AJKD
Original Investigation

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.

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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.[1] For older patients with multiple comorbid conditions, dialysis may not improve survival and may be detrimental to quality of life.[2] 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.[3,4]

Cognitive impairment is common in patients receiving long-term dialysis,[4,5] 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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surrogate decisions and patient preferences[6] 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.[3]

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.[7] 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.[8,9] 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[10,11] and the likelihood that physicians and family members will understand and comply with patients' wishes for end-of-life care.[10,12-14] It also increases the likelihood of a person dying in his or her preferred place, increases hospice use,[14,15] reduces hospitalization,[11,15] leads to less "aggressive" medical care at end of life,[14,16,17] and contributes to lower stress, anxiety, and depression in surviving relatives.[10,11,13,14]

The importance of ACP for people with CKD, especially during the later stages, has been highlighted in recent literature and clinical practice guidelines.[9,18-26] 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.[27] Qualitative studies were defined as those attempting to make sense of phenomena in terms of the meanings people bring to them.[28] 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.[29]

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).[30] 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,[31] 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.[32-34]

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.*[35] Meta-analysis was conducted using Review Manager 5 software (The

Box 1. Criteria Specified for Ratings of Good, Fair and Poor Quality for RCTs and Cohort Studies by the AHRQ US Preventive Services Task Force Procedure Manual

Criteria

- Initial assembly of comparable groups:
  - ◇ For RCTs: adequate randomization, including first concealment and whether potential confounders were distributed equally among groups
  - ◇ For cohort studies: consideration of potential confounders with either restriction or measurement for adjustment in the analysis; consideration of inception cohorts
- Maintenance of comparable groups (includes attrition, crossovers, adherence, contamination)
- Important differential loss to follow-up or overall high loss to follow-up
- Measurements: equal, reliable, and valid (includes masking of outcome assessment)
- Clear definition of interventions
- All important outcomes considered
- Analysis: adjustment for potential confounders for cohort studies, or intention-to-treat analysis for RCTs

Good

Meets all criteria: comparable groups are assembled initially and maintained throughout the study (follow-up at least 80%); reliable and valid measurement instruments are used and applied equally to the groups; interventions are spelled out clearly; all important outcomes are considered; and appropriate attention to confounders in analysis. In addition, for RCTs, intention-to-treat analysis is used.

Fair

Studies will be graded "fair" if any or all of the following problems occur, without the fatal flaws noted in the "poor" category below: Generally comparable groups are assembled initially but some question remains whether some (although not major) differences occurred with follow-up; measurement instruments are acceptable (although not the best) and generally applied equally; some but not all important outcomes are considered; and some but not all potential confounders are accounted for. Intention-to-treat analysis is done for RCTs.

Poor

Studies will be graded "poor" if any of the following fatal flaws exists: groups assembled initially are not close to being comparable or maintained throughout the study; unreliable or invalid measurement instruments are used or not applied at all equally among groups (including not masking outcome assessment); and key confounders are given little or no attention. For RCTs, intention-to-treat analysis is lacking.

Source: AHRQ.[31]

Abbreviations: AHRQ, Agency for Healthcare Research and Quality; RCT, randomized controlled trial.

Nordic Cochrane Centre, The Cochrane Collaboration) and a random-effects model to control for heterogeneity among samples and methods. When studies did not meet criteria for meta-analysis, a narrative approach to synthesis was undertaken.[32-34]

