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Title page

Title:

Advance care planning for adults with chronic kidney disease: A systematic integrative review.

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Abstract

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 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 to be of interest.

Results

Fifty-five articles met criteria reporting on 51 discrete samples. All patient samples included people with Stage 5 CKD; two 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/family outcomes in the form of improved wellbeing and anxiety following sessions with a peer

mentor. Insights from qualitative studies that have not been emphasised in interventions include the importance of instilling patient confidence that their advance directives will be enacted and discussing decisions about (dis)continuing dialysis separately from ‘aggressive’ life-sustaining treatments (e.g. ventilation).

Limitations

Whilst 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 regarding 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.

Index words

Chronic kidney disease, Renal failure, Advance care planning, Advance directives, Decision-making

Manuscript

Background

Chronic kidney disease (CKD) is a significant health problem internationally. Despite technological improvements, annual mortality rates for patients on dialysis are consistently high - 10% to 25% in both developed and emerging nations¹. For older patients with multiple comorbidities, dialysis may not improve survival and may be detrimental to quality of life (QOL)². The importance of supportive care for patients with end-stage kidney disease (ESKD) is increasingly recognized both for patients receiving dialysis and those who choose not to commence or to withdraw from dialysis^{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 dialysis after patients have lost capacity to decide for themselves. The emotional burden of family decision-making, and the poor concordance between surrogate decisions and patient preferences⁶, raises concerns that some patients may remain on dialysis for longer than they would have chosen. Some ESKD patients may also receive life-sustaining treatments (e.g. cardiopulmonary resuscitation [CPR], ventilation) that they would not have wanted if they could have chosen³.

Advance care planning (ACP) refers to a process of reflection, and discussion between a patient, their family and healthcare providers for the purpose of clarifying values, treatment preferences and goals of end-of-life (EOL) care⁷. ACP provides a formal means of ensuring healthcare 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-centred initiative that promotes shared decision-making, which may include the patient completing an advance directive (AD) that documents their 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 doctors and family members will understand and comply with patients' wishes for EOL care^{10,12-14}. It also increases the likelihood of a person dying in their preferred place, increases hospice use^{14,15}, reduces hospitalisation^{11,15}, leads to less 'aggressive' medical care at EOL^{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 has been highlighted in recent literature and clinical practice guidelines, especially during the later stages^{9,18-26}. We undertook a systematic integrative review of ACP in CKD in order to:

1. Identify what interventions have been developed, piloted and evaluated;
2. Identify which measures have been used in intervention and other studies ;
3. Establish evidence for the efficacy of interventions;
4. 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 adults with a primary diagnosis of CKD and/or families and the health professionals caring for this group. We excluded studies on children and adolescents because of the different implications for shared decision-making with families. Where samples included patients with other primary diagnoses, studies were included if >50% of the study group had CKD or where results for this sub-group were provided separately. Articles were excluded where it was not possible to determine what percentage of the study group had CKD. Because studies of any design have potential to inform clinical practice, we took an integrative approach that included research with qualitative, quantitative or mixed methods²⁷. Qualitative studies were defined as those attempting to make sense of phenomena in terms of the meanings people bring to them²⁸. 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 (e.g. verbatim patient statements). . Recent evidence suggests that limiting to English is unlikely to result in systematic bias²⁹.

Information sources

The electronic databases Medline, PsycINFO, Embase, AMED, CINAHL and Sociological Abstracts were searched from their earliest records until 29th April 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 keywords relating to CKD and ACP. Search terms for ACP were those developed by the Australian Palliative Care Knowledge Network, *CareSearch*³⁰. See Box 1 (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 one of two reviewers using an electronic (Microsoft Excel 2010) proforma specifying data items. Data items included study type (quantitative, qualitative, mixed methods), country of origin, aims, research questions, setting, sample characteristics and findings; for qualitative articles only: conceptual approach (e.g. grounded theory) and method of data collection (e.g. interviews); and for quantitative studies only: design (descriptive, analytic, 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 (e.g. adherence).

