SC092 REDUCED QUALITY OF LIFE IN ADPKD PATIENTS WITH CKD STAGE 1-3: THE CYSTIC I QUALITY OF LIFE STUDY

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Background and Aims: ADPKD is the most common inherited kidney disease in man, a major cause of end-stage renal disease and is a significant medical and economic burden across Europe. However the impact of this major disease on the quality of life of patients with preserved kidney function has not been systematically explored.

Method: The CYSTic 1 study was an academic prospective study designed to study the natural history of ADPKD, the impact of the disease on individual patients and the health economic costs on care systems across Europe in adult patients with preserved kidney function ($eGFR \ge 30$ mls/min). Around 400 patients were recruited from 6 expert centres across Europe (Belgium, France, Italy, Netherlands, Spain, UK) with baseline clinical data recorded including HR-QOL (Health-Related Quality of Life) incorporating a Kidney Disease QOL short form (KDQOL-SF v1.3 questionnaire), renal MRI for TKV (Total Kidney Volume) and DNA for genotyping. Here we report initial results based on baseline HR-QOL data in the UK patients.

Results: Detailed analysis was conducted on 76 patients recruited from a single centre (UK) whose mean age was 43 years, 53.9% were female with a mean eGFR-EPI of 69ml/min/1.73m² and mean height-adjusted TKV (Ht-TKV) of 664ml/m. The cohort was subdivided by groups based on eGFR stage (I, II, III), Ht-TKV (<>750ml/m) and genotype (PKD1 v PKD2/NMD) and correlated with HR-QOL scores. As expected, age, hypertension and Ht-TKV were significantly associated with eGFR stage. Of interest, flank pain was more frequently reported in patients with smaller kidneys (Ht-TKV<750) and patients with PKD1 more likely to be hypertensive. All QOL scores (SF36) were significantly lower in patients with progressively lower eGFR except for emotional well-being whereas Symptom/problem (p=0.043) and Sleep (p=0.021) (KDQOL-SF1.3) were significantly worse in patients with lower kidneys (nuction. SF36 scores for Physical functioning (p=0.01), General health (p=0.026) and physical component summary (PCS) (P=0.019) decreased in patients with more advanced disease defined by larger kidneys (ht-TKV>750).

Conclusion: In ADPKD patients with stage 1-3 chronic kidney disease (CKD), stepwise lower QOL scores were consistently found and significantly associated with decreasing eGFR. A notable reported item was disturbed sleep. Unexpectedly, patients with smaller kidneys reported significantly more flank pain. PKD1 patients and those with large kidneys were more likely to be hypertensive. Our results suggest that the impact of ADPKD on patients with stage 1-3 CKD is underestimated. Future work will investigate possible national differences and the relationship of HR-QOL with markers of disease within the entire cohort.