African Journal of Nephrology
Official publication of the African Association of Nephrology
Volume 26, No 1, 2023, 53-61

ORIGINAL ARTICLE

Quality of life of patients with kidney failure in sub-Saharan Africa: protocol for a systematic review of quantitative studies

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ABSTRACT

Introduction: The burden of chronic kidney disease (CKD) is rising in sub-Saharan Africa. Access to kidney replacement therapy (KRT) remains limited and modelling suggests a significant hidden burden of kidney failure managed without KRT. Kidney failure is contributing to serious health-related suffering (SHS) at a global level. Despite this, access to palliative care remains extremely disparate. There is an urgent need for greater palliative care provision for patients with kidney failure in sub-Saharan Africa. To inform this, it is important to understand their current quality of life. This article outlines our review protocol, ensuring transparency of our planned methods and reporting.

Methods and analysis: A comprehensive search will be conducted of MEDLINE (Ovid), EMBASE, CINAHL, African Index Medicus and Africa Journals Online. ProQuest Dissertations & Theses Global will be searched for grey literature. Eligible sources will be quantitative observational studies, conducted in sub-Saharan Africa, and published in English or French. The primary outcome measure will be quality of life of those with kidney failure, measured using a validated quality of life tool. Abstract screening, data extraction and risk of bias assessments will be conducted independently by two reviewers. Meta-analysis will be performed on study subgroups, if appropriate, based on heterogeneity of included studies; otherwise results will be summarised narratively. This protocol is structured according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidance.

Ethics and dissemination: Ethical approval is not required because this review will synthesise published data. Findings will be disseminated in a peer-reviewed journal.

PROSPERO registration ID: 275434

Keywords: quality of life; kidney failure; sub-Saharan Africa, systematic review.

INTRODUCTION

Non-communicable diseases (NCDs), including chronic kidney disease (CKD), are a growing public health problem worldwide, particularly in low- and middle-income countries (LMICs) [1]. Although more high-quality data are needed, the burden of CKD and kidney failure in sub-Saharan Africa is thought to be at least as great as in other LMICs and is expected to rise significantly [2-6], in line with the growing prevalence of other NCDs including hypertension and diabetes [7-10].

Recent systematic reviews have estimated the overall prevalence of CKD stages 3–5 across sub-Saharan Africa at 4.8% to 13.9% [5,6], with higher rates in at-risk pop-

Received 08 November 2021; accepted 18 October 2022; published 27 March 2023.
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ulations, including those with hypertension, diabetes and HIV [6]. Precise estimates are hampered by significant heterogeneity among studies, including differences in reporting and methods of calculating estimated glomerular filtration rate (eGFR) [3,5,6].

Patients living with advanced CKD are at risk of developing kidney failure during their lifetime, yet data on the prevalence of kidney failure in sub-Saharan Africa are particularly scarce, largely owing to a lack of renal registries in most African countries [11,12]. Estimates generated from modelling suggest a significant hidden burden of kidney failure in Africa, with only 9–16% of patients in need of kidney replacement therapy (KRT) able to access it [12-14]. For this reason, hundreds of thousands of people with kidney failure in Africa die every year without access to KRT [13]. Even for those who do start KRT, resource limitations affect the ability to provide optimal KRT on a long-term basis and discontinuation rates are high, with only 10% of adult incident dialysis patients continuing treatment beyond 3 months [14].

Patients with kidney failure in sub-Saharan Africa are therefore suffering even in settings where facilities for diagnosis and KRT are available. Indeed, kidney failure has been recognised as one of 21 conditions contributing to serious health-related suffering (SHS) at a global level [15-17]. However, global access to basic palliative care remains extremely disparate with 80% of the patients who experience SHS each year residing in LMICs [17]. Across sub-Saharan Africa, there have been significant and welcome advances in palliative care provision since 2004 [18], particularly in the context of HIV and cancer care, but distribution of palliative care services remains uneven, limited to relatively few countries, and big challenges remain in key areas including availability of essential medications [18]. There is therefore a continuing urgent need for greater provision of palliative care for patients suffering from kidney failure in sub-Saharan Africa [17].

In order to inform the development of these services, it is important to understand more about the quality of life (QoL) of patients currently living with kidney failure in sub-Saharan Africa, including those both with and without access to KRT. The term "quality of life" is a broad one used variably in the literature [19], but is defined by the World Health Organisation as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [20]. The term "health-related quality of life" (HRQoL) is also loosely defined, but can broadly be thought of as an individual's subjective experience of physical and mental health over time in relation to their overall functional and socioeconomic status [21].

A wide array of tools exists for measuring quality of life in population-based studies; these can generally be divided into generic and disease-specific assessment tools. The most commonly used generic quality of life assessment tool is the Medical Outcomes Study 36-Item Short Form (SF-36) [22,23]. Other frequently employed generic tools include the 12-Item Short Form Health Survey (SF-12) and the EuroQol (EQ-5D) [24,25].

Recommended disease-specific quality of life tools for patients with kidney failure include, though are not limited to, the KDQOL, the KDQOL-Short Form (KDQOL-SF), the Kidney Disease Quality of Life-36 (KDQOL-36) and the End Stage Renal Disease-Symptom Checklist Transplantation Module (ESRD-SCLTM) [27-30]. The KDQOL-SF was designed and validated for use in dialysis patients [26,27]. KDQOL-36 was originally validated in dialysis patients but subsequent evidence has emerged to support its use in pre-dialysis CKD patients [26,28]. The ESRD-SCLTM is recommended for assessment of quality of life in kidney transplant recipients [26,29].

