morbidity & mortality

Who will remember you when I have gone,
My darling ones, or who remember me?
Only in our wild hearts the dead live on.
Yet these frail engines bound to mystery
Break the harsh turn of all creation’s wheel,
For we remember China, Greece, and Rome,
Our mothers and our fathers, and we steal
From death itself its rich store, and bring it home.

MAY SARTON
"DEATH AND THE TURTLE"
Because of the scope of issues related to morbidity and mortality in ESRD patients, we have significantly expanded this chapter. This year, we use interval analyses to present new data on patterns of hospitalization and mortality—overall and cause-specific—in incident patients, and update analyses of survival in the prevalent population. Infectious hospitalizations continue to be a concern, particularly those for pulmonary infections and infections related to vascular access. We also present Bayesian mortality and hospitalization ratios by provider.

We look again this year at cancer and pregnancy in women with ESRD, further developing the definitions of these events. New figures compare data on morbidity in dialysis, transplant, CKD, and non-CKD patients, examining events such as myocardial infarction and pneumonia. And the final three spreads address withdrawal and hospice care in ESRD patients, incident and prevalent stroke, and dementia.

As illustrated in Figure 6.1, overall hospital admission rates have altered little since 1993. Cause-specific rates, however, have changed dramatically. Infectious and cardiovascular hospitalizations are up 23 and 10 percent, respectively, while those related to vascular access have fallen 25 percent. By primary diagnosis (shown on the following page), admissions are greatest in patients with diabetes—declining during followup time for patients on hemodialysis or with a transplant, but rising for those treated with peritoneal dialysis.

Five-year survival rates have improved across all ESRD populations—most dramatically in the transplant population. And new this year is evidence that the prevalent mortality rate has declined in patients with less than two years on treatment, and that it continues to fall for those with 2-5 years of therapy, and even for those who have been on therapy five or more years. This is a new development, since the overall prevalent mortality rate had been fairly stable for the 6-7 years prior to 2003.

Interval data on cause-specific hospitalizations show that older patients have higher early admission rates, which decline and then slowly increase during the five-year followup period. Asian patients have dramatically lower admission rates, during the entire followup period, for all hospitalizations and for those related to infection and other causes. Rates of admission that include a cardiovascular procedure, particularly stents and angioplasty, tend to increase over time, also true for the small percentage of admissions associated with valvular procedures. And rates of inpatient vascular access insertions fall dramatically during patients’ first five years on therapy.

Overall mortality rates are high in the first six months after initiation of ESRD therapy, then tend to fall in the next six months before increasing steadily during the next four years. These patterns show the dramatic effect of increasing time on dialysis, and the associated changing patterns of overall mortality and
cause-specific mortality over time. Interestingly, patterns seen for infectious and cardiovascular death are very similar to these.

In the prevalent dialysis population, hospitalizations for pulmonary infections continue to increase, particularly in patients on hemodialysis. Admissions for vascular access infections grew steadily between 1993 and 2002, but showed a modest decrease in 2003, possibly due to lower catheter insertion rates. Prevalent death rates continue to improve, yet rates for patients on peritoneal dialysis five years or longer remain high.

This year we assess provider-related outcomes, using Bayesian mortality and hospitalization ratios to compare data from 2002 and 2003. After adjusting for age, gender, race, primary cause of kidney failure, and time on dialysis, hospital-based units appear to have higher mortality rates than non-hospital-based units. In 2002, there were few significant differences between the individual large chains; in 2003, however, five of the large chains showed significant differences from each other, with the hospital-based units again having higher mortality rates than the non-chain and chain-based providers. Caution should be used in interpreting these figures, since hospital-based units may treat patients with worse vascular access problems and with additional comorbidities and complicating conditions, a basis for their increased mortality rates.

The complexity of the dialysis population is demonstrated by extraordinarily high event rates across all organ systems. Event rates in dialysis patients are much greater than those of non-CKD patients, and their mortality rates advance more dramatically with age than do the rates of transplant, CKD, and non-CKD patients.

Overall, hospitalization rates in dialysis patients have leveled off and for infection and cardiovascular disease, have decreased slightly. Improvements in preventive care are most likely associated with decreases in rates of events such as those noted for vascular access and infectious hospitalizations, and with progressively lower mortality rates for both incident and prevalent populations. These findings suggest that increased attention to the clinical practice guidelines may be having an impact on the morbidity and mortality of ESRD patients.

### CHAPTER HIGHLIGHTS

**Figure 6.1** Cause-specific hospital admission rates have changed dramatically since 1993. Infectious and cardiovascular hospitalizations are up 23 and 10 percent, respectively, while those related to vascular access have fallen 25 percent. **Figure 6.4** Five-year survival probabilities for ESRD patients continue to rise, despite the greater disease burden now carried by the incident population. **Figures 6.5** Since peaking in 1988, overall mortality rates in the prevalent dialysis population have fallen 11 percent, from 270 to 240 deaths per 1,000 patient years. **Figures 6.90–91** Dementia in ESRD patients is associated with substantial adverse outcomes: over two years, a 1.8 unadjusted risk of hospitalization, and a striking two-fold increased risk of death—70 percent of those with dementia die, versus 41 percent of those without.
interval analyses of hospital admissions by primary diagnosis show that rates tend to be slightly higher in the first twelve months after day 90 of ESRD, and are highest in diabetic patients throughout the entire study interval (Figure 6.2). The most dramatic change occurs in diabetic patients on peritoneal dialysis, in whom, between months six and 48, rates increase 23 percent. Younger patients are less likely to be hospitalized, and over a five-year period admission rates after day 90 of ESRD are generally 15 percent higher in females than in males (Table 6.a). There is little difference in rates when comparing whites and blacks. By primary diagnosis, however, admission rates for patients with diabetes are 20–25 percent higher than those found in patients carrying a diagnosis of hypertension.

