# Original Article

# Referral Criteria to Specialist Palliative Care for People with Advanced Chronic Kidney Disease: A Systematic



# Review

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## Abstract

Context. People with advanced chronic kidney disease (CKD) have significant morbidity, yet for many, access to palliative care occurs late, if at all.

**Objectives.** This study sought to examine criteria for referral to specialist palliative care for adults with advanced CKD with a view to improving use of these essential services.

Methods. Systematic review of studies detailing referral criteria to palliative care in advanced CKD conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guideline and registered (PROSPERO: CRD42021230751).

Data sources. Electronic databases (Ovid, MEDLINE, Ovid Embase, and PubMed) were used to identify potential studies, which were subjected to double review, data extraction, thematic coding, and descriptive analyses.

Results. Searches yielded 650 unique titles ultimately resulting in 56 studies addressing referral criteria to specialist palliative care in advanced CKD. Of 10 categories of referral criteria, most commonly discussed were: Critical times of treatment decision making (n = 23, 41%); physical or emotional symptoms (n = 22, 39%); limited prognosis (n = 18, 32%); patient age and comorbidities (n = 18, 32%); category of CKD/ biochemical criteria (n = 13, 23%); functional decline (n = 13, 23); psychosocial needs (n = 9, 16%); future care planning (n = 9, 16%); anticipated decline in illness course (n = 8, 14%); and hospital use (n = 8, 14%).

**Conclusion.** Clinicians consider referral to specialist palliative care for a wide range of reasons, with many related to care needs. As palliative care continues to integrate with nephrology, our findings represent a key step towards developing consensus criteria to standardize referral for patients with chronic kidney diseases. I Pain Symptom Manage 2023;66:541-550. © 2023 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

Palliative care, kidney failure, chronic (chronic kidney failure, ESKD, end-stage kidney disease, end-stage renal disease, renal disease, end-stage, renal failure, chronic, renal failure, end-stage), systematic review, referral, consultation

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# Key Message

This systematic review has identified a series of criteria for referral to specialist palliative care for people with advanced chronic kidney disease providing the foundation for developing practice consensus around access to palliative care for this group of patients.

#### Introduction

There is a significant and growing body of literature documenting the physical, social, psychological, and decision support needs of patients with advanced chronic kidney disease (CKD; glomerular filtration rate (GFR) category 4 and 5) and their families. <sup>1-3</sup> Attention to these needs is core to chronic disease management, and evidence supporting the benefits of early integration of palliative care into patient care across a number of chronic conditions including cancer, heart, and kidney failure, and respiratory disease is increasing. <sup>4-7</sup> These benefits include outcomes such as improved patient-reported symptom relief and experiences of care, improved family carer wellbeing and support, and reduction of acute health service use. <sup>8</sup>

Throughout the illness, the clinical management of people with kidney disease involves optimizing kidney function, cardiovascular risk factors, comorbidities, and albuminuria in addition to minimizing risks of nephrotoxicity. For people with advanced CKD, nephrologist review will also consider treatment approaches which may include kidney replacement therapies (dialysis or kidney transplantation) or conservative kidney management (care that focuses on providing holistic, patient-centered and active kidney disease management but not does include kidney replacement therapies). <sup>10</sup>

Across each of these treatment pathways, the potential contribution of the principles and practices of palliative care through the provision of kidney supportive care 10 integrated within existing kidney services as well as the role of a specialist palliative care referral has been highlighted. 11-14 Kidney supportive care is an approach aimed at improving the health-related quality of life for patients with advanced CKD and involves symptom management, psychological, social, cultural, and spiritual support, interventions to delay progression of kidney disease and minimize complications and can be provided together with therapies intended to prolong life.<sup>10</sup> Kidney supportive care involves a detailed understanding of the management of kidney disease and is typically delivered by nephrologists within existing renal services, or in some instances by palliative care specialists who have had specific training in kidney supportive care. 15 Referral to specialist palliative care defined as those with specialist palliative care training who may be part of renal supportive care or may sit outside renal care, may also be enacted to address more complex needs.

Despite significant needs, palliative care is underutilized even in settings where such care is available, and for many patients referral occurs late — within days of death. <sup>16,17</sup> The circumstances in which these specialist referrals are initiated in current practice-including the reasons for and timing of referrals- are not fully understood. As such the potential benefits of early engagement with palliative care, either through the addition of kidney supportive care or specialist palliative care involvement are not realized. Consistent with this, clinicians involved in kidney care commonly agree it would be useful to have defined triggers to underpin referral. <sup>18</sup>

The aim of this systematic review was to examine criteria for referral to specialist palliative care (defined as those with specialist palliative care training) for patients with advanced chronic kidney disease, to highlight current practices, and set a benchmark for improvement as we work globally to improve kidney care.

#### Methods

Design

We conducted a systematic review of studies meeting our aim to examine referral criteria for specialist palliative care for patients with advanced CKD (Stages 4 and 5 CKD classification). The review was registered with the International Prospective Register of Systematic Reviews (PROSPERO: CRD42021230751), with reporting guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). Involving only existing literature, ethics approval was not required. The review forms the first stage in a broader program of work by this team seeking to develop a standardized, consensus-based set of referral criteria, across a series of nonmalignant diagnoses, also including heart failure, dementia and respiratory disease.

