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Discussions during shared decision-making in older adults with advanced renal disease: a scoping review

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ABSTRACT

Objectives This review summarises the information available for clinicians counselling older patients with kidney failure about treatment options, focusing on prognosis, quality of life, the lived experiences of treatment and the information needs of older adults.

Design We followed the Joanna Briggs Institute Methodology for Scoping Reviews. The final report conforms to the PRISMA-ScR guidelines.

Data sources PubMed, PsycINFO, CINAHL, Embase, Scopus, Web of Science, TRIP and online repositories (for dissertations, guidelines and recommendations from national renal associations).

Eligibility criteria for inclusion Articles in English studying older adults with advanced kidney disease (estimated glomerular filtration rate <30 mL/min/1.73 m^2); published between January 2000 and August 2018. Articles not addressing older patients separately or those comparing between dialysis modalities were excluded.

Data extraction and synthesis Two independent reviewers screened articles for inclusion and grouped them by topic as per the objectives above. Quantitative data were presented as tables and charts; qualitative themes were identified and described.

Results 248 articles were included after screening 15 445 initial results. We summarised prognostic scores and compared dialysis and non-dialytic care. We highlighted potentially modifiable factors affecting quality of life. From reports of the lived experiences, we documented the effects of symptoms, of ageing, the feelings of disempowerment and the need for adaptation. Exploration of information needs suggested that patients want to participate in decision-making and need information, in simple terms, about survival and non-survival outcomes.

Conclusion When discussing treatment options, validated prognostic scores are useful. Older patients with multiple comorbidities do not do well with dialysis. The modifiable factors contributing to the low quality of life in this cohort deserve attention. Older patients suffer a high symptom burden and functional deterioration; they have to cope with significant life changes and feelings of disempowerment. They desire greater involvement and more information about illness, symptoms and what to expect with treatment.

Strengths and limitations of this study

- ► This review provides an interpretative summary of the information relevant to the shared decision-making process around treatment for older adults with end-stage kidney failure—a patient group with increasing numbers worldwide, unclear outcomes from treatment and for whom clinicians struggle to provide appropriate advice.
- ► The scoping review format, which collects information across a wide range, is relevant as there is a plethora of issues across multiple domains and sources to consider in the older adult. This review summarises information on prognosis, quality of life, lived experience of treatment and specific information needs in older patients.
- ► In order to preserve focus, this scoping review did not cover some topics relevant to treatment decisions such as the comparison between dialysis modalities (especially modified treatments such as assisted or incremental dialysis) or transplantation, techniques for presenting information or educating patients, or the logistic/financial barriers to treatment. We believe several of these topics require additional, separate reviews. In addition, our exclusion of non-English articles neglects research from some parts of the world.
- ► While this scoping review presents a wide range of information, it does not grade its quality or study its delivery to the patient; therefore, the use of this information in practice is dependent on the individual clinicians participating in the shared discussions.

INTRODUCTION

Physicians are uncomfortable about communicating prognosis to seriously ill patients.[1 2] This is also true for nephrologists looking after patients with advanced kidney disease.[3–7] There is evidence to suggest that patients receive insufficient information or are unrealistically optimistic about their prognosis.[8 9] Patients often wish they had received more information prior to commencing dialysis. For instance, they expect their doctors to provide them information about prognosis even without being prompted to do so.[10 11] Such descriptions highlight the shortcomings often encountered when older patients and their multiprofessional clinical teams

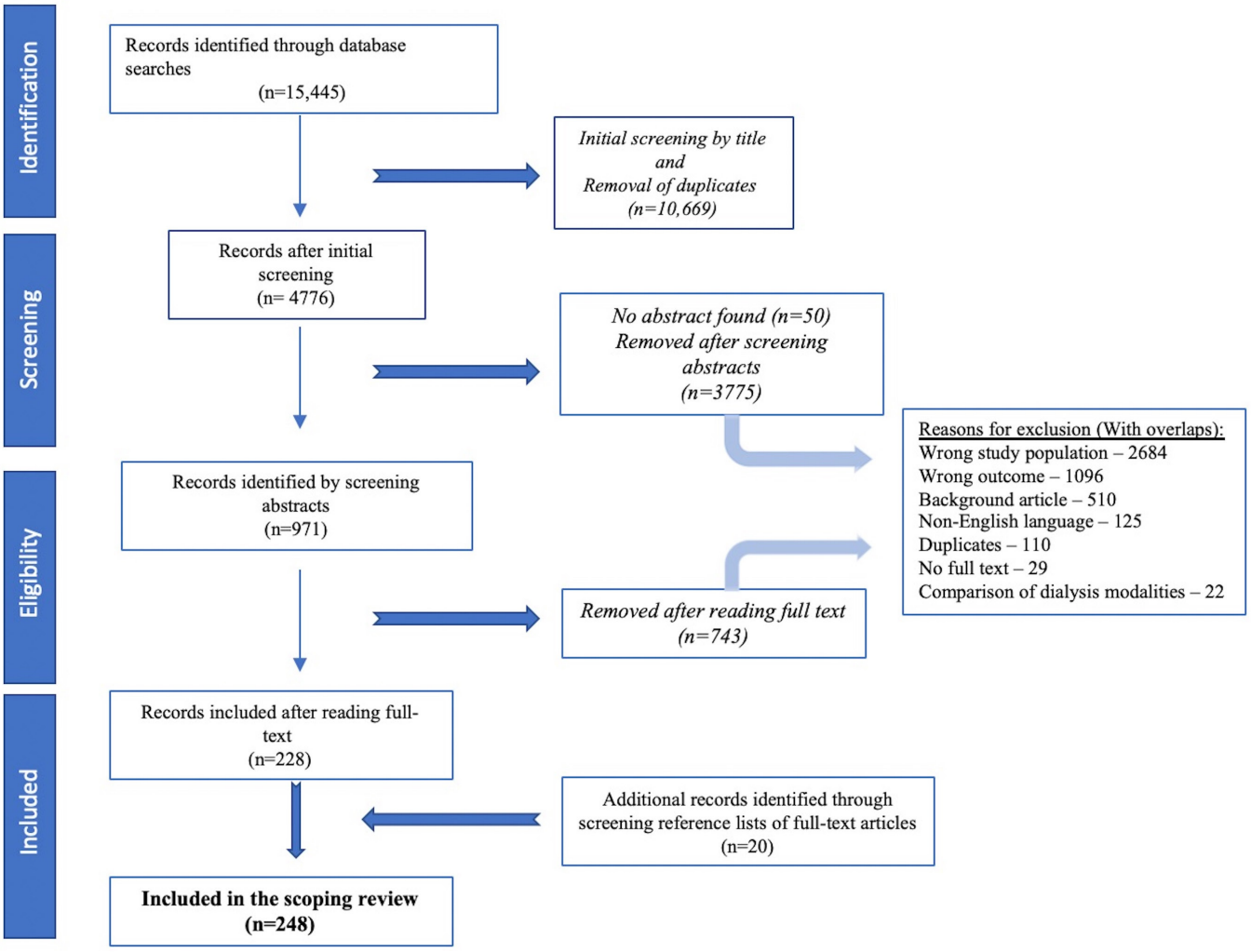

Figure 1 PRISMA flowchart for study inclusion.[29]

(doctors, renal nurses and other allied health personnel) approach the complex decisions about treatment options for advanced kidney disease.[12]

In older patients, the rate of progression of kidney disease may not be as rapid as their younger counterparts.[13] In addition, in older patients who do progress to end-stage kidney disease, treatment with dialysis, which is the default option, may not always lead to better outcomes or improve quality of life.[14 15] With this in mind, several nephrology centres across the world now offer a dedicated programme of conservative management or non-dialytic care (ie, holistic patient management that does not include dialysis or transplantation; sometimes called 'supportive care').[16–19] The current dilemma, for patients and physicians alike, is in deciding which among these two options—dialysis or non-dialytic, conservative management—is ideal for an individual patient.[20]

Professional nephrology associations call on the community to ensure that decisions regarding dialysis, especially in older, sicker adults, be made according to the principles of patient-focused, shared decision-making.[21 22] Open, transparent and complete sharing of information, particularly with regards to prognosis and quality of life, with dialysis treatment or otherwise, is an important part of this process. However, physicians may be handicapped by the lack of appropriate information regarding outcomes of the various forms of treatment in the older population.[23] Different prognostic instruments that predict renal worsening or survival exist, but while some are rigorously developed and validated, others may not be accurate or ideally developed.[24–27] There is a perceived paucity of information on outcomes other than survival—such as functional status or quality of life—that are important to patients.