A large number of systematic reviews have been conducted that explore the quality of life of patients living with kidney failure globally; 21 of these have been published since 2010 and are summarised in Supplementary Table S1 [31-51]. Almost all of the studies included in these systematic reviews were conducted in high- and upper-middle-income countries. Among these 21 reviews, the only primary studies conducted in sub-Saharan Africa included two from South Africa. One of these (Okpechi IG et al., 2013) [52] features in four systematic reviews [39,41,47,50] and the other, more recent study (Tannor EK et al., 2017) [53] features in only one [50]. It is therefore unclear how applicable the findings of these reviews are to patients suffering with kidney failure in sub-Saharan Africa. Studies from other sub-Saharan African countries may have been missed in these systematic reviews due to limitations introduced by inclusion criteria, including specific search terms, language and range of publication dates. To date, no systematic review has been conducted that specifically explores the quality of life of patients living with kidney failure in sub-Saharan Africa.

OBJECTIVES

The objective of this systematic review is to evaluate available quantitative evidence regarding the quality of life of patients living with kidney failure in sub-Saharan Africa.

In this review, kidney failure will be defined as follows:

- CKD G5* treated without KRT, including treatment with or without conservative care.
- CKD G5 treated with dialysis.
- Receipt of a kidney transplant.

These definitions are adapted for pragmatic purposes from the clinical trial definitions that were agreed at the recent International Society of Nephrology (ISN) consensus meeting, and from the KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease [54,55].

**Where G5 is "GFR category 5", defined by a glomerular filtration rate (GFR) of less than 15 mL/min/1.73 m^2, as outlined by the 2012 KDIGO Guidelines [55].*

METHODS

This protocol is structured according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidance [56].

ELIGIBILITY CRITERIA

Studies will be eligible for inclusion in the review if they meet the following criteria.

Study design

Eligible study designs will include cross-sectional studies, case-control studies, retrospective and prospective cohort studies, other observational studies and mixed-methods studies. For mixed-methods studies, only quantitative data will be extracted and analysed. Systematic reviews and meta-analyses will be included during screening in order to scan the reference lists for any eligible primary studies of the previously specified designs that may have been missed by the search strategy. However, data will not be extracted from systematic reviews or meta-analyses as this could lead to duplication of data from primary studies. Qualitative studies, interventional studies, case series and case reports will be excluded.

Studies included must evaluate quality of life using a generic or disease-specific quality of life tool validated in at least one language and healthcare setting. Studies will be excluded if they do not specify the quality of life assessment tool used.

Participants

Eligible studies will include adults and/or children with kidney failure, as defined by any of the following:

- CKD G5, not on KRT (either "pre-dialysis" or kidney failure being managed without KRT).
- Treatment with haemodialysis (HD)*.
- Treatment with peritoneal dialysis (PD)*.
- Receipt of a kidney transplant.

Studies involving patients with acute kidney injury (AKI) will be excluded, unless they include patients with both CKD G5 and AKI and report quality of life separately for each group.

**For the purposes of this review, a single session of dialysis will be adequate to meet these definitions.*

Intervention/Comparison

This systematic review will not include interventional studies. Patients with kidney failure in the studies referenced may be receiving no KRT, or KRT in the form of haemodialysis, peritoneal dialysis or transplant. Studies may include participants in one or more of these treatment modality groups, but will be included only if they report quality of life outcomes separately for each group. We will aim to determine the quality of life separately for patients with kidney failure in each treatment modality group.

Outcomes

The primary outcomes of interest will be the quality of life indicators described in the studies included using their specified, validated quality of life instruments. Studies referenced may use any validated generic or disease-specific quality of life tool.

These tools assess a range of quality of life dimensions, which differ slightly among them but broadly include physical health status, mental health status, social and everyday life activities as well as overall well-being [22-30].

For example, the 8 dimensions of the SF-36 are as follows [23]:

- Limitation of physical activity due to health problems.
- Limitation of social activity due to either physical or emotional health problems.
- Limitation of usual activities due to physical health problems.
- Limitation of usual role activities due to emotional problems.
- Physical pain.
- General mental health and psychological well-being.
- Vitality.
- General health perceptions.

Scores from these dimensions are grouped to form two summary scales, the physical component summary (PCS) and the mental component summary (MCS) [23].

The disease-specific tool KDQOL-SF combines these 8 generic quality of life dimensions from the SF-36 with 11 disease-specific dimensions [27]:

- Symptoms/problems
- Impact of kidney disease on everyday life
- Burden of kidney disease
- Work status
- Cognitive function
- Quality of social interaction
- Sexual function
- Quality of sleep
- Level of social support
- Encouragement from dialysis staff
- Patient satisfaction.

Studies will be excluded if they do not use a tool validated in at least one language in one health setting, or if they do not specifiy the tool used.

No secondary outcomes will be assessed.

Setting

Only studies carried out in sub-Saharan Africa will be included. To maximise inclusivity, for the purposes of this review, countries of sub-Saharan Africa will be defined as broadly as possible according to the MEDLINE MeSH term "sub-Saharan Africa" – which includes both Mauritania and Sudan – with additional inclusion of the island states of Comoros, Mauritius and Seychelles (which are included in classifications outlined by the United Nations and by the African Union) [57,58].

Studies carried out in the following countries will therefore be included:

Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cabo Verde, Central African Republic, Chad, Comoros, Congo, Côte d'Ivoire, Democratic Republic of Congo, Djibouti, Equatorial Guinea, Eritrea, Eswatini, Ethiopia, Gabon, The Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, São Tomé and Príncipe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, South Sudan, Sudan, Tanzania, Togo, Uganda, Zambia and Zimbabwe.

Patients may be receiving their treatment in primary, secondary or tertiary care.

Timeframe and publication status

Both published studies and grey literature will be included, dating from 1995 (after adoption of validated QoL tools) to the present day.

Language

Included studies will be limited to those written in English or French.

INFORMATION SOURCES

The following databases will be searched to identify eligible studies from 1 January 1995 to the present: MEDLINE (Ovid), EMBASE, CINAHL, African Index Medicus and Africa Journals Online. ProQuest Dissertations & Theses Global will be searched to identify eligible grey literature. Grey literature to be considered will include unpublished studies, dissertations, theses and conference abstracts. We will also manually scan the reference lists of included studies to identify any additional studies meeting the inclusion criteria.