Risk of bias

Integrative reviews require multiple tools to assess study quality. Risk of bias was assessed only for intervention studies according to criteria published by the Agency for Healthcare Research and Quality (AHRQ) US Preventive Services Task Force³¹ where an overall rating of ‘good’, ‘fair’ or ‘poor’ is allocated to each study (see Table 1). Each study was rated independently by two reviewers who then met to reach consensus.

Table 1 about here

Synthesis

With the exception of testing intervention efficacy (Objective 3), 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 analysis³²⁻³⁴.

Objective 2 – 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.

Objective 3 – Efficacy of ACP

The efficacy of ACP interventions was synthesised by meta-analysis where studies met criteria described in the *Cochrane Handbook of Systematic Reviews*³⁵. Meta-analysis was conducted using Review Manager 5 software and a random effects model to control for heterogeneity among samples and methods. Where studies did not meet criteria for meta-analysis, a narrative approach to synthesis was undertaken³²⁻³⁴.

Objective 4 – Barriers and facilitators and stakeholder’s perceptions of ideal ACP

Analysis of barriers and facilitators used the ‘multilevel’ approach³⁶ recommended by the *Cochrane Handbook of Systematic Reviews*³⁷, where qualitative and quantitative evidence is compared, guided by three 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 those interventions that match recommendations demonstrated higher efficacy (and, in the case of meta-analyses, does following, versus not following, these recommendations explain heterogeneity)?

Comparative analyses were summarised 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 via thematic synthesis³²⁻³⁴. Synthesis focused on information relevant to ACP only. Themes were independently generated by two 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 via hand searching, providing a total of 55 articles reporting on studies with 51 discrete samples³⁸⁻⁹³. See Figure 1 for a summary of inclusion/exclusion.

Figure 1 about here

Study characteristics

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

Table 2 about here

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

Risk of bias within studies

Of eight intervention studies identified, four were randomised controlled trials (RCTs)^{60,73,75,89}, two used a pre/post design^{54,92} and two reported post data without comparison^{54,77}. Rating of bias identified six of these studies as poor quality^{54,60,73,77,92} and two as fair^{75,89}; both fair quality studies used randomised allocation. Studies rated poor either omitted to control for drop-out and confounders or included no statistical analyses.

Synthesis of results

Objective 1 – Description of ACP interventions

Altogether, seven ACP interventions were evaluated in eight studies^{54,60,73,75,77,89,92}. One article reported on two interventions evaluated in separate studies⁵⁴, while another intervention was assessed at both pilot and evaluative phases by Song and colleagues (2009, 2010)^{73,75}. Details of the interventions are provided in Supplementary Table S4.

Interventions aimed to: educate nurses about discussing EOL care⁵⁴, facilitate documentation of preferences for EOL care in ADs^{60,77,89}, enhance communication between patients and their surrogate decision-makers about EOL care and preferences^{73,75}, introduce the topic of ADs to patients and assist them in expressing their resuscitation preferences⁷⁷, or deliver ACP as a component of a larger palliative care intervention⁹².

Only the intervention assessed by Song et al was explicitly theory-based^{73,75}, 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 pilot and evaluative phases was the intensiveness with which facilitators were trained (2.5⁷³ versus 3.5⁷⁵ days).

Three of the interventions were delivered by health care providers^{54,73,75,92}, one by trained patient mentors⁶⁰, two via printed materials^{77,89}, and two via video (one for nurses, the other for peer facilitators)^{54,60}. The interventions delivered by healthcare providers were a single education and interview session^{73,75}, an education program over an undefined number of sessions⁵⁴, and a needs-based palliative care consultation⁹². The peer-mentor ACP intervention was administered over five telephone calls and three face-to-face meetings with support from video⁶⁰, while interventions delivered via printed materials^{77,89} and video for nurses were administered as one-off only⁵⁴.

