SONG
STANDARDISED OUTCOMES IN NEPHROLOGY

Outcomes for clinical trials involving adults with chronic kidney disease: a multinational Delphi survey involving patients, caregivers and health professionals

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Background

Many outcomes of high priority to patients and clinicians are infrequently and inconsistently reported across trials in chronic kidney disease (CKD), which generates research waste and limits evidence-informed decision making. We aimed to generate consensus among patients/caregivers and health professionals on critically important outcomes for trials in CKD prior to kidney failure and the need for kidney replacement therapy, and to describe the reasons for their choices.

Methods

This was an online two-round international Delphi survey. Adult patients with CKD (all stages and diagnoses), caregivers and health professionals who could read English, Spanish or French were eligible. Participants rated the importance of outcomes using a Likert scale (7–9 indicating critical importance) and a Best–Worst Scale. The scores for the two groups were assessed to determine absolute and relative importance. Comments were analysed thematically.

Figure 1: Mean Likert scores of all outcomes for patients/caregivers in Delphi survey

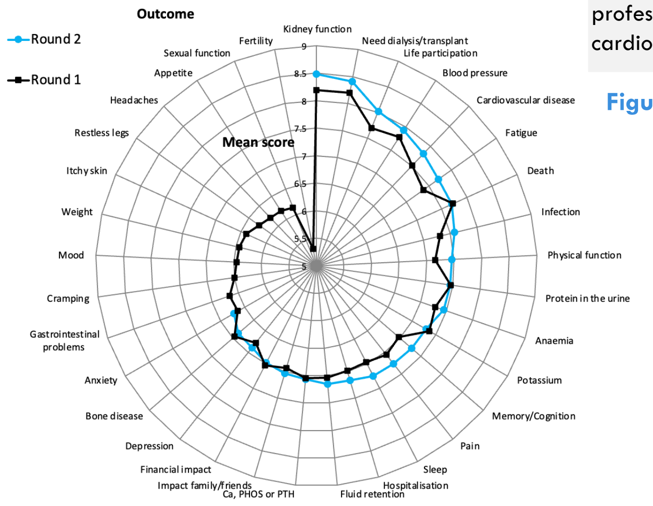
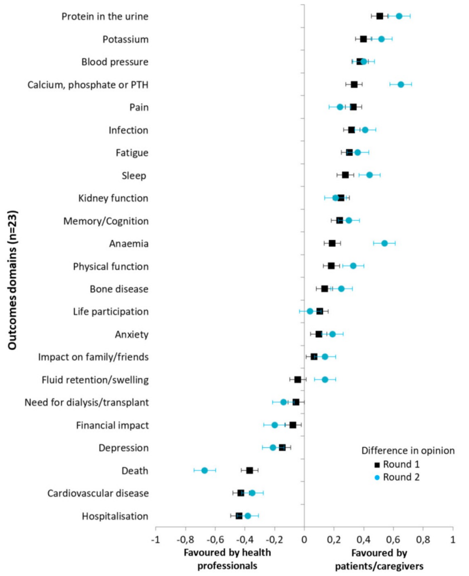


Figure 3: Proportion of critically important outcomes for patients/caregivers and HP



Aim

To generate consensus among patients/caregivers and health professionals on critically important outcome domains for trials in CKD prior to the need for KRT, and to describe the reasons for their choices.

Results

In total, 1399 participants from 73 countries completed Round 1 of the Delphi survey, including 628 (45%) patients/caregivers and 771 (55%) health professionals. In Round 2, 790 participants (56% response rate) from 63 countries completed the survey including 383 (48%) patients/caregivers and 407 (52%) health professionals. The overall top five outcomes were: kidney function, need for dialysis/transplant, life participation, cardiovascular disease and death. In the final round, patients/caregivers indicated higher scores for most outcomes (17/22 outcomes), and health professionals gave higher priority to mortality, hospitalization and cardiovascular disease (mean difference > 0.3). Consensus was based upon the two groups yielding median scores of ≥7 and mean scores > 7, and the proportions of both groups rating the outcome as 'critically important' being > 50%. Four themes reflected the reasons for their priorities: imminent threat of a health catastrophe, signifying diminishing capacities, ability to self-manage and cope, and tangible and direct consequences.

Conclusion

Across trials in CKD, the outcomes of highest priority to patients, caregivers and health professionals were kidney function, need for dialysis/transplant, life participation, cardiovascular disease and death.

Figure 2: Mean Likert scores of all outcomes for HP in Delphi survey.

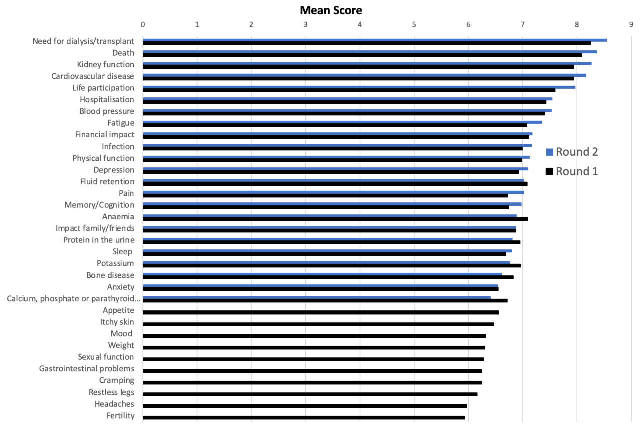
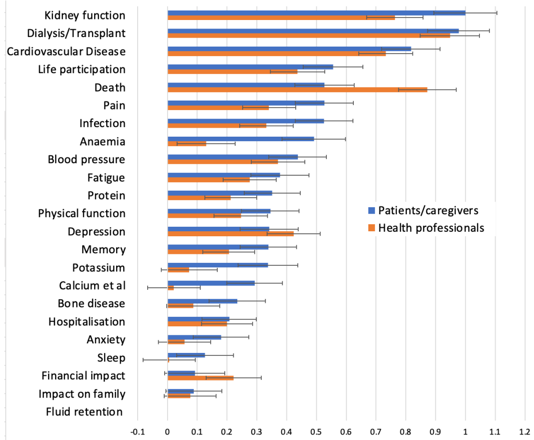


Figure 4: The relative importance score of outcomes from the BWS survey for patients/caregivers and HP



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