Dialysis registries in the world: Korean Dialysis Registry

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The Korean Society of Nephrology (KSN) end-stage renal disease (ESRD) registry was established in 1985 in which all KSN members are participating voluntarily: the ‘Insan Prof. Byung-Suk Min Memorial ESRD Patient Registry’. The ESRD registry committee of KSN has collected the data through the internet online program that was opened in 2001 and revised in 2013. The registry internet program has collected data throughout the years, which includes dialysis center information, vascular access, dialysis doses, and laboratory data with dialysis adequacy and rehabilitation status. In Korea, the number of dialysis patients has been rapidly growing (~8–9% per year) in recent years, especially elderly patients. The total number of patients with renal replacement therapy (RRT) was 75,042 at the end of 2013. The prevalence of RRT was 1446.4 patients per million population. The proportion of RRT for hemodialysis (HD) is 69.8%, for peritoneal dialysis (PD) is 10.0%, and for renal transplant is 20.2%. In about half (48%) of new dialysis patients, the underlying disease was diabetic nephropathy in 2013. Mean urea reduction ratio in HD was 68.1% in male patients and 74.2% in female patients. Survey on rehabilitation status of dialysis patients showed that 22% of HD patients have full-time job and 8% have part-time job. About 29% of PD patients have full-time job and 17% have part-time job.

The objectives and importance of the patient registry and statistical evaluation of dialysis patient can be summarized as follows: first, to estimate the numbers and regional distributions of target therapy patients by a dialysis special physician group; second, to evaluate the characteristics of the patients and dialysis therapy, and its complications or results based on scientific evidence; and third, to improve quality of dialysis therapy and provide information for socio-economic health administration and the future health plan.

The Korean Society of Nephrology (KSN) has a 30-year-old project in which all society members are participating voluntarily since 1985: the end-stage renal disease (ESRD) patient registry (the ‘Insan Prof. Byung-Suk Min Memorial ESRD Patient Registry’). The late Professor Min was a Korean pioneer in nephrology, who had successfully performed the first kidney transplantation (KT) of Korea in 1969 and reported the first KSN ESRD registry in the first volume of the journal of KSN in 1980. Tragically, he was assassinated in 1983 by a terror attack while working as a physician for president of Republic of Korea.

The data collection of KSN ESRD registry has been performed through internet online program since 2001. The internet speed in Korea is faster than that of any other countries in the world according to Akamai’s state of the internet report Quarter 4 2013. Furthermore, Korea has a single government-run national health insurance system. In this system, every hospital is using a unified drug and medical procedure code and electronic data interchange system through internet. The KSN ESRD registry is not directly connected to this health insurance system but the registry shares the same medical procedures classification and drugs with the unified code.

DATA COLLECTION METHOD
The nation-wide official KSN ESRD registry launched in 1985 was performed with post mail and paper questionnaires from the beginning to 1994. Electronic questionnaire with dial-up modem file transfer or the diskette mailing had been used from 1995 to 2000. From 2001, KSN ESRD registry has been performed with internet online questionnaire about dialysis center information, patient personal data, and dialysis adequacy. The registry program has been fully revised for personal information protection in 2013. A data security program has been applied, and newly included items were
vascular access, dialysate components, calcium and phosphorus control medication, and rehabilitation status. (Table 1) The program also has a graphic evaluation function of dialysis adequacy (single-pool Kt/V (spKt/V), normalized protein catabolic rate (nPCR)) and a peritoneal equilibrium test. The KSN ESRD registry internet program has been running throughout the year. Every KSN member can access anytime the dialysis adequacy data of their own dialysis center, which could be of some help for dialysis prescription. Average KSN ESRD registry response rate of past 3 years was ~70%.

**DATA ON DIALYSIS THERAPY IN KOREA**

**Data size**

At the end of April 2014, KSN ESRD registry has 763 dialysis center records, ~114,000 personal records, 325,000 hemodialysis (HD) records, and 35,000 peritoneal dialysis (PD) records.

**Prevalence and incidence of ESRD in Korea**

At the end of 2013 in Korea, the total number of patients with renal replacement therapy (RRT) was 75,042 (HD: 52,378; PD: 7,540; and functioning KT: 15,124; Figure 1a). The prevalence per million population (PMP) was 1009.6 for HD, 291.5 for KT, and 1,446.4 for overall ESRD. These ESRD prevalence rates were slightly higher than those in most European countries but were ~65% of those in the United States and ~55% of those in Japan according to the international comparison data of the annual United States renal data report. The annual increase in the rate of prevalence was ~8–9% per year during 2005–2013. The proportion of HD was 69.8%, PD 10.0%, and KT 20.2%.

