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Title Page

Title

The elderly patient considering treatment for advanced kidney disease: Protocol for a scoping review of the information available for shared decision making.

Authors

Rajesh Raj[1], Kiran DK Ahuja[2], Mai Frandsen[2], Matthew Jose[1]

Affiliations

[1]School of Medicine, University of Tasmania, Tasmania, Australia

[2]School of Health Sciences, University of Tasmania, Tasmania, Australia

Corresponding Author:

Dr Rajesh Raj, Consultant Nephrologist, Launceston General Hospital, Launceston, Tasmania, Australia 7250; Phone: +61 3 6777 6777 ; Email address: rajesh.raj@ths.tas.gov.au

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Abstract

Introduction

The elderly constitute one of the largest growing groups of patients on dialysis worldwide. Recent research suggests that dialysis may not have the same benefits in the older adult as it does in the younger patient. The recommended model to discuss treatment options in these patients is the shared decision-making model, where the clinical team discusses information with the patient and family, so that appropriate choices are made between dialysis or supportive ('non-dialysis') care. These discussions are difficult for clinicians as there is only incomplete information on prognosis with or without dialysis, the outcomes of dialysis, or the effects on the quality of life in the elderly patient. Published numbers are small, especially with supportive care. Most discussions on the lived experience of dialysis are in the 'gray literature'. A scoping review that attempts to summarise the information available to clinicians regarding the outcomes with dialysis or supportive treatment in the elderly was conceived, and this article discusses the protocol.

Methods

The scoping review will follow an adapted version of the protocol suggested by the Joanna Briggs institute. A directed search will look for relevant articles in English (within electronic databases and the grey literature), written between 2000 to 2016, which have studied patients aged over 65 with advanced renal disease (eGFR < 30). After screening by two independent reviewers, selected articles will be analysed using a data charting tool. Reporting will include descriptions, analysis of themes using qualitative software and display of information using charts.

Ethics and dissemination

This scoping review will analyse previously collected data, and so does not require ethical approval. Results will be disseminated through academic journals, conferences and seminars. The findings will summarise the available knowledge regarding the elderly with advanced renal disease, and be a repository of information for clinicians in the field.

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Strengths and Limitations of this study

- Previous reviews have not attempted to systematically collect, describe and synthesise all the considerations involved in making treatment decisions for the elderly with advanced renal disease across the quantitative and qualitative spectra of research.
- The illness and its treatments are significantly 'intrusive' to the lives of patients and their carers. Therefore, it is important to include the patient's perspective in treatment decisions . This scoping review will also include qualitative work and the gray literature, widening the sources of information further and beyond those for a traditional systematic review. This will potentially highlight other important, but previously neglected, considerations while discussing treatment in the elderly.
- Such a wide-ranging review can serve as a useful repository of information for clinicians and others working (or conducting research) in this area.
- Studies included will not undergo a formal quality assessment – this is part of the design, as a scoping review attempts to describe all the information available, rather than only select the highest quality of evidence.
- The review only considers material written in English. Potentially, large populations of the non-English-speaking world may not be represented. Our conclusions may not apply to the different cultural and social environments in these regions.

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Background

Approximately half of all patients on dialysis in Australia at the end of 2014 were aged 65 and above. Patients aged 65 to 85 years old have the highest incidence (patients per million) of renal replacement therapies[1]. These numbers will conceivably rise in the following years as the population on dialysis ages, and as incident patients are added. However, several researchers have suggested that the older patient may not do well on dialysis in terms of quality of life, preservation of independence or survival. Studies suggest that in the presence of severe comorbidities such as frailty or heart disease, there is no survival advantage to being on dialysis[2]. On the contrary, some elderly patients who choose not to have dialysis enjoy a good quality of life, and may not have a significantly shortened survival in comparison[2–6].

Several renal units now also offer a distinct, non-dialysis pathway of care for patients opting ***not*** to have dialysis treatment for end-stage renal disease – variously called the 'conservative', 'supportive' or 'renal palliative' care pathway[7]. For present purposes, the supportive or conservative care pathway is defined as the comprehensive care of patients choosing not to have dialysis, including a multi-disciplinary approach to symptom management, advance care planning and end-of-life care. The availability of such a pathway has meant that in many centers, non-dialysis care is no longer an abstract concept, but a valid and available treatment option.

Discussions around treatment options for the elderly patient with advanced renal disease can be difficult and confusing. Clinical practice recommendations suggest that when it comes to choosing a treatment pathway, renal physicians lead the discussions in a process of shared decision-making with patients, carers, general practitioners and other involved persons [8,9]. Renal physicians and nurses

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participating in these discussions now have to consider not only the data from studies of patients on dialysis, but also data from patients managed ‘conservatively’. However, this often proves difficult, since not enough information is available regarding the non-dialysis care pathway. Non-dialysis care for renal impairment is an actively evolving paradigm of care, with few practices backed by high-quality evidence, making standardization difficult. Additionally, most ‘conservative’ care is provided in ‘non-renal’ settings, by different specialists (e.g., multi-disciplinary clinics). Such factors make head-to head comparisons of the two modalities (dialysis versus non-dialysis) cumbersome.

There are other practical difficulties. Studies have shown significant variability in how different doctors make decisions about recommending dialysis[10,11]. Estimates of prognosis made by doctors are likely to be inaccurate. Age and non-renal factors may not always receive consideration. Factors such as comorbidities, frailty, mental status, dependency for transfers, and residence in a nursing home can all impact on the prognosis on dialysis, but it is difficult to consider these variables systematically in making decisions. Efforts to construct prognostic indices for the elderly considering dialysis have met with limited acceptance. Often, these indices document prognosis for patients already on dialysis; or they do not consider non-renal factors. Not surprisingly, patients may consider non-medical factors important to their decision – such as the number of hospital visits required, or the restrictions on travel[12,13]. Clinicians may not be aware of such research into patient and caregiver preferences for treatment or end-of-life choices.

