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Advance care planning with patients who have end-stage kidney disease a systematic realist review

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Review Article

Advance Care Planning With Patients Who Have End-Stage Kidney Disease: A Systematic Realist Review



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Abstract

Context. Patients with end-stage kidney disease have a high mortality rate and disease burden. Despite this, many do not speak with health care professionals about end-of-life issues. Advance care planning is recommended in this context but is complex and challenging. We carried out a realist review to identify factors affecting its implementation.

Objectives. The objectives of this study are 1) to identify implementation theories; 2) to identify factors that help or hinder implementation; and 3) to develop theory on how the intervention may work.

Methods. We carried out a systematic realist review, searching seven electronic databases: Medline, Embase, CINAHL, PsycINFO, Cochrane Library, Google Scholar, and ScienceDirect.

Results. Sixty-two papers were included in the review.

Conclusion. We identified two intervention stages—1) training for health care professionals that addresses concerns, optimizes skills, and clarifies processes and 2) use of documentation and processes that are simple, individually tailored, culturally appropriate, and involve surrogates. These processes work as patients develop trust in professionals, participate in discussions, and clarify values and beliefs about their condition. This leads to greater congruence between patients and surrogates; increased quality of communication between patients and professionals; and increased completion of advance directives. Advance care planning is hindered by lack of training; administrative complexities; pressures of routine care; patients overestimating life expectancy; and when patients, family, and/or clinical staff are reluctant to initiate discussions. It is more likely to succeed where organizations treat it as core business; when the process is culturally appropriate and takes account of patient perceptions; and when patients are willing to consider death and dying with suitably trained staff. *J Pain Symptom Manage* 2018;56:795–807. © 2018 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

advance care planning, advance directives, kidney failure, chronic, palliative care, realist review, renal dialysis

Introduction

Patients with end-stage kidney disease have a high disease burden and a mortality rate that exceeds age-

matched individuals with cancer and cardiovascular disease.^{1,2} Renal replacement therapy is life-long treatment to replace the normal function of the kidneys with either chronic dialysis (peritoneal dialysis or

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hemodialysis) or renal transplantation. However, older patients with end-stage kidney disease and additional comorbidities may not achieve improved functional status or live longer on renal replacement therapy. They may be unsuitable for renal transplantation and have complex technical challenges associated with initiating dialysis. Furthermore, some older patients may face the decision of whether or not to even start renal replacement therapy.²⁻⁴ Those who accept renal replacement therapy often experience a range of distressing psychological and physical symptoms.^{5,6} Despite this, many do not have conversations with loved ones or clinicians about end-of-life issues such as preferences in relation to admission to intensive care, referral to palliative care services, withdrawal from renal replacement therapy, resuscitation, or where they might choose to die.^{7,8} In this context, advance care planning may be a useful intervention to promote shared decision-making among patients, their families, and health care professionals.

Advance care planning is a process aimed at eliciting preferences of patients in relation to future care, including end-of-life preferences.⁹ It can help patients identify their future health priorities; make an advance decision to refuse a specific treatment (an advance directive); or to appoint someone with lasting power of attorney.¹⁰ Advance care planning is associated with considerable benefits in the general population including improved quality of life, decreased anxiety and depression among family members, reduced hospitalizations, increased uptake of hospice and palliative care services, and care that concurs with patient preferences.¹¹⁻¹⁵

Advance care planning is recommended as good practice for patients with end-stage kidney disease,¹⁶⁻¹⁸ although recent systematic reviews have demonstrated the limited evidence base for the effectiveness of advance care planning in this population.^{19,20} Furthermore, advance care planning is a complex process that can provoke cultural and personal sensitivities related to dying¹¹; and uptake is influenced by a range of personal and organizational factors.²¹ A review of barriers to advance care planning in the general population²² found that implementation was more likely to succeed when advance care planning was embedded in an evaluative research infrastructure, supported by organizational guidance, and part of clinical governance requirements. It was made more difficult when staff lacked time and training, by staff fears around upsetting patients and their relatives, and due to the difficulty of picking the right time for the discussion. Adhering to patients' preferences could be jeopardized by the unpredictability of clinical and organizational factors, and communication difficulties between health care organizations. Given that advance care planning is

recommended as best practice in end-stage kidney disease and yet is a complex and challenging process,²³ we carried out a realist review of the literature to identify factors that may help or hinder the implementation of advance care planning in this population.

Realist Review

A realist review aims to critically examine the interaction between context, mechanism, and outcome (characterized as context-mechanism-outcome configurations) in a sample of studies of an intervention,²⁴ seeking to establish "what works, for whom, and in what circumstances."²⁵

Underlying realist reviews are the assumptions of realist evaluation.²⁵ This proposes that an intervention works by changing the context for the people acting within it. Context is defined as "the spatial or geographical or institutional location into which programs are embedded" and "the prior set of social rules, norms, values and interrelationships gathered in these places which sets limits on the efficacy of program mechanisms" (²⁵, P. 70). These "mechanisms" are the reasoning, beliefs, feelings, motivations, and choices of individuals and groups, which lead to patterns of behavior that we recognize as outcomes.^{26,27}

When an intervention is introduced, it changes the context (by providing further reasoning, opportunities, permissions, legitimations, authorizations, and limitations), so presenting people with a different set of circumstances in which to exercise agency, leading to different outcomes. Of course, this is an interactive process and people will both reproduce and transform their new context, potentially producing a range of outcomes, some of them unintended by those devising the program.

This understanding is neatly summarized by Cheyne et al.:

"A programme comprises multiple elements or components which introduce ideas and/or opportunities for change into existing social systems; the process of how people interpret and act upon these opportunities/ideas are known as the programme's mechanisms." (²⁸, P1112)

Objectives

The objectives of the review were as follows:

1. To identify the dominant program theories in relation to how advance care planning can be successfully implemented.
2. To identify factors that may help or hinder the implementation of advance care planning, with reference to the Consolidated Framework For Implementation Research,²⁹ a pragmatic structure for identifying potential influences

on implementation, focused on the following constructs:

- The characteristics of the intervention
 - The outer and inner settings for implementation
 - The characteristics of the individuals involved
 - The implementation process
3. To develop theory based on context-mechanism-outcome configurations to help explain how the intervention may work.

Methods

We followed the RAMESES publication standards for realist syntheses in conducting and reporting our review.²⁴

Scoping the Literature

Before systematically searching the literature, we consulted with patient advocacy groups, health care professionals, and fellow researchers and carried out a rapid survey of systematic reviews, guidance, and policy documents relevant to advance care planning to identify key issues in this area of practice.

Search Methods for the Review

P. O'H and K. N. searched the following databases (from 1960 to 2016) using the relevant search terms or MESH/Thesaurus/Keyword headings for each database: Medline, Embase, CINAHL, PsycINFO, Cochrane Library, Google Scholar, and ScienceDirect. The Medline search terms, which were based on those proposed in a recent Cochrane review protocol,³⁰ are provided in [Table 1](#).

Selection and Appraisal of Documents

Documents were selected based on their relevance for theory building rather than their quality or methodological approach, which allowed us to include a range of literature. We included documents if they addressed advance care planning and end-stage kidney disease. We excluded documents that were not in English as we had no access to translation services. Finally, we excluded documents published before 2000 as we found no randomized controlled trials (RCTs) published before this date and the organizational and clinical context was likely to be significantly different for papers published earlier.

Realist reviews include a broad spectrum of studies, but the quality of studies is used to moderate findings. The methodological quality of empirical studies was assessed using the appropriate appraisal tool from the Critical Appraisal Skills Programme,³¹ and studies were classified as strong, moderate, or weak in terms of rigor.

Table 1

Search Strategy for Medline—Modified for Searches in CINAHL, Embase, PsycINFO, Cochrane Library, Google Scholar, and ScienceDirect

-
- 1) exp Advance Care Planning/
 - 2) (advance care adj (plan or plans or planning)).tw.
 - 3) (advance adj (directive* or decision*)).tw.
 - 4) living will*.tw.
 - 5) Right to Die/
 - 6) right to die.tw.
 - 7) Patient Advocacy/
 - 8) ((patient or patients) adj5 (advocat* or advocacy)).tw.
 - 9) power of attorney.tw.
 - 10) ((end of life or end-of-life) adj5 (care or discuss* or decision* or plan or plans or planning or preference*)).tw.
 - 11) Terminal Care/
 - 12) terminal care.tw.
 - 13) Treatment Refusal/
 - 14) exp Withholding Treatment/
 - 15) (treatment adj5 (refus* or withhold* or withdraw*)).tw.
 - 16) 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
 - 17) Renal Replacement Therapy/
 - 18) renal replacement therapy.tw.
 - 19) exp Renal Dialysis/
 - 20) dialysis.tw.
 - 21) (hemodialysis or haemodialysis).tw.
 - 22) (endstage kidney or endstage renal or end stage kidney or end stage renal).tw.
 - 23) (ESKD or ESKF or ESRD or ESRF).tw.
 - 24) 17 or 18 or 19 or 20 or 21 or 22 or 23
 - 25) 16 and 24
-

Data Extraction

Data were harvested from papers selected for full-text review by five reviewers (P. O'H., K. N., H. N., J. B., and J. C.) using a standardized data extraction form developed for a previous realist review,³² based on the RAMESES publication standards.²⁴ This form included sections related to the realist assessment, requiring the reviewer to seek information on the theoretical background and characteristics of the intervention, how it was thought to work, outer and inner settings for implementation, characteristics of the individuals involved, the implementation process, and the characteristics of the context thought to influence outcomes.

Analysis and Synthesis

Candidate theories were identified through a close reading of texts by two reviewers (P. O'H. and K. N.). Explicit theories were noted, and where absent, implicit theories deduced from the elements of the interventions. Data synthesis involved the two reviewers independently assessing each paper, identifying common components from the data extraction forms, and reflecting on candidate theories before coming together to discuss findings and achieve a consensus regarding the explanatory power of each. All authors then assessed the candidate theories and provided feedback. We privileged empirical papers in our final

analysis as these represent studies closest to particular practice contexts.

Results

Study Selection

Our initial search of databases produced 5687 documents (Figure 1). Removing duplicates left 3562 documents. Title review looking for documents relevant to advance care planning and end-stage kidney disease by two reviewers (K. N. and P. O'H.) excluded 3251 papers, with abstract review reducing this to 91 papers. The full text of these papers was reviewed by the two reviewers and a decision taken at this stage by the review authors to exclude 20 papers published before 2000 in the interests of organizational and clinical relevance to contemporary practice. This left 62 documents, of which 16 were opinion pieces, eight were

guidelines or policies, and 38 were empirical papers that formed the basis of this review.

Study Characteristics

Study Designs. The 38 empirical studies were of various designs (Supplemental Table 1). Three were literature reviews^{19,20,33}; five were RCTs^{34–38}; and another³⁹ a secondary analysis of an RCT.³⁸ Three were nonequivalent group designs^{40–42}; one single-group test-retest study⁴³; nine were qualitative studies^{44–52}; and 16 observational studies.^{53–68}

Methodological Quality. Thirteen studies were classified as “strong”^{19,20,46,47,49–51,53,55,60,63,65}, including one RCT³⁸; and 10 as “weak”^{33,34,40,41,43,48,54,59,62,67}; with the remaining 14 classified as “moderate.” One paper⁴² reported a protocol, so a judgment was not made.

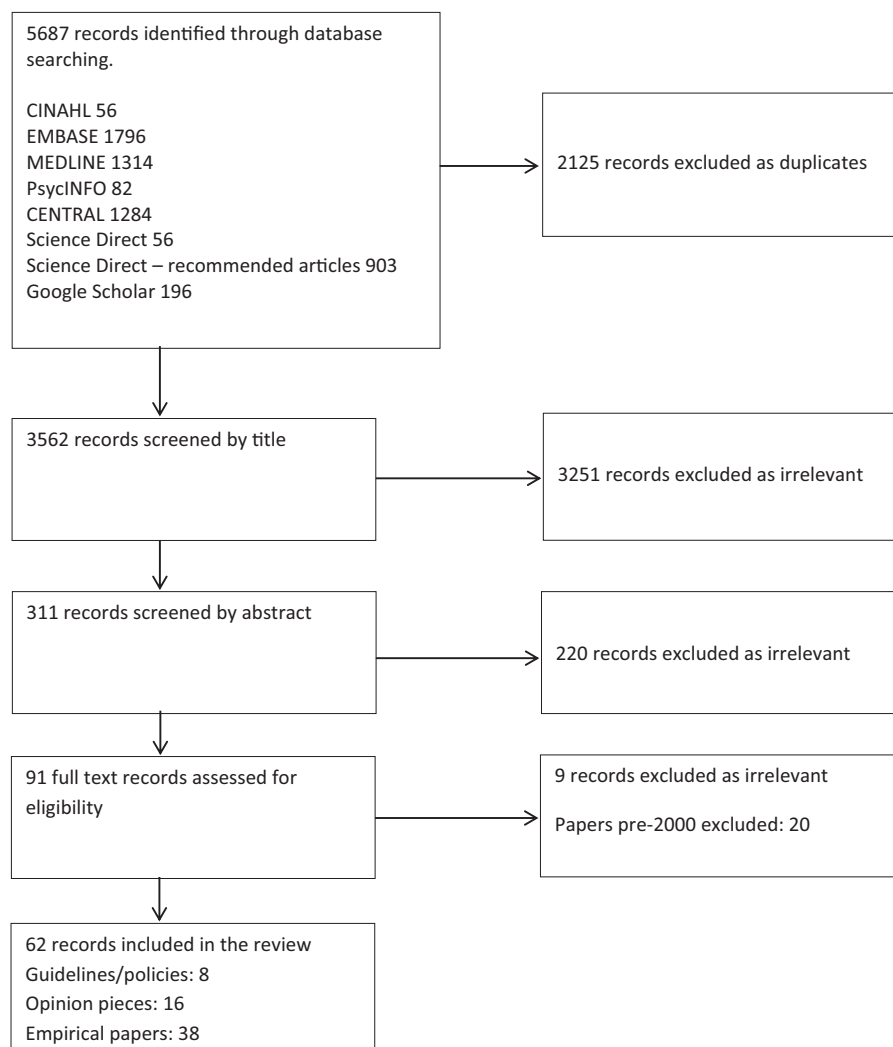


Fig. 1. Flowchart illustrating the search process.