The number of new patients undergoing RRT in 2013 was 12,183 (234 PMP). The number of new ESRD patients with HD, PD, and KT were 9,343(183.3 PMP), 884 (17.0 PMP), and 1,756 (33.7 PMP), respectively. The new PD patient number has been decreasing since 2007, whereas those of HD and KT have been continuously increasing; this is consistent with the trend in the United States.

The most common causes of ESRD in new patients were diabetic nephropathy, hypertensive nephrosclerosis, and chronic glomerulonephritis (40.8, 19.7, and 8.3%, respectively, Figure 1b). Among these three underlying diseases, the incidence of diabetic nephropathy increased quite rapidly during 1990–2000. The proportion of diabetic nephropathy in ESRD patients in Korea was one of the highest in the world which was similar with some Asian countries and the United States.

**RRT modalities**

Approximately 79% of new ESRD patients started HD as their initial RRT, whereas ~7% of patients started PD in 2013. The prevalence rates of HD, PD, and KT were 70, 10, and 20%, respectively.

The number of HD centers and HD machines has also been increasing rapidly in Korea. At the end of 2013, Korea had 709 HD centers and 19,917 HD machines. The ratio of machines per center was ~28 and the ratio of patients per machine was 2.6. Analysis of the distribution of ESRD patients according to the administrative regions in Korea showed that ~50% of HD patients and >50% of PD patients were located in the capital area.

**Dialysis patient demographics**

The gender ratio of men to women was 58% vs. 42% in HD therapy and 56% vs. 44% in PD therapy. Hepatitis B virus antigen was positive in 6% of dialysis patients and hepatitis C virus antibody was positive in 4%.

The mean age of dialysis patients was 59.8±14.0 years. The percentage of dialysis patients aged >65 years increased up to 39.5% of overall dialysis patients in 2013. The age distribution according to underlying disease showed that the peak age of chronic glomerulonephritis was 54.1 years and that of diabetic nephropathy was 62.3 years.

The age distribution of dialysis patients showed two peaks: one peak at the 50 years-old and another peak at the 65 years-old, which is implicating that at least two or more different disease groups are present in ESRD patients. About 46% of HD patients and 45% of PD patients had been undergoing dialysis for >5 years; these percentages had increased from 30 and 14% in 2001, respectively.

Approximately 54% of non-diabetic HD patients had been undergoing dialysis for >5 years, whereas only 36% of diabetic HD patients had been undergoing dialysis for >5 years. Similarly, ~51% of non-diabetic PD patients and 36% of diabetic PD patients had been undergoing dialysis for >5 years.

The mean body mass index was 22.13±3.5 kg/m² in HD patients and 23.98±3.6 kg/m² in PD patients; this showed a steady increase in both HD and PD groups. In HD patients,
the mean body mass index was 22.60 ± 3.5 kg/m² in diabetic patients and was 21.72 ± 3.3 kg/m² in non-diabetic patients.

The mean blood pressures were similar between HD patients and PD patients (100.1 ± 12.0 and 98.4 ± 14.4 mm Hg, respectively, but the pulse pressure was much higher in HD patients than in PD patients (64.5 vs. 53.5 mm Hg). Although the blood pressure of dialysis patients was decreasing, the pulse pressure of HD patients was increasing, which might be associated with the risk of cardiovascular morbidity.

**Characteristics of HD, PD, and erythropoietin therapy**

**HD frequency and dialyzer.** Most (91%) HD patients received dialysis three times per week; hemodiafiltration therapy was performed to 15% of HD patients but 51% of HD patients received dialysis therapy with a dialyzer which surface area was < 1.5 m².

**Vascular access for HD.** About 80% of HD patients had autologous arteriovenous fistula, and 48% of those were in left forearm, and 15% of HD patients had graft fistula. But 11% of HD patients received the dialysis therapy through catheters.

**PD catheter and dialysate dose.** PD patients (48%) had ‘swan neck’ PD catheter and 17% of PD patients had straight PD catheter. PD catheter insertion method was surgical in 67% of PD patients. The break-in period after catheter insertion was mostly 2–3 weeks in both surgical and trochar insertion. Automated PD therapy was applied to 25% of PD patients and PD dialysate volume of 10–12 liter per day was used in 48% of PD patients.