The clinician, therefore, has to contend with a wide range of information, which extends across quantitative and qualitative domains, before making a recommendation. A review that summarizes all the relevant, available information will be useful in this setting.

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Methods and Analysis

This scoping review will be undertaken in accordance with the Joanna Briggs Institute's methodology for scoping reviews[14].

From readings of published literature and clinical guidelines / recommendations, we anticipated, empirically, that five broad categories of information are likely to be relevant to the discussions around treatment options for the elderly, as follows:

a. Information about prognosis / survival in elderly patients on dialysis versus non-dialysis care
b. Information about quality of life in elderly patients treated with dialysis or non-dialysis care
c. Information describing the lived experience of the elderly with advanced kidney disease (on dialysis or non-dialysis care), and their carers
d. Information on the factors important to patients and their carers as they make treatment choices around advanced renal disease.
e. Other factors, not included above.

A preliminary search of the literature in The Cochrane Library, JBI Database of Systematic Reviews and Implementation Reports, TRIP database and Prospero failed to identify a scoping review that summarizes the entire range of considerations discussed briefly above.

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Operational Definitions:

Elderly:

This will include patients who are:

- Over the age of 65
- Described by primary researchers as 'elderly', 'geriatric' or 'older adult'

Patients with advanced renal disease

This is defined as patient populations in any of the following categories

- having established (> 6 weeks) renal impairment with an estimated GFR of less than 30 ml/min/1.73 m^2
- described as having 'advanced renal disease' by the primary researchers
- receiving education regarding renal replacement therapies
- On dialysis OR
- On non-dialysis, supportive or conservative care

Carers

Includes all individuals involved in directly caring for the patient, whether associated through family, friendship or marriage.

Clinicians

Includes doctors, nurses and allied healthcare staff directly involved in the medical care of, and the shared decision – making process with, patients and carers.

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Dialysis Care

Renal dialysis, including all forms of hemodialysis and peritoneal dialysis.

Non-dialysis or Supportive Care

Includes the care given to patients with advanced renal disease:

- Who choose not to undergo dialysis
- Who are described as having 'supportive', 'conservative' or 'palliative' renal care

Objectives

The objective of this review is to identify and summarise the nature and scope of information (both published and unpublished) available for consideration when discussing treatment options for advanced kidney disease with an elderly patient.

The study aims to synthesise information from quantitative and qualitative literature, so as to

(i) provide a coherent summary for clinicians and

(ii) explore the need for a comprehensive systematic review on the subject.

Review questions

The questions for this scoping review are (see table 1):

1. What information is available to guide discussions in the shared decision-making process for the elderly considering treatment options for advanced renal disease? Specifically, the details examined are:
    a. Markers of prognosis (survival) in the elderly patient with advanced kidney disease (on

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dialysis or on non-dialysis care)

b. Factors influencing quality of life in the elderly patient with advanced kidney disease (on dialysis or on non-dialysis care)

c. Lived experience of dialysis or non-dialysis care

2. What do we know about how decisions are made about treatment for advanced renal disease – that is, how is information presented, understood and acted upon?

Table 1 : Review Questions

1 (a) What are the markers of prognosis (survival) in the elderly patient with advanced kidney disease (on dialysis or on non-dialysis care) ?
1(b) What are the known factors influencing quality of life in the elderly patient with advanced kidney disease (on dialysis or on non-dialysis care)?
1(c) What information regarding the lived experience of dialysis or non-dialysis care is available?
2. What information is available about how decisions are made about treatment for advanced renal disease?

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Inclusion criteria

Study selection

This scoping review will consider, for all questions, studies that include elderly patients with advanced renal disease, their carers or the clinicians involved in their care, regardless of gender, region, diagnoses, or comorbidities.

Concept

For question 1(a), studies that report on prognosis, prognostic indices, survival and mortality data on the population described will be considered for inclusion.

For question 1(b), studies that describe quality of life data in this population, either in isolation or in relationship to other variables, including descriptive/observational and interventional studies will be included.

For question 1(c), qualitative studies and published and unpublished literature that describe the lived experience of these patients and their carers will be considered.

For question 2, studies that consider the factors around treatment choices made by patients, the experience of the decision-making process (including information needs) and the studies that have looked at clinicians providing advice to these shared decisions will be sought.

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Context

This scoping review will consider studies of the elderly patient population (defined above) in inpatient, outpatient, home or residential-care facility settings.

Sources : Study types

Studies with abstracts published in English will be included in the initial screening process. (please see Supplementary files: Appendix 1, Table 1 for a draft version of the initial appraisal tool).

Studies published since 2000 will be included so as to reflect the rising number of elderly patients on dialysis, the changing attitudes to the elderly in recent years and the establishment on non-dialytic, supportive care as a valid treatment option.

This scoping review will consider both quantitative and qualitative study designs, including:

1. experimental and quasi-experimental studies (randomized and non-randomized controlled trials), before and after studies and interrupted time-series studies.
2. Analytical and descriptive observational studies including prospective and retrospective cohort studies, case-control and cross-sectional studies, case series and case reports.
3. Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description and action research.

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4. We will also include searches of the grey literature (see description of databases below).
5. Textbook chapters and opinion papers will also be considered for inclusion.
6. We will also include recommendations made by national bodies involved in setting standards and providing guidelines for renal care.

Exclusion criteria

1. Research that exclusively addresses patients younger than 65 years of age, or patients with an eGFR greater than 30 ml/min/1.73m^2.
2. Studies in languages other than English

Search strategy

The search strategy will aim to find both published and unpublished studies , aiming to include articles written from January 2000 to April 2016.

