong 2007</td>
<td>73</td>
<td>--</td>
<td>73</td>
<td>CM only 23.4 months</td>
<td>Comorbidity</td>
<td>Median 79 yrs</td>
<td>Median 12</td>
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<td>1-yr survival 65%</td>
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<td>Range (4-31)</td>
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<td>Ellam 2009</td>
<td>69</td>
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<td>69</td>
<td>CM only 21 months</td>
<td>Serum albumin ≤3.5 g/dL</td>
<td>Median 80</td>
<td>&lt;15 MDRD</td>
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<td>Late referral</td>
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<td>Stage 5</td>
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</tbody>
</table>

*CM indicates conservative management without dialysis. Yrs indicates years. GFR indicates estimated glomerular filtration rate in milliliters per minute. RRT indicates renal replacement therapy. KPS indicates Karnofsky Performance Status score. CG indicates Cockcroft-Gault estimate. BMI indicates body mass index. MDRD indicates Modified Diet in Renal Disease study estimate. In the Smith 2003 study, 10 patients who were recommended to undergo CM chose dialysis and their survival with dialysis was not statistically significantly better than the 26 patients who were recommended for and received conservative management.
Estimating Prognosis for Survival: Recently there have been attempts to develop and test mathematical models for identifying patients with a poor short-term prognosis (Mauri 857). An integrated prognostic model takes into account the clinician’s estimate of prognosis, laboratory values, comorbidities (Couchoud 330, Di Lorio 399, Muers 3015, Glare 3016, Heyland 3017, Miskulin 3006, Couchoud), changes in comorbidity score over time (Miskulin 3006), functional status/fragility, QOL (Mapes 839, Lopez 812, Drayer 416, Rajagopalan 1047, Stojanovic 1222, Unruh 1309), and possibly the patient’s prediction of prognosis (Thong 1263). Two recent studies have supported the value of this approach. The simple “surprise question” is a strong indicator of 6-12 month mortality (Moss 3005) (Figure 3) and when combined with serum albumin, age and comorbid factors (dementia and PVD in particular) has a ROC of 0.82 predictive value (Cohen 3020).
Figure 3. Survival of Dialysis Patients by Surprise Question Response and Comorbidity Score

Survival curves for “surprise” question response and comorbidity score in days alive at 12 mo. Data are means ± SE. (A) Curves of “yes” and “no” response groups to the “surprise” question, “Would I be surprised if this patient died in the next year?” (B) Curves of the lower (<8) and higher (≥8) Charlson Comorbidity Index (CCI) score groups. Reprinted with permission from Moss 3005.
Many studies report the effect of prognostic factors on survival for patients with ESRD on dialysis, but most of these studies in large databases (USRDS, DOPPS) are investigating variables that may point to potentially treatable causes of increased mortality. Furthermore the survival time frame is often $\geq 1$ year. For the purposes of this guideline the working group was interested in estimating prognosis in the short-term (< 12 months) for the purpose of identifying patients who are likely to benefit from treatment with a predominantly palliative approach to care. It is assumed that all potentially treatable conditions have been addressed in these patients, and that the factors causing the poor prognosis are not reversible. Magnitude of risk conferred by individual risk factors can be estimated from existing data with increasing numbers of risk factors conferring increasing risk. Comparison of relative risks or hazards between studies in this literature poses a challenge. Diversity in studies includes both retrospective and prospective data collection, wide variation in number of patients observed (anywhere from less than 20 to 150,000), and wide variation in data sources (single dialysis facilities, multicenter studies, commercial dialysis chains, and regional and national registries). Additionally, the same variable may be defined differently either in data collection or for analytical purposes. For example, age may be analyzed in 1-, 5-, or 10-year increments or may be analyzed by groups with uneven distribution of years in them (e.g. $18-44, 45-64$, and $\geq 65$). The variable “age” may be used to represent age at start of dialysis or age at time of data collection. Nutritional status may be represented by a global assessment of the health care provider or may be single or multiple laboratory and/or physical measures. Understanding the varying definitions of variables sheds light on the differences between study results.

Other sources of variation include the type of population enrolled in each study, length of follow-up, and how deaths are designated. In the U.S. most, but not all, studies exclude the first 90 days of dialysis and so exclude deaths and withdrawals within this same time frame. Some studies enroll incident patients (patients who start dialysis in a defined time period) only while most enroll both prevalent (patients who are already being treated with dialysis for a variable amount of time prior to the start of the study) and incident patients. Length of follow-up can be as short as six months and as long as 20 or more years. Results from the studies may be reported annualized or within the time frame of the observations. Withdrawal is not always reported as a cause of death. On the CMS Death Notification form (revised in 2004), “withdrawal yes/no” is a separate item from cause of death. In addition uremia/withdrawal is listed as a cause of death. In the United States annually about 25% of patients withdraw from dialysis before death, and this number has been increasing over the past 10 years. In a recent DOPPS study (Bradbury 196), in which withdrawal from dialysis was assessed in the first 120 days of starting dialysis (when the majority of withdrawals occur), the mortality risk factors that predicted early mortality did not have a differential effect when withdrawal deaths were censored. This suggests that the very high early mortality in incident dialysis patients is not “caused” by withdrawal, and that it is likely that many patients die in the first few months of dialysis who may not have had a survival or QOL benefit from dialysis.
**Age is a powerful and consistent risk factor for death.** The older the patient, the shorter the patient’s survival is likely to be. For 1-year increments in age beginning at age 18, there is a remarkable consistency of risk ratios (RR) between 1.03 and 1.04 or a 3 to 4% increase in death rate per additional year of age.\textsuperscript{133-148} (Level A Prognostic Evidence) The effect of age is illustrated in Tables 3 and 4. In comparison to the U.S. population as a whole, dialysis patients live about one-fourth as long as non-dialysis patients of the same age and gender.
Table 3. Expected remaining lifetimes (years) of the general U.S. population, & of prevalent dialysis & transplant patients *general U.S. population, 2004; ESRD patients, 2006*

<table>
<thead>
<tr>
<th>U.S. 2004</th>
<th>All</th>
<th>Male</th>
<th>Female</th>
<th>White</th>
<th>Male</th>
<th>Female</th>
<th>African American</th>
<th>Male</th>
<th>Female</th>
<th>Native American</th>
<th>Male</th>
<th>Female</th>
<th>Asian</th>
<th>Male</th>
<th>Female</th>
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<td>68.8</td>
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<td>69.2</td>
<td>74.3</td>
<td>67.2</td>
<td>62.7</td>
<td>70.3</td>
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<td>15-19</td>
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<td>59.1</td>
<td>64.1</td>
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<td>64.4</td>
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</tbody>
</table>

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Although there has been a small but consistent decrease in mortality (in particular from cardiovascular causes) in prevalent hemodialysis patients over the past 20 years (USRDS 2009)(Figure 4 & Figure 5) there has been little improvement in survival of incident patients in the first 6-12 months of dialysis. The 30-120 day mortality rates remain extraordinarily high particularly in the elderly (Figure 6)(USRDS 2009). In the first 3 months after starting dialysis mortality rates have risen from 1993 to 2005.
Figure 4. Adjusted all-cause & cause-specific mortality in the first year of hemodialysis

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Figure 5. Adjusted all-cause mortality in the first year of hemodialysis, by month & age
These data and other studies suggest that it may be possible to identify a subset of elderly patients who will not benefit from starting dialysis and that dialysis in these patients may be associated with significant morbidity, deterioration in QOL, and the shortest survival. A prognosis prediction tool that incorporates the surprise question, age, comorbidities, and functional status is likely to be able to help identify these patients. Once identified, the kidney care team should engage the patient and family/legal agent in facilitated advance care planning discussions of goals of care, values regarding quantity and quality of life, and end-of-life treatment preferences.

Serum albumin level, both at baseline and during the course of dialysis treatment, is a consistent and strong predictor of death, with all but one of the studies showing a statistically significant relationship. (Level A Prognostic Evidence) The lower the serum albumin level, the higher the risk of death (Figure 7)(Pifer 2002). For example, an albumin of <3.0 grams per deciliter (g/dL) versus >4.0 g/dL confers a 4.4 times greater risk of early death. An albumin level <3.5 g/dL is associated with one year mortality of approximately 50%. (Level A Prognostic Evidence) A more recent large study from 2008 in incident dialysis patients from 1995 to 2004 with CMS 2728 forms completed supports the prognostic value of serum albumin. It demonstrates that serum albumin levels have declined over time in the incident US ESRD population and confirms the previously reported strong association with the first value after starting dialysis and mortality. With case-mix adjustment.
incident dialysis patients with an initial serum albumin less than 2.5 g/dL have an odds ratio of dying in 1 year more than 3 times greater than patients with a serum albumin equal to or greater than 4 g/dL (Kaysen 674).

Figure 7. Relative Risk of Mortality Based on Baseline Serum Albumin and Change at 6 Months

<table>
<thead>
<tr>
<th>Baseline albumin, g/dL</th>
<th>∆6-month albumin, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3.3</td>
<td>2.12†</td>
</tr>
<tr>
<td>3.3 to 3.7</td>
<td>1.42†</td>
</tr>
<tr>
<td>3.7 to 4.0</td>
<td>1.22*</td>
</tr>
<tr>
<td>&gt;4.0</td>
<td>1.00</td>
</tr>
<tr>
<td>&lt;5.3</td>
<td>1.98†</td>
</tr>
<tr>
<td>5.3 to 10</td>
<td>1.21</td>
</tr>
<tr>
<td>10 to 17</td>
<td>1.17</td>
</tr>
<tr>
<td>&gt;17</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Relative risk of mortality and quartiles of serum albumin, adjusted for baseline albumin (A), ∆albumin (B), demographics, and 15 comorbid conditions. *P < 0.05 and †P < 0.001 vs. 4th quartile. Reprinted with permission from Pifer 2002

Nutritional status is another powerful predictor of survival. Numerous markers of nutritional status have been studied: “cachexia” (provider assessment, not further defined), “undernourished” (documentation in the medical records of these words), obesity (based on information in the medical record from between one month prior to the onset of ESRD to six weeks after the first treatment), body mass index, subjective global assessment of nutritional status (per the method of Baker and Detsky), protein catabolic rate, skin fold thickness, and creatinine level. Cachexia, poor subjective global assessment of nutritional status, and “undernourished” all convey a significantly elevated risk of death. (Level B Prognostic Evidence)

Recently the malnutrition inflammatory complex syndrome (MICS) has been shown to predict short-term mortality (Kalantar 660) (Tables 5 & 6). The MIS (malnutrition inflammation score), CCI, and C-reactive protein (CRP) level were superior to the serum
albumin in predicting 12 month mortality (Kalantar 660). The MIS takes into account dry
weight change in the past 3-6 months, gastro-intestinal symptoms/appetite, functional
capacity, years on dialysis and severe comorbidities (CHF, AIDS, severe CAD, moderate
to severe COPD, metastatic cancer, and major neurologic conditions), muscle wasting,
loss of fat stores, BMI, serum albumin, and total iron binding capacity. Interleukin 6 and
tumor necrosis factor were also measured and although correlated with mortality, in the
multivariate analysis they did not add prognostic value to the above factors. (Kalantar
660)

Table 5. Associations between baseline nutritional and inflammatory markers and the risk
of death over the 12-month follow-up period, as reflected by mortality hazard ratios
(HRs) and 95% confidence intervals (CIs) in 378 MHD patients

<table>
<thead>
<tr>
<th>Mortality</th>
<th>Status of the fourth quarter (lowest or highest)</th>
<th>HR across all four quartiles (first to fourth)</th>
<th>HR for the fourth vs the first quartile</th>
<th>HR for the fourth vs the rest</th>
<th>Kaplan-Meier P for four quartiles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albumin (g/dl)</td>
<td>Lowest (&lt;3.63 g/dl)</td>
<td>1.84 (1.27-2.68)</td>
<td>9.80 (1.93-49.70)</td>
<td>2.24 (1.13-4.44)</td>
<td>0.0002</td>
</tr>
<tr>
<td>Pre-albumin (mg/dl)</td>
<td>Lowest (&lt;21 mg/dl)</td>
<td>1.17 (0.84-1.64)</td>
<td>2.18 (0.63-7.50)</td>
<td>1.79 (0.90-3.55)</td>
<td>0.04</td>
</tr>
<tr>
<td>Cholesterol (mg/dl)</td>
<td>Lowest (&lt;115.5 mg/dl)</td>
<td>1.14 (0.84-1.56)</td>
<td>1.80 (0.65-4.96)</td>
<td>1.62 (0.78-3.37)</td>
<td>0.6</td>
</tr>
<tr>
<td>TIBC (mg/dl)</td>
<td>Lowest (&lt;174 mg/dl)</td>
<td>1.28 (0.94-1.74)</td>
<td>1.46 (0.56-3.85)</td>
<td>1.80 (0.93-3.51)</td>
<td>0.2</td>
</tr>
<tr>
<td>CRP (mg/l)</td>
<td>Highest (&gt;8.4 mg/l)</td>
<td>1.81 (1.27-2.59)</td>
<td>6.31 (1.76-22.60)</td>
<td>3.27 (1.67-6.41)</td>
<td>0.005</td>
</tr>
<tr>
<td>IL-6 (pg/ml)</td>
<td>Highest (&gt;17.9 pg/ml)</td>
<td>2.23 (1.52-3.26)</td>
<td>27.44 (3.52-213.74)</td>
<td>3.97 (2.02-7.79)</td>
<td>0.0003</td>
</tr>
<tr>
<td>TNF-α (pg/ml)</td>
<td>Highest (&gt;9.26 pg/ml)</td>
<td>1.19 (0.88-1.62)</td>
<td>1.94 (0.73-5.13)</td>
<td>1.81 (0.89-3.70)</td>
<td>0.8</td>
</tr>
<tr>
<td>MIS (0-30)</td>
<td>Highest (&gt;8)</td>
<td>1.64 (1.17-2.31)</td>
<td>4.91 (1.81-13.30)</td>
<td>3.83 (1.82-8.4)</td>
<td>0.0002</td>
</tr>
</tbody>
</table>

Multivariate HR values are based on Cox proportional hazard regression models and adjusted for age, gender, race (Blacks vs others), ethnicity (Hispanics vs others), insurance status (Medicaid vs others), diabetes mellitus, Charlson co-morbidity score, dialysis vintage, dialysis dose (single-pool Kt/V), BMI and history of cardiovascular disease. All models are based on Poisson regression analyses.

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Table 6. Mortality and hospitalization predictability of markers of MICS using unifying multivariate models (Cox and Poisson) in 378 MHD patients

<table>
<thead>
<tr>
<th>Markers of MICS</th>
<th>Mortality (Cox)</th>
<th>Hospitalization frequency (Poisson)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>z-Statistics</td>
<td>P-value</td>
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<tr>
<td>MIS</td>
<td>3.13</td>
<td>0.002</td>
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<tr>
<td>Serum CRP</td>
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<td>0.001</td>
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<td>IL-6</td>
<td>−0.59</td>
<td>0.6</td>
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<tr>
<td>TNF-α</td>
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<td>0.7</td>
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<tr>
<td>Albumin</td>
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<td>0.3</td>
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<tr>
<td>Pre-albumin</td>
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<td>0.4</td>
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<tr>
<td>Creatinine</td>
<td>0.65</td>
<td>0.5</td>
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<tr>
<td>Total iron binding capacity</td>
<td>0.86</td>
<td>0.4</td>
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<td>Cholesterol</td>
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<td>nPNA (nPCR)</td>
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<td>0.4</td>
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<tr>
<td>Other covariates</td>
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<tr>
<td>Charlson co-morbidity index</td>
<td>3.75</td>
<td>&lt;0.001</td>
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<td>Age</td>
<td>1.75</td>
<td>0.08</td>
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<tr>
<td>Gender</td>
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<tr>
<td>Race (African Americans vs others)</td>
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<td>Ethnicity (Hispanics vs others)</td>
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<td>Diabetes mellitus</td>
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<td>Dialysis vintage</td>
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<td>Insurance status (Medicaid)</td>
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<td>Body mass index</td>
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<td>Kt/V (single pool)</td>
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<tr>
<td>History of cardiovascular disease</td>
<td>−1.79</td>
<td>0.07</td>
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</tbody>
</table>

nPNA: normalized protein nitrogen appearance; nPCR: normalized protein catabolic rate.

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Other laboratory values that correlate with malnutrition-inflammation and are predictors of short-term mortality are low serum cholesterol and low serum low phosphorus (Kalantar-Zadeh 660, Bradbury 196). Vitamin D levels and use of Vitamin D also have shown an association with mortality (Wolf 3004).

High serum troponin (Apple 43, Kanwar 669), BNP (Spinar 1202, Roberts 1077, Apple 43, Mallamaci 833), low blood pressure, use of a venous catheter for dialysis access (Agarwal 7), and unplanned start of dialysis (Bradbury 196) are also short-term mortality predictors.

Poor functional status is highly predictive of early death (RR ranges of 1.5 to 3). (Level A Prognostic Evidence) Fifteen of 16 studies reporting functional status show worse functional status is associated with early death. In studies where functional status and comorbidity are both measured, functional status sometimes displaces comorbidity in the multivariate analyses. A potential explanation of this finding may be that comorbidity measures are highly variable with regard to the manner in which they are defined and may not always capture severity. Functional status captures the severity of disability the patient is experiencing from whatever comorbid illness she or he may have. Measures of functional status used in these studies include ability to ambulate (yes/no), mild-severe mobility impairment, Karnofsky...
or modified Karnofsky scale,\textsuperscript{133,153,156,159,167-169,174} (Lopez \textsuperscript{812}). Gutman functional status,\textsuperscript{167} Activities of Daily Living,\textsuperscript{166,170} and the Medical Outcomes Study 36-item Short Form (SF-36).\textsuperscript{172} Frailty scores also correlate with increased mortality (johansen \textsuperscript{3021}). In most studies, functional status was assessed by the health care providers rather than the patients, who may rate their quality of life higher. The Karnofsky Performance Status scale is included in the Appendix. In particular the inability to transfer and falls are indicators of a poor prognosis. (Li \textsuperscript{779}) Dialysis in nursing home residents is associated with a marked decline in functional status at 1 year (only 13 percent maintained baseline function) and a 58 percent mortality (Tamura \textsuperscript{2009}). In another study of dialysis patients age 80 years or older, the initiation of dialysis was found to be marked by functional loss requiring community or private caregiver support or transfer to a nursing home in 30 percent of patients by 6 months. At the end of a year, 22 percent of patients remained independent, 31 percent were supported, and 44 percent were dead (Jassal \textsuperscript{2009}).

Comorbidity is the single most important determinant of outcome in ESRD patients on dialysis (Davies Nephrol Dial Trans \textsuperscript{2002}). Multiple different comorbid illnesses are related to risk of death on dialysis. These have been studied individually and aggregated into overall comorbidity scores. Unfortunately, definitions of congestive heart failure (CHF), ischemic heart disease, cardiovascular disease, etc. vary significantly from one study to the next. Despite these methodological shortcomings, comorbid illness must be taken into account in counseling patients about their prognosis. Scoring systems run the gamut from simply noting the presence of at least one comorbid illness,\textsuperscript{143,175,176} to grading the comorbidity burden,\textsuperscript{134} to using aggregations of ICD-9 codes from hospitalizations.\textsuperscript{177} One study specifically developed a severity of illness index for patients with ESRD.\textsuperscript{177} In all of these studies, having comorbid illness conferred higher risk although the magnitude of relative risk varied widely 1.11 to 12.8.(Level A Prognostic Evidence). The Charlson Comorbidity Index and modification of the Charlson Comorbidity Index for ESRD have good predictive value (Di Iorio \textsuperscript{399}, Hemmelgarn \textsuperscript{3019}, Sands \textsuperscript{3022})(Level A Prognostic Evidence). A Charlson Comorbidity Index score of equal to or greater than 8 has been shown to be associated with about a 50 percent one-year mortality (Beddhu, \textsuperscript{2002}).

Numerous comorbid conditions have been studied for their effect on survival:

diabetes, congestive heart failure (CHF), coronary artery disease (CAD), peripheral vascular disease (PVD), chronic obstructive pulmonary disease (COPD), and cancer.

