We think by feeling. What is there to know?
I hear my being dance from ear to ear.
I wake to sleep, and take my waking slow.

Theodore Roethke
"The Waking"
Because patients with chronic kidney disease are more likely to die than to reach end-stage renal disease, incident ESRD patients—who have survived CKD—are unique, and they pose particular challenges when transitioning to dialysis. This year we use data from the newly revised Medical Evidence form to provide a wider perspective on the care patients have received prior to beginning ESRD therapy.

These data—collected from May, 2005, through June, 2006—illustrate, for example, the use of different types of vascular access at the first outpatient dialysis treatment. As shown on the next page, more than four in five new patients are using a dialysis catheter when they start therapy, a number relatively consistent across all age, gender, and racial groups. A maturing arteriovenous fistula is present in just 19.1 percent of those with a catheter, and a maturing arteriovenous graft in 7 percent.

The high use of catheters at the start of dialysis is a significant concern, as the increased morbidity and mortality associated with this access are well known. Many have suggested that the rate arises from the number of patients whose vasculature is too poor to support an internal access. Yet this hypothesis appears contradicted by the increasing use of fistulas in the prevalent population. The initial use of catheters is moderately lower among patients who have seen a nephrologist prior to beginning therapy, but is still at 73 percent.

Anemia treatment appears to be the only other area in which pre-ESRD care by a nephrologist is associated with greater treatment levels. Estimated glomerular filtration rates, total cholesterol, glycosylated hemoglobin levels, and serum albumin levels do not seem affected by the type of physician seen prior to ESRD therapy.

Over the last decade there has been a slow but steady increase in mean hemoglobin levels at the initiation of ESRD treatment, from 9.2 to 10.3 g/dl between May, 1995, and May, 2006. The percent of patients receiving treatment with an erythropoiesis stimulating agent treatment prior to initiation has grown as well, but appears to have declined from a peak of 34.4 percent in September, 2004, to 30.9 percent in June, 2006. Some of this change may reflect more accurate reporting with the new Medical Evidence form, on which questions about ESA use have been revised to more clearly reflect treatment prior to the start of ESRD therapy itself, rather than prior to the first dialysis treatment. The flattening in the trend, however, began in the middle of 2003, pre-dating changes in the Medical Evidence form. Lower hemoglobin levels at initiation are associated with younger age, particularly in pediatric and young adult patients.

Data on hemoglobin levels achieved after dialysis initiation show that patients are now reaching a level of 12 g/dl more quickly than in any prior period.
Additional information reported on the new Medical Evidence form includes glycemic control in the diabetic population and cholesterol and triglyceride levels. Prior to the start of ESRD therapy, one-third of patients have glycosylated hemoglobin levels less than 7 percent. Cholesterol levels are above 200 mg/dl in 21 percent of patients reaching ESRD, and triglycerides higher than 200 mg/dl in 24 percent.

The new Medical Evidence form asks whether patients were informed of their transplant options prior to beginning therapy. Among patients younger than 65, 78–87 percent have received this information.

This year we present data on the incident ESRD population residing in long-term care facilities, again using new fields from the revised Medical Evidence form. Of the incident patients who are institutionalized when they begin therapy, 85 percent are living in a nursing home and 77 percent in an assisted living facility. Nephrology care prior to the start of ESRD therapy varies by living situation, as do typical biochemical data. Hemoglobin levels, for instance, are lower in nursing home patients than among those who are not institutionalized, a finding consistent with lower reported use of ESAs in this population. Estimated GFRs are higher in the nursing home population, consistent with increased comorbidity and with lower nutritional status and muscle mass, each of which may be associated with poor outcomes. Poor nutritional status is also consistent with lower reported albumin and total cholesterol levels.

In conclusion, the incident population is becoming older and more complicated in its comorbidity, and appears to be starting ESRD therapy with higher eGFRs—a reflection of both increasing disease burden and, in those with low BMIs, malnutrition as well. Almost 70 percent of patients starting ESRD therapy have hemoglobin levels less than 11 g/dl, the lower end of the target suggested by the National Kidney Foundation’s K/DOQI guidelines. Although patients appear to be initiating treatment with higher eGFRs, the level of comorbidity seems to be stabilizing in whites but continuing to increase among African Americans.