SEARCH STRATEGY

The specific literature search strategy was developed using a combination of medical subject headings (MeSH – for MEDLINE), Emtree terms (for EMBASE) and text words with the assistance of an experienced health sciences librarian.

The search strategy for Ovid MEDLINE and Emtree is included as Supplementary Table S2.

The search strategy framework includes search terms relating to kidney failure, geographical location and quality of life.

The search will be re-run if more than 24 months have elapsed between the initial search and submission for publication.

STUDY RECORDS

Data management

Citations and abstracts for the studies identified via the literature search will be uploaded to Rayyan [59], an online systematic review software management program. Articles written in French will be translated by seeking voluntary assistance through the Cochrane TaskExchange platform [60], or if this is unsuccessful, via Google Translate [61]. Duplicate reports of the same study will be removed. Full texts will be uploaded for studies that meet the inclusion criteria following abstract screening and for those for which there is uncertainty regarding eligibility.

Selection process

Two authors (CMS and CCS) will independently screen titles and abstracts identified by the search against the pre-specified inclusion and exclusion criteria using the abstract screening tool (see Supplementary Table S3).

Articles will be included if they:

a) Involve adults and/or children with kidney failure.
b) Are conducted in sub-Saharan Africa as defined for this review.
c) Are written in English or French.
d) Evaluate quality of life using a specified quality of life tool validated in at least one language/healthcare setting.
e) Report quality of life separately for patients in receipt of different treatment modalities, that is, CKD G5 not in receipt of KRT, or in receipt of haemodialysis, peritoneal dialysis or kidney transplant.
f) Are conducted using one of the pre-specified study methodologies.

The abstract screening tool will first be piloted on 10 abstracts as a training and calibration exercise [60]. Amendments to the screening tool will be avoided where possible but if necessary these will be documented and the study protocol amended.

Abstracts that clearly fail to meet the inclusion criteria using the screening tool will be removed, as will duplicate reports.

Full texts will be obtained for all studies that clearly meet the inclusion criteria using the screening tool or for which there is uncertainty regarding inclusion. In the event that there are multiple (but not identical) reports of the same study, these will be linked together. Two authors (CMS and CCS) will then independently screen the full text reports to determine if they meet the inclusion criteria. Any uncertainty or disagreement will be resolved via discussion, and if still unresolved, through involvement of a third author (EE). Reasons will be recorded for all excluded studies.

Reference lists from the included full texts will also be screened to identify additional studies meeting the inclusion criteria that may not have been identified through the literature search.

Studies that are ongoing, incomplete or unobtainable will be tagged and listed separately.

Data collection process

A specifically tailored data extraction tool will used to facilitate data extraction from the included studies (see Supplementary Table S4). Two reviewers (CMS and CCS) will independently extract data from each eligible study. To ensure consistency, a calibration exercise will be carried out before starting the data extraction process. Extracted data will be compared and any discrepancies will be resolved by discussion. In the event of unresolved disagreement, a third reviewer (EE) will adjudicate. Where uncertainty remains, study authors will be contacted by email to provide clarification, up to a maximum of two attempts.

Data Items

Data extracted will include:

- Study design
- Country
- Healthcare setting
- Demographic data of included participants
- Number of participants in each treatment modality group
- Duration of treatment if receiving KRT
- The type of quality of life assessment tool used
- The results of quality of life assessments, by dimension and overall
- The authors' conclusions

Data for each quality of life domain will be extracted separately for patients with CKD G5 not on KRT, those receiving HD, those receiving PD and those with a kidney transplant. In the event of missing information, the reviewers will attempt to contact the authors of the included studies by email to obtain this, up to a maximum of two attempts.

OUTCOMES AND PRIORITISATION

The primary outcomes will be the quality of life indicators assessed in the studies included.

Where studies use the same quality of life assessment tools, it may be possible to consider results from different studies together by grouping the results of assessments for the same quality of life domains.

All domains will be given equal consideration. Specific quality of life domains have been discussed previously.

RISK OF BIAS IN INDIVIDUAL STUDIES

Two reviewers (CMS and CCS) will independently appraise the quality of the included studies, including risk of bias, using the Joanna Briggs Institute (JBI) critical appraisal tools. These toolkits include separate checklists for prevalence studies, analytical cross-sectional studies, case-control studies and cohort studies [62-64]. The AXIS tool for critical appraisal of cross-sectional studies will also be used [62, 65,66]

Using these appraisal tools, each reviewer will independently assess the risk of bias in each study and come to an overall judgement as to whether it is of sufficient methodological quality to merit inclusion, or whether further information is needed. The assessments of the two reviewers will be compared and any disagreement will be resolved via discussion and, if required, involvement of a third reviewer (EE). The results of the risk of bias assessment will be included in the "summary of findings" table.

DATA SYNTHESIS

Studies will be divided into subgroups according to patient treatment modality (HD, PD, transplant or CKD G5 without KRT). Clinical and methodological heterogeneity of the included studies in each subgroup will be assessed by considering the populations, treatment nature, range of quality of life instruments used, trial designs and risk of bias. Within each subgroup, if the studies are considered too dissimilar then meta-analysis will not be attempted. Instead, a narrative synthesis will be performed. Summary tables and text will be used to describe the characteristics of the included studies and explain their findings.

In the event that studies appear homogeneous enough for meta-analysis – for example, a number of studies using the same quality of life instrument in patients receiving the same treatment modality – then suitable studies will be compared in a meta-analysis. This will be carried out using a random effects model to allow for residual heterogeneity. The I2 statistic will be used to assess statistical heterogeneity [67]. If substantial statistical heterogeneity is demonstrated (I2 > 50%), then a sensitivity analysis will be performed.

META-BIAS(ES)

To assess for outcome reporting bias, outcomes reported in the results section of each publishe study of each published study will be compared to those described in the study protocol, if this is available [68,69]. If a study protocol is not available, reported results will be compared to the intended outcomes described in the methods section [69]. In the event of partial or missing outcome data, study authors will be contacted with up to two attempts by email. The risk of bias associated with any persistent incomplete or missing results will be assessed using the Outcome Reporting Bias in Trials (ORBIT) classification system [70,71], the results of which will be recorded in the "summary of findings" table. If outcome reporting bias is suspected, this will be taken into account when considering the overall quality of evidence using the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach.