Diabetes conferred a higher mortality risk in the majority of cohorts in which it was studied.\textsuperscript{133,135,140,142,144,147,152,155,157,165,167,168,171,178-183} (Level A Prognostic Evidence) Some studies find diabetes’ significance diminishes when laboratory abnormalities are included in multivariate models.\textsuperscript{141,155} A few studies have explored whether having Type 1 or Type 2 diabetes confers more risk. After controlling for age, at least two studies suggest that Type 1 DM confers a significantly higher risk of death.\textsuperscript{145,146,184} Most studies found CHF to be predictive of poorer survival, with a relative risk anywhere from 14% to 84% higher than those without CHF.\textsuperscript{133,135,147-149,152,185} (Level A Prognostic Evidence) Numerous different names and definitions are used to describe the category of CAD (cardiovascular
illness, angina, ischemic heart disease, CAD, cardiovascular comorbidity, heart disease, and vascular disease). These syndromes are inconsistently associated with increased mortality: seven studies showed no significant impact and 14 studies showed an increased risk of anywhere from 26% up to 780% (Level A Prognostic Evidence). In 6 of 7 studies, PVD conveyed an increased risk of death between 11% and 862% (Level A Prognostic Evidence). Cancer confers anywhere from 30 to 250% increased risk of death (Level A Prognostic Evidence). The variability probably relates to the type of cancer that is lumped together within this variable. COPD confers an increased risk of 14 to 44% (Level A Prognostic Evidence).

The most consistent comorbid factors that predict less than 12 month survival are NYHA class 4 heart failure, moderate to severe COPD, severe PVD, dementia, severe behavioral conditions, AIDS, and metastatic cancer. QOL scores, depression, pruritus, and restless leg syndrome also correlate with poor outcomes (Mapes 839, Lopez 812, Drayer 416, Rajagopalan 1047, Stojanovic 1222, Unruh 1309, Rakowski 1049, Kurella 738, Wayatt 3002, Newcomer 3024, Postorino 1018).

Estimating the effect of blood pressure on risk of death presents a particular challenge. Blood pressure as a risk factor has been defined variably: diagnosis of hypertension as a comorbidity or etiology of the patient's ESRD, duration of hypertension (<10 years versus ≥10 years), mean arterial pressure for five years prior to starting dialysis, monthly mean arterial pressure during the years the patient is receiving dialysis, immediately pre-dialysis blood pressures, and immediately post-dialysis blood pressures. Regardless of the definition, chronic hypertension has been shown to convey either a lower risk of mortality or to have no significant impact. (Level B Prognostic Evidence) Lower immediate pre-dialysis blood pressures (per 5 mmHg fall in diastolic, <129 mmHg systolic) confer an increased risk of all-cause mortality and higher immediate pre-dialysis systolic blood pressures may be protective (≥150 mmHg) for all cause mortality. For cardiovascular mortality, the relative risk of a low immediate predialysis systolic blood pressure is even higher. There is a mild increase in risk at the highest level of systolic blood pressure as well (≥180 mmHg). Blood pressures in the 150-179 mmHg range are protective as compared to 140-149 mmHg. Immediate pre- and post-dialysis dialysis blood pressures ≥90 mmHg convey an increased risk for cardiovascular but not all cause mortality. (Level B Prognostic Evidence)

**Summary Risks and mathematical models:** Although mathematical models for estimating an ESRD patient's mortality risk are not readily available, results from multivariate analyses of various prognostic studies allow comparison of the magnitude of effect between risk factors. Newer statistical methods such as time-variate additive damage models (Argyropoulos 3008, Dekker 3025, Brunelli 30031) have the potential to improve mortality risk prediction. Couchoud et al developed and validated a model and scoring system from the French REIN database in incident dialysis patients to predict 6 month mortality (Couchoud). Independent risk factors were BMI<18.5, DM, CHF (stage 3,4), PVD (stage 3,4), unplanned dialysis, inability to transfer, active malignancy, and...
severe behavioral disorder. A point score was developed that predicted 6 month mortality with the intention to provide guidance for recommending a palliative approach to care (Table 7 and Table 8) (Couchoud). Mallamaci determined that adding the biomarkers CRP, BNP, and ADMA improved a prognostic model beyond demographics, comorbidities, and standard laboratory values (ie albumin, etc.) (Mallamaci 833). Cohen et al developed and validated a mathematical model for estimating patient survival at 6 months which used the surprise question, serum albumin, age, and presence or absence of two comorbidities: dementia and peripheral vascular disease. This model had a ROC of .82 (Cohen 3020).

Table 7. Adjusted odds ratios for 6-month mortality and points assigned to each risk factor in the training sample

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Adjusted OR^a (95% CI)</th>
<th>β-coefficient</th>
<th>Points^b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body mass index (kg/m²)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥18.5</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;18.5</td>
<td>1.3 (1.1–1.6)</td>
<td>0.283</td>
<td>2</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.2 (1.1–1.3)</td>
<td>0.180</td>
<td>1</td>
</tr>
<tr>
<td>Congestive heart failure stage III or IV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.3 (1.2–1.5)</td>
<td>0.289</td>
<td>2</td>
</tr>
<tr>
<td>Peripheral vascular disease stage III or IV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.3 (1.1–1.5)</td>
<td>0.269</td>
<td>2</td>
</tr>
<tr>
<td>Dysrhythmia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.2 (1.1–1.3)</td>
<td>0.170</td>
<td>1</td>
</tr>
<tr>
<td>Active malignancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.3 (1.1–1.5)</td>
<td>0.250</td>
<td>1</td>
</tr>
<tr>
<td>Severe behavioural disorder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.5 (1.2–1.8)</td>
<td>0.391</td>
<td>2</td>
</tr>
<tr>
<td>Totally dependent for transfers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>1.7 (1.4–2.0)</td>
<td>0.519</td>
<td>3</td>
</tr>
<tr>
<td>Initial context</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planned</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unplanned</td>
<td>1.5 (1.3–1.7)</td>
<td>0.305</td>
<td>2</td>
</tr>
</tbody>
</table>

^aMean odds ratio* for the five imputed datasets (multiple imputation for missing data). OR (95% CI): odds ratio (95% confidence interval).

^bPoints were assigned to each risk factor using β-coefficients (parameter estimates) from the multivariate logistic regression model. The β-coefficient for each risk factor was divided by the lowest β-coefficient (dysrhythmia) and rounded to the nearest integer.

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Table 8. Six-month mortality rates by risk score in the training and the validation samples

<table>
<thead>
<tr>
<th>Risk score</th>
<th>Training sample</th>
<th>Validation sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of deaths</td>
<td>Number at risk</td>
</tr>
<tr>
<td>0 Point</td>
<td>41</td>
<td>511</td>
</tr>
<tr>
<td>1 Point</td>
<td>39</td>
<td>508</td>
</tr>
<tr>
<td>2 Points</td>
<td>64</td>
<td>453</td>
</tr>
<tr>
<td>3–4 Points</td>
<td>160</td>
<td>628</td>
</tr>
<tr>
<td>5–6 Points</td>
<td>93</td>
<td>266</td>
</tr>
<tr>
<td>7–8 Points</td>
<td>50</td>
<td>98</td>
</tr>
<tr>
<td>≥9 Points</td>
<td>22</td>
<td>36</td>
</tr>
<tr>
<td>All</td>
<td>470</td>
<td>2500</td>
</tr>
</tbody>
</table>

**Mean** number of patients from the five imputed datasets (multiple imputation for missing data).

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Using the Catalanian data base Mauri et al developed and validated a 12-month mortality model in incident patients based on age, sex, cause of kidney disease, physical function, COPD, liver disease, CVD disease, dialysis vascular access, malnutrition, and malignancy (Table 9)(Mauri 857).
Table 9. Prognostic model for mortality at 1 year following initiation of haemodialysis treatment

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>B</th>
<th>SE</th>
<th>OR</th>
<th>95% CI of OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>-0.995</td>
<td>0.115</td>
<td>0.92</td>
<td>0.73–1.14</td>
</tr>
<tr>
<td>Age_16</td>
<td>0.310</td>
<td>0.055</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary renal disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard</td>
<td>0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.025</td>
<td>0.132</td>
<td>1.03</td>
<td>0.79–1.33</td>
</tr>
<tr>
<td>Systemic</td>
<td>0.971</td>
<td>0.210</td>
<td>2.64</td>
<td>1.75–3.99</td>
</tr>
<tr>
<td>Functional autonomy degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Limited</td>
<td>0.622</td>
<td>0.131</td>
<td>1.88</td>
<td>1.45–2.43</td>
</tr>
<tr>
<td>Special care</td>
<td>1.343</td>
<td>0.152</td>
<td>3.83</td>
<td>2.84–5.16</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>0.250</td>
<td>0.129</td>
<td>1.28</td>
<td>0.99–1.65</td>
</tr>
<tr>
<td>Malignant processes</td>
<td>3.535</td>
<td>0.886</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic liver disease</td>
<td>0.351</td>
<td>0.201</td>
<td>1.42</td>
<td>0.96–2.11</td>
</tr>
<tr>
<td>First vascular access by CV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AV fistula and no CV</td>
<td>0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>AV fistula and AV</td>
<td>1.177</td>
<td>0.210</td>
<td>3.24</td>
<td>2.15–4.90</td>
</tr>
<tr>
<td>Catheter and no AV</td>
<td>1.345</td>
<td>0.204</td>
<td>3.84</td>
<td>2.57–5.72</td>
</tr>
<tr>
<td>Catheter and CV</td>
<td>1.726</td>
<td>0.138</td>
<td>5.63</td>
<td>4.30–7.57</td>
</tr>
<tr>
<td>First vascular access by malnutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AV fistula and no malnutrition</td>
<td>0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>AV fistula and malnutrition</td>
<td>1.208</td>
<td>0.276</td>
<td>3.35</td>
<td>1.95–5.75</td>
</tr>
<tr>
<td>Catheter and no malnutrition</td>
<td>1.345</td>
<td>0.204</td>
<td>3.84</td>
<td>2.57–5.72</td>
</tr>
<tr>
<td>Catheter and malnutrition</td>
<td>1.697</td>
<td>0.181</td>
<td>5.46</td>
<td>3.83–7.78</td>
</tr>
<tr>
<td>Age_16 by Malignant processes</td>
<td>-0.417</td>
<td>0.125</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-5.799</td>
<td>0.401</td>
<td>0.003</td>
<td></td>
</tr>
</tbody>
</table>

8The OR and 95% confidence interval of the factors that intervene in an interaction cannot be calculated and analysed separately. Thus, interactions with dichotomous variables are expressed together. For non-dichotomous variables, only the B and the SE are presented in the table and the analysis of interactions is shown in Figure 2.

SE = standard error.

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Additional approaches to improving prognostic modeling include changes to comorbidities and severity of comorbidities over time (Miskulin 3006), and a self-learning rules based model (Geddes 510).

Predicting Who Will Die Within the First Year on Dialysis: Eleven articles specifically address issues in predicting early mortality and a number of other articles give data covering the first 90 to 180 days. In a prospective incident cohort, Barrett found that although a scoring system using age and comorbidity did predict prognosis, no score cutoff point combined high true-positive and low false-positive rates for predicting early death. Age, severity of heart failure, PVD, arrhythmias, malnutrition, malignancy, and myeloma were independent prognostic factors identified in the multivariate models. However, the best fit discriminant and logistic models were also unable to accurately predict early death within six months. Clinicians were accurate in assigning patients to prognostic groups up to a 50% risk of death by six months, above which they tended to overestimate risk. Clinicians were only marginally better than the predictive models in
determining whether a given high-risk patient would die. Soucie\textsuperscript{149} found that age, white race, male gender, severe activity impairment, lower albumin level, previous myocardial infarction, cancer, CHF, hypertension, depression, and smoking were all associated with death less than 91 days after initiating dialysis. This study did not attempt to look at the predictive value of their model for accurately identifying those who died. Barrett and Chandna\textsuperscript{193} concluded that trials of therapy may be a better idea than denying dialysis based on these results. (Level A Prognostic Evidence)

**Effect of Sentinel Events on Prognosis:** A few studies have addressed the specific issue of risk of death after intercurrent medical events while on dialysis. Two striking examples of events that have very high post-event mortality in ESRD patients on dialysis are acute myocardial infarction (AMI)\textsuperscript{185} and above the knee amputation (AKA)\textsuperscript{162}. Aulivola \textsuperscript{73}, Combe \textsuperscript{3011} (Level A Prognostic Evidence). For both of these events survival at one year is less than 50\% (38 to 44\% for AMI and 27\% for AKA). These events might be considered as reminders for discussions about end-of-life care and the benefits and burdens of ongoing dialysis with patients and their families. A recent study demonstrates the poor prognosis after strokes (Sozio \textsuperscript{3001}) and pneumonia (James \textsuperscript{3036}). Survival after CABG in ESRD is much worse than an aged-matched cohort, especially when associated with PVD and CVA (Rahmanian \textsuperscript{1045}, Kogan \textsuperscript{704}). Falls (and the number of falls) in the elderly is associated with increased mortality (Li \textsuperscript{779}). Table 10 displays the ranges of risk estimates from these studies.

<table>
<thead>
<tr>
<th>Table 10. Comparative Percent of Increased or Decreased Risk for Death for Eight Factors Studied in $\geq$ Two Studies with Multivariate Analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Risk Factor</strong></td>
</tr>
<tr>
<td>References</td>
</tr>
<tr>
<td>Bradbury \textsuperscript{196}</td>
</tr>
<tr>
<td>Percent increase or decrease risk</td>
</tr>
</tbody>
</table>
In the DOPPS study database a number of sentinel events were associated with withdrawal from dialysis: failure to thrive, gangrene, cancer, dementia, stroke, amputation, pneumonia, CHF, myocardial infarction, and gastrointestinal bleed. (Kerr 3033)

Box 2. Suggested Steps for Implementing Recommendation No. 3.

- Estimate prognosis based upon patient’s age, functional status, medical condition, including comorbidity and recent sentinel events, and the “surprise” question.
- Present the prognosis in a manner that is considerate of the patient’s emotional condition, balance the patient’s desire for quality and quantity of life, and provide reassurance that the physician has kept the patient’s best interest in mind. With the patient’s permission, invite the patient’s legal agent/family to participate in the discussion of prognosis and treatment options.
- Identify patient’s wishes and goals for treatment at onset of dialysis and again after any irreversible change in medical condition.
- Reassess and communicate prognosis on at least an annual basis, and more often as indicated by any major change in status.
- Communicate options, including option of stopping dialysis and receiving palliative and end-of-life care, at each reassessment.
- Provide recommendation to withhold/stop dialysis in patients who are not likely to benefit
- If shared decision making is not possible, conflict resolution should take place
- Consider palliative care or ethics consultation if needed (see recommendation #4)

Recommendation No. 4: Conflict Resolution

A systematic approach for conflict resolution is recommended if there is disagreement regarding the benefits of dialysis between the patient or legal agent (and those supporting the patient’s position) and a member(s) of the renal care team (Figure 6). Conflicts may also occur within the renal care team or between the renal care team and other health care providers. This approach should review the shared decision-making process for the following potential sources of conflict: 1) miscommunication or misunderstanding about prognosis, 2) intrapersonal or interpersonal issues, or 3) values. If dialysis is indicated emergently, it should be provided while pursuing conflict resolution, provided the patient or legal agent requests it.

Rationale

The ethical principles of beneficence, justice, nonmaleficence, and respect for patient autonomy support this recommendation. Disagreement regarding initiating or continuing dialysis may occur among the patient or legal agent, family members, renal care team, and/or other health care providers (e.g., intensivists and primary care physicians).

Observational evidence about disagreements suggests that patients’ or legal agents’ wishes are usually, but not always, honored.52-54,194-197 (Level C Observational Evidence) A single study indicates that nephrology nurses sometimes disagree with nephrologists’ decisions to continue dialysis. In this study, nurses perceived such disagreements as ethical conflicts, had no formal structure for raising and resolving the issue, and felt
unable to resolve their dilemma.\textsuperscript{197} (Level C Observational Evidence) The Working Group and other experts recommend conflict resolution using a due process approach, including an ethics consult or mediation, to facilitate clarification of the conflict and promote resolution. (Fine RL, \textit{Ann Intern Med} 2003.) If it is felt by the renal care team or the patient that an extramural ethics committee or consultant has more expertise, the renal care team or patient should feel free to consult them. There are no controlled studies of the outcomes of ethics consultation or mediation for dialysis patients, but the medical literature documents the benefits of ethics consultation in situations similar to dialysis in which the use of a life-sustaining treatment is at issue.

When the clinician determines based on the medical evidence that the burdens of dialysis substantially outweigh the benefits, he/she should meet with patient and family and present the factors that indicate a poor outcome with dialysis. The aim is to reach agreement about the goals of care. If agreement is not reached on the course of care, then a process of conflict resolution (see Figure 8) should be initiated and an ethics consultation should be considered.

Ethics consultation is a service provided by an ethics consultant or an ethics committee to help patients, legal agents, families, health care professionals or other involved parties address uncertainty or value conflicts that arise in patient care. Ethics consultants and committees possess knowledge and skills in ethics, law, interpersonal communication, and conflict resolution. Ethics consultations have been found to be helpful by physicians in clarifying ethical issues in patient care and assisting in patient management.\textsuperscript{198-204} (Level B Observational Evidence)

In contrast to 1990, a survey of nephrologists in 2005 indicated that a majority use ethics committees to assist with decision-making in challenging situations. (Holley JL, Clin J Am Soc Nephrol 2007)
Figure 8: Systematic Approach to Resolving Conflict between Patient and Kidney Care Team.

Shared Decision-Making:
- Patient: Personal history, values, preferences, and goals.
- Provider: Diagnostic, prognostic, and management expertise, values, and goals.

Do the patient and provider agree on the course of care?

- Yes
  
  Pursue agreed-upon care.

- No
  
  Involve consultants (medical, ethical, religious, ethnic, or administrative)
  
  Do the patient and provider now agree on the course of care?
  
  - Yes
    
    Pursue agreed-upon care.
  
  - No
    
    Involve ethics committee
    
    Do the patient and provider now agree on the course of care?
    
    - Yes
      
      Attempt to transfer care within institution
      
      Is this a possible solution to the problem?
      
      - Yes
        
        Pursue agreed-upon care.
      
      - No
        
        Attempt to transfer to another institution
        
        Is this a possible solution to the problem?
        
        - Yes
          
          Pursue agreed-upon care.
        
        - No
          
          Possible Remaining Options
          
          - Request local ESRD network to assist with arrangements for dialysis.
          - Involve a mediator or an extramural ethics committee.
          - Inform the patient/legal agent that dialysis will be withheld or stopped unless a court injunction to the contrary is obtained.
          - Provide treatment contrary to provider's professional values to truly respect the diversity of values in our society.
Box 3. Suggested Steps for Implementing Recommendation No. 4.

- **Extended conversation**
  - Why does the patient or legal agent desire dialysis when it is not recommended by the renal care team?
  - Why does the patient or legal agent refuse dialysis when it is recommended by the renal care team?
  - Does the patient or legal agent misunderstand the diagnosis, prognosis, and treatment alternatives?
  - Does the nephrologist misunderstand the patient’s or legal agent’s reasons for requesting dialysis?
  - Does the nephrologist understand the psychosocial, cultural, or spiritual concerns and values the patient or legal agent has?
  - Has the nephrologist consulted a psychologist, social worker, or chaplain for assistance in fully understanding the concerns of the patient or legal agent/family?

- **Consultation with other physicians**
  - Do other physicians agree or disagree with the attending physician’s recommendation to withhold or withdraw dialysis?
  - Is the request for dialysis by the patient or legal agent medically appropriate?

- **Consultation with an ethics committee or ethics consultants.**
  - Has the patient or legal agent been informed that the purpose of the ethics consult is to clarify issues of disagreement, and ideally, to enable resolution?
  - Has the patient or legal agent met with the ethics committee or ethics consultants to explain their perspective and reasoning behind their request for dialysis?
  - Can the ethics committee identify the reasons why the patient or legal agent is resistant to the physician’s recommendation to forgo dialysis?
  - Can the ethics committee identify the reasons why the health care provider is resistant to the patient’s or legal agent’s desire to begin or continue dialysis?
  - Has the ethics committee explained in understandable terms to the patient or legal agent its conclusions and the reasoning behind them?
  - Can the impasse be resolved with accommodation, negotiation, mediation, or a time-limited trial of dialysis?

- **Documentation**
  - The physician must document the medical facts and his/her reasons for the recommendation to forgo dialysis and the decision not to agree to the request by the patient or legal agent.
  - The consultants should also document their assessment of the patient’s diagnosis, prognosis, and their recommendations in the chart.

- **An attempt to transfer the patient’s care**
  - If reconciliation is not achieved through the above procedure and the physician in good conscience cannot agree to the patient or legal agent’s request, the physician is ethically and legally obligated to attempt to transfer the care of the patient to another physician.
  - Another physician and/or institution may not be found who is willing to accept the patient under the terms of the family’s request. Physicians and institutions that refuse to accept the patient in transfer and their reasons should also be documented in the medical record.
  - Consider consultation with a mediator, extramural ethics committee, or the ESRD Network in the region.
Box 3 Continued.