While discussing treatment options with older patients in the shared decision-making process, professionals have to draw on information from different sources (such as prognostic studies, reports of quality of life or experiences of patients already on dialysis), spread across multiple domains, and not easily available in a consolidated form. Such characteristics are well addressed when appraising the literature using the scoping review format, which reports on the breadth of information available in the area, intending to describe the field and uncover any gaps in the literature. We therefore undertook a scoping review to identify and summarise information from the

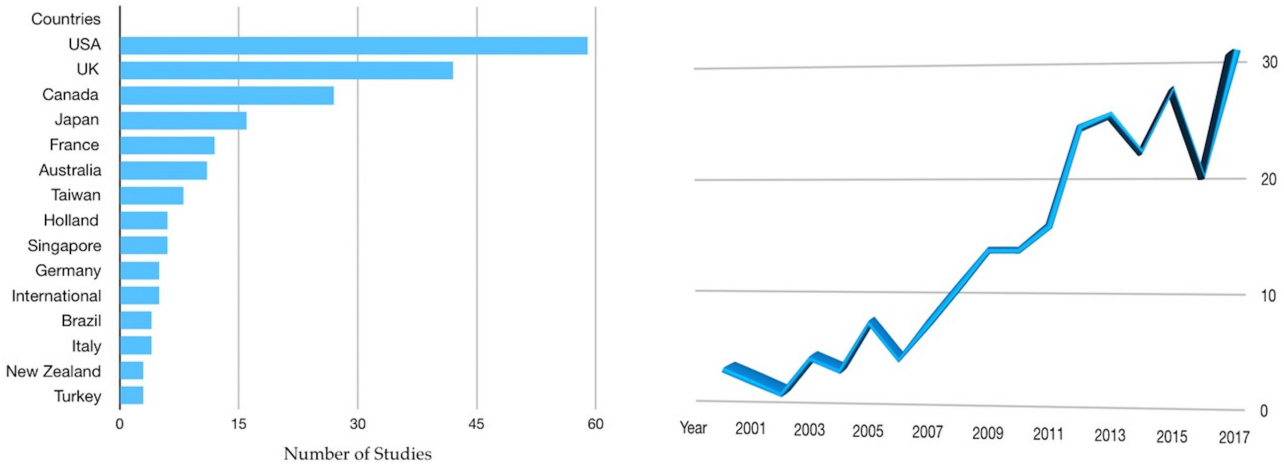

Figure 2 Countries of origin and years of publication of included articles.

published literature that might facilitate the discussions about treatment that multiprofessional healthcare team members conduct with older people who have advanced kidney disease.

Table 1 Parameters* included in prognostic studies

Sociodemographic	Comorbidities/organ function
Age	Number of comorbidities
Gender	Diabetes
Race	Hypertension
Institutionalisation (eg, nursing home)	Dementia
Nephrology care	Depression
Mode of treatment (dialysis vs non-dialysis care)	Visual impairment
Length of renal follow-up	Residual urine
Hospitalisations	Ejection fraction
Elective vs unplanned start	Biochemical tests
Related to dialysis	GFR estimated from serum creatinine
Elective vs unplanned start	Rate of fall of GFR
Dialysis access	Urine creatinine
Adequacy	Proteinuria
Length of session	Albumin
Years spent on dialysis	Haemoglobin
Functional status	Calcium
Self-rated health	Phosphate
Frailty	Parathyroid hormone
Mobility	HbA1c
Falls	Cholesterol
Dependence	C-reactive protein
Activities of daily living	Testosterone
Bedridden status	Plasma pro-ANP
Body composition	P-cresyl sulfate
Sarcopenia	Indole sulfate
Muscle mass and fat	

*Studied individually, or as part of other indices.
GFR, glomerular filtration rate.

METHODS

The scoping review adhered to the PRISMA-ScR checklist for scoping review conduct and reporting, as detailed in the online supplementary file 1.[28]

Objectives and research questions

The objective of this review was to identify and summarise the articles providing information relevant to discussions of treatment for advanced kidney disease with older patients. The specific questions for the review were developed after a scan of the literature and discussions with local clinicians and academics. We explicitly included questions that addressed the patient perspective. They were further refined by peer review during publication of the protocol. The objectives, inclusion criteria and methods for this scoping review were specified in a previously published protocol (see online supplementary file 2).[29]

In brief, this scoping review, conducted according to the Joanna Briggs Institute Protocol for Scoping Reviews, sought to address the following questions in the older patient with advanced kidney disease[30]:

- What are the factors affecting prognosis and survival (with dialysis treatment or with conservative management not including dialysis)?
- Which factors influence the quality of life?
- What information is available regarding the lived experiences with the various treatment pathways?
- What is known about the information needs of this population as they consider treatment options?

The study aimed to synthesise information from quantitative and qualitative literature, with reference to the research questions listed above, so as to

- Provide a coherent summary for clinicians, and
- Explore areas for future research.

Table 2 Prognostic indices developed in the renal population (pre-dialysis or incident patients on dialysis)

Author and year	Index	Description	Inception cohort (IC)	Validation cohort (VC)	Accuracy/results
Data from patients not yet on renal replacement therapy (RRT) or those receiving conservative, non-dialysis care					
Bansal *et al* 2005[104]	Predictive model (9 variables: including age, demographics, eGFR, urine albumin, comorbidities and smoking history)	5-year mortality in community-dwelling adults with chronic kidney disease (CKD) in two different study populations	n=828, Age 80±5.6 eGFR: 47±11; from the Cardiovascular Health Study	n=789; Age 74±2.8 eGFR: 50±9 from the Health, Ageing, and Body Composition Study	c-statistic*: IC: 0.72 (0.68–0.74) VC: 0.69 (0.64–0.74)
Landray *et al* 2010[105]	Prognostic models for risk of ESRD (4 variables: creatinine, phosphate, urinary albumin:creatinine ratio (UACR), female gender) and risk of death (4 variables: age, NT-pro BNP, troponin-T and cigarette smoking)	Risk of ESRD and risk of mortality in patients with CKD stages 3–5 in populations from two separate cohorts in Birmingham and East Kent, UK	n=382 Age: 61.5±14.3 eGFR: 21.8±10.7 Follow-up: 4.1 years ESRD rate: 12.1% per annum Mortality rate overall: 6.5% per annum; rates worse with more advanced CKD	n=213 Age: 65.1±13.5 eGFR: 21.6±13.6 ESRD rate: 12.1% per annum Mortality rate overall: 9.2% per annum (no UACR in Kent; all participants assigned 350 mg/g)	c-statistic: Prediction of ESRD: IC: 0.873 (0.836–0.909) VC: 0.91 (0.87–0.96) Prediction of mortality: IC: 0.82 (0.774–0.866) VC: 0.82 (0.75–0.89)
Tangri *et al* 2011[24]	Kidney Failure Risk Equation (most accurate model contains age, sex, eGFR, albuminuria, and serum calcium, phosphate, albumin and bicarbonate)	1-year, 3-year and 5-year risk of ESRD in patients with eGFR 10–59 in 2 Canadian populations	n=3449 Age 70±14 eGFR: 36±13 24% incidence of kidney failure	n=4942 Age 69±14 eGFR: 31±1.1 11% incidence of kidney failure; patient cohort from different area in Canada	c-statistic*: IC: 0.917 (0.901–0.933) VC: 0.841 (0.825–0.857) (also passed calibration and other estimates of accuracy)
Drawz *et al* 2013[106]	Veteran Affairs Risk Score (6 variables: age, CHF, systolic BP, eGFR, potassium and albumin)	1-year risk of ESRD in adults >65, with eGFR <30	n=1866 Age: 77.5±6.4 eGFR: 25±4.3 95% were male	n=819 Age: 78.16.4 eGFR: 24.9±4.3 97.8% were male (from a different health jurisdiction)	c-statistic*: IC: 0.854 VC: 0.823
Chua *et al* 2014[107]	UREA5 score (URate, Ejection fraction, Age, Arteriopathy—peripheral, Arteriopathy—CVA, Albumin, ALP)	1-year mortality in incident dialysis patients (HD and PD); retrospective study; based on parameters prior to dialysis initiation	n=983 Age: 60±13 eGFR: 6.6 (4.8–9.2) 22% >70 years	Not described	c-statistic*: IC: 0.74
Wick *et al* 2017[108]	Predictive model (7 variables, including age >80, eGFR, comorbidities, hospitalisation)	6-month mortality after dialysis initiation studied in patients >65 in a single Canadian centre based on values prior to initiation	n=2199 Age: 75.2±6.5 eGFR: <15 in 81.2% Patients starting dialysis between 2003 and 2012 in a regional registry in Canada 52% had CHF, 58% diabetes	No VC	c-statistic*: IC: 0.72 (well calibrated)
Schroeder *et al* 2017[109]	Predictive model: (8 variables including age, gender, eGFR, haemoglobin, proteinuria, systolic BP, antihypertensive medication use and diabetes)	5-year risk of needing RRT, in a retrospective cohort of patients with CKD not yet on RRT who were members of a US-managed care consortium	n=22 460 Age: 74.6±10.1 eGFR: 46.8±10.1 All those with a persistent stage 3 or 4 CKD	n=16 553 Age: 74.7±9.0 eGFR: 47.5±9.8 All those with CKD stage 3 or 4 from a geographically different branch of the managed health programme	c-statistic*: IC: 0.96 (0.95–0.97) VC: 0.95 (0.94–0.97) R^2 value: IC: 79.7 (78.6–80.8) VC: 81.2 (17.6–82.6)
Data from the incident period for patients on haemodialysis or peritoneal dialysis (both HD and PD)					