In the event that a meta-analysis is carried out containing 10 or more studies, funnel plots with tests for funnel plot asymmetry will be used to assess for reporting bias including publication bias and small-study effects, amongst other causes of heterogenicity [72].

CONFIDENCE IN CUMULATIVE EVIDENCE

The quality of evidence will be assessed using the GRADE approach. This will allow evaluation of the quality of the body of evidence across five domains: risk of bias, consistency, precision, directness, and probability of publication bias [73].

DISCUSSION

As far as we are aware, this will be the first systematic review to examine quality of life in people living with kidney failure in sub-Saharan Africa. Multiple systematic reviews exist that look at quality of life in the context of kidney failure in other, largely high- and upper-middle-income countries [31-51], but their findings are unlikely to be representative of patients living in sub-Saharan Africa due to the very small number of African studies included in these other reviews. Our systematic review will address an important issue because the prevalence of CKD and, by extrapolation, kidney failure, in Africa is growing, at a time when access to both KRT and palliative care on the continent remains limited [12-18]. As a result, there is thought to be a significant burden of kidney failure managed without KRT in Africa, leading to excess SHS [17]. In addition, in recent years there has been increasing recognition within the global nephrology community that in order to improve quality of kidney care a greater focus is needed on patient-centred outcomes including attention to symptom burden, quality of life and patient experience [74-76].

In order to guide development of palliative and supportive care services for patients with kidney failure in sub-Saharan Africa, it is important to understand more about the current need. This systematic review aims to contribute to this by synthesising available evidence on quality of life.

The anticipated strengths of this review include its broad search strategy and inclusive eligibility criteria, with inclusion of studies conducted in both English and French, and those involving both adults and children. The kidney failure definitions used have also been adapted to be as inclusive as possible. Potential limitations of this review may include the fact that it will be limited to observational quantitative studies, excluding qualitative and interventional studies, due to difficulty combining these different study types in a single systematic review. There may be scope for a later systematic review of qualitative studies focusing on this research question.

If the studies referenced demonstrate significantly heterogeneous populations, study designs and settings then this may also be a limitation, due to the challenge this would pose to undertaking a meta-analysis.

By publishing our results in a peer-reviewed journal the evidence generated will have an opportunity to influence patient care and health policy.

LIST OF SUPPLEMENTARY FILES

S1. Summary of systematic reviews of quantitative studies published since 2010 describing the quality of life of patients living with kidney failure.

S2. Search strategy for Ovid MEDLINE and Emtree EMBASE.

S3. Abstract screening tool.

S4. Data extraction tool.

ABBREVIATIONS

CKD	Chronic kidney disease
eGFR	Estimated glomerular filtration rate
HD	Haemodialysis
HRQoL	Health-related quality of life
KRT	Kidney replacement therapy
LMIC	Low- and middle-income countries
NCD	Non-communicable disease
PD	Peritoneal dialysis
PRISMA-P	Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols
QoL	Quality of life
SHS	Serious health-related suffering

Acknowledgements

The authors thank Richard Kielb, librarian at the University of Bristol, UK, for his support in developing our electronic database search strategy.

Author contribution statement

CMS initiated and designed the study protocol and drafted the initial manuscript. CCS, MRD, FC TY and EE reviewed initial and later drafts of the protocol, contributing to its revision. CMS edited the manuscript to produce the final draft. All authors reviewed and approved the final version of the manuscript.

Protocol registration and amendments

In accordance with guidelines, our systematic review has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) prior to starting the search and abstract screening, to minimise the need for amendments following registration (registration ID 275434). Any subsequent amendments to the protocol will be avoided where at all possible but if absolutely required will be dated, recorded contemporaneously with PROSPERO and described in full with the rationale in the final publication.

Funding and support

This systematic review has not been specifically funded or sponsored. However, CMS is employed by North Bristol NHS Trust as a locally funded "NIHR badged" Academic Clinical Fellow (ACF) and CCS is employed by Imperial College Hospitals, London as an NIHR-funded Academic Clinical Fellow (ACF).

Competing interests

MRD is deputy editor of the AJN and FJC is an associate editor.

Ethical approval and dissemination

Formal ethics committee approval will not be required for this systematic review because there will be no recruitment of human or animal research participants, primary data collection or use of identifiable information. The results of this systematic review will be published in a peer-reviewed journal.

Conflict of interest

The authors have no conflict of interest to declare.

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SUPPLEMENTARY FILES

Supplementary Table 1. Summary of systematic reviews of quantitative studies published since 2010 describing the quality of life of patients living with kidney failure.