Search Strategy: Identification of Studies

The electronic databases including MEDLINE, Embase, and PubMed were searched simultaneously in Ovid, searching for publications in the English language (due to lack of access to translations), from the database inception to December 22, 2021. De-duplication was undertaken using the Ovid de-duplication tool

A set of key terms and their related synonyms and/ or abbreviations were defined (Fig. 1 Search and Coding Strategy) and applied to titles, abstracts, key words, and subject headings specific to each database. In brief, this included searches combining the following Psychosocial

decision making

times

Critical

SEARCH STRATEGY - CONC	CEPTS SEARCHED				
Palliative and end of life care Kidney supportive care Kidney palliative care	AND Advanced chronic kidne	ey disease AND	AND Referral or integration (OR) Trials (OR) Guidelines		
Limits: English Language; Databa	ase inception to 22nd December 20	21			
INCLUSION CRITERIA Referral criteria for palliative care	identified	,			
Criteria	Examples	Criteria		Examples	
Physical/ emotional symptoms	-Pain, itch	Category of CKD/	Biochemical	-CKD G5/ glomerular filtration rate <15mL/min/m2	
Functional decline	-Deteriorating performance status	Hospital use		-Hospitalization for acute complication	
Care planning	-Assistance with advance care planning	Limited prognosis		-Surprise question suggests prognosis may be less than 12 months*	

treatment

-Existential concerns

-point in illness when need to

decide CKM versus dialysis

-carer needs

Fig. 1. Search & coding strategy \*would you be surprised if this person died in the next 12 months?

Anticipated decline in illness course

Patient characteristics

concepts, "Palliative Care," AND "Advanced Chronic Kidney Disease" AND: Referral/Integration," OR "Clinical trials," OR "Guidelines/ Consensus Statements." A manual search of gray literature was also conducted to ensure key papers were included from experts in the field, cross-checking reference lists of key papers for articles potentially meeting inclusion. The complete MEDLINE Search strategy is detailed in Appendix.

#### Eligibility: Inclusion and Exclusion Criteria

Studies were eligible for inclusion in this systematic review if they 1) were focused on advanced CKD in adult populations, and 2) detailed a "trigger" or a referral criterion or set of criteria for referral to specialist palliative care. We included those articles that used the term "kidney supportive care" when this was describing a service which included specialist palliative care as part of an integrative team managing needs of people with advanced CKD. We excluded articles of mixed populations including people with different diagnoses if the advanced CKD participants comprised ≤30% of the included sample or data were not reported as a separate cohort. Seeking a broad overview of the range of referral criteria proposed in the literature, we included those arising as a primary result of the study, as a component of a clinical trial, as a recommendation or implication of the study findings, or derived from reviews or clinical perspective on referral triggers. We included all original studies, reviews, systematic reviews, guidelines, editorials, commentaries, and letters, and excluded duplicates, case reports, and conference abstracts.

- Complications from dialysis

-Advanced age

-Comorbidities

- Progressive deterioration on diaylsis

#### Data Extraction and Coding

The study selection process from the total pool of discrete articles (n = 650) involved an initial screen of titles and abstracts by two researchers (A. C. and J. P.) independently. Studies were included for full-text review where either reviewer determined that the study met eligibility (n = 155). Discussion to reach a consensus occurred in the case of any discrepancies in the two reviewer's decisions for inclusion (n = 38), with a third reviewer as arbitrator (K. D.) available, but not required.

Full-text review involved extraction of referral criteria mentioned by the included studies and thematic categorization of factors, consistent with published reviews of referral criteria in other disease settings including cancer and advanced heart failure, respiratory disease, and dementia. The coding framework was discussed and refined with the research team to aid the clarity of results and interpretation of themes. The criteria were coded in full by one reviewer (J. P.), with double review of 20% of the final sample undertaken (AC) to validate categorization, ensure accuracy of coding, and minimize potential for reviewer bias.

#### Analyses

Data extracted from the final sample of articles (n = 56) were summarized using descriptive statistics, including counts, frequencies, and percentages.

<sup>\*</sup>would you be surprised if this person died in the next 12 months?

#### Results

#### Overview of Included Studies

Our systematic search of the literature identified 650 articles for potential inclusion (Fig. 2). An independent double review of titles and abstracts by two investigators, including a discussion of 38 articles (6%) where there was an initial discrepancy between reviewers, resulted in 155 articles being subjected to a full-text review. Of these, a further 99 were excluded as not meeting the aims of the review, resulting in a final sample of 56 that identified referral criteria to specialist palliative care in advanced CKD (Table 1).

Most of the included studies were conducted in the United States (45%), the U.K. (14%), and Asia (11%). Studies were predominantly published after 2010

(84%) in nephrology (48%) or palliative care (29%) journals. The studies utilized a range of methodologies, most commonly prospective nonrandomized studies and surveys (41%), reviews (39%), and retrospective studies (13%), with few randomized controlled trials (5%).

Most articles (61%) did not identify the specific palliative care setting for which the referral criteria were intended. Twelve studies (21%) specifically mentioned inpatient palliative care and 10 studies (18%) mentioned outpatient care.

Specific cohorts of interest across the studies of people with advanced CKD included people receiving treatment on dialysis (29%), conservative kidney management (16%), and those with mixed CKD G4-5 (34%), while 21% did not further characterize.