Objective 2 – 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 AD completion rates (see Table 3). Articles also commonly reported analyses examining socio-demographic and clinical variables predicting these measures. . Five of the eight intervention studies measured intervention acceptability^{54,77,89,92}. No studies assessed compliance with patient wishes at EOL, family

members' satisfaction with the patients' EOL care, nor the effect on the well-being of bereaved family members.

Table 3 about here

Objective 3 – Efficacy of ACP

Patient or family well-being, anxiety, or quality of life: Only the studies by Song and colleagues (2009, 2010)^{73,75} met criteria for meta-analysis stipulated by the *Cochrane Handbook of Systematic Reviews*³⁵, and two was considered too small a number for meta-analysis to be conducted. Neither study found a significant effect on wellbeing for either patients or surrogates.

Only the study by Perry et al (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 wellbeing and anxiety compared to their usual care counterparts⁶⁰.

Weisbord et al (2003) found no significant effect on symptoms or QOL from a palliative care intervention that included ACP alongside symptom management⁹².

Patient/surrogate decisional conflict, confidence and congruence: The two studies by Song and colleagues (2009, 2010) measured all these outcomes^{73,75}. Neither study found a significant effect for decisional conflict. In both studies, Song found an effect for concordance between patient wishes and surrogate knowledge of those wishes over time. In the 2009 study, there was also a rise in surrogate confidence in decision-making compared to baseline.

Tigert et al (2005) found that 70% of patients were prepared to state their CPR preferences after reading a pamphlet used to introduce the topic of ADs to ESKD patients and their surrogate decision-makers⁷⁷.

Patient-clinician communication and interaction: The two Song et al studies found a significant effect on both patient-clinician communication and interaction^{73,75}.

Health provider ACP competence and confidence: Following “several” teaching sessions, Hopkins et al (2011) reported moderate improvement in nurses’ self-reported knowledge about refusal to initiate dialysis, confidence in initiating EOL discussions with patients and familiarity with EOL resources; however, there was no control group⁵⁴. The same authors also reported improvements from an educational video describing methods to engage in EOL care planning, with 44% of nurse participants reporting greater confidence in initiating and pursuing EOL discussions after watching the video.

Completion of advance directives: Three studies examined how ACP interventions influenced documentation completion by patient and surrogate^{60,89,92}. Only the peer-mentor-facilitated ACP sessions tested by Perry et al (2005) increased AD completion compared to usual care; AD completion rates were also significantly higher than for ACP materials presented without facilitation⁶⁰.

Acceptability of ACP interventions: Results for acceptability of ACP interventions varied across different interventions and measures^{54,77,89,92}, but were generally positive. Sixty eight percent of patients and 76% of nephrologists rated the palliative care intervention worthwhile⁹², 70% of patients found an AD pamphlet helpful⁷⁷, and 93% of nurses found an educational video somewhat or very useful⁵⁴. Acceptability for three alternative ADs evaluated by Singer et al (1995) varied between 60% and 70%⁸⁹.

Objective 4 – Barriers and facilitators and stakeholder’s perceptions of ideal ACP

Findings in six qualitative studies informed how to do ACP in adults with CKD^{40,41,45,48,55,72}. See Table 4 for a matrix of recommendations developed via synthesis of results from these studies and cross-tabulation with the intervention studies.

Table 4 about here

Discussion

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 preferences and attitudes towards ACP and medical interventions at the EOL. The focal nature of decisions surrounding withdrawal of dialysis suggests a disease-specific approach

to ACP is warranted for people with CKD. A diversity of approaches and measures and paucity of controlled studies, however, 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 trialled to date have each focused on a single aspect of ACP such as nurse education, patient information, AD 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 settings¹⁰, and may be similarly beneficial for renal patients. A study reported by Kirchoff and colleagues (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 predominantly made up of patients with congestive heart failure^{95,96}.