Systematic Review	Review Question(s)	Date of search	Inclusion Criteria	Number of included studies	Geographic Scope of included studies	Design of included studies	Key results
Boateng EA, East L (2011)[31]	Impact of dialysis modality on QoL (HD vs PD)	Up to July 2010	Studies involving adult patients on dialysis; Must compare QoL between patients on HD and PD using a validated tool.	26	Netherlands (4) USA (3) UK (2) Taiwan (2) Malaysia (2) Greece (2) Turkey (1) Chile (1) China (1) Italy (1) Ireland (1) Denmark (1) France (1) Switzerland (1) Thailand (1) Canada (1) New Zealand (1)	Cohort (4) Cross-sectional (20) Retrospective analysis (2)	Overall, no significant difference in QoL between patients on HD or PD Mental health (MH) scores comparable to healthy population Role limitations due to physical health problems, physical functioning and vitality scores below average for healthy population
O'Connor NR et al. (2011)[32]	Summarise evidence on prognosis, symptom burden and QoL in patients with ESKD receiving CKM	Up to March 1, 2011	Studies describing patients with CKD5 or ESKD, at least some of whom must be receiving CKM. Must report on one or more of: prognosis, symptoms or QOL.	3 of the 13 included studies reported on QoL	UK (1) Hong Kong (1) Italy (1)	Cross-sectional (3)	Patients managed conservatively have a high symptom burden From the limited studies, QoL in patients receiving CKM appears similar to age-matched patients receiving dialysis
Wyld M et al. (2012)[33]	Compare utility-based QoL of adults with late-stage CKD receiving different treatment modalities (including meta-analysis and meta-regression)	Up to December 1, 2010	Studies including patients with pre-dialysis CKD3-5, or in receipt of KRT (HD, PD or KT) or CKM QoL utilities must be reported directly or could be calculated from SF-36 or SH-12 health surveys	190	(As % of utilities) Europe (46%) USA (30%) Other (23%)	(As % of utilities) Cross-sectional (66%) Cohort (17%) Case-control (10%) RCTs (5%)	For patients with late-stage CKD, treatment with dialysis is associated with a significant decrement in quality of life compared to treatment with kidney transplantation
Chan R et al. (2012)[34]	Examine the psychosocial correlates of QoL in patients on dialysis	January 1, 1988 – December 16, 2010	Studies of at least 10 adults of more receiving dialysis, assessing any of the four QoL domains using a specified instrument and reporting an association between at least one psychosocial variable with QoL	81	'English-speaking countries' (37) 44 from non-English-speaking countries: -Europe (22) -Asia (10) -Middle East (10) -South America (2)	Cross-sectional (73) Prospective (6) Interventional (2)	Moderate association found between psychosocial factors and QoL scores across QoL domains, the strongest associations being with stress, affect and cognitive appraisal.
García-Llana H et al. (2014)[35]	Assess the impact of psychosocial variables (depression, anxiety, stress) and treatment adherence on HRQoL in dialysis patients	January 2002 – August 2012	Studies assessing the relationship between at least one psychological variable (out of depression, anxiety or perceived stress) with adherence to treatment and HRQOL in adults on dialysis, using a standardised instrument.	38	Spain (7) Turkey (7) Brazil (6) USA (6) Taiwan (3) South Korea (2) Mexico Bosnia-Hertz Italy Russia Norway Colombia Poland	Cross-sectional (36) Cohort (1) Non-randomised interventional study (1)	All studies found that psychological variables (anxiety, depression and stress) have a negative impact on HRQoL in dialysis patients. Adherence to treatment was associated with better HRQoL.

Supplementary Table 1 continued. Summary of systematic reviews of quantitative studies published since 2010 describing the quality of life of patients living with kidney failure.

Systematic Review	Review Question(s)	Date of search	Inclusion Criteria	Number of included studies	Geographic Scope of included studies	Design of included studies	Key results
Panteli D et al. (2015)[36]	Compare mortality and QoL in patients treated with HDF compared with HD	Up to October 15, 2013	Studies comparing mortality and QoL between patients treated with HDF and HD	7 (assessing QoL)	(Several studies multi-country) USA Canada Norway Netherlands UK Germany Italy Spain Greece Serbia	RCT (2) Randomised cross-over (2) Cohort (1) Cross-sectional (2)	No evidence for better QoL with HDF treatment compared to HD treatment
Homaie Rad E et al. (2015)[37]	Compare HRQoL in patients receiving HD and PD, including meta-analysis	Up to September 30, 2014	Only cross-sectional studies conducted in Iran, measuring HRQoL in patients on HD or PD using a numerical scale	26	Iran only	Cross-sectional (26)	No significant difference in HRQoL between patients receiving HD and PD
Balogun SA et al. (2016)[38]	Explore QoL, perceptions and health satisfaction of older patients in receipt of KRT	January 1994 – December 2014	Studies assessing QoL, perceptions and/or health satisfaction of patients aged 65 years and over, receiving KRT	17 (assessing QoL)	Spain (3) UK (3) USA (3) Belgium (1) France (1) Canada (1) Serbia (1) Taiwan (1) Brazil (1) Japan (1) Singapore (1)	Cross-sectional (7) Prospective cohort (6) Retrospective cohort (3) Case-control and cross-sectional (1)	Overall and mental HRQoL scores of older adults on KRT similar to age-matched controls and younger individuals. Physical HRQoL scores lower than in younger controls.
Ho YF and Li IC (2016)[39]	Investigate HRQoL in patients treated with different dialysis modalities	January 1990 – May 2016	Studies comparing HRQoL in patients receiving HD and PD, using specified validated QoL tools	34	Turkey (5) UK (3) Greece (3) USA (3) Taiwan (3) Netherlands (3) China (2) Singapore (2) Brazil (2) Italy (1) Denmark (1) Iran (1) Malaysia (1) South Africa (1) Saudi Arabia (1) Spain (1) Poland (1)	Cross-sectional (27) Prospective cohort (6) Case-control (1)	Non-significant trend towards better HR-QOL in terms of physiological, psychological, social and disease symptoms in patients receiving PD No significant overall difference in HRQoL between patients receiving HD and PD.
Zazzeroni L et al. (2017)[40]	Comparison of QoL in patients receiving HD vs PD	January 2011 – June 2016	Studies must compare QoL in adult patients on HD vs PD Must use KDQOL-SF 1.3 or KDQOL-SF 36 to evaluate QoL English language only	7	Brazil (2) South Africa (1) Saudi Arabia (1) South Korea (1) USA (1) Singapore	Prospective (1) Cross-sectional (6)	Lower 'effect of kidney disease' in patients on PD Otherwise no significant difference in QoL between HD and PD
Tsai HB et al. (2017)[41]	Compare HRQoL in patients receiving CKM compared to those receiving dialysis	Up to June 30, 2016	Prospective or retrospective studies examining QoL of patients with kidney failure	4	UK (1) Italy (1) Hong Kong (1) Singapore (1)	Prospective cohort (3) Retrospective cohort 1)	Limited studies. No difference in physical component QoL scores but improved mental HRQoL over time in patients receiving CM

Supplementary Table 1 continued. Summary of systematic reviews of quantitative studies published since 2010 describing the quality of life of patients living with kidney failure.