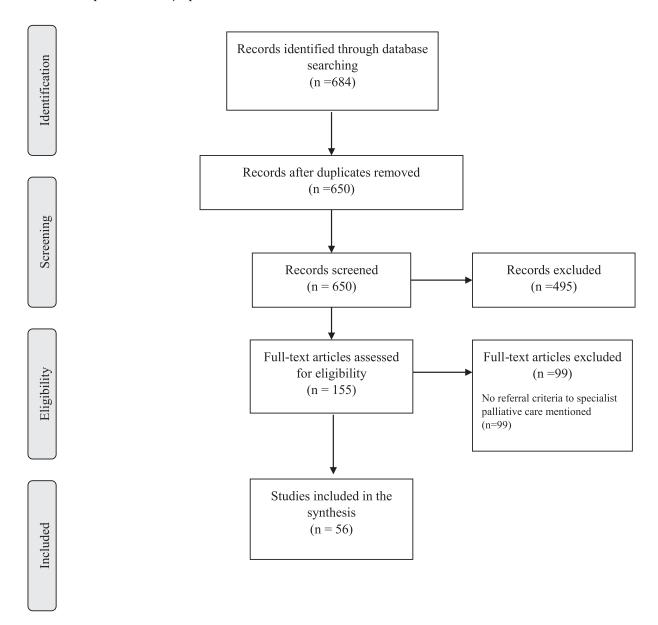


Fig. 2. PRISMA diagram.

Table 1

Publication Characteristics (N=56)

Article Characteristics	N (%)	
Study population		
Dialysis	16 (29)	
Transplant	0 (0)	
Conservative kidney management	9 (16)	
Mixed (e.g., stage 4 and 5)	19 (34)	
Not specified	12 (21)	
Article type	,	
Practice Guidelines, Expert consensus	0 (0)	
Prospective nonrandomized studies and surveys	23 (41)	
Prospective randomized trials	3 (5)	
Qualitative studies	1(2)	
Retrospective studies	7 (13)	
Review	22 (39)	
Trial design	0 (0)	
Publication year	. ,	
2003-2010	9 (16)	
2011-2020	47 (84)	
Journal type	,	
Kidney journals	27 (48)	
Palliative care journals	16 (29)	
General medical journals	6 (11)	
Other	7(13)	
Country	` /	
Europe	4(7)	
Australia	3 (5)	
UK	8 (14)	
United States	25 (45)	
Canada	1(2)	
Asia	6 (11)	
Not specified	8 (14)	
PC Service		
Specialist Palliative Care	29 (52)	
Hospice	2(4)	
Not specified	25 (45)	
PC Setting	. /	
Outpatient	10 (18)	
Inpatient	12 (21)	
Not specified	34 (61)	

Referral to a specific "Kidney Supportive Care" or "Kidney Palliative Care" service which involved specialist palliative care embedded within renal services, was mentioned by 8 studies (14%). 10,23–29 Other models of palliative care support for patients with advanced CKD described involved increased capacity in the renal workforce to deliver a palliative approach to care, 68,32 and home-based care delivered by primary care teams with support from hospital renal and palliative care services. 43

### Referral Criteria

We identified 10 major categories of referral criteria (Table 2), representing a diverse range of palliative care needs. The most discussed criterion in order of frequency were: Critical times of treatment decision making  $(n=23,41\%);^{10,11,24-26,28-45}$  physical or emotional symptoms  $(n=22,39\%);^{11,13,14,27-31,33,42,44,46-56}$  limited prognosis  $(n=18,32\%);^{25,31,33,35,40,42,48,50,53,54,57-64}$  patient age and comorbidities  $(n=18,32\%);^{11,23,28-30,33,36,40,42,44,48,54,55,61,63,65-67}$  category of CKD/ biochemical

criteria  $(n = 13, 23\%); ^{10,29,31,40,43,47,55,59,68-72}$  functional decline  $(n = 13, 23\%); ^{14,25,30,33,40,42,44,48,55,56,59,63,73}$  psychosocial needs  $(n = 9, 16\%); ^{13,14,27,29,31,44,48,51,52}$  future care planning  $(n = 9, 16\%); ^{13,14,27,29,31,44,48,51,52}$  Anticipated decline illness course  $(n = 8, 14\%); ^{11,25,36,59,61,64,66,72}$  and hospital use  $(n = 8, 14\%). ^{29,33,35,50,65,69,72,74}$ 

Just 11 studies (20%) cited factors which they tested or indicated were currently implemented in practice.

#### Discussion

This review reports the criteria discussed in the literature which underpin referral to specialist palliative care for patients with advanced CKD. We found ten categories of referral criteria and a focus on those related to critical times in treatment decision making. These decisions are often related to dialysis including the decision for conservative kidney management vs. dialysis, and considerations around continuing or ceasing dialysis. The identification of multiple and diverse criteria for palliative care referral in this review suggests a wide range of palliative care needs. Alongside the development of kidney supportive care globally, there is a future opportunity to develop, in advanced CKD, a clear consensus on when and who should be referred to specialist palliative care.