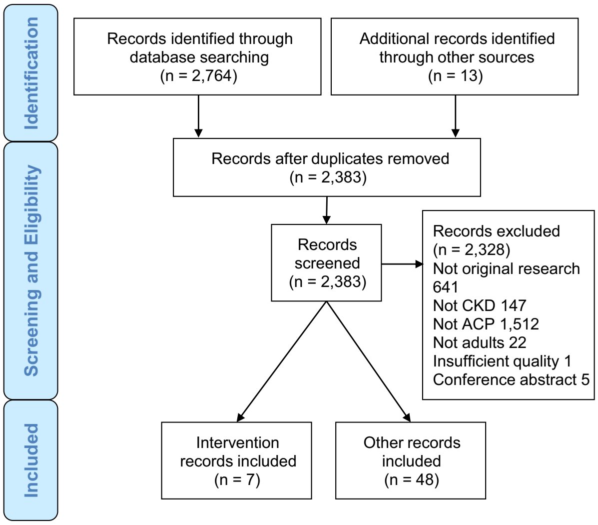

Figure 1. Flow chart of review selection process. Abbreviations: ACP, advance care planning; CKD, chronic kidney disease.

Implementation Considerations and Stakeholders' Perceptions

Analysis of barriers and facilitators to implementation used the multilevel approach[36] recommended by the *Cochrane Handbook*[37] when qualitative and quantitative evidence is compared, guided by 3 questions: (1) Which interventions match recommendations derived from patient/family/health professional views and experiences? (2) Which recommendations have yet to be tried in soundly evaluated interventions? (3) Have interventions that match recommendations demonstrated higher efficacy (and in the case of meta-analyses, does following vs not following these recommendations explain heterogeneity)?

Comparative analyses were summarized in matrices identifying the number of good-quality and other intervention studies that met each recommendation. This was intended to give a clear indication of gaps in the literature and further inform understanding of efficacy.

Recommendations used to populate the matrix were generated by thematic synthesis.[32-34] Synthesis focused on information relevant to ACP only. Themes were generated independently by 2 reviewers, who then met to reach consensus.

RESULTS

Study Selection

Of 2,764 results returned by database searches, 42 articles met inclusion criteria. A further 13 relevant articles were identified by hand searching, providing a total of 55 articles reporting on studies with 51 discrete samples.[38-93] See Fig 1 for a summary of inclusion and exclusion.

Study Characteristics

A summary of study characteristics is presented in Table 1. All patient samples included people with CKD stage 5 (also described as end-stage kidney disease), and 2 with CKD stage 4.

More detailed information about the design, samples, and interventions reported in intervention, descriptive, and qualitative studies is provided in Tables S1, S2, and S3, respectively.

Table 1. Summary of 51 Studies on ACP in CKD Identified Through Systematic Searches

Characteristic	No. (%)
Country	
United States	35 (69)
Other	16 (31)
Type	
Quantitative[a]	
Intervention	8 (15)
Descriptive	40 (74)
Qualitative	6 (11)
Sample[b]	
Patient	
CKD stage 5[c]	42 (82)
CKD mixed stages 4-5	2 (18)
Family/caregiver	6 (10)
Provider	11 (18)
Setting	
Inpatient	5 (10)
Outpatient	24 (47)
Various	22 (43)
ACP intervention	
Format	
Training	4 (50)
Information	2 (25)
Advance directive	2 (25)
Delivery	
1 on 1	4 (44)
Group	1 (11)
Materials only	4 (44)

Note: "Study" is used here to refer to research conducted with discrete samples; more than one study may be reported in one article and more than one article may report on the same study.

Abbreviations: ACP, advance care planning; CKD, chronic kidney disease.

[a] One evaluation and one descriptive analysis focused on the same sample.

[b] Seven studies included samples from more than one group.

[c] End-stage kidney disease.

Risk of Bias Within Studies

Of 8 intervention studies identified, 4 were randomized controlled trials,[60,73,75,89] 2 used a pre-post design,[54,92] and 2 reported post data without comparison.[54,77] Rating of bias identified 6 of these studies as poor quality[54,60,73,77,92] and 2 as fair[75,89]; both fair-quality studies used randomized allocation. Studies rated poor either omitted to control for dropout and confounders or included no statistical analyses.