**Anemia and erythropoietin therapy.** In 2013, the mean hemoglobin of HD patient was 10.4 ± 1.1 g/dl and that of PD patients was 10.3 ± 1.4 g/dl. Although PD patients theoretically have a lower prevalence of anemia than HD patients, the use of erythropoietin therapy has increased hemoglobin values in HD patients more than PD patients. About half (48%) of HD patients were injected with 8,000 or more units of erythropoietin per week, whereas only 39% of PD patients were injected with this level of erythropoietin and 19% of PD
patients were not injected with erythropoietin. The jump-up increase of both dialysis patients’ hemoglobin values in 2004 and 2005 was owing to increase in the reimbursement level of hemoglobin by the National Health Insurance.

**Laboratory data and medications.** Mean total calcium and phosphorous levels in HD patients were 8.87 ± 0.89 and 4.94 ± 1.63 mg/dl, respectively. Serum intact parathyroid hormone level of dialysis patients was showed as natural logarithmic scale distribution with mean value 215.3 pg/dl in HD patients. Calcium bicarbonate or acetate was used in 64% HD patient as phosphate binder and 26% of HD patients received vitamin D therapy. Mean values of serum albumin, creatinine, cholesterol, uric acid and HbA1c levels were 3.9 g/dl, 9.30, 145.8, 7.22 mg/dl and 6.87% in HD patients, respectively.

**Dialysis adequacy.** The mean of urea reduction ratio was 68.1% in male and 74.2% in female HD patients. This gender difference of dialysis adequacy resulted from the use of similar dialysis dose in men and women in spite of body mass difference between the genders. The overall mean urea reduction ratio was 70.7 ± 7.0%, which showed a steady increase.

The average nPCR and spKt/V were 0.97 ± 0.28 and 1.50 ± 0.29, respectively. Distribution of patient number according to nPCR and spKt/V in HD patients was shown Figure 1d. Similar to the urea reduction ratio, both these values were higher in women than in men. SpKt/V was higher in non-diabetic patients than in diabetic patients, presumably because of the quality of vascular access for dialysis. The recent PCR showed a slight decrease, presumably because of the increase in the proportion of elderly dialysis patients.

**Rehabilitation, morbidities, causes of death, and survival rates of dialysis patients**

**Rehabilitation.** Twenty-nine percent of PD patients had full-time job and 17% had part-time job, but only 22% of HD patients had full-time job in 2013. This means that higher rehabilitation rate was achieved in PD patients.

**Co-morbidity.** The most common complication (49.4%) in HD patients was vascular diseases, which included hypertension, cerebrovascular accident, and other vascular diseases. Furthermore, 61.9% of PD patients had vascular disease, and the infection complication rate was higher in PD patients (8.8%) than in HD patients (5.1%).

**Causes of death.** The causes of death in dialysis patients in descending order of frequency were cardiac cause (28.4%), infection (11.9%), and vascular disease (8.7%). Some year-to-year variation was observed because of limitations in death reports.

**Patient survival.** Overall five year patient survival of male dialysis patient was 71.7%, female patients was 74.2%. Five-year survival for HD and PD patient was 73.7% and 68.4%, respectively. Five-year survival of diabetic dialysis patients was 63.2%, chronic glomerulonephritis patients was 86.5%, and hypertensive nephrosclerosis patients was 78.1%. These survival rates were higher than those in the United States and Japan, but the Korean survival rate was calculated only from registered dialysis patients since 2001. The Korean ESRD registry covers only about two-thirds of all dialysis patients in Korea because registry enrollment is voluntary.

The 5-year survival rate was higher in HD patients than in PD patients (73.7 vs. 68.4%), and the 5-year survival rate was higher for chronic glomerulonephritis patients than for diabetic patients (86.5 vs. 63.2%).

**Kidney transplantation**

In Korea, 1756 cases of KT were performed in 2013, which included 750 deceased donors. The KT rate was 29 cases per 1000 dialysis patients, which was below the world average. However, the waiting number has been increasing sharply, and 14,181 surviving dialysis patients were enrolled in the Korean Network of Organ Sharing waiting list at the end of 2013.

**CONCLUSION**

The ESRD registry committee of KSN has been collecting data through internet online program since 2001. The program has included dialysis center information, dialysis patients’ personal data with laboratory data, newly included vascular access and rehabilitation status, graphic evaluation function of dialysis adequacy (spKt/V, nPCR), and a peritoneal equilibration test. The increasing proportion of elderly and diabetic patients in the Korean population has resulted in a rapid increase in the number of ESRD patients, which reached 1446 PMP at the end of 2013. A high proportion of diabetic ESRD patients (48%) and a decrease in the proportion of PD patients were recently observed. The adequacies of dialysis and anemia therapy have been steadily improving in Korea.

**DISCLOSURE**

The author declared no competing interests.

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