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Kidney Function decline in patients with ADPKD: data from the UK ADPKD RaDaR Registry

Dr Ragada El-damanawi[1,2], Ms Tess Harris[3], Professor Fiona Karet Frankl[4], Dr Thomas F Hiesmtra[1,2], Dr Daniel Gale[5], Dr Richard Sandford[4]

[1]Cambridge Clinical Trials Unit, Cambridge, United Kingdom, [2]Division of Experimental Medicine and Immunotherapeutics, Cambridge, United Kingdom, [3]PKD Charity, London, United Kingdom, [4]Division of Renal Medicine and Departments of Medical Genetics, Cambridge, United Kingdom, [5]Royal Free Hospital, London, United Kingdom

Background and Aims:
The National Registry of Rare Kidney Diseases (RaDaR) was established in 2010 by the UK Renal Association with the primary objective of creating a comprehensive registry to facilitate characterisation of and research into rare kidney diseases. The initiative also aimed to provide greater patient support. To date, more than 6500 ADPKD patients have been recruited, combining a wealth of longitudinal clinical, laboratory, imaging and genetic data spanning decades. We evaluated patient characteristics and patterns of disease progression in a pre-end stage kidney disease (pre-ESKD) ADPKD cohort, recruited across 88 centers in the United Kingdom.

Method:
In this large, observational cohort study, we included ADPKD participants from the RaDaR registry that were over the age of 16 years, with a baseline eGFR ≥ 20mls/min/1.73m2 and not currently taking tolvaptan. Patients with less than 1 year of kidney function follow-up data were excluded from the analysis. We examined the demographic and clinical characteristics and the development of kidney failure (defined as eGFR <15mls/min/1.73m2) or requirement for renal replacement therapy.

Results:
Of 6420 ADPKD patient records in RaDaR, 21.8% (n=1805) had no eGFR data, 24.1% (n=1545) had a kidney transplant, 0.9% (haemodialysis n=50, peritoneal dialysis n=8) were on dialysis and 8.4% (n=540) were on tolvaptan. 47 patients had died after RaDaR enrolment.

We included 1922 patients with a median of 16 (IQR 7-35) eGFR values observed over 3 decades (1991-2019) in the analysis. Median age was 43 years (IQR 32-53) with 56.0% (n=1076) older than 40 years and 55.5% (n=1062) female. The majority (67.8%, n=1303) were White British, 9.9% (n=190) were Black, Asian and minority ethnic (BAME), and for the remainder ethnicities were recorded as unknown. Baseline median eGFR was 73.8 mls/min/1.73m2 (IQR 48.5-99.1), and 35.3% (n=679) had an eGFR <60mls/min/1.73m2. Males had a lower baseline median eGFR compared to females (69.3; IQR 44.8-95.8 versus 78.3; IQR 52.8-102.7 mls/min/1.73m2, p<0.001), and those >40 years old also had worse baseline kidney function compared to younger patients (56.0 IQR 37.5-74.0 versus 98.3 IQR 81.2-118.2 mls/min/1.73m2, p<0.001).

During follow up, the proportion reaching ESKD increased with advancing age group from 1% (2/195) in 16-30 year old patients, to 2.7% (10/374) in those between 31-40 years, 10.8% (46/427) in those 41-50 years, 13.7% (65/474) in 51-60 year old's, 19.9% (55/277) in the 61-70 age category and finally 29.7% (52/175) in those aged ≥ 71 years old (figure).

Conclusion:

We report the proportion of patients reaching kidney failure across age categories in a large cohort of ADPKD patients. These data underestimate the true incidence of kidney failure in ADPKD as our analysis excluded patients with kidney failure at the point of RaDaR enrolment. Although limited by missing data for some participants, RaDaR provides a rapidly expanding and unprecedented resource for studying the natural history and treatment of ADPKD.