Chapter three
Patient characteristics

...I have a duty to speak the truth as I see it and to share not just my triumphs, not just the things that felt good, but the pain, the intense, often unmitigating pain. It is important to share how I know survival is survival and not just a walk through the rain.

Audre Lorde, Black Women Writers at Work
The complexity of the ESRD population has continued to evolve over the last two decades. In addition to dramatic changes in patient distribution by age, gender, and race, comorbid conditions have had an increasingly profound impact on patient survival after the start of therapy. In 1980 diabetes was the cause of ESRD in only 13.1 percent of new patients (see Reference Table A.1). Now, however, it is the primary diagnosis in 64 percent of Hispanic-Mexican patients, 55 percent of Hispanics of other origins, and 43 percent of non-Hispanics.

Patient selection for ESRD treatment also began to alter dramatically when in 1982 the payment system for dialysis changed to a prospective system under the “Composite Rate.” In the next decade the proportion of ESRD patients initiating dialysis with a primary diagnosis of diabetes increased more than 2.5 times, to 33.7 percent. And in the 1990s this proportion increased by another one-third, to 44.3 percent. The USRDS has been assessing the broader prevalence of diabetes not only as a primary contributor to ESRD, but as a complicating condition. In the 2002 ADR, the chapter by the Cardiovascular SSC evaluated the graded association between cardiovascular mortality and diabetes as a primary cause of ESRD, diabetes as a secondary complicating condition, and diabetes documented from medical services one year after the start of ESRD therapy. Understandably, patients with diabetes as a primary diagnosis have the most widespread organ system disease and the lowest survival. Those with diabetes as a secondary condition have the next lowest survival, and survival is best in relatively new diabetes patients. This year we have determined the total burden of diabetes—both primary and secondary—in patients who survive the first year of ESRD therapy, finding it to be 80 percent in Native Americans, 73 percent in Hispanics, 61 percent in Asians, 59 percent in blacks, and 58 percent in whites. Overall, 59 percent of new patients enter the program with some form of diabetes, making the burden of the disease far greater than previously considered.

Diabetic and non-diabetic patients carry other comorbid conditions as well, the occurrence of which has evolved over time. In patients surviving the first year of therapy, for example, the proportion with cardiovascular comorbidity increased dramatically in the late 1980s; growth has since slowed, but rates are still rising. There is also an increased number of patients entering therapy with cancer as a complicating diagnosis, most evident in patients with multiple myeloma (see Figure 2.31). These patients clearly add to the

