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Understanding the healthcare experiences of solid organ transplant recipients: a systematic review of qualitative research

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Background

In 2023, 172,409 patients received a solid organ transplant, worldwide[1]. Transplant recipients may experience, or require access to, wide-ranging support services and healthcare interactions at various timepoints following transplantation. Depending on the organ received and post-operative complications, transplant recipients may spend extended periods (~1-3 weeks) in hospital following transplantation[2]. This can include time in an intensive care unit, ward recovery, and wide-ranging preparations for discharge from various members of the healthcare team, where available (e.g. Physiotherapist, Psychologist, Dietician, Dermatologist)[2]. Healthcare interactions extend to life after transplant, as recipients require lifelong follow-up healthcare to monitor their health, manage their medication, and ensure any complications (e.g. signs of graft rejection, complications of long-term immunosuppression) are recognised and treated early[3]. Further, transplant recipients may require support for psychological distress (e.g. concerns about future health)[4], physical (e.g. weight gain)[5], social (e.g. social restrictions due to risk of infection) and role challenges (e.g. inability to work)[6].

Patient experience of healthcare encompasses a "combination of external and internal hospital processes, patient-centred attributes, patient-staff and staff-staff interactions during all episodes of care."[7]. In the United Kingdom, the National Health Service Organ Utilisation Group recently presented a vision for equitable transplant services that support and empower patients by placing the patient voice at the heart of shaping their healthcare services[8]. This is important because good patient experience is a fundamental requirement for high quality healthcare[9]. However, opportunities for transplant recipients' voices to be heard and taken into account in service improvement are currently limited. A recent scoping review identified eight publicly available measures of patient experience of solid organ transplantation healthcare for kidney or liver transplantation, with no available measures for heart, lung, or pancreas transplantation, and limited consideration of follow-up care[10]. This emphasises the value of qualitative research, which is well positioned to understand the experience and perspective of transplant recipients

on post-transplant care. Indeed, evidence derived from qualitative research has previously been integrated into clinical guidelines and policies in transplantation[11]. Therefore, a systematic review of existing qualitative research considering the depth and breadth of post-transplant healthcare experiences is both timely and novel. This has the potential to identify evidence gaps and provide valuable insights that can inform the development of novel measures of patient experience, and the delivery of high quality transplantation care.

Aim

This systematic review of qualitative research will aim to comprehensively understand the post-transplant healthcare experiences of solid organ transplant recipients.

Objectives

1. Identify and synthesise existing qualitative research reporting the post-transplant healthcare experiences of adult solid organ transplant recipients
2. Identify what and how different healthcare interactions are experienced by transplant recipients to understand the types of interactions (e.g. preparation for discharge) and the experiences of those interactions (e.g. being treated with dignity)
3. Examine commonalities and differences in healthcare experiences across different solid organs and healthcare settings
4. Outline evidence gaps in current understanding of healthcare experience by identifying patient subgroups and healthcare settings that are underrepresented across existing studies
5. Identify key areas where there may be opportunities to improve transplant healthcare services

Design

This systematic review of qualitative research will be registered with the Prospective Register for Systematic Reviews (PROSPERO), and reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework[12].

We have used the SPIDER framework[13] to inform our search strategy and eligibility criteria: Sample (adult solid organ transplant recipients); Phenomenon of Interest (transplant-related healthcare); Design

(qualitative methods, e.g. interviews, focus groups); Evaluation (healthcare experiences); Research type (qualitative research).

Throughout paper selection, data extraction, appraisal of transparency of reporting, and data synthesis, the reviewers will resolve any disagreements through discussion, involving a third reviewer where necessary.

Eligibility criteria

Inclusion criteria

A paper will be eligible if: (1) it is an original peer-reviewed article, available in English; (2) it reports the findings of qualitative research; (3) it elicits the experiences of people who received a solid organ (heart, lung, liver, kidney, pancreas, intestine) transplant as an adult (aged ≥18 years); and (4) the reported experiences are relevant to transplant-related healthcare from the point of transplantation onwards.