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 EOL care, arguably the most important outcome of ACP. The study by Kirchoff and colleagues found a non-significant trend towards influencing this outcome but was not appropriately powered⁹⁶. Complex interventions like ACP also benefit from measurement models that link processes to outcomes so that mechanisms of effect can be understood and replicated or adapted in future⁹⁷. 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 wellbeing and reduced anxiety following repeated peer mentor facilitated sessions⁶⁰. This and three other interventions have demonstrated impacts on process measures, including patient-clinician interaction and communication^{73,75}, patient-surrogate congruence in EOL care preferences^{73,75}, surrogate confidence⁷⁵, nurse confidence⁵⁴, and completion of ADs⁶⁰. Whilst the latter was the most commonly used measure in the studies reviewed, it is important to note that completion of ADs in isolation may not always influence care received at the EOL⁹⁸. Evidence for effects on nurse confidence is limited by poor study design and the absence of statistical analysis⁶⁰. 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 populations⁹⁹, this review found evidence for poor congruence between surrogate decision maker and patient preferences concerning EOL care decisions such as discontinuation of dialysis^{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. (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 EOL⁷³. It should be noted that this intervention was focused on African-Americans who tend to show stronger preferences for life-sustaining treatments at the EOL compared to other groups¹⁰⁰. More studies are needed that link concordance with measures of how decisions are informed by knowledge of EOL interventions across different patient populations.

Surprisingly, there are no studies examining ACP for CKD patients who are considering or have chosen a conservative/non-dialytic approach to care¹⁰¹. This is despite an emphasis in clinical practice guidelines that ACP should be available to all patients with CKD²⁶. 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 withdraw from dialysis¹⁰².

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 EOL wishes will be respected as a motivator for undertaking ACP; and distinguishing between decisions about dialysis 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 may be discussed less often than decisions about CPR and ventilation⁵⁰, 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 EOL 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), respecting patients' wishes not to discuss the topic if they prefer. One study found that less than 10% of CKD patients had discussed EOL care with health professionals, suggesting that more patients need to be given this opportunity⁴⁶. A qualitative study found that ESKD patients tended to wait for health professionals to raise ACP rather than raise it themselves⁴⁸, while another found that nephrologists discussed EOL issues based on prognosis but struggled to identify a suitable juncture¹⁰³. Without appropriately sensitive communication about prognosis, patients on dialysis may dramatically over-estimate their life expectancy¹⁰⁴. A further study found that nurses felt uncomfortable raising ACP for fear of upsetting patients, eliciting anger from families, and being denigrated by senior staff⁶¹. More research is needed on identifying and implementing facilitators to ACP at a systems level in nephrology clinics, to educate staff on the benefits of early ACP, and ensuring that staff have authorisation 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 (2006) may also be useful for both clinical and research purposes⁴².

Limitations

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 are also limited by the methods of the review. Data were extracted by only one author via an electronic proforma intended to limit bias. Review processes requiring subjective judgement to be made (e.g. quality rating) was carried out by two researchers working independently. Whilst we followed best-practice recommendations for integrating quantitative and qualitative findings³⁷, approaches to mixed methods remain in their infancy both in primary studies and reviews. Finally, a lack of detailed descriptions of interventions and process and outcome measures prevented more detailed analysis¹⁰⁵.

In conclusion, the current 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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Figure legends

Figure 1. Flowchart of review selection process

Supplementary materials headings

Box S1. Search strategy used for searching Medline

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 six qualitative studies exploring ACP in CKD

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Box S1. Search strategy used for searching Medline

Set#:	Search terms
1	exp Kidney Failure, Chronic/
2	Renal Insufficiency, Chronic/
3	(CRF or CKF or CRD or CKD).tw.
4	((chronic adj 3 renal) or (chronic adj3 kidney)).tw.
5	Kidney Diseases/
6	Renal Insufficiency/
7	Renal Dialysis/
8	dialysis.tw.
9	(pre-dialysis or "pre dialysis" or predialysis).tw.
10	(hemodialysis or haemodialysis).tw.
11	Or/1-10
12	(chronic or end-stage or "end stage" or endstage).tw.
13	11 and 12
14	exp Advance Care Planning/
15	(advance* adj3 plan*).tw.
16	exp Advance Directives/
17	Communication/
18	Physician-Patient Relations/
19	Professional-Patient Relations/
20	Caregivers/px
21	exp Family/px
22	Decision Making/
23	Choice Behaviour/