Main Objectives of the Studies. Intervention studies sought to evaluate the effect of advance care planning on use of services and on congruence of care at end-of-life with patients' wishes,^{19,20,37} or on congruence between patients and surrogates.^{34,36,38,39} Other studies focused on interventions to improve uptake of advance care plans,^{35,41} or to encourage professionals to support patients in making advance care plans.^{40,43} Most of the observational and qualitative studies concentrated on establishing patients' attitudes (or those of professionals⁵⁵ or family members⁴⁹) toward death, dying, end-of-life care, discussing treatment preferences, withdrawal of treatment, and making advance care plans or advance directives. Exceptions were those that looked for congruence between advance care plans and clinical outcomes,⁵³ and between surrogates' and patients' views on treatment preferences^{44,61}; and those that sought to examine the prevalence and contents of advance directives^{60,68} to evaluate patient-physician communication about end-of-life care⁵⁷; to explore the association between advance care planning and withdrawal from dialysis, use of hospice, and location of death⁵⁹; and to describe how seriously ill patients can be assisted to identify a surrogate.⁵⁸ Two studies were intended to inform interventions for staff training.^{48,51}

Study Populations. With the exception of three studies that focused on health professionals^{40,55} and family members⁴⁹, all studies were of patients with end-stage kidney disease, some including family members/surrogate decision-makers, and three including patients with other long-term conditions.^{34,37,41} A minority specified further characteristics for patient inclusion, such as aged over 50 years³⁴; or thought to be at risk of death in the next six⁴², 12³⁸, or 24 months³⁷; or with significant comorbidity.⁴³

Advance Care Planning Interventions. Three RCTs^{34,36,37} evaluated patient-centered advance care planning: a one-hour interview delivered by a trained facilitator to patients and their surrogates to help prepare surrogates to make decisions that honor the patient's preferences for care, leading to documentation of preferences. Song et al.³⁸ took a similar approach but in two sessions over two weeks. Simon et al.⁵² a qualitative study, reported an advance care planning process comprising trained facilitators, a workbook with suggestions for levels of intervention, and organizational processes that audit and operationalize advance care planning in medical records and treatment plans. Perry et al.³⁵ used trained peer mentors who had three face-to-face and five telephone contacts with patients over a two- to four-month period.

Outcomes of Advance Care Planning Interventions

The RCT intervention studies showed statistically significant improvements in congruence in statement of treatment preferences,^{34,36,38} surrogate decision-making confidence,³⁸ patient's perceived quality of communication,^{34,36} and decisional conflict³⁴; an increase in completion of advance directives; and comfort in discussing them.³⁵ Unexpected results were more intervention patients (37.7%) choosing to withdraw from dialysis than controls (17%)—although this had not been discussed in advance care planning³⁷—and a shift among participants toward using all possible life-sustaining treatments to prolong their lives.³⁶ The non-RCT intervention studies reported that electronic medical record reminders improved advance directive documentation⁴¹; that nurses self-reported increased efficacy in relation to upholding patients informed choices⁴⁰; and that there was no effect on number of advance directives.⁴³ In their review of RCTs or quasi-RCTs, Lim et al.²⁰ reported no effect on hospital admissions or use of treatments with life-prolonging or curative intent or on following patient's wishes at end of life.

Program Theories in Relation to How Advance Care Planning Can Be Successfully Implemented

Luckett et al.¹⁹ reflect the broad concept of advance care planning found in most studies when they characterize it as

“... 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 care. Advance care planning 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. Advance care planning is a patient-centered initiative that promotes shared decision-making, which may include the patient completing an advance directive that documents their wishes and/or the appointment of a substitute decision-maker.” (P. 762)

The theory is that once the patient, their family or surrogate, and the health professionals have a common understanding of the patient's preferences for end-of-life care, then they will be more likely to act together to enact those preferences, even if the patient loses capacity. A subtheme is that the patient will be less likely to choose (possibly futile) life-prolonging treatments (such as resuscitation and dialysis) at end of life and more likely to choose palliative care services and hospice care, which will enhance their quality of life until death. These views on the

nature and outcomes of advance care planning are reflected in many guidelines and opinion pieces.^{7,69–74}

The empirical studies provide more detailed explanations as to how advance care plans may work. Several studies report that the advance care planning process helps to prepare both the patient and the surrogate to make better decisions by helping the patient to clarify values and develop skills related to initiating discussions, and by actively involving the surrogate to help prepare for the emotional burden of decision-making.^{34,36–39} Systematically, eliciting patient preferences for end-of-life care allows concordant care to be provided.⁴² Other studies focused on the role of professionals, theorizing that addressing concerns about advance care planning, optimizing skills, and clarifying processes will legitimize advance care planning and encourage professionals to initiate discussions.^{40,48}

Some studies based their approach on previously published theories. Five papers reporting four RCTs^{34,36–39} described attempts to help the patient examine their own belief systems and integrate new information, based on the representational approach to patient education. This seeks to illuminate a person's illness representation—the set of thoughts that a person has about a health problem in five dimensions: identity, cause, timeline, consequences, and cure/control—to provide an opportunity for the person to reflect and to allow the clinician to provide individualized, acceptable information.^{75–78} One study⁶⁶ drew on components of the theory of planned behavior⁷⁹ to argue that a person who holds strong beliefs about death and dying and has a positive evaluation of advance care planning will more likely have a positive attitude toward making an advance care plan.

Calvin et al.^{45,54} developed a new “theory of personal preservation.” Patients on dialysis are thought to experience three phases: a redefined sense of self as they acknowledge a shortened lifespan; a response to this redefinition that asserted their individuality in terms of their resilience in the face of life's challenges, and finding meaning and optimism in their suffering, often through prayer or trusting in God's will; and finally living in the tension of acting responsibly to care for themselves and others, while managing the risks and uncertainty associated with treatment by fallible professionals. They did not see advance care plans as a means to maintain personal autonomy, preferring to leave such decisions to trusted family members, and to focus on negotiating present challenges. This theory (which has elements in common with that of Goff et al.⁵¹) is intended to inform communication around advance care planning. Similarly, Simon et al.⁵² propose a model in which preexisting ideas formed by “witnessing illness in self and

others” and “acknowledging mortality” lead to reflection on states of dysfunction in which patients would not want to live. These combine with the advance care planning process to produce a degree of peace of mind in that participants had planned to avoid burdensome states and reduced family stress.

Factors That May Help or Hinder the Implementation of Advance Care Planning

The Characteristics of the Intervention

One review concluded that interventions do not give comprehensive attention to patient, caregiver, health professional, and system-related factors.¹⁹ Giving structured feedback to facilitators on their delivery of advance care planning was thought to enhance the process.^{37,38} An electronic medical record–based reminder appeared to improve completion of advance directives by prompting discussions within the outpatient visit workflow.⁴¹ Tailoring advance directive documentation to patient needs and keeping documents short was thought to encourage completion,⁶³ whereas administrative and legal complexities discouraged completion.⁵⁸

The Inner and Outer Settings for Implementation

In terms of the inner organizational setting—which includes organizational structure, communications, culture, and capacity for change²⁹—implementation was enhanced by educating staff on the benefits of advance care planning.¹⁹ Advance care planning was more likely to be used when staff trained to facilitate appropriate discussions were available,^{34,36–38,48} when physicians actively recommended hospice care,⁵⁹ and where there were processes reflecting organizational endorsement such as administrative requirement for advance directives,⁵³ and a policy of providing support for staff education, patient information, and related safety and quality systems.⁴⁰ Overall, ensuring staff have time for advance care planning as “core business” supported implementation.¹⁹

On the other hand, the pressures of (and focus on) routine clinical work,^{33,46} a “conveyor-belt” culture in relation to providing hemodialysis,⁵⁰ lack of funds to support staff training,⁴⁸ and poor continuity of medical care,⁵⁷ all militated against uptake of advance care planning.

Turning to the outer setting—which includes external policies and incentives, patient needs and resources, and relationships with other (peer) organizations²⁹—wider cultural differences were reported to exert profound effects on advance care planning processes. In general, it appears that advance care planning is seen as a more normal part of health care in

the U.S.—all but one of the intervention studies⁴⁰ were carried out there. However, within the U.S., patients and families with lower socioeconomic status reported feeling disempowered in interactions with the dialysis team and therefore less likely to build trust and complete advance care plans.⁵¹ African Americans were described as more responsive than whites to an intervention that was highly inclusive of family surrogates, as this may align with their familial, religious, and communal frame of reference³⁹ and to be open to peer interventions because of a preference for oral traditions³⁵. Similarly, Asian Americans and Hawaiians (from cultures where family involvement and discussion, and collective decision-making, are important) expressed a preference for discussing advance care planning with family rather than health professionals.⁶⁶ African and Asian American patients were found to be more likely to engage in end-of-life discussions, but African Americans were less likely to prefer dialysis withdrawal at end of life and to complete a do-not-resuscitate directive.⁶⁷ In one rural study, reluctance of many patients to travel the necessary distance for tertiary care contributed to the low prevalence of in-hospital death.⁵⁹

A Saudi Arabian study⁶⁴ reported that Islam is in principle compatible with advance care planning, but that this was rarely discussed and patients were generally against “do-not-resuscitate” decisions—attitudes echoed in a study in the Republic of Ireland, where it was also reported that advance directives had no legal status, with very few people aware of their existence.⁵⁶ Miura et al.⁶¹ stated that Japanese culture includes the belief that one’s wishes are intuitively known to others, leading to an erroneous assumption that family members can correctly predict patient’s preferences for cardiopulmonary resuscitation or continuation of dialysis at end of life. Physicians may be paternalistic and families may see withdrawal of treatment as abandoning their duty to the patient, so that the physician defers to the family even against the patient’s advance directive, leading to inappropriately aggressive treatment at end of life. Similarly, Yee et al.⁵⁵ perceive Singaporeans may not be ready for advance care planning, as it can be confused with advance directives (and advance directives with euthanasia) by both health care professionals and patients. The family also plays an important role in health-related decisions and may sometimes disagree with patients’ preferences. A Spanish study reported that people are unfamiliar with advance directives and fear that physicians may withhold necessary treatments, leading to low uptake.⁶⁸ A study in the United Kingdom argued that there is a need for a culture shift from a “disease-focused” model toward a “holistic care-based” approach, normalizing discussions about preferences, priorities, and future care.⁵⁰

Characteristics of Individuals

A common finding was that patients and their families found it difficult to initiate conversations about future care with professionals, especially nephrologists.^{19,45,49,51} Patients expected professionals to take the initiative,^{19,33,46,47} but professionals were reluctant for fear of upsetting patients and families^{20,37,43,49,50,55,62} and in the case of nurses, upsetting senior staff.¹⁹ One study argued that a focus on technology had taken nephrologists away from offering emotional and spiritual support.⁶⁵

Patients were thought to overestimate their life expectancy¹⁹ and to distance themselves from thoughts of death,^{45,52} thus reducing their sense of urgency to have advance care planning discussions. Surrogates were often unaware of patients’ views and held different positions on care at end of life.^{19,44,55,61}

A trusting relationship with the person proposing advance care planning seemed to make acceptance by the patient^{35,51,56,68} and family members⁴⁹ more likely, with lack of trust, making discussions more difficult.

Theory Synthesis

In the following section, we seek to examine the interaction between the intervention (I), context (C), mechanism (M), and outcome (O) in relation to advance care planning, with a view to offering a theory to explain and support implementation (Figure 2).

Implementation of advance care planning entails two major intervention stages (I₁ and I₂). First, there is training for clinical staff that addresses concerns, optimizes skills, and clarifies processes (I₁). This helps clinical staff to appreciate the usefulness of advance care planning and to gain confidence to initiate discussions with patients and their surrogates (M). The second stage (I₂) is when the advance care planning documentation and processes are implemented. These should be simple, individually tailored, culturally appropriate, and actively involve surrogates. They are designed to explore the patient’s understanding of their condition, to elicit what the patient values in relation to their health and relationships, and on this basis to document their preferences for care and treatment in the event of incapacity.