Nursing home patients starting dialysis are very frail, and, with their poor nutritional status and increased comorbidity, appear to be among the most vulnerable to potential complications. High rates of catheter use across all ages, shown in previous data, may place the frail elderly at a particularly high risk for morbidity and mortality in the first year of treatment, a conclusion supported by rising death rates in patients age 75 and older during the first three months of dialysis therapy.

### Highlights

**Patient care at initiation:** data from the new Medical Evidence form 102
- **pre-ESRD care**
- **access use**
- **nephrologist care**
- **kidney dietitian care**
- **relationship of nephrologist care to laboratory values & access at initiation**
- **anemia & EPO at initiation**
- **mean hemoglobin**
- **ESA therapy**
- **hemoglobin & altitude**
- **biochemical characteristics**
- **serum creatinine**
- **serum albumin**
- **glycosylated hemoglobin**
- **cholesterol**
- **triglycerides**
- **kidney transplant options**
- **patients informed of transplant options at initiation**
- **institutionalized patients**
- **pre-ESRD care**
- **biochemical parameters**

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**Figure 3.1** Incident hemodialysis patients, 2005, with new (revised edition) Medical Evidence forms.
The most recent edition of the Medical Evidence form (2728), released in the spring of 2005, introduced new fields related to comorbidity, laboratory test values, and pre-ESRD care and vascular access. In this chapter, as well as in Chapters Eight and Ten and in our new chapter on Emerging Issues, we present preliminary data from these new fields.

Only 30.9 percent of patients beginning ESRD treatment are known to have used erythropoiesis stimulating agents (ESAs) in the year prior to therapy (Figure 3.2). This varies slightly by race, from 26.5 percent of African American patients to 35.7 percent of Asians. Half of new patients report no pre-ESRD use of ESAs.

Nearly 23 percent of new ESRD patients have been under the care of a nephrologist for a year or more, and approximately one in three for under 12 months (Figure 3.3). Thirty percent, however, have not seen a nephrologist prior to starting ESRD therapy; this ranges from 25.3 percent of Asian patients to 34.7 percent of those of Hispanic ethnicity.

Despite the importance of diet in the management of renal disease, few patients see a renal dietitian prior to starting ESRD therapy (Figure 3.4). Only 10.5 percent of all new patients, and only 8.9 percent of African Americans, have received dietary counseling any time prior to therapy.

The National Kidney Foundation’s K/DOQI guidelines promote the arteriovenous fistula as the preferred method of vascular access, yet slightly over 81 percent of new hemodialysis patients begin ESRD therapy with a catheter (Figure 3.5). By race and ethnicity, this ranges from 77.4 percent of Asian patients to 84.8 percent of Native American patients. Of new hemodialysis patients not using a fistula, 19.1 and 6.7 percent, respectively, have a maturing arteriovenous fistula or graft.

Figure 3.6 shows how care by a nephrologist prior to the initiation of ESRD therapy may influence laboratory values and vascular access choices after initiation. Median hemoglobin levels, for instance, appear to be higher in patients who see a nephrolo-
gist before initiation than in those who do not, at 10.3 versus 9.8 g/dl. And eGFRs in these patients are 0.6 ml/min/1.73 m² higher at initiation, indicating, perhaps, that they may be starting therapy with a greater disease burden.

Seeing a nephrologist before initiation does not appear to be associated with lipid control, nutritional markers, or diabetes control. A median cholesterol of 154 mg/dl is apparent in patients with pre-ESRD nephrologist care, compared to 152 mg/dl in those without. Median albumin levels are 3.5 mg/dl at initiation, regardless of nephrology care. And median glycosylated hemoglobin values are 6.7 and 6.6 percent, respectively, in patients receiving and not receiving pre-ESRD nephrologist care.

Nearly 46 percent of patients who have seen a nephrologist for less than a year have received an ESA—such as epoetin alfa and darbepoetin alfa—prior to starting therapy; this rises to 56.3 percent of those under nephrologist care for more than a year. Among patients who have not seen a nephrologist, in contrast, only 5 percent receive an ESA before starting ESRD treatment.

