

## Advance Care Planning for Adults With CKD: A Systematic Integrative Review

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**Background:** Recent clinical practice guidelines have highlighted the importance of advance care planning (ACP) for improving end-of-life care for people with chronic kidney disease (CKD).

**Study Design:** We conducted a systematic integrative review of the literature to inform future ACP practice and research in CKD, searching electronic databases in April 2013. Synthesis used narrative methods.

**Setting & Population:** We focused on adults with a primary diagnosis of CKD in any setting.

**Selection Criteria for Studies:** We included studies of any design, quantitative or qualitative.

**Interventions:** ACP was defined as any formal means taken to ensure that health professionals and family members are aware of patients' wishes for care in the event they become too unwell to speak for themselves.

**Outcomes:** Measures of all kinds were considered of interest.

**Results:** 55 articles met criteria reporting on 51 discrete samples. All patient samples included people with CKD stage 5; 2 also included patients with stage 4. Seven interventions were tested; all were narrowly focused and none was evaluated by comparing wishes for end-of-life care with care received. One intervention demonstrated effects on patient and family outcomes in the form of improved well-being and anxiety following sessions with a peer mentor. Insights from qualitative studies that have not been used to inform interventions include the importance of instilling patient confidence that their advance directives will be enacted and discussing decisions about (dis) continuing dialysis therapy separately from "aggressive" life-sustaining treatments (eg, ventilation).

**Limitations:** Although quantitative and qualitative findings were integrated according to best practice, methods for this are in their infancy.

**Conclusions:** Research on ACP in patients with CKD is limited, especially intervention studies. Interventions in CKD should attend to barriers and facilitators at the levels of patient, caregiver, health professional, and system. Intervention studies should measure impact on compliance with patient wishes for end-of-life care.

*Am J Kidney Dis.* 63(5):761-770. © 2014 by the National Kidney Foundation, Inc.

**INDEX WORDS:** Chronic kidney disease (CKD); renal failure; advance care planning (ACP); advance directives; decision making; end-of-life (EOL) care; palliative care; patient-centered care; systematic integrative review.

### Editorial, p. 739

Chronic kidney disease (CKD) is a significant health problem internationally. Despite technological improvements, annual mortality rates for patients on dialysis therapy are consistently high: 10%-25% in both developed and emerging nations.<sup>1</sup> For older patients with multiple comorbid conditions, dialysis may not improve survival and may

be detrimental to quality of life.<sup>2</sup> The importance of supportive care for patients with end-stage kidney disease is increasingly recognized both for patients receiving dialysis and those who choose not to commence or to withdraw from dialysis therapy.<sup>3,4</sup>

Cognitive impairment is common in patients receiving long-term dialysis,<sup>4,5</sup> leaving families and nephrologists to decide whether and when to withdraw therapy after patients have lost capacity to decide for themselves. The emotional burden of family decision making and the poor concordance between

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Received July 21, 2013. Accepted in revised form December 17, 2013. Originally published online January 16, 2014.

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0272-6386/\$36.00

<http://dx.doi.org/10.1053/j.ajkd.2013.12.007>

surrogate decisions and patient preferences<sup>6</sup> raises concerns that some patients may remain on dialysis therapy for longer than they would have chosen. Some patients with end-stage kidney disease may also receive life-sustaining treatments (eg, cardiopulmonary resuscitation [CPR] and ventilation) that they would not have chosen.<sup>3</sup>

Advance care planning (ACP) refers to a process of reflection and discussion between a patient, his or her family and health care providers for the purpose of clarifying values, treatment preferences, and goals of end-of-life care.<sup>7</sup> It provides a formal means of ensuring that health care providers and family members are aware of patients' wishes for care if they become unable to speak for themselves.<sup>8,9</sup> ACP is a patient-centered initiative that promotes shared decision making and which may include the patient completing an advance directive that documents his or her wishes and/or the appointment of a substitute decision maker.