These processes have their effect as patients develop trust in staff, clarify their values and beliefs about their condition, and learn skills to participate in discussions with clinical staff and others. Consequently, patients’ preferences are made known to clinical staff and surrogates, and surrogates are prepared emotionally for decision-making (M). These interventions, working through the mechanisms described, lead to greater

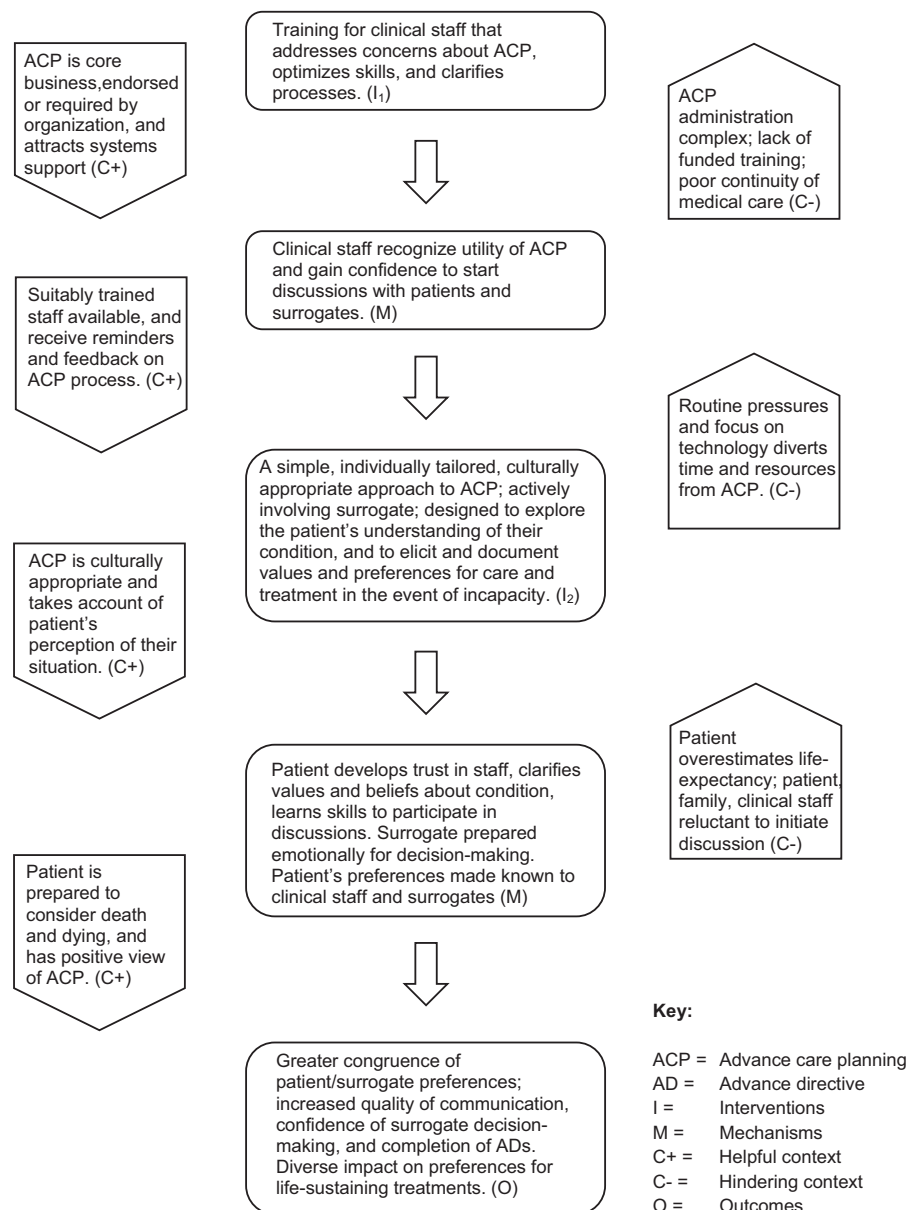


Fig. 2. Model for the implementation of advance care planning with patients who have end-stage kidney disease.

congruence between patient and surrogate on treatment preferences; increased quality of communication between patients and clinical staff; greater confidence in surrogates about decision-making on patients' behalf; and an increased rate of completion of advance directives. Preferences for life-sustaining treatments may increase or decrease under the influence of the sociocultural context (O).

These outcomes are hindered by a number of organizational issues: lack of funded training opportunities, administrative and legal complexities around advance care planning, the prioritization and pressures of routine care, and a focus on technological (rather than personal and spiritual) aspects of care.

Barriers may also arise from interpersonal issues: when the patient overestimates life expectancy and therefore does not appreciate the relevance of discussions about future care; and when the patient, family, and/or clinical staff are reluctant to initiate discussions about treatment decisions in the event of deterioration because of fears of causing distress (C).

On the other hand, advance care planning is more likely to succeed where it is acknowledged as core business and required or endorsed by the organization and therefore attracts resources to support education and quality assurance; when suitably trained staff are available and receive reminders and feedback on implementation; when the process and documentation

are culturally appropriate and take account of the patient's perception of their situation; and when the patient is prepared to consider death and dying and has positive view of advance care planning.

Discussion

Most of the included papers (25/38) reported observational or qualitative designs. These provide useful information on the perceptions, attitudes, and behavior of patients, families, and professionals in relation to death, dying, and advance care planning. However, there were only eight intervention studies found, of which five were RCTs, with 593 patients and 390 relative participants. RCT outcomes were diverse, showing statistically significant improvements in the quality of communication and confidence in decision-making, but no effect on hospital admissions or use of treatments with life-prolonging or curative intent, or on following patient's wishes at end of life. Indeed, only one RCT³⁷ attempted to measure whether patients received care in accord with their wishes, and low numbers precluded statistical analysis. No RCTs effectively investigated impact on use of health services, hospital admissions, or treatment, which ruled out any evaluation of cost-effectiveness. Of the RCTs, we judged only one³⁸ to be methodologically strong; the others to be moderate or, in one case, weak.

The commonly held theory that advance care planning will lead to a shared understanding of patient preferences for end-of-life care, and subsequent enactment of those preferences, with less recourse to life-prolonging treatments and greater use of palliative care services and hospice care, is only partially supported by the evidence. One study³⁷ reported that more intervention patients chose to withdraw from dialysis than controls, despite withdrawal not being discussed in advance care planning, but this result should be interpreted with caution as the paper does not specify numbers of participants for this subgroup analysis. Song et al.³⁶ report an increase in preference for life-sustaining treatment in their intervention group, attributing this to cultural and religious mores among their African American sample. Again, a small sample size ($n = 19$) invites cautious interpretation. It does seem that advance care planning can help clarify preferences and improve communication, but other outcomes remain unsupported or equivocal. These findings are consistent with two recent reviews,^{19,20} which concluded that the evidence base is weak in this population.

Unpicking the program theories in relation to how advance care planning could be successfully implemented, and identifying contexts that may help or

hinder, has allowed us to synthesize an integrated theory to explain and support implementation. Unsurprisingly, the first stage is staff training. However, it is important to note the focus of the training—to address staff concerns, clarify processes, and optimize skills—and its goal—to persuade staff of the usefulness of advance care planning and to give them confidence to start discussions with patients and their relatives. Training is less likely to be effective if it takes for granted the usefulness of advance care planning, marginalizes staff concerns, and does not engender confidence in the process.

Similarly, when addressing the second stage of implementation (the approach to the patient and relatives), the focus and goal of the approach are key ingredients for success. The advance care planning document and approach should be culturally appropriate, actively involve the surrogate, explore the patient's understanding of their condition, and elicit and document their values and preferences for care. The goal is for the patient (and their surrogate) to trust staff sufficiently that they are able to share their values and beliefs and gain confidence to enter into discussions with clinicians. The few detailed reports of advance care planning interventions largely described relatively short (e.g. one hour) guided interactions between the patient, their surrogate, and a trained facilitator, helping the patient and surrogate to clarify values and develop skills related to initiating discussions, preparing for decision-making, and leading to a document recording patient preferences. One hour is not a long time to spend making a plan for one's care in the event of deterioration, but it is significant in terms of professional time when there are competing priorities. This introduces the impact of context. In organizational terms, the umbrella concept is that advance care planning should be core business. That is, it should attract support in the form of policy, administrative processes, resources (funded training, staffing levels), quality assurance, and accountability. Advance care planning that is an "add-on" is likely to be swamped by the pressures of routine care. Interestingly, only two studies directly addressed organizational issues: one that reported training nurses to offer advance care planning in the context of a supportive policy framework of educative, patient information, safety, and quality systems⁴⁰; and the other examining the effectiveness of an electronic medical record-based reminder in improving advance directive documentation.⁴¹ The vast majority of studies focused on patient-staff interaction in relative isolation from the organizational context.

Surrounding and pervading organizations are the cultural and personal values that heavily influence the responses of both staff and patients to discussions about care at end of life. Advance care planning has largely

evolved within Western democracies and been developed by professional elites. Consequently, the approach typically embodies a cultural commitment to individual autonomy, which may sit uneasily with those with lower socioeconomic status, or from cultures, which privilege the family in decision-making. Similarly, professionals may assume advance care planning will entail refusing or curtailing treatment, when patients are inclined to continue and maximize interventions. Added to this is a reluctance on all sides to raise the issues of poor prognosis and death. For these reasons, it is important that the advance care planning process and documentation are culturally appropriate. It should take into account patient and family perceptions of their situation, including life expectancy and the likely efficacy of life-sustaining interventions; religious and cultural understandings of death, dying, and the place of medical care; together with preferences in relation to involvement of the family in decision-making. Given that patients have difficulty in raising advance care planning with professionals, there is a role for patient representative bodies and the charitable sector in educating patients and families in relation to advance care planning and advocating for health care organizations and professionals to take the lead in introducing it to patients.

Strengths and Limitations

Intervention studies were relatively few and often small, which limited our ability to comment on clinical or cost-effectiveness of advance care planning in this population. Other studies had diverse aims and designs, making synthesis a challenge. However, this diversity did serve to provide data on organizational and cultural aspects. Having said that, most studies did not set out to explain how advance care planning might work or to identify helping or hindering factors, which meant the authors had to glean some of these insights from the narrative and discussion sections of the papers.

Conclusions and Recommendations

Robust clinical trials are needed in this population to investigate the impact of advance care planning on enactment of patient preferences for end-of-life care; recourse to life-prolonging treatments; and use of palliative care services and hospice care.

Nevertheless, it is evident that for patients with end-stage kidney disease, advance care planning is much more than an administrative or merely intellectual task. On the contrary, it is an intensely human process in which a vulnerable patient is invited to consider their own deterioration and death, and to make plans for navigating various threatening possibilities. Despite this, there is already some evidence of positive outcomes for patients and their families in the form of congruence in statement of treatment preferences, surrogate decision-making confidence, improvements in perceived quality of communication and decisional conflict; an increase in completion of advance directives; and comfort in discussing them. Consequently, professionals have a responsibility to offer advance care planning to patients and to support them during the process. Given the significance and complexity of this task, professionals need organizational support in the form of policy endorsement; quality assurance; administrative systems; training that addresses concerns, optimizes skills, and clarifies processes; and staffing levels that allow time for proper attention to implementation. This will allow them to develop an approach to advance care planning that is designed to explore the patient's understanding of their condition, and to elicit and document values and preferences for care and treatment in the event of incapacity, but is also simple, individually tailored, culturally appropriate, and actively involves surrogates.

Bearing in mind the profound impact of cultural and organizational context, we recommend that patient groups, professionals, and their organizations

Table 2

Recommendations for the Development and Implementation of Advance Care Planning for Patients With End-Stage Kidney Disease

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- Patient representative bodies and the charitable sector should educate patients and families in relation to advance care planning and advocate for health care organizations and professionals to take the lead in introducing it to patients.
 - Organizations should make necessary preparations for implementing advance care planning as core business by developing appropriate policies and administrative and quality assurance processes, while providing resources for training and for sufficient staff to offer advance care planning effectively.
 - Staff trainers should seek to address concerns, optimize skills, and clarify processes, aiming to persuade staff of the usefulness of advance care planning and to give them confidence to start discussions with patients and their relatives.
 - Professionals should develop an approach to advance care planning that is simple, individually tailored, culturally appropriate, actively involves surrogates, and explores the patient's understanding of their condition.
 - When implementing advance care planning, professionals should aim to build trust with patients and their families; help the patient develop skills that will facilitate their participation in decision-making; and build confidence in surrogates for their role in speaking faithfully for the patient, should that become necessary.
 - Researchers should develop robust clinical trials to investigate the impact of advance care planning on patient and surrogate decision-making and emotional burden; enactment of patient preferences for end-of-life care; recourse to life-prolonging treatments; and use of palliative care services and hospice care. The impacts of organizational context and cultural and personal values on the acceptability and feasibility of advance care planning should also be investigated.
-

take a diagnostic approach to their particular situation when implementing advance care planning. In other words, they should consider the beliefs and expectations of the surrounding culture, their own resources, and how they can best organize advance care planning training and implementation to trigger the mechanisms and achieve the outcomes identified in our implementation model. Specific recommendations for stakeholders are offered in Table 2.