The type of vascular access with which a patient initiates dialysis also appears to be strongly influenced by pre-ESRD care. Nearly 95 percent of patients not under the care of a nephrologist, for instance, initiate therapy with a catheter, compared to 73.2 percent of those seeing a nephrologist, while AV fistula use is just 2.1 compared to 19.2 percent. And among patients not using a fistula at their first treatment, 25 percent with pre-ESRD nephrologist care have a maturing fistula at this time, compared to only 12.9 percent of those lacking such care.

After rising steadily through the late 1990s and in the early part of this decade, mean hemoglobin levels at initiation have flattened over the past year (Figure 3.7). In May, 2006, the overall level was 10.2 g/dl—10.1 for hemodialysis patients, 10.8 for those on peritoneal dialysis, and 11.6 for those with a preemptive transplant.

The percentage of new ESRD patients receiving an erythropoiesis stimulating agent (ESA) prior to starting therapy has followed a similar pattern (Figure 3.8). After increasing steadily from 1995 through the third quarter of 2004, ESA use began to decline—perhaps explaining in part the recent trend in lower pre-initiation hemoglobin levels. Patients who receive an ESA pre-initiation, however, continue to begin treatment with higher hemoglobin levels compared to those with no ESA prescription.

Recommendations from the National Kidney Foundation’s Kidney Disease Quality Outcomes Initiative (K/DOQI) now set a target hemoglobin of 11–12 g/dl. Almost one in three new ESRD patients begins therapy with a hemoglobin at or above this level; approximately 45 percent, however, begin with a hemoglobin of less than 10 g/dl, a number that has remained steady since 2004 (Figure 3.9).

Mean hemoglobin levels at initiation are highest in the oldest patients, in 2006 reaching 10.2–10.4 g/dl in those 65 and older (Figure 3.10). By race and ethnicity, levels are highest in whites and lowest in African Americans, at 10.3 and 9.8 g/dl, respectively.

Patterns of ESA use prior to initiation differ from those seen with hemoglobin levels (Figure 3.11). Pediatric patients, for example, are most likely to have received ESA therapy, at 39 percent compared to 25 percent of those age 20–44. By race and ethnicity, 34 percent of incident Asian patients receive this therapy, compared to 27 percent of African American and Hispanic patients.

In 2005, hemoglobin levels following initiation of therapy rose 2.0 g/dl, regardless of locational altitude (Figure 3.12). At month four, mean levels for patients living at altitudes below 1,000 feet and of 1,000–<2,500 feet are 12.5 g/dl. At higher altitudes of 2,500–<5,000 and 5,000 feet or greater, mean hemoglobins increase slightly to 12.6 and 12.9 g/dl, respectively. As altitude increases, plasma volume begins to contract, ultimately raising the body’s hemoglobin level. Figure 3.13 shows the interaction of altitude and hemoglobin, affirming a natural increase in erythropoiesis at higher altitudes in order to maintain oxygen carrying capacity by increasing the body’s hemoglobin concentration.

Hemoglobin levels following initiation show steady increases from month one to month four, reaching 10.8, 11.6, 12.1, and 12.5 g/dl, respectively, in 1996, 1999, 2000, and 2005 (Figure 3.14). By gender, hemoglobin levels were similar in males and females in both 1996 and 2005, but 1.6–1.7 g/dl higher in the latter year. In 1996, hemoglobin levels at month four were 10.9 and 10.6 g/dl, respectively, in whites and African Americans, and in 2005, 12.5 g/dl in both races—1.5 and 1.8 g/dl higher than 1996 levels.

Mean hemoglobins at initiation are generally higher in the northern half of the country and in some areas of the Southwest (Figure 3.15). In 2004–2005, the overall average hemoglobin at initiation for the entire country was 10.2 mg/dl, and reached 10.5 in patients residing in areas represented by the upper quintile.