- Request regional ESRD network to assist with arranging dialysis.
- Notification of the patient, legal agent, and/or family
  - If no other physician or institution can be found in the community or region by the treating nephrologist to provide dialysis as requested, the physician should inform the patient or legal agent that the nephrologist will cancel the patient’s dialysis orders and the dialysis center will no longer provide dialysis to the patient. The nephrologist is obligated to give the patient sufficient advance notice and the names and addresses of other nephrologists and other dialysis facilities in the area.
- The options of filing a grievance with the ESRD network (chronic patients only) or seeking legal or regulatory recourse by the patient or legal agent should be communicated.

Recommendation No. 5: Goal Clarification and Advance Care Planning

Advance care planning discussions should be based on an individual patient’s goals for care which are predicated on a realistic understanding of the patient’s condition and prognosis. The renal care team should encourage patient-family discussion and advance care planning and include advance care planning in the overall plan of care for each individual patient. Because advance care planning is an ongoing, interactive process that is shaped by changes in the patient’s clinical condition, prognosis, and available therapies, it requires revisiting the patient’s and family’s goals of care as changes occur. The goals of care should be clearly defined to reflect the patient’s stage of illness and informed preferences (where capacity allows) for management. Goals of care for the AKI, CKD, and ESRD patient, broadly defined, should be explicit about: 1) whether cure is feasible (where the main aim will be achieving that cure), 2) whether life can realistically be extended (where the main aim will include both extending survival and improving quality of life), and 3) whether the principal goal of care is palliative (where the main aim has moved away from extending survival towards improving the quality of remaining life and preparing for death). The key times of transition are likely to include: 1) when conservative, non-dialytic management is being considered; 2) preparation for and transition onto dialysis; 3) clinical deterioration despite dialysis, associated with increasing dependency; and 4) consideration of withdrawal from dialysis.

Goals of care should be reviewed annually and at times of rapid or unexpected clinical change, and in accordance with changing patient preferences and/or capacity. Outcomes and quality measures used in each phase of illness should be adjusted to appropriately reflect the goals of care.

The renal care team should attempt to obtain written advance directives from all dialysis patients and where legally accepted, physician orders for life-sustaining treatment (POLST) or similar state-specific forms should be completed as part of the advance care planning process for patients. At a minimum, each dialysis patient should be asked to designate a legal agent as an essential advance directive. Advance directives should be honored by dialysis centers, nephrologists, and other nephrology clinicians except...
possibly in situations in which the advance directive requests treatment contrary to the
standard of care (see recommendation #4).

Rationale

Advance care planning is a patient-centered, comprehensive, ongoing discussion among
care providers and their patients and families (or the patient’s designated legal agent)
about values, treatment preferences, decision-makers in the event of the patient’s
incapacity, and goals of care. The advance care planning process includes
communicating information to the patient and family about the current clinical condition,
prognosis, and treatment options within the context of the patient’s values and goals
which will ultimately guide medical decision-making. Because one’s medical condition
is a primary factor influencing treatment choices, advance care planning interactive
discussions must be re-visited at critical points in a patient’s care or whenever a patient or
a legal agent wishes to revisit these issues.

Advance care planning is grounded in the ethical principle of respect for patient
autonomy. Multiple observational studies demonstrate many, though not all, patients
want to communicate about their future medical care and to discuss their preferences for
care in the event they lose decision-making capacity. In observational studies and opinion surveys, nephrologists
report that patients’ and families’ preferences are very important to them in decision-
making, but physicians may not know their patients’ preferences or may incorrectly
assume patients’ preferences. Few physicians, nurses, and social workers on renal care teams discuss advance directives
electively with patients; most discussion appears prompted by a deterioration in the
patient’s health status. Patients and families generally assume physicians will introduce advance care planning discussions and
usually want these discussion to occur earlier in the course of CKD than they typically do
(Advance care planning can facilitate the
completion of written advance directives, but the advance care planning process itself can
increase congruence between patient, family, and physician understanding and therefore
improve satisfaction and compliance with patient preferences (Advance directives.
Key
components of advance care planning (See Boxes 4 and 5) can provide a structure for the
process (Advance directives are a legal and ethical means for communicating patients’ preferences
for end-of-life care to legal agents, families, renal care teams, and others. They are a
mechanism for facilitating adherence to patients’ end-of-life wishes by legal agents and
health care providers. Advance directives flow from advance care planning and are an
integral part of the process. Proxy directives (formally naming a person to make
decisions in the event the patient is unable to make his or her own decisions) and
instruction directives (e.g., living wills or do not resuscitate documents) are examples of
advance directives. Written advance directives are always preferable to oral directives
because they provide better legal protection. Some patients may not prefer or refuse
written directives. In such instances, it is acceptable to obtain an oral statement with a
witness present and to document the oral advance directive in the chart. Patients who

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decide to forgo dialysis should have an agreement to a do-not-resuscitate/do-not-intubate order and appointment of a legal agent on their charts. Such directives will help to avoid situations in which patients lacking written advance directives have their wishes overridden by a legal agent should the patient become incapacitated before death.

Studies show variability in how well patients understand and trust advance care documents. Several observational studies show that while most patients support the concept of advance directives, a minority actually complete them and certain groups of patients and families (e.g., ethnic minorities) are less likely than others to complete advance directives (Johnson JAGS 2008 ref).

Several attempts have been made to increase the use of advance directives. The Patient Self-Determination Act (PSDA), effective in 1991, mandated that health care providers advise patients of their rights to make health care decisions and to complete advance directives. The PSDA was mandated for facilities such as hospitals and nursing homes, and not specifically for free-standing dialysis units. Since the PSDA, one study has shown the proportion of inpatients with advance directives has not increased though documentation of their existence in the medical chart has increased from 6 to 35%. (Level C Observational Evidence) Having advance directives has been correlated with having discussions with health care providers about life-sustaining therapies. Providing patients educational material about advance directives has had variable impact on completion rates. Physician counseling has been shown to increase frequency of specification of a health care proxy in a geriatrics clinic, and an uncontrolled multidisciplinary intervention involving social workers and volunteers stimulated 71% of frail elders to complete an advance directive, among whom 96% specified a proxy. (Level C Observational Evidence) Efforts to increase the completion of advance directives have generally failed, making encouragement of advance care planning discussions among patients and families even more important. Patient-centered advance care planning can be effective in promoting shared decision-making between patients and their surrogates (Briggs #205).

Surveys show physicians in general are willing to honor advance directives, but that approximately a quarter express difficulty honoring directives when the directives conflict with what they personally think is best for patients. A scenario-based study of physicians at one academic center found that more specific preferences listed in advance directives were more likely to be followed. (Level C Observational Evidence) Seventy-three percent of the physicians said they would be willing to withhold resuscitation based on a general advance directive, 84% based on a specific statement, and 100% if the specific statement was supported by a prior discussion and a surrogate decision maker. Unfortunately, a cohort study of advance directives showed advance directive documents rarely contained specific information to guide care. (Level C Observational Evidence). Use of the Physician Orders for Life-Sustaining Treatment (POLST) has been adopted by multiple states and regions (www.POLST.org) in response to inadequacies in general written advance directives (Hickman, J Pall Med 2009;12:133-141). Unlike living wills (instruction directives) or documents naming legal agents (proxy directives), POLST forms are signed physician (in
Some states nurse practitioners are authorized to sign orders directing treatments based on patient choice. They have shown to be effective in honoring patients’ end-of-life treatment preferences (RAND Health, 2009). Where available, such documents are particularly applicable to many, if not most, CKD and dialysis patients and should be offered, completed, and honored.

Few studies have examined effects of advance care directives on clinical outcomes. A retrospective study of 182 chronic hemodialysis patients who died found those who completed advance directives were more likely to die in a planned, non-emergent fashion and to have a greater sense of control. Two randomized trials and a prospective uncontrolled study have failed to demonstrate that advance care planning affects clinical outcomes, while one observational study demonstrated advance directives can be widely promulgated, successfully communicated to physicians, maintained in continuity across health care venues, and guide care at end of life. Nearly all specified preferences were followed in this latter small homogenous community study. One of the randomized trials that involved 204 sick outpatients found no differences in health outcomes, perceived well-being, patient satisfaction or health care costs between patients randomized to receive advance directive instruction versus those randomized to usual care. Two randomized trials and a prospective uncontrolled study have failed to demonstrate that advance directive instruction versus those randomized to usual care. A large multisite trial of 9,105 medically ill hospitalized patients (including 204 in whom decisions to withhold dialysis were sometimes made) studied interventions aimed at improving end-of-life decision-making and reducing the frequency of a mechanically supported, painful, and prolonged process of dying. (Level C Observational Evidence) Interventions were designed to provide physicians with serial prognostic information for their patients, provide physicians with patient and surrogate responses to questions about preferences, and have specially trained nurses attempt to conduct advance care planning. The study found the following: half of the physicians misunderstood patient’s preferences to forgo CPR; nearly half of DNR orders were written within two days of death; approximately a third of patients who died spent at least ten days in an ICU; and half of conscious patients who died reported moderate to severe pain at least half of the time prior to death. The intervention failed to affect any of these factors. Retrospective analysis suggested the designed intervention failed to stimulate physician-patient communication about end-of-life care. A prospective uncontrolled study of written advance directives for nursing home patients found that while most life-sustaining therapy was provided in a manner consistent with patient’s or surrogate decision maker’s expressed preferences, there was no relationship between the written advance directive and the care provided. (Level C Observational Evidence) The study also found that care in the nursing home was more likely to be in conflict with patients’ wishes than care in the hospital, emphasizing the importance of transferring advance care planning between health care venues. A retrospective study of advance care planning in peritoneal dialysis patients in long-term care found that age and functional status strongly influenced plans not to hospitalize and not to attempt resuscitation but such plans did not affect patient survival. However, plans could be established for nearly all the 109 patients in this study, and no patient with a do not attempt resuscitation order underwent unwanted cardiopulmonary resuscitation. Taken together these studies show many aspects of end-of-life care, especially advance care planning, need to be
improved. Several studies suggest that nephrologists may be able to enhance communication of patients’ preferences for end-of-life care by facilitating patient-family discussions of patients’ specific treatment preferences and values regarding suffering. The five key components in advance care planning with ESRD patients include: facilitated ACP (Davison #369), documentation of the process and the patient’s preferences, timing of the discussion, involving the optimal systems and processes for success, and assessing the process through quality improvement (Davison #369). Patient participation is essential, as is the involvement of individuals identified by the patient as central to the process. Although patients and families expect physicians to raise the issues involved in advance care planning (Davison 361, Davison 369), other dialysis unit personnel such as social workers, nurses, or peer counselors, may be integral to the process.

Box 4. Suggested Steps for Implementing Recommendation No. 5.

- Assess decision-making capacity (see Toolkit).
- Include advance care planning in the overall plan of care for each individual patient
- Encourage patient-centered advance care planning among patients and families; raise the issue of advance care planning with each patient at the initiation of dialysis (earlier is preferred) and on at least a yearly basis. Hospitalizations and/or significant changes in medical, physical, or functional status should prompt reconsideration of advance care planning
- Discuss advance care planning by asking:
  - If you become unable to make decisions for yourself, whom do you want to make decisions for you?
  - If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering which would you choose?
  - Under what circumstances, if any, would you want to stop dialysis?
  - Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
- Where do you prefer to die and who do you wish to be with you when you die?
- Determine whether the patient has an appointed legal agent through a written advance directive.
- If the patient lacks decision-making capacity and has not completed an advance directive, arrange for or initiate the process for appointment of a surrogate according to state law.
- Encourage patients to be specific about their preferences with legal agent, family, friends, and providers.
- Document provider’s discussion and understanding of patient’s preferences, show the patient the documentation, and offer to assist the patient in documenting the patient’s agreement or modification of the documentation. Where available, complete a Physician Orders for Life-Sustaining Treatment (POLST) or similar form to translate patients’ wishes into medical orders (see www.polst.org)
- Place a copy of advance directives, do not resuscitate order card, and/or POLST form in multiple medical records as appropriate, including dialysis facility, commonly attended clinics, hospital, and nursing home.
- Encourage the patient, family and/or legal agent to carry a current copy of the patient’s advance directive, do not resuscitate order card, and/or POLST form whenever traveling or being admitted for overnight medical care.
Adapted from Davison#369, Rand Health ref. 249,223,225

Enhance patient and family understanding about their illness and end-of-life issues, including prognosis and likely outcomes of alternative plans of care

Define the particular patient’s key priorities in end-of-life care and develop a care plan that addresses these issues and identifies the patient’s overall goals of care

Enhance patient autonomy by shaping future clinical care to fit the patient’s preferences and values

Improve the process of health care decision-making generally, including 1) patient and family satisfaction with the advance care planning process, 2) health care provider understanding of advance care planning and advance directives, and 3) provider comfort in participating in advance care planning

Help patients find hope and meaning in life and achieve a sense of spiritual peace

Explore ways to ease the emotional and financial burdens borne by patients and families

Strengthen relationships with loved ones

Complete written advance directives, particularly those identifying a legal agent, do not resuscitate documents, and POLST documents where available

Recommendation No. 6: Forgoing (Withdrawing or Withholding) Dialysis*

It is appropriate to forgo (withhold initiation or withdraw ongoing) dialysis for patients with either AKI, CKD, or ESRD in the following situations:

- Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued
- Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents refuse dialysis or request that it be discontinued
- Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment
Non-dialytic therapy incorporating palliative care is an integral part of the decision to forgo dialysis in either AKI, CKD, or ESRD, and attention to patient comfort and quality of life while dying must be addressed directly or managed by palliative care consultation and referral to a hospice program (see recommendation #9).

Rationale

The legal and ethical principles supporting this recommendation include informed refusal, respect for patient autonomy, beneficence, non-maleficence, justice, and professional integrity. In both state and federal case law and by federal statute (PSDA), competent patients have an absolute right to accept or refuse medically indicated treatment. Authoritative psychiatry and nephrology opinion supports the notion that patients in the general nephrology setting who choose to forgo dialysis are neither psychopathological nor suicidal even though depression may be present (REF Cohen 316). At the same time, physicians are not ethically obligated to offer or deliver treatment that is not medically indicated. Relevant observational evidence is limited but suggests that withdrawal is common, with rates ranging from 17% to 50% of deaths in different dialysis populations. (Level C Observational Evidence) Most patients on chronic dialysis appear to know that withdrawal is an option. However, often patients have neither communicated and discussed their preferences with family or renal care team members, nor completed written advance directives (REF Nobel 946) (Level B Observational Evidence) A few studies suggest that patients with decision-making capacity most often initiate the discussion of withdrawal of dialysis themselves and that physicians most often raise the issue for patients without decision-making capacity. (Level C Observational Evidence) There is also evidence that patients often expect medical staff to initiate these discussions and that staff are reluctant for a variety of reasons including a lack of experience, either professional or personal, with end-of-life discussion (Russ 1090). For patients who lack decision-making capacity, substituted judgment in the absence of documentation of the patient’s feelings on life support may not be permitted in some states.

The evidence regarding patients’ preferences for continuing or discontinuing dialysis in the event of certain health states is based on studies using hypothetical vignettes. This evidence demonstrates some variability in hypothetical preferences among patients, with approximately 50 to 85% saying they would want to stop dialysis in conditions of severe permanent neurologic impairment such as severe dementia or permanent coma. (Level C Observational Evidence) Evidence is lacking regarding agreement between what patients say they would prefer hypothetically and what they actually do. Surveys and observational studies show nephrologists may be inconsistent and variable in their withdrawal practices. Prominent factors that they have reported affect their withdrawal decisions include patient’s neurologic and physical functional status, comorbidities, family wishes, and age. (Level C Observational Evidence) More recent evidence suggests that depression, as measured using survey and questionnaire methods, is associated with forgoing dialysis, although it is uncertain whether this depression is causative or a concomitant phenomenon (REF Davison 364, REF McDade-Montez 862) Previous studies have found that diabetes, severe pain, lack of a significant partner, Caucasian race, female gender, nursing home residence, and terminal illness are
associated with withdrawal from dialysis.  

Observational Evidence) More recent evidence suggests that inadequately treated pain may be an important concomitant of depression and independently predict withdrawal decisions. (REF Davison 364) (Level C Observational Evidence) Data on withholding of dialysis is limited. Information on withholding can be inferred from studies of referral practices. Of six relevant studies on dialysis referral, one large prospective cohort study indicates that the withholding rate for AKI is substantial (29%) and that increasing age and dementia were independent predictors of withholding in multivariate analyses adjusting for confounders. (Level B Observational Evidence) Two retrospective cohort studies and two studies using cross-sectional surveys suggest that withholding in ESRD increases with age (15% to 83% over age strata from 16 to >70 years old), and may be higher in women. (Level C Observational and Prognostic Evidence) These studies also suggest that cultural or financial contexts may influence physicians’ rates of initiating dialysis. A large Canadian survey study suggests that family practitioners and internists consider the following in their decisions on whom to refer for dialysis: age, serum creatinine level, mental and psychiatric status, distance from dialysis center, overcrowding of dialysis centers, and comorbid illnesses. (Level C Observational Evidence) Over half of the Canadian physicians felt rationing should be based on patient wishes, cognitive status, life expectancy, quality of life, age, and long-term institutionalization.

The ethical principles of beneficence and nonmaleficence allow and support a judgment that, in certain conditions, dialysis does not offer a reasonable expectation of benefit. The right of very sick patients or their legal agents to request dialysis must be considered within the framework of palliative care when dialysis might allow additional time deemed of acceptable quality by the patient; however this consideration must be balanced against continuing treatment that violates the ethical principle of professional integrity when dialysis is considered medically inappropriate. The renal team should be sensitive to patient goals and individual circumstances. For example, a person with a terminal illness may desire to have dialysis to help them live long enough for a special family event (e.g., the pending birth of a grandchild) or to participate in the ongoing family life in a way which is personally meaningful and in which the family participates directly in the care of the patient (e.g. home peritoneal dialysis). There are some anecdotal examples in which dialysis enables unexpected survival with subjectively acceptable quality of life for some functionally dependent elderly patients, patients with chronic cardiac or liver disease, or patients with terminal illness. An innovative alternative, a “No Dialysis Clinic” has been described in Great Britain in which patients with CKD who so chose are managed for the duration of their survival – even in this setting there are still some patients who ultimately opt for a short course of dialysis before they die (REF Wong 1372). In the acute hospital setting, review of hospital death experience suggests that advance directives often do not focus sufficiently on palliative measures when treatment is withdrawn (REF Nobel 946), but that family satisfaction can be favorably influenced by more discussion concerning general prognosis and comfort measures, even if these discussions prolong the process and even when terminal extubation is purposely chosen (REF Watch 1346, Gerstel 3003).
Generally, “terminal illness” for the purposes of hospice referral is defined as a life expectancy of less than or equal to 6 months if the disease process takes its normal course. AKI, CKD, or ESRD patients with non-kidney terminal illness include those with end-stage liver, heart, or lung disease who are deemed inappropriate organ transplantation candidates. Non-kidney terminal illnesses which AKI, CKD, or ESRD patients may have include end-stage cirrhosis with hepatorenal syndrome, severe congestive heart failure, widely metastatic cancer unresponsive to chemotherapy, end-stage pulmonary disease, end-stage acquired immunodeficiency syndrome, bone marrow transplant recipients with multiorgan failure, and advanced neurodegenerative diseases. Such conditions affect the survival of patients requiring renal replacement therapy.\textsuperscript{[73,74,76-80,132]} (Level A Prognostic Evidence) The survival for patients with intact kidney function and such selected terminal comorbid conditions may be estimated. When the expected survival for patients with a specific terminal illness but intact kidney function is estimated to be less than six months, it is logical to conclude that dialysis for patients with AKI, CKD, or ESRD and one or more of the above conditions is unlikely to extend survival beyond six months.

Another situation where dialysis may be considered medically inappropriate is a patient with permanent inability to purposefully relate to others. This is defined as being unable to recognize familiar persons, lacking orientation to self, place, and time, and the absence of higher cognitive functioning. All forms of severe irreversible dementia and permanent vegetative states fulfill this definition.

**Recommendation No. 7: Special Patient Groups**

It is reasonable to consider forgoing (not initiating or withdrawing dialysis) for AKI, CKD, or ESRD patients in the following situations:

- Those whose medical condition precludes the technical process of dialysis
- Those who have a terminal illness from non-renal causes; however, patients with terminal illnesses from non-renal causes may still gain some palliative benefit from dialysis, and this possibility should be duly considered.
- Those with stage 5 CKD over the age of 75 who meet two or more of the following criteria: 1) clinicians’ response of “No, I would not be surprised” to the surprise question; 2) high comorbidity score; 3) significantly impaired functional status such as inability to transfer, and 4) severe malnutrition (serum albumin <2.5 g/dL).

