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Evaluating Pain in Autosomal Dominant Polycystic Kidney Disease

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Background and Aims:
Chronic pain is prevalent in Autosomal Dominant Polycystic Kidney Disease (ADPKD) and is associated with a substantial quality of life burden. Literature describing ADPKD-related chronic pain (ACP) is limited, and generic pain management strategies are suboptimal with patients often reporting inadequate relief. Furthermore, the absence of a validated and widely accepted pain assessment tool (PAT) in ADPKD has posed a significant barrier to better pain management and research. We established an ADPKD PAT (APAT) and confirmed its feasibility and validity through administration to ADPKD patients participating in a randomised high water intake trial (NCT02933268).

Method:
A collaboration of key stakeholders (patients, ADPKD experts, trialists and pain specialists) constructed an ADPKD pain conceptual framework consisting of eight prioritised pain assessment domains. We constructed an APAT from components of previously validated pain assessment tools covering each of the prioritised pain domains. The finalised APAT was administered to participants in a feasibility trial which randomised adult ADPKD patients with an eGFR ≥20mls/min/1.73m2 to prescribed high water intake (HW) or ad libitum water intake (AW group) over eight weeks. Participants were asked to complete the APAT at least twice (baseline and week 8), although more frequent submissions were permitted.

Results:
93% (39/42) of trial participants with CKD stages 1-4 completed a total of 129 questionnaires. Each participant completed a median of 3 (range 1-10) questionnaires. In terms of baseline characteristics; mean age of respondents was 47±13 years, 90% (35) were White British ethnicity, and 59% (23) were female. Median disease duration was 14.2 (IQR 7.0-25.9) years, 69% had enlarged kidneys, 64% had hypertension and hepatic cysts were present in 59%.

Pain (52%) and associated analgesic use (29%) were prevalent. Participants with pain were more likely to report interference with mobility (25% vs 0%), self-care (20% vs 0%) and usual activities (31% vs 1%) compared to those with no pain ($p<0.001$). Pain was also associated with a higher risk of anxiety and depression (RR 2.97, CI 1.70-5.20, $p<0.001$). Pain severity was predicted by traditional risk factors of disease progression including increasing age (OR 1.07, $p=0.009$), eGFR <60mls/min/1.73m2 (OR 5.45, $p=0.021$), and hypertension (OR 12.11, $p=0.007$), but not kidney size, consistent with findings of previous studies. Neuropathic descriptors were not commonly used, while continuous and intermittent descriptors were more frequently selected by patients to describe their pain quality (figure).
The APAT achieved good internal consistency (Cronbach's alpha coefficient =0.91) and test-retest reliability was demonstrated with domain intra-class correlation coefficients ranging from 0.62-0.90.

Conclusion:

A bespoke APAT including components of previously validated pain assessment tools was reliable in evaluating pain in patients with ADPKD, and was acceptable to participants. Pain was prevalent among participants and associated with a substantial emotional and physical burden. The APAT represents a viable instrument for standardised evaluation of ADPKD pain in observational and interventional research.