An initial limited search of MEDLINE, Scopus, Embase, PsycInfo, CINAHL and Cochrane Library databases has been undertaken to identify articles on this topic. Analysis of the words contained in the titles, abstracts and index terms used to describe these articles was used to develop an initial list of search terms and keywords, as follows:

- Humans; Aged; Geriatric; Elderly; Older
- Chronic Kidney Failure; Chronic Renal Insufficiency; Renal Replacement Therapy;

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Renal Dialysis;

- Conservative care; Palliative care; supportive care; Withholding treatment
- Risk Assessment; Risk Factors; Logistic Models;
- Time Factors; Life Expectancy; Kaplan-Meier Estimate;
- Treatment Outcome; Prognosis; Prognostic score; Quality of life; Lived Experience; Adaptation, psychological;
- Patient Selection; Decision Making; Patient preference; Physician advice; doctor-patient communication; Surveys and questionnaires

The key words / search terms will be appropriately used for each database. As studies are being considered, their reference lists will be screened for additional studies.

Databases searched:

PubMed, , PsycInfo, CINAHL, Embase, Scopus, Mednar, Turning research into practice, NTIS, ProQuest Dissertations and Theses, Google Scholar, Current Contents

The search for unpublished studies will include electronic sources including OpenSIGLE, Healthcare Management Information Consortium (HMIC) database, National Technical Information Service (NTIS), PsycEXTRA, BIOSIS databases, Open Grey, Trove, EThOS, OATD.org, and OpenThesis.

The search for guidelines will include searches at the National Guideline Clearinghouse, www.cari.org, www.kdigo.org, the National Kidney Foundation (NKF-DOQI), Kidney Health

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Australia, the Renal Physicians Association, ERA-EDTA and national specialty organisations (USA,UK, Australia, European).

Data extraction

Data will be extracted from papers included in the scoping review using the draft data extraction tools listed in Appendix I (tables 2 to 5, see Supplementary material online) by two independent reviewers. The data extracted will include specific details about the populations, concept, context, and study methods of significance to the scoping review question and specific objectives. Any disagreements that arise between the reviewers will be resolved through discussion, or with opinion from a third reviewer. Authors of papers will be contacted to request missing or additional data where required. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report.

Data mapping / analysis / synthesis and presentation of the results

The extracted data will be presented in diagrammatic or tabular form that is relevant to the objectives and scope of this scoping review. We will summarize the information separately for each question that forms the basis of this scoping review.

For questions 1(a) and 1(b), we will present in tabular form the various factors reported to influence

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prognosis/survival and quality of life respectively, detailing the number of studies for each such factor, the number of patients studied, the settings, and provide comment about the generalizability of the findings.

For information addressing question 1(c) – 'the lived experience of dialysis'; and question 2 – 'other factors considered in the shared decision-making process', the findings will be displayed in tabular and diagrammatic form, and in addition, we will use N-Vivo © qualitative research software (QSR International, Australia) to attempt to synthesise the various themes that have been identified in the literature.

A narrative summary will accompany the tabulated and/or charted results and will describe how the results relate to the primary questions around shared decision-making in the elderly patient with advanced renal disease.

Ethics and dissemination

Ethical approval for the conduct of this study will not be required as this research only includes analysis of previously collected data. Results will be disseminated through academic journals, conferences and seminars.

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Conclusion

The elderly patient with renal disease is different from younger counterparts on several counts - survival, progression of disease, outcomes with therapy, comorbidities and considerations that influence quality of life. A 'one-size-fits-all' approach to counselling and prescribing renal replacement therapy cannot be recommended. This scoping review will attempt to synthesize the disparate pieces of information available, and to be a resource for clinicians advising such elderly patients.

Contributorship statement

RR is the primary and corresponding author and was responsible for initial discussion and the first and all subsequent drafts. KA, MF, and MJ were involved in the initial discussion and design of the study protocol. They contributed to the design of the work, and revised the drafts critically for content. All four authors 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.

Competing interests

All four authors (RR, KA, MF and MJ) have no competing interests to declare.

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Appendix 1

Table 1: Draft of initial appraisal tool (with example) for prospective studies

Title	Primary Author / Year	Type of paper (research / review / opinion / guideline, etc.	Concept	Relevant to question #	Population	Context	Methods	Main Findings / Comments	Included? Yes / No
Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5	Murtagh F, 2007	Clinical Research	Survival	1a	>75 yrs	Pre - dialysis clinics	Prospective observational	Direct prognostic information dialysis vs non-dialysis	Yes

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Table 2: Data extraction tool(with example) for articles addressing Qn 1(a) - Prognosis

Title	Primary Author / Year	Type of paper	Parameters studied	Population	Context	Methods	Main Findings / Comments
A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease	Couchod C; 2008	Clinical Research	6 – month mortality; using a calculated prognostic score	>75 yrs; Started dialysis between 2002 to 2006. N= 2500	Patients on dialysis	Prospective observational registry – based; tested prognostic variables, derived score; then validated	Median score was 2 points –mortality 17% ; Mortality varied from 8% to 70% according to score group

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Table 3 Data extraction tool(with example) for studies answering Qn 1(b) – factors influencing quality of life

Title (Year)	Primary Author	Type of paper	Factors studied	Population	Context	Methods	Main Findings / Comments
CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life	Brown M; 2015	Clinical Research	Survival, Symptoms, quality of life	>75 yrs; Cons. versus dialysis at time of decision	Pre - dialysis clinics, Palliative renal clinics	Prospective observational	Non-dialysis patients had stable QOL compared to pre-dialysis patients