**Rationale**

The ethical principles of beneficence and nonmaleficence allow and support a judgment that, in certain conditions, dialysis does not offer a reasonable expectation of benefit.\textsuperscript{[239,240]} Further, the right of patients or their legal agents to request dialysis must be balanced against continuing treatment that violates the ethical principle of professional integrity and that is considered medically inappropriate.\textsuperscript{[239-243]} The Working Group, however, felt that the renal team should be sensitive to patient goals and individual circumstances. For example, a person with a terminal illness may desire to have dialysis to help them live long enough for a special family event (e.g., the pending birth of a grandchild).
A situation where dialysis may be considered medically inappropriate is a patient with terminal illness from a non-kidney disease. In this guideline, terminal illness is defined as a life expectancy of less than or equal to 6 months from non-renal disease(s) in patients not deemed candidates for solid organ transplant. Conditions that may fall into this category are end-stage cirrhosis with hepatorenal syndrome, severe CHF, widely metastatic cancer unresponsive to chemotherapy, end-stage pulmonary disease, end-stage acquired immunodeficiency syndrome, bone marrow transplant recipients with multiorgan failure, and advanced neurodegenerative diseases. Such conditions affect the survival of patients requiring renal replacement therapy.73,74,76-80,132 (Level A Prognostic Evidence) The survival for patients with intact renal function and such selected terminal comorbid conditions may be estimated. When the expected survival for patients with intact renal function and particular comorbid conditions is less than six months, it is logical to conclude that dialysis for patients with AKI, CKD, or ESRD and one or more of the above conditions is unlikely to extend survival.

Another situation where dialysis may be considered medically inappropriate is a patient with permanent inability to purposefully relate to others. This is defined as being unable to recognize familiar persons, lacking orientation to self, place, and time, and the absence of higher cognitive functioning. All forms of severe irreversible dementia and persistent vegetative states fulfill this definition. Dialysis may also be inappropriate for patients with significant and ongoing problems with access for dialysis or failure to thrive. In addition, dialysis may be inappropriate for some patients who are unable to cooperate with the dialysis process. Such patients may be harmful to themselves, other patients, and personnel in the dialysis unit and may create an unsafe working environment.244 Examples of patients who might be in this category include those who require physical or chemical restraints or a sitter during dialysis to prevent harm to self or others in the unit.

There is increasing evidence that elderly patients with stage 5 CKD and high comorbidity scores, significant functional impairment, and severe malnutrition may not benefit from dialysis in terms of increased survival or improved quality of life. See Stage 4 and 5 CKD in the rationale for recommendation #3 for a discussion of these studies and findings.

**Recommendation No. 8: Time-Limited Trials**

For patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis, nephrologists should consider offering a time-limited trial of dialysis. If a time-limited trial of dialysis is conducted, the nephrologist, the patient, the patient’s legal agent, and the patient’s family (with the patient’s permission to participate in decision-making) should agree in advance on the parameters to be assessed during and at the completion of the time-limited trial to determine if dialysis has benefited the patient and if dialysis should be continued.
**Rationale**

Experts recommend time-limited trials of life-sustaining treatment such as dialysis in certain situations. The ethical principles of beneficence, nonmaleficence, and respect for patient autonomy provide support for this recommendation. The patient’s clinical course during the period of time-limited dialysis may provide patients and families with a better understanding of dialysis and its benefits and burdens and may provide the renal care team with a more informed assessment of the likelihood of the benefits of dialysis outweighing its burdens. For example, a patient who is uncertain about their QOL on dialysis may benefit from a time-limited trial. In this way, a time-limited trial of dialysis may promote informed shared decision-making. No research data regarding outcomes of time-limited trials of dialysis was found. The exact time period for the trial may be made on a case-by-case basis. For patients with ARF, time periods of days to two weeks may be reasonable; for patients with ESRD, time periods of one to three months are reasonable. If there is uncertainty about the inability of a patient to cooperate with dialysis, the patient should be considered for a time-limited trial of dialysis before it is withdrawn to enable all parties to evaluate the appropriateness of continuing dialysis. In one study, nephrologists who reported they were very well prepared to participate in end-of-life decision-making with dialysis patients were more likely to use time-limited trials than those who reported a lower level of preparedness. (Davison SN, Clin J Am Soc Nephrol 2006) Nephrologists who were very well prepared to participate in end-of-life dialysis decision-making were more likely to be aware of the first edition of the Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis clinical practice guideline.

**Recommendation No. 9: Palliative Care**

For all patients for whom the goals of care are primarily palliative (such as those who decide not to start dialysis, those deteriorating despite dialysis, or those who are withdrawing from dialysis), a palliative care approach and specific palliative care interventions should be offered to improve patient-centered outcomes. With the patient’s consent, a multi-professional team with expertise in renal palliative care--including nephrology professionals, family or community-based professionals, and specialist hospice or palliative care providers--should be involved in managing the physical, psychological, social, and spiritual aspects of end-of-life care for these patients. Physical and psychological symptoms should be routinely and regularly assessed, and actively managed. The professionals delivering care should receive training in assessment and management of symptoms, and in advanced communication skills. Patients should be offered the option of dying where they prefer, including at home with hospice care, provided there is sufficient and appropriate support to enable this option. Support should also be offered to patients’ families, including bereavement support where appropriate. Dialysis patients for whom the goals of care are primarily palliative should have quality measures distinct from patients for whom the goals of therapy are rehabilitative (life prolongation with improved functional capacity and other aspects of quality of life).
**Rationale**

The evidence shows that although patients and families place a high priority on good symptom control and preparation for death, both patients and professionals find it difficult to address these end-of-life issues. Nephrologists’ identification, assessment and management of symptoms is poor (1), and many symptoms (such as pain) are under-recognised and under-treated.(2;3) Nephrology professionals also find it challenging to help patients engage with end-of-life issues.(4) In addition, patients doing less well on dialysis often find it difficult to make sense of what they perceive as ‘not quite living’ while on dialysis and struggle with issues raised by the use of dialysis and the prolongation of poorer quality life.(4) To some extent, nephrology staff recognize the need for symptom control and the importance of psychosocial aspects of care, but implementation of these aspects of care are perceived to be difficult. (5)

Renal patients have considerable and complex healthcare needs towards the end of life. There is growing evidence of a high physical and psychological symptom burden among dialysis patients (2;6-10), especially among those with multiple co-morbidities. (1) Those who opt for conservative (non-dialytic) management (11) or dialysis withdrawal (12) have similarly high symptom burden, and need pro-active management.(13) While dying is peaceful and symptom-free for some, others experience considerable uncontrolled symptoms. (14)

There is some early evidence as to how these needs are best addressed.

General approach: The complex needs of those kidney patients with predominantly palliative goals of care are probably best addressed through the collaboration of nephrology professionals with family/community-based professionals, and hospice or palliative care providers (15,16). Who actually provides care may be determined by the strengths of local service programs, but the approach is characterized by:

1) holistic and patient-centered care;
2) multi-disciplinary professional collaboration to provide this care;
3) high quality, skilled communication, and sensitive advance care planning;
4) addressing needs across the physical, psychological, social and spiritual domains of care; and
5) consideration of family needs, including bereavement support

There is some evidence that those renal patients who use hospice are more likely to die at home, and may spend less time in acute hospital care (17). At home, symptoms may be more easily recognized and communicated (12).

Specific measures: Tools have been developed which can effectively measure symptoms (18) (19) (Davison SN, Kidney Int. May 2006, 69(9):1621-1625; Davison SN, Jhangri G, Nephrol Dial Transplant. 2006 Nov; 21(11): 3189-95.) and quality of life (20) towards the end of life, although there is limited validation as yet in populations with end-stage renal disease. Specific interventions [such as pharmacological interventions for pain (7;21) and depression (9)] have been identified as useful (22). In particular, using the WHO
analgesic ladder to treat pain has been shown to be effective for kidney patients (7; 23; 24).

There is an urgent need for further research to underpin renal palliative care recommendations (Davison 2010), especially in respect to conservative, non-dialytic management.

Although there is growing evidence relating to those on dialysis, little research has been undertaken to understand factors which might influence the recommendation for conservative, non-dialytic management. In the United Kingdom, older age, higher co-morbidity, and poorer functional status are associated with the recommendation for conservative management (Smith).

There is a need to define appropriate quality measures for patients whose main goal for dialysis is palliation as opposed to rehabilitation. Treatments delivered to dialysis patients with palliative care goals should be evaluated by quality measures such as documented discussion of patient’s prognosis, designation of a legal agent, pain and symptom assessment and management, documentation of an end-of-life care plan including patients’ preferences regarding life-sustaining treatments and preferred site of death, and timely referral to hospice. Quality care measures used for dialysis patients in whom the goals of care are rehabilitative such as dialysis adequacy, anemia and bone disease management, patient survival, and vascular access type and function are inappropriate for palliative care dialysis patients for whom the goals are maximizing comfort and minimizing procedures and hospitalizations. Furthermore, palliative care dialysis patients should not be included in the calculations of dialysis unit-specific standardized mortality ratios and quality measures for patients seeking rehabilitation to avoid misrepresentations of the quality of dialysis unit care on public reporting sites. Current practices of aggregating all dialysis patients regardless of their goals of care in quality measures discourages the appropriate setting and honoring of different expectations and goals for palliative and rehabilitative dialysis patients.
| No. | Box 6: Recommendations for end-of-life care practices in chronic kidney disease*  
(Davison 2010) |
|-----|---------------------------------------------------------------|
| 1.  | Identify patients who would benefit from palliative care interventions  
   a. Those who are being managed conservatively, i.e., a GFR ≤ 15ml/min/1.73m² with no dialysis.  
   b. High risk of death within the next year. Consider using an integrated prognostic model and/or the surprise question, “Would I be surprised if this patient died in the next year?”  
| 2.  | Screen for and manage pain and other physical symptoms routinely.  
   a. A simple tool such as the Edmonton Symptom Assessment Scale (ESAS) is appropriate and has been validated in CKD.  
| 3.  | Screen for and manage emotional, psychosocial and spiritual distress; refer to allied health professionals as appropriate.  
   a. The ESAS is also appropriate for screening for anxiety and depression.  
   b. A simple question such as “Do you have any spiritual needs or concerns that your health care providers may help address?” may be appropriate for screening for spiritual distress  
| 4.  | Assess patients’ desire for prognostic information  
| 5.  | Enhance pre-dialysis education.  
   a. Educate regarding conservative management options.  
   b. Education should include available palliative care and hospice services  
| 6.  | Routine advance care planning (ACP). How to facilitate these discussions is described in Recommendation 5.  
   a. Ensure patients and families are aware of the relevance of these discussions (i.e., have an understanding of their overall health state and prognosis)  
   b. Consider initiating ACP at the time that patients are being educated with respect to conservative management and renal replacement options.  
   c. Include discussions of patients’ goals of care, health states that the patient would no longer want dialysis, and preferred location of death.  
   d. Establish a surrogate decision-maker  
   e. Ensure that family and other important people (as identified by the patient) are present for these discussions, especially the surrogate decision-maker.  
| 7.  | Increase access to specialist palliative care including hospice  
| 8.  | Provide bereavement support to patients’ families where necessary.  
| 9.  | Incorporate palliative care training for all nephrology fellows with an emphasis on symptom management and advance care planning.  

**Recommendations and Rationales References**


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Section 5. Guideline Recommendations and Their Rationales for Neonates, Infants, and Children

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Introduction

Although dialysis has been used in adults to treat acute kidney injury (AKI) since the 1940s and end-stage renal disease (ESRD) since the early 1960s, due to technical issues and ethical concerns, dialysis did not become commonly available to children in the United States until the late 1960s [Chantler, 1979] and controversies regarding the use of dialysis in infants have persisted until recently [Cohen, 1987; Feinstein, 2008; Rheault, 2009].

Four distinct groups of children who could potentially benefit from dialysis have been identified: (1) infants with poorly functioning or nonfunctioning kidneys due to genetic conditions or a urological or kidney abnormality that is non-reversible; (2) infants with acute kidney injury without prior evidence of intrinsic kidney disease or urological abnormality; (3) children with acute kidney injury with or without prior evidence of kidney problems and; (4) children with chronic kidney disease whose kidney function overtime becomes progressively worse. As an outgrowth of increased provision of dialysis for each of these pediatric groups over the past three decades, evidence about its feasibility, tolerability and efficacy has led to continued improvements in dialysis techniques. In addition, longer-term experience with pediatric dialysis has allowed the accumulation of data regarding risk factors for poor short-term and long-term health and quality of life outcomes.

Prior to this, data on pediatric dialysis outcomes have not been systematically evaluated in an attempt to establish a clinical practice guideline regarding the initiation, non-initiation or withdrawal of dialysis for neonates, infants and children in the United States. In part, there has been an avoidance of developing a guideline because of the risk associated with basing clinical decisions about individual patients on population-based research. In part there has been a hesitation to recommend clinical practice regarding the initiation, non-initiation or withdrawal of dialysis in neonates, infants and children because there previously was limited research on which to base the recommendations. Presently the quantity and quality of research in this area is rapidly expanding.

In spite of the aforementioned challenges to develop a clinical practice guideline regarding the initiation, non-initiation or withdrawal of dialysis in children and infants, there are multiple benefits in doing so: (1) a clinical practice guideline can assist pediatric nephrologists in communicating their recommendations to medical colleagues and families in an objective and systematic manner (i.e. presenting age and disease-specific research and experience as the basis for recommending a particular course of action); (2) a clinical practice guideline can be a catalyst for the establishment of pediatric-specific resources for patients and their families in end-of-life planning; (3) a clinical practice guideline can provide health-care providers, with more limited expertise in pediatric kidney disorders, with additional information to help them formulate realistic expectations regarding dialysis interventions; and (4) a clinical practice guideline can provide a framework for addressing these difficult decisions.

Guideline development process
The clinical practice recommendations presented below were developed using the following six-step methodology. (1) The pediatric recommendations contained in the RPA/ASN 2000 Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis clinical practice guideline were reviewed by a workgroup comprised of five pediatric nephrologists, a child psychologist and a pediatric ethicist. (2) Research articles regarding pediatric dialysis outcomes published between 2000 and 2008 were retrieved from electronic data-bases and were systematically reviewed to determine if they contained evidence regarding shared decision-making or outcomes in initiating or withdrawing from dialysis in children with AKI or ESRD. Studies using the following types of designs were included for review: cohort (retrospective or prospective), case-control, and cross-sectional. No randomized controlled trials were found. (3) Review papers and clinical practice guidelines from non-US pediatric nephrology groups were reviewed and searched for additional unique references meeting the inclusion criteria. (4) Policy statements and guidelines written by the American Academy of Pediatrics (AAP) of relevance to this project were reviewed. (5) Each reference article was evaluated by at least two people in the workgroup to determine the type and quality of evidence it provided for assisting the workgroup in proposing recommendations pertaining to initiating and withdrawal of dialysis in pediatric patients. (6) A draft of the revised RPA 2010 adult Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis clinical practice guideline was reviewed. The guideline recommendations are summarized in Table 1.

Recommendation No. 1: Shared Decision-Making

A patient-physician relationship that promotes family-centered decision-making is recommended for all pediatric patients with AKI, CKD, or ESRD. In addition to involving pediatric patients to the extent that their developmental status allows, the kidney physician should involve parents and family members in determining health care decisions. Shared decision-making is recommended in determining treatment choices, including but not limited to the initiation, non-initiation, and withdrawal of dialysis. When the treating nephrologist feels that a pediatric patient’s parents or family are not participating in shared decision-making in the best interest of their child, the nephrologist should take steps to ensure that the pediatric patient has a legal guardian who is capable of assisting in health care decision-making. The use of medical ethics consultants and/or a hospital ethics committee is recommended as a means of resolving disagreements. Court involvement should be a last resort.

Rationale: The AAP has published 7 policy statements that support the use of shared decision-making in pediatric patients (see Table 2). The AAP policy statements and guidelines endorse family-centered decision-making in which provider-family partnerships are established to allow for evaluation of treatment options and choice of treatment interventions. Family-centered decision-making is supported by the ethical principles of beneficence, nonmaleficence and respect for autonomy. The AAP policy statements and guidelines not only support children’s participation in decision-making commensurate with their development and health status, but also state that children should not be excluded from health care decision-making without “persuasive reasons.” A prospective study evaluating influences on parent decisions to limit or withdraw life
support provides some evidence that shared decision-making is beneficial to parents too. [Sharman et al, 2005]:#7004

**Recommendation No. 2: Informed Permission, Informed Assent**

Physicians should fully inform patients with AKI, Stage 4 or Stage 5 CKD or ESRD and their parents about the diagnosis, prognosis, and all treatment options that are appropriate. Treatment options may include: 1) hemodialysis, peritoneal dialysis, or transplantation; 2) not starting dialysis and continuing conservative, non-dialytic management; or 3) stopping dialysis and receiving end-of-life comfort care. The kidney care team should inform parents about the potential benefits and burdens of dialysis initiation or dialysis withdrawal prior to providing or withdrawing treatment. In addition, children should be informed about their diagnosis, prognosis and treatment options in a developmentally appropriate manner, and if feasible, their assent regarding treatment decisions should be sought. As a component of informed permission, when the treating nephrologist determines that the dialytic treatment is no longer providing benefit (e.g. the risks outweigh the benefits, the underlying condition is progressive and dialysis is only prolonging the dying process) the nephrologist and the physician-team should approach the patient and family again and discuss the lack of benefits of dialysis given the patient’s medical condition.

**Rationale:** The AAP Committee on Bioethics policy statement on informed consent, parental permission and assent provide support for this recommendation [Pediatrics, 1995, 95(2) 314-317; reaffirmation published 2/1/2007]. The policy statement recommends that use of the term informed permission (rather than the term informed consent) to describe the ethically and legally mandated process of assisting parents in developing a comprehensive understanding of their child’s clinical situation in order for timely and informed decisions to be made among treatment alternatives.[Pediatrics, 1995, 95(2) 314-317] The process of informed permission is similar to that of informed consent and involves the following 4 elements: (a) provision of information; (b) assessment of patient’s or surrogate’s understanding of information; (c) assessment of capacity of patient or surrogate to make a decision; and (d) assurance of freedom of patient or surrogate to assist in the choice between treatment alternatives.[Pediatrics, 1995, 95(2) 314-317] The policy statement also points out that although children do not have legal authority to make independent health care decisions unless they have been determined to be “mature or emancipated minors” some children may in fact have decision-making capacity and in such cases their opinions should be particularly taken into account.[Pediatrics, 1995, 95(2) 314-317] This guideline encourages physicians to obtain child assent and “parental permission” in such a manner that there is a shared responsibility between the physician, the pediatric patient and the parents for treatment decisions.[Pediatrics, 1995, 95(2) 314-317] Furthermore the guideline recommends that medical personnel should, if possible, respect the wishes of a child who withholds or refuses assent until such time that the child gains a better understanding of his/her situation and comes to terms with the fears or other concerns regarding the proposed care.[Pediatrics, 1995, 95(2) 314-317]

The AAP Committee on Bioethics guideline regarding non-initiation or withdrawal of intensive care treatment for high-risk newborns provides specific guidance regarding
informed consent discussions with families of newborn infants who have a very poor prognosis [AAP, Pediatrics, 119(2), 2007]. The guideline acknowledges that determining what is in the best interest of a severely ill newborn is very difficult and points out that there is no ethical distinction between non-initiation and withdrawal of life-sustaining treatment in children with anticipated poor prognosis [AAP, Pediatrics, 119(2), 2007]. As in other AAP policy statements pertaining to pediatric medical care, shared decision-making between the parents and physicians, based on ongoing evaluation of the benefits and burdens of continuing intensive care treatments, is encouraged. [AAP, Pediatrics, 119(2), 2007] The guideline cautions that parents’ views of their child’s health status is influenced by how information is presented to them and that care should be taken to present information in a “frank and balanced” manner. [AAP, Pediatrics, 119(2), 2007] The guideline also stipulates however, that “the physician is not obligated to provide inappropriate treatment or to withhold beneficial treatment at the request of the parents.” [AAP, Pediatrics, 119(2), 2007] The AAP policy statement on religious objections to medical care strongly supports the importance of physicians’ safeguarding children’s rights to receive medically indicated medical care not withstanding parents’ religious beliefs to the contrary. [AAP, Pediatrics, 1997; 99(2), 279-281]

The AAP Committee on Bioethics guideline regarding forgoing life-sustaining medical treatment provides some frank advice to physicians both about how and what information should be provided to families of seriously ill children. [Pediatrics, 1994; 93;532-536, reaffirmation published May 1, 2009]. The guideline advises that during the course of obtaining informed permission, in addition to providing information regarding the risks, discomforts, side effects, and benefits of treatment alternatives, physicians should provide their opinion regarding the best option for the patient citing their reasons for their recommendations based on medical, experiential and moral factors. [Pediatrics, 1994; 93;532-536] Furthermore, the guideline advises that when a physician believes that a currently offered treatment is no longer providing benefit and should be forgone (not-initiated or ended), that families should be informed of this opinion without delay. [Pediatrics, 1994; 93;532-536] Furthermore, the guideline states that young children, “deserve to hear the general conclusions of decisions that will affect their continued survival” even though they may not necessarily be able to understand the details of the gravity of their medical condition. This will allow them to say goodbye to their loved ones. [Pediatrics, 1994; 93;532-536]

A multi-center study evaluated the extent to which health care providers who were currently treating children with life-threatening conditions were aware of published guidelines regarding initiating and withdrawal of life-sustaining medical treatments, were in agreement with the guidelines, and behaved in accordance with the guidelines. [Solomon et al., 2004: #7005] Surprisingly, 53% of the respondents were not aware of the ethical concordance of not starting and discontinuing a life-sustaining treatment (e.g dialysis). [Solomon et al., 2004: #7005] Furthermore, 57% of the respondents
acknowledged that sometimes they felt that they were saving children who should not be saved and 46% acknowledged feeling that the treatments they have offered children are overly burdensome. [Solomon et al, 2004: #7005]

**Recommendation No. 3: Estimating Prognosis**

To facilitate informed decisions about dialysis for pediatric patients with AKI, CKD, or ESRD, discussions should occur with the patient, parents, and/or legal guardian about prognosis, potential complications and quality of life. The nephrologist should acknowledge that the ability to predict survival in the individual patient is difficult and imprecise and should reassure the patient and family that there will be opportunity for additional discussions regarding prognosis over time. Given the likelihood that health status changes for the better or for the worse are likely to occur in pediatric patients with AKI, CKD, or ESRD, discussions about survival odds and physical and psychosocial outcomes should be repeated when indicated. Each discussion regarding prognostic outcomes and patient/parent decisions regarding treatment should be documented in detail and dated. In the event of questionable understanding of the prognostic data, it is recommended that additional resources be offered to the child and their family to ensure a reasonable understanding of likely outcomes and to allow for informed decision-making regarding treatment.