Figure 6.3 illustrates hospital admission rates in elderly patients immediately following the start of ESRD therapy. Rates are highest in the first six months after initiation, then fall by almost half in the next six months. Over the next 48 months rates remain quite steady in patients with a primary diagnosis of diabetes, at 2.2–2.3 admissions per patient year at risk; rates for those with hypertension or glomerulonephritis remain between 1.9–2.0 and 1.65–1.75, respectively.

Five-year survival probabilities for ESRD patients continue to rise, despite the greater disease burden now carried by the incident population (see Figure 6.3). Compared to those of the previous period, survival probabilities for patients initiating in 1994–1998 increased 7 percent overall—7 percent for hemodialysis, 9 percent for transplant, and 14 percent for peritoneal dialysis (Figure 6.4). By primary diagnosis, diabetic populations have seen the greatest improvement, though these patients also have the lowest five-year survival, at 27 and 23 percent for hemodialysis and peritoneal dialysis, respectively. In the most recent cohort, 34 percent of dialysis patients, and 73 percent of those with a transplant, survived at least five years.

Since peaking in 1988, overall mortality rates in the prevalent dialysis population have fallen 11 percent, from 270 to 240 deaths per 1,000 patient years (Figure 6.5). This change varies significantly, however, in terms of patient vintage. Mortality rates for patients on the therapy less than two years fell 24 percent between 1985 and 2003, to 220 deaths per 1,000 patient years. But for patients on the modality five or more years, rates grew 12 percent in the same period, reaching 271 in 2003. It is significant to note that mortality rates in patients with five or more years on dialysis have been stable and now appear to be dropping, thus allowing the overall mortality rate to decrease as well. This phenomenon may be associated with many factors, such as improved dialysis therapy, changes in iron therapy, higher hemoglobins, and changes in overall medical practice. Vitamin D therapy, for example, underwent dramatic changes in 2000 and 2001 with the increased use of Zemplar (see Figure 11.35), which has now been associated with lower rates of mortality. The decrease in the overall rate of mortality and the associated effects of changing medical practice warrant further investigation.

Tables of expected remaining lifetimes show the dramatic contrast between ESRD patients and the general population (Table 6.b). Among dialysis patients expected remaining lifetimes are slightly higher in men up to age 54 and are generally the same between the genders thereafter. In transplant patients, in contrast, with the exception of those younger than 15, expected lifetimes are consistently greater for women.

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**Table 6.a** Adjusted interval hospital admissions (per patient year at risk) after day 90 of ESRD, by age, gender, race, & primary diagnosis (incident patients age 20 & older)

<table>
<thead>
<tr>
<th>Months after day 90 of ESRD</th>
<th>0–6</th>
<th>6–12</th>
<th>12–18</th>
<th>18–24</th>
<th>24–30</th>
<th>30–36</th>
<th>36–42</th>
<th>42–48</th>
<th>48–54</th>
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<tr>
<td>20–44</td>
<td>2.04</td>
<td>2.16</td>
<td>2.08</td>
<td>2.00</td>
<td>1.91</td>
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<td>1.87</td>
<td>1.85</td>
<td>1.77</td>
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</tr>
<tr>
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</tr>
<tr>
<td>65–74</td>
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<td>2.18</td>
<td>1.94</td>
<td>1.92</td>
<td>1.91</td>
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<td>2.01</td>
<td>1.95</td>
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<td>2.07</td>
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<td>1.92</td>
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<td>1.63</td>
<td>1.65</td>
<td>1.63</td>
<td>1.67</td>
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<td>1.69</td>
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<tr>
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<td>1.97</td>
<td>1.95</td>
<td>1.92</td>
<td>1.91</td>
<td>1.93</td>
<td>1.94</td>
<td>1.91</td>
<td>1.89</td>
</tr>
</tbody>
</table>
6.4 Adjusted five-year survival by modality & primary diagnosis

Incident dialysis patients & patients receiving a first transplant in the calendar year

<table>
<thead>
<tr>
<th>Age</th>
<th>White</th>
<th>Black</th>
<th>All races</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2 year</td>
<td>0.84</td>
<td>0.78</td>
<td>0.81</td>
</tr>
<tr>
<td>2-&lt;5 year</td>
<td>0.75</td>
<td>0.71</td>
<td>0.73</td>
</tr>
<tr>
<td>5+ year</td>
<td>0.68</td>
<td>0.64</td>
<td>0.66</td>
</tr>
</tbody>
</table>

6.5 Adjusted mortality rates by vintage

6.6 Expected remaining lifetimes (years) of the general U.S. population & dialysis & transplant patients, by age, gender, & race

General U.S. population, 2002 & prevalent dialysis & transplant patients, 2003

<table>
<thead>
<tr>
<th>Age</th>
<th>All races</th>
<th>ESRD patients, 2003</th>
<th>All races</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>0.25</td>
<td>0.24</td>
<td>0.25</td>
</tr>
<tr>
<td>15-19</td>
<td>0.24</td>
<td>0.23</td>
<td>0.24</td>
</tr>
<tr>
<td>20-24</td>
<td>0.23</td>
<td>0.22</td>
<td>0.23</td>
</tr>
<tr>
<td>25-29</td>
<td>0.22</td>
<td>0.21</td>
<td>0.22</td>
</tr>
<tr>
<td>30-34</td>
<td>0.21</td>
<td>0.20</td>
<td>0.21</td>
</tr>
<tr>
<td>35-39</td>
<td>0.20</td>
<td>0.19</td>
<td>0.20</td>
</tr>
<tr>
<td>40-44</td>
<td>0.19</td>
<td>0.18</td>
<td>0.19</td>
</tr>
<tr>
<td>45-49</td>
<td>0.18</td>
<td>0.17</td>
<td>0.18</td>
</tr>
<tr>
<td>50-54</td>
<td>0.17</td>
<td>0.16</td>
<td>0.17</td>
</tr>
<tr>
<td>55-59</td>
<td>0.16</td>
<td>0.15</td>
<td>0.16</td>
</tr>
<tr>
<td>60-64</td>
<td>0.15</td>
<td>0.14</td>
<td>0.15</td>
</tr>
<tr>
<td>65-69</td>
<td>0.14</td>
<td>0.13</td>
<td>0.14</td>
</tr>
<tr>
<td>70-74</td>
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<tr>
<td>75-79</td>
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</tr>
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<td>80-84</td>
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<td>0.10</td>
<td>0.11</td>
</tr>
<tr>
<td>85+</td>
<td>0.10</td>
<td>0.09</td>
<td>0.10</td>
</tr>
</tbody>
</table>