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Table 4 Data extraction tool (with incomplete example) for studies answering Qn 1(c) – Lived experience of dialysis / non-dialysis care

Title (Year)	Primary Author	Type of paper	Aim/Scope	Population	Context	Methods	Main Findings / Themes /Comments
Meaning, comprehension, and manageability of end-stage renal disease in older adults living with long-term hemodialysis.	Karolich R; 2010	Quantitative and Qualitative Research	The association between perceived meaning of chronic illness and adherence to treatment	100 'elderly' patients (aged > 50); on dialysis	Dialysis clinic	Surveys; face-to-face interviews	Subjective meanings attached to illness influence how the illness is managed

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Table 5 Data extraction tool (with incomplete example) for studies answering Qn 2

Title (Year)	Primary Author	Type of paper	Aim/Scope	Population	Context	Methods	Main Findings / Themes /Comments
Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study	Schell,J; 2012	Qualitative Research	To describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy	11 nephrologists and 29 patients (aged > 65); with CKD or on dialysis	Pre - dialysis clinics, Palliative renal clinics	Focus groups; face-to-face interviews	Patient - reported themes were….

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Checklist for scoping review protocol,
[derived from:
The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI scoping reviews. The Joanna Briggs Institute 2015. 1–24.]

Criterion	Yes/No	Comment
Informative title with a clear indication of the topic of the scoping review	Yes	"The elderly patient considering treatment for advanced kidney disease: Protocol for a scoping review of the information available for shared decision making"
Use of the phrase 'scoping review' in title	Yes	See above
Clearly stated objective that is congruent with the title	Yes	See second paragraph under 'Methodology'
Clarity in the review questions	Yes	See table 1 in the text, and explanation in third paragraph under 'Methodology'
Appropriate Background Section	Yes	See text
Inclusion Criteria (Participant / Concept / Context)	Yes	See text under 'Methodology'
List of Sources of information	Yes	See text under 'Methodology'
Search Strategy	Yes	See text under 'Methodology'
Extraction of Results : Charting the results – use of draft charting tables	Yes	See text under 'Methodology'; see tables 1 – 5 in Supplementary material submitted online
Presentation of the Results	Yes	See text under 'Methodology'. Tables and narrative text will be used to present the results

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BMJ Open

The older patient considering treatment for advanced renal disease: Protocol for a scoping review of the information available for shared decision making.

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Manuscript ID	bmjopen-2016-013755.R1
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Date Submitted by the Author:	22-Oct-2016
Complete List of Authors:	Raj, Rajesh; Launceston General Hospital, ; University of Tasmania School of Medicine, Ahuja, Kiran; University of Tasmania, School of Health Sciences Frandsen, Mai; University of Tasmania, Jose, Matthew; University of Tasmania School of Medicine, ; Royal Hobart Hospital
Primary Subject Heading:	Renal medicine
Secondary Subject Heading:	Geriatric medicine, Palliative care, General practice / Family practice, Communication, Patient-centred medicine
Keywords:	GERIATRIC MEDICINE, Dialysis < NEPHROLOGY, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Chronic renal failure < NEPHROLOGY, Adult palliative care < PALLIATIVE CARE, Chronic Kidney Disease

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TITLE PAGE

Title

The older patient considering treatment for advanced renal disease: Protocol for a scoping review of the information available for shared decision making.

Authors

Rajesh Raj[1], (Rajesh.Raj@ths.tas.gov.au)

Kiran DK Ahuja[2] (Kiran.Ahuja@utas.edu.au)

Mai Frandsen[2] (Mai.Frandsen@utas.edu.au)

Matthew Jose[1] (Matthew.Jose@utas.edu.au)

Affiliations

[1]School of Medicine, University of Tasmania, Tasmania, Australia

[2]School of Health Sciences, University of Tasmania, Tasmania, Australia

Corresponding Author:

Dr Rajesh Raj, Consultant Nephrologist, Launceston General Hospital, Launceston, Tasmania, Australia 7250; Phone: +61 3 6777 6777 ;

Email address: rajesh.raj@ths.tas.gov.au

Keywords

Chronic Renal Failure, Dialysis, Geriatric Medicine, Adult Palliative Care, Protocols and Guidelines, Chronic Kidney Disease

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ABSTRACT

Introduction

Older adults constitute the largest group of patients on dialysis in most parts of the world. Management of advanced renal disease in the older adult is complex; treatment outcomes and prognosis can be markedly different from younger patients. Clinical teams caring for such patients are often called upon to provide information regarding prognosis and outcomes with treatment – particularly, the comparison between having dialysis treatment versus not having dialysis. These discussions can be difficult for clinicians because they have to contend with incomplete or nascent data regarding prognosis and outcomes in this age group. We aim to summarise the currently available information regarding the prognosis and outcomes of advanced renal disease in the older adult by means of a scoping review of the literature. This article discusses our protocol.

Methods

This scoping review will be undertaken in accordance with the Joanna Briggs Institute's methodology for scoping reviews. A directed search will look for relevant articles in English (within electronic databases and the grey literature), written between 2000 to 2016, which have studied older patients with advanced renal disease (eGFR < 30). After screening by two independent reviewers, selected articles will be analysed using a data charting tool. Reporting will include descriptions, analysis of themes using qualitative software and display of information using charts.

Ethics and dissemination

This scoping review will analyse previously collected data, and so does not require ethical approval. Results will be disseminated through academic journals, conferences and seminars. We anticipate that our summary of the currently available knowledge regarding the older adult with advanced renal disease will be a repository of information for clinicians in the field. We expect to identify areas of study that are suited to systematic reviews. Our findings can also be expected to influence guidelines and clinical practice recommendations in the future.