**Rationale:** Multiple studies support the initiation of dialysis for neonates, infants, and children with AKI without prior evidence of kidney problems although survival in these groups is highly variable.[Agras et al, 2004:#12; Andreoli, 2004:#33; Chen et al, 2004:#284; Morelli et al, 2007:#903; Wedekin et al, 2008:#1349; Askenazi et al, 2006:#64; Bock, 2005: #170; Chen et al, 2004:#284; Cavagnaro et al, 2007:#258; Strazdins et al, 2004:#7006; Walters et al, 2009:#7008] Although some studies suggest that mortality is particularly high in neonates that require dialysis post-operatively for cardiac abnormalities, it should, nevertheless, be offered.[Baskin et al, 2005: #116; Symons et al, 2007: #7007 Hui-Stickle et al, 2005: #612]

Neonates, infants and children who have higher disease severity scores and more significant life-threatening illness in the intensive care unit have been shown to have higher mortality rates.[Agras et al, 2004: #12; Andreoli, 2004:#33; Chen et al, 2004:#284; Baskin et al, 2005: #116; Askenazi et al, 2006:#64; Bock, 2005:#170; Hui-Stickle et al, 2005:#612; Cavagnaro et al, 2007:#258; Pedersen et al, 2008:#983; Pichler et al, 2007:#1000; Radhakrishnan et al, 2006:#1041; Wedekin et al, 2008:#1349; MacLauren et al, 2009:#7002; Williams et al, 2002:#7010; Symons et al, 2007:#7007]. Prediction of who will survive, however, is not possible and, in fact, many neonates, infants and children who receive dialysis for AKI recover kidney function with no apparent kidney dysfunction. An AAP policy statement opposes the use of population-based survival formulas as the principal determinants of whether critically ill infants and children should receive life-sustaining medical technology such as dialysis and supports the initiation of life-sustaining medical treatment until clarification of the clinical situation can occur [AAP, ethics and care of critically ill infants and children].
In regards to offering dialysis to children with ESRD, the literature suggests that outcomes and survival in infants and children on dialysis is at least as good as in adults who are maintained on chronic dialysis therapy. [Feinstein et al, 2008; NAPRTCS, 2008; Ferris et al, 2006: #472; Groothoff, 2005: #550; Fadrowski et al, 2007: #7001; White et al, 2006: #7009; McDonald et al, 2004: #865] Survival is so good in children receiving maintenance dialysis that quality of life rather than survival in most cases has become a major outcome of interest for physicians [Chiu et al, 2007: #295; McKenna et al, 2006: #869; Goldstein et al, 2008; Goldstein et al, 2006: Gerson et al, 2005]. In addition, even though survival in neonates and infants with ESRD (e.g. neonates and infants with poorly functioning or nonfunctioning kidneys due to genetic conditions or a non-reversible urological or kidney abnormality) is highly variable, studies support the initiation of dialysis. [Carey et al, 2007: #252; Feinstein, et al, 2008; Rheault et al, 2009; Wood et al, 2001] Mortality in this group is often attributed to comorbidities rather than dialysis failure.

Recommendation No. 4: Conflict Resolution

Conflict resolution interventions should be used when family members are not in agreement with one another, when children are not in agreement with their parents or when families are not in agreement with the physician regarding the initiation, non-initiation or withdrawal of dialysis. The following types of interventions are recommended to resolve conflicts: additional medical consultation(s); short-term counseling or psychiatric consultation for the child and/or family; a multidisciplinary conference; 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 resources would be appropriate to help determine next steps. Court involvement should be used as an intervention of last resort.

Rationale: The AAP has published several policy statements that provide advice regarding the resolution of disagreements relating to treatment decisions for seriously ill children. First and foremost the AAP endorses prevention of conflict through the ongoing use of shared decision-making. [AAP, Pediatrics, 2007; 119(2); 401-403; AAP, Pediatrics, 2001, 107(1), 205-209; AAP, Pediatrics, 1995, 95(2), 314-317; AAP, Pediatrics, 1994; 93(3), 532-536] When disagreements cannot be resolved through courteous communication efforts, the AAP encourages physicians to obtain additional medical consultation, convene a multidisciplinary conference and/or consult with a hospital ethics committee. Consultation with child protection specialists is also recommended by AAP in the case where non-initiation of dialysis would constitute medical neglect. In addition, counseling or psychiatric consultation for the child and/or family may be of benefit under certain circumstances, especially when there is disagreement between the parent and child regarding treatment options. The AAP cautions that court system involvement should be used as a last resort and reserved for situations in which “refractory disagreement” and “irreconcilable differences of opinion” continue in spite of attempts to resolve conflicts using less adversarial processes.
Recommendation No. 5: Advance Care Planning

Family-centered advance care planning is recommended for children with AKI, CKD, or ESRD and should include the establishment of treatment goals based on a child’s medical condition and prognosis. Advance care planning should be an ongoing process in which treatment goals are revised based on observed benefits and burdens of interventions (i.e., the child’s response to treatment) and the values of the child and the family. Advance directive discussions, a potential component of advance care planning, should be initiated when a child’s medical condition is believed to be irreversible and non-responsive to currently available treatments.

In the event that there is information regarding the questionable viability of a fetus, advance directive discussions should occur prior to the birth of the baby to allow for 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. Similarly, in infants with poorly functioning or nonfunctioning kidneys due to genetic conditions, those with a non-reversible urological or kidney abnormality and in infants and children with AKI without prior evidence of intrinsic kidney disease, advance care planning should include a discussion about advance directives. Also in children with AKI or with ESRD currently undergoing dialysis, the kidney care team should attempt to engage the child’s parents or legal guardian in a discussion regarding advance directives with developmentally appropriate input from the pediatric patient.

Rationale: Advance care planning is a clinical practice approach that has been endorsed as beneficial for adults and children with life-limiting medical conditions. Advance care planning is described as a family centered and culturally sensitive process that is initiated at diagnosis, is continued through the provision of end-of-life care and, involves an ongoing discussion about a child’s medical status, response to treatment and treatment goals. [Wharton et al, 1996] The advance care planning approach differs from routine clinical practice in its explicit recommendation to allow patient/family communication about medical concerns prior to the end-of-life period to be used as a springboard for discussions about patient/family values and wishes for end of life care should this be needed. [Henry et al, 2008] This practice approach is an extension of patient-centered care and shared decision-making. It has been influenced by the recognition that the end-of-life period is often difficult to identify and, as such, important information about patient/family treatment preferences in light of patient/family values may not be able to be used most effectively if it is obtained in the midst of a medical crisis. Advance care planning has also been shown to enhance patient satisfaction with health care services in both adult and pediatric patients.
Procedures for implementing advance care planning, including obtaining advance directives for pediatric patients vary widely, and are dictated by a variety of factors, including physician comfort in having such discussions [Dickens, 2009]. In pediatric patients with long duration and relatively mild morbidity associated with their CKD, advance directive discussions are often postponed until a medical crises necessitates that such a discussion occurs. However, both an AAP policy statement and a research study that evaluated parents’ attitudes about medical care of their critically ill child recommend that such discussions occur well in advance of the need for decisions regarding the use of dialysis and other life-sustaining medical treatments [Pediatrics, 1994; 93(3), 532-536; Sharman et al, 2005:#7004]. Similarly, two AAP policy statements support the value of prenatal counseling that includes discussion of advance directives when severe fetal abnormalities are detected prenatally. [Pediatrics, 2007; 119(2); 401-403 ; Pediatrics, 1996; 98(1), 149-152]

The Patient Self-Determination Act (PSDA) which took effect in 1991 requires Medicare and Medicaid institutional providers to provide adults receiving inpatient medical treatment or enrollment into a federally subsidized health care program with information regarding their rights to establish advance health care directives and encouragement to communicate their wishes regarding preferred treatment in the event of loss of capacity. The law does not require that children or their parents receive similar information and opportunities for advance care planning. Notwithstanding the failure of children’s fourteenth amendment constitutional rights to be acknowledged in the PSDA, several AAP policy statements and a research study strongly advocate for physicians and others to accord considerable weight to the expressed preferences of children to forgo life-sustaining medical treatment when such treatment preserves their biological existence only. [Pediatrics, 1994; 93(3), 532-536; Pediatrics, 1996; 98(1), 149-152; Sharman et al, 2005:#7004]

Recommendation No. 6: Forgoing (Withholding or Withdrawing) Dialysis

In the event that initiating or continuing dialysis is deemed to be harmful, of no benefit, or merely prolonging a child’s dying process, it should be forgone. The decision to forgo dialysis must be made in consultation with the child’s parents. Children should be given the opportunity to participate in the decision to forgo dialysis to the extent that their developmental abilities and health status allow. Additionally there are two circumstances when it is ethically permissible not to offer dialysis: infants with multiple organ failure for whom dialysis would be burdensome and serve only to prolong dying; and pediatric patients whose kidney failure is a consequence of a primary health condition that is non-reversible, non-treatable and/or terminal and for whom dialysis would cause undue suffering. Palliative care planning and treatment should occur in conjunction with any decision to forgo dialysis.

Rationale: The ethical principles supporting this recommendation include beneficence, nonmaleficence, and respect for autonomy. The legal principles supporting this recommendation include the best interest standard and professional integrity. From an
ethical perspective, if initiating or continuing dialysis is deemed to be harmful, of no
benefit, or merely prolonging dying and not in the best interest of the child, it should be
forgone. An AAP guideline acknowledges the stress physicians incur when they
recommend forgoing the use of life-sustaining medical technology and encourages
physicians to obtain support from a variety of resources during the process of
communicating their recommendation to families. [Pediatrics, 1994; 93(3), 532-536]
Furthermore, the AAP guideline recommends that those who “generally decline” to
participate in the limitation or withdrawal of therapy communicate their position to
patients and families as soon as their disinclination becomes relevant and arrange for care
by another physician who will be able to more objectively provide recommendations that
are in the best interest of the pediatric patient and are not unduly influenced by personal
morals. [Pediatrics, 1994; 93:532-536] With regard to the recommendation for taking
into account children’s preferences, while children do not have the legal authority to
decide to forgo dialysis, several recently published AAP policy statement strongly
advocate for physicians and others to accord considerable weight to the feelings and
opinions of children regarding this issue [Pediatrics, 1994; 93(3), 532-536; Pediatrics,
1996; 98(1), 149-152] Options for communicating to parents about non-initiation or
withdrawal from dialysis are presented in Table 3.

Recommendation No. 7: Special Patient Groups

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 treatment has been shown to improve
the quality of life in children. Alternatively, it is reasonable to consider forgoing dialysis
in patients 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. Also 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 consideration of withdrawing dialysis and initiating palliative
care.
Rationale: It has been shown in recent studies that patients that have secondary kidney failure due to their underlying disease may do better than their adult counterparts with dialysis [Ahuja et al, 2004:#17] Based on the ethical principles of beneficence and nonmaleficence, it is reasonable to initiate dialysis when a potential benefit of dialysis is anticipated. Alternatively, based on the ethical principles of beneficence and nonmaleficence, it is reasonable not to initiate dialysis in a pediatric patient with a non-kidney terminal illness when it can be predicted that the child will likely experience increased suffering with dialysis. Similarly, it is justifiable to stop dialysis for pediatric patients for whom the burdens of dialysis have been shown to substantially outweigh the benefits.

Recommendation No. 8: Time-Limited Trials

In children with AKI or ESRD there are no precedents for initiating time-limited trials of dialysis. In special circumstances when dialysis is initiated in conjunction with extra-corporal membrane oxygenation (ECMO), the dialysis is most often discontinued when ECMO is withdrawn due to patient non-viability.

Rationale: No data exist to support time-limited trials of dialysis in pediatric patients. Dialysis is generally initiated if potential benefit is anticipated and withdrawn if dialysis causes harm or if no benefit is derived.

Recommendation No. 9: Palliative Care

A palliative care plan should be developed for all pediatric patients with AKI or ESRD who forgo dialysis and are in need of end-of-life care assistance. The development of a palliative care plan is a continuation of the process of advance care planning and should be family-centered. Incorporation of the terminally ill child’s and family’s preferences into the palliative care plan concerning testing, monitoring and treatment is paramount. With the patient and/or parent and family consent, persons with expertise in palliative care, such as hospice professionals, should be involved in managing the medical, psychosocial, and spiritual aspects of end-of-life care for the child. Bereavement support should be offered to patients and families. Nephrologists and the child’s health care team should seek support, as needed, in dealing with the child’s dying process and death.

Rationale: It is generally agreed that palliative care seeks to enhance quality of life in the face of an ultimately terminal health condition by proactively addressing physical, emotional, psychosocial and spiritual/existential distress associated with the end-of-life process [Pediatrics, 2000, 106(2), 351-357]. Given the difficulty in determining temporal proximity to death for children with a terminal medical condition, the AAP recommends using a palliative care model in which components of palliative care are offered at
diagnosis (i.e., relief of pain and anxiety) and continued throughout the course of illness [Pediatrics, 2000, 106(2), 351-357]. An AAP policy statement presents advice regarding the development of a palliative care plan, and stresses the importance of ongoing communication with children and their families regarding end-of-life issues [Pediatrics, 2000, 106(2), 351-357]. The policy statement also acknowledges that significant barriers exist with regard to the provision of pediatric palliative care and recommends continued advocacy on behalf of children to alter existing reimbursement and regulatory policies that interfere with children receiving appropriate end-of-life services. [Pediatrics, 2000, 106(2), 351-357]

Conclusion

Neonates, infants and children with reversible and non-reversible kidney injury are potential candidates for dialysis (Level A and B Observational Evidence). Clinical experience and research has led to improvements in dialysis techniques and outcomes in children over the past three decades. Such experience and research has also allowed for the identification of risk factors for increased morbidity and mortality and decreased quality of life in children receiving dialysis for AKI or ESRD. This clinical practice guideline regarding shared decision-making in the non-initiation and withdrawal from dialysis for neonates, infants and children is meant to provide a framework for addressing the difficult situations that arise when a child is gravely ill. It is anticipated that these guideline will be revised based on additional input from clinicians and additional research.
REFERENCE LIST FROM RPA ARTICLE ABSTRACTION GROUP:


33 Andreoli SP. **Acute renal failure in the newborn.** Semin Perinatol 2004;28:112-23.


Additional References added by committee:
Chantler, C (1979) Renal failure in childhood. In Black D, Jones NF (eds). Renal

Feinstein, Rinat, Becker-Cohen, Ben-Shalom, Schwartz, Frishberg, 2008; The outcome
of chronic dialysis in infants and toddlers-advantages and drawbacks of haemodialysis.
Rheault, Rajpal, Chavers, Nevins. 2009. Outcomes of infants <28 days old treated with
617-622.
Cohen, 1987, Ethical and legal considerations in the care of the infant with end-stage
renal disease whose parents elect conservative therapy. An American perspective. Ped
Goldstein SL, Graham N, Warady BA, Seikaly M, McDonald R, Burwinkle TM, Limbers
Nephrol, 21, 846-850.
Gerson AC, Riley A, Fivush BA, Pham N, Fiorenza J, Robertson J, Chandra M,
Trachtman H, Weiss R, Furth SL, Assessing health status and health care utilization in
adolescents with chronic kidney disease, JASN, 16: 1427-1432.
staff. Department of Health UK.
Http://www.ncpc.org.uk/download/publications/advancedcareplanning.pdf (assessed
11/23/2009)
97;682-687.
### Table 1: Brief summary of pediatric clinical practice guideline

#### Summary of Recommendation

<table>
<thead>
<tr>
<th>Guideline Number</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A patient-physician relationship that promotes family-centered decision-making is recommended for all pediatric patients with AKI, CKD or ESRD.</td>
</tr>
<tr>
<td>2</td>
<td>Physicians should fully inform patients with AKI, Stage 4 or Stage 5 CKD or ESRD and their parents about the diagnosis, prognosis, and all treatment options that are appropriate.</td>
</tr>
<tr>
<td>3</td>
<td>To facilitate informed decisions about dialysis for pediatric patients with AKI, CKD or ESRD, discussions should occur with the patient, parents, and/or legal guardian about prognosis, potential complications and quality of life.</td>
</tr>
<tr>
<td>4</td>
<td>Conflict resolution interventions should be used when family members are not in agreement with one another, when children are not in agreement with their parents or when families are not in agreement with the physician regarding the initiation, non-initiation or withdrawal of dialysis.</td>
</tr>
<tr>
<td>5</td>
<td>Family-centered advance care planning is recommended for children with AKI, CKD or ESRD and should include the establishment of treatment goals based on a child’s medical condition and prognosis. Advance care planning should be an ongoing process in which treatment goals are revised based on observed benefits and burdens of interventions (i.e. the child’s response to treatment) and the values of the child and the family. Advance directive discussions, a potential component of advance care planning, should be initiated when a child’s medical condition is believed to be irreversible and non-responsive to currently available treatments.</td>
</tr>
<tr>
<td>6</td>
<td>In the event that initiating or continuing dialysis is deemed to be harmful, of no benefit, or merely prolonging a child’s dying process, it should be forgone.</td>
</tr>
<tr>
<td>7</td>
<td>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.</td>
</tr>
<tr>
<td>8</td>
<td>In children with AKI or ESRD there are no precedents for initiating time-limited trials of dialysis.</td>
</tr>
<tr>
<td>9</td>
<td>A palliative care plan should be developed for all pediatric patients with AKI or ESRD who forgo dialysis and are in need of end-of-life care assistance. The development of a palliative care plan is a continuation of the process of advance care planning and should be family-centered.</td>
</tr>
</tbody>
</table>
Table 2. Cited American Academy of Pediatrics policy statements and guidelines