Synthesis of Results

Description of ACP Interventions

Altogether, 7 ACP interventions were evaluated in 8 studies.[54,60,73,75,77,89,92] One article reported on 2 interventions evaluated in separate studies,[54] whereas another intervention was assessed at both pilot and evaluative phases by Song et al[73,75] (2009, 2010). Details of the interventions are provided in Table S4.

Interventions aimed to educate nurses about discussing end-of-life care,[54] facilitate documentation of preferences for end-of-life care in advance directives,[60,77,89] enhance communication between patients and their surrogate decision makers about end-of-life care and preferences,[73,75] introduce the topic of advance directives to patients and assist them in expressing their resuscitation preferences,[77] or deliver ACP as a component of a larger palliative care intervention.[92]

Only the intervention assessed by Song et al[73,75] was explicitly theory based, namely a representational approach based on models of "common sense" and "conceptual change."[94] Both studies evaluated a 1-hour ACP education and interview session administered by nurse facilitators. The only difference in the intervention between the pilot and evaluative phases was the intensiveness with which facilitators were trained (2.5[73] vs 3.5[75] days).

Three of the interventions were delivered by health care providers[54,73,75,92]; 1 by trained patient mentors[60]; 2 by printed materials[77,89]; and 2 by video (1 for nurses and 1 for peer facilitators).[54,60] The interventions delivered by health care providers were a single education and interview session,[73,75] an education program over an undefined number of sessions,[54] and a needs-based palliative care consultation.[92] The peer-mentor ACP intervention was administered over 5 telephone calls and 3 face-to-face meetings with support from video,[60] whereas interventions delivered by printed materials[77,89] and video for nurses were administered as one-off only.[54]

Description of ACP-Related Measures

In 45 quantitative studies, 110 measures were used, most commonly relating to patient and/or family preferences, attitudes and knowledge, and advance directive completion rates (Table 2). Articles also commonly reported analyses examining sociodemographic and clinical variables predicting these measures. Five of the 8 intervention studies measured intervention acceptability.[54,77,89,92] No study assessed compliance with patient wishes at end of life, family members' satisfaction with patients' end-of-life care, or the effect on the well-being of bereaved family members.

Efficacy of ACP

Patient or family well-being, anxiety, or quality of life. Only the studies by Song et al[73,75] (2009, 2010) met criteria for meta-analysis stipulated by the *Cochrane Handbook for Systematic Reviews of Interventions*,[35] and 2 was considered too small a number for meta-analysis to be conducted. Neither

Table 2. Measures Used in Quantitative Studies of ACP for Adults With Chronic Kidney Disease

Measure	Studies (n = 55)	Measures (n = 110)
Knowledge		
EoL medical interventions	5 (11)	5 (5)
ACP	3 (7)	3 (3)
Preferences		
Decision maker at EoL	7 (16)	7 (6)
EoL medical interventions	12 (27)	12 (11)
Information needs	4 (9)	4 (4)
Attitudes		
EoL medical interventions	4 (9)	4 (4)
Information and promotional material	4 (9)	4 (4)
Usefulness of advanced directives	5 (11)	5 (5)
Impact on quality of relationships	2 (4)	2 (2)
Level of comfort with EoL decision making	7 (16)	7 (6)
Completion and documentation of advance directives	18 (40)	18 (16)
Demographic factors predicting preferences, attitudes toward advance directives or EoL medical interventions	14 (31)	14 (13)
Communication		
Amount of communication between patient, family, and physician	6 (13)	6 (6)
Desire to discuss advanced directives	2 (4)	2 (2)
Patient-surrogate congruence in EoL care preferences	6 (13)	6 (6)
EoL care received	8 (18)	8 (7)
Patient/family well-being or coping	5 (11)	5 (5)

Note: Values are given as number (percentage).
Abbreviations: ACP, advance care planning; EoL, end-of-life.

study found a significant effect on well-being for either patients or surrogates.