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References

1. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. *Kidney Int* 2006;69:1621–1625.
2. USRDS. 2015 USRDS Annual Data Report Volume 1: CKD in the United States. United States Ren. Data Syst. 2016.
3. Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP. CKD in Elderly patients managed without dialysis: Survival, Symptoms, and quality of life. *Clin J Am Soc Nephrol* 2015;10:260–268.
4. Verberne WR, Geers ABMT, Jellema WT, Vincent HH, van Delden JJM, Bos WJW. Comparative Survival among older adults with advanced kidney disease managed Conservatively versus with dialysis. *Clin J Am Soc Nephrol* 2016;11: 633–640.
5. Douglas C, Murtagh F, Chambers E, Howse M, Ellershaw J. Symptom management for the adult patient dying with advanced chronic kidney disease: a review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus Group. *Palliat Med* 2009;23:103–110.
6. Davison SN, Jhangri GS. Existential and supportive care needs among patients with chronic kidney disease. *J Pain Symptom Manage* 2010;40:838–843.
7. Arulkumaran N, Szawarski P, Philips BJ. End-of-life care in patients with end-stage renal disease. *Nephrol Dial Transpl* 2012;27:879–881.
8. Davison SN. Advance care planning in patients with chronic kidney disease. *Semin Dial* 2012;25:657–663.
9. Royal College of Physicians. Advance care planning. Concise Guidance to Good Practice series. London: Royal College of Physicians, 2009. Available at: <http://www.rcplondon.ac.uk/resources/concise-guidelines-advance-care-planning>.
10. Detering KM, Silveira MJ. Advance care planning and advance directives Arnold RM, Savarese DM, editors. UpToDate 2018. Available at: <https://www.uptodate.com/>. Accessed February 19, 2018.
11. Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. *BMJ* 2013;347:1–6.
12. Bernacki RE, Block SD. American College of physicians high value care task Force. Communication about serious illness care goals. *JAMA Intern Med* 2014;174:1994.
13. Krouse RS, Rosenfeld KE, Grant M, et al. Palliative care research: issues and opportunities. *Cancer Epidemiol Biomarkers Prev* 2004;13:337–339.
14. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014;15: 477–489.
15. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014;28: 1000–1025.
16. Department of Health. National service framework for renal services part two: Chronic kidney disease, acute renal failure and end of life care. London: Department of Health, 2005.
17. National Institute for Health and Clinical Excellence. Chronic kidney disease quality standard 2012. Available at: <http://publications.nice.org.uk/chronic-kidney-disease-quality-standard-qs5>. Accessed July 1, 2014.
18. Crail S, Walker R, Brown M. Renal supportive and palliative care: position statement. *Nephrology* 2013;18:393–400. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/nep.12064/full>. Accessed August 27, 2014.
19. Luckett T, Sellars M, Tieman J, et al. Advance care planning for adults with CKD: a systematic integrative review. *Am J Kidney Dis* 2014;63:761–770.
20. Lim CED, Ng RWC, Cheng NCL, Gigolini M, Kwok C, Brennan F. Advance care planning for haemodialysis patients. *Cochrane database Syst. Rev* 2016;(7):CD010737.
21. Lovell A, Yates P. Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012. *Palliat Med* 2014;28: 1026–1035.
22. Lund S, Richardson A, May C. Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies. *PLoS One* 2015;10:e0116629.
23. Holley JL, Davison SN. Advance care planning in CKD: clinical and research opportunities. *Am J Kidney Dis* 2014; 63:739–740.
24. Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. *BMC Med* 2013;11:21.
25. Pawson R, Tilley N. Realistic Evaluation. London: SAGE Publications Ltd, 1997.
26. Higgins A, O'Halloran P, Porter S. The management of long-term Sickness absence in Large public sector health-care organisations: a realist evaluation using Mixed Methods. *J Occup Rehabil* 2015;25:451–470.
27. Archer MS. Structure, Agency, and the Internal Conversation. Cambridge: Cambridge University Press, 2003.
28. Cheyne H, Abhyankar P, McCourt C. Empowering change: realist evaluation of a Scottish Government

- programme to support normal birth. *Midwifery* 2013;29:1110–1121.
29. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander J, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci* 2009;4:50.
30. Lim CED, Siow S, Ho KEE, et al. Advance care planning for haemodialysis patients (Protocol). Available at: <http://doi.wiley.com/10.1002/14651858.CD010737>. Accessed September 8, 2017.
31. Critical Appraisal Skills Programme. Critical Appraisal Skills Programme. Available at: <http://www.casp-uk.net/casp-tools-checklists>. Accessed August 30, 2017.
32. O'Halloran P, Scott D, Reid J, Porter S. Multimedia psychoeducational interventions to support patient self-care in degenerative conditions: a realist review. *Palliat Support Care* 2014;1–14. Available at: http://journals.cambridge.org/abstract_S1478951514001229. Accessed December 3, 2014.
33. Noble H, Meyer J, Bridges J, Kelly D, Johnson B. Patient experience of dialysis REFUSAL or withdrawal—a review of the literature. *J Ren Care* 2008;34:94–100.
34. Briggs LA, Kirchhoff KT, Hammes BJ, Song MK, Colvin ER. Patient-centered advance care planning in special patient populations: a pilot study. *J Prof Nurs* 2004;20:47–58.
35. Perry E, Swartz J, Brown S, Smith D, Kelly G, Swartz R. Peer mentoring: a culturally sensitive approach to end-of-life planning for long-term dialysis patients. *Am J Kidney Dis* 2005;46:111–119. Available at: <http://www.sciencedirect.com/science/article/pii/S0272638605004610>. Accessed September 29, 2014.
36. Song M-K, Donovan HS, Piraino BM, et al. Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Appl Nurs Res* 2010;23:65–72.
37. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific advance care planning intervention on end-of-life care. *J Am Geriatr Soc* 2012;60:946–950.
38. Song M-K, Ward SE, Fine JP, et al. Advance care planning and end-of-life decision making in dialysis: a Randomized controlled trial Targeting patients and their surrogates. *Am J Kidney Dis* 2015;66:813–822.
39. Song M-K, Ward SE, Lin F-C, et al. Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *J Palliat Med* 2016;19:134–142. Available at: <http://online.liebertpub.com/doi/10.1089/jpm.2015.0232>. Accessed May 23, 2017.
40. Seal M. Patient advocacy and advance care planning in the acute hospital setting. *Aust J Adv Nurs* 2007;24:29–36.
41. Hayek S, Nieva R, Corrigan F, et al. End-of-Life care planning: improving documentation of advance directives in the outpatient clinic using electronic medical records. *J Palliat Med* 2014;17:1348–1352. Available at: <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0684>.
42. Eneanya ND, Goff SL, Martinez T, et al. Shared decision-making in end-stage renal disease: a protocol for a multicenter study of a communication intervention to improve end-of-life care for dialysis patients. *BMC Palliat Care* 2015;14:30.
43. Weisbord SD, Carmody SS, Bruns FJ, et al. Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients. *Nephrol Dial Transpl* 2003;18:1345–1352. Available at: <https://academic.oup.com/ndt/article-lookup/doi/10.1093/ndt/gfg105>.
44. Hines SC, Glover JJ, Babrow AS, Holley JL, Badzek LA, Moss AH. Improving advance care planning by accommodating family preferences. *J Palliat Med* 2001;4:481–489. Available at: <http://www.liebertonline.com/doi/abs/10.1089/109662101753381629>. Accessed May 23, 2017.
45. Calvin AO. Haemodialysis patients and end-of-life decisions: a theory of personal preservation. *J Adv Nurs* 2004;46:558–566. Available at: <http://doi.wiley.com/10.1111/j.1365-2648.2004.03030.x>. Accessed May 23, 2017.
46. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006;333:886.
47. Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clin J Am Soc Nephrol* 2006;1:1023–1028. Available at: <http://cjasn.asnjournals.org/cgi/doi/10.2215/CJN.01050306>. Accessed May 23, 2017.
48. Bristowe K, Shepherd K, Bryan L, et al. The development and piloting of the RENal specific Advanced Communication Training (REACT) programme to improve Advance Care Planning for renal patients. *Palliat Med* 2014;28:360–366. Available at: <http://journals.sagepub.com/doi/10.1177/0269216313510342>. Accessed May 23, 2017.
49. Calvin AO, Engebretson JC, Sardual SA. Understanding of advance care planning by family members of persons undergoing hemodialysis. *West J Nurs Res* 2014;36:1357–1373. Available at: <http://journals.sagepub.com/doi/10.1177/0193945913514637>. Accessed May 23, 2017.
50. Bristowe K, Horsley HL, Shepherd K, et al. Thinking ahead—the need for early Advance Care Planning for people on haemodialysis: a qualitative interview study. *Palliat Med* 2015;29:443–450. Available at: <http://journals.sagepub.com/doi/10.1177/0269216314560209>. Accessed May 23, 2017.
51. Goff SL, Eneanya ND, Feinberg R, et al. Advance care planning: a qualitative study of dialysis patients and families. *Clin J Am Soc Nephrol* 2015;10:390–400.
52. Simon J, Murray A, Raffin S. Facilitated advance care planning: what is the patient experience? *J Palliat Care* 2008;24:256–264.
53. Anderson JE, Sikorski I, Finucane TE. Advance care planning by or on behalf of peritoneal dialysis patients in long-term care. *Am J Kidney Dis* 2006;48:122–127.
54. Calvin AO, Eriksen LR. Assessing advance care planning readiness in individuals with kidney failure. *Nephrol Nurs J* 2006;33:165–170. Available at: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=16613411%0Ahttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed7&NEWS=N&AN=16613411>.
55. Yee A, Seow YY, Tan SH, Goh C, Qu L, Lee G. What do renal health-care professionals in Singapore think of advance care planning for patients with end-stage renal disease? *Nephrology (Carlton)* 2011;16:232–238.

56. Collins M, Lehane E. Perspectives on death, dying and advance care planning from patients RECEIVING haemodialysis. *J Ren Care* 2013;39:5–11.
57. Janssen DJ, Spruit M, Schols JMG, van der Sande FM, Frenken L a, Wouters EFM. Insight into advance care planning for patients on dialysis. *J Pain Symptom Manage* 2013;45:104–113.
58. Song M-K, Ward SE. Disconnect between emergency contacts and surrogate decision-makers in the absence of advance directives. *Palliat Med* 2013;27:789–792. Available at: <http://journals.sagepub.com/doi/10.1177/0269216312474486>.
59. Schmidt RJ, Weaner BB, Long D. The power of advance care planning in promoting hospice and out-of-hospital death in a dialysis Unit. *J Palliat Med* 2015;18:62–66. Available at: <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0031>.
60. Feely MA, Hildebrandt D, Edakkanambeth Varayil J, Mueller PS. Prevalence and contents of advance directives of patients with ESRD receiving dialysis. *Clin J Am Soc Nephrol* 2016;17:17. Available at: <http://login.ezproxy.library.ualberta.ca/login?url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medp&AN=27856490>.
61. Miura Y, Asai A, Matsushima M, et al. Families' and physicians' predictions of dialysis patients' preferences regarding life-sustaining treatments in Japan. *Am J Kidney Dis* 2006;47:122–130. Available at: <http://linkinghub.elsevier.com/retrieve/pii/S0272638605015167>. Accessed May 23, 2017.
62. Rodríguez Jornet A, Ibeas J, Real J, Peña S, Martínez Ocaña JC, García García M. [Advance directives in chronic dialysis patients]. *Nefrologia* 2007;27:581–592.
63. Nishimura A, Mueller PS, Evenson LK, et al. Patients who complete advance directives and what they prefer. *Mayo Clin Proc* 2007;82:1480–1486.
64. Al-Jahdali HH, Bahroon S, Babgi Y, Tamim H, Al-Ghamdi SM, Al-Sayyari AA. Advance care planning preferences among dialysis patients and factors influencing their decisions. *Saudi J Kidney Dis Transpl* 2009;20:232–239.
65. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 2010;5:195–204.
66. Kataoka-Yahiro MR, Conde FA, Wong RS, Page V, Peller B. Advance care planning among Asian Americans and Native Hawaiians receiving haemodialysis. *Int J Palliat Nurs* 2010;16:32–40. Available at: <http://www.magonlineibrary.com/doi/abs/10.12968/ijpn.2010.16.1.46181>.
67. Kurella Tamura M, Goldstein MK, Pérez-Stable EJ. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transpl* 2010;25:237–242.
68. Sánchez-Tomero JA, Rodríguez-Jornet A, Balda S, et al. Exploring the opinion of CKD patients on dialysis regarding end-of-life and Advance Care Planning. *Nefrologia* 2011;31:449–456.
69. Brown MA, Crail SM, Masterson R, et al. ANZSN renal supportive care 2013: opinion pieces [corrected]. *Nephrology (Carlton)* 2013;18:401–454. Available at: <http://doi.wiley.com/10.1111/nep.12065>. Accessed September 4, 2017.
70. Davison SN. The ethics of end-of-life care for patients with ESRD. *Clin J Am Soc Nephrol* 2012;7:2049–2057.
71. Gomm S, Farrington K. End of Life Care in Advanced Kidney Disease: A Framework for Implementation. London: NHS Improving Quality, 2015. Available at: <http://webarchive.nationalarchives.gov.uk/20160506191033/http://www.nhs.uk/nhs.uk/11739.aspx>.
72. Ontario Renal Network. Ontario Renal Network Palliative Care Report. Toronto: Cancer Care Ontario, 2016. Available at: <http://www.renalnetwork.on.ca/common/pages/UserFile.aspx?fileId=360709>.
73. Russon L, Mooney A. Palliative and end-of-life care in advanced renal failure. *Clin Med J R Coll Physicians Lond* 2010;10:279–281.
74. Warwick G, Mooney A, Russon L, Hardy R. Planning, Initiating and Withdrawal of Renal Replacement Therapy UK Renal Association 6 th Edition Draft Version (Feb 2013) Introduction Summary of clinical practice guidelines for Planning, Initiating and Withdrawal of Renal Replacement Therapy Summa. Bristol: UK Renal Association, 2013. Available at: <http://www.renal.org/docs/default-source/guidelines-resources/final-guideline-for-planning-initiation-withdrawal-of-rrt.pdf>.
75. Leventhal H, Nerenz D, Steele D. Illness representations and coping with health threats. In: Baum A, Singer J, eds. *Handbook of psychology and health, IV*. New York: Erlbaum, 1984:221–252.
76. Leventhal H, Diefenback M. The active side of illness cognition. In: Skelton J, Croyle R, eds. *Mental representation in health and illness*. New York: Springer Verlag, 1991:247–272.
77. Donovan HS, Ward S. A representational approach to patient education. *J Nurs Scholarsh* 2001;33:211–216.
78. Donovan HS, Ward SE, Song M-K, Heidrich SM, Gunnarsdottir S, Phillips CM. An update on the representational approach to patient education. *J Nurs Scholarsh* 2007;39:259–265. Available at: <http://doi.wiley.com/10.1111/j.1547-5069.2007.00178.x>. Accessed August 23, 2017.
79. Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process* 1991;50:179–211. Available at: <http://linkinghub.elsevier.com/retrieve/pii/074959789190020T>. Accessed August 30, 2017.