Not surprisingly, in many of the areas of the country in which hemoglobins are highest at initiation, the percentage of patients receiving ESAs prior to initiation is high as well (Figure 3.16). Approximately 32 percent of patients overall receive ESAs prior to starting therapy, increasing to an average of 43.6 percent for those residing in areas represented by the upper quintile.

**Figure 3.7** Incident ESRD patients with a first service date between May, 1995, & June, 2006; data from Medical Evidence form. **Figure 3.8** Incident dialysis patients, 2005; includes only those with a valid EPO claim in each of the first four months after initiation. **Figure 3.9** Incident dialysis patients, 2005; hemoglobin at initiation obtained from the Medical Evidence form. **Figure 3.10** Incident dialysis patients; includes only those with a valid EPO claim in each of the first four months after initiation. **Figures 3.11-16** Incident ESRD patients, 2004–2005; data from Medical Evidence form. By ESA; excludes patients residing in Puerto Rico & the Territories.
serum creatinine levels at the initiation of ESRD therapy have fallen steadily since 1995–2006 overall, and 2.3 mg/dl for patients age 20–44 (Figure 3.17). Levels range from a low of 5.4 mg/dl in patients age 75 and older to 8.7 in those age 20–44.

By race and ethnicity, initial creatinine levels remain highest in African Americans, at 7.6 mg/dl in 2006, and lowest in whites, at 6.1 (Figure 3.18).

Nearly 18 percent of new ESRD patients begin therapy with a serum creatinine level less than 4 mg/dl, a considerable increase from only 4.6 percent in 1995, suggesting that patients are starting therapy earlier in the course of their disease (Figure 3.19).

Patient distribution by initial serum creatinine level varies considerably by age, gender, and race and ethnicity (Figure 3.20). Among patients age 20–44, for instance, 6.7 percent begin therapy with a creatinine less than 4 mg/dl, while 30 percent have a level of 10 or greater. Among patients age 75 and older, in contrast, the numbers are reversed, at 26.3 and 4.6 percent, respectively. And only 8.9 percent of white patients have a creatinine of 10 mg/dl or higher, compared to 20.1 percent of African Americans. Overall, 60.7 percent of new patients begin therapy with an albumin below the test’s lower limit of normal (Figure 3.21). With the exception of children, this differs little by age. It does, however, vary by race and ethnicity, with 70 percent of Native American patients beginning therapy with a value under the lower limit, compared to 58 percent of white patients (Figure 3.22). And by primary diagnosis, only one in five patients with cystic kidney disease starts ESRD treatment with an albumin below the test’s limit, compared to 66.2 and 54.8 percent of those with primary diagnoses of diabetes and hypertension, respectively (Figure 3.23).

New fields on the revised Medical Evidence form request data on laboratory values at the initiation of ESRD therapy. The majority of new patients have a glycosylated hemoglobin level of 5 to less than 7 percent (Figure 3.24). This number rises by age in adult patients, from 49.4 percent of those age 20–44 to 68.2 percent of those 75 and older, and falls to 44.8 percent of pediatric patients. It varies little by gender or by race and ethnicity.

Nearly 21 percent of new patients have a cholesterol of 200 mg/dl or above—ranging from 12.9 percent of patients age 75 and older to 34.0 percent of children; from 16.1 percent of men to 26.7 percent of women; and from 18.7 and 16.4 percent of white and Native American patients to 25.2 and 25.8 percent of African Americans and Asians (Figure 3.25). And nearly 25 percent of new patients have a triglyceride level of 200 mg/dl or above (Figure 3.26). This higher level is most common in children, at 40.9 percent, and least common in patients 75 and older, at 16.1 percent. Results by gender are more similar than those for cholesterol, at 22.9 percent of males and 25.3 percent of females. And by race and ethnicity they vary from 18.1 percent of African American patients to 26.8 percent of Hispanics.