Continued

Table 2 Continued

Author and year	Index	Description	Inception cohort (IC)	Validation cohort (VC)	Accuracy/results
Couchoud *et al* 2009[110]	Predictive model (9 variables—including body mass index, comorbidities, functional status and unplanned dialysis initiation)	6-month mortality in older adults starting dialysis between 2002 and 2006 based on French REIN registry data at the time of initiation	n=2500 Age >75 eGFR: n.a. Randomly chosen from the registry	n=1642 Age >75 eGFR: n.a. Randomly chosen from registry; similar overall characteristics to inception cohort	c-statistic*: IC: n.a. VC: 0.7 (well calibrated; good transportability to 3 months and 12 months)
Wagner *et al* 2011[111]	Predictive model (13 variables in final model including age, demographics, comorbidities, primary kidney disease, treatment modality and biochemistry)	All-cause mortality, after the first 3 months, in adults >18, in the UK Renal Registry, incident to dialysis in the period 2002–2004; majority on haemodialysis	n=3631 Age: 64 (49–73) Creatinine: 7.2 (5.6–9.2) Random split; two-thirds of the original cohort	n=1816 Age: 64 (51–74) Creatinine: 7.2 (5.5–9.1) Random split; one-third of the original cohort	c-statistic*: IC: 0.75 (0.73–0.77) VC 0.73 (0.7–0.76) Both with good calibration
Kan *et al* 2013[112]	The New Comorbidity Index (11 comorbidity conditions included; age not part of the index; initially validated in separate dialysis populations without regard to age)	Mortality over the follow-up period (mean 3.25 years, median 1.56 years) in a population-based *validation study* cohort of older dialysis patients based on the presence of 11 comorbidities at baseline at the start of dialysis	Inception cohort, in a *different study*[113] (included 4 incident cohorts (n=1 20 134) and 1 prevalent cohort (n=1 42 157); *of all ages*; drawn from USRDS data 1999–2000)	n=21 043; Age: all >65; stratified into groups by age eGFR: n.a. 52% of patients in the lowest comorbidity score group Older age groups: more men, more comorbidities	c-statistic*: IC (in the separate inception study): 0.669[113] VC: 0.908 (0.897–0.919)
Dusseux *et al* 2015[114]	Predictive model (14 variables—including age, gender, body mass index, comorbidities, mobility and temporary catheter at start)	Prediction of 3-year survival rate around 70% in people over 70 starting dialysis; based on French REIN registry data at the time of initiation (high survival rates could suggest eligibility for transplantation)	n=8955; Median age: 78 (74–82) eGFR: n.a. (2002–2006)	n=7382 Median age: 79 (75–83) eGFR: n.a. Initiating dialysis between 2007 and 2008	c-statistic*: IC: 0.71 (0.69–0.71); VC: 0.71 (0.70–0.72) (well calibrated)
Thamer *et al* 2015[115]	Two predictive models—a simple risk score with 7 variables and a comprehensive risk score with 14 variables (age, gender, period of nephrology care, albumin, functional status, nursing home residents, comorbidities, hospitalisations)	Prediction of 3-month and 6-month mortality after initiation of dialysis in people ≥67 based on data from USRDS and Medicare/ Medicaid services who started dialysis in 2009–2010	n=52 796; Age: 76.9±6.5 eGFR: 12.2±5.1 (Jan 2009–Jun 2010)	n=16 645; Age: 76.8±6.5 eGFR: 12.2±5.1 (July–Dec 2010)	c-statistic*: IC: 0.681 VC: 0.712 (well calibrated)
Ivory *et al* 2017[116]	Ivory points score tool (8 variables, including age, weight, comorbidities, late referral, aetiology of CKD)	6-month mortality in a registry sample of adult patients commencing dialysis between 2000 and 2009 in Australia/ New Zealand based on logistic regression analysis of factors available at dialysis initiation	n=23 658 Age: 60±15 in survivors; 69±13 in deaths eGFR: <15 in 95%	VC 1: temporal validation n=5284 Age, eGFR: n.a. All patients >15 in the ANZDATA registry commencing dialysis in 2009–2011 VC 2: external validation n=32 664 Age, eGFR: n.a. All patients >18 in the UK regional registry commencing dialysis in 1999–2007	c-statistic* IC: 0.751 (poor calibration) VC 1: 0.755 (acceptable calibration) VC 2: 0.713 (poor calibration)

Continued

Table 2 Continued

Author and year	Index	Description	Inception cohort (IC)	Validation cohort (VC)	Accuracy/results
Chen *et al* 2017[117]	Predictive model (9 variables, including age, gender, race, primary disease, BMI, employment status, previous renal care, dialysis access, comorbidities)	5-year mortality in patients; baseline data at the initiation of dialysis in those ≥70 starting dialysis between 2006 and 2009 in the USRDS renal registry; to guide referral to kidney transplantation	n=79 681 Age: ≥70 eGFR: n.a. Randomly selected cohort from among patients ≥70 starting dialysis between 2006 and 2009 from USRDS registry data 41% had no nephrology care before initiating dialysis	VC 1 n=79 681 Age: ≥70 eGFR: n.a. Randomly selected cohort from among patients ≥70 starting dialysis between 2006 and 2009 from USRDS registry data 41% had no nephrology care before initiating dialysis VC 2: n=2397 Age: ≥70 eGFR: n.a. Patients ≥70 between 2006 and 2009, who received a kidney transplant before 2014	c-statistic* IC: 0.71 (0.70–0.71) VC 1: 0.71 VC 2: 0.60 (0.57–0.63; poor discrimination)
Data from incident patients on haemodialysis (HD)					
Mauri *et al* 2008[118]	Predictive model (10 variables—including age, gender, primary renal disease, functional status, comorbidities and malnutrition)	1-year mortality in all patients starting HD; using registry data at the time of initiation	n=3455 Validation cohort was randomly chosen 60% of the registry population Age: 64.6±14.4 (overall) eGFR: n.a.	n=2283 Cohort developed from randomly chosen 40% of same registry population (separate characteristics for validation cohort not provided)	c-statistic*: IC: 0.78 VC: 0.78 (well calibrated)
Floege *et al* 2015[119]	Predictive model (14 variables including age, smoking, BMI, comorbidities, dialysis parameters, laboratory data)	1-year and 2-year mortality, of all incident patients from a European patient database (AROii) between 2007 and 2009; validated in a population of incident and prevalent patients	First inception cohort: n=9722 Age: 64.4±14.7 Creatinine: 565.4±187.6 Incident patients at <3 months Second inception cohort: n=8783 Age: 64.3±14.7 Creatinine: 614.1±201.7 Incident patients 3–6 months	n=10 615 Age: 63.4±14.3 Creatinine: 777.9±256.4 Baseline data obtained at <3 months of initiation in the DOPPS III cohort	c-statistic*: IC: n.a. VC: 1 year, 0.72–0.73; 2 years, 0.72 R^2 value: IC: 1 year, 0.94; 2 years: 0.98 VC: n.a.
Fukuma *et al* 2017[120]	Predictive model (6 variables included age, gender, dementia, mental health, moderate activity and ascending stairs)	1-year decline in physical function in dialysis patients ≥65, defined as a decline to a score of 0 on the 12-item Short Form Health Survey Physical Function Score from the baseline score at initiation of HD	n=593 Age: 71.6±5.1 Years on dialysis: 5.8±5.3 Patients ≥65 included in the DOPPS Phases I and II in Japan, during 1996–2004 Mean BMI: 20.5±2.7 Mean baseline physical function score: 59.4±25.8	n=447 Age: 71.9±5.6 Years on dialysis: 6.3±6.2 Patients ≥65 included in the DOPPS Phases III and IV in Japan, during 2005–2012 Mean BMI: 21.0±2.5 Mean physical function score a baseline: 62.8±25.8	c-statistic* IC: 0.79 (0.74–0.84) VC: 0.76 (0.72–0.8) (well calibrated)

*c-statistic values closer to 1 indicate good discrimination; values near 0.5 indicate poor discrimination.
ALP, alkaline phosphatase; BMI, body mass index; BP, blood pressure; CHF, congestive heart failure; CVA, cerebrovascular accident; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; n.a, not applicable; USRDS, United States Renal Data System.