Only the study by Perry et al[60] (2005) found a significant effect on any of these outcomes, with African Americans participating in peer-mentor–facilitated ACP sessions showing greater improvement on subjective well-being and anxiety compared with their usual-care counterparts.

Weisbord et al[92] (2003) found no significant effect on symptoms or quality of life from a palliative care intervention that included ACP alongside symptom management.

Patient/surrogate decisional conflict, confidence, and congruence. The 2 studies by Song et al[73,75] (2009, 2010) measured all these outcomes. Neither study found a significant effect for decisional conflict. In both studies, Song et al[73,75] found an effect for concordance between patient wishes and surrogate knowledge of those wishes over time. In the 2009 study, there also was an increase in surrogate confidence in decision making compared to baseline.

Tigert et al[77] (2005) found that 70% of patients were prepared to state their CPR preferences after reading a pamphlet used to introduce the topic of advance directives to patients with end-stage kidney disease and their surrogate decision makers.

Patient-clinician communication and interaction. The 2 Song et al[73,75] studies found a significant effect on both patient-clinician communication and interaction.

Health provider ACP competence and confidence. After "several" teaching sessions, Hopkins et al[54] (2011) reported moderate improvement in nurses' self-reported knowledge about refusal to initiate dialysis therapy, confidence in initiating end-of-life discussions with patients, and familiarity with end-of-life resources; however, there was no control group. The same authors also reported improvements from an educational video describing methods to engage in end-of-life care planning, with 44% of nurse participants reporting greater confidence in initiating and pursuing end-of-life discussions after watching the video.

Completion of advance directives. Three studies examined how ACP interventions influenced documentation completion by patients and surrogates.[60,89,92] Only the peer-mentor–facilitated ACP sessions tested by Perry et al[60] (2005) increased advance directive completion compared to usual care; advance directive completion rates also were significantly higher than for ACP materials presented without facilitation.

Acceptability of ACP interventions. Results for acceptability of ACP interventions varied across different interventions and measures,[54,77,89,92] but generally were positive. Sixty-eight percent of patients and 76% of nephrologists rated the palliative care intervention worthwhile,[92] 70% of patients found an advance directive pamphlet helpful,[77] and 93% of nurses found an educational video somewhat or very useful.[54] Acceptability for 3 alternative advance directives evaluated by Singer et al[89] (1995) varied from 60%-70%.

Implementation Considerations and Stakeholders' Perceptions

Findings from 6 qualitative studies informed how to carry out ACP in adults with CKD.[40,41,45,48,55,72] See Table 3 for a matrix of recommendations developed by synthesis of results from these studies and cross-tabulation with the intervention studies.

DISCUSSION

To our knowledge, this is the first systematic review to focus exclusively on studies concerned with ACP in CKD. It shows that studies to date have been mostly descriptive, exploring patient and family

Table 3. Implementation of Recommendations From Qualitative Research in ACP Interventions for People With Chronic Kidney Disease

Recommendation From Qualitative Studies	Interventions Addressing the Recommendations
Patients should be seen as individuals in world view and preferences, and appropriate timing of ACP	Perry[60] (2005), Song[73,75] (2009, 2010), Weisbord[92] (2003)
Emphasis should be on patients being autonomous/taking control and "getting things settled"; taking care of family (eg, avoiding burdening them with decision making is a strong motivator)	Perry[60] (2005), Song[73,75] (2009, 2010)
Medical team should initiate ACP, give information and advice (rather than make decisions), be empathetic and affirm preferences	Hopkins[54] (2011), Tigert[77] (2005)
Patients should be helped to acknowledge and accept their limited prognosis	Perry[60] (2005), Song[73,75] (2009, 2010)
Discussion of poor prognosis should be balanced by hope	Perry[60] (2005), Song[73,75] (2009, 2010)
Efforts should be made to improve patient health care knowledge and literacy	Song[73,75] (2009, 2010)
Families should be involved in ACP, acknowledging that family relationships, viewpoints, and perceptions of trust have both positive and negative potentials	Surrogates only
Patients should be made to feel confident that their advance directives will be enacted	None
Financial factors should be considered when discussing treatments	None
Patients should be exposed to others' positive experiences and viewpoints on ACP, including its social desirability	Perry[60] (2005)
ACP should be framed as a process of reflection rather than a "cold form"	Perry[60] (2005), Song[73,75] (2009, 2010)
Decisions about continuing dialysis should not be grouped with those regarding aggressive life-sustaining treatments (eg, CPR, ventilation); patients may perceive these intervention types very differently	None