CHAPTER HIGHLIGHTS

**Figure 3.3** In 2000, 45 percent of diabetics and 37 percent of non-diabetics who survived one year on dialysis had cardiovascular comorbidity, compared to only 25 and 18 percent in 1984. **Figure 3.8** The mean hemoglobin at initiation rose from 9.2 g/dl in May 1995 to 10.0 g/dl in May 2002, a 9 percent increase, while the percent of patients using EPO in the pre-ESRD period grew from 22 to 32. **Figure 3.11** The percent of patients initiating dialysis with a hemoglobin less than 11 g/dl decreased from 84 in May 1995 to 74 in May of 2002, a 12 percent reduction. Even more dramatically, the percent initiating with a hemoglobin level less than 10 g/dl fell from 68 to 53, a 22 percent reduction over the seven-year period.
complexity of the population under ESRD treatment. Information on the Medical Evidence form allows us to assess some of the care provided to chronic kidney disease patients prior to ESRD. Only thirty-two percent of new ESRD patients, for example, receive EPO treatment before beginning therapy. And while mean hemoglobins at initiation rose overall from 9.2 g/dl in May 1995 to 10 g/dl in June 2002, these levels are still well below the minimum target set by the National Kidney Foundation’s K/DOQI guidelines of 11 g/dl. The lowest hemoglobin levels continue to occur in children and in blacks. Serum creatinine levels at initiation are declining, while estimated glomerular filtration rates (eGFRs) are increasing—indicating, perhaps, that patients are beginning ESRD therapy earlier in the course of their chronic kidney disease. We have assessed the association between eGFR and incident patient comorbidity, and found a direct relationship which suggests that this earlier initiation of therapy may be due to increased comorbidity, with conditions such as fluid overload and congestive heart failure amplifying the need for renal replacement therapy. Based on these findings, eGFR at initiation appears to reflect severity of disease. Because risks of mortality and hospitalization are greater for those with high eGFR levels at the start of therapy, these clinical associations complicate any interpretation of earlier dialysis initiation. Additionally, there are emerging concerns over the accuracy of the estimating equation from the Modification of Diet in Renal Disease Trial (MDRD). Severely malnourished patients with marked loss of muscle mass may appear to have lower serum creatinines and higher eGFRs, which would in turn be associated with a lower survival. Additional research is needed to validate this formula in patients with severe renal failure to determine the best method of assessing residual renal function. Insurance coverage of the incident population may have important implications for the delivery of care in both the pre-ESRD period and the early months of dialysis. The greatest proportion of patients with no coverage at the start of therapy occurs among blacks, followed by Hispanics and Asians. At initiation, almost 60 percent of ESRD patients are covered by Medicare, Medicaid, or a combination of both. These dual-eligible patients, many of whom live in the southern states, may be particularly vulnerable to cutbacks in Medicaid payments, particularly for prescription drugs. They may also be disproportionately affected by shortfalls in the 2003 state budgets. The composition of the incident ESRD population continues to change, placing increasing demands on the provider care system. This complexity affects not only the individual patients, but also the insurance coverage needed to pay for their care. In future USRDS studies we will focus on the degree of insurance coverage and how it influences care and associated outcomes.
Because comorbid conditions were not included on the Medical Evidence form until its revision in 1995, it is difficult to assess long-term trends in the comorbidity of patients beginning ESRD therapy. We are able, however, to use inpatient hospitalization records to track cardiovascular complications since 1984. In diabetic patients surviving at least one year after the start of ESRD, the percent of patients hospitalized with cardiovascular disease increased 25 percent between 1990 and 2000; for congestive heart failure, ischemic heart disease, and peripheral vascular disease, growth was approximately 50 percent (Figure 3.3). The percent of non-diabetics hospitalized with cardiovascular disease increased 17 percent overall. Between 1996 and 2000, however, rates for both patient cohorts leveled off.

Since 1995, the proportion of new ESRD patients with a cardiovascular comorbidity reported on the Medical Evidence form increased from 48.6 to 50.6 percent of the population (Figure 3.4). The amount of congestive heart failure was generally steady across racial and ethnic categories, while that of peripheral vascular disease decreased in most populations—1.4 percent overall, and 14.5 percent among Asians. Rates of ischemic heart disease increased 15.9 percent overall, and nearly 22 percent in blacks. The greatest changes, however, occurred among Native Americans. Between 1995 and 2002 the proportion of these patients...
with any kind of cardiovascular comorbidity increased 33 percent, and 64 percent for those with ischemic heart disease. The differences between the number of patients beginning ESRD therapy with a cardiovascular comorbidity, and those with cardiovascular hospitalizations in the first year, points to the poor survival of these patients in the first year of treatment (see pages 109 and 111).

Most patients beginning ESRD therapy with a diagnosis of cancer are white (Figure 3.5). Between 1995 and 2002, rates of cancer among new patients decreased for Native Americans, but increased for other patients—as much as 43 percent for patients of Hispanic ethnicity. Rates of alcohol dependence and smoking decreased among almost all populations, though smoking increased 4.3 percent among Asians and 23 percent among Native Americans. Rates of COPD decreased slightly for Asians, but among Native Americans increased 61 percent. In 2002, patients were more likely to be able to ambulate on their own and to arrive at therapy without assistance; the proportion of patients unable to ambulate or transfer decreased by this time for all patients but those of Asian descent, in whom they increased 11.4 and 6.7 percent, respectively.

Because comorbidity reporting on the Medical Evidence form is voluntary, reported comorbidities can be underestimated by 30–50 percent. These trends therefore need to be viewed with caution, and supporting data are needed to assess them more completely.