Exclusion criteria

A paper will be excluded if: (1) it only reports the findings of quantitative research. Mixed- or multi-methods studies will be eligible if qualitative elements otherwise meet the eligibility criteria; (2) it elicits the experiences of paediatric transplant recipients (aged <18 years) or adults who received their transplant as a paediatric patient. These patients may be treated in paediatric units so likely have different healthcare experiences that are beyond the scope of this review; (3) the transplant recipient's experiences are described by someone else (e.g. family-member); (4) the participants have not yet received a transplanted organ; and (5) the experiences are related to a specific novel intervention (e.g. as part of a trial), that is not usual care.

Search strategy

Searches will be conducted from inception on the following five bibliographic databases: MEDLINE (and other non-indexed citations) (OVID), Embase (OVID), CINAHL (EBSCO), PsycINFO (OVID), and Scopus. Our search strategy will encompass three key concepts, namely: organ transplant, healthcare experiences, qualitative methods.

The development of search terms will be informed by previously published search strategies on solid organ transplant recipient experiences[10,14]. To formulate a combination of appropriate medical subject headings and keywords, we will consult with an experienced information specialist; final search terms will be tailored in line with the specific subject headings used by each database. To retrieve any additional papers for inclusion, we will hand-search the reference lists and forward citations of eligible papers and relevant systematic reviews.

Paper selection

Paper selection will follow a two-stage process. Firstly, titles and abstracts of papers identified through the bibliographic database searches will be independently screened by two blinded reviewers, using Rayyan software. Any paper referring to the healthcare experiences of solid organ transplant recipients will be retained for full-text screening. If full-text is not readily available, we will use an inter-library loan, or request it from the corresponding author.

Two reviewers will then independently screen the full texts against the eligibility criteria. Any paper excluded during full-text screening will be given a coded exclusion reason to ensure transparency when completing the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram[15].

Data extraction

Data extraction will be conducted by one reviewer and, for accuracy, checked by a second reviewer. To facilitate this, we will create and pilot a structured form and refine as needed. If multiple included papers report different findings from the same study, this will be treated as a single study (sample) in the synthesis (although sample characteristics may be derived from multiple papers). Data extraction decisions will be informed by the available published material.

We will extract the following data: study setting; study aim; healthcare episode; sample characteristics (sample size, organ(s) received, sex, age, ethnicity, socio-economic status, employment status, rurality, time since transplant, co-morbid conditions); study design; sampling method; recruitment; data collection method; location; data analysis strategy; author-reported key findings (e.g. themes). We will

summarise the sample characteristics to document the level of diversity within, and across, the samples of included qualitative research.

Appraisal of transparency of reporting

To appraise the reporting of each included paper, we will use an amended version of the widely used Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist[16]; this will be completed by one reviewer and checked by a second reviewer. The COREQ checklist considers three dimensions, namely: research team and reflexivity; study design; and analysis and findings. Example items include "How were participants selected?" and "What was the duration of the interviews or focus groups?". We will count the number of included papers that report each item, and the number of items reported by each included paper. We are conscious of the potentially reductionist nature of checklists for qualitative research, including concerns regarding their credibility[17]; thus, appraisal will not be used to "measure" study quality, rather highlight where there is variability, and potential room for improvement, in the reporting of qualitative research.

Data synthesis

In accordance with the RETREAT criteria for selecting a qualitative evidence synthesis approach[18], our review question, timescale, resources, expertise, and purpose warrant the use of a thematic synthesis[19]. Firstly, we will import the included paper PDFs into NVivo for storing, coding, and searching of the qualitative data. One reviewer will then conduct line-by-line coding of the text and quotes in the results sections of included papers to inductively identify the healthcare interactions experienced by transplant recipients. Two additional reviewers will independently conduct line-by-line coding on a sub-sample of the included papers, to ensure consistency in the identified healthcare interactions. Where a study reports data related to pre- and post-transplant healthcare experiences that can be distinguished, only the post-transplant data will be coded.

The review team will discuss and reach consensus on the similarities and differences between the identified healthcare interactions to generate descriptive themes that portray the relevant areas of healthcare experience. Two reviewers will independently review the data within each descriptive theme to generate analytical themes that consider *how* each area of healthcare is experienced. The review team will

again discuss and reach consensus on these themes, which will present key strengths within, and areas where there may be opportunities to improve, healthcare services.

Dissemination plans

This systematic review of qualitative research will be published in a relevant peer-reviewed journal, and presented at relevant (inter)national conferences. The findings will also be shared with national patient advisory groups and charities.

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