

Incidence of Autosomal Dominant Polycystic Kidney Disease (ADPKD) among ESRD Patients in the United States, 1991-2003

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Introduction

- Several previous studies of United States Renal Data System (USRDS) records have assessed the characteristics of autosomal dominant polycystic kidney disease (ADPKD) patients suffering from end-stage renal disease (ESRD).
 - Abbott et al., (*Clinical Nephrology*, 2002) analyzed records of 375,152 patients who became ESRD-incident from January 1992 to June 1997, and noted that 1.5% of these patients had ADPKD at ESRD onset.
 - Perrone et al., (*AJKD*, 2001) analyzed records of 217,167 patients who became ESRD-incident between 1990 and 1996, and noted that 4.7% of these patients had ADPKD at ESRD onset.
- Both studies utilized the "Primary Cause of Renal Failure" field on the CMS Medical Evidence Form 2728 (ME) to assess ADPKD prevalence, but did not search subsequent Medicare claims for ADPKD diagnoses.
- We used the ME 2728 Form and Medicare claims to determine incidence of ADPKD among ESRD patients, from 1991 to 2003 and investigated the characteristics of ESRD patients with ADPKD.

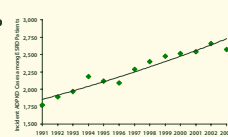
Methods

- We searched both MEs and Medicare claims between 1991 and 2003 for instances of the following ICD-9 diagnosis codes:
 - 753.1 – Cystic Kidney Disease,
 - 753.12 – PKD, unspecified type,
 - 753.13 – PKD, autosomal, dominant, and,
 - 753.14 – PKD, autosomal recessive.
- Instances of non-specified codes 753.1 and 753.12 among patients age < 20 were excluded.
- ADPKD was defined by the presence of diagnoses 753.1, 753.12, or 753.13 on the ME form or at least one inpatient claim and the absence of diagnosis 753.14 on all inpatient claims.
- So that claims for radiologic screening could not be inadvertently utilized to identify ADPKD cases outpatient claims were excluded from the analysis of ADPKD incidence.
- Disease burden was assessed during the initial 12 months following onset of ESRD, regardless of whether ADPKD was subsequently diagnosed; each disease was considered present if at least one inpatient claim or at least two outpatient claims included applicable diagnosis codes.

Results

- There were 29,443 cases of ADPKD identified between 1991 to 2003 among ESRD patients.
- Of these, 86.0% were identified from MEs, 90.0% were identified from diagnosis 753.13 (ADPKD), and 7.2% were identified from diagnosis 753.12 (Unspecified PKD).
- Between 1991 and 2003, incident ADPKD cases among all ESRD patients grew by 3.2% (95% CI: 2.8-3.8) annually.
 - Annual cases grew by 2.7% (95% CI: 2.2-3.3) in whites, while a 5.2% (95% CI: 4.4-6.1) increase was noted for blacks; difference in growth rates was significant ($p < 0.01$).
- The mean age of patients at the onset of ESRD demonstrated no clinically significant changes from 1994 to 2003, with averages approaching 56 years.
- Male patients represented roughly 55 percent of ADPKD incident cases, while white patients represented roughly 80 percent.
- Overall ESRD incidence outpaced ADPKD incidence from 1994 to 2003.
- Over 15% of patients suffered from ASHD, roughly 12% experienced CHF, and more than 10% had diabetes.
- However, no temporal trends in extra-renal comorbidity were observed.

Number of Incident ADPKD Cases among ESRD Patients, 1991-2003
Log-linear regression estimate is displayed.



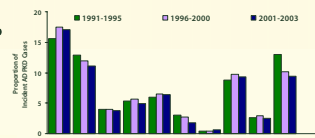
Number of Incident ADPKD Cases among ESRD Patients, by Race, 1991-2003
Log-linear regression estimate are displayed.



Characteristics of ESRD Patients with Incident ADPKD, 1994-2003

	1994 (N=2,179)	1995 (N=2,089)	1996 (N=2,263)	1997 (N=2,399)	1998 (N=2,477)	1999 (N=2,510)	2000 (N=2,536)	2001 (N=2,639)	2002 (N=2,639)	2003 (N=2,572)
Age at ESRD Onset (Mean and SD)	56.1 (14.7)	55.1 (13.9)	56.9 (13.8)	56.6 (13.8)	56.3 (14.0)	56.4 (13.8)	56.0 (14.1)	56.1 (14.1)	56.3 (14.3)	55.2 (13.7)
Pediatric Cases (N and %)	41 (1.9)	17 (0.8)	5 (0.2)	12 (0.5)	8 (0.3)	10 (0.4)	13 (0.5)	15 (0.6)	14 (0.5)	19 (0.7)
Gender: Female (N and %)	1025 (47.0)	979 (46.3)	926 (44.3)	1025 (44.9)	1099 (45.8)	1147 (46.3)	1106 (44.0)	1167 (46.0)	1146 (43.1)	1202 (46.7)
Gender: Male (N and %)	1154 (53.0)	1110 (53.7)	1143 (55.7)	1258 (55.1)	1300 (54.7)	1330 (54.7)	1404 (54.8)	1369 (54.8)	1513 (56.9)	1370 (53.3)
Race: White (N and %)	1793 (82.3)	1741 (82.4)	1692 (81.0)	1830 (80.2)	1977 (82.4)	2022 (81.4)	2013 (80.2)	2039 (80.4)	2125 (79.9)	2021 (78.6)
Race: Black (N and %)	320 (14.7)	297 (14.0)	312 (14.4)	367 (15.8)	344 (14.3)	371 (15.0)	396 (15.3)	387 (14.6)	433 (16.3)	422 (16.4)
Race: Other (N and %)	66 (3.0)	76 (3.6)	85 (4.1)	86 (3.7)	78 (3.3)	84 (3.4)	101 (4.0)	110 (4.2)	101 (3.8)	129 (5.0)
ESRD Incident Patients	69,968	71,791	77,860	82,201	87,121	91,560	93,966	96,289	100,625	102,547
% ADPKD Cases	3.13%	2.94%	2.68%	2.78%	2.73%	2.71%	2.67%	2.63%	2.64%	2.53%

Comorbidity Proportions of Incident ADPKD Cases among ESRD Patients, by ESRD-onset Vintage, 1991-2003



Conclusions

- From 1991 to 2003, the rate of ADPKD incidence has grown faster than the US population (1.2% annually), but more slowly than the ESRD population.
- ADPKD incidence among black patients has significantly exceeded incidence among whites.
- It is unclear whether the higher rate of ADPKD incidence growth reflects more extensive radiologic testing of patients with renal disease or that a true increase in ADPKD incidence is occurring.
- The higher rate of incidence is unlikely simply due to an increased rate of acceptance into dialysis programs of older and sicker patients, a reason that may account for the rise in ESRD incidence since the age at onset of ESRD among ADPKD cases has not changed.
- Exclusive use of ME data to gather evidence of ADPKD may underestimate ADPKD incidence by 10 to 20%.
- It remains to be investigated whether Part A outpatient or Part B claims can inform ADPKD incidence calculations.