In general medical settings, ACP has been shown to increase patient and family satisfaction with care<sup>10,11</sup> and the likelihood that physicians and family members will understand and comply with patients' wishes for end-of-life care.<sup>10,12-14</sup> It also increases the likelihood of a person dying in his or her preferred place, increases hospice use,<sup>14,15</sup> reduces hospitalization,<sup>11,15</sup> leads to less "aggressive" medical care at end of life,<sup>14,16,17</sup> and contributes to lower stress, anxiety, and depression in surviving relatives.<sup>10,11,13,14</sup>

The importance of ACP for people with CKD, especially during the later stages, has been highlighted in recent literature and clinical practice guidelines.<sup>9,18-26</sup> We undertook a systematic integrative review of ACP in CKD in order to identify what interventions have been developed, piloted, and evaluated; identify which measures have been used in intervention and other studies; establish evidence for the efficacy of interventions; and inform understanding of barriers and facilitators to implementation, as well as stakeholders' perceptions of ideal approaches.

## METHODS

### Eligibility Criteria

We included articles published in peer-reviewed English-language journals reporting original research. Samples had to be of adults with a primary diagnosis of CKD and/or families and health professionals caring for this group. We excluded studies of children and adolescents because of the different implications for shared decision making. When samples included patients with other primary diagnoses, studies were included if >50% of the study group had CKD or results for this subgroup were provided separately. Articles were excluded when it was not possible to determine what percentage of the study group had CKD. Because studies of any design have the potential to inform clinical practice, we took an integrative approach that included research with qualitative, quantitative, or mixed methods.<sup>27</sup> Qualitative studies were defined as those attempting to make sense of phenomena in terms of the meanings people bring to them.<sup>28</sup> We limited our

search to peer-reviewed literature to ensure a minimum standard among methods of included studies. To further control quality, we excluded published conference abstracts and case studies and required articles reporting qualitative studies to provide an aim and at least one sample of raw data (eg, verbatim patient statements). Recent evidence suggests that limiting to English is unlikely to result in systematic bias.<sup>29</sup>

### Information Sources

The electronic databases MEDLINE, PsycINFO, Embase, AMED (Allied and Complementary Medicine Database), CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Sociological Abstracts were searched from their earliest records until April 29, 2013. We also hand searched the reference lists of included articles.

### Searches

The search strategy made use of Medical Subject Headings (MeSH) or equivalent and key words relating to CKD and ACP. Search terms for ACP were those developed by the Australian Palliative Care Knowledge Network, CareSearch ([www.caresearch.com.au](http://www.caresearch.com.au)).<sup>30</sup> See *Item S1* (provided as online supplementary material) for an example.

### Study Selection

Inclusion/exclusion was undertaken by a single reviewer after dual coding of 100 articles found agreement to be 99%.

### Data Collection and Items

Data were extracted by 1 of 2 reviewers using an electronic (Microsoft Excel 2010) pro forma specifying data items. Data items included study type (quantitative, qualitative, and mixed methods), country of origin, aims, research questions, setting, sample characteristics, and findings; for qualitative articles only: conceptual approach (eg, grounded theory) and method of data collection (eg, interviews); and for quantitative studies only: design (descriptive, analytic, and intervention), whether cross-sectional or longitudinal, and outcomes. Data items for interventions included their focus/purpose, theoretical derivation, delivery, intensity, and any information available about training and feasibility (eg, adherence).

### Risk of Bias

Risk of bias was assessed for only intervention studies according to criteria published by the Agency for Healthcare Research and Quality (AHRQ) US Preventive Services Task Force,<sup>31</sup> for which an overall rating of good, fair, or poor is allocated to each study (see *Box 1*). Each study was rated independently by 2 reviewers, who then met to reach consensus.

### Synthesis

With the exception of testing intervention efficacy, which used meta-analysis, synthesis took a narrative approach using techniques described by Popay and colleagues, namely tabulation, textual descriptions, grouping and clustering, transformation of data to construct a common rubric, vote counting, and translation of data through thematic and content analysis.<sup>32-34</sup>

#### Description of ACP-Related Measures

Extracted information regarding measures was tabulated to indicate frequency and range and the existence, or otherwise, of a standard set.

#### Efficacy of ACP

The efficacy of ACP interventions was synthesized by meta-analysis when studies met criteria described in the *Cochrane Handbook for Systematic Reviews of Interventions*.<sup>35</sup> Meta-analysis was conducted using Review Manager 5 software (The

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