Inclusion criteria

The scoping review included articles that addressed older adults with advanced kidney disease and focused specifically on survival/mortality, factors affecting prognosis or quality of life, descriptions of the lived experience of treatment (on dialysis or conservative management) or descriptions of the information needs of older adults. These four areas were developed by consensus between the authors after considering the areas of relevance to the dialysis decision.

In order to capture all relevant data, we included all studies where the population studied was described by primary researchers using terms such as 'elderly', 'aged', 'geriatric' or 'older', without pre-specifying an age cut-off to define the older adult. Advanced kidney disease was defined for this review as an estimated glomerular filtration rate (eGFR) ≤30 mL/min/1.73 m^2.

We included articles from the time period of January 2000 to August 2018. This time period was chosen so as to reflect the increasing number of older patients on dialysis, the changing attitudes to the treatment of older adults in recent years and the establishment of conservative care without dialysis as a valid treatment option. All forms of research, involving both quantitative and qualitative methods, and articles that were published in peer-reviewed literature as well as the 'grey' literature were included. The focus was on information that was likely to be of value in choosing whether to have dialysis (any type of dialysis) or not. Only articles written in English were included (as we had limited translation resources).

Exclusion criteria

- Research that did not address older adults (see operational definition above) as the main population or as a subpopulation of interest,
- Research that primarily focused on those with an eGFR >30 mL/min/1.73 m^2,
- Research exclusively comparing variations of dialysis treatment modalities or transplantation with each other,
- Research describing the effects of interventions other than dialysis, or
- Research with reports in languages other than English.

Search methodology

Databases searched included PubMed, Embase, PsycINFO, CINAHL, EbscoHost, Mednar, Cochrane, TRIP databases and Web of Science for peer-reviewed research, and OpenSIGLE, Open Grey, Trove, EThOS, OATD.org and OpenThesis for grey literature. Websites of national specialty societies and clinical guideline collections were also searched. Searched terms included those relevant for older patients, chronic kidney disease, dialysis, conservative management, prognosis, survival, quality of life, lived experiences and information needs. These terms were adapted to suit searches in individual databases; examples of search terms are provided as online supplementary file 3.

Initial screening of articles was undertaken by two researchers (RR and ST) working independently, using the web-based Rayyan QCRI software (Qatar Computer Research Institute and Qatar Foundation, Qatar).[31] Charting of included studies and the extraction of relevant information were done using FileMakerPro16 (FileMaker, California, USA) and Microsoft Excel software (Microsoft, Washington, USA). Separate data extraction forms and charting sheets were used for the four different research questions, as shown in the published protocol.[29] For included articles, the following data were extracted: primary author, year of publication, type of research, modality of treatment studied, population, focus of research and main findings. Forms used for final data extraction are provided as online supplementary file 4.

Patient and public involvement

We did not involve patients or members of the public in the design or conduct of this scoping review. However, two of the research questions for the scoping review directly summarised reports of patient experiences and information needs.

RESULTS

Figure 1 shows the flowchart summarising the selection of studies to be included in this scoping review and the reasons for exclusion. All 15445 articles identified in databases were imported into the reference management software as detailed. Subsequent screening of titles and removal of duplicates provided 4776 articles for review with abstracts. These articles were divided into groups depending on the questions of the survey, and 971 articles used for full-text review. Cohen's kappa for inter-rater agreement between the two reviewers during the initial (blinded) screening of articles for inclusion was 0.54, suggesting 'moderate' agreement.[32] Conflicting decisions regarding suitability for inclusion were subsequently resolved by discussion among the authors. Finally, 228 articles were included, along with 20 articles found by hand-searching reference lists of included articles, making up 248 articles selected for analysis (see online supplementary file 5 for list of included studies). This included three theses obtained from screening of the grey literature.

The majority of included articles have primary authors resident in the English-speaking countries—USA, UK, Canada and Australia. Japan, France, Taiwan and Holland were the other significant contributors (figure 2). A greater proportion of research literature was written in the previous 5 years (2012–2017); the number of articles on older patients with kidney failure showed an increasing trend in recent years.

Overall, half the included articles refer to patients on haemodialysis exclusively; 18% were studies on patients not on dialysis and 5% included all older patients with end-stage kidney disease, regardless of treatment choice. Peritoneal dialysis patients alone contributed to 8% of

studies while 17% included patients undergoing both peritoneal and haemodialysis.

For purposes of analysis, the included studies were analysed in groups, according to the research questions for the review detailed above (prognosis, quality of life, lived experiences and information needs, respectively). The following section on results is also presented according to these questions.

Characteristics of studies describing prognosis

In all, 112 articles that specifically focused on the prognosis of the older patient with advanced kidney failure were included in the review. Thirty-four were single-centre studies; 28 involved patients in multiple centres, while 24 studies, often with participant numbers in excess of 1000, were conducted as registry-based research. Sixty-six studies (61.8%) were retrospective studies (including 20 out of the 24 registry-based studies). Studies that only included patients on haemodialysis predominated (39 studies).

Content and scope of studies describing prognosis

Mortality/survival was the the most common prognostic outcome of interest. Other outcomes were also studied, usually in addition to mortality and included quality-of-life outcomes, time to renal replacement therapy/end-stage kidney disease, hospitalisation and functional or nutritional status.

Researchers considered several different variables for inclusion as prognostic markers (table 1). The stated aim in several papers was to use easily available, clinical indicators to predict prognosis. Most commonly, researchers used a combination of variables—clinical, laboratory, demographic or instrument-based data to derive prognosis. These variables could be grouped into sociodemographic variables (including age, nursing home residence), comorbidities, functional status, nutritional parameters, aspects of nephrology or dialysis care, and biochemical variables (see online supplementary file 6 for a detailed list).

A common method was to use a combination of variables in order to predict prognosis. While some studies investigated particular combinations of variables in single cohorts, others reported inception and validation cohorts, presenting the combination of variables as an index or prognostic score. Some of these scores were developed specifically in patients with renal failure, while others were adaptations of prognostic tools used in the general population. Table 2 describes such indices that were developed exclusively in the older patient or use age as a variable in the index to derive prognosis (therefore making them suitable for use in the older population).

We identified 12 studies that compared dialysis treatments with conservative management without dialysis. Table 3 lists these studies, in chronological order, where the older population has been the focus of comparisons between dialysis or conservative management.

Characteristics of studies describing effects on quality of life

Eighty studies representing research that evaluated the factors influencing the quality of life in older adults on dialysis were selected. Of these, 29 were clinical research papers, the rest being reviews of related topics or expert opinion. Among the 29 articles reporting on original clinical research, 24 used questionnaires or surveys to interrogate quality of life. The supplementary materials include a list of the commonly used instruments to measure quality of life in elders on dialysis.

Content and scope of articles discussing factors influencing quality of life

Table 4 lists the factors affecting quality of life, identified from analyses of the included articles. They have been separated into modifiable and non-modifiable factors for convenience.

Age had an impact on quality of life. While physical aspects of quality of life in the elders were low, especially once on dialysis, other aspects of quality of life such as life satisfaction, mental component scores or social well-being appeared to be more stable in older than younger patients.[33 34]

Researchers who compared the quality of life outcomes in older people between the conservatively managed pathway versus the renal replacement pathway reported either no major differences between the two or worse quality of life with dialysis.[35–37]

Psychological factors were relevant to quality of life. Depression scores, spiritual and emotional well-being and even cognitive impairment have been reported to affect quality of life.[38 39] Functional impairments and frailty, diminished exercise and impaired activities of daily living all worsened quality of life. Despite diminishing functional status, rates of hospitalisation were not significantly different between older and younger patients on dialysis.[40] For patients already on dialysis, several dialysis-related factors contributed to quality of life. These included the number of years on dialysis, alterations in dialysis regimes or the duration of dialysis sessions. Finally, other comorbidities such as diabetes, myocardial infarction and stroke worsened quality of life.

Characteristics of studies describing lived experience with advanced kidney disease

Ninety-four studies that reported on the experiences of older adults living with advanced kidney failure were included. The majority of articles (74 of 94) detailed original clinical research; 23 employed qualitative analysis, usually in the form of interview or focus group analysis, while 29 used a particular tool or instrument to assess one of the aspects of experience. A list of the common instruments used in these studies is provided as online supplementary material, sorted according to the area of analysis.