Overall* 25.2 23.4 26.6 25.3 23.5 26.7 23.0 20.8 24.7 Overall* 5.5 5.6 5.4 15.1 14.6 15.9
At six months after day 90 of ESRD, hospital admissions overall are highest in patients age 75 and older (Figure 6.6). At 12 months rates fall slightly and are comparable to those for patients age 20–44; they remain so through the following four years. Not surprisingly, admissions for cardiovascular complications are highest in older patients.

Women tend to have slightly higher admission rates overall and for cardiovascular disease, infection, and other complications (Figure 6.7). It is noteworthy that their cardiovascular admission rates are higher—a cause for concern, since in the general population cardiac disease is the greatest cause of mortality in women.

Hospitalization rates for all causes are comparable in whites and blacks, and lowest in the Asian population (Figure 6.8). Asians also have lower admission rates for cardiovascular disease, though a clear increase in these rates is evident starting at month 24.

Figures 6.9–11 illustrate rates for admissions with cardiovascular procedures. At month six, rates are highest in patients age 65–74, and a distinct upward trend is evident over the five-year period for patients age 45–64 (Figure 6.9). Patients age 45–74 are the most likely to have an admission for a bypass procedure, and admissions with a stent insertion or angioplasty are highest for this group as well.

Overall, women have approximately 10 percent higher rates for admissions with a cardiovascular procedure; rates by gender, however, vary by procedure. Rates for admissions with bypass surgery, for example, are 15–41 percent lower in women, while those with stents or angioplasty are 7–20 percent lower (Figure 6.10).

By race, rates for admissions with all cardiovascular procedures are similar in whites and blacks, but cause-specific rates can vary considerably (Figure 6.11). At month six, blacks have 47 percent fewer admissions with bypass surgery and 42 fewer admissions with a stent or angioplasty. This disparity is evident throughout the five-year period, though the differences do narrow in the later months.

Inpatient vascular access insertion rates are highest at month six for all age groups, and fall quite dramatically thereafter (Figure 6.12). Catheter insertion rates are higher than those for fistulas or grafts in all age groups—at month six, for example, rates for catheter insertions are 6–8 times higher than those for fistulas and 3–4 times higher than those for grafts.

Overall inpatient vascular access insertion rates are higher in females than in males; this is also true for catheter and graft insertions (Figure 6.13). Women have 19–36 percent higher catheter insertion rates, but have slightly lower fistula creation rates. Rates of graft creation are higher in females, which may indicate that female vasculature is more suited to graft creation than fistula creation.

By race, overall inpatient vascular access insertion rates at month six are 40 percent higher in Hispanics than in whites, but while these higher rates are evident throughout the entire five-year interval, the relative difference decreases as time on ESRD grows (Figure 6.14). Insertion rates for catheters are highest in Hispanics through the first two years, but are then surpassed by rates for blacks until year four, at which point there is virtually no difference.

The remarkably high rate of inpatient catheter insertion should serve as a reminder that practitioners need to move toward greater compliance with K/DOQI vascular access guidelines, which call for increased use of fistulas as the primary vascular access.
ADJUSTED INTERVAL ADMISSIONS WITH CARDIOVASCULAR PROCEDURES AFTER DAY 90

6.9 by age incident dialysis patients age 20 & older

- All cardiovascular procedures
- Bypass
- Stent/angioplasty
- Valve procedures

Admissions per 1,000 patient years at risk

6.10 by gender incident dialysis patients age 20 & older

- All cardiovascular procedures
- Bypass
- Stent/angioplasty
- Valve procedures

6.11 by race/ethnicity incident dialysis patients age 20 & older

- All cardiovascular procedures
- Bypass
- Stent/angioplasty
- Valve procedures

ADJUSTED INTERVAL INPATIENT VASCULAR ACCESS INSERTIONS AFTER DAY 90

6.12 by age incident hemodialysis patients age 20 & older

- All vascular access insertions
- Fistulas
- Catheters
- Grafts

6.13 by gender incident hemodialysis patients age 20 & older

- All vascular access insertions
- Fistulas
- Catheters
- Grafts

6.14 by race/ethnicity incident hemodialysis patients age 20 & older

- All vascular access insertions
- Fistulas
- Catheters
- Grafts
interval analyses of cause-specific mortality (starting 90 days after initiation of therapy) show that, across categories of age, gender, and race, rates tend to be high at six months, fall—often quite dramatically—over the next six months, and then rise steadily during the following four years (Figures 6.15–17).

By age, for example, overall mortality between months six and 12 falls nearly 21 percent for patients age 75 and older, and 25 percent for pediatric patients (Figure 6.15). The decrease is equally dramatic for mortality caused by cardiovascular disease, by infection, and by other causes of death. Between months 12 and 60, rates increase steadily for most age groups; cardiovascular mortality, for example, rises 66 percent for patients age 20–44, and 55 percent for those age 45–64. Rates of infectious mortality in younger adults, in contrast, fall nearly 15 percent in the same period.

The pattern of a sharp fall followed by a steady increase is particularly noticeable in rates by gender (Figure 6.16). Overall rates differ little between males and females. Cardiovascular mortality rates are quite similar in the first year; by five years, however, the rate is 10 percent higher in men. Rates of infectious mortality, however, are consistently greater in women.