Strengths and Limitations of the Proposed study

- Previous reviews have not attempted to systematically collect, describe and

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synthesise all the considerations involved in making treatment decisions for the older adult with advanced renal disease across the quantitative and qualitative spectra of research - this will be a strength of the proposed study.

- Since the illness and its treatments are significantly 'intrusive' to the lives of patients and carers, a scoping review across quantitative, qualitative and grey literature domains can highlight the patient's perspective, widening the sources of information further and beyond those traditionally used in previous systematic reviews in the area.
- Such a wide-ranging review can serve as a useful repository of information for clinicians and others working (or conducting research) in this area; it can suggest areas for further systematic reviews and contribute to generating guidelines.
- The scoping review conducted according to this protocol will address the information available for the shared decision-making process in the older adult. So as to preserve focus, it does not include other aspects of dialysis decision-making, including how this information is presented / received, types of decision-making models, decision science, the impact of health literacy, socioeconomic factors, mental capacity and cognition, cultural /language barriers or resource limitations.
- Studies included will not undergo a formal quality assessment – this is part of the design, as a scoping review attempts to describe all the information available, rather than only select the highest quality of evidence.
- This protocol is for a scoping review that only considers material written in English. Potentially, large populations of the non-English-speaking world may not be represented. Our conclusions may not apply to the different cultural and social environments in these regions.

BACKGROUND

Approximately half of all patients on dialysis in Australia at the end of 2014 were aged 65 and above. Patients aged 65 to 85 years old have the highest incidence (patients per million) of renal replacement therapies.[1] These numbers will conceivably rise in the following years as the population on dialysis ages, and as incident patients are added. However, several researchers have suggested that the older patient may not do well on dialysis in terms of quality of life, preservation of independence or survival. Studies suggest that in the presence of severe comorbidities such as frailty or heart disease, there

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is no survival advantage to being on dialysis.[2] On the contrary, some older patients who choose not to have dialysis enjoy a good quality of life, and may not have a significantly shortened survival in comparison.[2–6]

Several renal units now also offer a distinct, non-dialysis pathway of care for patients opting ***not*** to have dialysis treatment for end-stage renal disease – thus providing another valid and available treatment choice for these patients.[7] This pathway may be called the 'conservative', 'supportive' or 'renal palliative' care pathway.

Principles of holistic care in the management of the older patient are widely applicable – including detailed symptom management, advance care planning, functional assessment and appropriate support, and targeted measures to improve quality of life. However, uncertainty exists regarding the benefits of dialysis therapy in the older adult. Predicting which older patient will do well on dialysis is quite difficult.

Nephrologists and other members of the renal team are often central to the discussions around treatment choices for advanced renal impairment. National organisations, such as the Australia New Zealand Society of Nephrology or the Renal Physicians Association in the USA, suggest a process of shared decision making for patients considering dialysis.[8,9] Shared decision making is defined as "a process by which a healthcare choice is made by the patient (or significant others, or both) together with one or more healthcare professionals".[9] Clinical practice recommendations in this area suggest that "nephrologists do not shy away from these discussions" - rather, they suggest, treating teams ought to have "realistic discussions" with patients about survival and quality of life both with and without dialysis treatment.[8,9]

The provision of information is an important component of shared decision making, as exemplified in several popular models of the process. For instance, in the Inter-Professional Shared Decision Making Model,[10] 'information exchange' is an integral part of the process. Similarly, in the model suggested by Elwyn and colleagues,[11] which consists of a 3-step shared decision making model for clinical practice – "choice talk, option talk and decision talk", provision of information is an integral part of discussions about options and choice. Accurate information is central to shared decision-making, as it "rests upon knowing and understanding the best available evidence on the risks and benefits across all available options, while ensuring that the patient's values are taken into account".[10] However, providing or accessing such information often proves difficult for the clinician, since sufficient, comprehensive information is not readily available.

Comprehensive conservative treatment for renal impairment that does not include dialysis is an actively evolving paradigm of care, with few practices backed by high-quality

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evidence, making standardization difficult. Additionally, most such care is provided in heterogeneous settings, by different professionals (e.g., multi-disciplinary clinics). Such factors make head-to head comparisons of the two modalities (dialysis versus non-dialysis) cumbersome, limiting the information available for a discussion comparing the two pathways.

There are other practical difficulties. Studies have shown significant variability in how different doctors make decisions about recommending dialysis.[12,13] Estimates of prognosis made by doctors are likely to be inaccurate. Age and non-renal factors may not always receive consideration. Factors such as comorbidities, frailty, mental status, dependency for transfers, and residence in a nursing home can all impact on the prognosis on dialysis, but it is difficult to consider these variables systematically in making decisions. Efforts to construct prognostic indices for the older adult considering dialysis have met with limited acceptance. Often, these indices document prognosis for patients already on dialysis, or they do not consider non-renal factors. Not surprisingly, patients may consider non-medical factors important to their decision – such as the number of hospital visits required, or the restrictions on travel.[14,15] Clinicians may not be aware of such research into patient and caregiver preferences for treatment or end-of-life choices.

In summary, there are uncertainties and gaps in knowledge when renal teams are called upon to provide appropriate comparisons between treatment with or without dialysis in the older patient with advanced renal disease. The life-sustaining nature of dialysis presents difficulties in the design of a randomised trial comparing dialysis treatment to treatment without dialysis in this population. Given this scenario, the scoping review methodology, extending across quantitative and qualitative research domains, appears well-suited as a first step in detailing the breadth of information available in this particular area at present. From the information gathered, we anticipate that the need for future systematic reviews in particular areas will be identified.

METHODS AND ANALYSIS

(Please see figure 1 for a flowchart detailing the major steps in the scoping review).