<table>
<thead>
<tr>
<th>Title</th>
<th>AAP Committee</th>
<th>Most recent update or reaffirmation</th>
<th>Original Publication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noninitiation or withdrawal of intensive care for high-risk newborns</td>
<td>AAP: Committee on Fetus and Newborn</td>
<td>Pediatrics, 2007; 119(2); 401-403 &quot;&quot;</td>
<td>Revision of: Pediatrics, 1995; 96(2), 362-363. The initiation or withdrawal of treatment for high-risk newborns</td>
</tr>
<tr>
<td>Ethics and the care of critically ill infants and children</td>
<td>AAP Committee on Bioethics</td>
<td>Pediatrics, 1996; 98(1), 149-152</td>
<td></td>
</tr>
<tr>
<td>Religious objections to medical care</td>
<td>AAP Committee on Bioethics</td>
<td>A statement for reaffirmation of this policy was published on Feb 1, 2007 and August 1, 2009</td>
<td>Pediatrics, 1997; 99(2), 279-281</td>
</tr>
<tr>
<td>Guidelines for forgoing life-sustaining medical treatment</td>
<td>AAP Committee on Bioethics</td>
<td>A statement for reaffirmation of this policy was published on Oct 1, 2004 and May 1, 2009</td>
<td>Pediatrics, 1994; 93(3), 532-536</td>
</tr>
<tr>
<td>Institutional Ethics Committees</td>
<td>AAP Committee on Bioethics</td>
<td>A statement for reaffirmation of this policy was published on Oct 1, 2004 and May 1, 2009</td>
<td>Pediatrics, 2001, 107(1), 205-209</td>
</tr>
<tr>
<td>Informed consent, parental permission, and assent in pediatric practice</td>
<td>AAP Committee on Bioethics</td>
<td>A statement of reaffirmation for this policy was published on Feb 1, 2007</td>
<td>Pediatrics, 1995, 95(2), 314-317</td>
</tr>
<tr>
<td>Palliative care for children</td>
<td>AAP Committee on Bioethics and Committee on Hospital Care</td>
<td>A statement of reaffirmation for this policy was published on Feb 7, 2007</td>
<td>Pediatrics, 2000, 106(2), 351-357</td>
</tr>
</tbody>
</table>
Table 3. Options for communicating information to parents about non-initiation or withdrawal from dialysis (Adapted from Levetown and the American Academy of Pediatrics Committee on Bioethics, Pediatrics 2008;121:21441-e1460)

<table>
<thead>
<tr>
<th>Clinical Judgment</th>
<th>Usual Method of Communicating Message</th>
<th>Alternative Method of Communicating Message</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLINICAL JUDGMENT: “The dialytic treatment is no longer providing benefit.”</td>
<td>“Let’s stop heroic treatment.”</td>
<td>“At this time, I think the wisest thing we can do is to understand how sick Sarah is and stop treatments that are not working for her. I think we should do all we can to ensure her comfort and yours, make sure there are no missed opportunities, and ensure we properly celebrate her life. I will follow your lead on this. Some ideas that have helped other families include getting her home with help for you if you wish, or you may choose to have her friends and your family come here instead and have a party; you can bring her clothes so that she will look like herself, bring in her music or a photo album and relive some of your best memories of her, make a mold of her hand so that you will always have her hand to hold, or anything else that would be a proper celebration of her life.”</td>
</tr>
<tr>
<td>RATIONALE: (a) the risks outweigh the benefit; (b) the underlying condition is progressive; and (3) dialysis is prolonging the dying process.</td>
<td>“Let’s stop aggressive treatment.”</td>
<td>“We will do all we can to ensure he is as comfortable as possible.”</td>
</tr>
<tr>
<td>“Usual” Method of Communicating Message: “We are recommending withdrawal of care for Marisa.”</td>
<td>“Marcia is too ill to get better. We need to refocus our efforts on making the most of the time she has left.”</td>
<td>“There is nothing more we can do for Adam.”</td>
</tr>
<tr>
<td>Alternative Method of Communicating Message: “We need to change the goals of our care for Adam. At this point we clearly cannot cure him, but that does not mean we can’t help him and your family.”</td>
<td>“Johnny is not strong enough to keep going.”</td>
<td>“Johnny is a strong boy and has fought hard with us to beat his disease. Unfortunately, as much as we wish we could, we cannot cure Johnny. At this point we are hurting him rather than helping, giving him side effects, and keeping him from being at home or taking a trip, or whatever he really wants to do in the time he has left.”</td>
</tr>
<tr>
<td>Alternative Method of Communicating Message: “We need to stop active treatment for Dwayne.”</td>
<td>“The goal of curing Dwayne’s disease, despite the best efforts of a lot of smart and hard-working people, is no longer possible. We are so sorry and wish that that were different. I have cared for many children who are as sick as your son. It is very hard on all of us, especially you, his parents and family when the treatments do not work as we had hoped. Many parents like you have agreed to stop efforts to cure when they are not working, as difficult as that is. Would you like me to put you in touch with some of the other parents who have been through this too?”</td>
<td>“We need to stop heroic treatment.”</td>
</tr>
</tbody>
</table>
General Checklist Regarding Shared Decision-Making Recommendations

The Working Group developed the following checklist that gives examples of items that could be added to long-term care plans to monitor implementation of shared decision-making recommendations.

- Patient has been screened for depression.
- Patient score indicates possible depression.
- If screened positive, patient has been referred for possible treatment.
- Patient has been screened for mental status.
- Patient score indicates possible cognitive impairment.
- If cognitive impairment is indicated, have potentially reversible contributors been ruled out?
- Patient has been assessed for decision-making capacity.
- Patient’s preference for a legal agent has been elicited.
- Patient or designated legal agent has been provided information on advance directives.
- Patient has signed durable power of attorney for health care on chart.
- Patient has signed living will in chart.
- Patient has completed a Physicians Orders for Life-Sustaining Treatment (POLST) Paradigm form.
- Circumstances, if any, under which patient would desire discontinuation of dialysis have been documented on chart.
- Circumstances, if any, under which patient would not want CPR, mechanical ventilation, or tube feeding.
- Patient or designated legal agent has been provided prognostic information.

- Estimated survival prognosis is: ___________________________ from ________________, date __________. (e.g., table, model, clinician)
- Present and projected future quality of life and/or functional status has been discussed. If assessed, instrument used ________, score: ________, date: ________.
Has an intervention been planned to improve quality of life or functional status?

Examples of Useful Tools

There are multiple validated tools that can be used to assess depression, mental status, decision-making capacity, quality of life, and prognosis. Choice of a particular tool is dependent upon issues such as preferences, resources, and provider familiarity and training. The Working Group did not endorse particular instruments, but provide the following examples that they believe to be useful.

Depression Screening Instruments

There are many validated instruments that can be used to screen for depression. A systematic review of nine of these instruments shows they all have approximately equal sensitivity in detecting depression.275 Below is an example of two-item depression screening instrument: The PRIME-MD.276 Anyone who screens positive should have his or her diagnosis confirmed with a diagnostic interview or tool.

Example: The PRIME-MD

These questions will help your doctor better understand problems that you may have. Your doctor may ask you more questions about some of these items. Please make sure to check a box for every item.

During the PAST MONTH, have you OFTEN been bothered by little interest or pleasure in doing things? o yes o no

During the PAST MONTH, have you OFTEN been bothered by feeling down, depressed, or hopeless? o yes o no

If patient answers “yes” to either question, proceed with the following patient evaluation, otherwise stop.

<table>
<thead>
<tr>
<th>Major Depression</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the last 2 weeks, have you had any of the following problems nearly every day?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Trouble falling or staying asleep, or sleeping too much?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>2. Feeling tired or having little energy?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>3. Poor appetite or overeating?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>4. Little interest or pleasure in doing things?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>5. Feeling down, depressed, or hopeless?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>6. Feeling bad about yourself – or that you are a failure – or have let yourself or your family down?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television?</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>
8. Being so fidgety or restless that you were moving around a lot more than usual? If “No,” What about the opposite – moving or speaking so slowly that other people could have noticed? Count as “Yes” if “Yes” to either question, or if psychomotor agitation or retardation observed during interview. | YES | NO |
---|---|---|

9. In the last two weeks, have you had thoughts that you would be better off dead or hurting yourself in some way? If “Yes,” tell me about it. | YES | NO |

10. Are answers to five or more of No. 1 to No. 9 “Yes” (one of which is No. 4 or No. 5)? | YES Major depressive disorder; go to No. 12 | NO |

**Partial Remission of Major Depression**

11. Have you ever had a time when you were either much more down or depressed, or had even less interest or pleasure in doing things? If Yes: At that time, did you have many of the problems that I just asked you about, like trouble sleeping, concentrating, feeling tired, poor appetite, little interest in things? Count as “Yes” only if, in the past, patient probably had five of symptoms No. 1 to No. 9 and acknowledges some current depressed mood, or little interest or pleasure. | YES Partial remission of major depressive disorder. | NO |

**Dysthymia**

12. Over the last 2 years, have you often felt down or depressed, or had little interest or pleasure in doing things? Count as Yes only if also Yes to: Was that on more than half the days over the last 2 years? | YES | NO Go to No. 14. |

13. In the last 2 years, has that often made it hard for you to do your work, take care of things at home, or get along with other people? | YES Dysthymia; go to No. 16. | NO |

**Minor Depression**

14. Was Major Depression (including partial remission) diagnosed at #10 or #11? | YES Go to No. 16. | NO |

15. Are answers to two or more of #1 to #9 Yes (one of which is #4 or #5)? | YES Minor depressive disorder. | NO EXIT. |

**Bipolar**

16. Did a doctor ever say you were manic-depressive or give you lithium? If Yes: When was that? Do you know why? | YES Add R/O depressive disorder. | NO |
<table>
<thead>
<tr>
<th>Depression Due to Physical Disorder, Medication, or Other Drug</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Are current depressed symptoms probably due to the biological effects of a physical disorder, medication or other drug?</td>
</tr>
<tr>
<td>Summary of Diagnoses Made (ICD-9-CM codes appear in parentheses)</td>
</tr>
</tbody>
</table>
Cognitive Assessment Tools

Montreal Cognitive Assessment (MOCA)

VISUOSPATIAL / EXECUTIVE

Copy cube

Draw CLOK (Ten past eleven) (3 points)

Contour Numbers Hands

NAME:

Education:

Sex:

Date of birth:

DATE:

MONTREAL COGNITIVE ASSESSMENT (MOCA)

MEMORY

Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

FACE VELVET CHURCH DAISY RED

1st trial

2nd trial

ATTENTION

Read list of digits (1 digit/sec). Subject has to repeat them in the forward order Subject has to repeat them in the backward order


4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt

LANGUAGE

Repeat: I only know that John is the one to help today. The cat always hid under the couch when dogs were in the room.

Fluency / Name maximum number of words in one minute that begin with the letter F (N ≥ 11 words)

ABSTRACTION

Similarity between e.g. banana - orange = fruit train - bicycle = watch - ruler

DELAYED RECALL

Has to recall words with NO CUE

FACE VELVET CHURCH DAISY RED

Points for UNCLUES recall only

OPTIONAL

Category cue

Multiple choice cue

© Z. Nesredine MD Version 7.0 www.mocatest.org Normal: ≥ 26 / 30

Administered by:

TOTAL

Add 1 point if ≤ 12 yr edu
Trail Making Test Part B

**Assessment of Decision-Making Capacity**

Decision-making capacity is the capacity to 1) understand one’s medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including nontreatment; 3) judge the relationship between the treatment options and one’s personal values, preferences, and goals; 4) reason and deliberate about one’s options; and 5) communicate one’s decisions in a meaningful manner. Lack of decision-making capacity is different from cognitive impairment. It is possible for someone to be mildly demented and have decision-making capacity. Traditionally, decision-making capacity has been assessed by clinical interview. In the last several years a number of standardized instruments have become available. An example of one of these instruments is presented below.

**Example: Aid to Capacity Evaluation (ACE)**

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a checkmark.

<table>
<thead>
<tr>
<th>1. Able to understand medical problem.</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Able to understand proposed treatment.</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Able to understand alternative to proposed treatment (if any).</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment).</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment.</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Able to appreciate reasonably foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment).</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**NOTE:** For questions 7a and b, a “Yes” answer means the person’s decision is affected by major depression or psychosis.

<table>
<thead>
<tr>
<th>7a. The person’s decision is affected by major depression.</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7b. The person’s decision is affected by delusion/psychosis.</th>
<th>YES o</th>
<th>UNSURE o</th>
<th>NO o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations: _______________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Overall Impression**

<table>
<thead>
<tr>
<th>Definitely Capable</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probably Capable</td>
<td>O</td>
</tr>
<tr>
<td>Probably Incapable</td>
<td>O</td>
</tr>
<tr>
<td>Definitely Incapable</td>
<td>O</td>
</tr>
</tbody>
</table>

**Comments**

(For example; need for psychiatric assessment, further disclosure and discussion with patient, or consultation with family)

The initial ACE assessment is the first step in the capacity assessment process. If the ACE is definitely or probably incapable, consider treatable or reversible causes of incapacity (e.g., drug toxicity). Repeat the capacity assessment once these factors have been addressed. If the ACE result is probably incapable or probably capable, then take further steps to clarify the situation. For example, if you are unsure about the person’s ability to understand the proposed treatment, then a further interview that specifically focuses on this area would be helpful. Similarly, consultation with family, cultural, and religious figures and/or a psychiatrist, may clarify some areas of uncertainty.

Never base a finding of incapacity solely on your interpretation of domain 7a and 7b. Even if you are sure that the decision is based on a delusion or major depression, we suggest that you always get an independent assessment.

Time taken to administer ACE: ______ minutes

Date: Day: _____ Month: _______ Year: _______ Hour: _______

Assessor: ____________________________________________
Examples of Questions to Help Discuss End-of-Life Issues

The following table provides examples of questions that may be helping in discussing end-of-life issues with patients.


<table>
<thead>
<tr>
<th>Potentially Useful Open-Ended Questions About End-of-Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What concerns you most about your illness?</td>
</tr>
<tr>
<td>• How is treatment going for you (your family)?</td>
</tr>
<tr>
<td>• As you think about your illness, what is the best and the worst that might happen?</td>
</tr>
<tr>
<td>• What has been most difficult about this illness for you?</td>
</tr>
<tr>
<td>• What are your hopes (your expectations, your fears) for the future?</td>
</tr>
<tr>
<td>• As you think about the future, what is most important to you (what matters the most to you)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potentially Useful Questions With Which to Explore Spiritual and Existential Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is faith (religion, spirituality) important to you in this illness?</td>
</tr>
<tr>
<td>• Has faith (religion, spirituality) been important to you at other times in your life?</td>
</tr>
<tr>
<td>• Do you have someone to talk to about religious matters?</td>
</tr>
<tr>
<td>• Would you like to explore religious matters with someone?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>More Direct Questions That May Be Useful with Patients Who Want to Discuss Spiritual and Existential Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What do you still want to accomplish during your life?</td>
</tr>
<tr>
<td>• What thoughts have you had about why you got this illness at this time?</td>
</tr>
<tr>
<td>• What might be left undone if you were to die today?</td>
</tr>
<tr>
<td>• What is your understanding about what happens after you die?</td>
</tr>
<tr>
<td>• Given that your time is limited, what legacy do you want to leave your family?</td>
</tr>
<tr>
<td>• What do you want your children and grandchildren to remember about you?</td>
</tr>
</tbody>
</table>
Advance Directives

Advance directives are oral or written statements by a patient with decision-making capacity expressing his/her preferences for a surrogate and 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. There are two types of advance directives, a living will and a health care proxy. The health care proxy is known in some states as a medical power of attorney or a durable power of attorney for health care. The living will, also known as an instruction directive, indicates a patient’s wishes to be followed if he loses decision-making capacity. Wishes may refer to care in the event of particular medical conditions such as a terminal illness or a persistent vegetative state. The health care proxy designates a person to make decisions for a patient when the patient loses decision-making capacity. In some states, both of these functions are combined in the living will.

The U.S. Congress enacted the Patient Self-Determination Act 215 to require that information concerning written directives be provided to all adults at the time of admission as a hospital inpatient, at the time of admission as a skilled nursing facility resident, in advance of coming under the care of a home health agency, or at the time of initial receipt of hospice care. State laws vary with regard to written directives.

Resources for Advance Care Planning and Advance Directives

The Kidney End-of-Life Coalition provides information and resources to assist dialysis professionals, facilities, and patients with advance care planning and advance directive completion.  

http://www.kidneyeol.org/

Below is the website link for Caring Connections, a website offering information about advance care planning and free downloads of state-specific, legal advance directives  

http://www.caringinfo.org/stateaddownload

The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program to convert patients’ end-of-life wishes into easily identifiable, portable, and reviewable medical orders which are honored throughout the health care system is recognized as a preferred practice by the National Quality Forum in its A National Framework and Preferred Practices for Palliative Care and Hospice Care Quality published in 2006. The POLST Paradigm program was also recognized as a model practice for implementing advance care planning by RAND Health in their Advance Directives and Advance Care Planning: A Report to Congress published in 2009. The website link for the POLST Paradigm Program is below.

www.polst.org

Below is a model advance care planning policy that dialysis facilities may find helpful in developing their advance directive policies and procedures to comply with the Conditions for Coverage published by the Centers for Medicare and Medicaid Services in 2008 which in Subpart C- Patient Care, Section § 494.70 Condition: Patients’ Rights, requires dialysis facilities to have policies with regard to advance directives.
Advance Care Planning in Dialysis Facilities*

I. Policy

It is the policy of (name of the dialysis facility) to respect the right of patients with decision-making capacity to execute advance directives documents and to have these documents respected by personnel of the dialysis facility.

II. Rationale for the Policy

Adoption of these policies and procedures enhances the dialysis facility’s ability to provide the medical care sought by patients. Their implementation is a major step in assuring respect for patient autonomy and the patient’s ability to exercise his or her right to self-determination concerning medical treatment.

III. 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 health care proxy and for future medical care determined prospectively (sometimes including the completion of a written advance directive), updated periodically, and respected when the patient no longer has the capacity to participate in medical decision-making.

Advance Directive: A statement by a patient with decision-making capacity expressing his/her preference for a health care proxy 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 or regulations 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 in the event of particular medical conditions, such as terminal illness or a persistent vegetative state); 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 durable power of attorney for health care. In some states both instruction and proxy directives may be combined into one advance directive form. Some patients may want to state their preferences verbally to their family and to dialysis staff and not put them into writing. Any expressed preferences should be documented in the patient’s dialysis medical record. Such verbal statements constitute oral advance directives. (Since written advance directives are preferable from a legal perspective, the remainder of this policy and procedure refers to written advance directives.)

Attending Physician: A licensed physician with staff privileges in the dialysis facility who has primary responsibility for treatment of the patient. (In the case of dialysis patients, this physician is likely to be the nephrologist primarily assigned to the supervision of the patient’s dialysis and related care.) If more than one physician shares the responsibility for care of the patient, any of those physicians may act as the attending physician under this policy.

Decision-Making Capacity: The capacity of a patient to 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her 
personal values, preferences and goals; 4) reason and deliberate about his/her options; and 5) communicate his/her decision in a meaningful manner. Assessment of decision-making capacity is a clinical judgment made by the patient’s attending physician.

**Health Care Agent, Proxy, Surrogate, Guardian, Medical Power of Attorney, or Durable Power of Attorney for Health Care:** A person, who in accordance with applicable state laws, has been selected by a patient or who, in accordance with applicable state laws, has been appointed, and has been given the authority to make informed health care decisions for the patient in the event the patient loses decision-making capacity. The appropriate terminology may vary from state to state, but the intent to allow an individual to pre-assign decision-making authority to another person is common among all such instruments. To the extent permitted by applicable state law, the health care agent may have the opportunity to be guided in his/her decision-making by prior knowledge of the patient’s wishes through conversations and/or the stipulations in a written advance directive.

**Living Will:** The living will, also known as an instruction directive, indicates a patient’s wishes to be followed if he/she loses decision-making capacity. Wishes may refer to care in the event of particular medical conditions such as a terminal illness or a persistent vegetative state. The patient may indicate that he/she wishes under certain circumstances to have or continue treatments such as dialysis or CPR or to discontinue or refrain from such treatments.

**Patient Without Decision-Making Capacity:** A patient who in accordance with the clinical judgment of the attending physician, clinical practice guidelines, and applicable state laws, has been declared to lack the capacity to: 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her personal values, preference and goals; 4) reason and deliberate about his/her own options; and 5) communicate his/her decision in a meaningful manner.

**IV. Procedures**

A. ______________________(facility should designate a specific individual, committee or category of health professionals, i.e. social worker, nurse, clinician) will assume ultimate responsibility for assuring compliance with the advance directive policies and procedures and assuring that each patient is advised of his/her rights under the policies. The responsible individual(s) will be well informed about advance directives and relevant state laws and will be comfortable with and capable of discussing issues related to death and dying. The individual(s) will also have an awareness of how cultural diversity affects the views and concerns of persons of different ethnic and religious groups towards death and dying. Designated staff should assure that their personal beliefs and values about death and dying are not imposed onto the patient and family.