Abbreviations: ACP, advance care planning; CPR, cardiopulmonary resuscitation.

preferences and attitudes toward ACP and medical interventions at the end of life. The focal nature of decisions surrounding withdrawal of dialysis therapy suggests that a disease-specific approach to ACP is warranted for people with CKD. However, a diversity of approaches and measures and paucity of controlled studies mean that it is not yet possible to draw conclusions about the most effective ways to conduct ACP for patients in this group.

The few interventions trialed to date have each focused on a single aspect of ACP, such as nurse education, patient information, advance directive completion, or patient/surrogate congruence. No intervention that met our inclusion criteria took a comprehensive approach to ACP that included attention to patient-, caregiver-, health professional–, and system-related factors. A "whole-system" approach to ACP has been shown to be effective in improving outcomes for patients and their surviving relatives in other settings[10] and may be similarly beneficial for patients with kidney disease. A study reported by Kirchoff et al[95,96] (2010, 2012) examined the effect of a comprehensive ACP intervention, but could not be included because patients with CKD constituted only a minority (42%) of the sample, which was made up predominantly of patients with congestive heart failure.

The second weakness identified by this systematic review is that intervention studies have used only a limited variety of measures. No study measured compliance with patient wishes for end-of-life care, arguably the most important outcome of ACP. The study by Kirchoff et al[96] found a nonsignificant trend toward influencing this outcome, but was not appropriately powered. Complex interventions such as ACP also benefit from measurement models that link processes to outcomes so that mechanisms of effect can be understood and replicated or adapted in the future.[97] This approach was lacking in the intervention studies we found.

Only one ACP intervention has demonstrated effects on patient or family outcomes, namely improved subjective well-being and reduced anxiety following repeated peer-mentor–facilitated sessions.[60] This and 3 other interventions have demonstrated impacts on process measures, including patient-clinician interaction and communication,[73,75] patient-surrogate congruence in end-of-life care preferences,[73,75] surrogate confidence,[75] nurse confidence,[54] and completion of advance directives.[60] Although the last item was the most commonly used measure in the studies reviewed, it is important to note that completion of advance directives in isolation may not always influence care received at the end of life.[98] Evidence for effects on nurse confidence is limited by poor study design and the absence of statistical analysis.[60] Results on intervention acceptability are difficult to interpret because each study used a different measure, and only one has provided comparative data.[54,77,89,92] None of the intervention studies looked at the effect of ACP on outcomes for bereaved family members.

In line with findings from other patient populations,[99] this review found evidence for poor congruence between surrogate decision maker and patient preferences concerning end-of-life care decisions such as discontinuation of dialysis therapy.[49,56,64,84] Descriptive studies show that surrogates are influenced by a combination of factors external to their perception of patient preferences or best interests when making medical treatment decisions, such as their own treatment preferences and perceptions of what most people would choose in the same circumstances.[56,64] The nurse-facilitated ACP intervention studied by Song et al[73] (2010) improved concordance between patient wishes and surrogate knowledge of those wishes, but the intervention group still showed a strong preference for life-sustaining treatments at the end of life. It should be noted that this intervention was focused on African Americans, who tend to show stronger preferences for life-sustaining treatments at the end of life compared with other groups.[100] More studies are needed that link concordance with measures of how decisions are informed by knowledge of end-of-life interventions across different patient populations.