With the exception of infectious mortality, rates by race are highest among white patients, and they increase steadily for this population after one year (Figure 6.17). Some of the most dramatic growth by race is seen in the Asian population; overall rates rise 54 percent in the four years following the first year of therapy, while rates of cardiovascular and infectious mortality increase 76 and 63 percent, respectively.

Figures 6.18–26 present interval mortality analyses for major cardiovascular diagnoses, sudden death, malignancy, and infections, including bacteremia/septicemia and pulmonary infection. Many of these also show rates decreasing between months six and 12, then rising steadily over the next four years. In dialysis patients, for example, rates of mortality due to AMI rise 45 percent between months 12 and 60, from 9 to 13 deaths per 1,000 patient years (Figure 6.18), while rates of sudden death rise 21 percent in the same period, from 62.5 to 75.4. Rates of mortality due to bacteremia/septicemia in the same population increase 31 percent, from 12 to 16 (Figure 6.24).

Because the transplant population is smaller, and generally healthier as well, mortality rates within it are more volatile than those in the dialysis population. Clear across all causes of death, however, is the lower mortality rate for these patients. At five years after initiation, for example, the rate of mortality due to sudden death is 75 per 1,000 patient years in dialysis patients, and only 14 for patients with a transplant.

[Figure 6.15] incident dialysis patients, 1997–2001 combined; adjusted for gender, race, & primary diagnosis. Incident patients, 1996, used as reference cohort. [Figure 6.16] incident dialysis patients, 1997–2001 combined; adjusted for age, race, & primary diagnosis. Incident patients, 1996, used as reference cohort. [Figure 6.17] incident dialysis patients, 1997–2001 combined; adjusted for age, gender, & primary diagnosis. Incident patients, 1996, used as reference cohort. [Figures 6.18–26] incident ESRD patients; adjusted for age, gender, race, & primary diagnosis. Incident patients, 1996, used as reference cohort. For Figure 6.21, “sudden death” includes cardiac arrhythmia & cardiac arrest.
Hospitalization & mortality, by modality

At month six after day 90 of ESRD, adjusted hospital admission rates for peritoneal dialysis patients are 24 percent lower than those for hemodialysis patients (Figure 6.27). As time on dialysis increases, however, these differences lessen, and by year three the rates are the same. Transplant patients are admitted to the hospital far less often than their dialysis counterparts, and their admission rates fall as their time with a functioning graft increases. Transplant patients also spend less time in the hospital. At month six, for example, hospital days for these patients are 50 and 27 percent lower than those of hemodialysis and peritoneal dialysis patients, respectively.

In hemodialysis patients, admission rates for cardiovascular disease are 18–33 percent higher than those for infection (Figure 6.28). The opposite holds true in peritoneal patients, in whom, after month six, rates for infection actually outpace rates for cardiovascular disease, and are 8–24 percent higher through year five. Rates of admission for cardiovascular disease and infection are markedly lower in the transplant population, while hospital days for cardiovascular disease and infection over the study interval are similar within each modality.

Trend analyses show that hospital admissions for pulmonary infection in hemodialysis patients have grown 24 percent since 1993, while a slight fall in vascular access infections occurred in 2003, and may be due to a decreased use of hemodialysis catheters (Figure 6.29). Further study is warranted in this area. Admissions for peritonitis in peritoneal dialysis patients have fallen 38 percent. For cardiovascular procedures, rates have fallen 17 percent for hemodialysis patients, but have increased 12 and 31 percent in the peritoneal dialysis and transplant populations, respectively. And for heart catheterizations, admission rates have grown 41 and 12 percent in hemodialysis and peritoneal dialysis patients, but have fallen 22 percent for those with a transplant.

Between the 1989–1993 and 1994–1998 periods, five-year survival for
diabetic patients who begin therapy on peritoneal dialysis grew 23 percent; for patients starting on hemodialysis the change was 12 percent (Figure 6.30). These latter patients, however, continue to have slightly better survival, with 27 percent living five years after initiation compared to 23 percent of those on peritoneal dialysis. Among patients with primary diagnoses other than diabetes, 37–41 percent survive five years; rates here are slightly higher for those on peritoneal dialysis.

The overall decrease in mortality rates since 1985—8 percent for hemodialysis patients and 12 percent for those on peritoneal dialysis—continues to mask significant differences by vintage (Figure 6.31). Compared to those on the modality less than two years, for example, hemodialysis patients with a vintage of five or more years had a 19 percent higher mortality rate in 2003. In the peritoneal dialysis population, this difference reaches 94 percent. Rates for patients of the youngest vintage have fallen 21 and 42 percent for hemodialysis and peritoneal dialysis, respectively; for patients of older vintage, however, rates have increased 11 and 21 percent.

Interval analyses of cause-specific mortality rates in incident hemodialysis patients show a dramatic fall between months six and 12, and parallel decreases for mortality due to cardiovascular disease, infection, or other causes (Figure 6.32). Rates for patients on peritoneal dialysis, in contrast, do not exhibit this same initial fall, but rather tend to increase steadily in the five years following initiation.

(Figures 6.27–28) incident ESRD patients age 20 & older, 1997–2001 combined; adjusted for age, gender, race, & primary diagnosis; incident ESRD patients, 2001, used as reference cohort. Rates for transplant patient are censored three years after the transplant date & are shown only through month 30. Cause-specific categories in Figure 6.28 determined from principal ICD-9-CM procedure codes. (Figure 6.29) period prevalent ESRD patients; rates adjusted for age, gender, race, & primary diagnosis. ESRD patients, 2003, used as reference cohort. Cardiovascular procedure category excludes vascular access procedures. (Figure 6.30) incident dialysis patients; adjusted for age, gender, & race. ESRD patients, 1996, used as reference cohort. Modality determined on first ESRD service date; excludes patients transplanted or dying during the first 90 days (five-year survival probabilities noted in parentheses). (Figure 6.31) period prevalent dialysis patients; rates adjusted for age, gender, race, & primary diagnosis. Dialysis patients, 2001, used as reference cohort. (Figure 6.32) incident dialysis patients; rates adjusted for age, gender, race, & primary diagnosis. ESRD patients, 1996, used as reference cohort.
in the 2004 ADR the USRDS introduced new methods to assess mortality on a provider level. These Bayesian methods help stabilize rates, particularly for smaller units, which have considerably more variability in their death and hospitalization events compared to larger providers.