Systematic Review	Review Question(s)	Date of search	Inclusion Criteria	Number of included studies	Geographic Scope of included studies	Design of included studies	Key results
Liu F et al. (2017)[42]	Assess the efficacy and safety of nocturnal HD versus conventional HD (including impact on QoL)	Up to January 2016	Trials investigating effect of nocturnal HD versus conventional HD in patients with kidney failure on one of several pre-specified outcomes, one being QoL	7 (assessing QoL)	Canada (4) USA (3)	RCT (5) Prospective cohort (1) Case-control (1)	Low quality studies, but QoL physical components may be better with nocturnal HD; No difference between nocturnal and conventional HD for overall QoL or mental components.
Ekbert K et al. (2018)[43]	Assess QoL in elderly patients with ESRD receiving CKM compared with HD	2007-2017	Studies comparing QoL in patients over 65 years of age with ESRD receiving CKM or HD	2	UK (1) Singapore (1)	Prospective cohort (2)	Too few studies but no significant difference between QoL in older patients treated with CKM vs HD
Araújo NSS et al. (2018)[44]	Assess the QoL of paediatric kidney transplant recipients	Up to June 2018	Studies evaluating QoL in paediatric kidney transplant recipients using specific, validated tools	8	UK (1) Sweden (1) Greece (1) Norway (1) Turkey (1) India (1) South Korea (1) Canada (1)	Cross-sectional (4) Case-control (3) Cohort (1)	QoL in children with kidney transplant was worse than that of healthy children, but better than that of children with pre-transplant ESKD.
Ren Q et al. (2019)[45]	Assess QoL, symptoms and sleep quality of elderly patients with ESKD undergoing CKM	Up to March 12 2018,	Studies must assess QOL, symptom burden or sleep quality in elderly patients >= 60 years with CKD5 or ESKD Must include at least one group receiving CKM, palliative or hospice care, and a control group Must be a cohort study, case-control study or RCT	6 (assessing QoL)	UK (2) Australia (1) Singapore (1) Hong Kong (1) Italy (1)	Prospective cohort (5) Retrospective cohort (1)	Overall similar QoL in elderly patients undergoing CKM compared with those on dialysis
Bercalu A et al. (2019)[46]	Assess the impact of religiosity and spirituality on QoL in dialysis patients	January 1980 to December 2018	Studies assessing religiosity or spirituality of adult patients with ESKD on dialysis in addition to quality of life assessment	50 19 assessing overall QoL	North America (16) South America (16) Europe (3) Middle East (7) South-East Asia (8)	Cross-sectional (49) RCT (1)	Religiosity and spirituality are correlated with better QoL across most QoL parameters in dialysis patients
Chuasuwan A et al. (2020)[47]	Comparison of HR QoL between PD and HD patients	Up to April 2017	Studies assessing HRQoL in patients with CKD5 or ESKD Must compare two groups of patients in two of the following treatment groups: HD, PD, KT or CM Must measure QoL using the SF-36, EQ-5D or KDQOL	21	USA (3) UK (3) Turkey (3) Poland (3) Netherlands (2) Ireland (1) China (1) Greece (1) Malaysia (1) South Africa (1) Singapore (1) Taiwan (1)	Cross-sectional (19) Prospective (2)	Patients with CKD stage 5 or ESRD treated with PD had better generic HRQoL than HD patients. PD patients also had higher specific HRQoL scores in the subdomains of physical functioning, role limitations due to emotional problems, effects and burden of kidney disease.

Supplementary Table 1 continued. Summary of systematic reviews of quantitative studies published since 2010 describing the quality of life of patients living with kidney failure.

Systematic Review	Review Question(s)	Date of search	Inclusion Criteria	Number of included studies	Geographic Scope of included studies	Design of included studies	Key results
Verberne WR et al. (2020)[48]	Compare symptoms and HRQoL between older patients with EKSD who have opted for CKM vs dialysis	Up to October 1, 2019	Studies comparing PROMs, symptoms or HRQoL between patients who chose either CKM or dialysis	10 reporting HRQoL	UK only (2) Australia only (1) UK and Australia (1) Netherlands (2) Hong Kong (2) Singapore (1) Italy (1)	Observational cohort (10)	Heterogeneous data, but CKM has the potential to achieve similar HRQoL to dialysis in selected older patients
Budhram B et al. (2020)[49]	Compare the change in QoL over time among similar patients on different dialysis modalities and provide insights on the impact of dialysis modality on PROMs	January 1, 2000 to December 31, 2019	Studies comparing adults on different dialysis modalities with repeat QoL measurements over time using a standardised QoL tool	11	UK (2) Canada only (2) USA only (1) Canada and USA (1) Brazil (1) France (1) Japan (1) Germany (1) South Korea (1)	RCT (2) Prospective cohort (9)	No significant difference in the changes in overall global QoL measures between home dialysis (HHD or PD) and ICHD. However, there were significant differences in the changes in individual QoL domains over time. Absolute QoL measures favoured PD over ICHD at each time point
Bonenkamp AA et al. (2020)[50]	Compare the differences in HRQoL between patients receiving home dialysis and in-centre HD worldwide	2007 to 2019	RCTs and observational studies comparing HRQoL in adult patients receiving home dialysis (PD or HHD) and ICHD 3 studies compared HHD with ICHD; the rest compared PD with ICHD	42 They state 41 but table lists 42	Turkey (5) Greece (4) Brazil (3) UK (3) USA (3) Malaysia (3) South Korea (2) Japan (2) Poland (2) Portugal (2) Spain (2) South Africa (2) China (2) Saudi Arabia (1) Iran (1) Georgia (1) Netherlands (1) Singapore (1) Germany (1) Thailand (1)	Prospective cohort (4) The rest cross-sectional No RCTs	Overall pooled data showed marginally better HRQoL for home dialysis patients, but lots of geographical variation and heterogeneity between studies due to varying practices confounding factors and poor study quality. Therefore unable to reach a definitive conclusion.
Schmalz G et al. (2020)[51]	Examine the oral health-related QoL of adults undergoing KRT	January 1, 2009 – December 31, 2019	Studies assessing oral health-related QoL of adults undergoing KRT using a specific tool	12	Iran (2) Germany (2) Spain (2) Brazil (2) Poland (1) Finland (1) Turkey (1) USA (1)	Cross-sectional (11) Prospective cohort (1)	Patients undergoing KRT experiences reduced oral health-related QoL