Figure 3.3: In incident ESRD patients surviving one year plus 90 days after initiation; hospitalization data from REBUS inpatient hospitalization diagnosis codes. Because the USRDS is now using a different method of identifying primary payors, data in this figure differ slightly from those presented in Figure 2.4 of the 2002 ADR. Figures 3.4–5: In incident ESRD patients with a first service date between May 1995 & June 2002: data from Medical Evidence form.
While the proportion of patients who receive EPO prior to ESRD therapy has increased since 1996, rates of EPO use remain low (Figures 3.6–7), particularly in relation to the low hemoglobin levels seen in patients beginning therapy. By age, male pediatric patients are the most likely to receive pre-ESRD EPO, and male patients age 20–44 the least. Among females, rates are more consistent across ages. By race, the lowest rates of EPO therapy occur among black and Native American males, while the highest are seen in females of Asian ancestry.

Since early 1995 the overall mean hemoglobin at initiation has increased from 9.2 to 10 g/dl (Figure 3.8). Patients treated with EPO prior to beginning ESRD therapy have hemoglobin levels 0.4–0.5 g/dl higher than those receiving no EPO. The percentage of patients receiving EPO prior to initiation increased from 21.6 to 32.4 between 1995 and 2002.

Between May 1995 and June 2002, the percent of patients with initial hemoglobins above 11 g/dl—the K/DOQI target—rose from 15.9 to 26.1, a 64 percent increase (Figure 3.11). The proportion of patients with levels of 12 g/dl and above rose 80 percent.

Patients age 75 and above have the highest hemoglobin levels at initiation, while levels are lowest in pediatric patients (Figure...
3.12. By race, hemoglobin levels are highest among white patients (Figure 3.13). Among males they are lowest in blacks and Hispanics, and among females the lowest levels are found in blacks and Native Americans.

Patients who begin ESRD therapy on hemodialysis consistently have the lowest initial hemoglobin levels, while those starting therapy with a transplant have the highest (Figure 3.14).

Figures 3.6–3.8, 3.11–3.14 incident ESRD patients with a first service date between May 1995 & June 2002; data from Medical Evidence form.

Figures 3.9–10 incident ESRD patients, 2000–2001 combined, by HSA, unadjusted; data from Medical Evidence form.

3.10 · Mean hemoglobin (g/dl) at initiation

3.11 · Patient distribution, by mean monthly hemoglobin (g/dl) at initiation

3.12 · Mean hemoglobin at initiation, by age & gender

3.13 · Mean hemoglobin at initiation, by race/ethnicity & gender

3.14 · Mean hemoglobin at initiation, by first modality
Between 1995 and 2002, mean blood urea nitrogen (BUN) levels among new ESRD patients decreased 7.7 mg/dl (Figure 3.15). In black and Asian patients, this decrease was 8.5 and 8.0 mg/dl, respectively. By age group, the largest change was seen in patients age 75 and older, whose mean BUN levels fell 9.3 percent, from 95.1 to 86.3 mg/dl (Figure 3.16). Similar patterns are apparent in data on initial serum creatinine levels, which decreased 1.7 mg/dl for blacks during this period, and 1.4 mg/dl for patients age 75 and older (Figures 3.18–19).

Patients with low serum creatinine levels are often assumed to have high levels of residual renal function. This is not always the case, however, as many of these patients may have poor nutrition and low muscle mass. Caution should therefore be used in interpreting the data as a reflection of earlier initiation.

The hypothesis that patients are beginning therapy at an earlier stage of chronic kidney disease may, however, be supported by the steady increase in estimated glomerular filtration rates (eGFRs) at initiation (Figures 3.21–23). Since 1995 the mean eGFR at the beginning of ESRD therapy has increased 2.1 ml/min/1.73 m² overall, to 9.6. By race, the lowest increase—1.6 ml/min/1.73 m²—has occurred in Asians, while the mean eGFR of whites has increased 2.2 ml/min/1.73 m². Pediatric patients tend to have the highest eGFRs, and patients age 20–44 the lowest. The greatest increase in initial levels since 1995 has occurred in patients age 75 and older, from 8.2 to 10.7 ml/min/1.73 m². Concerns have recently been raised, however, regarding the methods used to estimate GFR in patients with advanced renal failure (particularly diabetic patients, for whom the formulas have not been validated), and these should be acknowledged when considering the data.