B. All clinical staff will be made familiar with advance directives and will be oriented with the facility’s written policies and procedures.
C. Upon adoption of these policies and procedures, a determination of decision-making capacity will be made by the patient's attending or rounding physician or other licensed professional as allowed by state law on the patient’s admission to the dialysis unit, yearly, and whenever there is a change in the patient's neurological status.

D. A determination will be made if each patient has previously signed any type of advance directive authorized by state law. Upon adoption of these policies and procedures, existing patients will be asked. A new patient will be asked upon admission to a dialysis facility for the initiation of dialysis treatment.

E. If the patient has existing advance directives, he/she will be requested to provide a copy to the facility for placement in the patient’s dialysis medical record.

F. If the patient, either new or existing, is unable to participate in discussions with staff of the facility, an effort will be made through discussion with the patient’s legal guardian or authorized health care proxy according to state law to determine if the patient has previously signed any type of advance directive. An effort will be made to obtain a copy of any such advance directive for placement in the patient’s dialysis medical record.

G. Any existing advance directive document(s) will be reviewed and discussed with the patient if he/she is able to participate in such discussions. The patient will also be asked if he/she is comfortable with the existing advance directive or desires to execute a new one.

H. If the patient has not signed advance directives, the responsible staff member(s) will have a discussion with and provide written information to the patient about advance directives and applicable state laws regarding advance directives.

If the patient does elect to complete an advance directive document, the following are helpful questions to ask during the advance care planning process:

- If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering and medical procedures such as breathing machines and feeding tubes, which would you pick and why?
- Under what circumstances, if any, would you want to stop dialysis?
- Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
- Where do you prefer to die and who do you wish to be with you when you die?
(Applicable state forms for advance care planning can be obtained through Caring Connections, www.caringinfo.org)

a. Patients new to dialysis who have not signed advance directives will be approached within one month of initiation of dialysis therapy. Since the prospect of beginning dialysis is overwhelming to most individuals, patients who have not previously signed advance directives may not wish to discuss or sign advance directives at the time of admission. If at all possible, however, patients will be encouraged to complete a medical power of attorney to allow for a decision-maker in the event of an emergency.

I. If it is determined that the patient has not signed advance directives and the patient’s decision-making capacity is temporarily impaired due to a medical condition, e.g. uremia, the initial discussion of advance directives will be delayed until the patient can participate in the process.

J. If the patient does not have advance directives and does not wish to discuss or sign advance directives the first time he/she is approached, the topic will be approached again within three months. However, regardless of whether the patient completes an advance directive, he/she will be asked to provide the name of a person he/she would want to make decisions for him/her in the event of incapacity. This person’s name shall be documented in the advance directive section of the patient’s dialysis medical record.

K. If the patient still does not elect to complete advance directives, his/her decision will be respected. However, in conjunction with long-term care planning, or if the patient’s physical condition deteriorates, appropriate staff will once again offer to discuss advance care planning if the patient so desires.

L. When a discussion regarding advance directives occurs with the patient, the discussion, as well as the patient’s decision whether or not to sign advance directives, will be noted in the progress notes of the dialysis medical record. The patient’s long-term care plan will include pertinent information on advance directives that will be regularly updated as needed.

M. If the patient chooses to complete advance directives, the dialysis medical record will be marked in a manner that makes it readily apparent to staff that an advance directive exists. There will be a standardized section of the patient’s dialysis medical record that is devoted to documenting end-of-life preferences. A copy of the advance directives document(s) will also be maintained in the dialysis medical record in a form that complies with applicable state law, if any.
N. The patient’s advance directives, if any, will be reported at periodic patient care meetings to ensure that staff members are familiar with the existence of that patient’s advance directives.

O. Staff assigned to deal with advance directives in the facility will promptly notify any third party designated to act under the advance directives if circumstances arise which are addressed by the patient’s advance directive.

P. The patient will be advised to discuss his/her advance directives and provide a copy of them to any person designated as a health care proxy or authorized to act under a health care power of attorney or similar advance directives. The patient will also be advised to discuss his/her advance directives and provide a copy of the advance directives to one or more of the following groups of people: his/her personal physician, significant other, family, friend, attorney or religious adviser. If the patient desires, a facility staff person will facilitate discussions with these individuals.

Q. Advance directives will be reviewed with the patient on a semi-annual basis, at approximately the time of the patient’s long-term care planning meeting, or more frequently if there is significant change in the patient’s physical condition, to determine if changes in the advance directives are necessary. The facility will periodically review any health care proxy to ensure that the designated person can still act as proxy and that the contact information is current.

a. If the patient alters his/her advance directives, the facility should document that the superseded advance directive was revoked. If a copy of the revoked advance directive is maintained, it should be clearly marked to distinguish that it has been revoked. (Facilities should determine if applicable state law mandates how revocation is documented.)

R. The dialysis patient or his/her health care proxy is responsible for giving a copy of his/her advance directive to health care professionals treating the patient. With a signed release from the patient or proxy, the dialysis facility will provide a copy of the advance directives to the following:

a. A hospital at the time of any future admission;

b. Another dialysis facility upon permanent transfer or transient treatments;

c. Any treating physician, home health agency, hospice, nursing home or health maintenance organization which provide service to the patient; or

d. Any ambulance service, transportation provider or EMT, which provides transport to the patient.
Prognostic Tools

Modified Charlson Comorbidity Index

Completed by _______________ Date of completion _______________ Time ____________

Assigned Weights of diseases

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Assigned Weights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myocardial Infarction (any form of coronary artery disease)</td>
<td>1</td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td></td>
</tr>
<tr>
<td>Peripheral Vascular Disease</td>
<td></td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td></td>
</tr>
<tr>
<td>Connective tissue Disease</td>
<td></td>
</tr>
<tr>
<td>Ulcer Disease</td>
<td></td>
</tr>
<tr>
<td>Mild Liver Disease</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>2</td>
</tr>
<tr>
<td>Moderate or severe renal disease</td>
<td></td>
</tr>
<tr>
<td>Diabetes with end-organ damage</td>
<td></td>
</tr>
<tr>
<td>Any tumor</td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td></td>
</tr>
<tr>
<td>Moderate or Severe Liver Disease</td>
<td>3</td>
</tr>
<tr>
<td>Metastatic solid tumor</td>
<td>6</td>
</tr>
<tr>
<td>AIDS</td>
<td></td>
</tr>
</tbody>
</table>

For each decade over the age of 40 years of age, add a score of 1. Non-diabetic dialysis patients received a minimum score of 2 for moderate to severe renal disease, and...
diabetic patients received a minimum score of 4 (2 for diabetic end-organ damage and 2 for end-stage renal disease).

Total score of the patient _____/_____.

### MALNUTRITION INFLAMMATION SCORE (M.I.S.)

#### (A) Patients’ related medical history:

1. **Change in end dialysis dry weight (overall change in past 3-6 months):**
   - 0: No decrease in dry weight or weight loss <0.5 kg
   - 1: Minor weight loss (0.5 kg but <1 kg)
   - 2: Weight loss more than one kg but <5%
   - 3: Weight loss >5%

2. **Dietary Intake:**
   - 0: Good appetite and no deterioration of the dietary intake pattern
   - 1: Somewhat sub-optimal solid diet intake
   - 2: Moderate overall decrease to full liquid diet
   - 3: Hypocaloric liquid to starvation

3. **Gastrointestinal (GI) symptoms:**
   - 0: No symptoms with good appetite
   - 1: Mild symptoms, poor appetite or nauseated occasionally
   - 2: Occasional vomiting or moderate GI symptoms
   - 3: Frequent diarrhea or vomiting or severe anorexia

4. **Functional capacity (nutritionally related functional impairment):**
   - 0: Normal to improved functional capacity, feeling fine
   - 1: Occasional difficulty with baseline ambulation, or feeling tired frequently
   - 2: Difficulty with otherwise independent activities (e.g. going to bathroom)
   - 3: Bed/chair-ridden, or little to no physical activity

5. **Co-morbidity including number of years on Dialysis:**
   - 0: On dialysis less than one year and healthy otherwise
   - 1: Dialyzed for 1-4 years, or mild co-morbidity (excluding MCC)
   - 2: Dialyzed >4 years, or moderate co-morbidity (including one MCC)
   - 3: Any severe, multiple co-morbidity (2 or more MCC)

#### (B) Physical Exam (according to SGA criteria):

6. **Decreased fat stores or loss of subcutaneous fat (below eyes, triceps, biceps, chest):**
   - 0: Normal (no change)
   - 1: Mild
   - 2: Moderate
   - 3: Severe

7. **Signs of muscle wasting (temples, clavicle, scapula, ribs, quadriceps, knee, interosseous):**
   - 0: Normal (no change)
   - 1: Mild
   - 2: Moderate
   - 3: Severe

#### (C) Body mass index:

8. **Body mass index: BMI = Wt(kg) / Ht(m)**
   - 0: BMI <18 kg/m²
   - 1: BMI: 18-19.9 kg/m²
   - 2: BMI: 20-24.9 kg/m²
   - 3: BMI: ≥25 kg/m²

#### (D) Laboratory Parameters:

9. **Serum albumin:**
   - 0: Albumin: >4.0 g/dL
   - 1: Albumin: 3.5-3.9 g/dL
   - 2: Albumin: 3.0-3.4 g/dL
   - 3: Albumin: <3.0 g/dL

10. **Serum TIBC (total Iron Binding Capacity):**
    - 0: TIBC: ≥250 mg/dL
    - 1: TIBC: 200-249 mg/dL
    - 2: TIBC: 150-199 mg/dL
    - 3: TIBC: <150 mg/dL

### Total Score = sum of above 10 components (0-30):

---

*MCC (Major Comorbid Conditions) include CHF class III or IV, full blown AIDS, severe CAD, moderate to severe COPD, major neurological sequelae, and metastatic malignancies of s/p recent chemotherapy.

* Suggested equivalent increments for serum transferrin are: >200 (0), 170-200 (1), 140-170 (2), and <140 mg/dL (3).

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body mass index (kg/m²)</td>
<td></td>
</tr>
<tr>
<td>≥18.5</td>
<td>0</td>
</tr>
<tr>
<td>&lt;18.5</td>
<td>2</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>1</td>
</tr>
<tr>
<td>Congestive heart failure stage III or IV</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>2</td>
</tr>
<tr>
<td>Peripheral vascular disease stage III of IV</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>2</td>
</tr>
<tr>
<td>Dysrhythmia</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>1</td>
</tr>
<tr>
<td>Active malignancy</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>1</td>
</tr>
<tr>
<td>Severe behavioral disorder</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>2</td>
</tr>
<tr>
<td>Totally dependent for transfers</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>0</td>
</tr>
<tr>
<td>Presence</td>
<td>3</td>
</tr>
<tr>
<td>Initial context</td>
<td></td>
</tr>
<tr>
<td>Planned dialysis</td>
<td>0</td>
</tr>
</tbody>
</table>
Unplanned dialysis (late referral) 2

Risk of death increases with the score. Patients with ≥9 points had a predicted 6-month mortality of 62% in the derivation sample (2,500 patients) and 70% in the validation sample (1,640 patients).


Prognostic Tables
Following are prognostic tables for AKI and ESRD.

Tables for AKI
The first table below gives gross ranges of mortality synthesized from the literature review. The second table below gives examples of multivariate predictive models of mortality that can be used in acute renal failure. Four of these models are available as part of an ICU ARF Severity Score tool at a “living” web-based ARF database (www.bio.ri.ccf.org/arf). The web site uses these models to generate readily available prognostic measures of mortality (e.g., give the probability of mortality of a particular patient when compared to groups of patients with similar scores). A provider enters characteristics of their particular patient and the probability of their hospital mortality is calculated (see Table 19 for a sample print-out).

Table 17. Expected Intensive Care Unit and Hospital Mortality for Dialysis Patients with AKI

<table>
<thead>
<tr>
<th></th>
<th>Heterogeneous Patient Populations</th>
<th>Bone Marrow Transplant Patients</th>
<th>Post-Surgical Patients</th>
<th>Post-Trauma Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICU Mortality</td>
<td>≈ 50 – 65%</td>
<td>≈ 60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Mortality</td>
<td>≈ 50 – 85%</td>
<td>≈ 85%*</td>
<td>45 – 65%</td>
<td>50 – 80%</td>
</tr>
</tbody>
</table>

*Based on one small (n < 100) retrospective study.

Table 18. Predictive Models of Mortality for Dialysis Patients with AKI

APACHE II122: Acute physiologic score based on 12 physiologic measures, age, and the presence of severe chronic health problems.

APACHE III: Refinement in APACHE II regarding scoring of physiologic measures plus adds location prior to ICU as variable.

*Brietzke129: Includes age, health status, initial or delayed renal failure, oliguria, sepsis, and physiologic severity of illness.

Bullock123: Includes 6 variables: Age, jaundice, cardiovascular complications, hypercatabolism, pulmonary complications, and clinical presentation in terms of urine output.

*Chertow77: Includes mechanical ventilation, malignancy, and nonrespiratory organ system failure.

Cioffi124: Produces a prognostic index based on age, number of blood transfusions, cardiac surgery, the
interval between the onset of ARF and dialysis and preoperative hypotension.

*Liano*\(^{118}\): Includes metabolic, cardiovascular, respiratory, renal(2), neurological(2), and personal(2) variables.

Lohr\(^{125}\): Includes five significant variables: Systolic blood pressure, assisted ventilation, CHF, sepsis, and gastrointestinal dysfunction.

**Mortality Prediction Model (modified)**\(^{127}\): Seven variables: cardiovascular, neurological, hematology/malignancy, infection, CPR. Replaces the number of organ system in failure with information about use of CPR before ICU admission.

*Paganini*\(^{121}\): Includes gender, respiratory failure requiring intubation, hematologic dysfunction, bilirubin, surgery, creatinine, BUN, and number of failed organ systems.

Rasmussen\(^{128}\): Variables included not clear.

**Simplified Acute Physiologic Score**\(^{129}\): Consists of a selection of measurements of the original APACHE, without an adjustment for chronic health problems.

**Simplified Acute Physiologic Score-Extended**\(^{130}\): As above plus 8 more physiologic measures.

**Simplified Acute Physiologic Score-Reduced**\(^{130}\): Uses five physiologic variables only.

Schaefer\(^{80}\): Uses six metabolic, cardiovascular (2), respiratory, infection, and chronic disease variables.

SS\(^{131}\): Modification of the APACHE II containing additional physiological measures but not including the reason for ICU admission.

*Indicates models available on website.

**Table 19. Acute Renal Failure Severity Score Validation Probabilities for Sample Patient.**\(^{282}\)

<table>
<thead>
<tr>
<th>Patient No.</th>
<th>Subjective Prediction (0-9)</th>
<th>Difference (in Days) between Prediction and First Day of Dialysis</th>
<th>Cleveland Clinic Foundation</th>
<th>Chertow (pseudo)</th>
<th>French Study Group (pseudo)</th>
<th>Liano (pseudo, outcome = ATN)</th>
<th>Hospital Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>26,934</td>
<td>5</td>
<td></td>
<td>0.969</td>
<td>0.724</td>
<td>I/E*</td>
<td>1</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*I/E* – indicates patient did not meet inclusion criteria
### Tables for End-Stage Renal Disease

#### Table 20. Expected Remaining Years of Life For 1996 U.S. Prevalent Hemo- and Peritoneal Dialysis Populations by Age, Race, and Sex (USRDS, 1998 ADR, p.76)

<table>
<thead>
<tr>
<th>Age</th>
<th>Black Male</th>
<th>Black Female</th>
<th>White Male</th>
<th>White Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>16.8</td>
<td>15.9</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>25-29</td>
<td>14.5</td>
<td>14.1</td>
<td>11.3</td>
<td>11</td>
</tr>
<tr>
<td>30-34</td>
<td>12.7</td>
<td>12.5</td>
<td>9.4</td>
<td>9.3</td>
</tr>
<tr>
<td>35-39</td>
<td>11.3</td>
<td>11.4</td>
<td>8</td>
<td>7.9</td>
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<tr>
<td>40-44</td>
<td>10</td>
<td>9.8</td>
<td>6.9</td>
<td>7.1</td>
</tr>
<tr>
<td>45-49</td>
<td>8.6</td>
<td>8.5</td>
<td>6.1</td>
<td>6.3</td>
</tr>
<tr>
<td>50-54</td>
<td>7.3</td>
<td>7.1</td>
<td>5.2</td>
<td>5.2</td>
</tr>
<tr>
<td>55-59</td>
<td>6.3</td>
<td>6.3</td>
<td>4.4</td>
<td>4.5</td>
</tr>
<tr>
<td>60-64</td>
<td>5.2</td>
<td>5.3</td>
<td>3.7</td>
<td>3.9</td>
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<tr>
<td>65-69</td>
<td>4.2</td>
<td>4.4</td>
<td>3.1</td>
<td>3.3</td>
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<tr>
<td>70-74</td>
<td>3.5</td>
<td>3.7</td>
<td>2.7</td>
<td>2.9</td>
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<td>75-79</td>
<td>2.9</td>
<td>3.0</td>
<td>2.4</td>
<td>2.5</td>
</tr>
<tr>
<td>80-84</td>
<td>2.5</td>
<td>2.5</td>
<td>2.1</td>
<td>2.1</td>
</tr>
<tr>
<td>85+</td>
<td>2.1</td>
<td>2.0</td>
<td>1.7</td>
<td>1.7</td>
</tr>
</tbody>
</table>

#### Table 21. One (from Day 91-One Year +90 Days), Two-, Five-, and Ten-Year Survival Probabilities by Age in All USRDS Patients (from USRDS, 1998 ADR, Reference Tables E14-20).

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>95.54</td>
<td>94.41</td>
<td>83.73</td>
<td>71.26</td>
</tr>
<tr>
<td>25-29</td>
<td>91.5</td>
<td>88.2</td>
<td>76.17</td>
<td>61.28</td>
</tr>
<tr>
<td>30-34</td>
<td>89.43</td>
<td>83.66</td>
<td>70.85</td>
<td>53.92</td>
</tr>
<tr>
<td>35-39</td>
<td>89.77</td>
<td>83</td>
<td>63.19</td>
<td>45.17</td>
</tr>
<tr>
<td>40-44</td>
<td>89.89</td>
<td>81.67</td>
<td>60.91</td>
<td>40.06</td>
</tr>
<tr>
<td>45-49</td>
<td>89.25</td>
<td>79.05</td>
<td>53.23</td>
<td>32.33</td>
</tr>
<tr>
<td>50-54</td>
<td>87.73</td>
<td>77.69</td>
<td>47.01</td>
<td>22.54</td>
</tr>
<tr>
<td>55-59</td>
<td>84.63</td>
<td>71.01</td>
<td>39.43</td>
<td>14.13</td>
</tr>
<tr>
<td>60-64</td>
<td>80.51</td>
<td>65.63</td>
<td>30.31</td>
<td>8.89</td>
</tr>
<tr>
<td>65-69</td>
<td>75.70</td>
<td>58.44</td>
<td>22.55</td>
<td>4.81</td>
</tr>
<tr>
<td>70-74</td>
<td>71.88</td>
<td>51.63</td>
<td>17.67</td>
<td>2.61</td>
</tr>
<tr>
<td>75-79</td>
<td>66.05</td>
<td>46.07</td>
<td>13.69</td>
<td>1.4</td>
</tr>
<tr>
<td>80-84</td>
<td>61.61</td>
<td>39.74</td>
<td>8.6</td>
<td>0.81</td>
</tr>
<tr>
<td>85+</td>
<td>53.91</td>
<td>32.26</td>
<td>5.2</td>
<td>0</td>
</tr>
</tbody>
</table>

\(^a\)Number in parentheses denotes year of incidence.
Table 22. 1-Year and 2-Year Survival by Albumin for HD Patients Starting Dialysis between 1987 and 1991 (Goldwasser, 1993).156

<table>
<thead>
<tr>
<th>Albumin (g/dL)</th>
<th>1-Year</th>
<th>2-Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥3.5</td>
<td>86%</td>
<td>76%</td>
</tr>
<tr>
<td>&lt;3.5</td>
<td>50%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Table 23. 18-Month Survival for Prevalent Patients by Albumin (Lowrie, 1990).155