This year we report Bayesian mortality ratios by provider, and compare them to one another for 2002 and 2003, as shown in Figures 6.33–39. Overall mortality ratios show little difference among the chains, with hospital-based and non-chain providers having higher ratios than the others in 2002. The same analyses, however, repeated for 2003, show less significant differences in the non-chain providers and more variability among the chains. Fewer such inconsistencies appear in the cause-specific mortality ratios for cardiovascular disease, but there are greater differences for infectious mortality. These differences in outcomes also appear to relate to geographic location, which may merit increased attention in the future.

Hospitalization ratios by provider and geographic location are reported in Figures 6.40–47. These analyses report overall results without direct comparisons of provider groups. Dialysis Clinics, Inc. appears to have lower ratios for all causes and for cardiovascular hospitalizations. Hospital-based units have higher ratios, particularly for infectious hospitalizations. The chain-specific infor-
mation shows divergence, with Gambro having higher infectious and cardiovascular hospitalization ratios compared to other chains. These data will require more complete assessments to determine if these results are consistent or whether they vary as do those reported for mortality.

These comparisons highlight the difficulty of using any single year to assess a provider network, and show trends should be addressed over time. Also, while providers are consolidating, assessing them may be difficult since new acquisitions may require more time to address programmatic changes. From this perspective, it may be better to address outcomes in providers that have been in a system for at least one year to account for changing procedures. The USRDS will explore these approaches to provide the clearest picture of how providers are doing in terms of overall outcomes.

Since 1993, hospitalization rates for breast cancer and for cervical, uterine, and ovarian cancer have decreased by 23 and 16 percent, respectively (Figure 6.49). These changes may be a positive indication of a more proactive role by renal practitioners in prescribing cancer monitoring in these patients. When compared to admission rates for cervical, uterine, and ovarian cancer, breast cancer admission rates are considerably higher—61 percent in 2003. While these higher rates may at first be a cause for alarm, they may be explained by the inference that increased monitoring has led to earlier detection of breast cancer, with subsequent hospitalizations for the treatment of this disease.

Hospitalization rates for breast cancer in diabetics and non-diabetics have fallen 14 and 32 percent, respectively, since 1993, while rates for cervical, uterine, and ovarian cancer are 11 and 20 percent lower (Figure 6.50). When comparing yearly trend rates between diabetics and non-diabetics for each cancer, no clear patterns emerge.

By race, hospitalization rates for breast cancer and for cervical, uterine, and ovarian cancer have fallen for both whites and individuals of other races since 1993, and as of 2003 rates by race for each cancer type were virtually the same (Figure 6.51).

Treatment rates for cancer reflect changes in clinical practice over the past decade (Figure 6.52). In breast cancer patients, for instance, chemotherapy treatment rates have doubled. In patients with cervical, uterine, or ovarian cancer, the use of radiation therapy has fallen 46 percent, accompanied by a substantial increase (38 percent) in chemotherapy treatment rates over the same period.

Data on pregnancy and outcomes in women with ESRD show that the mean age of pregnant patients was 31.5 in 2002 for those on dialysis, and 28.3 for those with a transplant—both higher than in the general population (Figure 6.53). Dialysis patients tend to have considerably more cardiovascular comorbidity, GI disease, liver disease, and dysrhythmia; transplant patients, however, are more likely to have diabetes (Figure 6.54).

Since 1991 the number of obstetrician visits in the three months before delivery has grown slightly for dialysis patients, while remaining relatively stable for those with a transplant (Figure 6.55). The number varies little by race, and in 2002 reached 6–9 visits.

Pregnancy rates and their trends over time vary significantly by modality (Figure 6.56). Since 1991 the rate in the dialysis population has increased 20–23 percent overall and in non-white patients, while falling 3.9 percent in whites. In the transplant population, in contrast, the rate has fallen 48.6 percent overall, 66 percent for non-whites, and 38 percent for whites.

Complications related to pregnancy follow no clear trends (Figure 6.57). In 2002, 25 percent of dialysis patients, and 21 percent of those with a transplant, suffered a hemorrhage, while 16 and 26 percent, respectively, went into early labor.

While the rate of live births is considerably higher in transplant patients than in those on dialysis, it has, like the pregnancy rate, fallen sharply since 1991—50 percent for those younger than the mean age, and 54 percent for those older (Figure 6.58). For both modalities, the live birth rate is greatest in the youngest patients.

Hemoglobins increase in 68 percent of patients following their pregnancy (Figure 6.59). The average increase is 1.02 g/dl—from 10.24 before the pregnancy to 11.26 after.

Two years after the start of a pregnancy, the probability of survival is 20 percent higher in non-diabetic patients compared to diabetics, at 0.7 and 0.9, respectively (Figure 6.60).