Content and scope of studies describing lived experience with advanced kidney disease

Several studies used scores or indices to study life on dialysis; importance is also given to symptoms, functional and cognitive aspects (and, particularly in this age group, to

Table 3 Studies comparing conservative management (CM) and renal replacement therapy (RRT, all forms of dialysis)

Author/year	Aim/objectives	Population of interest	Main findings*	Conclusions/comments
Joly *et al* 2003[121]	Comparison of survival between CM and RRT in octogenarians; predictors of poor prognosis; most data obtained prospectively	All patients ≥80 with a creatinine clearance <10 mL/min (Cockcroft-Gault formula), not yet on dialysis; seen in a single French unit in 1989–2000 n=146 (CM: 37; RRT: 107) Age: CM: 84.1±2.9; RRT: 83.2±2.9 Later referral, poor functional status and diabetes were more common in CM cohort; no of comorbidities similar between both cohorts	Survival: less with CM (8.9 vs 28.9 months) Factors significantly associated with: 1-year mortality: poor nutritional status, late referral and functional dependence Mortality beyond the first year: peripheral vascular disease	In those >80, best 1-year survival is seen in those with early referral, normal BMI and good functional status (Most dialysis decisions here were taken by multidisciplinary team; all subsequently accepted by patients)
Smith *et al* 2003[88]	Comparison of survival between CM and RRT, in a group of pre-dialysis patients in a single UK hospital, analysing outcomes according to initial choice and eventual treatment, prospective study	All pre-dialysis patients presenting for assessment/ counselling regarding RRT options in a renal clinic, classified into two groups based on recommended therapy—CM or RRT; followed for 3 to 57 months; eventual treatment choice and outcomes studied n=321 (recommended: CM 63; RRT 258) Age: 61.5±15.4 (recommended: CM 71±12; RRT 59±15) RRT: 186 started treatment; rest died or chose CM CM: 11 switched to RRT eGFR: by derivation, <10 in both groups	Survival: Recommended CM: 6.3 vs 8.3 months if switched to RRT (not statistically significant) Cox PH: no survival benefit of RRT in those recommended for CM, regardless of eventual choice Likelihood of CM recommendation: older, sicker, diabetic, more functionally impaired, less likely to survive 1 year	In those older, more functionally impaired, more comorbidities and diabetes, who are recommended for CM, no survival benefit from RRT
Murtagh *et al* 2007[122]	Comparison of survival between CM and RRT in patients ≥75 from 4 UK renal units; retrospective study	All patients ≥75 receiving renal care, with survival calculated from the date of first recorded eGFR ≤15 n=129 (CM 77, RRT 52) Median age: CM 83; RRT 79.6 Comorbidities: similar CM cohort: older; but otherwise similar	After eGFR ≤15: Median survival time: less in CM (540 vs 588 days) 1-year survival rate: lower in CM (68% vs 84%) 2-year survival rate: lower in CM (47% vs 76%) Survival in those with high comorbidity: no statistical difference CM vs RRT	In those >75 with severe comorbidity, no significant survival advantage for RRT over CM
Carson *et al* 2009[89]	Comparison of clinical outcomes (survival, hospitalisation) for patients who had ESRD and chose either CM or RRT	Patients older than 70 who either started RRT or attended CM clinic from 1997 to 2003 n=202 (CM 29; RRT 173) Age: CM 81.6; RRT 76.4 eGFR: median value at start of RRT was 10.8. For CM group, survival calculated from the time they were estimated to reach eGFR 10.8 Comorbidity scores: similar in both groups	CM cohort was older. Survival: less with CM (13.9 vs 37.8 months) Hospitalisation: *less* with CM during follow-up; CM cohort more likely to die at home or hospice than hospital (OR 4.15)	In those >70, RRT provided longer survival (by 2 years) than CM, but there were similar number of hospital-free days in both RRT and CM
Chandna *et al* 2011[123]	Comparison of survival between CM and RRT in patients with ESRD with high vs low comorbidity in UK clinic from 1990 to 2008	All adults progressing to stage 5 CKD seen in clinic over 18 years; followed from the time of first recorded eGFR @10 to 15 n=844 (CM 155, RRT 689) Ages: CM 77.5±7.6; RRT 58.5±15 eGFR: 13.2±1.4 in both groups at study entry Comorbidity scales scored for every participant	CM was older and had greater comorbidities Survival (median) with low comorbidity: less in CM (29.4 vs 36.8 months) Survival, severe comorbidity: less in CM (20.4 vs 25.8 months) (non-significant difference in survival with severe comorbidity)	In those >75 with severe comorbidity, no significant survival advantage for RRT over CM

Continued

Table 3 Continued

Author/year	Aim/objectives	Population of interest	Main findings*	Conclusions/comments
Hussain *et al* 2013[69]	Comparison of survival, hospital admissions and palliative care access between CM and RRT cohorts of older patients in a single UK unit; studied retrospectively	All patients aged >70 and eGFR <20, receiving advice regarding CM vs RRT during pre-dialysis education. Survival was calculated from three time points: when the eGFR was <20, <15 and <12 n=441 (CM 172, RRT 269) Age: CM 82±5.6; RRT 77±5 Comorbidity (CCI), WHO performance score worse in CM cohort; CM cohort more likely to be institutionalised	Survival from all three time points: less with CM Survival from eGFR <20 20.4 years less with CM Difference in survival between CM and RRT is reduced in those >80: when CCI score is high when performance score worsens Hospitalisation risk: more with RRT than CM (RR 1.6) Palliative care review: more with CM (85% vs 4% of patients)	In those >80, no survival advantage for RRT over CM In those >70, increasing performance score or increasing comorbidities reduces the survival advantage for RRT over CM
Seow *et al* 2013[124]	Comparison of change in health-related quality of life between CM and RRT in patients with advanced age and severe comorbidity	Pre-dialysis patients eGFR 8–12, who were >75 or had CCI >8, seen in single hospital Quality of life for assessed with KDQOL-SF v1.2, Chinese and English versions, administered by interviewer n=101 (CM 63, RRT 38) Age: CM: 78; RRT 71 eGFR: similar in both groups eGFR decline: faster in RRT group	PCS, MCS stable in CM group; no significant difference from RRT group RRT group: improved cognition function scale, but worse scores on effective kidney disease and burden of kidney disease scale	In those >75 with severe comorbidity, RRT did not improve kidney-specific symptoms or significantly improve QOL domains compared with CM
Shum *et al* 2014[90]	Comparison of clinical outcomes (survival, hospitalisation, institutionalisation, EOL care) for Chinese patients with CKD stage 5 that chose either CM or PD	Adults ≥65; followed for at least 1.5 years from first dialysis assessment visit; retrospectively chosen from the period 2003–2010; n=199 (CM 42; PD 157) Age: CM 75.3±5.7; PD: 73.4±5.3 eGFR ≤15 for study inclusion	CM cohort was older, less likely to have home help with PD. Survival: less with CM (2.35 vs 3.75 years) Hospitalisation: *more* with CM cohort than PD cohort even after adjusting for age, comorbidity and functional status Institutionalisation: risks were similar EOL care: CM cohort more likely to receive renal palliative care; less bothersome interventions at EOL	In those >65, home-based PD provided greater survival than CM, with less hospitalisation and equal risk of institutionalisation
Brown *et al* 2015[35]	Comparison of survival, symptom burden and quality of life between CM and RRT in older patients in a single Australian unit; studied prospectively	All patients receiving care in pre-dialysis, renal supportive care or emergency dialysis start pathways Symptoms, quality of life assessed using surveys n=467 (CM 122, RRT 345) Age: CM 82±9; RRT 67±14 eGFR at study entry: 16 in both groups	Survival: less with CM (20 vs 33 months) Survival in those >75: less with CM (19 vs 31 months) Mean survival from eGFR <15: less with CM (13 vs 20 months) Mean survival, eGFR <15, age >75: less with CM (aHR 4.4) mean survival, age >75, comorbidities (IHD or CHF) ≥2: not statistically different Symptom control: similar in both CM and RRT Quality of life changes: similar in both CM and RRT	In those >75, with cardiac plus other comorbidities, no survival advantages from RRT over CM

