RAPID-ADPKD (Retrospective epidemiologic study of Asian-Pacific patients with rapid Disease progression of Autosomal Dominant Polycystic Kidney Disease): Design and Methods

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Objectives: For effective treatment and early intervention in Autosomal dominant polycystic kidney disease (ADPKD) patients, identifying subgroups with rapid renal progression are important in ADPKD. This study was designed to identify the clinical characteristics of rapidly progressing ADPKD patients in Asia-Pacific area.

Methods: The RAPID-ADPKD is a multinational retrospective observational cohort study of ADPKD patients in the Asia-Pacific area.

Results: Six hospitals from six regions (Australia, China, Hong Kong, South Korea, Taipei and Turkey) are participating in this study. Adult ADPKD patients, diagnosed by the unified criteria and with eGFR ≥45 mL/min/1.73m² at baseline will be included. Patients with other comorbidities that can affect renal function will be excluded. Demographic information, clinical characteristics, premorbid comorbidities, medications, eGFR, radiologic findings that can calculate height adjusted total kidney volume (htTKV), PKD-related complications and the PRO-PKD score will be collected. Rapid progression will be defined as when any of the following criteria are met: (i) an annual eGFR decline ≥ 5 mL/min/1.73m² in 1-year and/or ≥2.5 mL/min/1.73m² per year over a period of 5-years; (ii) an increase in htTKV ≥ 5% per year from ≥ 3 radiologic images; (iii) Mayo classification 1C, 1D, or 1E or kidney length from ultrasonography of >16.5 cm (iv) PKD1 truncated mutation with early symptoms (PRO-PKD score > 6). All other patients without any of the criteria are classified as slow progression. The clinical characteristics of rapid progression group will be compared to slow progression group. In addition, the incidence rate, age of diagnosis, treatment complications between rapid and slow progression will be analyzed. The planned sample size of the cohort is 1,000 patients, and as Feb 28th 2018, data from 400 patients have been collected.
Conclusions: RAPID-ADPKD is the first large-scale multinational retrospective observational study of ADPKD in Asia-Pacific region and will identify the clinical characteristics, risk factors for disease progression and patterns of complications in Asian populations with ADPKD.