Abbreviations: CKD, chronic kidney disease; CKM, conservative kidney management; ESKD, end-stage kidney disease; ESRD, end-stage renal disease; HD, haemodialysis; HDF, haemodiafiltration; HHD, home haemodialysis; HRQoL, health-related quality of life; ICHD, in-centre haemodialysis; KRT, kidney replacement therapy; KT, kidney transplant; MH, mental health; PD, peritoneal dialysis; PROMs, patient-reported outcome measures; QoL, quality of life; RCT, randomised controlled trial

Supplementary Table 2. Search strategy for Ovid MEDLINE and Emtree.

Search #	Search terms
1.	kidney failure.tw.
2.	exp Renal Insufficiency/
3.	renal failure.tw.
4.	chronic renal insufficiency.tw.
5.	renal insufficiency.tw.
6.	exp Renal Insufficiency, Chronic/
7.	chronic kidney insufficiency.tw.
8.	kidney insufficiency.tw.
9.	exp Kidney Diseases/
10.	kidney disease*.tw.
11.	renal disease*.tw.
12.	exp Kidney Failure, Chronic/
13.	chronic kidney.tw.
14.	chronic kidney disease.tw.
15.	chronic renal disease.tw.
16.	Chronic renal.tw
17.	chronic kidney disease stage 5.tw.
18.	stage 5 chronic kidney disease.tw.
19.	CKD.tw.
20.	CKD stage 5.tw.
21.	advanced kidney disease.tw.
22.	advanced renal disease.tw.
23.	end stage kidney disease.tw.
24.	end-stage kidney disease.tw.
25.	end stage renal disease.tw.
26.	end-stage renal disease.tw.
27.	ESKD.tw.
28.	ESRD.tw.
29.	kidney injury.tw.
30.	Renal injury.tw
31.	end stage kidney failure.tw.
32.	end-stage kidney failure.tw.
33.	end stage renal failure.tw.
34.	end-stage renal failure.tw.
35.	kidney dysfunction.tw.
36.	chronic kidney dysfunction.tw.
37.	advanced kidney dysfunction.tw.
38.	renal dysfunction.tw.
39.	chronic renal dysfunction.tw.
40.	advanced renal dysfunction.tw.
41.	kidney impairment.tw.
42.	chronic kidney impairment.tw.
43.	renal impairment.tw.
44.	chronic renal impairment.tw.
45.	nephropathy.tw.
46.	chronic kidney failure.tw.
47.	chronic renal failure.tw.
48.	exp Renal Replacement Therapy/
49.	renal replacement therap*.tw.
50.	kidney replacement therap*.tw.
51.	exp Dialysis/
52.	exp Renal Dialysis
53.	renal dialysis.tw.
54.	kidney dialysis.tw.
55.	haemodialysis.tw.
56.	hemodialysis.tw.
57.	exp Peritoneal Dialysis/
58.	peritoneal dialysis.tw.
59.	Dialysis/ or exp Peritoneal Dialysis, Continuous Ambulatory/
60.	automated peritoneal dialysis.tw.
61.	exp Kidney Transplantation/
62.	kidney transplant*.tw.
63.	renal transplant*.tw.
64.	non-dialysis.tw.
65.	advanced CKD.tw.
66.	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65
67.	exp "Africa South of the Sahara"/
68.	sub-Saharan Africa.tw.
69.	exp Africa, Southern/
70.	southern africa.tw.
71.	south* africa.tw.
72.	exp Africa, Eastern/
73.	east* africa.tw.
74.	exp Africa, Western/
75.	west* africa.tw.
76.	exp Africa, Central/
77.	central africa.tw.
78.	67 OR 68 OR 69 OR 70 OR 71 OR 72 OR 73 OR 74 OR 75 OR 76 OR 77
79.	exp Angola/
80.	Angola*.tw.
81.	exp Benin/
82.	benin*.tw.
83.	exp Botswana/
84.	botswana*.tw.
85.	batswana*.tw.
86.	exp Burkina Faso/
87.	burkina faso.tw.
88.	burkinabe.tw.
89.	exp Burundi/
90.	burundi*.tw.
91.	exp Cameroon/
92.	cameroon*.tw.
93.	exp Cabo Verde/
94.	cape verd*.tw.
95.	cabo verd*.tw.
96.	exp Central African Republic/
97.	central african republic.tw.
98.	exp Chad/
99.	chad.tw.
100.	chadian.tw.
101.	exp Comoros/
102.	comoros.tw.
103.	comorian.tw.
104.	exp Congo/
105.	congo.tw.
106.	republic of the congo.tw.
107.	congolese.tw.
108.	exp "Democratic Republic of the Congo"/
109.	democratic republic of the congo.tw.
110.	democratic republic of congo.tw.
111.	exp Djibouti/
112.	djibouti*.tw.
113	exp Equatorial Guinea/

Supplementary Table 2 continued. Search strategy for Ovid MEDLINE and Emtree.