24 Problem Solving/
25 Advance Directive Adherence/
26 "Outcome and Process Assessment (Health Care)"/
27 "Outcome Assessment (Health Care)"/
28 "Process Assessment (Health Care)"/
29 ((assess* adj3 outcome*) or (outcome* adj3 evaluat*)).tw.
30 Or/14-16 or 17-29
31 13 and 30
32 limit 31 to english language
limit 32 to (addresses or autobiography or bibliography or biography or comment
or dictionary or directory or editorial or in vitro or interactive tutorial or lectures or
letter or news or newspaper article or patient education handout or periodical index
33 or portraits or video-audio media or webcasts)
34 32 not 33

Table 1. Criteria specified for ratings of good, fair and poor quality for randomised controlled trials and cohort studies by the Agency for Healthcare Research and Quality (AHRQ) US Preventive Services Task Force Procedure manual ^{31*}

Criteria:	<ul style="list-style-type: none">•Initial assembly of comparable groups:<ul style="list-style-type: none">◦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, cross-overs, 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 percent); 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.

* Available online at

<http://www.uspreventiveservicestaskforce.org/uspstf08/methods/procmanual.pdf>

Table 2. Summary of 51 studies* on advance care planning in chronic kidney disease identified through systematic searches

Characteristic		N (%)		
Country	USA	35 (69)		
	Other	16 (31)		
Type	Quantitative**			
		Intervention	8 (15)	
		Descriptive	40 (74)	
	Qualitative		6 (11)	
Sample***	Patient			
		Stage 5 CKD (ESKD)	42 (82)	
		Mixed Stage 4/5 CKD	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	1:1	4 (44)	
		Group	1 (11)	
		Materials only		4 (44)

ACP = advance care planning; CKD = chronic kidney disease; ESKD = end stage kidney disease

* 'Study' is used here to refer to research conducted with discrete samples; >1 study may be reported in one article and >1 article may report on the same study.

**One evaluation and one descriptive analysis focused on the same sample.

***Seven studies included samples from more than one group.

Table 3. Measures used in quantitative studies of advance care planning for adults with chronic kidney disease

Measure		Studies		Measures	
		(N=55)		(N=110)	
		N	(%)	N	%
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 towards 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 end-of-life care preferences	6	(13)	6	(6)
EOL care received		8	(18)	8	(7)
Patient/family well-being or coping		5	(11)	5	(5)

EOL = end-of-life

Table 4. Implementation of recommendations from qualitative research in advance care planning 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 (2005), Song (2009, 2010), Weisbord (2003) ^{60,73,75,92}
Emphasis should be on patients being autonomous/taking control and 'getting things settled'; taking care of family (e.g. avoiding burdening them with decision-making is a strong motivator)	Perry (2005), Song (2009, 2010) ^{60,73,75}
The medical team should initiate ACP, give information and advice (rather than make decisions), be empathetic and affirm preferences	Hopkins (2011), Tigert (2005) ^{54,77}
Patients should be helped to acknowledge and accept their limited prognosis	Perry (2005), Song (2009, 2010) ^{60,73,75}
Discussion of poor prognosis should be balanced by hope	Perry (2005), Song (2009, 2010) ^{60,73,75}
Efforts should be made to improve patient healthcare knowledge and literacy	Song (2009, 2010) ^{73,75}
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 (2005) ⁶⁰
ACP should be framed as a process of reflection rather than a 'cold form'	Perry (2005), Song (2009, 2010) ^{60,73,75}
Decisions about continuing dialysis should not be grouped with those regarding aggressive life-sustaining treatments (e.g. CPR, ventilation); patients may perceive these intervention types very differently	None