Continued

Table 3 Continued

Author/year	Aim/objectives	Population of interest	Main findings*	Conclusions/comments
Verberne *et al* 2016[85]	Comparison of survival between CM and RRT in patients ≥70; retrospective study single Dutch hospital	All patients ≥70 receiving renal care in one centre, eGFR <20 Survival calculated from time of decision regarding RRT/CM n=311 (CM 107, RRT 204) Age: CM 82.5±4.5; RRT 75.9±4.4 eGFR: CM 15.3, RRT 13.1 eGFR decline: similar in both groups Comorbidities: similar	Survival: less with CM (0.5 vs 2.8 years at eGFR <10; 1.5 vs 3.1 years at eGFR <15) Survival in those over 80: no statistically significant advantage (1.4 vs 2.1 years, p=0.08) Survival in those with high comorbidity: benefit of RRT significantly reduced (1 vs 1.8 years, CM vs RRT)	In those >80, no significant survival advantages for RRT over CM
Martinez Echevers *et al* 2016[86]	Comparison of survival between CM and RRT in older patients in a single Spanish unit; studied prospectively	All patients aged >70 receiving care in the advanced CKD clinic, with separate analyses in those with CKD stage 5 regarding CM vs RRT and survival Group with eGFR <15: n=162 (CM 93, RRT 69). Median age: CM 78; RRT 76 eGFR at study entry: 14 in both groups	Survival (overall study duration): less with CM (39 vs 65 months) Survival from eGFR <15: less with CM (21 vs 46 months) Survival in those >75: less with CM (p=0.003) Survival in those >80: no difference between CM vs RRT Survival in those with IHD: no difference between CM vs RRT Survival with high comorbidity CCI score: less with CM (p=0.009)	In those >80, no survival advantages from RRT over CM In those >70 with IHD, survival benefit of RRT is reduced
Chandna *et al* 2016[125]	Investigation of role of rate of kidney function decline on survival and treatment choices in older patients with ESRD seen in UK clinic from 1995 to 2010	Patients over 75 years old progressing to eGFR 10–15, seen in renal clinics between 1995 and 2010 (second follow-up eGFR taken prior to dialysis start or prior to death (CM patients) to calculate the rate of decline of eGFR) n=250 (CM: 158; RRT: 92) Age: 80.9±4 (CM: 82±4.1; RRT: 79.1±3.1) Index eGFR: 13.3±1.4 in both groups Follow-up eGFR: CM: 8.8±3.2; RRT: 6±2.5 Median rates of eGFR decline (mL/min/month): CM: 0.21; RRT 0.45 (p<0.001)	CM cohort: similar age, more comorbidities, but *slower rate of decline* in eGFR Survival: less in CM (23.1 vs 38.2 months) Survival with high comorbidity: less in CM (20.3 vs 28.4 months; p<0.049) High rate of eGFR decline: worse survival in CM, minimal effect in RRT Predictors of RRT choice: Age >75, gender, comorbidity, rate of decline of eGFR (CM choice is more often taken in patients with *low* rates of decline)	In those >75 with high comorbidity, only marginal advantage of RRT Rapid rates of eGFR decline worsens survival in those >75 managed with CM
Reindl-Schwaighofer *et al* 2017[126]	Comparison of survival between CM and RRT in the same era, using Austrian registry data for haemodialysis patients; studied retrospectively	All patients >65 years starting haemodialysis between 2002 and 2009 in the Austrian dialysis and transplant registry were compared with patients managed conservatively, after the GFR declined <10; in a single hospital (aged >65, in 2002–2009); bootstrapping used for propensity scores n=CM 174; RRT (only HD) 8622 Age: CM 81.22±7.23; RRT 74.06±5.78 eGFR: CM <10; RRT not specified	CM cohort: 95% female, more comorbidities Survival: less with CM (1.1 months vs 26.9 months) Survival benefit: less with CM (HD HR for death 0.39) survival benefit beyond 2 months: better with CM (non-significant)	In those >65, with comorbidities, survival benefit for RRT did not persist beyond 2.9 months (females) or 1.9 months (males) compared with CM

*CIs, IQRs and p values not included for all articles.
BMI, body mass index; CCI, Charlson comorbidity index; CHF, congestive heart failure; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; EOL, end of life; ESRD, end-stage renal disease; HD, haemodialysis; IHD, ischaemic heart disease; MCS, mental component score; PCS, physical component score; PD, peritoneal dialysis; PH, proportional hazards.

Table 4 Factors affecting quality of life

Potentially modifiable factors	Non-modifiable factors
Physical status	Age
Functional decline	Gender
Frailty	Race
Symptom burden	Socioeconomic status (some aspects amenable to interventions)
Unplanned dialysis starts	Comorbidities (some aspects amenable to interventions)
Depression	Years spent on dialysis
Cognitive impairment	
Positive social relationships	
Sleep disturbances	
Impaired nutrition	
Cardiovascular health	
Dialysis-related factors (session length, regimens, etc)	

falls). Discussions of decision-making, survival and ageing were also common.

Older patients reported difficulties in getting information, feeling disempowered and dominated by the healthcare team and not being part of decisions.[41] Patients reporting disempowerment were more likely to regret the decision to go onto dialysis; this was more common if they started dialysis due to family compulsions.[42] Patients wanted greater involvement in deciding practical aspects of dialysis such as dry weight, the time of treatment, dietary restrictions or the access to use for dialysis.[41]

Coping and adaptation to treatment were important parts of the narrative. Successful coping was vital.[43] Patients that coped successfully had "a transformed care dynamic, positive appraisal and active everyday engagement".[44] Useful coping strategies included letting go, overcoming, keeping a sense of humour, looking at the good side of things and thinking positively.[45 46]

The incurability of kidney failure forces patients to reinvent themselves, make compromises or adopt beliefs or behaviours discordant with medical opinion.[47–50] Despite these burdens, the majority of patients reported satisfaction with treatment and improvement of symptoms; another study found that the majority of patients reported no decision regret or ambivalence about starting dialysis.[51 52] It should be noted, however, that patients' decisions, goals and expectations are not static but change with time as different issues emerge.[42 53]

Patients constantly reflect on themselves in relation to others—being a burden, receiving help or having other relationships.[48 54] Partnership was frequently mentioned, whether spousal or with professionals.[44 55] Patients reported close and supportive relationships with healthcare professionals in some centres; dialysis nurses often encouraged patients to be independent and assisted with coping.[52] Otherwise, elders reflected on the busy cultures of units, with infrequent opportunities to speak to doctors.[56]

Several included studies referred to the effects of dialysis on the functional status of older patients, particularly in the first 6 months where up to 30% face decline.[57–59] This is even worse in patients living in nursing homes where 61% declined in functional status or died within the first 3 months; this figure was 87% at 1 year.[60] Falls are common, particularly soon after dialysis.[61]

The symptom burden was high, and this was confirmed by qualitative studies which provided stories of suffering and burden inflicted by dialysis.[62] Despite this, scores of mental components of quality of life and satisfaction with life appear to be stable and equal to or better than that for younger patients.[33] Other correlates of a good quality of life in these studies included living with family rather than alone or in a nursing home and having widespread social relationships. The social well-being of older dialysis patients did not decline significantly with time.[63 64] Physical scores were uniformly lower.[60 65 66] There were several interactions among these factors, such as those between cognition and depression, physical decline and risk of falling and insomnia and depression.[67 68] Octogenarians were frequently hospitalised for infections; while those patients who had access to a conservative management pathway were less likely to be admitted to hospital, particularly at the end of life.[40 69]

Older patients are aware of impending mortality and frequently contemplate death.[70] These topics are difficult to talk about.[71] The haemodialysis machine is seen as a lifeline as it attempts to relieve suffering even though dialysis can be seen as a prison, or between life and death.[41 47 54] Thoughts of stopping dialysis arise often—increasing age, female gender, dementia and prior cerebral vascular disease are risk factors for withdrawal.[72 73]

Characteristics of studies reporting on information needs of the older patient

A total of 32 articles, mostly published in the last 10 years, were concerned with information needs of older patients with advanced kidney failure. Seventeen articles were original research papers, eight were opinion pieces and six were reviews (predominantly narrative reviews). Most research was in the qualitative realm (12/17 interviews and focus groups analysis; 4/17 survey-based analysis).

Content and scope of studies reporting on information needs in the older patient

Thematic analysis of the included studies revealed the broad themes which are summarised in figure 3. The most frequently reported theme related to the need for complete information about treatment modalities, including non-dialysis pathways. Such information is not uniformly provided to patients—discussion about conservative care options, for instance, was more likely to happen if the particular renal unit had an established conservative treatment pathway.[8]

With a perceived uncertainty regarding kidney disease and its treatment requirements, patients desired information about kidney disease, progression and the symptoms