<table>
<thead>
<tr>
<th>Average Albumin Concentration (g/dL)</th>
<th>N exposed</th>
<th>N Died</th>
<th>Risk of Death</th>
<th>RR to Index of 4.01-4.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;4.5</td>
<td>124</td>
<td>10</td>
<td>0.0806</td>
<td>0.83</td>
</tr>
<tr>
<td>4.01-4.5</td>
<td>3,931</td>
<td>382</td>
<td>0.0972</td>
<td>1.00</td>
</tr>
<tr>
<td>3.51-4.0</td>
<td>6,517</td>
<td>1399</td>
<td>0.2147</td>
<td>2.21</td>
</tr>
<tr>
<td>3.01-3.5</td>
<td>1,266</td>
<td>598</td>
<td>0.4724</td>
<td>4.86</td>
</tr>
<tr>
<td>2.51-3.0</td>
<td>157</td>
<td>107</td>
<td>0.6815</td>
<td>7.01</td>
</tr>
<tr>
<td>≤2.5</td>
<td>29</td>
<td>21</td>
<td>0.7241</td>
<td>7.45</td>
</tr>
</tbody>
</table>

Table 24. Patient Functional Status and Mortality Among 10,355 Incident HD and PD Patients, Network 6, 1989 to 199 (McCellan, 1994).168

<table>
<thead>
<tr>
<th>Functional Status</th>
<th>N</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Normal*</td>
<td>1,128</td>
<td>13.1</td>
</tr>
<tr>
<td>Mildly Impaired</td>
<td>3,215</td>
<td>37.3</td>
</tr>
<tr>
<td>Moderately Impaired</td>
<td>2,748</td>
<td>31.8</td>
</tr>
<tr>
<td>Severely Impaired</td>
<td>1,538</td>
<td>17.8</td>
</tr>
</tbody>
</table>

*Unadjusted mortality rate expressed as deaths per 100 dialysis years
†Reference Group


<table>
<thead>
<tr>
<th>Year</th>
<th>1 Year</th>
<th>2 Year</th>
<th>3 Year</th>
<th>4 Year</th>
<th>5 Year</th>
<th>6 Year</th>
<th>7 Year</th>
<th>8 Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>DM</td>
<td>78 %</td>
<td>60%</td>
<td>48%</td>
<td>40%</td>
<td>32%</td>
<td>28%</td>
<td>25%</td>
<td>21%</td>
</tr>
<tr>
<td>Non-DM</td>
<td>83%</td>
<td>74%</td>
<td>67%</td>
<td>60%</td>
<td>55%</td>
<td>50%</td>
<td>48%</td>
<td>44%</td>
</tr>
</tbody>
</table>

Table 26. Cardiac Mortality (%) After Acute Myocardial Infarction by Year Myocardial Infarction Occurred (Herzog, 1998).185

<table>
<thead>
<tr>
<th>Year of AMI</th>
<th>1 Year</th>
<th>2 Year</th>
<th>3 Year</th>
<th>5 Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985-1989</td>
<td>39.3</td>
<td>51.3</td>
<td>60.0</td>
<td>71.7</td>
</tr>
<tr>
<td>1990-1995</td>
<td>42.2</td>
<td>52.0</td>
<td>59.3</td>
<td>65.4</td>
</tr>
</tbody>
</table>
Table 27. All Cause Mortality (%) After Acute Myocardial Infarction by Etiology of ESRD: 1977-1995 Incident Patients with a Myocardial Infarction ESRD (Herzog, 1998).185

<table>
<thead>
<tr>
<th>Year of AMI</th>
<th>1 Year</th>
<th>2 Year</th>
<th>3 Year</th>
<th>5 Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985-1989</td>
<td>56.0</td>
<td>71.3</td>
<td>80.7</td>
<td>90.0</td>
</tr>
<tr>
<td>1990-1995</td>
<td>61.7</td>
<td>74.2</td>
<td>82.0</td>
<td>89.1</td>
</tr>
</tbody>
</table>

Table 28. All Cause Mortality (%) After Acute Myocardial Infarction by Etiology of End-Stage Renal Disease (Herzog, 1998).185

<table>
<thead>
<tr>
<th>Etiology</th>
<th>1 Year</th>
<th>2 Year</th>
<th>3 Year</th>
<th>5 Year</th>
<th>10 Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>62.3</td>
<td>77.2</td>
<td>86.1</td>
<td>93.3</td>
<td>99.1</td>
</tr>
<tr>
<td>Hypertension</td>
<td>60.79</td>
<td>73.5</td>
<td>81.3</td>
<td>90.4</td>
<td>97.9</td>
</tr>
<tr>
<td>Other</td>
<td>55.4</td>
<td>68.9</td>
<td>77.5</td>
<td>86.9</td>
<td>95.8</td>
</tr>
</tbody>
</table>

Table 29. Cumulative Survival Following First Amputation After Renal Failure For Medicare End-Stage Renal Disease HD and PD Prevalent Patients 1991 through 1994 (Eggers, 1999).162

<table>
<thead>
<tr>
<th>Sub-Group</th>
<th>Days Post Amputation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>419</td>
</tr>
<tr>
<td>35-44</td>
<td>2342</td>
</tr>
<tr>
<td>45-54</td>
<td>4038</td>
</tr>
<tr>
<td>55-64</td>
<td>6365</td>
</tr>
<tr>
<td>65-74</td>
<td>7956</td>
</tr>
<tr>
<td>≥75</td>
<td>3324</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>16970</td>
</tr>
<tr>
<td>GMN</td>
<td>892</td>
</tr>
<tr>
<td>HTN</td>
<td>4059</td>
</tr>
<tr>
<td>Level of Amputation</td>
<td></td>
</tr>
<tr>
<td>Toe</td>
<td>7806</td>
</tr>
<tr>
<td>Below Knee</td>
<td>12380</td>
</tr>
<tr>
<td>Above Knee</td>
<td>4691</td>
</tr>
</tbody>
</table>
Assessment of Quality of Life or Functional Status

Patients and their providers may find it helpful to monitor patient-centered outcomes such as functional status or quality of life. The terms generally refer to functioning or well-being in one or more domains (e.g., physical, psychological, social, occupational, sexual, etc.). Poor functional status is highly predictive of early death in dialysis patients (for a discussion of this evidence, see Recommendation #3 of this guideline). Both generic and disease-specific instruments have been used to assess quality of life or functional status in hemodialysis patients. Of the studies reviewed for this guideline, 97 reported quality of life data from 72 unique studies. The 72 studies used over 150 different assessment instruments and strategies to assess quality of life, functional status, psychosocial adjustment, and related constructs. An accurate account of the instruments is difficult because several studies used instruments that were poorly described or poorly referenced. Several studies used unstandardized and/or single-item instruments with unknown or questionable reliability and validity. The most frequently used standardized and well-known instruments included variations of the Karnofsky Performance Status Scale (n=23), the Medical Outcomes Study 36-item Short Form (SF-36) (n=14), the Beck Depression Inventory (n=9), and the Sickness Impact Profile (n=8). Disease-specific instruments, such as the Kidney Disease Quality of Life (KDQOL) instrument, were also used less frequently. Quality of life and functional status can be assessed by a variety of methods: patient self-report, interviewer administered, and provider or significant other ratings. It is not clear to what extent provider or patient reports of quality of life for a particular patient are comparable. Only three studies reviewed for this guideline examined differences between providers and patients’ ratings of QOL. One study compared patients’, nurses’, and nephrologists’ ratings in 119 dialysis patients; the second compared patients’ and nurses or dietitians’ ratings of 49 patients; and a third study compared patients self-ratings to nurses’ ratings in 256 patients. Although these studies suggest that patients’ and providers’ ratings are significantly different, these results should be interpreted with caution because of multiple methodological problems.

Quality of life measurement in dialysis has developed rapidly in the past several years. Readers wishing to implement a program to monitor quality of life may wish to consult two recent reviews of quality of life measures used in dialysis settings. These developments include the modifications of the Dartmouth COOP Functional Health Assessment Charts for dialysis use and the creation by the Johns Hopkins Patient Outcome Research Team CHOICE study of the CHOICE Health Experience Questionnaire. In addition, one of the studies reviewed for this guideline reported on a clinic’s experience in using the SF-36 as an outcome measure over a three-year period.

The Working Group felt that patients are the best judges of their quality of life and that patients’ views should be respected. The most commonly used self-report instrument to assess quality of life or functional status in our systematic review of the literature was the SF-36. A few patients, however, are incapable or unwilling to rate their quality of life. An example of an instrument that is provider rated, the Karnofsky Performance Status Scale, is provided on the following page.
The Karnofsky Performance Status Scale (KPS) is an older and widely used method of quantifying the functional status of cancer patients and was the most commonly used instrument to assess functional status in our systematic review of the renal literature. As originally conceived, the KPS has three alphabetic groups for classifying patients’ ability to work, to carry on normal activity, and to care for themselves. These alphabetic groups are further divided into 11 categories, which cover all possible levels of functioning from completely normal (100) to dead (0). Modifications of the scale have also been used, including a 4-point version. Although originally designed as a clinician rating scale, patient self-report versions are also available.

### KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS
#### RATING (%) CRITERIA

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal no complaints; no evidence of disease.</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care.</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent.</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
</tbody>
</table>

National Kidney Foundation Checklists

The National Kidney Foundation’s *Initiation or Withdrawal of Dialysis in End-stage renal disease: Guidelines for the Health Care Team* included helpful checklists to follow in initiating dialysis, withdrawing dialysis, and in helping patients to prepare for dying.

**Initiation of Dialysis Checklist**

Patient’s name, address, and telephone number:

______________________________

______________________________

Name, address, and telephone number of surrogate designated by advance directive, if applicable:

______________________________

______________________________

Names, addresses, and telephone numbers of significant other and family members (contact only with the consent of the patient if competent, or otherwise, the surrogate):

______________________________

______________________________

______________________________

1. Pre-evaluation information:

   a. If applicable, attach a copy of the patient’s advance directive(s) or other statement(s) of the patient’s wishes and decisions regarding life sustaining medical treatment. State the type of directive executed.

   ____________________________

   ____________________________

   b. Materials should be reviewed for familiarization. The patient/surrogate should be asked to clarify any matters which may be unclear, incomplete or not in compliance with applicable state law. If the advance directive is only a treatment directive, ask if the patient wishes to designate a surrogate. If there is only a surrogate designation, ask if a treatment directive is considered appropriate.

   ____________________________

   ____________________________

   ____________________________

   ____________________________

   ____________________________

   ____________________________

   ____________________________
c. Assess whether the patient has the capacity to make medical decisions concerning initiation of dialysis and/or regarding other matters likely to require decisions in the foreseeable future (i.e. circumstances that would warrant a DNR order or discontinuation of dialysis). Document the methods used to determine capacity.

d. If the patient lacks capacity, assess whether it is temporary or permanent or related only to one of more medical decisions. Document the methods used to determine capacity.

e. If the patient lacks capacity and does not have an advance directive designating a surrogate, the physician or health care team treating the patient should consult with legal counsel to determine who can make medical decisions for the patient and what, if any, restrictions apply to such authority. The person who can act, the legal basis for that person’s authority (i.e. health care power of attorney, health care proxy, court appointed guardianship, parent of minor) and the limitations on her/his authority are as follows:

f. Date, time and place of the discussion and decision to initiate or withhold dialysis, including the name of the person(s) making the decision and who else was present.

g. If there was a decision to withhold dialysis, identify any close family members/others who might object to withholding dialysis, and determine if the patient/surrogate has discussed not initiating dialysis with them. Explain why they might object to the decision to withhold dialysis.

2. Evaluation of Patient:

a. Determine the reasons or conditions underlying the patient’s/surrogate’s desires regarding initiation of dialysis. Such assessment should include specific medical, physical, spiritual and psychological issues, as well as interventions which could be appropriate.

Some of the potentially treatable factors that might be identified by the assessment are:

- Fear of dialysis, possibly due to a lack of information about treatment;
- Underlying medical disorders, including the prognosis for short- or long-term survival on dialysis;
- The patient’s assessment of quality of life and ability to function prior to initiation of dialysis and preconceptions of anticipated quality of life and ability to function after initiation of dialysis;
- The patient’s short- and long-terms goals;
- The burden that cost of treatment/medications/diet/transportation may have on the patient/family/others;
- The patient’s psychological condition, including conditions/symptoms that may be caused by uremia;
- Undue influence or pressure from outside sources, including the patient’s family;
- Conflict between the patient and others.

b. If the patient/surrogate does not want dialysis initiated, consideration might be given to the use of psychometric tools, such as the Beck Depression Inventory, the Karnofsky Scale, the SF 36 Health Survey or similar measurement instruments. They could aid in identifying specific problems which could impact the decision. Identify any such tools used and the results.

c. 1. Have the patient/others received education about various ESRD treatment modalities and settings and the possibility of a trial period on dialysis to permit them to make an informed and knowledgeable decision on whether to initiate dialysis? Describe.

2. Have the patient/others spoken to dialysis patients with similar illnesses and/or cultural and socioeconomic backgrounds to learn the patient’s/other’s perspective of the quality of life on dialysis?

d. If the patient/surrogate does not want dialysis initiated, did he/she consent to referral to a counseling professional? (e.g. social worker, pastoral care, psychologist or psychiatrist) If yes, identify and describe any findings or recommendations.
1. If the patient/surrogate does not want dialysis initiated, are there interventions that could alter the patient’s circumstances which might result in him/her considering it reasonable to initiate dialysis? Describe possible interventions.

2. Does the patient/surrogate desire the proposed intervention(s)?

3. A determination has been made that the following intervention(s) will be undertaken.

f. In cases where the surrogate has made the decision to either initiate or withhold dialysis, has it been determined that the judgment of the surrogate is consistent with the stated desires of the patient? Describe.

3. The Dying Process if ESRD Treatment is Withheld:

a. Have the patient/others been given advice and information on the clinical course of the patient dying of uremia or an underlying illness? Describe.

b. Have the patient/others been provided with counseling and information on bereavement issues? Describe.

c. Have the patient/others been advised that the health care team will attempt to provide them with all necessary emotional, spiritual, social and medical assistance and support possible? The following assistance and support have been offered:

d. Has the question of where the patient desires death to occur been discussed with the patient/surrogate? The patient/surrogate has made the following decision:
1. If the patient desires to die at home, have the patient/care givers been offered assistance in obtaining supportive services from agencies and providers, including hospice and home health care? (List services offered and those that were accepted.)

2. Has there been discussion about whether emergency medical services in the community will honor DNR orders or an advance directive?

3. If the patient/surrogate has decided not to initiate dialysis at this time, has he/she advised that the decision can be reconsidered at a later date and given serious consideration by the physician?
Withdrawal of Dialysis Checklist

Patient’s name, address, and telephone number:

Name, address, and telephone number of surrogate designated by advance directive, if applicable:

Names, addresses, and telephone numbers of significant other and family members (contact only with the consent of the patient if competent, or otherwise, the surrogate):

1. Pre-evaluation Information:
   a. If applicable, attach a copy of the patient’s advance directive(s) or other statement(s) of the patient’s wishes and decisions regarding life sustaining medical treatment. State the type of directive executed.

   b. Materials should be reviewed for familiarization. The patient/surrogate should be asked to clarify any matters which may be unclear, incomplete or not in compliance with applicable state law. If the advance directive is only a treatment directive, ask if the patient wishes to designate a surrogate. If there is only a surrogate designation, ask if a treatment directive is considered appropriate.

   c. Assess whether the patient has the capacity to make medical decisions concerning withdrawal of dialysis. Document the methods used to determine capacity.
d. If the patient lacks capacity, assess whether it is temporary or permanent or related only
to one or more medical decisions. Document the methods used to determine capacity.

e. If the patient lacks capacity and does not have an advance directive designating a
surrogate, the physician or health care team treating the patient should consult with legal
counsel to determine who can make medical decisions for the patient and what, if any,
restrictions apply to such authority. The person who can act, the legal basis for that
person’s authority (i.e. health care power of attorney, health care proxy, court appointed
guardianship, parent of minor) and the limitations on her/his authority are as follows:

f. If there was a decision to withdraw dialysis, indicate the date, time and place of the
discussion and decision to withdraw dialysis, including the name of the person(s) making
the decision and who else was present.

g. If there was a decision to withdraw dialysis, identify close family members/others who
might object to withdrawal of dialysis, and determine if the patient/surrogate has
discussed withdrawing dialysis with them. Explain why they might object to the decision
to withdraw dialysis therapy.

2. Evaluation of Patient:

a. Determine the reasons or conditions underlying the patient/surrogate desires regarding
withdrawal of dialysis. Such assessment should include specific medical, physical,
spiritual and psychological issues, as well as interventions which could be appropriate.

Some of the potentially treatable factors that might be included in the assessment are:

- Underlying medical disorders, including the prognosis for short- or long-term
  survival on dialysis;
- Difficulties with dialysis treatments;
- The patient’s assessment of his/her quality of life and ability to function;
- The patient’s short- and long-terms goals;
- The burden that costs of continued treatment/medications/diet/transportation may
  have on the patient/family/others;
- The patient’s psychological condition, including conditions/symptoms that may be
  caused by uremia;
- Undue influence or pressure from outside sources, including the patient’s family;
- Conflict between the patient and others;
Dissatisfaction with the dialysis modality, the time or the setting of treatment.

b. If the patient/surrogate wishes to withdraw from dialysis, consideration might be given to the use of psychometric tools, such as the Beck Depression Inventory, the Karnofsky Scale, the SF 36 Health Survey or similar measurement instruments. They could aid in identifying specific issues which could impact the decision. Identify any such tools used and the results.

c. If the patient/surrogate wishes to withdraw dialysis, did he/she consent to referral to a counseling professional? (e.g. social worker, pastoral care, psychologist or psychiatrist) If yes, identify and describe any findings or recommendations.

d. 1. If the patient/surrogate wishes to withdraw dialysis, are there interventions that could alter the patient’s circumstances which might result in him/her considering it reasonable to continue dialysis? Describe possible interventions.

2. Does the patient/surrogate desire the proposed intervention(s)?

3. A determination has been made that the following intervention(s) will be undertaken.

e. In cases where the surrogate has made the decision to either continue or withdraw dialysis, has it been determined that the judgment of the surrogate is consistent with the stated desires of the patient? Describe.

3. The Dying Process if ESRD Treatment is Withdrawn:

a. Have the patient/others been given advice and information on the clinical course of the patient dying of uremia or of the patient’s underlying illness? Describe.
b. Have the patient/others been provided with counseling and information on bereavement issues? Describe.

c. Have the patient/others been advised that the health care team will attempt to provide them with all necessary emotional, spiritual, social and medical assistance and support possible? The following assistance and support have been offered:

d. Has the question of where the patient desires death to occur been discussed with the patient/surrogate? The patient/surrogate has made the following decision:

e. 1. If the patient desires to die at home, have the patient/care givers been offered assistance in obtaining supportive services from agencies and providers, including hospice and home health care? (List services offered and those that were accepted.)

f. If the patient/surrogate has decided to withdraw dialysis, has he/she been advised that the decision can be reconsidered at a later date and given serious consideration by the physician?
**Preparation for Dying Checklist**

(The physician might consider discussing and providing this checklist to the patient/surrogate after a determination has been made not to initiate or to withdraw dialysis.)

The patient/surrogate may wish to consult with an attorney, accountant, spiritual advisor or others to discuss these or other matters that may be important given the patient’s particular circumstances. Consideration should be given to providing copies of the relevant documents, such as an advance directive, to the patient’s surrogate, the patient’s family/significant other, primary physician and/or attorney.

A patient who has decided not to initiate or to withdraw dialysis should have or consider preparing the following documents:

- A will.
- Signed advance directive (living will, durable health care power of attorney or health care proxy, DNR order) complying with applicable state law.
- A durable power of attorney complying with applicable state law designating someone to act on the patient’s behalf on all matters other than medical, including legal, financial, banking and business transactions. (A power of attorney must be “durable” if it is to remain in effect even if the individual becomes unable to make his or her own decisions or dies.)
- An inventory, including the location of her/his bank, brokerage and other financial accounts, stock and bond holdings not in brokerage accounts, real estate and business records and documents, medical and other insurance policies, pension plans and other legal documents.
- Names, addresses and telephone numbers of attorney, accountant, family members/significant other, friends and business associates who should be notified of the death or may have information that will be helpful in dealing with estate affairs.
- Documentation concerning preferences for funeral/memorial services, burial or cremation instructions and decisions about organ, tissue or body donation.
- Written or video or audio taped message to family/significant other, business associates and friends.

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**Pain Assessment and Management for Dialysis Patients**

The Mid-Atlantic Renal Coalition and the Kidney End-of-Life Coalition supported, in part, under CMS Contract #HHSM-500-2006-NW005C, developed an evidence-based algorithm for the assessment and treatment of pain in dialysis patients. Clinical Algorithm &Preferred Medications to Treat Pain in Dialysis Patients. (1-10)


The references for this evidence-based algorithm are the final 10 references in the Toolkit References below.
Tool Kit References


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303. Milde FK, Hart LK, Fearing MO. Sexuality and fertility concerns of dialysis
patients...including commentary by Watts RJ and Zarifian A with author response.