{Figures 6.49–6.51} period prevalent female dialysis patients, age 20 & older. Female dialysis patients, 2003, used as reference cohort; cancer admissions determined from principal ICD-9-CM diagnosis codes. (Figure 6.49) adjusted for age, race, primary diagnosis, & vintage. (Figure 6.50) adjusted for age, race, & vintage. (Figure 6.51) adjusted for age, primary diagnosis, & vintage. (Figure 6.52) prevalent female dialysis patients, age 20 & older, with at least one inpatient cancer claim during the year. Includes only patients alive, with Medicare as a primary payor, & without a transplant for the complete year. (Figures 6.53–60) point prevalent female ESRD patients, age 14–45, 1991–2002. Transplant cohorts include only patients within two years of most recent graft on January 1. — {Figure 6.53} average
Figures 6.61–69 compare inpatient morbidity and mortality event rates in four patient cohorts: ESRD patients (dialysis and transplant), and non-ESRD Medicare patients (with and without CKD). ESRD patients were point prevalent on January 1, 2002. For the prevalent CKD and non-CKD cohorts, diabetes and CKD were defined during a one-year entry period in 2001. The followup period for ascertainment of clinical events in all four groups extended from January 1, 2002, to December 31, 2003. Clinical events were defined by inpatient ICD-9-CM diagnosis codes, and the rates presented were adjusted for race, gender, and diabetes.

Several general patterns are present that are common to all event types. Within each age category, event rates tend to increase as follows: non-CKD < transplant < CKD < dialysis. Increments in event rates with increasing age are greater in the dialysis population than in the other three populations. Rates in the youngest group of dialysis patients usually exceed those seen in the oldest group of non-CKD patients.

The data in these figures also allow one to compare rates of different clinical events within each of the four cohorts defined above. In dialysis patients, congestive heart failure is the most frequent clinical event, followed by peripheral vascular disease and bacteremia/septicemia. Among transplant and CKD patients, congestive heart failure is the most frequent clinical event, followed by peripheral vascular disease and pneumonia. Among non-CKD patients, congestive heart failure is the most frequent event, followed by pneumonia and peripheral vascular disease.

These data show that both the presence and the severity of chronic kidney disease appear to be risk multipliers for common, serious medical conditions. This risk multiplier effect is most obvious in dialysis populations, where the likelihood of develop-
Adjusted rates of pneumonia, by age
prevalent adult Medicare patients

Adjusted rates of bacteremia/septicaemia, by age
prevalent adult Medicare patients

Adjusted rates of hip fracture, by age
prevalent adult Medicare patients

Adjusted rates of cancer, by age
prevalent adult Medicare patients

Adjusted rates of mortality, by age
prevalent adult Medicare patients

Adjusted rates of one of these life-threatening events is very high.

(Figures 6.61–6.69) Prevalent adult Medicare patients. ESRD (dialysis & transplant): patients prevalent on January 1, 2002 & with Medicare as a primary payor. CKD & non-CKD (general Medicare patients): included patients survive a one-year entry period in 2001, have continuous Medicare coverage with no HMO coverage, & do not have ESRD. CKD & diabetic status are defined during the one-year entry period. Followup is a maximum of two years, from January 1, 2002, to December 31, 2003. Events are defined by the first cause-specific inpatient ICD-9-CM diagnosis code during followup. Rates are adjusted for gender, race, & diabetic status. The reference cohort consists of all included patients (ESRD, CKD, & non-CKD).
Morbidty & Mortality

Withdrawal & hospice care in the Medicare ESRD population

Here we describe patterns of use of dialysis withdrawal and hospice care among 115,239 deceased patients in the USRDS 2001–2002 two-year Medicare cohort. Withdrawal and hospice status of the deceased cohort are depicted in Figure 6.70. Almost 22 percent withdrew from dialysis, and 13.5 percent used hospice. Of those who withdrew, only 41.9 percent utilized hospice. “Chronic failure to thrive” (an outdated term previously used in geriatrics to describe symptoms of dementia, functional decline, and/or depression) is the most common reason given for withdrawal (42.9 percent), followed by the non-specific “acute medical complications” and “other” (Figure 6.71).

As described in Figure 6.72, most patients who used withdrawal or hospice were white, and their use increased with age. The mean age of those who withdrew or used hospice was about 74, compared to 69 for those who used neither.

To analyze the site of death and costs during the last six months of life, we used a subset of 91,687 subjects of the above cohort who were on dialysis for the entire six months prior to death. Table 6.e shows the site of death for this cohort by withdrawal and hospice use. Three times as many hospice patients died at home compared to non-hospice patients, but only 23 percent of hospice patients died in the hospital compared to 69 percent of non-hospice patients. Among hospice patients, the mean Medicare costs and number of hospital days during the last week of life were half of those for all patients who died (Table 6.f).

Using the two-year cohort, Tables 6.c–d list the ten states with the highest and lowest percentage of patients who used hospice, among those who withdrew from dialysis. There is marked variation, between states, in the the percentage using hospice after withdrawal, from 16.7 percent in Maine to 54.6 percent in Iowa, even though they had a similar percentage who withdrew (39.1 percent and 37.1 percent, respectively).

The three maps in Figures 6.74–76 illustrate geographic variations in use of withdrawal and hospice, and the percentage of those who used hospice among those who withdrew. In Figure 6.77, the mean age of all those deceased is shown in the left map, and mean age among those who used hospice in the right map. Although there is some correlation between mean age by state and hos-
Overall