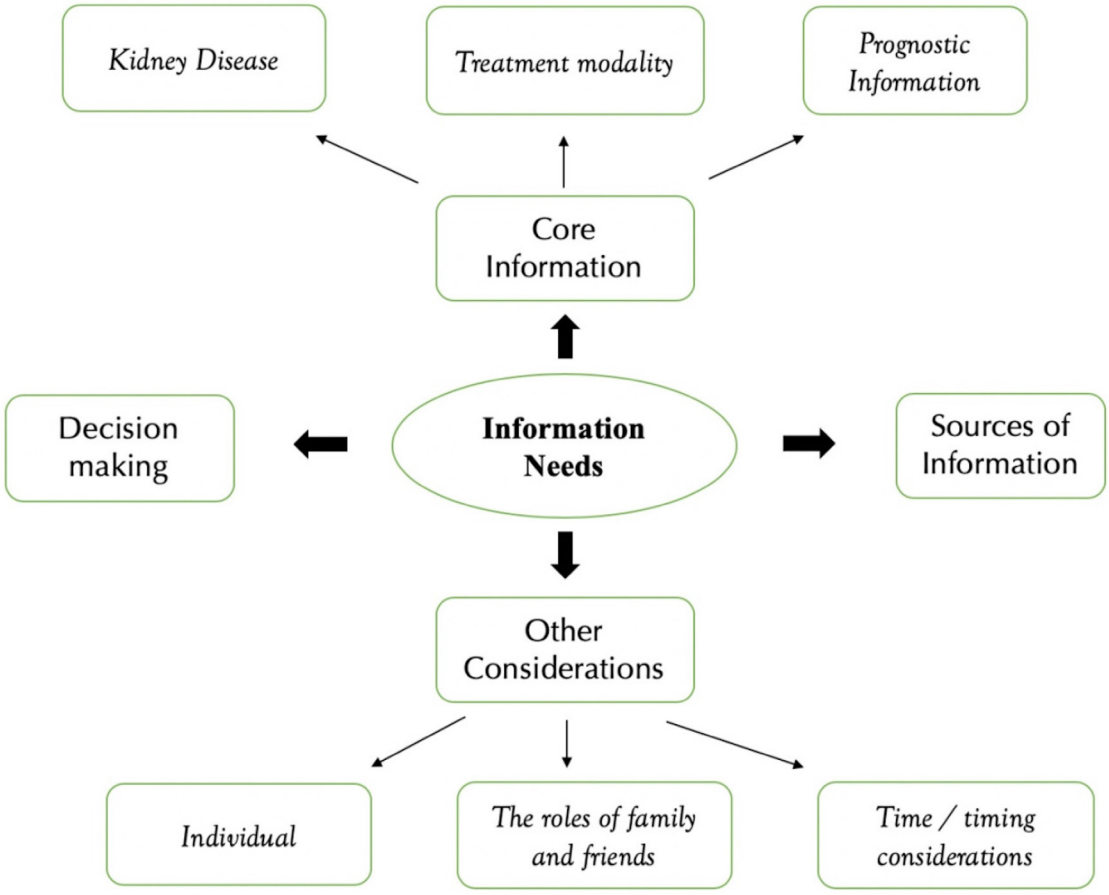

Figure 3 Information needs—themes elicited.

that may arise, especially with non-dialysis pathways of treatment. Even though survival was an important aspect of prognosis, of relevance to patients, they often report not receiving information regarding this. Clinicians are hesitant or unwilling to discuss prognosis for many reasons (uncertainty, not wanting to take away hope, etc).[7] Yet, this is vital information which could affect the choices patients make about therapy. Fine and colleagues, in two separate questionnaire-based studies on pre-dialysis populations, showed that patients expect doctors to give them prognostic information even without being prompted.[10 11]

Mortality, and thoughts about dying, were very common, especially in those considering conservative treatment or discontinuation of dialysis. Some patients were reticent to engage with the topic of discontinuation and death because they found themselves overwhelmed, and continued dialysis even without making a deliberate choice to do so—they did not want to think about other options since they knew that death was certain without dialysis.[74] The frequent discussion of mortality and consideration of future care by older patients suggest that they will be amenable to advance care planning discussions.

Information needs and dialysis decisions are a fluid process, subject to change for most patients.[75] With apparently limited choices, the alternative to dialysis appeared to be death.[76] Patients welcomed the opportunity to participate in shared decision-making but regretted the 'pressure' they felt from the clinical team for a decision.[77] They sought information on the outcomes if they did not have dialysis or withdrew from treatment.[74] In general, they requested information pertinent to the older patient and reflective of patient-centred values and considerations.[78] Patients had their own estimates about the importance of quality of life or survival on dialysis rather than the perceived benefits of treatment.[78–80] As expected, patients had different preferred learning styles—for instance, some preferred visual aids or written information rather than verbal. It was important that information be presented in small chunks, in simple rather than complex terms and avoiding medical jargon.[81]

Several practical issues were important to patients. These included information on the need for lifestyle, diet or fluid intake changes, travel, hospital visits, anticipated support needs and availability of support services in the community.[82]

DISCUSSION

Older patients with kidney failure turn to their clinicians—nephrologists, renal nurses, educators and other allied health staff—to discuss their choices of treatment. This scoping review attempted to summarise the

published information that is available for use by clinicians for these discussions.

An important consideration is that of prognosis with treatment. The majority of articles addressing prognosis focused on mortality as an outcome. The risks of further progression of renal impairment and development of end-stage kidney disease are also relevant to prognosis. Table 2 lists multiple validated prognostic indices created from combining multiple predictors to estimate either mortality or risk of progression to end-stage kidney disease in older patients. Use of these indices have been recommended as an important part of the shared decision-making process.[22 83 84]

The studies summarised in table 3, contrasting dialysis care with non-dialysis conservative management, are a reminder that specific consideration ought to be given to discussions of prognosis since this information could influence treatment choice. Advancing age has its own prognostic import which needs to be considered separately from other factors.[12] Older patients, especially those with multiple comorbidities, may not derive the same survival benefit from being on dialysis as their younger counterparts.[69 85 86] We recommend the use of tools and models developed specifically in older individuals to estimate the risks of mortality and the risks of progressing to end-stage kidney disease since there are practical implications in this age group. For instance, patients with a high risk of mortality and a low risk of progression to end-stage kidney disease may be better suited to a non-dialysis, conservative treatment pathway.[84]

When elders discuss treatments such as dialysis, they face the prospect of significant changes to their lifestyle, and therefore there is often a consideration of the resultant quality of life (often rated equally important as 'quantity', or longevity). A conservative pathway of care, especially if this aligns well with patients' values, could potentially offer better or equal quality-of-life experience when compared with dialysis.[35 37 87] Other factors merit consideration—such as the reduced odds of hospitalisation on a conservative pathway or the greater likelihood that with this pathway, patients were more likely to die in a place of their choice or receive palliative care before their death.[15 35 36 69 88–90] It is worthwhile remembering, however, that within the literature, conservative management has mostly been compared with routine dialysis modalities such as thrice-weekly in-centre haemodialysis. Dialysis treatment can be potentially modified to suit the needs of older, frailer individuals—such as by the provision of assisted peritoneal dialysis or reduced frequency of haemodialysis sessions. In a recent paper by Iyasere *et al*, it was shown that when patients were provided with assistance in performing peritoneal dialysis at home, they achieved quality-of-life scores that were better than a contemporaneous cohort of conservatively managed patients.[91] The comparisons between particular modalities of treatment become relevant once the patient makes the choice to have dialysis—however, they were not within the scope of this review. It must be acknowledged that the local availability of treatments tailored to the older patient may influence treatment choice. If such modified treatments can be offered, then this information, including the potential benefits and compromises, ought to be presented to patients.

There is a paucity of original research on the quality of life and the (potentially modifiable) factors that affect quality of life, as also evidenced by a 2017 systematic review.[92] Included studies (29 detailing clinical research) suggests that age, gender, physical status, comorbidities, cognition and psychological variables such as depression affected quality-of-life outcomes in older patients.[82 84 87 91] Our review identified a few potentially modifiable factors that could improve quality of life in elders considering dialysis. As shown in table 4, some of these factors, such as depression, sleep disturbances or poor nutrition, may be amenable to intervention in the pre-dialysis stage itself. Brown suggests that engaging patients in discussion, emphasising lifestyle effects of treatment, considering benefits of all interventions—even renal clinic visits—are additional measures to improve quality of life in elders with advanced chronic kidney disease.[82] If specific measures can be instituted to improve the quality-of-life experiences of patients in various pathways, the differences in patient-reported experiences may be much less significant—this is a developing area of clinical practice and research.[91 93 94]

We anticipated that the reports of the lived experience of previous older patients on dialysis would offer valuable insights for those now considering options. Our review suggests that while some patients were able to cope successfully and 'reinvent themselves' in their new lives, others described negative outcomes.[59] The lived experience of such patients is dominated by disempowerment, lack of knowledge, cognitive impairment, depression, difficulties with strict regulations regarding diet, fluid and dialysis timings, and finally, functional decline, which called into question their relationships with family and made them feel a burden to others. Such descriptions should prompt clinicians to ensure that older patients receive appropriate information about potential lifestyle changes prior to starting—this will also mitigate the reports of regret at having started dialysis.[51 95 96]

Patients' relationships—personal and professional—play an important role. Multiple social connections and close family relationships appear to improve the experience of dialysis. Healthcare professionals, as expected, play important roles in these patients' lives, which extends beyond the initial provision of information for discussion. The reports of functional and cognitive decline suggest that clinicians should inform potential patients of these risks and also periodically measure physical status, functional impairment and cognitive status so that appropriate interventions can be planned early.[93 97] Qualitative studies in this population frequently involve discussions of death and mortality, suggesting the importance of discussions regarding end-of-life care or advance care directives early in the patient course.