Appendix

Supplemental Table 1
Empirical Studies

First Author, Country, and Objectives	Population, Setting, and Intervention	Design and Methodological Rigor (Strong/Moderate/Weak)	Key Results	How the Intervention Was Thought to Work	Contextual Features Thought to Influence Implementation
<p>Systematic reviews</p> <p>Lim (2016), Australia. Objectives: To determine whether advance care planning in hemodialysis patients, compared with no or less-structured forms of advance care planning, can result in fewer hospital admissions or less use of treatments with life-prolonging or curative intent, and if patient's wishes were followed at end of life.</p>	<p>Systematic review: RCTs or quasi-RCTs with hemodialysis patients. Intervention: ACP is where the responsible physician helps the patient (with their family) to reflect on their future care, consults the patient on their priorities and preferences and levels of care, manages transition from active to palliative care, and, together with any spokesperson appointed by the patient, acts as an advocate for the patient in the event of incapacity, drawing on the patient's documented preferences.</p>	<p>Systematic review. Rigor: Strong (comprehensive search strategy and rigorous assessment of study quality).</p>	<p>Two studies (three reports) that involved 337 participants investigated advance care planning for people with ESKD. Neither of the included studies reported outcomes relevant to the review. Study quality was assessed as suboptimal. The results suggested patients were highly satisfied with the quality of communication and greater levels of comfort. Discussion regarding ACP and end-of-life care did not destroy hope or cause unnecessary discomfort or anxiety to patients. Given the lack of evidence for advance care planning for people receiving hemodialysis, large scale, well-designed RCTs involving people with ESKD are necessary to determine the efficacy and value of advance care planning for patients.</p>	<p>Aiding patients to establish options and priorities for end-of-life care enables preferences to be maintained according to individual wishes. ACP enables patients to prepare for death, strengthen relationships with loved ones, achieve control over their lives, and relieve burden on others.</p>	<p>The most significant barrier may be lack of physician intervention to initiate and guide advance care planning discussions.</p>
<p>Luckett (2014), Australia. Review objectives: 1) To identify what interventions have been developed, piloted, and evaluated. 2) To identify which measures have been used in intervention and other studies. 3) To establish evidence for the efficacy of interventions. 4) To inform understanding of barriers and facilitators</p>	<p>Systematic review: Samples had to be adults with a primary diagnosis of CKD and/or families and the health professionals caring for this group. Intervention: 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.</p>	<p>Systematic integrative review using narrative and meta-analysis. Rigor: Strong (comprehensive search, assessment of study quality, rigorous meta-analysis/synthesis).</p>	<p>Fifty-five papers were included in the review. 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. Qualitative studies showed the importance of</p>	<p>Loss of cognitive capacity is common, leaving families and nephrologists to decide whether to withdraw dialysis, so that patients may continue on dialysis or be resuscitated or ventilated, when they would have chosen otherwise. ACP facilitates an opportunity for discussion of treatment preferences, ensuring health care providers and family members are aware of patients' wishes.</p>	<p>Interventions do not give comprehensive attention to patient, caregiver, health professional, and system-related factors. Implementation enhanced by educating staff on the benefits of early ACP and ensuring staff have time for ACP as "core business." Patients tended to wait for health professionals to raise ACP and dramatically overestimated their life expectancy; nephrologists discussed EOL issues</p>

to implementation as well as stakeholders' perceptions of ideal approaches.

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).

based on prognosis but struggled to identify a suitable juncture; nurses felt uncomfortable raising ACP for fear of upsetting patients, families, and senior staff; judging the optimal timing for the ACP was difficult. Surrogates are influenced by their ideas rather than patient preferences, leading to poor congruence concerning EOL care decisions such as discontinuation of dialysis.

Noble (2008), UK.

Review questions:

- 1) What are the experiences of those opting not to have dialysis to treat renal disease and their carers?
- 2) What is the difference in experience and trajectory to death, for those withdrawing from dialysis compared with those choosing not to start dialysis?

Systematic review: Studies were included if they had been peer-reviewed and included adult populations with a principal diagnosis of ESRD.

No specific intervention but advance care planning was included.

Systematic narrative review:

Papers were themed. Rigor: Weak (quality of studies not assessed; analysis is not clearly reported).

Of eight intervention studies identified, four were RCTs, two used a predesign/postdesign, and two reported postdata without comparison. Rating of bias identified six of these studies as poor quality and two as fair.

Fifty-one quantitative papers and three qualitative papers included in the review.

The presence of an advance directive requesting the cessation of dialysis, in addition to the family preference to stop dialysis, led to most nephrologists saying that they would stop dialysis. American nephrologists were more likely to stop than German or Japanese nephrologists. If the family disagreed with the patient's advance directive, nephrologists were less willing to stop dialysis.

Patients identified hope as central to the advance care planning process in that hope helped them to identify future goals of care and influenced their willingness to engage in end-of-life discussions.

Potential barriers to hope were a reliance on health care professionals to initiate end-of-life discussions and the need for staff to focus on their daily clinical work.

Randomized controlled trials

Briggs (2004), USA

Objectives: To examine feasibility of patient-centered advance care planning (PC-ACP) and reliability of data collection instruments.

Patients aged 50 yrs or more (and surrogates) attending heart failure, renal dialysis, and cardiovascular surgery clinics.

Intervention: One-hour PC-ACP interview, delivered by an experienced ACP facilitator; focused on patient understanding/misconceptions of condition and ACP; what the patient would want the

Pilot RCT: patient/surrogate pairs. Randomized to PC-ACP ($n = 13$) or "usual care" ($n = 14$)—written material on advance directives, with referrals to trained advance care planning facilitators if requested. Predialysis patients offered a class on dialysis treatment choices and consequences.

The experimental group had superior outcomes in congruence in statement of treatment preferences, decisional conflict, and patient's perceived quality of communication; but not in surrogate's perceived quality of communication, patient knowledge of ACP, or surrogate knowledge of ACP.

Deeply involving the surrogate as the patient clarifies their values and preferences will enable them to better represent the patient.

Interviewer skilled in facilitating difficult conversations regarding future medical care.

(Continued)

Supplemental Table 1
Continued

First Author, Country, and Objectives	Population, Setting, and Intervention	Design and Methodological Rigor (Strong/Moderate/Weak)	Key Results	How the Intervention Was Thought to Work	Contextual Features Thought to Influence Implementation
Kirchhoff (2012); USA Objectives: 1) to identify patient choices using patient-centered advance care planning (PC-ACP) compared with usual care, and 2) for those patients who died, to assess whether their EOL care was in accord with their choices stated on study intake.	<p>chosen surrogate to understand and act on; summary of choices and need for future discussions.</p> <p>Patients (and their surrogates) with a diagnosis of end-stage congestive heart failure (CHF) or ESRD; at risk of serious complication or death in the next two years; receiving outpatient medical care, from two centers in Wisconsin.</p> <p>Intervention: 1–1.5 hour PC-ACP interview, delivered by a trained ACP facilitator to assess the patient and surrogate understanding of illness; provide information about treatment options and their benefits and burden; assist in documentation of treatment preferences; help prepare surrogates to make decisions that honor the patient's preferences; ending with the documentation of patient preferences for care using the Statement of Treatment Preferences form.</p>	<p>Rigor: Weak (Randomization not concealed. Gender and surrogate (spouse/child) imbalance in the groups. Small sample size).</p> <p>RCT: 313 patients with CHF ($n = 179$) or ESRD ($n = 134$) and their surrogates who were randomized to receive either PC-ACP ($n = 160$; CHF = 88, $r = 70$) or usual care ($n = 153$; CHF = 89, $r = 64$).</p> <p>Rigor: Moderate (clear objectives, adequate randomization, not blinded, good follow-up, underpowered).</p>	<p>Among ESKD patients, significantly more experimental patients (37.7%) chose to withdraw from dialysis than controls (17%)—however, this was not discussed in the interview.</p> <p>Hundred and ten deaths; 74% ($n = 81$) of the patients made their own decisions until death and therefore received care in accord with their wishes. Patients and surrogates were usually appreciative of discussions. They asked why no one had raised these issues earlier.</p>	<p>When we are doing disease-specific planning, we are really helping prepare both the surrogate and the patient to face future decisions in a more informed and prepared way.</p>	<p>The facilitators (selected nurses, social workers, and chaplains) were trained in delivery of the intervention and observed during the study. They received video-taping, evaluation, and feedback.</p> <p>Health professionals reluctant to hold sensitive discussions. Routinizing the discussions requires a facilitator and dedicated time, checking to see if preferences have changed.</p>
Perry (2005); USA Objectives: To explore the impact of peer mentors (dialysis patients trained to help other patients) on end-of-life planning.	<p>Patients from 21 dialysis centers across Michigan.</p> <p>Intervention: Peers were trained through an advance directive (AD) workshop and also completed their own ADs. Eight contacts with patients over a two- to four-month period: three face-</p>	<p>RCT: 203 participants in three groups: usual care ($n = 81$); printed material on AD ($n = 59$); peer intervention ($n = 63$).</p> <p>Rigor: Moderate (randomization briefly described; nonblinded outcome assessment).</p>	<p>Peer mentoring significantly increased the completion of ADs overall; most prominently among African Americans, also improving comfort discussing subjective wellbeing and anxiety. Among white patients, printed material on ADs</p>	<p>Face-to-face relationship with someone with similar experiences engenders trust, which motivates completion of ADs.</p>	<p>African Americans may be more open to peer interventions because their culture partakes of oral, rather than written traditions, which may be mistrusted.</p>

<p>Song (2010), USA Objectives: To determine the feasibility and acceptability of patient-centered advance care planning (PC-ACP) among African Americans and their surrogate decision-makers.</p>	<p>to-face and five by phone. Discussion of chronic illness experiences, values, spirituality, fears, AD issues, and documents.</p> <p>African Americans over 18 with stage 5 CKD receiving either center hemodialysis or home peritoneal dialysis for at least three months and their surrogates.</p> <p>Intervention: One-hour PC-ACP interview, delivered by a trained ACP facilitator. Addressing: 1) representational assessment of participants' beliefs about their illness; 2) exploration of misunderstandings about CKD and life-sustaining treatment, including dialysis; 3) creation of conditions for conceptual change; 4) introduction of replacement information; and 5) summarization of the discussion.</p>	<p>Pilot RCT: 19 patient/surrogate pairs. Randomized to PC-ACP ($n = 11$) or "usual care" ($n = 8$)—written information on advance directives provided by a nurse or social worker who encouraged patients to complete an AD and addressed their questions about life-sustaining treatment options. Questions about medical options were referred to physicians.</p> <p>Rigor: Moderate (clearly focused question, randomization acceptable, outcome data collectors blinded, very small sample size).</p>	<p>decreased reported suicidal ideation.</p> <p>Significantly greater congruence and quality of communication in the intervention dyads.</p> <p>No significant difference in patient-clinician interaction, patient's difficulty in making choices, surrogate's comfort in decision-making, or psychospiritual wellbeing of the patient and surrogate.</p> <p>A shift among participants toward using all possible life-sustaining treatments to prolong their lives.</p>	<p>PC-ACP promotes skills related to initiating discussions, assisting individuals in the identification of values and goals related to their health care, and developing educational and organizational systems that are effective in implementing an individual's plan of care.</p>	<p>African Americans typically prefer continuing life-sustaining treatment.</p>
<p>Song (2015); USA Objectives: To test the effect of an ACP intervention on preparation for EOL decision-making for dialysis patients and surrogates, and for surrogates' bereavement outcomes.</p>	<p>Patients dialyzed for at least six months and at risk of dying in the next 12 months, and their surrogates, from 20 dialysis centers in North Carolina.</p> <p>Intervention: A psychoeducational intervention to help patients clarify EOL preferences and prepare the surrogate for making decisions on the patient's behalf, with a trained nurse facilitator at the center and a follow-up session at home two weeks later, with completion of a "goals of care" document to indicate patient preferences and ADs. Facilitator adherence to protocol monitored.</p>	<p>RCT: 210 dyads randomized to intervention ($n = 109$) and control ($n = 101$) groups.</p> <p>Rigor: Strong (concealed randomization, blinded outcome assessment, sample size adequate, although small for bereavement measures).</p>	<p>Dyad congruence and surrogate decision-making confidence were better in the intervention group, but patient decisional conflict did not differ between groups.</p> <p>Forty-five patients died during the study. Intervention surrogates had less anxiety, depression, and post-traumatic distress than controls.</p>	<p>ACP can help prepare patients and surrogates for treatment decision-making at the end of life by providing individualized information on effectiveness of mechanical supports at the end of life; by helping the patient to clarify values; and by actively involving the surrogate to help prepare for the emotional burden of decision-making.</p>	<p>Intervention sessions were audited for fidelity and refresher training offered. African Americans have been reported as less amenable to ACP, but the focus on decision-making rather than advance directives could have made this more acceptable.</p>

