

Patient and Caregiver Priorities for Outcomes in Hemodialysis: An International Nominal Group Technique Study

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Background: In the context of clinical research, investigators have historically selected the outcomes that they consider to be important, but these are often discordant with patients' priorities. Efforts to define and report patient-centered outcomes are gaining momentum, though little work has been done in nephrology. We aimed to identify patient and caregiver priorities for outcomes in hemodialysis.

Study Design: Nominal group technique.

Setting & Participants: Patients on hemodialysis therapy and their caregivers were purposively sampled from 4 dialysis units in Australia (Sydney and Melbourne) and 7 dialysis units in Canada (Calgary).

Methodology: Identification and ranking of outcomes.

Analytical Approach: Mean rank score (of 10) for top 10 outcomes and thematic analysis.

Results: 82 participants (58 patients, 24 caregivers) aged 24 to 87 (mean, 58.4) years in 12 nominal groups identified 68 outcomes. The 10 top-ranked outcomes were fatigue/energy (mean rank score, 4.5), survival (defined by patients as resilience and coping; 3.7), ability to travel (3.6), dialysis-free time (3.3), impact on family (3.2), ability to work (2.5), sleep (2.3), anxiety/stress (2.1), decrease in blood pressure (2.0), and lack of appetite/taste (1.9). Mortality ranked only 14th and was not regarded as the complement of survival. Caregivers ranked mortality, anxiety, and depression higher than patients, whereas patients ranked ability to work higher. Four themes underpinned their rankings: living well, ability to control outcomes, tangible and experiential relevance, and severity and intrusiveness.

Limitations: Only English-speaking participants were eligible.

Conclusions: Although trials in hemodialysis have typically focused on outcomes such as death, adverse events, and biological markers, patients tend to prioritize outcomes that are more relevant to their daily living and well-being. Researchers need to consider interventions that are likely to improve these outcomes and measure and report patient-relevant outcomes in trials, and clinicians may become more patient-orientated by using these outcomes in their clinical encounters.

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The primary objective of clinical research is to improve the health care and well-being of patients, yet researchers have historically selected the outcomes they consider to be most important, with limited input from patients.¹⁻³ Consequently, many studies may not have focused on the problems or outcomes that are relevant and meaningful to patients and their families. This can impede shared decision making and the uptake of research findings into clinical practice, resulting in research waste.⁴⁻⁶

In the context of dialysis, outcomes valued by patients, such as fatigue, caregiver respite, employment, and ability to travel,⁷⁻⁹ are not typically measured in clinical studies. Instead, biochemical measures are commonly used, possibly because they require fewer resources and less time and are easier to measure.¹⁰ However, the correlations between surrogate laboratory markers and mortality or quality-of-life outcomes remain largely uncertain.^{11,12} Furthermore, although researchers regard mortality as an important outcome, and often the most important or primary outcome, despite the growing numbers of trials involving patients on dialysis therapy, no intervention has been shown to improve survival.² These observations suggest that stronger emphasis on patient well-being as an important outcome to be measured and reported in studies and closer alignment between these outcomes and the choice of interventions to be trialed are required.

There are growing international efforts toward more patient-centered research, typically focusing on 2 major issues: the research question and the outcomes measured. These trends in nephrology are embryonic and largely confined to kidney transplant recipients.¹³ Patient and caregiver perspectives on the relative importance of outcomes for research in hemodialysis are largely unknown.^{8,14} The aim of this study was to generate a ranked set of outcomes considered important and relevant to patients and their caregivers, with a view to informing patient-centered research in hemodialysis.

METHODS

Study Design and Participants

We used a combined focus group/nominal group technique¹⁵⁻¹⁷ to identify and rank hemodialysis outcomes considered important to patients on hemodialysis therapy and their caregivers and to discuss the reasons behind these ranking decisions. Caregivers, defined as family members/friends involved in the care of the patient, were included given their role in shared decision making and the impact that hemodialysis can have on their lives. We recruited participants from 4 dialysis units in Australia (Sydney and Melbourne) and 7 units in Canada (Calgary) and applied purposive sampling to obtain variation of demographic (age, sex, and educational attainment) and clinical characteristics (in-center vs home hemodialysis, diagnosis, and dialysis vintage). We considered participants eligible if they were English speaking, older than 18 years, able to give informed consent, and medically

fit enough to attend a focus group/nominal group session. We reimbursed participants for their time and travel expenses. The Human Research Ethics Committee of the Western Sydney Local Health District (HREC2009/6/4.15), Monash Health (13082B), and The University of Calgary (REB15-0708) approved this study.

Data Collection

Each 2-hour focus group/nominal group consisted of 3 phases: (1) discussion of general experiences relating to hemodialysis, (2) individual and group identification of hemodialysis outcomes, and (3) individual ranking among outcomes (Item S1, available as online supplementary material). The nominal group technique is a facilitated structured small-group discussion used to generate ideas and reach consensus.¹⁷ The process involves generating, recording, discussing, and voting/ranking of ideas.¹⁸ Participants can suggest ideas (ie, outcomes) and prioritize the suggestions of all group members. This approach minimizes dominance of the discussion by individuals and fear of direct rejection.¹⁸ The nominal group technique has been used effectively within various areas of health research, including cancer and kidney transplantation, to elicit patient priorities for health care.^{13,15,18} Groups were convened in a meeting room and facilitated by either A.T., R.U.S., H.T.-T., S.T., or K.S.-M. Initially, participants identified outcomes they believed were important and relevant to hemodialysis. The facilitator supplemented this list with outcomes reported in systematic reviews of interventions for adults on hemodialysis therapy. Participants then individually ranked outcomes in the consolidated list in order of importance. Sessions were audio recorded and transcribed. From March through May 2015, the focus/nominal groups were convened until data saturation, defined as when no new outcomes or reasons were being identified in subsequent groups.

Data Analysis

Nominal Group Ranking

The highest ranked outcome for each participant was given a value of 10, and the least important, a value of 1. Outcomes that were not ranked in a participant's top 10 outcomes were assigned a value of zero. We used individual rank scores for participants across all 12 focus/nominal groups to determine a mean rank score for the top 10 most important outcomes from the combined outcomes. Because the number and type of outcomes in the group lists varied, the mean rank score (range, 0-10) for each outcome was calculated based on the number of participants who ranked that outcome. We also calculated the number of participants who ranked an outcome in the top 10 most important outcomes. Mean rank scores were calculated separately for patients and caregivers and by country, with the statistical significance of the differences assessed on the basis of a *t* test, considered significant at $P < 0.05$. Rank scores for outcomes considered by only a small number of groups will reflect the specific discussions and dynamics of those groups, and the mean values will provide a biased estimate of the relative importance of those outcomes. Therefore, mean rank scores for the main results have been calculated for outcomes identified by 4 or more groups.

Qualitative Analysis

We imported the transcripts into HyperRESEARCH (version 3.7.2; ResearchWare Inc) software for qualitative data analysis. Using thematic analysis, R.U.S. reviewed the transcripts line by line and inductively coded for concepts and themes that emerged from the data that provided reasons behind participants' ranking choices. Similar concepts were grouped into themes and sub-themes. The preliminary findings were discussed among R.U.S., A.T., and J.C.C. (investigator triangulation) to ensure that the

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