Body mass index (BMI) among new ESRD patients increased an average of 1.8
kg/m² between 1995 and 2002 (Figure 3.24), a 7 percent increase. Asian and pediatric patients consistently have the lowest BMIs, and their levels changed the least over the period. Native American patients and those age 45–64, in contrast, present with the highest BMIs, and their indices have increased 2.5 and 1.9 kg/m², respectively.

These increasing BMIs in ESRD patients are a source of concern. Chronic ESRD patients constitute a biased sample of patients, as they are healthy enough to have survived to ESRD. It is not clear, therefore, how trends in BMIs should be interpreted, particularly when high indices in the general population are associated with an elevated risk of death, while the reverse is true in the population with ESRD.

Figures 3.15–26 incident ESRD patients with a first service date between May 1995 & June 2002; data from Medical Evidence form.

Figures 3.22–23 eGFR calculation for ages 0–18 from Schwartz et al., & for ages 19 & above from Levey et al.
Estimated glomerular filtration rates & outcomes

On the previous spread we illustrate recent changes in biochemical markers at the initiation of ESRD therapy. It is unclear, however, whether lower BUN and creatinine levels and higher eGFRs show that patients are beginning dialysis earlier because they have greater comorbidity, or because they are receiving better care in the pre-ESRD period. A number of investigators have attempted to interpret eGFR at initiation as an indication of early referral for dialysis. This idea may, however, be complicated by the advanced comorbidity linked in observational studies to higher eGFR levels. To investigate this question we look here at eGFR levels in relation to comorbidity, and also at outcomes in the twelve months following the start of ESRD therapy.

We calculated Charlson scores (a measure of comorbidity) for patients age 67 or older who had two years of medical services prior to starting ESRD therapy in 2000. In both males and females, across age groups, and across most races and ethnicities, there is an almost linear relationship between higher Charlson scores and higher eGFR levels (Figure 3.27). This provides strong evidence that lower BUN and creatinine levels at the initiation of therapy, along with higher eGFR levels, are related not to improved pre-ESRD care, but rather to increased comorbidity.

This hypothesis that higher eGFRs at the initiation of ESRD therapy are a surrogate for increased comorbidity and, therefore, predict increased mortality competes with the hypothesis that earlier initiation of ESRD therapy leads to improved survival. To test these theories, we used probability models to determine the risk of hospitalization and mortality. We obtained Medical Evidence form data on age, gender, race, primary diagnosis, and ethnicity, and calculated body mass index and eGFR from values supplied on the form. We then looked at outcomes in a one-year followup period.

Probabilities of hospitalization and mortality follow similar patterns, increasing with higher eGFR levels (Figures 3.28–30). Pa...
Patients with the highest eGFRs at the start of dialysis therapy are the most likely to be hospitalized in the first year of ESRD, and the least likely to survive that year. This pattern is consistent in both white and black patients, though blacks have higher survival rates. These data, then, strongly support the hypothesis that eGFR at initiation is a surrogate for disease severity, and a predictor of poor patient outcomes.

Placed within a clinical context, it seems reasonable to assume that patients and physicians are more likely to initiate dialysis at later stages if patients are in other ways stable. It is equally likely that physicians initiate patients earlier due to indications of fluid overload, acidosis, hyperkalemia, declining nutritional status, or pericarditis, the usual indications for starting renal replacement therapy. These types of selection bias, intrinsic in observational data, complicate any interpretation of outcomes associated with eGFR.
Insurance coverage of incident patients

The highest proportion of ESRD patients covered solely by Medicaid live in California, Arizona, portions of Washington and Oregon, and areas of the Gulf Coast and Atlantic Seaboard; coverage is almost three times higher in these areas than in the lowest quintile (Figure 3.31). Medicare-only coverage is most common in the South and along the East Coast, and least common in Upper Midwest and western states; patients here are more likely to have combined coverage from Medicare and another payor.