Data from this study suggest that it is most frequently treatment-based factors that prompt referral to palliative care, and in particular, times of critical decision making surrounding dialysis. This includes both the commencement, emergence of problems during, and consideration of discontinuing dialysis. The consideration of dialysis and its different phases obviously represent key time points for decision-making that are core elements of the care of people with advanced CKD. It also represents opportunities for introducing aspects of kidney supportive care into kidney care. In the conceptualization of a model of kidney supportive care, Davison recommended specific attention be directed towards identifying those at high risk of mortality, high symptom burden including pain, and with particular needs for support around decision making of treatment and end of life care. 48 However, she notes that for many, the severity of pain and other symptoms may not be recognized by kidney care teams<sup>75</sup> and remain untreated.4

Set within the context of the evolving paradigm of kidney supportive care, <sup>10</sup> our review reflects the changing global landscape in the management of CKD. Recognizing the advantages of the integration of palliative care practices and principles for all kidney patients, international experts have led the expansion and adoption of this "generalist" approach to addressing palliative care needs through the development of kidney supportive care. <sup>10</sup> The global development of kidney

Table 2
Palliative Care Referral Criteria for Advanced Chronic Kidney Disease (N=56) and the Key Individual Criteria

Criteria Mentioned by Studies	Frequency N (%) a	Setting N			References	
		IP b	OP b	NS b		
Critical times of treatment decision making	23 (41)	2	6	15	10,11,24-26,28-45	
Decided for dialysis	5				29,33,35-37	
Decided for CKM/ not for dialysis	15				10,11,24-26,28,32,33,38-44	
Considerations around continuing or withdrawal of dialysis	6				25,28,29,33,44,45	
Point in illness when need to decide dialysis vs. CKM	8				25,28-34	
Physical and Emotional Symptoms	22 (39)	4	6	12	11,13,14,27-31,33,42,44,46-56	
Fatigue	1				46	
Pain	3				13,49,54	
Cognitive disturbance	3				46,47,50	
Pruritis	1				47	
Psychological symptoms	7				14,29,31,42,46,51,52	
High symptom burden (not specified)	16				11,14,27-31,33,42,44,46,48,51,53,55,5	
Limited Prognosis	18 (32)	2	3	13	25,31,33,35,40,42,48,50,53,54,57-64	
"Surprise question" using 12 month prognosis	7 ` ´				48,50,53,54,58,60,62	
"Surprise question" using 6 month prognosis	2				33,50	
Prognostic tools	1				42	
Poor prognosis — not specified	8				25,31,35,40,57,59,61,63,64	
Patient Age and Comorbidities	18 (32)	1	5	12	11,23,28-30,33,36,40,42,44,	
8	(3.7)				48,54,55,61,63,65-67	
Cancer	1				54	
Other poor prognosis illness	10				11,30,33,40,42,44,48,54,61,65	
Age	11				23,28,29,33,36,40,48,55,63,66,67	
Category of CKD/ biochemical criteria	13 (23)	2	5	6	10,29,31,40,43,47,55,59,68-72	
$CKD G5/eGFR < 15 mL/min/1.73m^2$	9				10,29,31,40,43,47,55,68,71	
$CKD \ G4 \ / \ eGFR \ 15-29 \ mL/min/1.73m^2$	6				29,40,43,55,69,70	
CKD G3	1				55	
$Albumin < 2.5 \ m/dL$	1				55	
Functional Decline	13 (23)	2	1	10	14,25,30,33,40,42,44,48,55,56,59,63,73	
AKPS < 40, $AKPS$ other	4				33,42,48,55	
Reduced functional status,	7				25,40,42,55,56,59,73	
Increased dependency for ADLs,	5				14,42,44,55,63	
Frailty	2				30,48	
Psychosocial needs	9 (16)	3	2	4	13,14,27,29,31,44,48,51,52	
Family Support	1				51	
Psychological support	3				27,31,51	
Emotional support ns.	3				29,51,52	
Conflict	3				14,44,48	
Spiritual distress	2				13,51	
Anticipated decline in illness course	8 (14)	3	1	4	11,25,36,59,61,64,66,72	
Complications from dialysis	2 ` ′				25,61	
Progressive deterioration on dialysis	5				11,25,59,61,72	
Dialysis + a poor prognostic factor / advanced age	4				36,59,64,66	
Hospital Use	8 (14)	3	2	3	29,33,35,50,65,69,72,74	
Admission	6				33,35,50,65,69,74	
Multiple admission	1				29	
ICU	1				72	
Future care planning	9 (16)	3	2	4	13,14,27,31,42,44,47,52,56	
Advance care planning	4				13,44,52,56	
End of life planning around care of dying/goals of care	4				14,27,31,44	
Patient/ Caregiver request for palliative care	2				42,47	

<sup>&</sup>lt;sup>a</sup>N (%) = Number of discrete studies mentioning a referral criteria related to that category, with the percentage relevant to the total number of studies included (n = 56).

supportive care services and the considerable number and nature of different criteria put forward as prompting specialist palliative care referral (as distinct from kidney supportive care) in this review point to several important considerations as this field continues to progress.