(Continued)

Supplemental Table 1
Continued

First Author, Country, and Objectives	Population, Setting, and Intervention	Design and Methodological Rigor (Strong/Moderate/Weak)	Key Results	How the Intervention Was Thought to Work	Contextual Features Thought to Influence Implementation
<p>Song (2016)*; USA Objectives: To compare the efficacy of an ACP intervention on preparation for end-of-life decision-making and postbereavement outcomes for African Americans and whites on dialysis. *A secondary analysis of data from Song (2015)</p>	<p>Patients dialyzed for at least six months and at risk of dying in the next 12 months, and their surrogates, from 20 dialysis centers in North Carolina. Intervention: a psychoeducational intervention to help patients clarify EOL preferences and prepare the surrogate for making decisions on the patient's behalf, with a trained nurse facilitator at the center and a follow-up session at home two weeks later, with completion of a "goals of care" document to indicate patient preferences and ADs. Facilitator adherence to protocol monitored.</p>	<p>A secondary analysis of data from a randomized trial comparing an ACP intervention (Sharing Patient's Illness Representations to Increase Trust [SPIRIT]) with usual care was conducted. There were 420 participants and 210 patient-surrogate dyads (67.4% African Americans). Rigor: Moderate (the study was not powered to test the interaction of the intervention with race).</p>	<p>Among African Americans (but not whites), the intervention was superior to usual care in improving dyad congruence and surrogate decision-making confidence two months after intervention and in reducing surrogates' bereavement depressive symptoms.</p>	<p>ACP can help prepare patients and surrogates for treatment decision-making at the end of life by providing individualized information on effectiveness of mechanical supports at the end of life, by helping the patient to clarify values, and by actively involving the surrogate to help prepare for the emotional burden of decision-making.</p>	<p>It may be that the intervention aligns with African Americans' familial, religious, and communal frame of reference; whites in the control group seemed to benefit simply from being asked thought-provoking questions repeatedly.</p>
<p>Non-RCT intervention studies Eneanya (2015), USA Objectives: To test the shared decision-making renal supportive care communication intervention to systematically elicit patient and caretaker preferences for end-of-life care so that care concordant with patients' goals can be provided.</p>	<p>Hemodialysis patients who are at high risk of death in the ensuing six months, attending 16 dialysis units associated with two large academic centers. Intervention: Nephrologists and social workers will communicate prognosis and provide EOL planning in face-to-face encounters with patients and families using a social work-centered algorithm. Follow-up sessions with the social worker will take place monthly to provide further support, education, information, and referral to resources such as hospice.</p>	<p>Protocol for a prospective cohort study with a retrospective cohort serving as the comparison group.</p>	<p>Protocol: No results</p>	<p>The intervention systematically elicits patient preferences for EOL care, so that concordant care can be provided.</p>	
<p>Hayek (2014), USA. Objectives: To examine the</p>	<p>Hundred and fifty-seven patients aged >65 yrs,</p>	<p>Design: Test-retest of nonequivalent</p>	<p>Of the initial pre-intervention sample</p>	<p>By adding AD to the patient's active problem list, its</p>	<p>E-mail and visual alerts contribute to information</p>

<p>effectiveness of an electronic medical record (EMR)-based reminder in improving AD documentation rates.</p>	<p>CHF, COPD, AIDS, malignancy, cirrhosis, ESRD, or stroke attending a hospital outpatient clinic. Intervention: Adding a visual reminder of “Advanced Directives Counseling” to the EMR problem list of outpatients with high risk for morbidity/mortality.</p>	<p>groups—initial cross-sectional estimation of the percentage of patients with documented ADs; retested twice over the following year. Rigor: Weak (design open to confounding, fair sample size. Lack of detail on physicians’ AD discussions with patients).</p>	<p>(n=100) none had AD documented. 588 patients were screened and 157 (26.7%) were eligible. Over 6 months, 64 of these patients were seen in clinic; 38 had AD on their problem list. By the end of the study, 29 (76%) charts with the EMR reminder had documentation of an AD, compared to 3 (11.5%) of those without. Results suggest that EMR reminders may improve AD documentation rates.</p>	<p>importance is highlighted and seen as equivalent as the patient’s medical problems, therefore encouraging physicians to address them.</p>	<p>overload, leading physicians often to either ignore or avoid them. The intervention in the present study was simple, cost-effective and did not require any extra financial or human resources. Combining AD discussions with the outpatient visit workflow serves as a reminder to the health care provider.</p>
<p>Seal (2007), Australia Objectives: To explain the role of patient advocacy in the advance care planning process.</p>	<p>Nurses on the palliative care, respiratory, renal and colorectal pilot wards, and the hem-oncology coronary care, cardiology, and neurology/geriatric control wards. Intervention: The Respecting Patient Choices Program (RPCP) to improve use of AD through a framework of educative, patient information, safety and quality systems, and policy support for ACP, plus equipping mainly nurses, through a comprehensive two day training course, with skills and resources to facilitate the process.</p>	<p>A prospective nonrandomized controlled trial, with focus groups. 74 in the intervention group; 69 in the control group. Rigor: Weak (nonvalidated questionnaires; nonrandomized trial with nonequivalent control group).</p>	<p>Statistically significant differences in favor of the intervention wards in nurses’ self-reported willingness, efficacy, and job satisfaction in relation to upholding patients informed choices about their end-of-life treatment, supported by focus group findings.</p>	<p>Being able to provide information to patients while they were still well enough to talk with their families stimulated communication, enabling people to determine their future care and easing their concerns about loss of control. The program provided a legitimate platform for nurses to empower patients and to advocate on their behalf.</p>	<p>Organizational endorsement of ACP with framework of RPCP encouraged nurses to be patient advocates. Pressure from medical staff and relatives to treat at all costs can prevent the patients’ wishes being respected.</p>
<p>Weisbord (2003), USA. Objectives: To identify symptom burden, health-related quality of life (HRQoL) and advance directives in extremely ill hemodialysis patients to assess their suitability for palliative care and to ascertain the acceptability of palliative care to patients and specialist health professionals.</p>	<p>Nineteen patients who received outpatient dialysis three times per week in a hospital, for at least three months, and had modified Charlson comorbidity scores of P8.</p>	<p>Single-group test-retest study. Each patient completed surveys to assess symptom burden, HRQoL, and prior advance care planning. Palliative care specialists then visited patients twice and generated recommendations. Patients again completed the surveys, and dialysis charts were reviewed to assess nephrologists’ compliance with recommendations and nephrologists’</p>	<p>Patients: mean age 67 yrs, majority male, six of the 19 patients died before end of the study. Advance care planning: Twelve patients (63%) had never spoken to their nephrologist about their wishes for care at the end of life; five (26%) had never spoken to their family or friends. Six (32%) had executed a living will, and of these, four had informed their nephrologist verbally and three had presented a copy</p>	<p>Patients have significant symptom burden and impaired HRQoL. Only a small number officially documented their wishes for their future care.</p>	<p>Nephrologists did not implement recommendations related to addressing advance directives or to pursuing workup for ongoing medical problems. Patients may discuss these issues with nurses, dieticians, and social workers, so incorporating palliative care may depend on their input.</p>

(Continued)

Supplemental Table 1
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First Author, Country, and Objectives	Population, Setting, and Intervention	Design and Methodological Rigor (Strong/Moderate/Weak)	Key Results	How the Intervention Was Thought to Work	Contextual Features Thought to Influence Implementation
		documentation of symptoms reported by patients on the symptom assessment survey. Rigor: Weak (small, single-group test-retest study).	of the document to their nephrologist. Seventeen patients (89%) reported having someone they desired to make medical decisions for them at the end of life; six (32%) had formally appointed this person in writing as a surrogate decision-maker. Postintervention assessment: no differences were observed in symptoms, HRQoL, or number of patients making advance directives as a result of the intervention.		

First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
Observational studies Al-Jahdali (2009), Saudi Arabia. Objectives: To examine the preferences for CPR and end of life medical intervention among Saudi HD patients.	Hundred patients from two hospitals hemodialyzed for two yrs or more (mean duration 6.0 years).	Multicenter cross-sectional, observational study. Data collection: questionnaire completed during dialysis capturing demographics, education, employment, family size, knowledge of CPR, mechanical ventilation, and ICU admission; and responses to scenarios on EOL decisions, medical interventions, CPR, ICU admission, and surrogate decision-makers. Rigor: Moderate (questionnaire trialed on a sample of patients, appropriate use of statistics to interpret data).	More than 95% of patients had little or no knowledge about CPR, intubation, and mechanical ventilation; majority wanted their physician to make decisions about CPR if they did not have an AD, and only 22% believed that decisions should be made by family members. Overall, physicians should advise patients about their disease/prognosis and discuss the effects of future medical interventions. Informed patients can make rational choices about EOL issues.	Limited patient education about CPR and ventilatory support. ACP preferences are rarely discussed with patients and their families. Physicians may lack time, training, or be uncomfortable with EOL discussions.	In Saudi society, ADs are not routinely discussed (not for religious reasons but) because physicians fear distressing patients.
Anderson (2006), USA. Objectives: To establish the preferences and directives of severely ill dialysis	Hundred and nine peritoneal dialysis (PD) patients in an academic nursing home.	Design: Retrospective chart review of PD patients. Patients were followed up to death or loss to follow-	60.6% of patients were women, 54.1% were white, 45.0% African American, and 0.9% Asian.	Nonadherence with DNH and ACPR plans may have occurred due to decisions about hospitalization	The near-complete participation with ACP is attributable to the facility's explicit

<p>patients/surrogates and whether these change with time or are influenced by patient's functional status; and whether ACPs established by patients correlate with clinical outcomes.</p>		<p>up during a 14-year period (1986 to 2000). Rigor: Strong (all data extracted systematically and appropriate use of statistics).</p>	<p>ACPs were obtained for 108 patients. Do not attempt resuscitation (DNAR) status was significantly associated with increased age, lower ADL scores, coronary disease, amputation, and dementia. In compliance with ACP: patients indicating do not hospitalize (DNH) spent as much time in hospital as those planning to accept hospitalization. Seven of 46 patients designated attempt CPR (ACPR) had CPR attempted. For these chronically ill patients, age and functional status strongly influence DNAR and DNH plans. ACP was not conclusive in determining events during acute illness.</p>	<p>during times of acute illness with patients who retained capacity (or their surrogates) who changed their minds. CPR not being attempted for ACPR patients may be because CPR is rarely performed in nursing homes.</p>	<p>requirement for ACP, the commitment of staff in ACP participation, and high rates of face-to-face discussions with patients and family. African American patients participated in ACP as often as whites due to discussions and inclusion of family members.</p>
<p>Calvin (2006), USA. Objectives: To develop an instrument to assess readiness of patients with chronic kidney disease to discuss advance care plans.</p>	<p>Questionnaire assessed for content validity by a panel of four experts in end-of-life care, and a patient panel of five persons currently being treated with HD in an inpatient setting. Thirty-item instrument piloted with another sample of 10 patients on HD.</p>	<p>Design: Development of a questionnaire. Rigor: Weak (content validity and reliability assessed in the instrument but only using a small sample. Inadequate reporting of results from the pilot questionnaire).</p>	<p>Content validity—Most patients rated the items as very relevant and very clear, but the professional panel ratings were more varied. Reliability—Cronbach's alpha (0.88) for the 30-item questionnaire. Patients also reported the item was "helpful and not difficult" and "gave me something to think about."</p>	<p>The questionnaire has the potential to ease the initiation of ACP discussions for health care providers—AD completion may remain low among patients with kidney failure because health care professionals are not assessing patient readiness to discuss ACP.</p>	
<p>Collins (2013), Ireland. Objectives: To investigate the views of HD patients on death and dying; beliefs about what is worse than death; likelihood of talking about death and dying and issues related to end-of-life care and ACP.</p>	<p>Fifty HD (minimum three months) adult patients attending a hospital dialysis unit.</p>	<p>Design: Cross-sectional, questionnaire (modified version of the EOL survey developed by Life's End Institute) survey with a convenience sample of all adult patients. Rigor: Moderate (clear objectives, adequately sized convenience sample).</p>	<p>Most participants were comfortable discussing death, but not always among family, with most wanting medical interventions to extend life. The control of pain and other symptoms, being physically comfortable and being at peace spiritually were the most important issues at end of life.</p>	<p>Generally, dialysis patients believed that their chances of survival were as good as anyone else's and did not see themselves as having a terminal illness, so issues relating to death and dying were rarely considered. The majority wanted medical intervention to extend life.</p>	<p>ADs have no legal status in Ireland, and very few people are aware of their existence. Health care professionals developed good relationships with patients allowing the discussion of sensitive topics and providing accurate information supported informed decisions.</p>