This scoping review will be undertaken in accordance with the Joanna Briggs Institute's methodology for scoping reviews.[16]

From readings of published literature and clinical guidelines / recommendations, we anticipated, empirically, that five broad categories of information are likely to be

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relevant to the discussions around treatment options for the older adult, as follows:

a. Information about prognosis / survival in older patients with advanced renal disease managed either with or without dialysis treatment
b. Information about quality of life in older patients with advanced renal disease managed either with or without dialysis treatment
c. Information describing the lived experiences of the older adult with advanced renal disease
d. Information on the factors important to older patients and their careers as they make treatment choices around advanced renal disease.
e. Other factors, not included above.

A preliminary search of the literature in The Cochrane Library, JBI Database of Systematic Reviews and Implementation Reports, TRIP database and Prospero failed to identify a scoping review that summarizes the entire range of considerations discussed above.

Operational Definitions:

Older Adult:

Different chronological ages have been used in the literature to define the term 'older adult' or 'elderly'.[17] In order to include all relevant data, we will include studies where the population studied has been described by primary researchers as 'elderly', 'geriatric' or 'older adult' without specifying beforehand an age cut-off to define the older adult. In the summaries created, we will mention the ages of patients included under this term in relevant studies.

Patients with advanced renal disease

This is defined as patient populations in any of the following categories

- having established (> 3months) renal impairment with an estimated GFR of less than 30 ml/min/1.73 m²
- described as having 'advanced renal disease' by the primary researchers
- receiving education regarding renal replacement therapies
- On dialysis OR
- On non-dialysis, supportive or conservative care

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Carers

Includes all individuals involved in directly caring for the patient, whether associated through family, friendship or marriage.

Clinicians

Includes doctors, nurses and allied healthcare staff directly involved in the medical care of, and the shared decision – making process with, patients and carers.

Dialysis Treatment

Renal dialysis, including all forms of hemodialysis and peritoneal dialysis, including in-centre, home-based, assisted or self-care approaches.

Conservative Care

Includes care given to patients with advanced renal disease who have decided not to undergo dialysis treatment, described as 'non-dialysis, 'supportive', 'conservative' or 'palliative' renal care.

Objectives

The objective of this review is to identify and summarise the nature and scope of information available for consideration when discussing treatment options for advanced renal disease with an older patient.

The study aims to synthesise information from quantitative and qualitative literature, so as to

(i) Provide a coherent summary for clinicians and

(ii) Explore the need for future comprehensive systematic reviews on the subject.

Review questions

The questions for this scoping review are as follows (summarised in table 1):

1. What information is available to be used in the shared decision-making process for the older adult considering treatment options for advanced renal disease? Specifically, the details examined are:
    a. Markers of prognosis (survival) in the older patient with advanced renal disease

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b. Factors influencing quality of life in the older patient with advanced renal disease

c. Reports of lived experiences of older adults undergoing treatment (with or without dialysis) for advanced renal disease.

2. What do we know about the information needs of older adults and their carers as they consider treatment options for advanced renal disease?

Table 1 : Review Questions

1. What are the factors affecting prognosis and survival in the older patient with advanced renal disease either choosing to have dialysis treatment, or choosing to have conservative care without dialysis?
2. a. What factors influence the quality of life in the older patient being treated for advanced renal disease? b. What information is available regarding the lived experiences of older adults treated for advanced renal disease?
3. What is known about the information needs of older adults and their carers considering treatment options for advanced renal disease?

Inclusion criteria

Study selection

This scoping review will consider, for all questions, articles that addresses the older adult with advanced renal disease, their carers or the clinicians involved in their care, regardless of gender, region, diagnoses, or comorbidities (See Figure 1). Articles from peer-reviewed scientific literature as well as those from grey literature will be considered (details below).

Concept

The core concept of this scoping review is to provide a summary of the breadth of information relevant to discussions and decision-making in the older adult with advanced renal disease who is considering treatment options. The primary focus is on the information that is likely to be of value in choosing whether to have dialysis (any type of

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dialysis) or not. With regard to the specific questions articulated above,

- For question 1, studies that report on prognosis, prognostic indices, survival and mortality in the population described will be considered for inclusion.
- For question 2 (a), studies that describe quality of life data in this population, either in isolation or in relationship to other variables, including descriptive/observational and interventional studies will be included.
- For question 2 (b), studies that describe the lived experience of these patients and their carers will be considered.
- For question 3, studies that have described the information needs of older adults and their carers around the decision-making process in advanced renal disease will be considered.

Context

This scoping review will consider articles pertaining to the older adult in inpatient, outpatient, home or residential-care facility settings.

Sources: Study types

(Please see Supplementary files: Appendix 1, Table 1 for a draft version of the initial appraisal tool).

This scoping review will consider both quantitative and qualitative study designs, including:

1. experimental and quasi-experimental studies (randomized and non-randomized controlled trials), before and after studies and interrupted time-series studies.
2. Analytical and descriptive observational studies including prospective and retrospective cohort studies, case-control and cross-sectional studies, case series and case reports.
3. Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description and action research.
4. We will also include searches of the grey literature (see description of databases below).
5. Textbook chapters and opinion papers will also be considered for inclusion.
6. We will also include recommendations made by national bodies involved in

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setting standards and providing guidelines for renal care.

Studies published from January 2000 to October 2016 will be included 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. Only studies with abstracts published in English will be included in the initial screening process.