First, there is a clear role for kidney care teams in providing kidney supportive care, as a core component of all CKD management and one that is not dependent upon a persons' treatment pathway. Reflecting this changing environment, some of the factors underpinning referral to specialist palliative care highlighted by this review such as decision for CKM vs. dialysis will be readily and most appropriately addressed within the provision of kidney supportive care. In this case, moving forward, opportunities for upskilling of core competencies for kidney care teams in aspects of kidney supportive care are essential to ensure the appropriate and timely access and integration of palliative care for people with advanced CKD. The priority assigned to

<sup>&</sup>lt;sup>b</sup>Setting: IP = inpatient, OP = outpatient, NS = setting not specified.

various patient symptom needs as criteria for palliative care referral highlights how much these affect patients with advanced CKD, and emphasis the need for shared symptom management approaches<sup>18</sup> and mutual training on symptom control.

Inherent in this task is a need for reconciling the variation of terms into the description of commonly agreed and consistently used approaches. In this review, the conceptualization of "palliative care" and, in some instances, how this form of care was put into practice differed across services. In some settings patients receiving conservative kidney management would have access to kidney supportive care, which may include a team of kidney and palliative care clinicians collaborating to provide care 18 or it may be provided by kidney care teams who intentionally adopt a palliative care approach into care. 10 International leaders in nephrology have sought to respond to this variation through careful definition and description of a model of conservative kidney management. 10,76,77 The clarification and adoption of the terms "kidney supportive care" and "conservative kidney management" will do much to progress the field and reduce misunderstandings.

Alongside this focus, there remains the important task of expert- and patient-led delineation of the factors or circumstances which may trigger a referral to specialist palliative care. This specialist level of support may be particularly warranted to support those patients and their kidney care providers who have a higher complexity of need. This may relate to, for example, difficult clinical decision-making around treatment pathways, support with complex family dynamics, or the presence of multiple compounding factors requiring specialist support. Building on this review, an agreed recommendation or minimum standards of who and when specialist palliative care should be considered would considerably advance the field. In such an endeavor, attention to both individual circumstances and their combination which might prompt referral is a priority.

There are limitations to this systematic review which require mention. Our search was inclusive but nevertheless yielded only 56 articles and included only those studies where specialist palliative care referral was the focus. Kidney supportive care alone that did not describe inclusion of a palliative care clinician did not meet our eligibility criteria. That said, the 8 included studies identified which mentioned referral to kidney supportive care also mentioned palliative care. With just a small number of the studies in our review having included the criteria for referral as part of an empirical prospective design (5% were randomized studies), we are unable to comment on the utility of the criteria put forward since these have largely not yet

been subject to evaluation. Such a formal evaluation will be critical to take the field forward.

In conclusion, our systematic review has identified a diverse range of criteria which may prompt a referral to specialist palliative care for people with advanced CKD. Conducted in the evolving global context of kidney supportive care, this review demonstrated that referral was most commonly related to critical times associated with treatment decision making, in particular dialysis. These times may represent a standardized point in the management of CKD where kidney care teams seek to also incorporate a holistic palliative approach to care ensuring an appropriate focus on quality of life regardless of the treatment pathway. To progress in this field, a clear understanding of the role and benefits of kidney supportive care in integrated kidney care is required, with attention to a reconciling of differences in terminology of palliative care, conservative kidney management and kidney supportive care. Such current differences are likely to add to the variation in practice and clinical uncertainty around these important decisions. It is likely that leadership will continue to emerge from both palliative care and nephrology and their collaborative efforts remain core to the successful progression of the field. A shared clear understanding will lead to a common sense of responsibility for addressing palliative care needs, with the roles of kidney and palliative care teams readily delineated. In turn, this will enable the development of consensus around those criteria which may trigger a referral to specialist palliative care, and their subsequent empirical evaluation.

#### Data Availability

The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.

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# References

- 1. Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. Adv Chron Kidney Dis 2007;14:82–99.
- 2. Bristowe K, Selman LE, Higginson IJ, Murtagh FE. Invisible and intangible illness: a qualitative interview study of patients' experiences and understandings of conservatively managed end-stage kidney disease. Ann Palliat Med 2019;8: 121–129.
- 3. Shah KK, Murtagh FE, McGeechan K, et al. Quality of life among caregivers of people with end-stage kidney disease managed with dialysis or comprehensive conservative care. BMC Nephrol 2020;21:1–8.
- **4.** Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Datab Syst Rev 2013;2013;CD007760.
- 5. Henoch I, Ekberg-Jansson A, Löfdahl C-G, Strang P. Benefits, for patients with late stage chronic obstructive pulmonary disease, of being cared for in specialized palliative care compared to hospital. A nationwide register study. BMC Palliat Care 2021;20:1–13.
- **6.** Hui D, Hannon BL, Zimmermann C, Bruera E. Improving patient and caregiver outcomes in oncology: team-based, timely, and targeted palliative care. CA: Cancer J Clin 2018;68:356–376.
- 7. Sobanski PZ, Alt-Epping B, Currow DC, et al. Palliative care for people living with heart failure: European association for palliative care task force expert position statement. J Cardiovasc Res 2020;116:12–27.
- 8. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. Ann Palliat Med 2015;4:99–121.
- **9.** Chen TK, Knicely DH, Grams ME. Chronic kidney disease diagnosis and management: a review. JAMA 2019;322: 1294–1304.
- 10. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Int 2015;88:447–459.
- 11. Kane PM, Vinen K, Murtagh FEM. Palliative care for advanced renal disease: a summary of the evidence and future direction. Palliat Med 2013;27:817–821.
- 12. Douglas C. Palliative care for patients with advance chronic kidney disease. JR Coll Physicians Edinb 2014;44: 224–231.
- 13. Davison SN. Integrating palliative care for patients with advanced chronic kidney disease: recent advances, remaining challenges. J Palliat Care 2011;27:53–61.
- 14. Lam DY, Scherer JS, Brown M, Grubbs V, Schell JO. A conceptual framework of palliative care across the continuum of advanced kidney disease. Clin J Am Soci Nephrol: CJASN 2019;14:635–641.
- 15. Hole B, Hemmelgarn B, Brown E, et al. Supportive care for end-stage kidney disease: an integral part of kidney