Table 5 Implications for practice

Domains to consider	Practical steps	Expected benefit in older adults
Making information easy to grasp for the older person	Specifically, in older individuals, consider how information is provided: avoid medical jargon, make allowances for cognitive impairment and depression	Promotes health awareness Strengthens decision-making Mitigates regret after starting treatment
Involvement of carers/family/friends	Proactively identify relevant carers especially in frail, dependent elders and include them in discussions or when planning support	Promotes carer involvement which is important to older patients Mitigates carer burden
Risk of disease progression to end-stage kidney disease	Use prognostic indices developed in the older population to provide realistic estimates of disease progression (see table 2)	Identifies patients less likely to progress and more suited for supportive measures at that particular time
Survival with end-stage kidney disease	Use prognostic indices developed in the older population to provide realistic estimates of survival (see table 2)	Fosters realistic expectations of survival benefit
Quality-of-life outcomes	Counsel older patients regarding possible adverse quality of life with treatment, including risk of physical deterioration Explore patients' expectations from treatment and check alignment with patients' values	Promotes the choice of therapy appropriate to patients' values/expectations for life Fosters realistic expectations Mitigates regret after starting treatment
Lessons from the experiences of other older people	Counsel patients regarding lifestyle changes; functional worsening; impact on daily life, relationships; persistent symptom burden; time commitments; need for coping strategies	

Finally, we surveyed the literature on patients' information needs. Patients are interested in their prognosis (survival, eventual outcome) with and without dialysis treatment.[4] However, decision-making for patients, carers and their healthcare professionals does not rely merely on survival statistics.[82] There is specific interest in the impact of dialysis on personal outcomes such as quality of life.[10 11 76 80 95 98] Older patients already on dialysis tell us that they would have liked more practical knowledge about what is actually involved in having dialysis, as well as the effects of dialysis on daily life. Matters relevant to older patients ought to be presented in a non-technical, jargon-free manner, with patient participation, and giving them 'more rather than less'. Our review did not address the methods of provision of information.

The information needs of patients summarised above are of central importance in discussions of treatment. Although these included articles capture the patient perspective, it would be beneficial for future researchers to seek patient and public involvement even during the initial design of questions for a review. Such early involvement could potentially highlight more gaps in the literature that addresses patient needs.

Practical implications

Older patients are a unique group and clinicians preparing to counsel them about treatment choices ought to prepare deliberately. Table 5 lists a few practical steps for the clinical team to consider based on the domains uncovered in our scoping review. The primary aim of this discussion is to help patients make appropriate choices, with realistic expectations of benefits from treatment and a good understanding of the changes in lifestyle occasioned by the treatment.

It is worthwhile to consider how the information from this scoping review may be used within recommended frameworks for communication and decision-making in this patient group. Schell and Cohen suggested the SPIRES framework (the acronym SPIRES standing for set-up, perceptions and perspectives, invitation, recommendation, empathise, summarise and strategise) to help patients weigh up the benefits and risks of dialysis.[99] Similarly, Rosansky and colleagues suggested a framework incorporating clinical and patient considerations in arriving at a shared decision.[100] Figure 4 suggests how available information as summarised in this scoping review can be used to guide decisions as these frameworks are applied.

In this review, we did not address how this information ought to be presented to patients. This is a crucial area of research, as there needs to be enquiry into the appropriate method of educating older patients as opposed to younger cohorts. Subsequently, the effectiveness of these

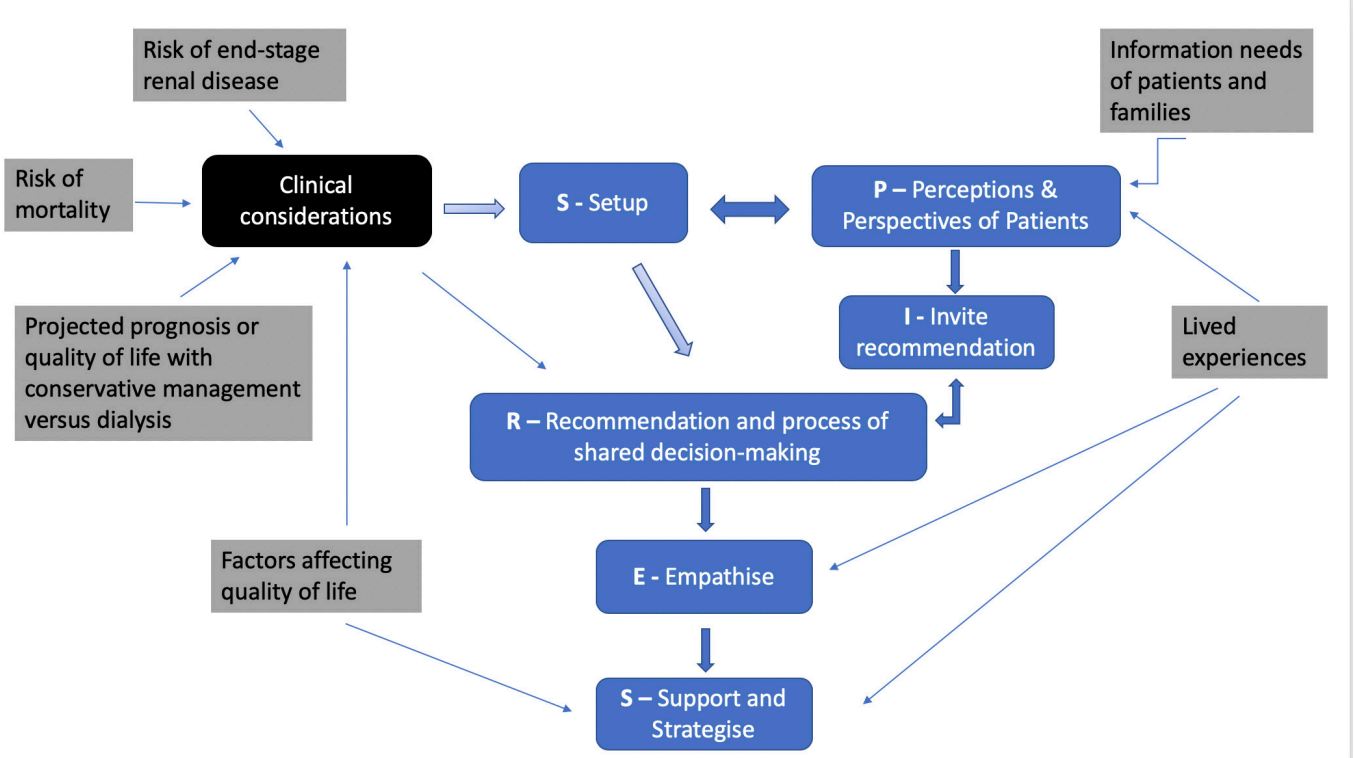

Figure 4 Using available information in a framework for decision-making. Adapted from Schell and Cohen[99] and Rosansky *et al*.[100] Grey text boxes: information available to guide decisions. Bold arrows: suggested steps in the frameworks. Light arrows: influences.

interventions and this shared decision-making process need to be studied. Patient-reported outcome measures such as quality of life, satisfaction with care or absence of decisional conflict may reflect on the success of the process.[101–103] Other indicators may include indirect evidence such as the proportion of patients withdrawing from treatment pathways after initial selection or starting treatment. These and other areas for future research are highlighted in box 1 below.

CONCLUSION

Not all older patients progress to end-stage kidney failure, and clinicians can use scores that predict the risk of this progression, so that discussions and plans are conducted appropriately to the patient's expected course. For those older patients who reach end-stage kidney failure, length of survival is an important consideration when comparing dialysis treatment to conservative care, particularly if there are multiple comorbidities. Clinicians now have several validated indices to help with prognostication. However, as evident from this scoping review, longevity or survival are not the only factors patients and families take into account—there are other expectations of treatment, such as the anticipated quality of life or functional status. Some factors influencing quality of life are modifiable. The study of lived experiences of dialysis in older people informs us of the requirements for patients to adapt to their new realities, and the problems from functional deterioration, dependency and persistent symptoms. Patients should be forewarned about these potential outcomes and preventive measures considered. All information ought to be presented in a manner that the older patient can easily understand, retain and apply. Further research is needed into quality-of-life outcomes in older individuals, methods of efficient communication of information and assessment of the success of shared decision-making.

Box 1 Areas for future research

1. Prediction of outcomes other than survival (eg, quality of life, functional decline).
2. Factors influencing quality of life in older patients (and the effects of modifying these factors).
3. Modifications of treatment to support older individuals (assisted peritoneal dialysis, incremental dialysis, etc) and their effects on patient choices and outcomes.
4. Improving the communication of information, and monitoring delivery and understanding.
5. Studies of the effectiveness of the shared decision-making process in older patients with kidney disease.
6. Interventions to promote carer education and support.

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Contributors RR is the primary and corresponding author for the first and all subsequent drafts. RR and KDKA were responsible for initial discussion. RR, KDKA, MF and MJ were involved in subsequent discussion and design of the

study protocol. RR and ST performed the study selection process independently. All five authors contributed to the design of the work, revised the drafts critically for content and approved the final version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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