Search #	Search terms	Search #	Search terms	Search #	Search terms
114.	equatorial guinea.tw.	151.	malian.tw.	183.	exp Sudan/
115.	equatoguinean.tw.	152.	exp Mauritania/	184.	sudan*.tw.
116.	exp Eritrea/	153.	mauritania*.tw.	185.	exp South Sudan/
117.	eritrea*.tw.	154.	exp Mauritius/	186.	south sudan*.tw.
118.	exp Eswatini/	150.	mali.tw.	187.	exp Tanzania/
119.	eswatini.tw.	151.	malian.tw.	188.	tanzania*.tw.
120.	swazi*.tw.	152.	exp Mauritania/	189.	zanzibar*.tw.
121	exp Ethiopia/	153.	mauritania*.tw.	190.	pemba*.tw.
122.	ethiopia*.tw.	154.	exp Mauritius/	191.	exp Togo/
123.	exp Gabon/	155.	mauriti*.tw.	192.	togo*.tw.
124.	gabon*.tw.	156.	exp Mozambique/	193.	exp Uganda/
125.	exp Gambia/	157.	mozambique.tw.	194.	uganda*.tw.
126.	gambia.tw.	158	mocambique.tw.	195.	exp Zambia/
127.	gambian.tw.	159	mozambican.tw.	196.	zambia*.tw.
128.	exp Ghana/	160.	exp Namibia/	197.	exp Zimbabwe/
129.	ghana*.tw.	161.	namibia*.tw.	198.	zimbabwe*.tw.
130.	exp Guinea/	162.	exp Niger/	199.	79 OR 80 OR 81 OR 82 OR 83 OR 84 OR 85 OR 86 OR 87 OR 88 OR 89 OR 90 OR 91 OR 92 OR 93 OR 94 OR 95 OR 96 OR 97 OR 98 OR 99 OR 100 OR 101 OR 102 OR 103 OR 104 OR 105 OR 106 OR 107 OR 108 OR 109 OR 110 OR 111 OR 112 OR 113 OR 114 OR 115 OR 116 OR 117 OR 118 OR 119 OR 120 OR 121 OR 122 OR 123 OR 124 OR 125 OR 126 OR 127 OR 128 OR 129 OR 130 OR 131 OR 132 OR 133 OR 134 OR 135 OR 136 OR 137 OR 138 OR 139 OR 140 OR 141 OR 142 OR 143 OR 144 OR 145 OR 146 OR 147 OR 148 OR 149 OR 150 OR 151 OR 152 OR 153 OR 154 OR 155 OR 156 OR 157 OR 158 OR 159 OR 160 OR 161 OR 162 OR 163 OR 164 OR 165 OR 166 OR 167 OR 168 OR 169 OR 170 OR 171 OR 172 OR 173 OR 174 OR 175 OR 176 OR 177 OR 178 OR 179 OR 180 OR 181 OR 182 OR 183 OR 184 OR 185 OR 186 OR 187 OR 188 OR 189 OR 190 OR 191 OR 192 OR 193 OR 194 OR 195 OR 196 OR 197 OR 198
131.	guinea*.tw.	163.	niger.tw.		
132.	exp Guinea-Bissau/	164.	exp Nigeria/		
133.	guinea-bissau*.tw.	165.	nigeri*.tw.		
134.	exp Cote d'Ivoire/	166.	exp "Sao Tome and Principe"/		
135.	ivory coast.tw.	167.	principe.tw.		
136.	cote d'ivoire.tw.	168.	sao tome*.tw.		
137.	ivorian.tw.	169.	exp Reunion/		
138.	exp Kenya/	170.	reunion.tw.		
139.	kenya*.tw.	171.	exp Rwanda/		
140.	exp Lesotho/	172.	rwanda*.tw.		
141.	lesotho.tw.	173.	exp Senegal/		
142.	basotho.tw.	174.	senegal*.tw.		
143.	exp Liberia/	175.	exp Seychelles/		
144.	liberia*.tw.	176.	seychell*.tw.		
145.	exp Madagascar/	177.	exp Sierra Leone/		
146.	madagasca*.tw.	178.	sierra leone*.tw.		
147.	exp Malawi/	179.	exp Somalia/		
148.	malawi*.tw.	180.	somali*.tw.	200.	78 OR 199
149.	exp Mali/	181.	exp South Africa/	201.	66 AND 200
150.	mali.tw.	182.	south africa*.tw.	202.	limit 201 to yr="1995 -Current"

Supplementary Table 3. Abstract screening tool.

Question number	Screening Question	Action	
1.	Does the study involve adults or children with kidney failure?*	If yes or unsure, go to question 2	If no, exclude study
2.	Was the study conducted in sub-Saharan Africa?**	If yes or unsure, go to question 3	If no, exclude study
3.	Is the study written in English or French?	If yes or unsure, go to question 4	If no, exclude study
4.	Does the study evaluate quality of life?	If yes or unsure, go to question 5	If no, exclude study
5.	Does the study use a specified quality of life tool that has been validated in at least one language/healthcare setting?	If yes or unsure, go to question 6	If no, exclude study
6.	Does the study report quality of life separately for patients receiving different treatment modalities for kidney failure?	If yes or unsure, go to question 7	If no, exclude study
7.	Is the study an interventional study, qualitative study, case report or case series?	If yes, exclude study	If no or unsure, go to question 8
8.	Is the study across-sectional study, case-control study, retrospective cohort study, prospective cohort study, other type of observational study or mixed methods study?	If yes or unsure, obtain full article for review.	If no, exclude study

*"Kidney failure" as defined in review protocol
**"Sub-Saharan Africa" as defined in review protocol

Supplementary Table 4. Data extraction tool.

Part (a)

Study ID	Study design(s)	Country/ countries	Healthcare setting		Number and demographics (age range, sex) of participants in each treatment group				Duration of treatment for kidney failure, if specified (average and range)				QoL instrument(s) used
			Public or private?	Primary, secondary or tertiary care?	No KRT	HD	PD	KT	No KRT	HD	PD	KT	
e.g. 001													
e.g. 002													
e.g. 003													

Part (b)

Study ID	QoL instrument(s) used	Overall results of QoL assessment, with reference to - Specific QoL dimensions - Any variation with patient characteristics e.g. age and sex	Results of QoL assessment by treatment modality				Authors' conclusions	Risk of bias assessment
			No KRT	HD	PD	KT		
e.g. 001								
e.g. 002								
e.g. 003								