Surprisingly, there are no studies examining ACP for patients with CKD who are considering or have chosen a conservative (ie, nondialytic) approach to care.[101] This is despite an emphasis in clinical practice guidelines that ACP should be available to all patients with CKD.[26] This gap has been acknowledged by the US Kidney End-of-Life Coalition, which provides online information for patients and health professionals on ACP and palliative care, including resources on choosing not to start or to withdraw from dialysis therapy.[102]

Future ACP interventions are especially encouraged to incorporate the following strategies recommended by qualitative research: acknowledgement of the role that family can play, both positively and negatively, in ACP; reassurance to patients that their end-of-life wishes will be respected as a motivator for undertaking ACP; and distinguishing between decisions about dialysis therapy withdrawal from choices about other life-sustaining treatments such as CPR and ventilation. The latter is particularly of interest because of results from a descriptive study suggesting that withdrawal from dialysis therapy may be discussed less often than decisions about CPR and ventilation,[50] emphasising the need for a CKD-specific approach to ACP.

Qualitative studies have further highlighted the following important considerations for ACP in CKD: the individuality of preferences for ACP and end-of-life care, the optimal timing for the ACP intervention (balancing the imperative to raise ACP early because of risk of cognitive decline with sensitivity to patient and family readiness), and respecting patients' wishes not to discuss the topic if they prefer. One study found that $<10\%$ of patients with CKD had discussed end-of-life care with health professionals, suggesting that more patients need to be given this opportunity.[46] A qualitative study found that patients with end-stage kidney disease tended to wait for health professionals to raise ACP rather than raise it themselves,[48] whereas another found that nephrologists discussed end-of-life issues based on prognosis, but struggled to identify a suitable juncture.[103] Without appropriately sensitive communication about prognosis, patients on dialysis therapy may dramatically overestimate their life expectancy.[104] A further study found that nurses were uncomfortable raising the issue of ACP for fear of upsetting patients, eliciting anger from families, and being denigrated by senior staff.[61] More research is needed on identifying and implementing facilitators to ACP at a systems level in nephrology clinics, educating staff on the benefits of early ACP, and ensuring that staff have authorization and time for ACP as "core business."[26] Assuming it can be validated, the tool for measuring readiness to discuss ACP in patients with CKD reported by Calvin and Eriksen[42] (2006) also may be useful for both clinical and research purposes.

Our findings are limited by the number and quality of studies identified. Meta-analysis was not possible, requiring us to take a narrative approach to synthesis of quantitative studies. Our results also are limited by the methods of the review. Data were extracted by only one author by an electronic pro forma intended to limit bias. Review processes requiring subjective judgment to be made (eg, quality rating) were carried out by 2 researchers working independently. Although we followed best-practice recommendations for integrating quantitative and qualitative findings,[37] approaches to mixed methods remain in their infancy in both primary studies and reviews. Finally, a lack of detailed descriptions of interventions and process and outcome measures prevented more detailed analysis.[105]

In conclusion, the present review found that most research on ACP in CKD to date has been descriptive and has focused on people who have chosen to pursue dialysis rather than conservative management.

Unlike ACP interventions found successful in other patient groups, interventions in CKD have not paid attention to barriers and facilitators at the levels of patient, caregiver, health professional, and system. Future intervention studies should measure impact on compliance with patient wishes for end-of-life care.

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SUPPLEMENTARY MATERIAL

Table S1: Studies evaluating ACP for patients with CKD.

Table S2: Descriptive studies of ACP by patients with CKD.

Table S3: Characteristics and findings of 6 qualitative studies exploring ACP in CKD.

Table S4: Details of ACP interventions evaluated in patients with CKD.

Item S1: Search strategy used for searching MEDLINE.

Note: The supplementary material accompanying this article (http://dx.doi.org/10.1053/j.ajkd.2013.12.007) is available at www.ajkd.org

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