**Figures 3.17–19** incident ESRD patients with a first service date between May, 1995, & June, 2006; data from Medical Evidence form. **Figure 3.20** incident ESRD patients with a first service date between January, 2005, & June, 2006; data from Medical Evidence form. **Figures 3.21–23** incident ESRD patients with a first service date between May, 1995, & June, 2006; data from Medical Evidence form. In Figure 3.21, 2006 pediatric data not graphed due to small patient cohort. **Figures 3.24–26** incident ESRD patients, 2005, with new (revised edition) Medical Evidence forms.
3.21 Patient distribution, by age
incidence ESRD patients

3.22 Patient distribution, by race/ethnicity
incidence ESRD patients

3.23 Patient distribution, by primary diagnosis
incidence ESRD patients

3.24 Patient distribution, by glycosylated hemoglobin (HbA1c) level at initiation, age, gender, & race/ethnicity, 2005 incidence ESRD patients

3.25 Patient distribution, by total cholesterol level at initiation, age, gender, & race/ethnicity, 2005 incidence ESRD patients

3.26 Patient distribution, by triglyceride level at initiation, age, gender, & race/ethnicity, 2005 incidence ESRD patients

More on data from the new Medical Evidence form:
8.2–7 (pediatric patients).
ew to the recently revised Medical Evidence (ME) form is a question on whether a patient has been informed of his or her kidney transplant options. Data from the first of these forms shows that 70.4 percent of new dialysis patients are told of their options (Figure 3.27). This rises to 83.6 percent of patients age 20–44, but falls to 55.4 percent of those age 75 and older. It varies little by gender, and by race and ethnicity is lowest among whites, at 68.9 percent, and greatest among Hispanics, at 74.1 percent. Seventy-two percent of patients not institutionalized at the start of dialysis therapy are informed of their options, compared to 44.4 percent of those in a nursing home, and 53.9 percent of those in assisted living facilities (Figure 3.28).

Seventy-four percent of patients receiving pre-ESRD care from a nephrologist are informed of their transplant options as they begin ESRD therapy, compared to 64.4 percent of those not under such care (Figure 3.29). The most common reason reported for patients not being informed is that they are not assessed for transplant (Figure 3.30). This is true of 39.4 percent of patients, while 33.9 are reported to be medically unfit, and 27.6 percent are unsuitable candidates for transplant due to age.

In its section on comorbidity, the revised ME form includes new fields asking whether a patient is institutionalized and, if so, whether he or she lives in an assisted living facility, a nursing home, or elsewhere. Eighty-five percent of institutionalized patients starting ESRD therapy reside in a nursing home, while 7.7 percent are in assisted living (Figure 3.31). The percentage living in nursing homes rises by age, is similar by gender, and, by race and ethnicity, is lowest in Native American patients, at 75.0 percent.

Of the patients beginning ESRD therapy, 27.1 percent of those living in nursing homes have seen a nephrologist for less than a year and 12.4 percent have been under nephrologist care for 12 months or more; this is in contrast to 36.2 and 23.1 percent, respectively, of non-institutionalized patients (Figure 3.32).

Data on biochemical parameters at the start of ESRD therapy show that 45.6 percent of patients who are not institutionalized have a hemoglobin level less than 10 g/dl, compared to 49.7 percent of those in a nursing home (Figure 3.33). The number of patients receiving an erythropoiesis stimulating agent prior to therapy is highest among those in assisted living facilities, at 38.3 percent, and lowest among those in nursing homes, at 20.6 percent. Twenty-six
percent of those in a nursing home begin treatment with an eGFR of 15–30 ml/min/1.73 m², compared to 14.7 percent of patients who are not institutionalized. Total cholesterol levels are lowest among institutionalized patients, while patients in nursing homes are most likely to begin therapy with an albumin lower than the test’s lower limit. And glycosylated hemoglobin levels are slightly higher among patients who are institutionalized.

Among new ESRD patients living in a nursing home, a primary diagnosis of diabetes is slightly more common than in the non-institutionalized population, at 48.5 compared to 41.0 percent (Figure 3.34). Not surprisingly, patients living in nursing homes or assisted living facilities have greater comorbidity, with 84.3 and 74.5 percent, respectively, reporting five or more comorbidities at the start of ESRD therapy, compared to only 15.9 percent in the non-institutionalized population. 