- services across a range of income settings around the world. Kidney Int Suppl 2020;10:e86–e94.
- **16.** Tamura MK, O'Hare AM, Lin E, et al. Palliative care disincentives in CKD: changing policy to improve CKD care. Am J Kidney Dis 2018;71:866–873.
- 17. Sturgill D, Bear A. Unique palliative care needs of patients with advanced chronic kidney disease—the scope of the problem and several solutions. Clin Med 2019;19:26.
- 18. Ducharlet K, Philip J, Kiburg K, Gock H. Renal supportive care, palliative care and end-of-life care: perceptions of similarities, differences and challenges across Australia and New Zealand. Nephrology 2021;26:15–22.
- 19. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. 2009; 151:264-269.
- **20.** Chang YK, Kaplan H, Geng Y, et al. Referral criteria to palliative care for patients with heart failure: a systematic review. Circ Heart Fail 2020;13:e006881.
- 21. Mo L, Geng Y, Chang YK, et al. Referral criteria to specialist palliative care for patients with dementia: a systematic review. J Am Geriatr Soc 2021;69:1659–1669.
- **22.** Philip J, Collins A, Smallwood N, et al. Referral criteria to palliative care for patients with respiratory disease: a systematic review. Eur Respir J 2021;58:2004307.
- 23. Brown MA, Collett GK, Josland EA, et al. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. Clin J Am Soc Nephrol: CJASN 2015;10:260–268
- 24. Crail S, Walker R, Brown M. Renal Supportive Care working g. Renal supportive and palliative care: position statement. Nephrology (Carlton, Vic.) 2013;18:393–400.
- 25. Moss AH. Integrating supportive care principles into dialysis decision making: a primer for palliative medicine providers. J Pain Symptom Manag 2017;53:656–662. e1.
- **26.** Murtagh FEM, Burns A, Moranne O, Morton RL, Naicker S. Supportive care: comprehensive conservative care in end-stage kidney disease. Clin J Am Soc Nephrol: CJASN 2016;11:1909–1914.
- 27. Noble H, Rees K. Caring for people who are dying on renal wards: a retrospective study. EDTNA/ERCA J (English ed.) 2006;32:89–92.
- 28. Purtell L, Sowa PM, Berquier I, et al. The kidney supportive care program: characteristics of patients referred to a new model of care. BMJ Support Palliat Care 2018:bmjspcare-2018-001630.
- **29.** Scherer JS, Harwood K, Frydman JL, et al. A descriptive analysis of an ambulatory kidney palliative care program. J Palliat Med 2020;23:259–263.
- **30.** Couchoud C, Arnaud DB, Lobbedez T, et al. Access to and characteristics of palliative care-related hospitalization in the management of end-stage renal disease patients on renal replacement therapy in France. Nephrology (Carlton, Vic.) 2017;22:598–608.
- **31.** Murtagh FEM, Murphy E, Shepherd KA, Donohoe P, Edmonds PM. End-of-life care in end-stage renal disease: renal and palliative care. Br J Nurs (Mark Allen Publishing) 2006;15:8–11.
- 32. Noble HR, Agus A, Brazil K, et al. Palliative care in chronic kidney diSease: the PACKS study—quality of life,