Patients who use hospice

Highest % of withdrawing patients who use hospice

Lowest % of withdrawing patients who use hospice

Site of hospice days & death

Percent of patients withdrawing who used hospice, by state

Table: Count: Total withdrawal using hospice

<table>
<thead>
<tr>
<th>State</th>
<th>Count</th>
<th>Withdrawal using hospice</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td>517</td>
<td>339</td>
<td>65.6</td>
</tr>
<tr>
<td>Florida</td>
<td>1,674</td>
<td>1,096</td>
<td>65.5</td>
</tr>
<tr>
<td>Nevada</td>
<td>84</td>
<td>51</td>
<td>60.7</td>
</tr>
<tr>
<td>Colorado</td>
<td>273</td>
<td>161</td>
<td>59.0</td>
</tr>
<tr>
<td>Iowa</td>
<td>335</td>
<td>183</td>
<td>54.6</td>
</tr>
<tr>
<td>Ohio</td>
<td>959</td>
<td>523</td>
<td>54.3</td>
</tr>
<tr>
<td>Michigan</td>
<td>1,200</td>
<td>649</td>
<td>54.1</td>
</tr>
<tr>
<td>Texas</td>
<td>2,018</td>
<td>1,015</td>
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<tr>
<td>Illinois</td>
<td>973</td>
<td>472</td>
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<tr>
<td>Utah</td>
<td>159</td>
<td>74</td>
<td>46.5</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>State</th>
<th>Count</th>
<th>Withdrawal using hospice</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maine</td>
<td>144</td>
<td>24</td>
<td>16.7</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>119</td>
<td>26</td>
<td>21.8</td>
</tr>
<tr>
<td>Virginia</td>
<td>750</td>
<td>198</td>
<td>26.4</td>
</tr>
<tr>
<td>Montana</td>
<td>90</td>
<td>25</td>
<td>27.8</td>
</tr>
<tr>
<td>Hawaii</td>
<td>77</td>
<td>22</td>
<td>28.6</td>
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<tr>
<td>Massachusetts</td>
<td>581</td>
<td>168</td>
<td>28.9</td>
</tr>
<tr>
<td>South Carolina</td>
<td>275</td>
<td>81</td>
<td>29.5</td>
</tr>
<tr>
<td>West Virginia</td>
<td>198</td>
<td>60</td>
<td>30.3</td>
</tr>
<tr>
<td>South Dakota</td>
<td>89</td>
<td>27</td>
<td>30.3</td>
</tr>
<tr>
<td>Tennessee</td>
<td>521</td>
<td>162</td>
<td>31.1</td>
</tr>
</tbody>
</table>

Eliminates Alaska, with only 26 withdrawals

Costs & site of death for deceased patients

<table>
<thead>
<tr>
<th>Withdrawal</th>
<th>Hospice</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>19,517</td>
<td>12,058</td>
<td>91,687</td>
</tr>
<tr>
<td>Mean costs: last six months of life</td>
<td>$52,305</td>
<td>$54,979</td>
</tr>
<tr>
<td>Mean costs: last week of life</td>
<td>$4,918</td>
<td>$53,339</td>
</tr>
<tr>
<td>Mean hospital days: last week of life</td>
<td>2.8</td>
<td>1.4</td>
</tr>
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</table>
The epidemiology of stroke in ESRD patients has begun to receive more attention in the literature, but stroke still ranks below other cardiovascular disease outcomes in identification of modifiable risk factors, clinical trials, and implementation of preventive measures. This is surprising, given its substantial impact on cognition, function, quality of life, and mortality.

In these analyses we define both stroke and TIA as stroke (TIA constitutes approximately 30 percent of the combined stroke/TIA counts here), and include claims from both Medicare Parts A and B—i.e., not only strokes that occur during hospitalization, because some patients with strokes may choose not to be hospitalized. Stroke rates here are thus substantially higher than those reported in the literature.

The rate of incident stroke in both incident and prevalent hemodialysis populations is markedly elevated compared to the non-ESRD population, and increases with age (Figures 6.78, 6.84, 6.85). In incident hemodialysis patients ages 67-74, the rate is 27.2 and 29.3 strokes per 100 patient years in whites and blacks, respectively.

The prevalence of stroke in white peritoneal dialysis patients is slightly lower than that of hemodialysis patients, but for those age 85 and older, rates for black peritoneal dialysis patients are double those of black hemodialysis patients, at 87.4 versus 45.8 (Figure 6.84). Among transplant patients, stroke prevalence rates are about one-third to one-half of those for hemodialysis patients, except again in blacks age 85 and older, in whom the rate is similar to that of peritoneal dialysis patients.

Incident stroke in the 2000 ESRD population is associated with high rates of hospitalization and mortality over a two-year followup period (Figures 6.79–80). At the end of one and two years of followup, about 85 and 95 percent of hemodialysis and peritoneal dialysis patients have been hospitalized at least once, compared to 64 and 83 percent hospitalized among hemodialysis patients without incident stroke.

Survival following incident stroke in dialysis patients is abysmal, similar to the poor survival associated with other cardiovascular events in ESRD patients. Less than 50 percent are alive at 12 months, compared to more than 70 percent in those without
incident stroke, and two-thirds are dead at two years followup, compared to half without stroke. The mortality rate for peritoneal dialysis patients with incident stroke is slightly lower than that of hemodialysis patients until 12 months of followup, after which it surpasses the hemodialysis rate and reaches 74 percent at two years.

The rate of recurrent stroke by age in incident dialysis patients is over twice that of incident stroke; in white and black hemodialysis patients age 67–74 it is 73.1 and 90.4 strokes per 100 patient years, respectively (Figure 6.81). Among black and other race patients, as well as all peritoneal dialysis patients age 75–84, the rate approaches 110.

Hospitalization and mortality rates in the year following recurrent stroke are similar to those for incident stroke (Figures 6.82–83).

The associations of diabetes and hypertension with incident stroke are not unexpected; hypertension and diabetes together have a stronger effect than either alone, but diabetes by itself is more strongly associated with stroke than hypertension in both hemodialysis and peritoneal dialysis patients (Figure 6.86). The oldest diabetic peritoneal dialysis patients have the highest rate of incident stroke, similar to their high rates of other cardiovascular outcomes.

The majority of incident strokes and vascular episodes in prevalent ESRD patients are ischemic, occurring twice as often as TIA and ten times as often as hemorrhagic strokes (Figure 6.87). The percent of patients with each type of stroke who also have atrial fibrillation is only slightly higher in those with ischemic stroke than hemorrhagic, and increases substantially with age.

These data point to the remarkably high disease burden associated with stroke in dialysis patients, and the need to design effective interventions for stroke prevention. Aggressive management of diabetes, hypertension, and atrial fibrillation are starting points, but the roles of elevated lipids, homocysteine, and inflammatory markers in the evolution of stroke in ESRD patients also need to be further explored.

