Original Investigation

Research Priority Setting in Kidney Disease: A Systematic Review

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Background: Resources for research are insufficient to cover all unanswered questions, and therefore difficult choices about allocation must be made. Recently there has been a move toward more patient-centered research. This study aims to evaluate approaches to research prioritization in kidney disease and describe research priorities of patients with kidney disease, their caregivers, the health care providers involved in their care, and policy makers.

Study Design: Systematic review.

Setting & Population: Studies that elicited patient, caregiver, health care provider, or policy maker priorities for research in kidney disease were included.

Search Strategy & Sources: MEDLINE, EMBASE, PsycINFO, and CINAHL were searched to May 2014.

Analytical Approach: Descriptive synthesis.

Results: We identified 16 studies (n = 2,365 participants) conducted in the United States, the Netherlands, Australia, Canada, and internationally. Only 4 (25%) studies explicitly involved patients. Various priority-setting methods were used, including the Delphi technique, expert panels, consensus conference, ranking or voting surveys, focus groups, and interviews, of which the process was described in detail by 11 (69%) studies. The priority areas for research most frequently identified across studies were prevention of acute kidney injury, prevention of chronic kidney disease progression, fluid and diet restrictions, improving vascular access, kidney transplant survival, access to transplantation, patient education, and psychosocial impact of chronic kidney disease.

Limitations: Most studies were conducted in high-income countries.

Conclusions: The priorities identified by kidney disease research priority-setting exercises are broad ranging, but patient involvement is uncommon and the processes often are incompletely described. Establishing research priorities using a prespecified and transparent process that engages patients, caregivers, and health care providers is needed to ensure that resources are invested to answer questions that address the shared priorities in kidney disease.

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INDEX WORDS: Chronic kidney disease (CKD); kidney disease; renal failure; dialysis; acute kidney injury (AKI); epidemiology and outcomes; research priorities; priority setting; research agenda; patient-centered research; funding body strategy.

Health and medical research is a colossal enterprise. In 2010, an estimated US $240 billion was expended on research on the life sciences, mostly biomedical.[1] Recently it has been suggested that 85% of this is wasted because of problems in the design, conduct, analysis, and reporting of research.[2,3] Mitigating such waste begins with ensuring that research is done in areas that are relevant to the users of research—clinicians, patients, and policy makers—and does not simply represent the specialized interest of researchers. This is especially important for publicly funded research, which is allocated with the intent to improve the health and well-being of populations. Although substantial funding for research is available, it is insufficient for the demand and thus some form of prioritization is inevitable. A recent analysis of funding in the United Kingdom suggests that currently ∼59% is spent on pure basic research; 27%, on pure applied

research; and 13%, on user-led basic research.[3] Although "novelty" and "creativity" have been believed to be important attributes in surviving the peer-review system, empirical evidence suggests the opposite and that peers tend to approve of research like their own rather than support truly novel thinkers.[3] Many approaches to research prioritization exist, but frequently approaches are not transparent.[4]

Recently, with the movement toward more patient-centered care, the mismatch between the research interests of patients and researchers has become more evident,[5-7] and the research agenda pursued by funders appears to be driven largely by health professionals, academics, and industry.[7-9] However, the past decade has seen a gradual turn of the tide, including the establishment of the James Lind Alliance (JLA) to facilitate partnerships involving patients, caregivers, and clinicians to identify and prioritize treatment uncertainties.[10-12] There are increasing efforts to identify shared research priorities using explicit processes, which have been done in cancer,[13] stroke,[14] diabetes,[15] and recently chronic kidney disease (CKD). Manns et al[16] (2014) applied the JLA process[12] to identify the top 10 research priorities for patients on or nearing dialysis therapy. The prioritized topics identified included communication among patients and providers, dialysis modality options, itching, access to kidney transplantation, heart health, dietary restrictions, depression, and vascular access. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) also recently sought wide-ranging input from scientists, clinicians, and lay people by online discussion and voting to identify research priorities to develop a "cohesive, integrated vision of future research opportunities to be pursued by the kidney research community and supported by the NIDDK."[17]

This study aims to evaluate approaches to research prioritization in kidney disease and describe the research priorities of all relevant stakeholders (patients with kidney disease, their caregivers, health care providers, and policy makers) involved in their care. Mapping current research priority setting in kidney disease can guide future priority-setting initiatives to achieve transparency and inclusivity and promote the conduct of research that is relevant, appropriate, and meaningful to patients with kidney disease and everyone involved in their care.

METHODS

Selection Criteria

Studies with an explicit aim to identify research priorities (eg, topics and question) and that elicited patients', health care providers', or policy makers' priorities for research in acute kidney injury (AKI) and CKD stages 1 to 5, 5D (dialysis), and 5T (transplantation) were included. Surveys and qualitative studies including consensus methods (Delphi technique and workshops)

were eligible. Studies assessing priorities for program delivery or policy (eg, organ allocation) were excluded, as were duplicate articles, epidemiologic studies, nonresearch articles (policy documents, clinical guidelines, editorials, commentaries, and conference or meeting reports with no information about participants and methods), grey literature, and articles not published in peer-reviewed journals. No language restrictions were applied.

Data Sources and Searches

Medical Subject Headings (MeSH) terms and text words for CKD and AKI were combined with text words for research priorities and research agenda (Table S1, available as online supplementary material). Searches were conducted in MEDLINE, EMBASE, PsycINFO, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) from inception to May 1, 2014. We also searched reference lists of relevant articles and reviews, Google Scholar, JLA, and PubMed. We screened titles and abstracts and deleted those that did not meet the inclusion criteria. Full texts of potentially relevant studies were obtained and assessed for eligibility.

Appraisal

Different approaches have been taken in health research priority setting and there is no single gold-standard methodology or process. However, principles of good practice have been proposed.[4] We appraised each study using the 2010 Viergever et al[4] checklist for health research priority setting. The checklist includes 9 domains of good practice for health research prioritization processes: context, use of a comprehensive approach, inclusiveness, information gathering, planning for implementation, criteria, methods for deciding priorities, evaluation, and transparency. The checklist is not designed to "judge" the level of quality among different prioritization methods (eg, expert panels, consensus conferences, and focus groups). Three reviewers (S.Ch., S.Cr., and A.T.) independently assessed each study. Any disagreements were resolved through discussion.

Synthesis

We conducted a descriptive synthesis to summarize and compare research priorities identified in the primary studies. Each article was imported into HyperRESEARCH, version 3.0.3 (ResearchWare Inc; 2009), software for managing and coding textual data. A.T. coded the research priorities reported in each paper. These were summarized descriptively according to the type/stage of kidney disease (AKI; CKD stages 1-5, 5D, and 5T; and nonspecified stage) and the standard classification of research questions/topics (etiology, diagnosis, primary prevention, secondary prevention, treatment, prognosis, health services, psychosocial and knowledge, and economic considerations).[18,19] To draw comparisons, the types/stages of kidney disease were mapped against the type of research question. S.Ch. and S.Cr. read the articles to ensure that all relevant data were extracted and coded into the appropriate categories.

RESULTS

Literature Search and Study Characteristics

We included 16 studies (Fig 1). Study characteristics are provided in Table 1. Five studies did not report the number of participants. The other 11 articles involved 2,635 participants in total. Only 4 (25%) studies reported patient and/or caregiver involvement in the priority-setting process.[16,17,20,21] Priority-setting methods included the Delphi technique, expert panels, consensus conference, ranking or voting surveys, focus groups, and interviews.