Exclusion criteria

1. Research that does not address older adults (see operational definition above) as a main or sub-population of interest.
2. Research that exclusively addresses patients with an eGFR greater than 30 ml/min/1.73m^2.
3. Studies in languages other than English

Search strategy

An initial limited search of MEDLINE, Scopus, Embase, PsycInfo, CINAHL and Cochrane Library databases has been undertaken to identify articles on this topic. Analysis of the words contained in the titles, abstracts and index terms used to describe these articles was used to develop an initial list of search terms and keywords, as follows:

- Humans; Aged; Geriatric; Elderly; Older
- Chronic Kidney Disease; Chronic Kidney Failure; Chronic Renal Insufficiency; Renal Replacement Therapy; Renal Dialysis;
- Conservative care; Palliative care; supportive care; Withholding treatment
- Risk Assessment; Risk Factors; Logistic Models;
- Time Factors; Life Expectancy; Kaplan-Meier Estimate;
- Treatment Outcome; Prognosis; Prognostic score; Quality of life; Lived Experience; Adaptation, psychological;
- Patient Selection; Decision Making; Information Needs; Patient preference; Patient Education; Physician advice; doctor-patient communication; Surveys and questionnaires

The key words / search terms will be appropriately used for each database. As studies are being considered, their reference lists will be screened for additional studies.

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Databases searched:

PubMed, PsycInfo, CINAHL, Embase, Scopus, Mednar, Turning research into practice, NTIS, ProQuest Dissertations and Theses, Google Scholar and Current Contents.

The search for articles in the grey literature will include electronic sources including OpenSIGLE, Healthcare Management Information Consortium (HMIC) database, National Technical Information Service (NTIS), PsycEXTRA, BIOSIS databases, Open Grey, Trove, EThOS, OATD.org, and OpenThesis.

The search for guidelines will include searches at the National Guideline Clearinghouse, www.cari.org, www.kdigo.org, the National Kidney Foundation (NKF-DOQI), Kidney Health Australia, the Renal Physicians Association, ERA-EDTA and national specialty organisations (USA, UK, Australia, European).

Data extraction

Data will be extracted from papers included in the scoping review using the draft data extraction tools listed in Appendix I (tables 2 to 5, see Supplementary material online) by two independent reviewers, and entered into spreadsheets. The data extracted will include specific details about the populations, concept, context, and study methods of significance to the scoping review question and specific objectives. Any disagreements that arise between the reviewers will be resolved through discussion, or with opinion from a third reviewer. When required, authors of papers will be contacted if possible to request missing or additional data. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report.

Data mapping / analysis / synthesis and presentation of the results

The extracted data will be presented in diagrammatic or tabular form that is relevant to the objectives and scope of this scoping review. We will summarize the information separately for each question that forms the basis of this scoping review.

For questions 1 and 2(a), we will present in tabular form the various factors reported to influence prognosis/survival and quality of life respectively, detailing the number of studies for each such factor, the number of patients studied, the settings, and provide comment about the generalizability of the findings.

For information addressing question 2(b) – 'the lived experience of dialysis'; and question 3 – 'information needs for the shared decision-making process', the findings will be

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displayed in tabular and diagrammatic form, and in addition, we will use N-Vivo © qualitative research software (QSR International, Australia) to synthesise the various themes identified.

A narrative summary will accompany the tabulated and/or charted results and will describe how the results relate to the primary questions around shared decision-making in the older patient with advanced renal disease. We anticipate that the identification of information needs will also guide the organization of the information collected.

ETHICS AND DISSEMINATION

Ethical approval for the conduct of this study will not be required as this research only includes analysis of previously collected data. Results will be disseminated through academic journals, conferences and seminars. We will attempt to publish our findings in international open-access, peer-reviewed medical journals so that they are freely available.

CONCLUSION

The older patient with renal disease is different from younger counterparts on several counts – comorbidity burden, disease progression, survival, outcomes with therapy, and considerations that influence quality of life. A 'one-size-fits-all' approach to counselling and prescribing renal replacement therapy cannot be recommended. The scoping review proposed will attempt to synthesize the disparate pieces of information available, and to be a resource for clinicians advising such older patients.

Contributorship statement

RR is the primary and corresponding author and was responsible for initial discussion and the first and all subsequent drafts. KA, MF, and MJ were involved in the initial discussion and design of the study protocol. They contributed to the design of the work, and revised the drafts critically for content. All four authors approved the final version to be published.

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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.

Competing interests

All four authors (RR, KA, MF and MJ) have no competing interests to declare.

Funding for the Study

No funding, financial or other support is being sought, or has been received for the preparation of this protocol or the proposed scoping review.

Figures:

Figure 1: Flowchart of proposed scoping review

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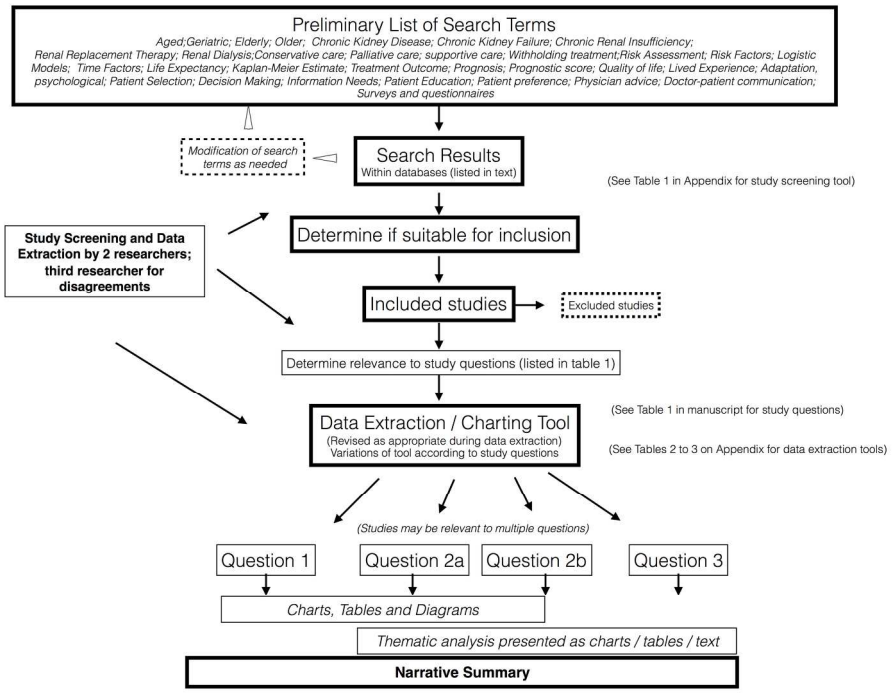

