

# What are the psychosocial factors that influence access to kidney transplantation (and their outcomes) for children and young people?

## A Systematic Literature Review Protocol

<b>Title of the review</b>	<i>A systematic review to examine the range of psychosocial factors that influence access to kidney transplantation and their outcomes in children.</i>
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## Background

For children and young people (CYP) with End Stage Kidney Disease (ESKD) that require Renal Replacement Therapy (RRT), kidney transplantation is often seen as the gold standard to optimise health and reduce mortality[1]. Health-Related Quality of Life (HR-QoL) also presumably improves when a CYP receives a kidney transplant compared with dialysis[2]. Recent evidence has also shown that minimising time on dialysis reduces complications and morbidity for these CYP[3]. Furthermore, kidney transplantation is three times more cost effective than dialysis, for each year the patient's transplant continues to function[4].

However not everyone eligible for a kidney transplant is accessing one. Preliminary work indicates huge variation in transplantation access, practice and outcomes between all 13 paediatric nephrology units in the UK[5-7]. Recent national survey data showed that current barriers to renal transplantation include psychosocial factors, which make up 19% of the barriers[8]. However, it is not clear what is meant by 'psychosocial factors' in this study alone.

This systematic literature review aims to explore and identify the range of psychological and social factors that influence how soon a CYP with ESKD can access a kidney transplant.

The PICOC (Population, Intervention, Comparison, Outcome & Context) framework has been used to define the research question.

## Review Question

1. What are the psychosocial factors that influence access to kidney transplantation in children and young people?
  - a. Identify the psychological or social factors that are taken into consideration when a health care professional is deciding how soon a CYP with ESKD should be wait-listed for a deceased-donor kidney transplant or start preparing for a living donor kidney transplant.
  - b. Identify the psychological or social factors associated with expedited or delayed access to kidney transplant wait-listing or living-donor preparation.
  - c. Identify the psychological or social factors associated with expedited or delayed access to kidney transplant after being wait-listed or prepared for living-donation.
2. What are the psychosocial factors that influence kidney transplantation outcomes in children and young people?
  - a. Identify the psychological or social factors associated with improving or deteriorating HR-QoL after kidney transplantation.
  - b. Identify the psychological or social factors associated with deteriorating kidney transplant eGFR or optimally sustained eGFR after kidney transplantation.
3. Identify the psychological or social factors that are deemed important to a CYP with ESKD and their carers when it comes to a 'good' or 'bad' HR-QoL.

## Searches

An electronic database search strategy has been developed in collaboration with a medical librarian (Ms Heather Chesters).

1. Years considered: 1<sup>st</sup> January 1964 till 30<sup>th</sup> September 2020

- a. Successful immunosuppression with azathioprine in mismatched patients were shown in 1962-1964. Since then, paediatric kidney transplantations were being performed. Therefore, the search will include literature published from 1964 onwards[9].

## 2. Language: English Only

This search strategy uses a combination of Medical Subject Headings (MeSH) and relevant controlled vocabulary.

The following electronic databases will be used: Medline, PsychInfo, CINAHL and Web of Science.

Reference lists of papers identified from the above sources will be hand searched. Furthermore, experts and authors of key papers in the field will be contacted to ensure relevant sources have not been overlooked.

If the search takes place before 30<sup>th</sup> September 2020, the electronic database will be searched again to capture new publications released between the initial search date and 30<sup>th</sup> September 2020. All search results will be downloaded on to and managed via EndNote®.

## Types of Studies to be included

The following study designs are eligible, as long as they have been peer-reviewed. As this review will be including quantitative, qualitative and mixed-method studies, the eligibility criteria were developed with features from both PICO (Population, Intervention, Comparison, Outcome)[10] and SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type)[11].

1. Quantitative research
  - a. Randomised controlled trials
  - b. Cohort studies
  - c. Case studies
2. Qualitative research
  - a. Case studies
  - b. Ethnographic studies
  - c. Phenomenological studies
  - d. Grounded Theory
  - e. Any study using qualitative methods for data collection or analysis (e.g. interviews, focus groups and thematic analysis).
3. Mixed-Method Studies

Excluding: Editorial comments, Reviews and Conference abstracts

## Condition or Domain being studied

Psychological or social factors that influence (delay or facilitate) access to kidney transplantation in children and young people

## Participants / Population

Inclusion:

1. <18 years old
2. Study includes both participants <18 years and >18 years old

3. Carers of patients aged <18 years old
4. Health Care Professionals who look after patients aged <18 years old
5. Any of the following characteristics of the <18-year-old-participant apply:
  - Not on any Renal Replacement Therapy but has End Stage Kidney Disease
  - On dialysis (in-centre or home haemodialysis or peritoneal dialysis)
  - Post kidney transplantation

#### Exclusion:

1. Pregnant
2. Kidney and other organ transplantation in same participant
3. Study includes participants without a kidney condition (i.e. requirement of non-kidney organ transplantation)

## Intervention(s), Exposure(s)

Factors influencing a child or young person's access to kidney transplantation from a psychological or social perspective will be studied. These include factors at individual and household levels (including carer and siblings if relevant).

Factors may include (but not limited to):

- Mental Health – Depression, Anxiety, Stress, Optimism
- Family Functioning – Cohesion, Family structure
- Socioeconomic factors – Food insecurity, Household income, Level of carer education

## Comparator(s)/Control

Not applicable as studies will not be screened for inclusion or exclusion on the basis of 'comparator' or 'control'. However, where appropriate, studies designed with comparators or controls will be considered in the analysis where the aim is to evaluate the effect psychosocial parameters have on paediatric patient access to kidney transplantation.