{Figures 6.78 & 6.81, 6.84–87} per 100 patient years. {Figures 6.78–83} incident dialysis patients, 2000, without stroke claims in previous two years. For Figures 6.79–82, event occurring at least 30 days after initial stroke; Figures 6.78 & 6.81, racial PD data missing due to low counts. Figures 6.82–83, “PD no stroke” category missing due to low counts. {Figure 6.84} period prevalent ESRD patients, 2003. {Figures 6.85–87} point prevalent ESRD patients, 2003, with Medicare as primary payor for two years.
The epidemiology of dementia in ESRD patients has received little attention. Here we describe the prevalence and incidence of dementia in point prevalent ESRD populations. Because dialysis patients are not routinely assessed for dementia, these rates are largely underestimates.

The prevalence of dementia in hemodialysis patients rose 7 percent between 2001 and 2003, but incidence grew 5 percent, a high rate relative to the rise in prevalence (total prevalence and incidence not shown). This is likely due to their low two-year survival rate of 30 percent (Figure 6.91), diabetes becoming the most common primary diagnosis (diabetes doubles the risk of dementia in non-ESRD patients), and possibly to improved reporting of dementia.

As in the non-ESRD population, age is strongly associated with prevalent dementia in hemodialysis patients (Figures 6.88–89). In 2003, incident dementia rates among blacks grew from 1.4 percent in those age 44–65, to 10.3 percent in patients age 85 and older; among whites, the rates were 1.2 and 6.4 percent respectively. Dementia rates in peritoneal dialysis patients are much lower than in hemodialysis patients, and very low in transplant patients (Figures 6.88 and 6.93).

In 2001 and 2003, the prevalence and incidence of dementia across all age groups...
were higher in blacks than in whites (Figures 6.88 & 6.93), a pattern also seen in the non-ESRD population.

Alzheimer’s disease comprises 65–70 percent of all dementias in the non-ESRD U.S. population; in the hemodialysis population, in contrast, vascular dementia (due to cerebral ischemia) is almost as common as Alzheimer’s (Figure 6.89). This may reflect the high cardiovascular risk factor profile most dialysis patients bring to dialysis initiation, and the approximate 30 percent prevalence of stroke in hemodialysis patients over age 65 (Figure 6.84).

Dementia in ESRD patients is associated with substantial adverse outcomes: over two years, a 1.8 unadjusted risk of hospitalization, and a striking two-fold increased risk of death—70 percent of those with dementia die, versus 41 percent of those without (Figures 6.90–91). In 2002, approximately $16,100 more Medicare dollars were spent for an ESRD patient with prevalent dementia than for one without (Figure 6.92).

Factors associated with incident dementia on logistic regression are age, stroke (AOR of 2.3), diabetes, black race, and hypertension (Table 6.g). Improved stroke prevention measures such as more aggressive combined management of diabetes, hypertension, and atrial fibrillation may help decrease the risk of dementia in ESRD patients.

These data suggest the need for a standard cognitive evaluation, prior to dialysis initiation and annually thereafter, to assess the patient’s ability to comply with medications and fluid intake, and to make informed decisions regarding initiation and continuation of maintenance dialysis.
**Figure 6.1** Cause-specific hospital admission rates have changed dramatically since 1993. Infectious and cardiovascular hospitalizations are up 23 and 10 percent, respectively, while those related to vascular access have fallen 25 percent.

**Figure 6.4** Five-year survival probabilities for ESRD patients continue to rise, despite the greater disease burden now carried by the incident population.

**Figures 6.12–14** The remarkably high rate of inpatient catheter insertions should serve as a reminder that practitioners need to move toward greater compliance with K/DOQI vascular access guidelines, which call for increased use of fistulas as the primary vascular access.

**Figures 6.15–17** Interval analyses of cause-specific mortality show that rates tend to be high at six months, fall over the next six months, and then rise steadily during the following four years.

**Figures 6.18–26** Clear across all causes of death is the lower mortality rate for transplant patients. At five years after initiation, the rate of mortality due to sudden death is 75 per 1,000 patient years in dialysis patients, and only 14 for patients with a transplant.

**Figure 6.29** Hospital admissions for pulmonary infection in hemodialysis patients have grown 24 percent since 1993, while a slight fall in vascular access infections occurred in 2003—possibly due to lower use of catheters. **Figure 6.31** Compared to those on the modality less than two years, hemodialysis patients with a vintage of five or more years had a 20 percent higher mortality rate in 2003. In the peritoneal dialysis population, this difference reaches 94 percent.

**introduction** Comparisons of Bayesian mortality and hospitalization ratios highlight the difficulty of using any single year to assess a provider network.

**Figure 6.56** Since 1991 the pregnancy rate in the dialysis population has increased 20–23 percent overall and in non-white patients, while falling 3.9 percent in whites. In the transplant population, in contrast, the rate has fallen 48.6 percent overall, 66 percent for non-whites, and 38 percent for whites.

**Figures 6.61–68** Both the presence and the severity of chronic kidney disease appear to be risk multipliers for common, serious medical conditions. This risk multiplier effect is most obvious in dialysis populations, where the likelihood of developing one of these life-threatening events is very high.

**Figure 6.70** Only 3.5 percent of dying ESRD patients use hospice, compared to the national average of over 22 percent. ESRD patients lag significantly behind oncology patients in hospice use, despite the fact that they have comparable morbidity.

**Figures 6.79–80** Incident stroke in the 2000 ESRD population is associated with high rates of hospitalization and mortality over a two-year followup period.

**Figures 6.90–91** Dementia in ESRD patients is associated with substantial adverse outcomes: over two years, a 1.8 unadjusted risk of hospitalization, and a striking two-fold increased risk of death—70 percent of those with dementia die, versus 41 percent of those without.