Patients whose Medicare coverage is accompanied by EGHP or other insurance coverage are most likely to be white, while minority populations are disproportionately represented among patients with Medicare or Medicare/Medicaid coverage, and among those with no insurance coverage (Figure 3.32). The distribution of Hispanic patients by insurance coverage is similar to that of other minority populations.
Between 1995 and 2002 the proportion of patients covered solely by Medicaid at the start of therapy fell 12.3 percent, to 10.8 percent (Figure 3.33). Almost one-fifth of Native Americans, however, were covered by Medicaid in 2002, an increase of more than 50 percent. Similar dramatic increases occurred in other types of coverage for Native Americans, as the number with no insurance dropped from more than a third to only 7 percent. The number of Asian patients with no insurance dropped almost 43 percent during the same period.

**Figure 3.31** Incident ESRD patients, 2001, by HSA, unadjusted; data from Medical Evidence form.

**Figure 3.32** Incident ESRD patients, 2001; data from Medical Evidence form.

**Figure 3.33** Incident ESRD patients with a first service date between May 1995 & June 2002; data from Medical Evidence form.

### Insurance groups
- None: No insurance
- DVA/oth: DVA or other
- EGHP: Employer Group Health Plan only
- EGHP + M: EGHP with Medicare secondary
- M/caid: Medicaid only
- M & M: Medicare & Medicaid
- M w/oth: Medicare with other secondary
- M/care: Medicare only
INTRODUCTION  ■  Figure 3.1 Diabetes as a primary diagnosis accounts for 64 percent of ESRD cases in Mexican Hispanics, 55 percent in Hispanics of other origins, and 43 percent in non-Hispanics. ■ Figure 3.2 The total burden of diabetes, both primary and secondary, in ESRD patients surviving one year is 80 percent for Native Americans, 73 percent for Hispanics, 61 percent for Asians, 59 percent for blacks, and 38 percent for whites. COMPLEXITY OF THE PATIENT POPULATION  ■  Figure 3.3 In 2000, 45 percent of diabetics and 37 percent of non-diabetics who survived one year on dialysis had cardiovascular comorbidity, compared to only 25 and 18 percent in 1984. EPO USE & ANEMIA TREATMENT  ■  Figures 3.6–7 EPO use prior to dialysis is lowest in those age 20–44, and in blacks and Native Americans. ■ Figure 3.8 The mean hemoglobin at initiation rose from 9.2 g/dl in May 1995 to 10.0 g/dl in May 2002, a 9 percent increase, while the percent of patients using EPO in the pre-ESRD period grew from 22 to 32. ■ Figure 3.11 The percent of patients initiating dialysis with a hemoglobin less than 11 g/dl decreased from 34 in May 1995 to 74 in May of 2002, a 12 percent reduction. Even more dramatically, the percent initiating with a hemoglobin level less than 10 g/dl fell from 68 to 53, a 22 percent reduction over the seven-year period. ■ Figure 3.12 Female pediatric patients and those age 20–44 continue to have the lowest hemoglobins at the initiation of ESRD treatment—9.1 and 9.4 g/dl, respectively. ■ Figure 3.13 Native American women and black patients of both genders have the lowest hemoglobin levels at the start of therapy. ■ Figure 3.14 At the beginning of therapy, hemoglobin levels in peritoneal dialysis patients are more than one-half g/dl higher than those in hemodialysis patients. BIOCHEMICAL & PHYSICAL CHARACTERISTICS  ■  Figures 3.15–20 Since 1995, blood urea nitrogen and serum creatinine levels have fallen by 8.2 and 17.4 percent, respectively. ■ Figures 3.21–23 Estimated glomerular filtration rates have increased 27 percent over the last eight years, so that individuals are starting therapy on average with 9.6 ml/min/1.73 m² of residual renal function. ■ Figures 3.24–26 Overall body mass index has increased 7 percent over the last seven years, from 25.7 to 27.5 kg/m². ESTIMATED GFR & OUTCOMES  ■  Figure 3.27 Estimated GFRs and Charlson scores appear to be linearly related within age, gender, race, and ethnicity. ■ Figures 3.28–30 Survival probability appears to be inversely related to eGFR. INSURANCE COVERAGE OF INCIDENT PATIENTS  ■  Figures 3.31–33 Minority populations are disproportionately covered by Medicaid only, Medicare and Medicaid, and Medicare without secondary insurance. Hispanic populations also contain a large proportion of patients who have no insurance coverage at the initiation of dialysis.