## Context

This review will include studies conducted in a Tertiary Paediatric Nephrology Unit in a high or middle-income country.

## Outcome(s)

1. Quantitative Study outcomes include (but not limited to):
  - a) Time to receive kidney transplant after wait-listing
  - b) Mortality rate after wait-listing without receiving kidney transplant
  - c) Health-related Quality of Life (HR-QoL) pre-transplantation; must use validated measure if participants completed a questionnaire
2. Qualitative Study will be included if the participant has provided an account of their experience either through interview or focus groups. Outcomes of interest include (but not limited to):
  - a) Psychological or social factors that delay professionals from wait-listing a patient for a kidney transplant
  - b) Psychological or social factors that delay preparation of patients for a kidney transplant

## Measure(s) of Effect:

1. Quantitative Studies:
  - Given that paediatric populations with ESKD are relatively smaller than adult populations, studies involving this cohort are likelier to be smaller. Therefore, reviewing the odds ratio is less likely to be skewed than relative risk ratio.
2. Qualitative Studies:
  - “Measures of effect” not applicable.

## Secondary Outcome(s)

1. Quantitative Study outcomes include (but not limited to):
  - a) Time to kidney transplant failure post-transplantation
  - b) Time to kidney transplant deterioration in eGFR post-transplantation
  - c) Health-related Quality of Life (HR-QoL) post-transplantation; must use validated measure if participants completed a questionnaire
2. Qualitative Study will be included if the participant has provided an account of their experience either through interview or focus groups. Outcomes of interest include (but not limited to):
  - a) Psychological or social factors related to positive health and/or HR-QoL outcome post kidney transplantation
  - b) Psychological or social factors related to adverse health and/or HR-QoL outcome post kidney transplantation
  - c) Psychological or social factors that matter to patients with ESKD (pre- and/or post-transplantation), in terms of their lived experience
  - d) Psychological or social factors that matter to carers of patients with ESKD (pre- and/or post-transplantation), in terms of their lived experience

## Measure(s) of Effect:

1. Quantitative Studies:
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2. Qualitative Studies:
  - “Measures of effect” not applicable.

## Data Extraction (Selection and Coding)

### Study selection:

The three main reviewers are Dr Ji Soo Kim, Dr Jo Wray and Dr Stephen D Marks. Data to be extracted and terminology will be clarified and agreed beforehand. The third reviewer will aim to resolve any disagreements.

- i. Initial electronic database search will be carried out to assess the eligibility of studies that are relevant against the inclusion criteria. This selection process will be done by reviewing the title, abstract and full text.
- ii. Duplicate references will be removed and full text of remaining relevant papers will be retrieved on EndNote®.
- iii. The first and second reviewers will independently use the inclusion and exclusion criteria to select relevant literature from the database search.

- iv. The third reviewer will check the two literature lists with the first and second reviewers to resolve any disagreements around studies to be included and reach consensus on a final literature list on EndNote®.
- v. A PRISMA flow-diagram will be produced to document studies included in this review
- vi. References of the final literature list will be hand-searched for other relevant publications, including grey literature.

#### **Data extraction:**

Data extraction of included studies will commence using excel spreadsheets by the First reviewer. Data extracted by the First reviewer will be checked by the Second reviewer. Discrepancies will be discussed and resolved with the Third reviewer.

Extracted data will capture: – Title, Date of publication, Author(s), Location/Setting, Study Design, Population characteristics (participant demographics, baseline characteristics such as mode of Kidney Replacement Therapy or diagnosis, site setting (e.g. country) and Summary of Findings

Study authors will be contacted regarding any data unavailable in the publication for further verification.

## Risk of Bias (Quality) Assessment

The First Reviewer will appraise the quality of included studies and check all decisions with the Second and Third Reviewer for consensus. Any disagreement will be resolved by discussion between all three reviewers.

First, the quality of studies included in the review will be assessed using the Mixed Methods Appraisal Tool (MMAT, Hong et al 2018).

Next, the quality of Randomised Controlled Trials (RCT) will be assessed using the Cochrane Risk of Bias Tool.

Qualitative studies will be checked for how appropriate their sources and analyses are in the contexts which the studies took place. The influence the researcher may have on the study will also be assessed.

Non-RCT quantitative studies will be assessed in terms of how selection bias was minimised (e.g. study's sampling strategy and how representative of the paediatric population with ESKD it is). Non-RCT quantitative studies will also be assessed with regards to attrition bias (e.g. drop-out rate), appropriate use of measurements (e.g. use of validated questionnaires) and how complete the outcome data is.

## Strategy for Data Synthesis

In the event that the majority of studies or a considerable number of studies (at least 3 or more with the same outcome measures) are quantitative, then a meta-analysis can be conducted if the number of participants and number of responses to each questionnaire item is known for each included study[12]. Meta-analysis will be done using a random-effects model with RevMan®, assuming there is statistical heterogeneity in the results of the quantitative studies. Where there is statistical heterogeneity, a sensitivity analysis can be done to assess how robust the study is in terms of its' design and sample size. If there are more than 10 quantitative studies, a funnel plot can be done to check for reporting bias.

If the majority of studies are qualitative, then the choice of synthesis will depend on the nature of these studies. If the qualitative studies have more 'thick descriptions'[13] (e.g. detailed contexts of the study participants), a meta-ethnography will be done[14]. If the qualitative studies are rich in themes but have 'thin descriptions', a thematic synthesis will be done instead[15]. Where a meta-analysis, meta-ethnography or thematic synthesis cannot be applied, findings from this review will be reported using a narrative synthesis[16].

## Analysis of Subgroups/Subsets

Not applicable

## References

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