Institutionalized patients (n=4,534 in 2005)

<table>
<thead>
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<th>Percent of Patients</th>
<th>Age</th>
<th>Gender</th>
<th>Race/ethnicity</th>
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<tr>
<td>All</td>
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<td>20-44</td>
<td>45-64</td>
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<tr>
<td>M</td>
<td>F</td>
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<td>White</td>
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Not inst. AL NH Other

Biochemical parameters in patients institutionalized at initiation of ESRD, 2005 incident ESRD patients

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<td>160-&lt;200</td>
<td>15-30</td>
<td>15-30&lt;br/&gt;&amp;&lt;15 ml/min/1.73 m²</td>
</tr>
</tbody>
</table>

Total cholesterol < test’s lower limit | Albumin < test’s lower limit | HbA1c

<table>
<thead>
<tr>
<th>Percent of Patients</th>
<th>Primary diagnosis</th>
</tr>
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<tr>
<td>Not inst. AL NH Other</td>
<td>Other GN HTN Diabetes</td>
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</table>

Primary diagnosis & comorbidity in institutionalized pts, 2005 incident ESRD pts

More on transplantation: Chapter Seven.
patient care at initiation: data from the new ME form

Figure 3.2 Only 24 percent of patients beginning ESRD treatment are reported to have used erythropoiesis stimulating agents one year prior to therapy. Figure 3.3 Thirty percent of new ESRD patients have not seen a nephrologist prior to starting ESRD therapy. Figure 3.4 Only 10.5 percent of all new patients have received dietary counseling any time prior to therapy. Figure 3.5 Slightly over eighty-one percent of new hemodialysis patients begin ESRD therapy with a catheter.

anemia & EPO use at initiation

Figure 3.7 After rising steadily through the late 1990s and in the early part of this decade, mean hemoglobin levels at initiation have flattened over the past year. Figure 3.8 The percent of new ESRD patients receiving an erythropoiesis stimulating agent prior to starting therapy has fallen slightly since late 2005. Figure 3.9 Approximately 45 percent of new ESRD patients begin therapy with a hemoglobin of less than 10 g/dl, a number that has remained steady since 2004.

biochemical characteristics

Figure 3.19 Nearly 18 percent of new ESRD patients begin therapy with a serum creatinine level less than 4 mg/dl; 24 percent initiate with a level of 8 mg/dl or above. Figure 3.21 Nearly 61 percent of new patients begin therapy with an albumin below the test’s lower limit of normal. Figure 3.24 The majority of new ESRD patients have a glycosylated hemoglobin level of 5 to less than 7 percent. Figure 3.25 Nearly 21 percent of new patients have a cholesterol of 200 mg/dl or above. Figure 3.26 More than one in five new patients has a triglyceride level of 200 mg/dl or above.

kidney transplant options

Figure 3.27 Seventy percent of new ESRD patients are told of their transplant options prior to beginning therapy. This number rises to 83.6 percent in patients age 20–44, and falls to 55.4 percent of those age 75 and older. Figure 3.29 Seventy-four percent of patients receiving pre-ESRD care from a nephrologist are informed of their transplant options as they begin ESRD therapy, compared to 64.4 percent of those not under such care. Figure 3.30 Thirty-nine percent of patients who are not informed of their transplant options have not been assessed for transplant.

institutionalized patients

Figure 3.31 Nearly 66 percent of institutionalized patients starting ESRD therapy reside in a nursing home, while 7.7 percent are in an assisted living facility. Figure 3.32 Of the patients beginning ESRD therapy, only 12.4 percent of those living in nursing homes have seen a nephrologist for more than a year, and 27.1 percent have been under nephrologist care for less than 12 months; this is in contrast to 23.1 and 36.2 percent, respectively, of non-institutionalized patients. Figure 3.34 Patients living in nursing homes or assisted living facilities have greater comorbidity, with 84.3 and 75.3 percent, respectively, reporting five or more comorbidities at the start of ESRD therapy, compared to only 15.3 percent in the non-institutionalized population.

chapter summary

maps National means & patient populations for maps can be found in the Excel file for this chapter—on our website at www.usrds.org, & also on the CD-ROM included at the back of this book.