(Continued)

Supplemental Table 1
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First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
Davison (2010), Canada. Objectives: To evaluate EOL care preferences of CKD patients, highlight gaps between current EOL care practice and patients' preferences, and to help prioritize and direct future innovation in EOL care policy.	Hundred CKD patients (stages 4 and 5) in dialysis, transplantation, or predialysis clinics in a university-based renal program.	Design: Survey development and implementation ($n = 584$). Survey developed from literature review aiming to identify patients' preferences and expectations of EOL care, such as place of death, symptom treatment, and advance care planning. Preferences for hypothetical clinical EOL scenarios were also included. Rigor: Strong (survey rigorously reviewed by experts and piloted in four dialysis units; large sample).	Patients relied on decision-making by the nephrology staff for EOL care; pain and symptom management, ACP, and psychosocial and spiritual support. ACP: Patients were comfortable discussing EOL issues with family and nephrology staff, yet less than 10% had done so, and only 38.2% had completed an advance directive Patients had poor knowledge of palliative care options and of their illness trajectory; 84.6% felt well informed but only 17.9% felt that their health would deteriorate over the next year. 61% regretted their decision to start dialysis. EOL care that patients most wanted was better education and support for staff, patients, and families, greater involvement of family, more focus on pain and symptom management, what to expect clinically near the end of life, palliative care, and hospice services.	CKD patients need to be better informed with EOL care issues; symptom management was a significant priority for patients but pain in CKD is both underrecognized and undertreated. Current EOL clinical practices do not meet the needs of patients with advanced CKD.	Doctors and nurses are vital for providing emotional, social, and spiritual support. However, a focus on technology has drawn physicians away, leaving emotional and spiritual support mainly to nursing staff and other professionals such as social workers and spiritual counselors.
Feely (2016), USA. Objectives: To retrospectively examine the prevalence and contents of ADs used by HD patients.	Review of medical records of all HD patients ($n = 808$) in an academic medical center.	Design: Retrospective review of medical records of all HD patients over a five-year period (2007–2012). Data collected: Demographics, prevalence of ADs, and content analysis of those ADs with emphasis on management of EOL interventions	Forty-nine percent had ADs; 10.6% mentioned dialysis; and 3% specifically addressed dialysis management at EOL. Patients who had ADs were older. For HD patients who had ADs, more addressed CPR, mechanical ventilation, artificial	Patients may have had ADs because they are more aware of their reduced life span and are encouraged by health professionals, especially, when they have comorbidities and see a range of professionals.	Patients receiving in-center HD come into contact with several health care professionals and create multiple opportunities for this high-risk group to complete ACP.

<p>Janssen (2013), The Netherlands Objectives: To investigate HD patient preferences for life-sustaining treatments; and to examine the quality of patient-physician communication about EOL care, including barriers and facilitators to this communication.</p>	<p>Eighty ESRD HD patients attending dialysis departments in six hospitals.</p>	<p>including dialysis. Rigor: Strong (large sample size, clear objectives, and results well described and discussed). Design: Cross-sectional, observational study examined palliative care needs using a convenience sample of ESRD patients. Validated questionnaires, administered at home or during dialysis sessions, to measure comorbidity, quality of life, willingness to accept life-sustaining treatment, and quality of/ barriers to communication. Nephrologists completed a questionnaire on ACP for each patient to evaluate if they discussed prognosis of survival, preferences for CPR and mechanical ventilation, the EOL, and palliative care with the patient.</p>	<p>nutrition and hydration, and pain management than dialysis. All patients communicated their choices for life-sustaining treatments and place of death. Thirty percent of patients discussed life-sustaining treatments with their nephrologist, and quality of patient-physician communication about EOL care was rated poor. Barriers and facilitators to end-of-life care communication were identified, e.g., barrier's "I would rather concentrate on staying alive than talk about death"; and facilitators "my doctor cares about me as a person."</p>	<p>Sixty-five percent of patients reported that they were not ready to talk about the care they want if they get very sick, making it unlikely that they would initiate ACP discussions. Patient-physician communication about end-of-life care is poor: prognosis, dying, and spirituality are infrequently discussed. Most patients stated that they wanted CPR but are likely not aware of low success rates with CPR.</p>	<p>In this setting, continuity of care was lacking and patients did not know which doctor was going to be caring for them at the EOL, which hindered development of ACP.</p>
<p>Rodriguez Jornet (2007), Spain. Objectives: To investigate dialysis patients' wishes for health care if their condition became untreatable; and to provide patients the opportunity to create an AD.</p>	<p>Hundred and thirty-five dialysis patients (aged 18–95 yrs) on dialysis for more than three months and not expected to die within three months.</p>	<p>Rigor: Moderate (small convenience sample but validated questionnaires used). Design: Questionnaire gathering data on demographics, medical status, and preference for interventions in the event of deterioration. Rigor: Weak (statistics not a good fit for the design and no details regarding validation of the questionnaire).</p>	<p>Sixty-four patients (47.8%) did not want CPR, respirator, tube feeding, or dialysis in case of coma, persistent vegetative state, severe dementia or terminal illness. Preference for nonintervention associated with older age. ACP occurs with both the physician-patient and also within the family especially with their children as decision-makers. Reasons for not responding to the questionnaires were patient reluctance to think about those situations and fear of their answers being misinterpreted.</p>	<p>Patients were more likely to create an AD if they had experience of a family member previously being ill.</p>	<p>Physicians are somewhat reluctant to talk about the issue of ADs with patients.</p>

(Continued)

Supplemental Table 1
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First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
Kataoka-Yahiro (2010), USA Objectives: To ascertain the attitudes to death and dying and completion of ACP among Asian American (AA) and native Hawaiian (NH) patients receiving hemodialysis for stage 4–5 CKD; and to discover with whom such patients prefer to discuss ACP.	Fifty outpatients from four dialysis centers; patients were of AA or NH ethnicity; stage 4–5 CKD.	Design: Descriptive, cross-sectional survey design. A convenience sample of 50 participants aged 30–82 yrs was interviewed face-to-face. Data collection: EOL survey (43-item questionnaire) along with demographic information such as gender, age, ethnicity, marital status, level of education, current employment status, and annual household income. Rigor: Moderate (limited sample and survey questions were not developed from the theory of planned behavior framework; therefore, concepts can only be described and explored and compared descriptively).	Most participants perceived dying as an important part of life and were comfortable talking about death but expressed concerns and fears about EOL issues. Aspects of ACP, such as planning a funeral service, getting finances in order, and completing the will were important. Most participants' attitudes about ACP were positive, but less than half (40%) had completed ACP. AAs and NHs would prefer to discuss ACP with family members rather than health or legal professionals.	If participants have strong beliefs about death, dying, and ACP and have a positive evaluation of ACP, they will more likely have a positive attitude toward ACP.	The authors commented that family involvement and discussion, and collective decision-making, are important among AAs and NHs.
Kurella Tamura (2010), USA. Objectives: To investigate whether preferences for withdrawal and engagement in ACP varies by age, race, or ethnicity.	Sixty-one patients (black, Latino, Asian, white) from two dialysis units.	Questionnaire designed to ascertain dialysis withdrawal preferences in five health states. Questionnaire and dialysis unit records used to find out engagement in ACP, completion of advance directives, do-not-resuscitate (DNR) or do-not-intubate orders. Rigor: Weak (no information on who administered questionnaires; small sample and subgroups).	Fifty-seven percent of participants reported EOL discussion with a health care provider; 38% had completed an advance directive, and 10% had a DNR order. Blacks and Asians were more likely to engage in EOL discussions, but no black or Latino participants completed DNR orders as compared with 10% of Asians and 24% of whites. Blacks less likely to prefer dialysis withdrawal compared with other ethnic groups; this difference not explained by age, education, comorbidity, and other	The results show that in this diverse population, age and race/ethnicity had clear patterns of association with treatment preferences and with engagement in ACP. Unexpectedly, younger patients and minorities did not have lower rates of engagement in each of the various aspects of ACP; rather the specific pattern of engagement differed by age and race/ethnicity groups.	ACP may be less likely to be completed in cultures where patients rely on family members to advocate for their care preferences.

<p>Miura (2006), Japan. Objectives: To assess how accurately family members and physicians can predict patients' wishes about medical care and treatment (including dialysis and CPR) under various medical scenarios.</p>	<p>Four hundred fifty dialysis patients in 15 hospitals and their family members and physicians.</p>	<p>Design: A questionnaire survey administered among 450 dialysis patients in 15 hospitals, along with their family members and physicians Data collection: Survey determined preferences for CPR and dialysis therapy under various circumstances. Rigor: Moderate (large, convenience sample; questionnaire was not validated, and patients and family had opportunity to discuss answers).</p>	<p>confounders. Rate of engagement in EOL discussions higher than documentation of ACP for all age and most ethnic groups. Three hundred ninety-eight (88%) patients/family members/physicians responded. Sixty-eight percent of family members correctly predicted patients' preferences for CPR. Sixty-seven percent predicted patients' preferences for dialysis if they were severely demented. Sixty-nine percent predicted patients' preferences for dialysis if they had terminal cancer. Corresponding figures for physicians were 60%, 68%, and 66%. However, Kappa coefficient analysis indicated that neither family members nor physicians more accurately predicted their patients' wishes about life-sustaining treatments than expected by chance alone. (All kappa coefficients <0.4.) Patients with specific EOL preferences should leave better advance directives. Median age of patients when they submitted an AD was 67 yrs. Of the 476 patients, 434 had a designated health care agent, and 340 had granted the agent powers to consent for procedures, to access information and to withhold and withdraw life-sustaining treatments. Three hundred thirty-nine had submitted a combined AD (incorporating a living will and a power of attorney).</p>	<p>Only half of patients expected their family members to correctly predict their wishes for CPR or continuation of dialysis therapy. These results suggest that it is impossible to know patient preferences without proper communication.</p>	<p>Japanese culture includes the belief that one's wishes are intuitively known to others; physicians may be paternalistic; and families may see withdrawal of treatment as abandoning their duty to the patient.</p>
<p>Nishimura (2007), USA. Objectives: To determine health care preferences expressed by patients in ADs and to identify characteristics of patients who completed them.</p>	<p>Four hundred seventy-six participants who were inpatients or outpatients of a hospital, with a range of conditions (only 32 with renal insufficiency), who submitted an AD.</p>	<p>Design: A computer-generated random sample (of >25,000 patients) was selected. Data were extracted from the hospital's electronic patient information system on AD characteristics (e.g. type of AD and number of pages), and contents (e.g., designation of health care agent, decision-making powers given to the agent, and specific health care requests) were recorded.</p>	<p>Knowledge of what types of information patients include (and do not include) would highlight the EOL concerns that are important to patients and possibly point out inadequacies in the current use of ADs. The most effective AD should allow a patient to name a health care agent, to state their preferences, is detailed yet easy to use, and is disease specific.</p>	<p>A combined AD seemed more convenient for the patients; long ADs could discourage patients; a variety of form types should be offered as some prefer writing more detailed comments and others not.</p>	

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Supplemental Table 1
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First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
Sanchez-Tomero (2011), Spain. Objectives: To examine patient familiarity with an advance directive document (ADD) and the proportion with an ADD or a legal representative; acceptance of AD in dialysis units, and patients' opinions regarding the ADD and their attitudes to EOL care.	Hundred and fifty-four dialysis patients in seven hospital or peripheral dialysis units.	Rigor: Strong (large random sample and ADs assessed by at least two reviewers). Patients received information explaining AD and completed a questionnaire designed to discover their opinions of the ADD. Rigor: Moderate (unclear if questionnaires were validated; however, large sample size, number of sites, and appropriate statistical analyses).	Most patients expressed a desire for pain control (308). For the clinical situations of dying or permanent unconsciousness, most patients (371) expressed the preference to avoid general life-support but did not explicitly address common life-sustaining treatments including CPR, HD, mechanical ventilation, artificial nutrition and hydration, blood transfusion. Questionnaires were distributed to 265 patients and 154 (58.11%) responded. Only 7.9% of patients had an ADD, and 6.6% had formally appointed a representative, but 60.9% had empowered another person to represent them and their wishes, should they lose capacity. Over 65% did not want mechanical ventilation, tube feeding, continued dialysis, or resuscitation if they had cardiac arrest. Most patients were clear as to their wishes for future care, but stating these in a written document was rare. Fifty-four percent said they would like to create an ADD, whereas 43.7% said they would not; 51.6% said that an ADD should be created before dialysis treatment begins, whereas 65% said that this option	The patients in this study had clear wishes regarding their EOL care, despite the lack of AD documentation. However, the authors commented on the importance of having these wishes written in an official ADD, which leads to a greater likelihood that they are respected.	In Spain, familiarity with ADDs is very limited, and patients may be suspicious that making an ADD will lead to doctors withholding necessary treatments. Hospital protocols would help facilitate ADDs.