- decision making, costs and impact on carers in people managed without dialysis. BMC Nephrol 2015;16:104.
- 33. Scherer JS, Wright R, Blaum CS, Wall SP. Building an outpatient kidney palliative care clinical program. J Pain Symptom Manag 2018;55:108–116. e2.
- 34. Swidler MA. Geriatric renal palliative care. J Gerontol. Series A, Biol Sci Med Sci 2012;67:1400–1409.
- **35.** Bansal AD, Schell JO. A practical guide for the care of patients with end-stage renal disease near the end of life. Semin Dial 2018;31:170–176.
- **36.** Feely MA, Swetz KM, Zavaleta K, et al. Reengineering dialysis: the role of palliative medicine. J Palliat Med 2016;19:652–655.
- **37.** Schwarze ML, Schueller K, Jhagroo RA. Hospice use and end-of-life care for patients with end-stage renal disease: too little, too late. JAMA Int Med 2018;178:799–801.
- 38. Chan KY, Yip T, Yap DYH, et al. Enhanced psychosocial support for caregiver burden for patients with chronic kidney failure choosing not to be treated by dialysis or transplantation: a pilot randomized controlled trial. Am J Kidney Dis 2016;67:585–592.
- **39.** Cohen LM, Moss AH, Weisbord SD, Germain MJ. Renal palliative care. J Palliat Med 2006;9:977–992.
- 40. Lai C-F, Tsai H-B, Hsu S-H, et al. Withdrawal from long-term hemodialysis in patients with end-stage renal disease in Taiwan. J Formos Med Assoc 2013;112: 589–599
- **41.** Noble H, Chesser A, Kelly D. The cessation of dialysis in patients with end-stage renal disease: developing an appropriate evidence base for practice. EDTNA/ERCA J (English ed.) 2005;31:208–211.
- **42.** Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the supportive and palliative care indicators tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 2014;4:285–290.
- 43. Teruel JL, Rexach L, Burguera V, et al. Home palliative care for patients with advanced chronic kidney disease: preliminary results. Healthcare (Basel, Switzerland) 2015;3:1064–1074.
- 44. Fassett RG, Robertson IK, Mace R, et al. Palliative care in end-stage kidney disease. Nephrology (Carlton, Vic.) 2011;16:4–19
- **45.** Bansal AD, Schell JO. Recognizing the elephant in the room: palliative care needs in acute kidney injury. Clin J Am Soc Nephrol: CJASN 2017;12:1721–1722.
- 46. Boje J, Madsen JK, Finderup J. Palliative care needs experienced by Danish patients with end-stage kidney disease. J Renal Care 2020;47:169–183.
- **47.** Castner D, Bednarski D. The intersection of the Medicare end-stage renal disease (ESRD) benefit and hospice: an overview for home care and hospice clinicians. Home Healthc Nurse 2011;29:464–476.
- **48.** Davison SN. The ethics of end-of-life care for patients with ESRD. Clin J Am Soc Nephrol: CJASN 2012;7:2049–2057.
- **49.** Fleishman TT, Dreiher J, Shvartzman P. Pain in maintenance hemodialysis patients: a multicenter study. J Pain Symptom Manag 2018;56:178–184.
- 50. Germain MJ, Davison SN, Moss AH. When enough is enough: the nephrologist's responsibility in ordering dialysis treatments. Am J Kidney Dis 2011;58:135–143.

- 51. Grudzen CR, Richardson LD, Morrison M, Cho E, Morrison RS. Palliative care needs of seriously ill, older adults presenting to the emergency department. Acad Emerg Med 2010;17:1253–1257.
- **52.** Gunda S, Thomas M, Smith S. National survey of palliative care in end-stage renal disease in the UK. Nephrol, Dial, Transplant 2005;20:392–395.
- 53. Jawed A, Moe SM, Moorthi RN, Torke AM, Eadon MT. Increasing nephrologist awareness of symptom burden in older hospitalized end-stage renal disease patients. Am J Nephrol 2020;51:11–16.
- 54. Lai C-F, Cheng C-I, Chang C-H, et al. Integrating the surprise question, palliative care screening tool, and clinical risk models to identify peritoneal dialysis patients with high one-year mortality. J Pain Symptom Manag 2020;60:613–621. e6.
- 55. Tavares APDS, Santos CgdS, Tzanno-Martins C, et al. Kidney supportive care: an update of the current state of the art of palliative care in CKD patients. J Bras Nefrol 2021;43: 74–87.
- 56. 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 hemodialysis patients. Nephrol, Dial, Transplant 2003;18:1345–1352.
- 57. Couchoud CG, Beuscart J-BR, Aldigier J-C, et al. Development of a risk stratification algorithm to improve patient-centered care and decision making for incident elderly patients with end-stage renal disease. Kidney Int 2015;88:1178–1186.
- 58. Feyi K, Klinger S, Pharro G, et al. Predicting palliative care needs and mortality in end stage renal disease: use of an at-risk register. BMJ Support Palliat Care 2015;5:19–25.
- **59.** Grubbs V, Moss AH, Cohen LM, et al. A palliative approach to dialysis care: a patient-centered transition to the end of life. Clin J Am Soc Nephrol: CJASN 2014;9: 2203–2209.
- **60.** Haydar SA, Almeder L, Michalakes L, Han PKJ, Strout TD. Using the surprise question to identify those with unmet palliative care needs in emergency and inpatient settings: what do clinicians think? J Palliat Med 2017;20:729–735.
- **61.** Jang C-S, Wang J-D. Predicting mortality and life expectancy in patients under prolonged mechanical ventilation and maintenance dialysis. J Palliat Med 2020;23:74–81.
- **62.** Pang W-F, Kwan BC-H, Chow K-M, et al. Predicting 12-month mortality for peritoneal dialysis patients using the "surprise" question. Perit Dial Int 2013;33:60–66.
- **63.** Schell JO, Germain MJ, Finkelstein FO, Tulsky JA, Cohen LM. An integrative approach to advanced kidney disease in the elderly. Adv Chronic Kidney Dis 2010;17:368–377.
- **64.** Scherer JS, Holley JL. The role of time-limited trials in dialysis decision making in critically ill patients. Clin J Am Soc Nephrol: CJASN 2016;11:344–353.
- 65. Singh R, Hwang F, Berlin A, et al. Patients with end-stage renal disease and acute surgical abdomen: opportunities for palliative care. J Palliat Med 2019;22:635–643.
- 66. Courtright KR, Madden V, Gabler NB, et al. Rationale and design of the randomized evaluation of default access to palliative services (REDAPS) trial. Ann Am Thorac Soc 2016;13:1629–1639.
- **67.** Germain MJ, Cohen LM. Maintaining quality of life at the end of life in the end-stage renal disease population. Adv Chron Kidney Dis 2008;15:133–139.