Figure 1: Flowchart of proposed scoping review
figure 1 for a flowchart
209x148mm (300 x 300 DPI)

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Appendix 1

Table 1: Draft of initial appraisal tool (with example) for prospective studies

Title	Primary Author / Year	Type of paper (research / review / opinion / guideline, etc.	Concept	Relevant to question #	Population	Context	Methods	Main Findings / Comments	Included? Yes / No
Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5	Murtagh F, 2007	Clinical Research	Survival	1	>75 yrs	Pre - dialysis clinics	Prospective observational	Direct prognostic information dialysis vs non-dialysis	Yes

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Table 2: Data extraction tool (with example) for articles addressing Question 1: Prognosis and Survival

Title	Primary Author / Year	Type of paper	Parameters studied	Population	Context	Methods	Main Findings / Comments
A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease	Couchod C; 2008	Clinical Research	6 – month mortality; using a calculated prognostic score	>75 yrs; Started dialysis between 2002 to 2006. N= 2500	Patients on dialysis	Prospective observational registry – based; tested prognostic variables, derived score; then validated	Median score was 2 points –mortality 7% ; Mortality varied from 8% to 70% according to score group

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Table 3 Data extraction tool (with example) for studies answering Question 2(a) – factors influencing quality of life

Title (Year)	Primary Author	Type of paper	Factors studied	Population	Context	Methods	Main Findings / Comments
CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life	Brown M; 2015	Clinical Research	Survival, Symptoms, quality of life	>75 yrs; Cons. versus dialysis at time of decision	Pre - dialysis clinics, Palliative renal clinics	Prospective observational	Non-dialysis patients had stable QOL compared to pre-dialysis patients

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Table 4 Data extraction tool (with example) for studies answering Question 2(b) – Lived experience of dialysis / non-dialysis care

Title (Year)	Primary Author	Type of paper	Aim/Scope	Population	Context	Key Phenomena	Main Findings / Themes /Comments
Meaning, comprehension, and manageability of end-stage renal disease in older adults living with long-term hemodialysis.	Karolich R; 2010	Quantitative and Qualitative Research	The association between perceived meaning of chronic illness and adherence to treatment	100 'elderly' patients on dialysis	Dialysis clinic	Survey, face-to-face interviews.	Subjective meanings attached to illness influence how the illness is managed

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Table 5 Data extraction tool (with incomplete example) for studies answering Question 3

Title (Year)	Primary Author	Type of paper	Aim/Scope	Population	Context	Method	Main Findings / Themes /Comments
Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study	Schell,J; 2012	Qualitative Research	To describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy	11 nephrologists and 29 patients (aged > 65); with CKD or on dialysis	Pre - dialysis clinics, Palliative renal clinics	Focus groups; face-to-face interviews	Patient - reported themes were….

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PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 **4**:1

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review *(**scoping** review)*	☒	☐	Page 1, Lines 9-10
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	☐	☐	
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	☐	☐	
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	☒	☐	Page 1, Lines 13-30
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	☒	☐	Page 12, Lines 52-57; Page 13, Lines 3-7
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	☐	☐	
Support					
Sources	5a	Indicate sources of financial or other support for the review	☒	☐	Page 13, Lines 16-18
Sponsor	5b	Provide name for the review funder and/or sponsor	☐	☒	(None)
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	☐	☒	(None)
INTRODUCTION					

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Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Rationale	6	Describe the rationale for the review in the context of what is already known	☒	☐	Pages 4-6
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	☒	☐	Page 7, Lines 33-44; Table 1 on Page 8, Line 15-34
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	☒	☐	Page 8, Line 40 to Page 10, Line 25
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	☒	☐	Page 11, Lines 6-21
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	☒	☐	Page 10, Line 29-58
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	☒	☐	Page 11, Lines 26-29; Pages 18-21
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	☒	☐	Page 11, Lines 26-41 Page 16; See Figure 1
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	☒	☐	Page 11, Lines 26-41
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	☒	☐	Page 11, Lines 29-59; Page 12, Lines 1-13
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	☒	☐	Page 11, Lines 29-59; Page 12, Lines 1-13

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Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	☐	☐	
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	☐	☐	
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)	☐	☐	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	☐	☐	
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	☒	☐	Page 11, Line 44 to Page 12, Line 13
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	☐	☐	
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	☐	☐	

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Checklist for scoping review protocol

[derived from:
The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI scoping reviews. The Joanna Briggs Institute 2015. 1–24.]

Criterion	Yes/No	Page	Lines
Informative title with a clear indication of the topic of the scoping review	Yes	1	9-10
Use of the phrase 'scoping review' in title	Yes	1	10
Clearly stated objective that is congruent with the title	Yes	7	34-44
Clarity in the review questions	Yes	7-8	Page 7,48 - Page 8,34
Appropriate Background Section	Yes	3	45
Inclusion Criteria (Participant / Concept / Context)	Yes	8	37
List of Sources of information	Yes	11	6-21
Search Strategy	Yes	10	29-58
Extraction of Results : Charting the results – use of draft charting tables	Yes	11	24-59
Presentation of the Results	Yes	11 -12	Page11,50- Page12, 14

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