<p>Schmidt (2015), USA. Objectives: To review the effect of advance care planning on withdrawal from dialysis, use of hospice, and location of death.</p>	<p>Sixty-five former dialysis patients who died over five years, who attended a rural outpatient dialysis unit.</p>	<p>Retrospective review of dialysis and medical records. Rigor: Weak (small sample, single center, little detail on data collection methods).</p>	<p>should only be given to people if they ask for it. Sixty-five deaths occurred during the five-year review period. Of these, 46 (71%) occurred out of hospital, and 33 (51%) followed withdrawal from dialysis. Advance care planning was associated with a low incidence of death in hospital and, among those who withdrew from dialysis, high use of hospice.</p>	<p>Patients were routinely asked if they had an AD and completed a “scope of treatment” form. Physicians discussed withdrawal of dialysis with those considered likely to die within six months.</p>	<p>Hospice care was actively recommended by physicians. A reluctance of many rural patients to travel the necessary distance for tertiary care clearly contributes to the low prevalence of in-hospital death, and all patients who died in hospital did so after an acute event prompted hospitalization. Some states demand</p>
<p>Song (2013), USA. Objectives: To describe how chronically seriously ill patients can be assisted to identify a surrogate who would act as their decision-maker if their condition suddenly deteriorates and whether these surrogates were the same as their documented emergency contacts.</p>	<p>Ninety-four African American or Caucasian patients attending outpatient dialysis centers in North Carolina for at least six months.</p>	<p>A descriptive cross-sectional study using eligibility assessment and baseline data from an ongoing efficacy trial of an EOL communication intervention. Rigor: Moderate (small convenience sample).</p>	<p>Three of the 94 patients already had a surrogate documented in an AD. The remaining 91 came to that decision after working through guiding questions with the recruiter. Thirty-two patients (34%) named a spouse, 29 (30.9%) named a child, 17 (18.1%) named a sibling, five (5.3%) named a parent, three (3.2%) named a friend, and eight (8.5%) named another person. Of the 94 surrogates, 60 (63.8%) were listed as emergency contact; 34 (36.2%) were not.</p>	<p>Without a named surrogate decision-maker, people acting as emergency contacts may find themselves becoming the decision-maker, despite neither the patient nor the emergency contact agreeing to this.</p>	<p>Some states demand notarization for an advance directive, and this may cause a reliance on emergency contacts for decision-making.</p>
<p>Yee (2011), Singapore. Objectives: To explore the knowledge, attitudes, and experience of renal health care professionals in Singapore with ACP for patients with ESRD.</p>	<p>Five hundred sixty-two renal physicians, renal nurses, renal medical social workers (MSWs), and other allied health professionals working in government hospitals, private sector, and</p>	<p>Cross-sectional survey: 41-item questionnaire with four sections: demographics of respondents, knowledge of, attitudes to, and experience of ACP. Survey “distributed” to</p>	<p>No differences in sociodemographic characteristics between those who appointed a different person for their surrogate versus those who appointed the emergency contact as a surrogate. Six hundred twenty surveys distributed; 562 returned (90.6% response rate). Hundred percent of MSWs considered ACP discussions part of their role, compared with 82.4% of doctors, 37.1% of</p>	<p>Physicians fear upsetting family, report lack of time, and perceive that Singaporeans may not be ready for ACP. In Asian societies, the family plays an important role in health-related decision</p>	

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Supplemental Table 1
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First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
	voluntary groups offering subsidized dialysis.	health care professionals working in renal units. Authors do not state how this was done, for example, by post or other means. Rigor: Strong (good sample size, high response rate, statistics were appropriate and well explained).	nurses, and 38.1% of other health professionals. MSWs and doctors had higher knowledge scores than the other groups. Nurses were least confident in discussing ACP and most afraid of distressing patients and families, whereas MSWs were most confident. For doctors, the main barriers to discussing ACP were shortage of time, concerns about family reaction, and their belief that patients were not ready to discuss ACP.		and may sometimes conflict with patient's preferences. ACP can be confused with AD (and AD with euthanasia) by professionals and patients. Nurses have most contact time with patients but most see ACP as part of the physician or MSW role.
Qualitative studies Bristowe (2014), UK Objectives: To develop and pilot a REal-specific Advanced Communication Training (REACT) program to address the needs of ESKD patients and renal professionals.	Patients with ESKD and professionals from two large renal units in London teaching hospitals.	Two-part study: 1) development of REACT by one multiprofessional focus group and patient experience survey ($n = 171$) and 2) piloting of the program with nine nurses/health care assistants and seven renal consultants. Rigor: Weak (generic satisfaction survey; small sample for evaluation of training).	Patient survey: 71% felt confident to ask questions; 65% felt treatment options had been clearly explained; but only 50% felt that their concerns were taken seriously; 48% felt that they had been sufficiently involved in treatment decisions. Focus group identified need for better information about EOL and patient/carer perspective; skills and practice for difficult discussions; opportunity to debrief. REACT was found acceptable, but no significant increase in staff confidence.	Inadequacies in EOL care for renal patients must be addressed, but renal professionals need tailored training and support to optimize their skills and address concerns in managing ACP discussions.	Challenges remain in prioritizing communication training in busy renal units and identifying funding to provide high-quality training with adequate follow-up.
Bristowe (2015), UK Objectives: To investigate experience of patients starting HD, impact on quality of life, and	Patients with ESKD from two NHS hospitals.	Qualitative study; semistructured interviews with 20 patients, from two NHS hospitals, purposively sampled for age, time on	Themes: Looking back, emotions of commencing hemodialysis; current experiences, illness, and treatment burdens; and	Given a changing population, there is a need for a culture shift from a "disease-focused" model toward a "holistic	"Conveyor belt" culture, with prioritization of "getting you on and off" rather than caring for the individual. This

preferences for future and EOL care to inform understanding and timing of ACP.		dialysis, and symptom burden. Thematic analysis. Rigor: Strong (careful data collection, analysis, and findings well described).	looking Ahead, facing the realities. Challenges: Getting information, communicating with staff and “conveyor belt” culture of hemodialysis units, lack of opportunity to discuss their future if health deteriorated, and variable involvement in treatment decisions. Discussion of issues was more acceptable to some than others.	care-based” approach, normalizing discussions about preferences, priorities, and future care.	experience was compounded for those reliant on hospital transport, for which there was often a lengthy wait, with difficult recovery the next day. Staff avoid discussion of future due to fear of causing distress.
Calvin (2004); USA Objectives: To explore what happens as hemodialysis patients make decisions about EOL treatment and to develop a substantive theory to explain this phenomenon.	Hemodialysis patients attending three outpatient centers in central Texas.	Grounded theory; semistructured interviews with 20 participants. Rigor: Moderate (insufficient data presented to support the findings).	Patients chose to focus on living rather than dying. A substantive theory of “personal preservation” was developed. This consists of three phases: knowing the odds for survival, defining individuality (beating the odds, discovering meaning, being optimistic, and having faith in a higher force), and personal preservation (being responsible and taking chances).	When health care providers do not know what hemodialysis patients prefer with regard to life-sustaining treatment, they feel obligated to do everything possible to preserve patients’ lives.	Patients protected themselves by trusting their family members with EOL decisions and distancing themselves from death. Some patients saw advance directives as, primarily, for others’ legal protection, as opposed to their own autonomy.
Calvin (2014), USA Objectives: To explore hemodialysis patients’ family members’ understanding of EOL decision-making processes. Aimed to address 1) family members’ constructions of ACP and 2) family members’ perceptions of health care providers’ roles and responsibilities in ACP.	Family members of persons attending hemodialysis outpatient facilities in Houston.	A qualitative descriptive design, with a Glaserian approach to the analysis. Eighteen family members were recruited primarily from outpatient dialysis facilities and interviewed individually. Rigor: Strong (design and recruitment appropriate; analysis and findings clear).	Family members feel a call to duty to protect patients by 1) sharing burdens, 2) normalizing life, and 3) personalizing care. Participants and patients live with burdensome uncertainties. Participants spoke of health care providers’ general lack of care and struggled to articulate health care providers’ responsibilities in ACP because they had not experienced ACP. Participants avoided thoughts of death and normalized life to protect patients. Personalizing care involved being present during encounters with health care providers	To honor patients’ values and medical treatment preferences, health care providers need to communicate with family members because of the patient’s loss of decision-making capacity.	Lack of trust in health care providers. Patients, their families, and health care professionals are reluctant to discuss EOL treatment preferences or formulate advance directives.

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Supplemental Table 1
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First Author, Country, and Objectives	Population and Setting	Design, Methods of Data Collection, and Methodological Rigor (Strong/Moderate/Weak)	Key Results	Explanation of the Results	Contextual Features Thought to Influence Implementation
Davison & Simpson (2006), Canada Objective: To understand hope in the context of ACP from the perspective of patients with ESRD.	Patients with ESRD selected from the renal insufficiency, hemodialysis, and peritoneal dialysis clinics at a Canadian university-affiliated renal program.	Twenty-three individual interviews with 19 patients (14 expected to require dialysis within the next 12 months). Rigor: Strong (design and recruitment strategy appropriate, data analysis, and findings clear).	and respecting wishes. Participants' hopes were shaped by personal values. They perceived ACP as a means of enhancing hope by providing information early in the illness that focuses on the impact on daily life, empowering patients, and enhancing relationships with staff and loved ones. These were key factors in sustaining patients' ability to hope and helped them to imagine possibilities for a future that were consistent with their values and hopes.	Comprehensive care of patients with ESKD requires skill in ACP to lay out a set of values and processes for approaching EOL decisions and identify preferences for future goals of care.	Participants were willing to discuss EOL but expected professionals to initiate and guide them through the process of ACP. They did not feel they should have to ask for prognostic information. Reliance on health professionals to initiate EOL discussions and the daily focus of clinical care were perceived to be potential barriers to hope.
Davison (2006b), Canada Objectives: To obtain views of patients with ESRD on the salient elements of ACP discussions and to discover their preferences regarding how ACP could be facilitated by the health care team.	Patients with ESRD from renal insufficiency, hemodialysis, and peritoneal dialysis clinics; Northern Alberta Renal Program at the University of Alberta.	Ethnographic study consisting of personal interviews with 24 patients. Participants purposively selected on their willingness to discuss issues and were stratified by age, gender, and dialysis modality. Rigor: Strong (research design and recruitment strategy appropriate; findings and analysis clear).	Patients' views on benefit of ACP varied significantly and reflected beliefs, fears, and wishes for EOL care. Patients wished for more information earlier in their illness, and information giving was viewed as a critical element of the ACP process. Patients also required information about the impact of interventions on daily life. Patients requested that health care professionals should initiate ACP, use lay language and be empathetic, and affirm self-worth in patients.	Argument for shifting the focus away from the traditional information giving and document completion model of advance directives and replacing it with a relational, patient-centered process that focuses on broader goals of care.	Tension between patient priorities for ACP (focused on how care plans affect them and their loved ones in daily life) rather than that of clinical practitioners (statistical effectiveness of treatments). Physicians clearly seen by patients as having responsibility for initiating and guiding ACP. No standards of care regarding when to initiate or how to conduct ACP discussions.
Goff (2015), USA Objectives: To inform the development of an intervention focused on improving ACP. To elicit recommendations for how dialysis teams	Patients and family members attending two dialysis units in Massachusetts and New Mexico.	Applied grounded theory approach. In-depth interviews with 13 patients and nine family/friends; interviews were audio-taped, professionally transcribed, and analyzed	Most patients and family/friends felt options available for EOL care should be discussed through ACP, but few patients or family/friends reported discussing	Patients' life experiences influenced their dialysis experiences and their views of ACP, for example, the suffering they observed in the dialysis unit affected their views.	Negative dialysis experiences, including lack of a personal connection to the nephrologist and dialysis team, dissatisfaction with communication, and

should discuss ACP.		in an iterative process. Rigor: Strong (research design and recruitment strategy appropriate. Data analysis and findings clear)	prognosis, life goals, or options for care with health care professionals. Several patients and family/friends had discussed ACP with the primary care physician, but this was not shared with the nephrologist.	Patients less critical of their dialysis experience had higher education/income levels or were older.	disenfranchisement may diminish trust in the dialysis team. Patients and family/friends with lower socioeconomic and/or minority status felt disempowered and discouraged from ACP. Some staff minimized the seriousness of dialysis, and staff could do more to reduce feelings of humiliation and dependency that patients experience as dialysis patients.
Hines (2001), USA Objectives: To determine whether differences in values and preferences for the ACP process may be reasons family members are inadequately informed to act as surrogates.	Hemodialysis patients from two regions—New York and West Virginia, USA.	Face-to-face and telephone surveys using structured questionnaires. Participants: 242 dialysis patients and their designated surrogates Rigor: Moderate (rationale for how interview questions were decided upon not clear).	Ninety percent of patients designated a family member as their surrogate. Generally, conversations about EOL issues did not increase surrogate knowledge of patients' values or preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them. Compared with patients, surrogates were less likely to want to prolong the patient's life if it entailed suffering and were more concerned about being certain before stopping life-sustaining treatments.	Despite reliance on family member surrogates to make EOL decisions, surrogates often lack knowledge of the patient's values and preferences. Patients may overestimate the degree of autonomy their surrogates want to exercise.	Physicians may assume that patients who report having talked with their family will have adequately prepared them for surrogate decision-making.

Abbreviations: RCT = randomized controlled trial; ACP = advance care planning; ESKD = end-stage kidney disease; CKD = chronic kidney disease; EOL = end of life; ESRD = end-stage renal disease; PC-ACP = patient-centered advance care planning; CHF = congestive heart failure; AD = advance directive; EMR = electronic medical record; HD = hemodialysis; CPR = cardiopulmonary resuscitation.