ACP = advance care planning; CPR = cardiopulmonary resuscitation

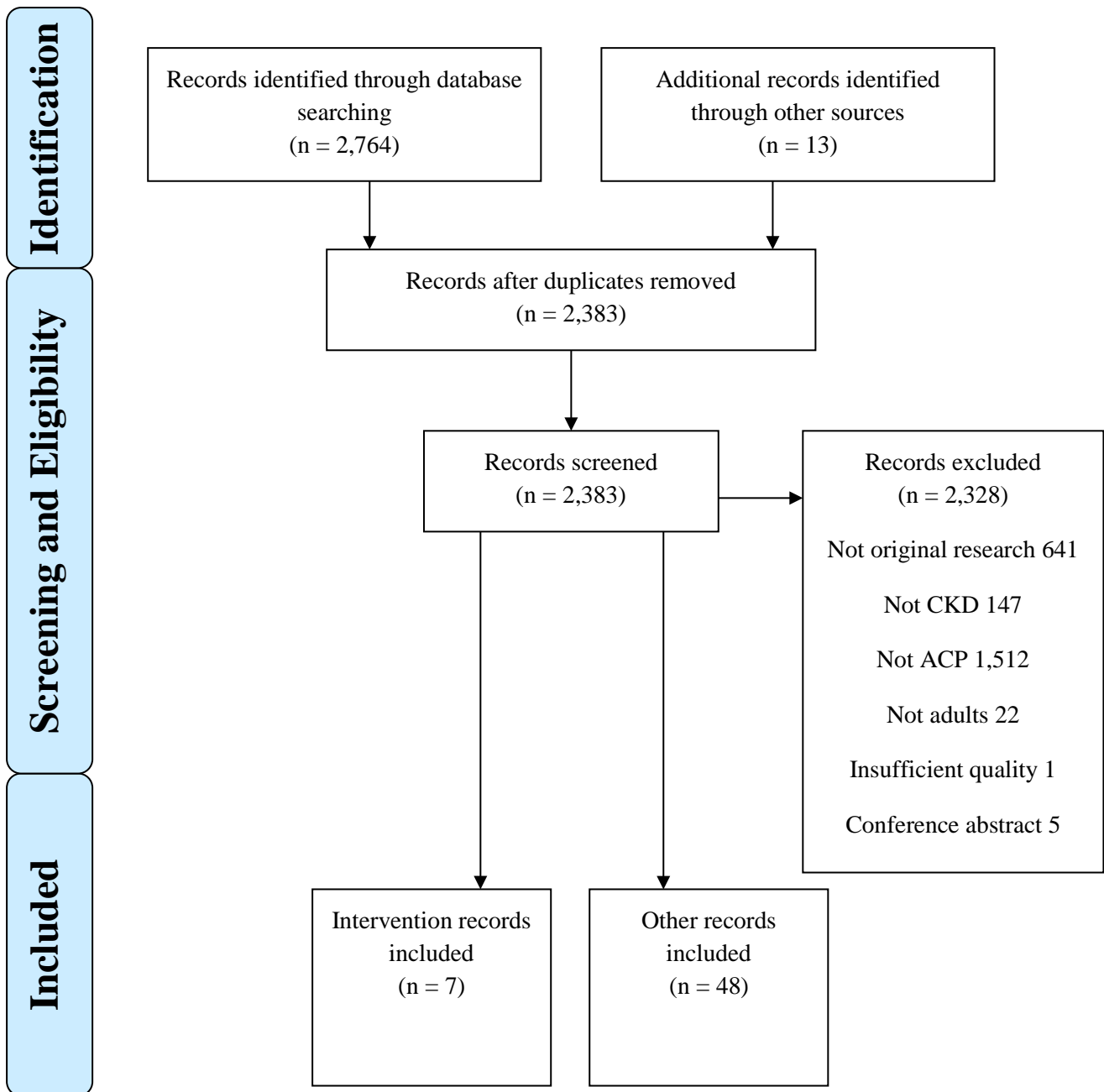


Figure 1. Flowchart of review selection process