- **68.** Chiu HH, Murphy-Burke DM, Thomas SA, Melnyk Y, Kruthaup-Harper AL, Dong JJ, Djurdjev O, Saunders S, Levin A, Karim M, Hargrove GM. BC renal palliative care committee. Advancing palliative care in patients With CKD: from ideas to practice. Am J Kidney Dis 2021;77:420–426.
- **69.** Ernecoff NC, Wessell KL, Hanson LC, et al. Elements of palliative care in the last 6 months of life: frequency, predictors, and timing. J Gen Int Med 2020;35:753–761.
- **70.** Ernecoff NC, Wessell KL, Hanson LC, et al. Electronic health record phenotypes for identifying patients with latestage disease: a method for research and clinical application. J Gen Int Med 2019;34:2818–2823.
- 71. Grudzen CR, Shim DJ, Schmucker AM, et al. Emergency medicine palliative care access (EMPallA): protocol for a multicenter randomized controlled trial comparing the effectiveness of specialty outpatient versus nurse-led telephonic palliative care of older adults with advanced illness. BMJ Open 2019;9:e025692.
- 72. Okon TR, Vats HS, Dart RA. Palliative medicine referral in patients undergoing continuous renal replacement

- therapy for acute kidney injury. Renal Fail 2011;33:707–717.
- 73. Murtagh FEM, Addington-Hall JM, Higginson IJ. End-stage renal disease: a new trajectory of functional decline in the last year of life. J Am Geriatr Soc 2011;59:304–308.
- 74. Nenova Z, Hotchkiss Jr. J. Appointment utilization as a trigger for palliative care introduction: a retrospective cohort study. Pallia Med 2019;33:457–461.
- **75.** Weisbord SD, Fried LF, Mor MK, et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. Clin J Am Soc Nephrol 2007;2:960–967.
- **76.** Harris DCH, Davies SJ, Finkelstein FO, et al. Strategic plan for integrated care of patients with kidney failure. Kidney Int 2020;98:S117–s134.
- 77. Levey AS, Eckardt KU, Dorman NM, et al. Nomenclature for kidney function and disease-executive summary and glossary from a kidney disease: improving global outcomes (KDIGO) consensus conference. Eur Heart J 2020;41:4592–4598

# Appendix 1. Search Strategy Medline

- 1. exp Palliative Care/
- 2. Palliative Medicine/
- 3. (Palliative or palliation).ti,ab,kw.
- 4. exp Terminal care/
- 5. exp Hospice Care/
- 6. Hospices/
- 7. exp Advance Care Planning/
- 8. ((terminal or hospice or supportive or "end-of-life" or dying) adj3 care).ti,ab.
- 9. (care adj3 end adj3 life).ti.
- 10. (conservative adj3 (care or management)).ti,ab.
- 11. "renal supportive care".ti,ab. "kidney supportive care".ti,ab.
- 12. hospice\*.ti,kf.
- 13. <u>1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11</u> or 12
- 14. exp "Referral and Consultation"/
- 15. (referr\* or consult\*).ti,ab,kf.
- 16. Patient Transfer/
- 17. exp "Delivery of Health Care, Integrated"/
- 18. (integrate\* or integrating or integration or collaborat\*).ti,ab,kf.
- 19. ((providing or provision or needs or assessment or specialist\* or specialty or facilitator\* or barrier\* or initiat\*) adj5 palliative).ti,ab,kf.
- 20. exp Decision Making/ and ((renal or kidney) adj3 (failure or disease)).ti,ab,kf.
- 21. 14 or 15 or 16 or 17 or 18 or 19 or 20
- 22. 13 and 21
- 23. exp renal failure/
- 24. ((renal or kidney) adj3 (failure or disease or advanced or "end stage")).ti,ab,kf.
- 25. ("Chronic kidney disease" or "CKD" or "ESKD"). ti,ab.

- 26. dialysis.ti,ab,kf.
- 27. <u>23 or 24 or 25 or 26</u>
- 28. **22 and 27**
- 29. (randomized or randomised or randomly).ti,ab.
- 30. exp clinical trial/
- 31. groups.ab.
- 32. multicenter study.pt.
- 33. (trial or multicenter or multi center or multicentre or multicentre).ti.
- 34. (comparative study not review).pt.
- 35. exp Validation Studies/
- 36. exp Evaluation Studies/
- 37. 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36
- 38. 13 and 27 and 37
- 39. exp Guideline/
- 40. exp Practice Guidelines as Topic/
- 41. consensus development conference.pt.
- 42. consensus development conference nih.pt.
- 43. (position adj3 (statement\*1 or paper)).ti.
- 44. (guideline\* or consensus).ti.
- 45. (practice adj parameter\*).ti.
- 46. 39 or 40 or 41 or 42 or 43 or 44 or 45
- 47. 13 and 27 and 46
- 48. (Palliative or palliation or "renal failure").ti,kf.
- 49. exp \*Palliative Care/
- 50. Palliative.ab. /freq=2
- 51. 48 or 49 or 50
- 52. 28 or 38 or 47
- 53. **51 and 52**
- 54. (13 and 27) not 53
- 55. ((renal or kidney) adj3 (advanced or end-stage)).ti.
- 56. 54 and 55
- 57. 53 or 56
- 58. limit 57 to english language